

Encountering Pain

Hearing, seeing, speaking



Edited by

Deborah Padfield and **Joanna M. Zakrzewska**

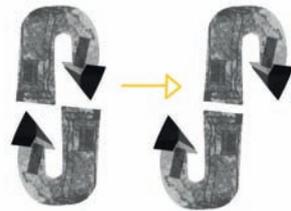
UCLPRESS

Encountering Pain

Encountering Pain...



...is an individual experience, it can be all consuming and yet invisible, and when you are in pain you are the only one that can really communicate that pain. So encountering pain makes you vulnerable to miscommunication, because you need to communicate something that could be quite complex, when your ability to articulate your need for relief is compromised by the nature of your pain.



Encountering pain? The thought alone? I don't know.



...in any form can feel like being compressed in a shrinking iron box in which one is entirely alone. Serious pain dominates every conscious moment, and into dreams as well. Pain comes in many forms, sudden, like painshock, or slow and intensifying, with many distinctions in between. Graphic images and photographs are the most descriptive ways of illustrating different kinds of pain to anyone with imagination, and so much more helpful than asking a person to pick a number from 1 to 10. All schools should have these paincards. They transcend language and culture differences, and behavioural differences of all kinds. Living with pain, stepping on from encountering pain, is unique to each individual. If people can understand what causes it in its different forms, it should be possible to endure and overcome much of it – just as one tries to explain it to children as they grow to learn about pain. The importance of pain conferences/seminars/workshops is the sharing of experiences. This can diminish the awful sense of isolation brought on by pain. Encouraging feelings of identity with others, and then the ability and courage to discuss and explore ways of reducing pain in so many forms.

Figure 0.1 Compilation of images and texts from 'Encountering Pain' conference delegates. We are grateful to Veronica Brinton, Malgorzata Dawidek, Connie Di, Wendy French, Ben J. Hartley, Andrew Lucas, Susanne Main, Elena Manea, Rebecca Pardo, Clare Plumley, Maiada Salfiti, Anna Sexton, Joan Simons, Erin Solomons, Virna Teixeira and Timothy Wainwright, all of whom contributed an image or text for this compilation and the one at the end of the book (Fig. 25.2)

...by voicing it
(as medical interpreter) is a strange experience.
A foreign pain goes through your body,
softens and darkens your voice and leaves behind
its bitter taste.

my body undulates
in the pillow's hollow
rocked by
the bed
rocked by
the carpet
rocked by
the skirting boards
the walls
sway
the paintings
change
places and shapes
objects
dissolve
bookcases
lean
over the table
the ceiling
subsides
the whole world
pulses
a kerria leaf
trembles
and
falls
the sky
oscillates



...is influenced by memories and it might be possible to look back in one's memory to find a point where pain was less critical or possibly did not even exist. There may be other circumstances where pain arises because a new experience awakens the memory of past trauma. The area of memory is critical to the artist who is nervously attempting to keep traces of her body while at the same time considering the perception of collective memory. The body experiences a crisis as it is intimidated by the possibility of forgetting. Memory has an important part to play as an essential perception of one's wellbeing, something that has often been lost when pain is experienced. Pain is closely associated with uncertainty and this is difficult to consider. The positive thing is that on stage there is no place for that uncertainty. It is possible that art will enable us to convey that feeling again, operating through personification as a means of awakening memory. Pain can often result in bodily fragmentation so that a person in pain has a body that is essentially fragmented. Yet choosing to present and show this inner fragmentation mostly motivates and then empowers me as an artist.

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Hearing, seeing, speaking

Edited by
Deborah Padfield and Joanna M. Zakrzewska

 **UCL**PRESS

This book is dedicated to the memory of Professor Lisa Jardine, whose insight and support enabled this work to be done and to all people living with pain: past, present and future.

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Contents

List of figures	xii
List of tables	xvii
Notes on contributors	xviii
Acknowledgements	xxxi
Foreword	xxxv
<i>Rita Charon</i>	
Introduction I: Encountering pain	1
<i>Deborah Padfield and Joanna M. Zakrzewska</i>	
Introduction II: What is pain? A neurobiological perspective	17
<i>Deborah Padfield and Maria Fitzgerald</i>	
Part I: Hearing	
1. How to listen for the talk of pain	33
<i>Rita Charon</i>	
2. Three testimonies from those living with pain	46
<i>Liz Aldous, Ann Eastman and Alison Glenn</i>	
3. Approaches to images: An art therapist's perspective on photographic images of pain used to communicate the experience of pain in medical consultations	81
<i>Helen Omand</i>	
4. Pleurisy I–V	104
<i>Rebecca Goss</i>	

5. From boardroom to consulting room to jobcentre plus: The bureaucracies of pain <i>Jens Foell</i>	111	17. The tree, spring and well <i>Sharon Morris</i>	286
6. Living with trigeminal neuralgia: Interview from <i>Pain Under the Microscope</i> <i>Chandrakant Khoda</i>	132	18. Challenges in managing pain in India <i>Preeti Doshi</i>	289
7. <i>Karuṇā</i> (करुणा in devanāgarī) <i>Anusha Subramanyam</i>	139	19. Disabled lives with an undercurrent of pain: A Hindu perspective and first-person testimony <i>Abha Khetarpal and Satendra Singh</i>	300
Part II: Seeing		20. Acute pain is sexy and chronic pain is not: Language, communication and transformation <i>Jennifer Patterson</i>	315
8. The photograph as a mediating space in clinical and creative encounters <i>Deborah Padfield</i>	147	21. Intellectual empathy as conflict resolution in the interdisciplinary team <i>Tom Chadwick</i>	336
9. How images change non-verbal interaction in chronic pain consultations <i>Amanda C de C Williams</i>	177	Part IV: The future	
10. Picturing pain <i>Suzannah Biernoff</i>	190	22. Visual images: Implications for clinical practice <i>Joanna M. Zakrzewska</i>	349
11. Making charcoal for drawing <i>Onya McCausland</i>	214	23. What is the pain experience and how can we control it? Perspectives from neuroscience <i>Kirsty Bannister and Anthony H. Dickenson</i>	355
12. The art of pain and intersubjectivity in Frida Kahlo's self-portraits <i>Minae Inahara</i>	219	24. Reflecting on 'Encountering Pain' <i>Giskin Day</i>	370
13. The thing about pain: The remaking of illness narratives on social media <i>Elena Gonzalez-Polledo and Jen Tarr</i>	230	Afterword: Communicating chronic pain <i>Jonathan Wolff</i>	379
14. Exhibiting pain: The role of online exhibitions in sharing creative expressions of chronic physical pain <i>Susanne Main</i>	244	Index	383
Part III: Speaking			
15. 'Me' and 'my pain': Neuralgia and a history of the language of suffering <i>Joanna Bourke</i>	255		
16. Language and images in pain consultations <i>Elena Semino</i>	269		

List of figures

0.1	Compilation of images and texts from ‘Encountering Pain’ conference delegates	ii
0.2	‘The Ash, Yr Onnen: Winter, y gaeaf’ from ‘For the Ash: Yr Onnen’, <i>The Moon and a Smile</i> , Glynn Vivian Art Gallery, 2017. Giclée archival print. © Sharon Morris	xxxiv
0.3	A photomicrograph of a section through the dorsal horn of the spinal cord. Generously provided by Dr Stephanie Koch, Senior Research Fellow, UCL	29
2.1	Deborah Padfield with Liz Aldous, ‘Untitled’ from the series <i>Face2face</i> , 2008–13. Digital Archival Print. © Deborah Padfield	47
2.2	Deborah Padfield with Liz Aldous, ‘Untitled’ from the series <i>Face2face</i> , 2008–13. Digital Archival Print. © Deborah Padfield	49
2.3	Deborah Padfield with Liz Aldous, ‘Untitled’ from the series <i>Face2face</i> , 2008–13. Digital Archival Print. © Deborah Padfield	50
2.4	Deborah Padfield with Liz Aldous, ‘Untitled’ from the series <i>Face2face</i> , 2008–13. Digital Archival Print. © Deborah Padfield	51
2.5	Deborah Padfield with Liz Aldous, ‘Untitled’ from the series <i>Face2face</i> , 2008–13. Digital Archival Print. © Deborah Padfield	51
2.6	Deborah Padfield with Liz Aldous, ‘Untitled’ from the series <i>Face2face</i> , 2008–13. Digital Archival Print. © Deborah Padfield	52
2.7	Documentation of the ‘Encountering Pain’ conference at UCL, 2016. © Nir Segal	54
2.8	Deborah Padfield photographed by Ann Eastman, in front of a photographic portrait of Ann. Menier Gallery, London, 2011. © Ann Eastman	58
2.9	Deborah Padfield with Ann Eastman, ‘Untitled’ from the series <i>Face2face</i> , 2008–13. Digital Archival Print. © Deborah Padfield	60
2.10	Deborah Padfield with Ann Eastman, ‘Untitled’ from the series <i>Face2face</i> , 2008–13. Digital Archival Print. © Deborah Padfield	62
2.11	Deborah Padfield with Ann Eastman, ‘Untitled’ from the series <i>Face2face</i> , 2008–13. Digital Archival Print. © Deborah Padfield	63
2.12	Deborah Padfield with Ann Eastman, ‘Untitled’ from the series <i>Face2face</i> , 2008–13. Digital Archival Print. © Deborah Padfield	64
2.13	Deborah Padfield with Ann Eastman, ‘Untitled’ from the series <i>Face2face</i> , 2008–13. Digital Archival Print. © Deborah Padfield	66
2.14	From the exhibition <i>Mask:Mirror:Membrane</i> , at the Menier Gallery, London, 2011. © Ann Eastman	67
2.15	Deborah Padfield with Ann Eastman, ‘Untitled’ from the series <i>Face2face</i> , 2008–13. Digital Archival Print. © Deborah Padfield	69
2.16	Deborah Padfield with Alison Glenn, ‘Untitled’ from the series <i>Face2face</i> , 2008–13. Digital Archival Print. © Deborah Padfield	71
2.17	Deborah Padfield with Alison Glenn, ‘Untitled’ from the series <i>Face2face</i> , 2008–13. Digital Archival Print. © Deborah Padfield	73
2.18	Deborah Padfield with Alison Glenn, ‘Untitled’ from the series <i>Face2face</i> , 2008–13. Digital Archival Print. © Deborah Padfield	75
2.19	Deborah Padfield with Alison Glenn, ‘Untitled’ from the series <i>Face2face</i> , 2008–13. Digital Archival Print. © Deborah Padfield	77
2.20	Deborah Padfield with Alison Glenn, ‘Untitled’ from the series <i>Face2face</i> , 2008–13. Digital Archival Print. © Deborah Padfield	79
3.1	Deborah Padfield, ‘Untitled’ from the series <i>Perceptions of Pain</i> , 2001–06. C-type print. © Deborah Padfield, reproduced by kind permission of Dewi Lewis	90
3.2	Deborah Padfield with Liz Aldous, ‘Untitled’ from the series <i>Face2face</i> , 2008–13. Digital Archival Print. © Deborah Padfield	90
3.3	Deborah Padfield with John Pates, ‘Untitled’ from the series <i>Perceptions of Pain</i> , 2001–06. C-type print. © Deborah Padfield, reproduced by kind permission of Dewi Lewis	91
3.4	Deborah Padfield with John Pates, ‘Untitled’ from the series <i>Perceptions of Pain</i> , 2001–06. C-type print. © Deborah Padfield, reproduced by kind permission of Dewi Lewis	92
3.5	Deborah Padfield, ‘Untitled’ from the series <i>Perceptions of Pain</i> , 2001–06. Silver Gelatin Print. © Deborah Padfield, reproduced by kind permission of Dewi Lewis	94
3.6	Deborah Padfield with Linda Williams, ‘Untitled’ from the series <i>Face2face</i> , 2008–13. Digital Archival Print. © Deborah Padfield	96
5.1	Photograph of the game ‘Pass the Bomb’. © Jens Foell	115
5.2	Illness, sickness and disease (after Blaxter 2010)	116
5.3	Constant adversarial struggle (Toye et al. 2013)	118

5.4	Two models of illness deception (A) and compensation neurosis (B) (Bass 2014). Reproduced by permission of Sage Publications (A) and American Psychiatric Press (B)	119	8.4	Deborah Padfield with Linda Williams, 'Untitled' from the series <i>Face2face</i> , 2008–13. Digital Archival Prints. © Deborah Padfield	162
5.5	Condition descriptors classified by age groups in Disability Living Allowance and Attendance Allowance 2011/12 (DWP)	124	8.5	Deborah Padfield with Linda Williams, 'Untitled' from the series <i>Face2face</i> , 2008–13. Digital Archival Prints. © Deborah Padfield	163
5.6	Descriptors for allocation to Work Related Activity Group (WRAG) in Employment Support Allowance claims (DWP 2017)	127	8.6	Deborah Padfield with Linda Williams, 'Untitled' from the series <i>Face2face</i> , 2008–13. Digital Archival Prints. © Deborah Padfield	163
6.1	Deborah Padfield with Jillie Abbott and Chandrakant Khoda, 'Untitled' from the series <i>Face2face</i> , 2008–13. Digital Archival Print. © Deborah Padfield	133	8.7	Deborah Padfield with Linda Williams, 'Untitled' from the series <i>Face2face</i> , 2008–13. Digital Archival Prints. © Deborah Padfield	164
6.2	Deborah Padfield with Chandrakant Khoda, 'Untitled' from the series <i>Face2face</i> , 2008–13. Digital Archival Prints. © Deborah Padfield	134	8.8	Deborah Padfield with Linda Williams, 'Untitled' from the series <i>Face2face</i> , 2008–13. Digital Archival Prints. © Deborah Padfield	164
6.3	Deborah Padfield with Chandrakant Khoda, 'Untitled' from the series <i>Face2face</i> , 2008–13. Digital Archival Prints. © Deborah Padfield	136	10.1	'Horror and Agony. Copied from a photograph by Dr Duchenne', from Charles Darwin's <i>The Expression of the Emotions in Man and Animals</i> (Fig. 21). Creative Commons Licence	191
6.4	Deborah Padfield with Chandrakant Khoda, 'Untitled' from the series <i>Face2face</i> , 2008–13. Digital Archival Prints. © Deborah Padfield	137	10.2	Wolcott's Instant Pain Annihilator (c. 1863). Library of Congress, Washington D.C. Creative Commons Licence	194
6.5	Deborah Padfield with Chandrakant Khoda, 'Untitled' from the series <i>Face2face</i> , 2008–13. Digital Archival Prints. © Deborah Padfield	137	10.3	<i>Martyrdom of Saint Sebastian</i> (circular illustration). Oil painting. Wellcome Collection. Creative Commons Licence	201
7.1	Anusha Subramanyam re-creates images with her body in response to photographic images from the <i>Perceptions of Pain</i> and <i>Face2face</i> projects. All documentary images. © Nir Segal	140	10.4	Henry Peach Robinson, <i>Fading Away</i> , 1858. Albumen silver print from glass negatives. Creative Commons Licence	203
7.2	Anusha Subramanyam re-creates images with her body in response to photographic images from the <i>Perceptions of Pain</i> and <i>Face2face</i> projects. All documentary images. © Nir Segal	141	10.5	<i>Portrait of Private William Kearsley</i> , by Henry Tonks, c. 1917, pastel. RCSSC/P 569. 36. © Museums at the Royal College of Surgeons	206
7.3	Anusha Subramanyam re-creates images with her body in response to photographic images from the <i>Perceptions of Pain</i> and <i>Face2face</i> projects. All documentary images. © Nir Segal	141	11.1	Charcoal clamp, Cannop Hill Forest of Dean Sculpture Trail. October 2015. © Onya McCausland	215
7.4	Anusha Subramanyam re-creates images with her body in response to photographic images from the <i>Perceptions of Pain</i> and <i>Face2face</i> projects. All documentary images. © Nir Segal	142	11.2	Heap of burned charcoal on Cannop Hill, Forest of Dean Sculpture Trail. October 2015. © Onya McCausland	217
7.5	Anusha Subramanyam re-creates images with her body in response to photographic images from the <i>Perceptions of Pain</i> and <i>Face2face</i> projects. All documentary images. © Nir Segal	142	11.3	Charcoal measure, Cannop Hill, Forest of Dean Sculpture Trail. March 2016. © Onya McCausland	217
8.1	Deborah Padfield with Rob Lomax, 'Untitled' from the series <i>Perceptions of Pain</i> , 2001–06. C-type print. © Deborah Padfield, reproduced by kind permission of Dewi Lewis	150	14.1	Main's poster for the 'Encountering Pain' conference 2016. © Susanne Main	245
8.2	Deborah Padfield with John Pates, 'Untitled' from the series <i>Perceptions of Pain</i> , 2001–06. C-type print. © Deborah Padfield, reproduced by kind permission of Dewi Lewis	160	16.1	Deborah Padfield, 'Untitled' from the series <i>Perceptions of Pain</i> , 2001–06. C-type print. © Deborah Padfield, reproduced by kind permission of Dewi Lewis	273
8.3	Deborah Padfield with Chandrakant Khoda, 'Untitled' from the series <i>Face2face</i> , 2008–13. Digital Archival Print. © Deborah Padfield	161	16.2	Deborah Padfield, 'Untitled' from the series <i>Perceptions of Pain</i> , 2001–06. C-type print. © Deborah Padfield, reproduced by kind permission of Dewi Lewis	276
			16.3	Deborah Padfield with John Pates, 'Untitled' from the series <i>Perceptions of Pain</i> , 2001–06. C-type print. © Deborah Padfield, reproduced by kind permission of Dewi Lewis	278

16.4	Deborah Padfield with Liz Aldous, 'Untitled' from the series <i>Face2face</i> , 2008–13. Digital Archival Print. © Deborah Padfield	281
18.1	A traditional Indian dance form called Bhangra from the northern state of Punjab. Photographed by Preeti Doshi in 2015 in Mumbai. © Preeti Doshi	292
23.1	The peripheral, spinal and brain areas involved in the processing of painful messages. © Kirsty Bannister and Anthony Dickenson	358
25.1	'The Ash, Yr Onnen: Summer, yr haf', from 'For the Ash: I'r Onnen', <i>The Moon and a Smile</i> , Glynn Vivian Art Gallery, 2017. Giclée archival print. © Sharon Morris	382
25.2	Compilation of images and texts from 'Encountering Pain' conference delegates	406

List of tables

5.1	Illness, sickness and disease (after Blaxter 2010)	117
16.1	Word counts for patients and consultants in different sections of the consultations. © Elena Semino	271
16.2	Selection of overused semantic domains in the patient section of Card Data as compared with the patient section of Rest Data. © Elena Semino	275
16.3	Concordance of 'feel' in Card Data for patients. © Elena Semino	279

Notes on contributors

Liz Aldous is a proud Lutonian. Her list of medical conditions could fill one side of A4, but, despite that, she is more than just a list of diagnoses. Aldous trained as an Occupational Therapist, gaining her first job at a mental health unit in London in 1986. Aldous was diagnosed with ME and returned to Luton to be with her parents. Following treatment, she returned to part-time work in 1995. These were difficult years, but she reconnected with her creative side, gaining a qualification in textiles, which led to a job teaching in adult education. In 2005, she met her partner and married in 2013. Aldous always had a desire to volunteer abroad and in 2016 went to the Greek Islands to help with the refugee crisis. Following a diagnosis of facial pain in 2010, Aldous participated in the *Face2face* project, which provided her the confidence to go back to work. Aldous is a respected community artist and was nominated Lutonian of the Year in 2016. She believes she will always struggle with managing multiple chronic health problems and the rollercoaster of having bipolar disorder. Aldous's lifetime passion is art for mental wellbeing.

Kirsty Bannister is Lecturer in Neuropharmacology and Principal Investigator at King's College London. During her post-doctoral placement at UCL in the Neuropharmacology of Pain laboratory, Bannister investigated descending mechanisms of pain control in both normal and pathological conditions. Her main research interests now include investigating the central modulation of pain at the bench and bedside while maintaining a passion for translating basic science to the patient. She has led multiple symposia at international meetings and in 2017 won the EFIC IBSA publication award for an original research

article. In 2019 she was awarded an Academy of Medical Sciences grant to investigate the functionality and anatomy of endogenous descending controls, and an NC3Rs grant to investigate refinement of peri-operative analgesic regimes for rodent models of chronicity. Bannister is an Associate Editor of *Pain* journal and a member of the European Pain Federation Research Committee for Translational Research.

Suzannah Biernoff is Reader in Visual Culture in the Department of History of Art at Birkbeck, University of London, and co-director of Birkbeck's Medical Humanities Research Group. Her books, focussing on histories of the body, faciality and ways of seeing, include *Sight and Embodiment in the Middle Ages* (Palgrave Macmillan, 2002) and *Portraits of Violence: War and the aesthetics of disfigurement* (University of Michigan Press, 2017). In 2014 she was awarded a Wellcome Trust Small Grant for *Visualising Illness*, a programme of events that brought together stakeholders with an interest in visual first-person responses to illness and pain, including clinicians, art therapists, artists and art historians. Her current research focusses on cinema and the unbeautiful, investigating the ways in which film has created, perpetuated and challenged stereotypes of facial difference over the past century.

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Tom Chadwick is a freelance researcher and PhD candidate at the University of Manchester. Chadwick has worked in health and policy

research with universities and charities including the National Centre for Social Research, UCL, London School of Economics and the Samaritans. Chadwick specialises in the political sociology of health and illness. Currently they are conducting ethnographic research with feminist and anti-feminist social movements, exploring how narratives of male vulnerability and ill-health function as political tools. Chadwick's somewhat eclectic role on the *Encountering Pain* project – researcher, administrator, personal assistant, qualitative consultant, film editor – gave them a unique insight into the highs and lows of truly interdisciplinary work, an experience which Chadwick explores in [Chapter 21](#) of this book.

Rita Charon is a general internist, literary scholar and the originator of the field of narrative medicine. She is Professor and Founding Chair of the Department of Medical Humanities and Ethics and Professor of Medicine at Columbia University. She completed her MD at Harvard and PhD in English at Columbia. Her research focusses on the consequences of narrative medicine practice, reflective clinical practice and healthcare team effectiveness. She is Director of the Virginia Apgar Teaching Academy for Medical Educators and Columbia Commons IPE, the health sciences campus interprofessional education and practice programme. Among many other awards she is the recipient of a Guggenheim Fellowship and a Rockefeller Bellagio residency. She is visiting professor at many universities in the US and abroad, teaching narrative medicine theory and practice funded by NIH, NEH and private foundations. She publishes extensively in leading medical and literary journals and her most recent book, co-authored with seven colleagues, is *The Principles and Practice of Narrative Medicine* (Oxford University Press, 2017).

Giskin Day is Course Director for the intercalated BSc in Medical Sciences with Humanities, Philosophy and Law at Imperial College, which she combines with part-time PhD study at King's College London. She originally trained as a botanist in South Africa, before moving to London where she worked in publishing and at the Science Museum. After completing an MSc in Science Communication at Imperial College London, she joined the staff to develop a cross-faculty humanities programme. Day was awarded the Imperial College President's Medal for outstanding contribution to teaching in 2015 and was made a National Teaching Fellow in 2016. Her PhD topic is the expression and reception of gratitude in healthcare. Day has a particular interest in the

role of the arts in fostering understandings of the phenomenology of illness experiences.

Anthony Dickenson is Professor of Neuropharmacology in the Department of Neuroscience, Physiology and Pharmacology at University College London. He gained his PhD at the National Institute for Medical Research, London, and has held posts in Paris, California and Sweden. His research interests are pharmacology of the brain, including the mechanisms of pain and how pain can be controlled in both normal and pathophysiological conditions, and how to translate basic science to the patient. Dickenson is an Honorary Member of the British Pain Society, was a member of the Council of the International Association for the Study of Pain for six years and is Section Editor of the journal *Pain*. He has authored over 360 refereed publications, has an H index of 100 and is a founding and continuing member of the Wellcome Trust-funded London Pain Consortium. Dickenson has given plenary lectures at numerous prestigious international and national meetings including GPs and schools.

Preeti Doshi is Senior Consultant and In-Charge of the Pain Clinic at Jaslok Hospital and Research Centre, Mumbai, India. She obtained a Fellowship in Advanced Pain Therapies from Perth, Australia, and is a Fellow in Interventional Pain Practice (FIPP-World Institute of Pain). Doshi lectures at local, national and international conferences and courses and has numerous publications in textbooks and journals to her credit. She organises educational programmes on pain and put together a unique hybrid course with IASP, 'IASP-ISSP Evidence-based Multidisciplinary Pain Management Programme' in Mumbai in 2017. She organised an international symposium and live Advanced Pain Therapies workshop, 'Comprehensive Review of Interventional Pain Therapies' in collaboration with Weill Cornell Medical College, New York, in 2007. She is former Vice President of the Indian Society for Study of Pain (ISSP) and currently Treasurer of The Neuromodulation Society and Organising Secretary of an international meeting on Neuromodulation scheduled to take place in Mumbai in 2021.

Ann Eastman studied art and graphic design, which led to a long, successful career working on a fascinating spectrum of design projects that evolved to encompass writing and filmmaking. When Eastman eventually retired, happy and healthy, she studied art history, painted,

worked in an art gallery and as a volunteer designer for local charities. Suddenly she began to experience ferocious attacks of facial pain, diagnosed as trigeminal neuralgia. During periods of remission, her consultant Joanna M. Zakrzewska encouraged her to get involved with Deborah Padfield, who was creating images for PAIN CARDS and an exhibition, *Mask:Mirror:Membrane*, followed by an assignment in the Science Museum called 'Pain Less' featuring research into pain management. When Eastman's pain-controlling medication had to be withdrawn due to potentially fatal side effects, she opted for neurosurgery – also not without serious risks. Fortunately, the surgery was successful and she resumed normal life as a busy senior citizen.

Maria Fitzgerald is Professor of Developmental Neurobiology in the Department of Neuroscience, Physiology and Pharmacology, UCL. She has worked in pain research all her professional career, driven by the belief that understanding and alleviating pain can only be achieved through a fundamental understanding of biological mechanisms. Her laboratory focusses upon the spinal cord and brain neuronal circuits that underlie acute and chronic pain and how these circuits develop in early life. Fitzgerald is a Fellow of the Academy of Medical Sciences and of the Royal College of Anaesthetists Faculty of Pain Medicine, and an Honorary Member of the British Pain Society and of the International Association for the Study of Pain. In 2016 she was elected a Fellow of the Royal Society as a world leader in the science of pain, whose work has had a major impact on the treatment of pain in infants.

Jens Foell currently works as a GP in North Wales (primary care and unscheduled care) and teaches at Imperial College London. He trained in Germany in rehabilitation medicine and social medicine with special focus on musculoskeletal disability, including manual medicine and acupuncture. In 1999 he moved to the UK and trained as a GP. From 2004 to 2018 he worked in London in an inner-city practice and in academic primary care, with particular focus on addressing health inequalities and the intersection between the healthcare system and processes of social administration (benefits) in teaching and research. He enjoys helping the ones you cannot help. Unfortunately, but not surprisingly, this led to a deeper interest in bureaucracy and processes of social administration. This could be glorified to 'interest in a systemic view on pain disability', but in real life it is the art and craft of muddling through.

Alison Glenn is a former interior designer and perspective artist. She has worked for a number of architectural practices on commercial projects and has run her own interior design business. Life became challenging after suffering with excruciating and debilitating facial pain for a number of years which was finally resolved after a diagnosis of trigeminal neuralgia by Joanna M. Zakrzewska followed by a microvascular decompression (MVD) procedure at the National Hospital for Neurology and Neurosurgery, London, in 2011. Glenn has been fortunate to have been pain-free ever since. Glenn became involved with the UCL *Face2face* design project when she was approached by Deborah Padfield and Zakrzewska to be one of the participants on the research project, which involved co-creating images with Padfield conveying experiences during her time with facial pain at set points, before, during and after surgery. Glenn enjoys time spent with family and friends and loves to travel. She is a keen watercolour painter and is a member of a local reading group.

Elena Gonzalez-Polledo is Senior Lecturer in Anthropology at Goldsmiths, University of London. Gonzalez-Polledo's research interests encompass gender transition, the biosciences and digital anthropology. She is the author of *Transitioning: Matter, gender, thought* (Rowman and Littlefield International, 2017), co-editor of the volumes *Painscapes: Communicating pain* (Palgrave, 2018) and *Queering Knowledge: Analytics, devices and investments after Marilyn Strathern* (Routledge, 2020), and of the book series *Theorising Ethnography: Concept, context, critique* (Routledge). She has published widely in journals such as *New Media and Society*, *Social Media + Society*, *Journal of Political and Social Psychology* and *Sociology of Health and Illness* on the anthropology of bodies and digital anthropology.

Rebecca Goss is a poet, tutor and mentor living in Suffolk. Her first full-length collection, *The Anatomy of Structures*, was published by Flambard Press in 2010. Her second collection, *Her Birth* (Carcenet/Northern House, 2013) was shortlisted for the 2013 Forward Prize for Best Collection, won the Poetry category in the East Anglian Book Awards 2013 and in 2015 was shortlisted for the Warwick Prize for Writing and the Portico Prize for Literature. *Carousel*, her collaboration with the photographer Chris Routledge, was published by Guillemot Press in 2018. Goss' third full-length collection, *Girl*, was published with Carcanet/Northern House in 2019 and shortlisted for the East Anglian Book Awards 2019. She has an MA in Creative Writing from Cardiff University and a PhD by Publication from the University of East Anglia.

Minae Inahara is Associate Professor in the Graduate School of Human Development and Environment, Kobe University, Japan. She received her PhD in philosophy from the University of Hull in 2007. Inahara specialises in gender studies, philosophical practices, feminist phenomenology, philosophy of disability and clinical philosophy. She was an Uehiro Research Fellow at the University of Tokyo Center for Philosophy (UTCP) and an Assistant Professor affiliated to the Graduate School of Letters (Clinical Philosophy) at Osaka University. Inahara has introduced the notion of incorporating feminist phenomenology into the criteria for disability, beyond the conventional theory of disability based on a social model. She established a new conception of embodiment that ensures the inclusion of the relegated, who are deprived of opportunities to develop their abilities in society.

Abha Khetarpal is a writer, counsellor, teacher, social worker, motivational speaker and activist. She is a National Awardee and one of the 100 Women Achievers in India. She is also a polio survivor who has been advocating for the rights of persons with disabilities and believes that accessibility is a pre-requisite for an inclusive world. She is Honorary Counsellor for students with disabilities at UCMS and GTB Hospital, New Delhi, and member of the Sexual Harassment Committee of the Department of Disability Affairs, Ministry of Social Justice and Empowerment. Her major focus remains on women with disabilities. She is the author of manuals such as *Keeping You Abreast: A handbook on breast cancer self-examination* (Cross the Hurdles, 2013) and *Going with the Flow: Handbook on menstrual management and hygiene* (Cross the Hurdles, 2015). She has launched the first mobile application, *Cross the Hurdles*, in India and developed a free self-paced course in comprehensive sexuality education for adults and teens with disabilities in India.

Chandrakant Khoda landed at London Heathrow in 1971 as a 20-year-old Ugandan Indian immigrant fleeing Idi Amin's regime, with only a £10 note in his pocket. He was not well educated and he took a job at the earliest opportunity, working as stock-taker in the commercial vehicle industry in Leicester. In 1976, he moved to London where he landed a job in the IT sector, in which his career continued for 23 years before he was forced to take redundancy. He currently works as a part-time deputy with the Ministry of Justice at the Court of Protection, helping manage the financial affairs of vulnerable people who have started to become confused and forgetful, and so can no longer look

after their money themselves. He keeps himself busy looking after four young grandchildren, and playing more golf now than squash.

Khoda was shocked when he developed symptoms of trigeminal neuralgia (not very well known to him). After a private visit to the oral surgery and orthodontics department at a BUPA hospital, it was confirmed to him that the episodes of intermittent stabbing pain above his right cheek, which lasted for a few seconds in bouts over 5–10 minutes, needed the attention of a neurosurgeon. He was diagnosed with neuralgia and it was decided that he should move from medication to surgery (MVD).

At that time, he had to stop working, phone calls were too painful to take, and eventually eating and even drinking water became too painful. During this entire period, he was under the guidance of his spiritual guru, Morari Bapu. The surgery was successfully carried out by Dr Neil Kitchen, Consultant Neurosurgeon (UCLH) and his team in May 2011.

During this period, Khoda agreed to participate in a research project with Joanna M. Zakrzewska and Deborah Padfield. He felt the personal visits with Padfield were very productive and useful, and gave him a lot of confidence to help overcome the pain leading to the surgery. He was very proud to see his photographs at the exhibition at the Menier Gallery in London, later in 2011. This raised awareness of the condition and he hopes Padfield's efforts are starting to bear fruit.

Khoda's pain has now completely vanished, and his life has been completely transformed.

Onya McCausland is an artist and Senior Research Fellow at the Slade School of Fine Art. In 2017 she completed a practice-led PhD at the Slade where she also helped to establish Drawing Methodologies, a new cross-departmental drawing course. Her work explores environmental contexts and concerns that address the materials and materiality of how painting and paint relates to the earth (as being made from chemical elements and processes) and human cultures, perceiving and conceiving of landscapes through materiality of place, and the overlap and conflation of human and geological time frames, as well as traditions of art that relate to specific sites and places. Her work is shown internationally, recently in *Working On It*, Helsinki Contemporary, Finland, in 2020; *Europe After The Rain*, Newlyn Gallery, Cornwall, in 2019; *Aerial Landscapes*, Flat Time House, London, in 2019; *Turning Landscape*, Camden Arts Centre, London, in 2014; and *White Earth*, Kettle's Yard, Cambridge, in 2011.

Susanne Main is an Associate Lecturer at The Open University. *Exhibiting Pain* was a doctoral research project which Main designed to draw together her multidisciplinary background. The project incorporated medical sociology, museum studies and chronic pain lived experiences, including her own. This novel exhibition approach allowed for exploration of audience responses to creative representations of persistent physical pain and the benefits to be found in sharing these. Additionally, Main's own experiences with chronic pain enabled a reflexive and subjective approach to the analysis and discussion of the research project. This work is now being developed for further publication and for application in pain management programmes to aid patients' expression of their pain experiences.

Sharon Morris is an artist, poet and Professor at the Slade School of Fine Art, UCL. Fascinated by the relation between words and images, her work is best described as cross-disciplinary. Her artworks include exhibitions of photography, video, film, installation and live performance-readings. Her poetry collections, *False Spring* (Enitharmon, 2007), *Gospel Oak* (Enitharmon, 2013) and artist's book *The Moon is Shining on My Mother* (Enitharmon, 2017), were published by Enitharmon Press. Metaphorical and symbolic, her work addresses the overarching theme of place, for example the site of Gospel Oak as a discursive relation between Hampstead Heath and the City of London. Her current interest is in macaronic forms, that is the juxtaposition of languages, English and Welsh, in relation to photographs and drawings of the landscape of west Wales. Using the philosophy of C. S. Peirce and psychoanalytic theory, her critical writings address the theorisation of subjective experience through the verbal and visual.

Helen Omand is an HCPC-registered art psychotherapist who has worked with children and adults. She currently works in a therapeutic art studio for adults experiencing enduring mental health difficulties and is a lecturer and tutor on the MA in Art Psychotherapy at Goldsmiths, University of London. She has spoken at conferences including the International Art Therapy Practice/Research conference at Queen Mary University and has published in peer-reviewed journals. Helen's research interests include studio art therapy, and the relationship between working as an art therapist and artistic practice. Before training as an art psychotherapist, she previously worked as a filmmaker and artist practitioner in community arts and in arts in health.

Deborah Padfield is a visual artist and Senior Lecturer in Arts and Health Humanities at St George's, University of London, and Lecturer (Teaching) at the Slade School of Fine Art, UCL, where she undertook both her PhD and post-doctoral fellowship. Collaborating with leading clinicians and academics, her research explores the potential of photographic images, co-created with people living with pain, to facilitate doctor-patient communication. In 2001, she collaborated with Dr Charles Pither and patients and staff from Input Pain Unit St Thomas' Hospital, London, on the project *Perceptions of Pain*, resulting in a series of publications and a touring exhibition. The work was further developed with Joanna M. Zakrzewska and patients and staff from UCLH, resulting in ongoing exhibitions, publications and films. She has been funded by numerous bodies, including: Sciart Consortium, ACE, AHRC, CHIRP UCL and HEIF. Padfield is also the recipient of many awards. She exhibits and lectures nationally and internationally and is a council member and trustee of the Association for Medical Humanities (AMH).

Jennifer Patterson was elected President of the Association for Medical Humanities in 2019. She is part-time Senior Lecturer in the Faculty of Education and Health and Human Sciences at the University of Greenwich, and a practicing complementary therapist of 15 years. An interdisciplinary feminist critical theorist, she sees writing as experience-based activism related to equity and social justice. She uses visual and verbal methods, discourse and narrative analysis, to question and disrupt normative cultural and ethical assumptions in the Medical/Health Humanities and Sustainability. Since obtaining a PhD in radical embodied readings of twentieth-century French Surrealist poetry and art (UCL), she has taught Women's Studies (MA) at Ruskin College, and trained in narrative medicine with Rita Charon in New York. She leads projects with practical applications, is currently working on the *Listening to Patients* project and co-edited *Body Talk in Medical Humanities: Whose language?* (Cambridge Scholars, 2019).

Elena Semino is Professor of Linguistics and Verbal Art in the Department of Linguistics and English Language at Lancaster University, and Director of the ESRC Centre for Corpus Approaches to Social Science. She holds a Visiting Professorship at the University of Fuzhou in China. She specialises in health communication, medical humanities, corpus linguistics, stylistics, narratology and metaphor theory and analysis. Her main interests in health communication are: communication about pain; first-person accounts of autism and schizophrenia; and

communication about cancer and the end of life. Her work involves a combination of qualitative and quantitative analyses, drawing from the tools and techniques of corpus linguistics. She has (co-)authored 100 academic publications, including: *Metaphor in Discourse* (Cambridge University Press, 2008) and *Metaphor, Cancer and the End of Life: A corpus-based study* (Routledge, 2018).

Satendra Singh is Professor of Physiology at University College of Medical Sciences and GTB Hospital, Delhi. He is an Executive Member of the Delhi Medical Council and visiting scholar at the MacLean Center for Clinical Medical Ethics at University of Chicago. He is a disability rights activist who has brought many policy reforms including inclusion of disability competencies in the new competency-based medical education curriculum in India. He is also a member of the Delhi State Committee for Research on Disability as well as the Delhi State Advisory Board on Disability. He is the founder of Doctors with Disabilities: Agents of Change and founded the Medical Humanities Group at his institution in 2009, which launched *Research and Humanities in Medical Education*, a peer-reviewed, online, open-access journal on medical humanities in 2014, of which he is deputy editor-in-chief.

Anusha Subramanyam is Artistic Director of Beeja. She is a thought leader, an inspiring performer, dance maker and teacher who has focussed on integrating dance, education and somatic and contemplative practices into her work. A champion for South Asian and inclusive dance practice, she developed her dance practice in a wide range of settings – from formal stage to venues as varied as hospitals, village halls, museums and even London Underground stations. Anusha has taught people from a range of backgrounds, abilities and experience. Her main aim in her teaching is to expand the understanding of dance to help students create their own practice and enjoy dancing. She curates events like the Dance Festival Croydon and Croydon International Mela, showcasing dance from a variety of genres along with her partner Vipul Sangoi. She has received numerous awards for her work such as the Asian Women of Achievement Award in Culture, 2011 presented by IWA, UK, and 'Nritya Acharya Ratna' by Milapfest, for 2017.

Jen Tarr is Senior Lecturer in Social Science Research Methods at Newcastle University. A health sociologist by training, her current research interests are in the fields of chronic pain, digital, visual and other

sensory methods. She was principal investigator for *Communicating Chronic Pain: Interdisciplinary strategies for non-textual data*, funded by the ESRC/National Centre for Research Methods. Her research has been published in journals such as *Qualitative Research* and *Sociology of Health and Illness*, and she is co-editor, with E. J. Gonzalez-Polledo, of *Painscapes: Communicating pain* (Palgrave Macmillan, 2008). She is currently working on a monograph about the range of ways in which visual images are used in relation to pain expression, diagnosis and treatment.

Amanda C de C Williams is Professor of Clinical Health Psychology at UCL, and a consultant clinical psychologist at the Pain Management Centre, University College London Hospital NHS Foundation Trust (UCLH). She also works for the International Centre for Health and Human Rights. While working clinically in an inpatient and outpatient pain management programme with an active research component, she completed her PhD, and subsequently moved increasingly into academic work. Her particular interests are application of evidence-based medicine to pain, particularly by systematic review and meta-analyses; developing evolutionary perspectives to pain and associated behaviour; behavioural expression of pain and its interpretation; better recognition and treatment of pain from torture; and the use of wearable technology to extend healthcare into patients' own environments. She has written over 250 papers and chapters on pain and psychology.

Jonathan Wolff is Alfred Landecker Professor of Values and Public Policy, Blavatnik School of Government, University of Oxford Governing Body Fellow, Wolfson College, Oxford. He is a political philosopher, and was previously Professor of Philosophy and Dean of the Faculty of Arts and Humanities at UCL.

Joanna M. Zakrzewska is a Consultant and Honorary Professor in facial pain at UCLH NHS Foundation Trust. After obtaining dental (King's College London) and medical (University of Cambridge) degrees, and specialist training in oral medicine, Zakrzewska specialised in orofacial pain and was awarded a personal chair at Queen Mary's School of Medicine and Dentistry. Between 2007 and 2015, she set up an award-winning multidisciplinary facial pain service, the largest in the UK, and is now setting up a national Trigeminal Neuralgia Institute, a condition in which she is a world expert. She is the author of four books,

contributor to 20 chapters and author of over 130 peer-reviewed papers. Zakrzewska has worked with Deborah Padfield over the last seven years to determine how the medium of photography could enable improved communication about pain. Funding for a post-doctoral programme with an interdisciplinary team led to several publications, exhibitions and a conference <https://www.ucl.ac.uk/encountering-pain/>, including participation in the Wellcome Friday night spectacular 'On the pursuit of pain'.

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There are many individuals who have supported and helped shape the process of the project and development of this volume, too numerous to name, but we would like to thank Laura Cream and Gemma Moore from Public Engagement (PACE) UCL in particular for their huge amount of support and encouragement throughout the process, Lucy Stagg for her constant support throughout the three years of the CHIRP project, and Graham Treacher, who has lived with the project and the book for many years, constantly offering support and encouragement.

We would also like to thank Sara Borga, Mariana Gomes Gonçalves, Cyrus Hung and Jocelyn McGregor for their untiring help with the conference and throughout the lengthy process of bringing this publication together, and Tom Chadwick for his insightful comments on drafts of the manuscript and help with the index, as well as Annie Bartlett, Fiona Padfield and Saskia Sarginson for reading individual chapters, which greatly clarified the texts. We are grateful to Chris Penfold and the editors and production team at UCL Press for their belief in this volume and immense patience and support throughout the production process, to Liron Gilenberg for her striking cover design and to the copy editors at Borchier, in particular George McBeth for his elegant and detailed copyediting, and Bhaskar Raman for the immense care, enthusiasm and skill with which he oversaw this project, as well as to our peer-reviewers for their comments, which significantly enhanced the final texts.

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- Friends of UCLH
- Biomedical Research Centre, UCL

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We hope the result will benefit past, current and future patients and all of those who live with or witness pain.



Figure 0.2 ‘The Ash, Yr Onnen: Winter, y gaeaf’ from ‘For the Ash: I’r Onnen’, *The Moon and a Smile*, Glynn Vivian Art Gallery, 2017. Giclée archival print. © Sharon Morris

Foreword

Rita Charon

Encountering Pain: Hearing, seeing, speaking is an extraordinary experiential gathering of persons encountering pain and persons who want to know how to relieve pain. I attend many medical conferences about pain and its treatment. As a general internist with a specialty in narrative medicine, I have championed attentive and skilled listening to patients’ accounts of their illness narratives. I have taught many a seminar, course and workshop on how to listen more accurately and empathically to our patients.

Never have I attended a professional gathering like the ‘Encountering Pain’ conference. The experts in this landmark conference were the patients themselves. We physicians, nurses, chaplains, physical therapists, acupuncturists and meditation trainers were the students of those who live with pain. It is unusual indeed for patients’ voices to carry the highest authority in a professional meeting. Despite the moderate progress medicine has made towards patient-centredness, we professionals usually manoeuvre ourselves into the position of power.

This time, we were the humble students of those who lived the experience of pain. During a long walk to the conference on our first day, I listened as the London business executive with trigeminal neuralgia told me her saga. I wept to myself to hear the dismissiveness of the dentist, and the ENT doctor and the uncalled-for suggestion that ‘stress’ was the cause of this disabling and life-altering pain.

When will medicine recognise the urgency of pain? When will doctors be trained to diagnose especially those treatable causes of pain? What might shift our tendency to blame patients for their own distress?

This conference showed the way. In a brilliant creative move, its organisers made sure that patients’ voices predominated throughout

the two-day gathering. The contributors included patients who live with pain, who have achieved remission from pain and who foresee more pain to come. Trigeminal neuralgia was only one among a host of clinical conditions in which intractable pain predominates. In addition to those who suffer pain, the conference heard from scientists, historians, dancers, poets, playwrights, filmmakers and painters. Interpretive dance from an Indian dancer/choreographer punctuated the programme and returned us time and time over to a state of receptive contemplation. Music and visual arts told the wordless stories of suffering. Workshops engaged participants in creative writing and interpretive study of colour and design. In plenary sessions for all 200 participants and in small workshops for 10 or 12 participants, we came to attend to one another's perspectives, however much they differed from our own. We came to trust the motives of one another – no blame, no shame, no pulling rank.

Instead, in what felt like a magic circle of art and science, we came, unusually quickly, to be able to witness one another's stories and to be able to change our own concepts of patienthood and doctorhood. We broke through into a shared language of pain, finding ourselves partners across the divides of culture and power towards a state of care.

This conference opened the way to a revolutionary approach to patient-centred care and provided evidence that egalitarian conversations about pain and suffering can expose fresh means of improving healthcare. The chapters in this book probe these new avenues of care. Written by the patients, scientists, social science researchers and artists involved in the conference, they detail specific methods and approaches by which the spirit of the gathering translates into reliable and replicable clinical and research action. I foresee that these chapters will not just inspire, but guide readers towards collaboration, creative vision and clinical commitment to an ideal – treating those who suffer pain and disability with expertise, with compassion, with hope and with healing.

Introduction I: Encountering pain

Deborah Padfield and Joanna M. Zakrzewska

Pain exposes for all of us deep problems of meaning ... Unremitting pain is, I believe, our contemporary central dilemma. (Charon 2016)

This book emerged from an international conference, 'Encountering Pain', held at UCL in July 2016, which brought together those who live with pain, their carers, clinicians, academics and artists (<http://www.ucl.ac.uk/encountering-pain>). Its aim was to share insights and expand the debate around pain, in particular chronic pain.

What became evident was the value of interdisciplinary approaches and in particular the meeting and integration of patient and clinician perspectives. As one of the delegates wrote:

bringing artists, poets, scientists, historians, linguists, psychologists, GPs, anthropologists, etc. together was inspiring. It felt like the beginning of something; how each discipline interconnected within the event ... the emphasis on the relational showed so much potential.

The emphasis on the relational continues into this book, which attempts to integrate all of these voices into a manual for healthcare professionals, students, academics, artists and, most importantly, for those who live with pain. Rita Charon, who pioneered the field of narrative medicine, describes pain as exposing some of the fundamental truths about medicine:

Issues that in other fields of healthcare might be treated as marginal or fleeting are, in pain medicine, irrevocably central:

trust and trustworthiness, steadiness of commitment, investment in the patient's future, and recognition of the other. (Charon 2005, 29)

There may not yet be a cure for chronic pain but there is room for 'accompanying' people with pain along their journeys. Persistent pain makes demands on language inextricably bound up with the demands of moving beyond our individual experience to empathise with that of another. It raises ethical challenges in its management unlike those associated with any other condition (Schatman 2011). This book attempts to address some of these challenges by providing a guide through personal testimonies, creative extracts and cutting-edge science. The interdisciplinary nature of the volume is crucial, since dialogue between those working in the medical sciences and those in the arts and humanities remains woefully inadequate. In interrogating the struggle to communicate pain, the volume places discordant paradigms side by side, shifting register between creative, academic and personal contributions. Together they offer new knowledge and hope.

The volume starts from the premise that those living with chronic pain *feel* the pain they say they are feeling and suffer in diverse ways as a consequence. Pain can have a devastating impact on lives, resulting in a loss of confidence, feelings of worthlessness and lack of purpose, as well as leading to problems with finance, employment, relationships and sense of identity. We hope that by raising awareness of pain's impact on people's lives and on their communities, this publication can help the healing process. Pain is fast becoming a central issue for policy-makers and the editors and authors seek to contribute ways of improving the lives of patients, healthcare professionals and the wider community. The book aims to:

- Increase understanding of the ways in which the arts and their methods can facilitate pain encounters and dissolve conventional hierarchies.
- Increase understanding of ways in which pain is seen and experienced in non-English speaking cultural contexts.
- Explore the value of patient narratives to all aspects of medicine.
- Stimulate creative thinking around the challenges of encountering and communicating pain by integrating rigorous scientific chapters with those based on creative practices.
- Collectively generate new knowledge about pain and disseminate this knowledge to a wider audience.

The challenge of persistent pain

Once obvious causes have been ruled out, chronic pain is largely diagnosed through language. Yet it is notoriously difficult to communicate (Semino 2013; Notcutt 2012). Defined as having lasted for more than three months and resulting in central brain changes, chronic pain no longer acts as a warning but as a faulty signal becoming at best 'a confusing label' and at worst 'hopelessly inadequate' (Boddice 2014). Some academics have argued that pain resists description in language while others claim that it can generate language, considering pain a nexus where feeling and language overlap (Jung 2019). It remains hard to capture within the commonly used verbal or numerical rating scales, presenting a problem both to those who require and those who provide treatment. Those in pain seek to express it not only linguistically but also through bodily movements, emotional reactions and artistic expressions. This was the starting point for the arts and health research project, *Face2face* (<https://www.ucl.ac.uk/encountering-pain/past-projects>), on which the conference and this volume builds.

Face2face overview

Face2face was a collaboration between the editors, visual artist Deborah Padfield and facial pain consultant Joanna M. Zakrzewska, with staff and patients from University College London Hospital NHS Foundation Trust (UCLH). It researched whether and how photographic images of pain co-created with patients could help them communicate their pain to clinicians, and whether images could expand the dialogue around pain in the consulting room and improve mutual understanding. It posited that images could encourage a democratisation of the consulting space, removing the conventional hierarchies between clinician and patient, and facilitate access to other ways of 'knowing' and communicating pain. The materiality of the visual as opposed to verbal metaphor allows a different type of sharing to take place, while the ambiguity of the visual metaphor encourages negotiation.

Pain so often evades constriction into traditional measures such as 'rate your pain on a scale of 1–10'. The challenge was to create a visual language capable of capturing and communicating its subjective and emotional nature. This is particularly relevant where it has existed for many years and become part of a complex picture. The aim was also to expand existing metaphors for conveying pain, which currently focus on notions of injury and damage, even when there is no evidence of tissue

damage or lesion. The textures and forms of the photographs created during *Face2face* aimed to act on bodies as well as perceptions, so that the senses as well as the mind could be drawn into a shared metaphorical and imaginative space. We don't just conceptualise pain's meaning, we experience its meaning. In this way, images bring us much closer to the lived experience of pain than language alone. The hypothesis was that these visual representations, co-created with people living with pain, could help us formulate a broader definition, highlighting aspects of pain experience that we need to address, both as individuals and as a society.

Unlike an earlier project, *Perceptions of Pain* (see Padfield 2003), *Face2face* focussed mainly on facial pain. Facial pain has all the challenges associated with musculoskeletal pain, as well as additional ones specific to its role in daily functioning, such as, eating, drinking and talking. The central strand of the *Face2face* project was the co-creation with patients of photographs that reflected their unique experience of pain. That the images were co-created was very important so as not to re-appropriate patients' experience after their many diagnostic imaging processes in the hospital.

We were lucky to collaborate with highly committed and creative patients who volunteered to work with us. Many have also contributed to this volume. They found the process therapeutic, as is evidenced in Chapter 2. However, their prime motivation for taking part was to contribute to the creation of a tool that could help others and raise public awareness, thus speeding up paths to accurate diagnosis and appropriate treatment. Participants collaborated with the artist (DP) in a series of one-to-one workshops spread out over six to 12 months, resulting in several hundred photographs for each participant. These were subsequently narrowed down to a selection of six of the most meaningful images for that individual. The workshops occurred at three points during their management journey: before, during and after treatment. This meant that the images reflected changes made in pain perception and avoided the negativity of experience being trapped within a single disturbing image.

Resultant research – 'Pain: Speaking the Threshold'

The research that arose from the study involved integrating a selection of images co-created during the earlier project, *Perceptions of Pain* (Padfield 2003), with a selection of those co-created during *Face2face*

(Padfield 2012; Ashton-James et al. 2017) to form a pack of 54 laminated PAIN CARDS, each with a single image of pain on the front.

The cards were then piloted by ten clinicians from UCLH in their consultations, two using the images (study group) and two without (control group). It was the first time that clinicians had met the patients, the primary goal being pain assessment and development of a treatment plan. In this part of the study, participating patients had not been involved in making the images. They were given the cards in the waiting room before their consultation, asked to pick out any that resonated for them and take these with them into their consultation to use as triggers to facilitate discussion of their pain.

The consultations were filmed, and clinician and patient asked to complete post-consultation questionnaires independently. The video footage, transcriptions and completed questionnaires make up a unique body of material, subsequently analysed by a distinguished multi-disciplinary team, who have all contributed to this publication. The paradigms and their findings are articulated within individual chapters spread throughout the book, by Helen Omand, Deborah Padfield, Elena Semino, Amanda C de C Williams and Joanna M. Zakrzewska, and combined in recent multidisciplinary papers (Ashton-James et al. 2017; Semino, Zakrzewska and Williams 2017; Padfield, Chadwick and Omand 2017; and Padfield et al. 2018).

Structure

The book is divided into four parts: (I) Hearing, (II) Seeing, (III) Speaking and (IV) The future. Each part includes aspects of the central questions emerging from the conference, including: how do we respond when we encounter the pain of another? What happens when our own bodies encounter pain? What tools are available for communicating pain? What contribution do non-linguistic expressions of pain play in its communication? How can we respond better when encountering bodies in pain? Clarification of current thinking on the science of pain and the need to bring together methodologies and expertise from a range of disciplines and cultures to improve our understanding.

The collection is bookended by a Foreword from Rita Charon and an Afterword by the philosopher Jonathan Wolff. Both these authors emphasise the value of attentive listening and effective communication. They highlight the importance of engaging with other perspectives in order to find a shared language for pain as well as the need

for collaborative action. The Foreword opens with Charon's comments, which encourage us to learn from those who live with pain. She also asks: when will medicine learn the urgency of pain?

The second introduction takes the form of an interview with eminent neurobiologist Maria Fitzgerald who 'parks the mystery of pain' on one side to provide a neurobiological explanation against which to set the range of disciplinary perspectives which follow. Addressing frequently asked questions such as whether you can see pain and what the relationship is between physical and emotional pain, she expertly probes the central question underpinning the volume: what is this thing called pain?

Part I: Hearing

Charon's thought-provoking [Chapter 1](#) builds on her Foreword, and draws on a range of material highlighting the high stakes present in conversations about pain in medical environments. She acknowledges the challenges patients face when attempting to translate their slippery and bewildering bodily experiences into verbal language. Her chapter exposes the complexities and 'deep problems of meaning with pain', advocating an openness between the person *with* and the person *witnessing* pain. She concludes that uniting patients and clinicians, both creatively and clinically, can help in mutually developing trust and trustworthiness, enabling patients to tell of 'the serious matters that envelop a life with pain and suffering'.

In [Chapter 2](#) we are reminded of the reasons for this work through the vivid personal testimonies of the core participants who co-created the images: Liz Aldous, Ann Eastman, Alison Glenn and Chandrakant Khoda (in [Chapter 6](#)). They provide moving accounts of their long journey to find accurate diagnosis and treatment. Their experience highlights their courage and fortitude, as well as the extent of suffering they endured before receiving appropriate pain management. The testimonies offer valuable information for other patients going through similar journeys and remind us of the central purpose of this work – to improve patient experience. They provide hope that strategies *can* be found to manage pain and so reduce its impact. They also encourage us to remain open to a wide variety of methods and approaches, which may not always be the conventional ones.

In dialogue with these testimonies, Helen Omand provides in [Chapter 3](#) an art therapist's perspective on the use of photographic

images to communicate pain. She examines the video footage of ways in which these images have been used by other patients to describe their pain via the photograph as an object positioned between two people (patient and clinician) thus forming a clinician/patient/art object triangle. She draws on psychoanalytic theory to illuminate how meaning was grappled with and unravelled. She explores different ways in which the photographs, when placed between two people, became meaning-making objects. In particular she focusses on how triangular relating, symbolisation and transactional uses of the image were explored during the *Face2face* consultations, drawing on three case examples.

In contrast to the theoretical analyses, Rebecca Goss' five 'Pleurisy' poems in [Chapter 4](#) vividly evoke the experience of pleurisy, and the dearth of existing language with which to describe it. Having never previously been ill (the only pain she claimed to have experienced was that of childbirth) and echoing the central theme of this volume, Goss reflects on how she spent much of the time in her sickbed 'mentally trying to articulate' what she was feeling. She asks, 'Where was the language for pain?'

[Chapter 5](#), by Jens Foell, moves from the personal and subjective to the impersonal and interpersonal, discussing more broadly the bureaucratic contexts and politics surrounding pain encounters. While acknowledging that pain influences social and intrapersonal relationships, his chapter focusses on the processes of social administration within which these encounters take place. The chapter explores how healthcare and the welfare system have become fragmented and how interdisciplinary working is the exception rather than the norm. With third sector organisations and independent providers carrying out work which has been outsourced by the Department of Work and Pensions, challenges are created for patients within the welfare and return-to-work programmes. When pain is not represented as an entity in its own right it is not independently coded. Foell concludes that 'Pain without a lesion is a condition charged with moral judgement'. He argues that if persistent pain were identified as a 'thing', as a *disease in its own right*, it could shift pain experience into an amoral space.

Concluding this first part of the book is [Chapter 7](#), featuring a series of photographs of dancer Anusha Subramanyam as she responds to some of the images co-created during *Face2face*. Movement is introduced as an alternative to the stasis experienced by so many people in pain. At the conference, her generosity and invitation to learn simple rhythms through hand gestures brought us all together. This spirit parallels the belief that collaborative action is the way forward. Alongside

the photographs, Anusha's enigmatic and poetic texts remind us of the range of individual and cultural approaches to pain and suffering.

Part II: Seeing

The second part begins with [Chapter 8](#), in which artist Deborah Padfield outlines the rationale behind the use of photography as a way of communicating the subjective experience of pain. Drawing on key photographic theorists, she provides an in-depth discussion of why visual photographic metaphors might help us understand and acknowledge the suffering of others. She articulates ways in which she believes that photographic representations of pain can improve patient-clinician dialogue and interaction.

In [Chapter 9](#), clinical health psychologist Amanda Williams offers a granular analysis of the ways in which these photographic images influenced the non-verbal interaction in a series of chronic pain consultations piloting the images at UCLH. She discusses the social context in which interactions happen around pain, emphasising that multiple factors are at work. She notes that 'both the person in pain and the clinician, caregiver, or other observer are subject to intrapersonal and interpersonal influences'. As context, she discusses other examples where images have been used within communication, and explores notions of empathy and rapport more broadly, exposing the challenges of operationalising emotional skills training and assessment among medical students. Her analysis evidences that when pain images are present, clinicians used more affiliation behaviour. Patient-clinician rapport appears to be enhanced when patients use pain-related images to communicate their pain, but she cautions that the results also suggest surprisingly that clinicians' behaviours 'show more difference than patients'.

Williams uses two case studies to discuss the interactions around the images in nuanced ways, demonstrating the dynamic interchange between speaker and listener. She concludes by asserting the urgent need to find better ways of facilitating empathic interactions between doctors and patients, particularly in the area of chronic pain where there is so much scepticism and uncertainty, arguing that photographic images may be one way of supporting this.

[Chapters 10](#) and [11](#), by Suzanne Biernoff and Onya McCausland respectively, complement each other, the first providing a theoretical lens on the challenge of capturing pain through art, and the second

a practice-based one, exploring sensational drawing and its parallels with touch in the clinic. Beginning with Darwin's search for a means of picturing pain through classical images of transcendence and the Christian iconography of suffering, Biernoff identifies the relationship between physical appearance and emotional response. She draws attention to how *disfiguring* pain – the kind that 'unmakes' the world, as Elaine Scarry puts it – makes a surprisingly belated appearance in Western art. The chapter provides an elegant exposé of ways in which pain in modern art moved from being that which was endured in silence to becoming 'a tool of protest and provocation: an event that transforms the meaning of spectatorship as well as art's contract with beauty and visual pleasure'. Ultimately the chapter raises important questions about pain and its representation, notions of beauty and abjection, and ways in which these are culturally influenced.

McCausland approaches the theme as a practising artist, using touch, sensation and line to explore equivalence and resemblance rather than representation. Based on her workshops, McCausland reveals how the use of collaboration and dialogue, sensation and touch can create 'gaps between words, meanings and marks on paper' and 'open cracks into new experiential insights'.

Minae Inahara's [Chapter 12](#) resonates with the same notion of the 'experiential' through her phenomenological analysis of the self-portraits of Mexican painter, Frida Kahlo. Inahara not only reflects on Kahlo's experience of pain but on her own, arguing that depictions of pain from the perspective of the pain sufferer can help others understand it better. She sees Kahlo's paintings as interlacing body, mind and self, rejecting a mind-body duality and using the chapter to connect Kahlo's paintings to the concept of intersubjectivity. She explores the significance of Kahlo's self-portraits for Merleau-Ponty's notion of the body as expression, where the body is seen as the way in which a human being interacts with the world – both embodied and expressive. Inahara refutes any notion of fixed identity seeing the lived body as expressing subjectivity while gaining meaning from intersubjective relations. She concludes that by 'lending her body to the world, Kahlo changed the lived world with her paintings'.

It is our hope that in some way the fusion of perspectives in this book can equally increase understanding of the lived experience of pain and importantly, help shape future approaches towards it.

Contemporary expressions of chronic pain in social media, their shareability within the world and potential to influence it are discussed

in [Chapter 13](#) by Elena Gonzalez-Polledo and Jen Tarr and in [Chapter 14](#) by Susanne Main. Gonzalez-Polledo and Tarr argue that conventional illness narratives ‘collapse multiple temporal, social, psychological, physical and emotional dimensions of pain’ and that experiences like pain can fall ‘outside the ability of narrative to adequately account for them’. They identify ways in which platforms such as Flickr and Tumblr can act to disrupt cohesive narratives through the ways their materials are accessed and interacted with. It is a fascinating interrogation into the parallel fragmentary and multimodal nature of content within these platforms and the fragmentary and multilayered character of chronic pain itself. As in [Chapter 12](#), the power of vivid depictions of pain by sufferers themselves is signalled, in addition to their ability to evoke sensation and build community. Gonzalez-Polledo and Tarr conclude with a call to clinicians and the public to engage more meaningfully with chronic pain in social media.

In [Chapter 14](#), Susanne Main picks up the same theme with an examination of the role of online exhibitions in sharing creative expressions of chronic physical pain. Main builds on her earlier argument that creative methods may help to communicate pain when language fails. She describes how she developed her online exhibition, *Exhibiting Pain*, in order to increase understanding of the lived experience of pain and as a means of collecting data for her own research project. The chapter includes a poster which clearly sets out her methods and results, which are then discussed further in the text. She asserts that the online platform she uses provides a global reach and that easy access encourages engagement. The contributions act as triggers to facilitate online discussion resonating beyond the visual image and stimulating discussion among those *with* as well as those *without* chronic pain, additionally providing a resource for describing pain to family and friends. Once again, the value to those living with chronic pain of sharing experience is highlighted along with the accompanying reduction in feelings of isolation and the creation of community.

Part III: Speaking

Opening the third part, Joanna Bourke’s [Chapter 15](#) explores the challenge of finding a language for pain and the allure of metaphors. She outlines ways in which these have changed over time with suffering, spawning ‘rich metaphorical languages to aid in communication ...

such as ... the dog that bites, a knife that stabs, and a fire that burns’. Acknowledging Sontag’s problematic relationship with metaphor, Bourke focusses on changing trends in medical debates and language specifically around headaches and neuralgia, providing vivid examples. She identifies ways in which pain descriptions are highly gendered with the increased likelihood of female sufferers being pathologised. Interestingly, Bourke argues that despite the richness of metaphorical descriptions historically, figurative languages for *all* kinds of pain has been ‘progressively stripped from clinical textbooks’. The result, she observes, is that misery has been reduced for the clinician ‘to its separate component parts (nervous, visceral, chemical, neurological, and so on) within the physiological body’ and the ‘patient’s narrative seen as suspect’.

In [Chapter 16](#), linguist Elena Semino asks what happens when people with chronic pain have the opportunity to use visual images when speaking with a doctor. Using a combination of qualitative and quantitative computer-aided analysis Semino presents the findings of a rigorous linguistic analysis of the 17 pain consultations involving visual images from the *Face2face* project. She focusses specifically on the differences between the sections of the consultations in which the images are actively used, and those in which the images are not used. Her findings are fascinating, drawing on analysis of specific extracts of footage and dialogue. Her simultaneous discussion of the role that metaphor plays in communication and thinking about subjective states such as emotions, illness and pain is revealing and sheds light not only on observations elsewhere within this volume, but more widely on the language we resort to when we search for ways to communicate pain.

Following this study there is a shift in register to Sharon Morris’ poignant use of metaphor and startling imagery in her three poems, ‘The tree, spring and well’. The language here is sharp, pricking the reader like needles striking through the ‘heart and thorn at my lips’. Here we touch a world which cannot be communicated through charts or prose, but which reconnects us with our innate feelings, fears and hopes. She skilfully illuminates the spaces placed between words and images, so that multiple meanings hang suspended and we turn towards imagination rather than data.

In contrast, Preeti Doshi ([Chapter 18](#)) explores the difficulties when the metaphors, conceptualisations and language of clinician and patient are not shared, and it is difficult to find meaning within the gaps. She identifies the challenges of managing pain in India, with its diverse ethnicities, religions, cultures and beliefs, and a massive population

of 1.3 billion spread across 28 states and seven union territories. She reinforces the need to rely on patients' narrative when pain itself is invisible and the importance therefore of communication, particularly where there may be a vast disparity of cultural beliefs and pain perception between speakers. She identifies the paucity of systematic epidemiological studies on pain and its management published from developing countries, including India. She also draws attention to the fact that with the considerable increase in life expectancy in the past decade, India has witnessed an unprecedented rise in the number of people struggling to get adequate treatment for pain (National Research Council 2012). Her chapter takes the challenges of pain management beyond the NHS in the UK, providing a broader perspective on managing pain in developing nations. It provides an opportunity to learn from diverse conceptions and visualisations of suffering, identifying the multiple approaches used to address them globally.

Chapter 19 by Abha Khetarpal and Satendra Singh complements these insights, offering a personal understanding of what it means to live with pain and disability in India. The authors identify ways in which pain and disability are inextricably intertwined on social, cultural and economic planes, and explores their relationship in detail. They do this both theoretically and through personal testimony. The struggles of those living with disability and pain are graphically illuminated through the personal reflections from both authors, one describing life as a woman with a disability growing up in India, and one as a male medical student and subsequently doctor with a disability. Hindu approaches to suffering are also discussed. Expanding cultural notions of pain has to be a helpful part of a broader conversation around pain and its meanings. The chapter ends by describing the changes brought about in the Indian medical education system through advocacy by the authors. They assert that through 'encountering pain, by embracing our disability identity and by moving away from medical to social and human rights models of disability, we can bring change. We can bring reforms and policy changes'.

In Chapter 20, Jennifer Patterson takes pain as a multi-factorial experience using multilayered approaches to writing as the most apposite means for its exploration. Taking an interdisciplinary approach to the relationship between pain and language, Patterson argues that since language can change thinking, it offers further potential therapeutic value for pain. She explores a range of ideas about pain located within the broad contexts of many individual worldviews or belief systems (ontology), arguing though that pain itself is still predominantly treated

within the Western biomedical culture. She employs a reflexive and creative feminist approach, or as she describes it, a form of prospective *bricolage* or DIY, which draws, as this volume does, on interdisciplinary knowledge.

It is the enactment of an interdisciplinary methodology that is the subject of Tom Chadwick's insightful analysis in Chapter 21 of the 'Pain: Speaking the Threshold' process and research project, described earlier. Drawing on one-to-one interviews, he reflects on the collaborative process to understand how apparently discordant paradigms can work together productively. He argues that interdisciplinary knowledge can make us wiser in our lives as well as in our understanding of the suffering of others. He concludes that it is 'intellectual empathy' and mutual respect which allows such diverse disciplines to work together, silencing what he terms the 'dismissive voice' and valuing 'critical but respectful, discomfort'. He argues that it is the adoption of what he terms 'intellectual empathy' which allowed us to collaborate successfully and resolve conflicts and tensions as a team when they inevitably arose. His insights have value for other projects.

Part IV: The future

It is the notion of moving forward that fuels the final part of the volume. In Chapter 22, Joanna M. Zakrzewska discusses challenges and recommendations for pain management in the future. She identifies the difficulties for clinicians in appreciating the reality of someone's pain when there are currently no biomarkers to validate the diagnosis. Her chapter outlines the ways in which she has explored the use of metaphors and images as a means of eliciting patient narratives and better understanding their experience. Resonating with the chapters by Semino and Charon, Zakrzewska contends that metaphor provides a profound means of communicating complex information, observations, reflections and feelings. She details a number of ways in which she uses the images produced during *Face2face* in her own pain clinics, and the impact of the images when used in lectures, conferences and exhibitions. Sounding a note of caution about the potential for images to arouse negative as well as positive feelings, Zakrzewska concludes with her hopes that the PAIN CARDS can provide both patients and clinicians with 'another method of discussing pain'.

As a companion to Maria Fitzgerald's introduction to the neurobiological explanation of pain, Bannister and Dickenson provide

in [Chapter 23](#) a companion neuroscientific and pharmacological explanation of why we feel pain and how we can control it. They provide clear descriptions of highly complex neural processes, aimed at the lay reader as much as the specialist. They begin with explanations of how the ‘switch from an acute to a chronic pain state is no longer advantageous to our survival and in fact is wholly detrimental’. Following an examination of a range of pain types and their underlying molecular mechanisms and explanations of both the excitatory and inhibitory systems, they maintain that scientists are beginning to understand the complex links between pain and emotions. In order for pain to be better controlled, the current knowledge we have of the mechanisms of pain needs to be translated into therapy. They reassure readers that ‘there are many pre-clinical and clinical specialists working towards the advent of bigger, better, more effective analgesics and therapies’ seeing the future as ‘hopeful’.

In [Chapter 24](#), Giskin Day draws on the work of Arthur Frank (sociologist and author of *The Wounded Storyteller*) to make an argument about the value of generosity – a characteristic that weaves its way through the texts in this volume. As an expert in humanities education for medical students, she also draws attention to the benefits of exposing healthcare students to similar openness, making them aware of its value in their future clinical practice and patient encounters. She describes the coming together of communities in order to better understand pain through a nexus of theory, experiment, creativity, philosophy and psychology. What emerges, she contends, are *new opportunities* for increased understandings, and the ways in which we can communally make sense of pain. She underlines ways in which volumes such as this and the medical humanities more widely, can inform medical students and better prepare them for complex clinical interactions.

Jonathan Wolff’s eloquent final words in the Afterword also highlight the collaborative nature of this volume and endeavour. He argues that the more we can come together to understand the experience of pain, the more chance we will have of finding ways of managing or mitigating it. Wolff concentrates on issues of communication, seeing the involvement of the arts, and this volume in particular, as a means of opening up new modes for communicating pain and creating ‘a universal new language for expressing pain in its multiple forms’. He observes that communicating how something feels to someone who has never felt it may well require a new set of tools, which the arts might supply.

Concluding thoughts

Japanese culture identifies two additional senses to the commonly recognised five. These are ‘movement’ and ‘the sense of the other’. If these additional senses were paid attention to in the clinic, dialogue might become more fluid, encouraging psychological as well as physical movement, privileging hearing and understanding of the Other over speaking oneself. This correlates with the medieval view of the sympathetic nervous system which viewed *my* feelings as well as *your* feelings as part of the same sympathetic nervous system – itself not so far removed from current mirror neuron theory (Rizzolatti and Sinigaglia 2008). It reminds us that effective exchange requires not only generosity but movement, a shifting of positions in response to the exchange and a sensitivity to, and understanding of, the other speaker.

In the film *Pain Under the Microscope* (Padfield and Omand 2016) screened at the conference, clinical health psychologist (UCL) Amanda Williams observed that

It is hard to think about what people need to communicate without saying that to do so there must be someone who listens, and not just one person who listens but a listening world ... and I don’t *think* that listening understanding world is there. So we can say all sorts of things about what people should express, but that makes them more vulnerable because they meet disbelief. (Padfield and Omand 2016)

This volume aims to be a tool for reducing disbelief, improving understanding and encouraging that ‘listening understanding world’ – an embodiment of the spirit of exchange and interdisciplinarity.

This collection is unique. Its authors are distinguished pain experts, academics, artists and/or people living with pain but it is inherently informed by all of those who contributed to the conference whether through discussion or presenting a poster, paper session, activity or workshop. As the Foreword reminds us, ‘The experts in this landmark conference were the patients themselves. We physicians, nurses, chaplains, physical therapists, acupuncturists and meditation trainers were the students of those who live with pain’.

Recognising this, we invited all delegates to complete the phrase ‘*encountering pain ...*’ using words, imagery or music; the wonderful responses that came back form the images at the start and end of the book (Figs. 0.1 and 25.2).

The pages of this volume are thus imbued with the experience of many voices. As Rita Charon put it in the Foreword, we hope this publication ‘will not just inspire but guide readers towards collaboration, creative vision, and clinical commitment to an ideal – treating those who suffer pain and disability with expertise, with compassion, with hope and with healing’.

The book and its insights are offered as a gift to those who live with, treat, research or represent pain, and it aims to be pivotal in building and retaining a community of people interested in multidisciplinary approaches to the dilemma of persistent pain. We hope you will find the following pages useful. Feel free to contact us with your own responses.

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Introduction II: What is pain? A neurobiological perspective

Maria Fitzgerald in conversation with Deborah Padfield

(Extract from transcript of interview for the film *Pain Under the Microscope*, Padfield and Omand 2016, revised 2018)

Speaker key

- DP Deborah Padfield (Interviewer)
MF Maria Fitzgerald (Interviewee)

*

- DP In this interview, I want to try to untangle exactly what pain is, the process of seeing and perceiving it; and question whether the process of perceiving it can actually change how you experience it.
- So, to start off with, how would you describe pain?
- MF I would describe pain as a neurobiologist because that’s what I am and by that, I mean that it would be a very mechanistic description. I consider that pain is an experience. It is an emotional experience that arises because of activity in specific neuronal pathways in the periphery of your body, and also in your spinal cord and in your brain. So, I see pain as the result of neuronal activity in specific brain areas. However, I absolutely understand that other people see pain differently and some people see pain in a much broader context than that.
- DP I didn’t expect you to say that pain was an emotion because from one of our conversations before there seemed to be a very physiological basis to your description of pain. So, if pain is an emotion, can you describe something about the pain processing

and how that interacts with emotional processing? Or how you do distinguish between emotional and physical pain, or don't you?

MF Without getting very pedantic – we do have to be a bit careful with language here – generally speaking, biologists when they're talking to each other they talk about 'nociception', which is not a word that most people use. It basically means the perception of a noxious stimulus, i.e. tissue-damaging stimulus. The reason that they use 'nociception' rather than 'pain' is because they do acknowledge that pain is a human emotion, whereas, nociception is a neurobiological process. However, in order to improve communication, we tend to use the words interchangeably, which does create confusion, but I think we can deal with that confusion.

Ultimately any experience that we have – me looking at you, listening to my voice, looking at the light through the window – are human experiences that all have underlying them a set of neural pathways that we can follow and trace, and they have the potential to go wrong. As a neurobiologist I could almost say I'm going to park the mystery of pain to one side, instead here is a process that I can understand. I can use that knowledge to try and help the people who are suffering unduly from pain.

DP Would you say emotional processes influence those physiological processes or not?

MF I think it might be good to go back to a simple approach to pain. From the most simple of organisms, something like a snail, right the way through to a human, we have a set of reflexes in common that are absolutely essential for life. Without them it would be hard to live. Those processes or reflexes are often called 'pain' reflexes. If something hurts you, burns you, cuts you, you instantly react to it. Your body puts together a set of reactions, some of them will be obvious ones, like you will move the affected area away. However, some of them you will not be so aware of, for example your heart rate will go up and you will gasp for oxygen, which are reflexes to help you to run away. These are all basic escape and life-preserving reactions that are incredibly important, and you could argue that this is the beneficial side of pain: it teaches you from childhood to avoid anything that might hurt you.

These so-called autonomic reactions cause your heart rate to go up, and make you breathe more heavily, to help you move quickly. These escape reactions are very helpful if you

can escape, but they can become, in themselves, associated with pain. So, if you have those same reactions to, for example, the loss of someone you love or to a very stressful situation, many people begin to use the word pain and it is completely reasonable that they should do so. Whilst I don't have a problem with these emotional reactions being called 'pain', my own view of pain is one that is present in both simple organisms and in all of us from when we are very young. It is a life-preserving reaction to a tissue-damaging stimulus, something that might threaten the integrity of our bodies.

Where I think most people become more interested in pain is when it lasts much longer than that. So, you might have an area of tenderness around a wound that can sometimes last for some weeks. Again, the purpose of that is easy to understand, it is protecting that area and discouraging you from using it because you don't want it to get hurt again or get infected. Lasting pain and tenderness has a purpose – it is there to protect that region. The difficulty is that in some cases an injury leads to pain goes on and on, so that it is not just a life-preserving reaction nor does it have protective benefits; sometimes it doesn't even seem to have a clear origin, like a wound. It is this kind of pain that we don't understand enough about, but which causes great suffering and is extremely important.

DP So that leads us on to chronic pain. Just now you were describing the physiological symptoms and the physiological effect in the body even in the absence of a clear origin. That is *not* emotions affecting pain, and yet a lot of people when they talk about chronic pain describe the isolation brought about by pain, or the anxiety it causes. In these cases, the emotional processing or the emotional state actually affects the symptoms and increases pain, which is almost the opposite of what you are saying?

MF Another thing to understand about pain is that our brain, our central nervous system, has the ability to switch pain off or inhibit it. Again, if we go back to this basic biological need for self-preservation there are situations that we can see specifically in animals, where the obvious pain behaviour will be suppressed if the animal needs to do something else that, in evolutionary or biological terms, is more important. For instance, that might be to eat or, as I said, to run away. Therefore, we definitely have within us, within our brain, the ability to switch pain off or dampen it down. We use that a lot, and can be very aware of it, such as with

distraction. If something is hurting, it's often the case that if we become very involved in something else then it doesn't seem to hurt so much. And that is a basic mechanism whereby the brain is able to modulate the amount of information that is coming to it. This is a kind of feedback loop, if you've got information originally from a wound of some kind, which activates neurons and activates the brain; the brain can then send information back down to the spinal cord and switch off the information at the point of entry.

This is what's called a 'descending control', from the brain to the spinal cord. Its discovery has been extremely important in that it has explained a great deal about how distraction works and how expectation can enhance pain, whilst other types of information can decrease pain. However, I think that it has led people to a conclusion that, if not false then certainly unsubstantiated, that pain can be created by the brain itself. This is the idea that pain, if you like, has no reality, there is no noxious input which is activating those areas, and that the pain has become a fiction or creation of the brain. I'm not convinced that there is any actual real evidence of that.

- DP Are you saying there is always a biological basis or something happening physiologically or biologically? But would you also argue that emotions themselves – loss, grief or loneliness – could not act to modulate or intensify the experience of pain?
- MF I certainly think they could modulate it. It's quite evident that many aspects of our experience and the context in which we are in will modulate the experience of pain. What I meant was that I'm not convinced that pain can be entirely created by the brain as a fiction if you like, as a fantasy, as a psychosis.
- DP I completely agree with you on that one. So, in short, is there a difference between the physical and psychological pain or actually are they always to some extent interwoven? What you've described seems to be some kind of network or mesh, with lots of things influencing each other. Do they separate into different pains or are they always interconnected?
- MF I think separating them is only interesting and important from the point of view of trying to understand the pathways, and trying to heal it. I don't think many people would argue that they do not know the difference themselves between the pain they feel when they touch a hot kettle and the pain of loss. That's not to say that the same word can't be applied, and that some of the same feelings can't be invoked, but there is a difference.

What I'm saying is that maybe during development – and this is a theory, I don't know if it is true – we set up a pathway that allows us to very effectively distinguish a noxious stimulation such that we protect ourselves. It has an aversive effect, we don't like it, it has a unique unpleasantness, and we learn it in order to avoid anything that will damage us. I am speculating that the same pathway becomes, if you like, associated with the pain of loss, of grief, of loneliness and, therefore, we use the same words to describe it. Maybe even some of the same parts of the brain are activated. The use of pain language is very interesting in this context. For example, 'she stabbed me in the back', 'my heart is broken'. These are all noxious events that if they actually happened would hurt a great deal, would make you do anything to heal them, so you use that language to describe the emotion. But I don't think these pains are actually the same.

- DP Do you think those pathways can be remembered by the body? For example, if you have a physical event or an emotional moment followed by another painful event, physically or emotionally, can those pathways get intensified?
- MF They might well be; that makes a lot of sense. But in the end, fundamentally pain is the most intense sensation that we experience. It is not surprising that events that happen in our life, which are extremely unpleasant and cause us a great deal of unhappiness, should be associated with pain and the same language used. However, I do think there is a problem with assuming that they are really the same and assuming they should be treated in the same way. So, when people ask me the question, 'aren't physical pain and emotional pain the same thing?' I answer, 'I don't think so'.
- DP What's really interesting is that it points to the problem that we have with language ...
- MF Yes.
- DP What you are saying is that we use the same terminology for everything we deem to be damaging, threatening, or something that we are averse to. Would it be helpful if we had different terminology?
- MF Unfortunately, in terms of the language of pain I wish I could say more but I'm not an anthropologist. However, I do understand from my reading that this is common in many, many societies not just our own. I can't help feeling there is a reason why we have a

set of physiological reactions that we associate with unhappiness. There is the emotion, but there is also the fact that we can't seem to breathe, you feel like something is crushing your chest, you feel agitated, you can't sleep, etc. These things are all part of the emotion of unhappiness and grief, but they are also the reaction. These are the instant reaction that your body has if it's hurt and I just wonder whether in a sense our brain is almost interpreting them in the same way even though, as rationalists, we know they are different.

DP I am so fascinated. Yes, a lot of the metaphors we use for emotional pain are of damage or of injury, but not all of them are. I wonder if it is just because that is the language we have, and we have no other way of explaining it.

MF It is the best language because it is universal ... everyone understands pain, everyone experiences it, and everybody knows it's aversive and life threatening and bad – there's nothing good about it. What better language to use when you want to explain how horrible you feel? However, whilst it may be effective on a personal level, clinically it causes confusion.

DP It might cause confusion, but it is important to understand what is happening for people emotionally as well as physically when they are suffering from chronic pain – I'm particularly interested in chronic pain, as you know. When someone has had pain for a long time, can talking about and sharing the psychological aspects of their experience help to actually reduce the physical pain levels? Could the issue of terminology impair this? Or is it all actually a physiological process, and the emotions around it are not going to change that physiological sensation?

MF Firstly, I don't think it is just language. I was just addressing your specific question about when neurobiologists talk about pain in a very mechanistic way and people always say to me, 'oh but there's the pain of loss'. So no, I don't think it's bad that we use the same language, but I think we have to be very careful about what it is we are talking about.

So, you asked me the question of whether the context and the emotional state of a person might influence the amount of physical pain that they feel. I think that the answer to that is definitely yes. That has been shown in many, many studies and there are many things that will affect the amount of physical pain that we feel. For example, you and I might be given exactly the same highly controlled noxious stimulus, exactly the same spatial

dimensions, same temperature on exactly the same part of our body. And yet we might well, when asked to score or rate our pain experience, from 1–10 or 1–100, put them at completely different points. Because pain is not an absolute event it is something that we have learned, how we score our experience will depend enormously on our past experiences of pain.

Take a very young child for instance, who is old enough to use these simple scores, which can be either numeric or colour coded. They fall over in the playground and they graze their knee, you look at it and you think to yourself that that must hurt, but it doesn't look too bad i.e. you make a judgement on the basis of your own experience. But the child cries and screams and will almost always rate their pain at the top end of the scoring. In the past there was a view that children exaggerated their pain, that one did not need to take it too seriously, they were 'attention-seeking'. But I interpret it completely differently. This is probably the first, or one of the first pain experiences, the child has ever had and it is, therefore it is the worst they've ever had, so it is right that the score is at the top of the scale. So this is not attention-seeking, it is the reality of the child's experience. And the parent, while concerned, is also thinking that in their own experience, the pain cannot be that bad.

And perhaps another very simple example – which stems from the fact that we all have different experiences as we grow up and experience different things in our families – research has shown that female medical students will often be more concerned about, for instance, the existence of chronic back pain than male medical students are. This is because they have been told a lot by their mothers and their grandmothers about their rheumatism, back pain, migraine, etc. Generally speaking, mothers don't often tell their sons about these things, they are more likely to tell their daughters. This is a major research area, which I'm just touching upon, but what we can take from it is that our understanding of pain is shaped all the time by all kinds of experiences.

So yes, we have these pathways and what our actual perception and understanding of pain is going to be is enormously shaped by our life experiences.

DP I know a lot of your papers are on the development of the pain processes from very early infancy. Can you talk a bit about how the pain system develops? When you were talking just now, you focussed on how the pain experienced by a child is responded to

by the people around them. For example, if they are given support or if they are not given support, will that also become part of their pain processing development, and will that affect how they respond to pain later on? Or is it already set to some extent?

MF One of the interesting things about looking at pain processing in new-born infants is that there are already pain-related genetic differences between them and they have also experienced different environments in the uterus. So, despite the fact that they have relatively little postnatal experience compared to older children, you can already see quite a lot of inter-infant, inter-individual differences in the reactions to a noxious stimulus. As we grow up, a combination of life experience and genetic background determines our own particular sensitivity to noxious stimulation.

In other words, an infant will continue to be shaped by their experiences as they grow up. For example, in animal experiments you can show that a small, localised wound in early life – that heals quickly and from which the animal recovers quickly – if performed at a particular stage of early development, can affect that animal's pain reactions later on in life. When the animal grows up and is then wounded again in the same area it is much more reactive than those animals that had not received that early life experience. Studies of this kind are done under highly controlled conditions, and so how transferrable they are to the human condition is open to question, but they do indicate that it is possible in a mechanistic way to actually alter the future sensitivity of pain pathways from an early injury.

So, for children that undergo surgery or medical conditions when they are young there is certainly a real possibility that their pain pathways are altered. However, the brain is a very flexible thing, it is constantly changing and therefore these children are not going down a fixed pathway of doom, not at all, and there are a great deal of options to change the developmental pathways.

Your parents and your carers are obviously going to influence those pathways too. How could they not? A really good example of this is something that is not particularly traumatic and is to do with the uptake of inoculations. A recent survey performed in Canada asked random mothers in the street – hundreds of them – if they had had their child inoculated and if not, why not. The majority of mothers who themselves did not like needles, had not

had their child inoculated. Even though they were not going to have the injection themselves, because *they* did not like needles and think that needles hurt, they were not going to have their child inoculated. So that is an example of somebody's attitude towards pain, and their experience of pain, having an enormous impact on the health of their child, never mind the child's reaction to pain.

That fear of what is, in the end, a brief needle prick, may in turn influence the pain sensitivity of the child. We all know that some people will brush a pain off and some people will make a great deal of it and this could be the result of 'learned' pain reactivity in infancy.

DP Yes, some things will be much more significant to or meaningful for some people, and a completely different thing will be meaningful for another person.

MF Exactly, there should be no assumption that one reaction is right, and one is wrong. Some people seem genuinely stoical about pain but that is not always good, it may be that they ignore important messages that are telling them that something isn't right. Similarly, people who are oversensitive should not be thought to be attention-seeking or hysterical, as there is a likelihood that they genuinely have more nociceptive input coming into their central nervous system. They could have more brain activity to the same stimulus as someone else.

DP And we don't know why exactly?

MF We don't know why. It is an area of intense research: to what extent your genetic make-up, and to what extent your experience impacts upon your reaction or sensitivity to pain.

DP If you were to have a visual image of pain, how would you visualise it? Do *you* have an image for pain?

MF I have different visual images for different kinds of pain. So, if somebody chooses an image of jagged glass to describe their pain, I think of something very sharp. However, I have a very different image for a kind of whole-body pain. For something like fibromyalgia pain – which is increasingly common, where people generally feel that their whole body hurts – I would visualise maybe a sea of red, like the poppies at the Tower of London, which is a sea of red created by thousands of ceramic poppies that have all been put into the ground of the moat. It is an absolutely amazing piece of art but it made me think of pain rather than of blood.

DP Yes, that links very well with the PAIN CARDS. What drove you to be interested in thinking about pain or researching pain, and what fascinates you about pain?

MF Pain fascinates me because it is such a basic biological sense. Every single living creature responds in a very reactive way to a noxious stimulus. Therefore, as a biologist it is fascinating to understand the pathways that underlie these reactions, while also recognising pain as fundamental to the human condition. I work a lot with clinical colleagues who look after infants and children who are in pain and work hard to relieve this pain. What any parent will say is, please can you relieve their pain or, in the worst scenario, please can my child die without pain? It is such a fundamental desire to avoid pain, not only on our own account but also on behalf of others; we don't want other people to feel pain either. That is such a powerful thing. To me it is more interesting than any other sense – taste, vision, hearing – which are all incredibly important, I don't in any way want to belittle them, but they do not have the power of pain. It has the ability to destroy people's lives. Neuroscientists are beginning to map the pathways, and we should be able to control it better soon. That's why I'm so fascinated by it.

DP In terms of the PAIN CARDS, do you think patients could actually use these images as a trigger to talk about their experience both physically and emotionally? Do visual images trigger a different type of language than just being asked a question?

MF One hundred per cent, yes. Visual images definitely help, especially where language is limited and words are limited, and also where you can be hugely influenced by who you are talking to. Talking to a sympathetic person, somebody who seems to understand what you're saying is different from talking to somebody who doesn't.

Ron Melzack, a Canadian psychologist, developed a classic scale for people with chronic pain that was entirely based on language. The scale divided into words, some of which are to do with the intensity of the pain, some attempt to describe the qualities of the pain and the longevity of the pain and so on. Every year I ask our first-year undergraduates, who are reading neuroscience, to identify a painful event either for themselves, a relative or a friend. It can be a brief experience or a long-lasting one, and they must ask the person who has experienced the pain to use Ron Melzack's scale.

Here at UCL, we are very fortunate because it is a very multi-cultural community and we have students from all over the world and from all different backgrounds, which is fantastic. Many of them say that they went through it with a friend or relative, who didn't know what some of the words meant and also, that the scale is designed for people who find adjectives and adverbs useful for them. So, I would honestly say that the PAIN CARDS have an important role to play, as the patient does not need any language; they can just see the pain in a picture, decide whether it seems to be appropriate for their pain and just give it to somebody, who can look at it and begin to understand what it is that they are feeling. I guess both parties may need a visual imagination, but to me it would be really useful. However, it would not be so useful for infants, and many of the images may need to be adapted for children. But, yes, I think the PAIN CARDS are incredibly important.

DP Something really interesting you said there in relation to what you said in the beginning when you were talking about pain being aversive: I'm wondering if there is something about the physical image that could trigger some similar effects on the body, e.g. sweating or increasing heart rate?

MF It might, I don't think it does for me personally, but it is a very interesting question and could easily be measured. I imagine it could have this effect on somebody who is *in* pain, and it is certainly true that a very sad and unpleasant image in the news can have that effect on people.

Biologically we are programmed, in a way, for pain to be associated with an injury and to go away when the injury goes away. We are all aware that pain can go on and on, but we are a little impatient of it in others. It becomes increasingly difficult for the sufferers to describe how they feel to their colleagues and friends who do not have the pain. So, to my mind, visual images would help a great deal.

DP What do you see when you look down a microscope at a pain neuron, what are you looking at and what do you see?

MF There are not really any 'pain' neurons as such, because pain is an experience generated by a whole intact nervous system. Instead these neurons are responsible for coding noxious input – I can call them 'pain neurons', but I'd rather call them 'nociceptive neurons'. They also appear to, under some circumstances, go wrong in the sense that they begin to send messages or codes as if they are

receiving a noxious input when in fact they are not. In these cases, they are sending information to the brain to generate pain when actually there is no longer any obvious wound or injury there. These neurons are capable of getting into a state of overexcitement, as if they're having little mini epileptic fits. They generate pulses – voltage pulses that all neurons produce – wrongly and inappropriately so that the individual begins to feel pain even though there is no injury or damaged body area.

So that's how a 'pain neuron', as you call it, might be a useful image. If people realise that it is not their fault, it is not that they are going mad, but that instead, for reasons that sadly we don't yet understand, some pain neurons begin to fire their pulses, without an input. Us neuroscientists need to discover ways to stop them from doing that. That is what I mean by taking a very mechanistic approach: you park the emotion to one side and just think, if we could get in there and stop those neurons from behaving like that then maybe we could relieve a lot of suffering.

Fig. 0.3 shows some neurons in the spinal cord that normally receive input from noxious or tissue-damaging skin nerves but also have the ability to go wrong, and do exactly what I described. There are also neurons that are in the brain and which are normally responsible for dampening down, or inhibiting, and stopping pain from getting too bad – these neurons can also go wrong so that instead of dampening pain down, they can start to enhance it and make it worse.

DP And you can physically let me see that?

MF Yes. Neurons are a type of cell and all cells in the body have particular proteins in them, which are unique to them. Therefore, we can use techniques to stain those proteins so that we can associate them with neuronal function. We can also record the pulses of electrical activity in these neurons to measure their role in the pain pathways in the spinal cord and brain.

DP How do you feel when you look at them?

MF Well, I've never stopped loving the visual image of any aspect of the brain. Neurons make the most beautiful image in my opinion. They have a lovely chunky cell body with a lot of machinery in them, because they are so busy all the time. They also have these fantastic branches that spread out and allow them to receive lots of inputs and connect to many brain areas. When I look at them, I just think, what a beautiful thing!

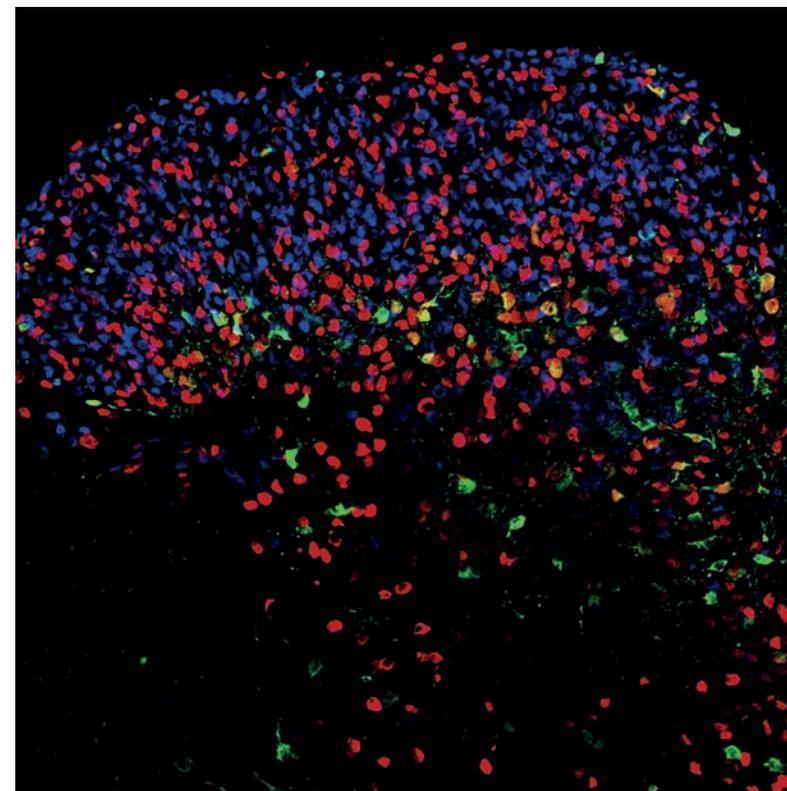


Figure 0.3 A photomicrograph of a section through the dorsal horn of the spinal cord. The brightly coloured neurons receive pain, itch, touch and temperature signals from the body and process the information before transmitting it up to the brain. It is here, in the spinal cord, that pain can be either amplified or dampened down by excitatory or inhibitory neurons depending on contextual information sent down from the brain. In this way levels of attention or expectation, for example, can modulate pain. (Lmx1b (blue, defines excitatory neurons), Pax2 (red, defines inhibitory neurons), RORb Thy1 (green, defines a further subtype of neuron)). Generously provided by Dr Stephanie Koch, Senior Research Fellow, UCL

Part I

Hearing

1

How to listen for the talk of pain

Rita Charon

How pain exposes deep problems of meaning

Unremitting pain is among our most pressing contemporary health dilemmas. Adding to the infectious disease plagues of current and earlier centuries and neck-and-neck with the today's coeval plagues of chronic multisystem illness, untreatable pain – cancer pain, war veterans' post-battlefield disorders and the sufferings of trauma survivors – has become the signature disease of our time (Institute of Medicine 2011).¹ Conflating physical and psychical sources, unremitting pain not only bests our best efforts to control it, but gives lie to the mind–body dualism that, until recently, obscured true attention to the problem of pain. Pain is an etiologically democratic force: it does not discriminate among biological disease, the effects of war, the results of trauma, the sequelae of poverty, the result of mental illness or the consequences of natural disasters. The contemporary opioid addiction epidemic in the United States demonstrates that no class or group is excluded from a risky search for relief from pain, including the pain of boredom and meaninglessness (Murthy 2016; Volkow and McLellan 2016).²

Physical, psychical, existential and oppressive, pain can come, unannounced, to those who have done nothing to deserve it. From forest fires or tsunamis to an osteosarcoma in a 10-year-old, some forms of pain and suffering seem, by nature, to be sacrificial, as if brought either as a test of virtue or a lurid occasion of grace. Other pain seems translational, as if pain becomes the only language for a hurt so deep it is unsayable by the person suffering the pain and inaudible to those who might help to mitigate it (Brison 2003; Barker 1993).³ More sinisterly, sometimes pain is inflicted as a means of transactional messaging: the beheading of *Wall*

Street Journal journalist Daniel Pearl by the Islamic State, the abduction of young Nigerian girls by Boko Haram and the military crackdown on Rohingya Muslims by Myanmar's armed forces are examples of pain inflicted as a means of informational currency in large-scale power conflicts. Finally, some pain is inflicted indiscriminately in order for someone else – for example, slumlords or proprietors of unsafe nursing homes – to reap monetary profit. This is criminal pain.

How we encounter others' pain

There are many uses of the innumerable opportunities a modern life supplies for regarding – at a distance, through the medium of photography – other people's pain. 'Photographs of an atrocity may give rise to ... a call for peace. A cry for revenge. Or simply the bemused awareness, continually restocked by photographic information, that terrible things happen' (Sontag 2004, 19).

Susan Sontag describes the contemporary threat that ubiquitous representations of pain can dull the sensations of spectators to its reality. The bombardment of movies, video games and internet sites depicting graphic wholesale violence has concerned teachers and psychotherapists for decades; such excessive exposure to other people's pain threatens to alter viewers' thresholds for the unacceptable.

In contrast to regarding the pain of others, *witnessing* the pain of others can advance a true acknowledgement of experienced suffering. The Greek chorus in ancient drama enabled theatregoers to vicariously stand by the victims of violence or pain in the play. Truth and Reconciliation Commissions give citizens the means to bear witness to atrocities done in the name of their country, whether in South Africa in the wake of apartheid or in Canada in response to systemic violence against First Nation peoples. The constant public presence of the Mothers of the Plaza de Mayo on Buenos Aires's central plaza steadfastly kept alive the plight of the 'disappeared' during the Argentinian military's Dirty War in the 1970s and 1980s. As I jog around Washington Square Park in New York City on a Sunday morning, I pass a group of Quakers standing under the Arch, silently holding signs for peace. They stand there all morning, enacting for those of us enjoying the park the necessity to add our voices and bodies to struggles for justice and the end to war.

Witnessing the pain of others is a reciprocal act. Such witnessing can afford relief and recognition for the sufferer. And, when authentic, such acts embroil the one who witnesses in some degree of suffering.

Literary scholar Geoffrey Hartman and psychoanalyst Dori Laub established the Fortunoff Video Archive at Yale University to gather videotaped testimony of Holocaust survivors. They emphasise the requirement that the one listening should not treat the testimony as simply data or information, but rather that the witness enter the effort of the one giving testimony to find and articulate the core of the experience being relived (Felman and Laub 1992). When the listener is able to achieve such authentic listening, he or she is exposed to the presence of the evil suffered, getting 'second-degree' trauma, or what those who work in trauma care call the 'traumatisation of the listener'.

There is a reciprocity not only to receiving testimony, but also to giving it. Hartman describes how the Holocaust survivor experiences a reciprocity even within the self, in effect, witnessing oneself witnessing:

If authenticity is to prevail, the survivor as witness to the traumatic event will be at once a first person and a second person: one who is able, despite everything, to say 'you' to the self that has remained, one who seeks an 'I-Thou' relationship with a disappeared or damaged self. (Hartman 2002, 19)

How powerful an act it is to tell of one's pain. Through the process of articulating the world of suffering in the presence of one committed to authentic listening, the teller meets and recognises the suffering self, perhaps helping the process of reintegration of the suffering self with the knowing self.

Pain as an intersubjective event

The Death of Ivan Ilych is perhaps the best-known fictional representation of unwitnessed pain and suffering. St Petersburg lawyer and judge Ivan Ilych suffers a horribly painful terminal illness alone, severed from his family and friends by their refusal to acknowledge what he suffers and by the pervasive deceit that prevents any of them from frank confrontation with his plight. He is rescued from his torture when he recognises the suffering that his disease causes in his young son; by compassionating his family, his own pain diminishes:

And suddenly it grew clear to him that what had been oppressing him and would not leave him was all dropping away at once from two sides, from ten sides and from all sides. He was sorry for them,

he must act so as not to hurt them; release them and free himself from these sufferings. ‘How good and how simple!’ he thought. ‘And the pain?’ he asked himself. ‘What has become of it? Where are you, pain?’

He turned his attention to it.

‘Yes, here it is. Well, what of it? Let the pain be’.

‘And death ... Where is it?’

He sought his former accustomed fear of death, and did not find it. ‘Where is it? What death?’ There was no fear because there was no death’. (Tolstoy 1960, 155–6)

Within healthcare professions and the lay public, there is a growing realisation that pain is an intersubjective event. Not only is the transaction a reciprocal one with suffering on both sides, it also brings the full subjectivity of both sufferer and witness into pain’s act. The only instrument that can register the presence and intensity of pain is the human witness, because pain has no objective outward signs or biological markers that can be measured and confirmed. Asking a patient to rate the level of pain on a scale of 1 to 10 – an absurd effort that, in retrospect, we learn was introduced into clinical practice with the help of the pharmaceutical industry trying to enlarge the market for opioids – has led only to confusion about experienced pain (Keefe 2017). We might consider pain to be, primarily, a semiotic phenomenon. Whether in the parlance of anaesthesiologists and neuroscientists who speak of ‘nociception’ as the noxious sequela of tissue damage (Coakley and Shelemay 2007) or in the parlance of poets and memoirists who tell us that ‘pain has an element of blank’ (Dickinson 1924) we can but treat pain as a signal from deep inside one person that is emitted first to alert the sufferer that some damage is underway and then to communicate its presence to another, if only to the anonymous reader.

‘Intersubjectivity’ refers to the contact possible between two persons, not when they are present in their social or bureaucratic or economic roles but when they are present as their full selves, as that entity they refer to when they say ‘me’. The German philosopher Edmund Husserl, who established the philosophical field of phenomenology in the early twentieth century, posited the concept of intersubjectivity as a means by which two subjects can apprehend one another’s independent existence through a practice of mutual empathic recognition. Such recognition enables both an awareness of self and awareness of an Other within a shared sense of the life-world of humans

or the home-world of a particular culture or community. The process of intersubjectivity starts with what Husserl called the ‘phenomenological reduction’: one puts aside or brackets the ‘natural attitude’, defined as commonly held understandings of phenomena in the real world. Bracketing is necessary in order to actually perceive something or someone in the world, to perceive it freshly and without bias, rescuing the perception from the homogenising absorbed assumptions that can distort a view of the authentic. The phenomenologists who followed Husserl, including Maurice Merleau-Ponty, Edith Stein, Jean-Paul Sartre, Emmanuel Levinas and Paul Ricoeur, added to Husserl’s insights regarding the human being’s capacity to perceive, with full subjectivity, the presence of another. Levinas regards the confrontation with the Other as not only the start of ethics but the start of subjectivity itself: ‘A calling into question ... is brought about by the other. We name this calling into question of my spontaneity by the presence of the Other, ethics’ (Levinas 1969, 43).

Psychoanalysts have deepened the meaning of intersubjectivity in another direction, describing the human being’s capacity to pierce the boundaries of another’s self, often wordlessly, towards experiencing that other’s inner world (Bollas 1987; Loewald 1980; Mitchell 2000).⁴ In the well-going analysis, the analyst comes to recognise the analysand’s ebb and flow of tides of feelings, the stops pulled, the barriers raised, the gates of trust opened, one crack at a time, while the analysand finds the unexpected and unexperienced freedom to escape irony, to let fly, to do without the usual defences because of finding themselves in the presence of safety instead of existential danger. Over years, conditions of freedom happen. The patient comes to recognise their hiding from the self and then can choose to avoid doing so. He or she comes to enter and experience feelings previously forbidden – rage, lust, profound tenderness, dependence, trust. All this takes place between two persons who simply talk to one another, in one another’s presence. It gives promise for the good to any situation where two human beings make deep commitments to hear one another out, to respect the gravity of what is learned about the other, to reflect back what one hears and comes to know, and to forget nothing.

So, to say that pain is an intersubjective phenomenon means that it is constituted by several entities – the consciousness of the sufferer, of the witness, of the sufferer’s entourage, sometimes of the one who has caused the pain to begin with. Recognising the intersubjectivity of pain calls for many fundamental changes in routine healthcare: family members require intensive care for their own wounds. Clinicians need

expert care in response to their own sense of loss, sometimes guilt, always sadness. In the presence of trauma or violence, the perpetrators of the suffering must also be called upon to give accounts of themselves, either as individuals or in collective acts of reconciliation. Because pain is a universal truth in a life lived in time, all involved as witnesses of anyone's pain come to recognise their own futures in the pain of another. Such universalising of the existential being-in-time profoundly changes the nature of the relation between sufferer and carer, calling us to discover our standing as fellow mortals in the face of time.

The telling of pain and the listening for pain

Pain does not only happen during terminal illnesses or in acute care hospitals. Most routine general practitioner visits contain descriptions of pain. Yet even these more routine episodes of pain are difficult for patients to express. Perhaps by examining why 'routine' pain is hard to describe, we might have more insight into the complexities of expressing severe pain.

Because pain is a multimodal experience without commonly understandable or sharable metrics, anyone finds it hard to describe his or her own pain. It is not the same as saying 'cherry red' or 25° Fahrenheit. Words come slowly to most persons who try to articulate what their pain feels like. Scholars and artists have turned to visual depictions of pain to better communicate the sensations being endured (Padfield 2003). Even with words at the ready to articulate a sensation, some patients may withhold from their physician a description of pain because of their fear of what it might connote. Patients may not realise what is 'worth' telling their doctor. Elements of power and powerlessness enter these scenes of telling, for doctors or nurses or therapists control how much time is given for a medical appointment and what kinds of things merit discussion. Some symptoms are embarrassing to discuss, either because they are in an intimate part of the body or they may have been caused by something the patient ought not to have done. To admit to symptoms is for some people diminishing, taking away from a sense of self as strong and inviolable. All of these factors are common and can silence a patient from even mentioning a symptom of pain.

Ordinary language may not be adequate as an avenue to tell about pain. I have found in my practice that patients often use detours in conversation to arrive at a description of their pain. One patient, a

jazz bass player, could not even talk about the post-operative pain he suffered since major abdominal surgery. Instead, he told of his deep regret that he could not stand with his bass through a set. He was beset with great loss, lethargy, hopelessness along with anger towards the surgeon who, he thought, must have botched the operation to have left him with such pain. Why had he even agreed to this risky operation if this life with pain would be the result? I remember talking with him about jazz musicians that we both knew – I live in Greenwich Village in New York City and have come to know a fair bit about the contemporary jazz scene. We met not over his abdominal CT scans but over Ron Carter's unending brilliance and what about that phenomenal Christian McBride? Somehow, after two or three visits pretty much devoted to jazz – and also getting results that showed good progress since the operation – the patient could listen to my explanation of the pain of post-operative adhesions and could try the simple means I described to lessen the pain. He was gradually able to hear my assurance that he was, in fact, healing from the operation and that he could look forward to resuming his life in music. Some months later, he springs into my office for a follow-up visit, and with dramatic flair says, 'I got a gig to play at Lincoln ... Hospital!' Playing music in the lobby of the local city hospital was just as great for him as playing at New York City's famed Lincoln Center!

The most complex uses of language are recruited in describing pain, not just by the metaphysical poets but by all of us common sufferers. Another patient with diffuse and migratory symptoms said that as soon as he drank anything, it came right out the other end. He seemed so fixated on this feature of his illness. I remember asking him, 'Is it as if you're a metal pipe that water flows through?' He says, 'Yes!' with great energy, as if I were the one to have come up with the image and not he. And what a strange image it was, the more we inspected it: emptying out his own body and replacing it with the inorganic, cold outlines of plumbing. By our use of his own visualised representations of his body in our conversation about his illness, we were able to stay focussed on his phenomenal experience of his symptoms without escaping to abstract pain scales or hackneyed overused adjectives. We were working from *his* database of sensations towards a far more explicit and accurate shared understanding of what he was going through. In this case, the use of a complex metaphor tipped me off to the depth of work this patient was undertaking to undergo and represent to me his bodily sensations. (I cannot tell whether the clinical benefit flowed from the productive interpretation of the metaphor or simply the effort to

take the metaphor seriously, but I am confident that the acknowledgement of it was important for the eventual good outcome.) Although it took a long time and consultations with many brilliant specialists, his symptoms were finally diagnosed as a rare neurological disorder whose treatment has dramatically ameliorated his symptoms.

Many factors interfere with the listening for pain. Clinicians listen to their patients within diagnostically salient frames of reference. They hear with more fidelity patients' utterances that point to a specific diagnosis that might, in turn, point to a helpful intervention. So, a complaint of crushing, sub-sternal chest pain (suggesting coronary artery disease, a condition we know how to treat) will elicit far more interest than will a complaint of migratory, non-localised, fuzzily described total body pain. Implicit bias and prejudice can cause clinicians to disregard complaints of pain offered by a patient – certain cultures are thought to have low pain thresholds; persons who are substance users will almost invariably be thought to be magnifying pain in order to obtain pain medicines (Hall et al. 2015). Doctors are trained to make decisions, and many of them are intolerant of ambiguity or uncertainty. The premature jump to closure, often leading to a faulty conclusion, is the casualty of the refusal to live in doubt (Morris 1991; Belling 2012).

Although medical and nursing schools and clinical training programmes realise that they have to give their trainees some sort of skills for listening to their patients, typically short courses in 'communication skills' are thought to be adequate. Sadly, such communication skills sometimes amount to providing some scripted lines ('sorry for your loss'), canned quasi-emotion ('I know how you feel') or routinised responses to complaint ('we'll see what we can do about that'). Since patients' memories of having been ridiculed or scorned have long lives, lack of skill in listening to patients and respecting their concerns may diminish the effectiveness of care throughout a patient's career of illness (Thernstrom 2010).

Listening *for* pain requires personal commitment, bravery, generosity in the use of the self and a battery of hard-won skills. These skills are necessary in all realms of healthcare, from intensive psychoanalysis to routine primary care. Perhaps the clinicians with most need for and most benefit to be gained from the rudiments of training for listening are 'clinicians of the body' who practice their discipline without a psychological or mental-health focus on emotions, language or relationships. They are often the ones to whom are offered those first, tentative, pivotal descriptions of pain. If a physician or nurse

or physical therapist were to dismiss an early description of pain, there might not be a second chance to hear it. Yet if they register the gravity of the complaint and demonstrate a desire to join with the patient in addressing it, they open a door towards a future of care.

Close readers, radical listeners

My colleagues and I in the Program in Narrative Medicine at Columbia University in New York City have introduced the practice of teaching the skills of close reading and creative writing as a means towards deepening the listening capacity of our learners (Charon et al. 2017). Briefly, close reading is what used to be restricted to literature majors or creative writers: the kind of reading that reads and rereads and rereads, the reading in which every word counts, in which importance is attached to the words themselves and to what they point to, to the plot, to the form, to the music of the language. It is a reading aware of the time frames, space frames, figural language and frames of reference of a text. The close reader is one who values what language conveys, who treasures the words, who does not squander the evidence of talk.

The best way to establish close reading as a habit is to pair it with creative, responsive writing. Whenever we teach these skills, we guide learners in very close readings of texts or very close inspection of visual images. (Close looking is akin to close reading). We have been expanding the media of our texts to include visual arts, cinema, sculpture, drama, dance and music, because the closeness of attention can be achieved with all these visual and audial forms. These different media hold in common the capacity to represent some reality so as to convey it to another (Alber 2017). We follow this *perceiving* stage with a *representing* stage in which learners write – freely, spontaneously, first-draft – in response to an expansive writing prompt that does not restrict the writing to a particular topic or genre. When students read aloud what they've created in a few minutes to their colleagues, they discover what they didn't even know they knew! Hence is proven for them right there in class the power of reading, of seeing and of conferring form, through composing the written text, onto their own arising thoughts and sensations and realisations. Narratively trained clinicians use these skills in routine practice, writing their impressions of a complex encounter with a patient to discover themselves what they have perceived about the patient. Showing what they've written to the patient proves to the patient their desire to understand and often

deepens what the patient chooses to share next: it is a narrative path towards clinical intimacy and trust (Charon 2012).

The next step in this creative pedagogy is to recognise the parallel between close reading or looking and close listening. The close reader learns to hold in mind multiple contradictory interpretations of statements or multiple contradictory versions of events, and these capacities can migrate to their listening practices as they learn to 'listen like a reader' in close listening. To be a close listener is to accept paradox, ambiguity and doubt; to not prematurely foreclose on the meaning of what is said. We have of late been calling this form of listening 'radical listening' to bring into view the power of listening to another without exporting one's own implicit biases, one's limited worldview, one's private calculus of value or worth onto the utterances of another. Repeating Husserl's practice of bracketing in the phenomenological reduction, the radical listener intentionally sets aside the 'natural attitude' of one's own beliefs and prejudices to open the self to whatever is being emitted by the teller, framed within that teller's worldview and imagined from the originating perspective. Imagine how such radical listening might change what happens in the clinical setting, the political setting, the religious setting, the highly polarised and divisive settings that now are endangering us all (Gilligan 2015; Fullilove 2013; McCann n.d.).⁵

The close reader and the close listener will let themselves be transported where the words bring them. Enchantment and recognition occur with regularity for the reader/listener who is not a suspicious reader bent on ferreting out secrets or adept at getting *under* what the speaker says to what he or she might *really* mean (Felski 2008).⁶ Instead, a different covenant between speaker or writer and listener or reader emerges: they give one another 'the benefit of the doubt' and, simultaneously, the benefit of doubt. We try to encourage in our learners the practice of focussing on the text itself, the habit of inviting and recognising all possible meanings and the experience of *joining* with the teller (be that a long-dead author or a patient sitting with one in the clinic) in creating meaning from whatever code has been used to represent it.

We have brought our teaching of close reading and close listening to a great variety of learners. The graduate students in the Master of Science in the Program in Narrative Medicine at Columbia and its associated Certification of Professional Achievement online course rely heavily on the skills of close reading and responsive writing. Under narrative medicine's guidance, medical students at Columbia University

are required to write in their portfolios, electronic archives where students collect all their writing and visual artwork over their four years of medical school. A faculty member, who has received rigorous training in close reading himself or herself, is allowed to read and respond to the portfolio writing that a student elects to share. This faculty member accompanies the student throughout the four years of training becoming an ever-more-capable reader for the student, whose writing typically increases in its capacity to capture and represent very complex lived experience in the course of medical training (Cunningham et al. 2018).

Beyond academic settings, we have brought the teaching of close reading and responsive writing to inmates in prisons, trauma survivors, patients with dementia, high school students aspiring to health professions, persons living with cancer, students and trainees in multiple health professions and clinicians of many specialties and disciplines. In all these settings, we coach readers and those who look at visual images to take in all that the medium is able to emit in an effort to expand their 'bandwidth' when meeting with patients. We have found that such training leads to self-awareness and effective collaboration among members of groups. Narrative medicine methods improve the functioning of healthcare teams and curbs the emotional exhaustion of clinicians' burnout. Current research underway at Columbia is examining the longitudinal writing of medical students as they traverse the identity-shaking ordeals of becoming doctors; our preliminary findings point to the capacity of students' writing itself to show them things about themselves (Miller et al. 2014; Sands, Stanley and Charon 2008; Charon, Hermann and Devlin 2016).⁷

The healing word

Think how clinical care for pain might improve with deep attention to the language of pain. With commitment and skill on the part of clinicians to listen unguardedly for the pain, and with risky willingness on the part of patients to tell of what they undergo, the ground of care will shift. Gates of trust will open to allow truth to be spoken and heard. Creative efforts will be poured into the larger purpose of letting one person's lived experience be heard and comprehended by another. Patients will feel confident that their clinicians really want to know all the salient dimensions of their suffering and not only those that deal with physical or biological aspects of their situation. They will be free, because of the mutually developing trust and trustworthiness, to

tell of the serious matters that envelop a life with pain and suffering. Because both patients and clinicians accept that they live in this world of time, they will recognise themselves as fellow mortals, all contained within the human conditions of limited time. United existentially, they will be united creatively and clinically. Instead of existing at objective, clinical, arm's-length distance, they will move near one another towards recognising and then relieving whatever parts of suffering can be lifted, in both the patients and the clinicians. This will bring a new day for healthcare.

Notes

- 1 *Relieving Pain in America*, a report prepared by the Institute of Medicine, gives an overview of the scale and scope of the pain crisis in the US.
- 2 Murthy (2016) and Volkow and McLellan (2016) outline policy proposals for addressing the opioid crisis and discuss the complications of treating pain in the climate of the substance abuse epidemic.
- 3 Susan J. Brison tells of being brutally raped in the mild countryside of the south of France; her writing of her ordeal had to wait over two decades for her to gather the wherewithal to tell of it. Pat Barker has written brilliantly about the telling of pain in the *Regeneration* Trilogy set in the First World War British army, especially in *Regeneration*.
- 4 See Bollas (1987); Loewald (1980); and Mitchell (2000) for psychoanalytic theories of authenticity and intersubjectivity in analytic practice.
- 5 We have been working with such scholars and activists as Carol Gilligan, Mindy Fullilove and Colum McCann in developing training workshops in radical listening. See Gilligan (2015); Fullilove (2013); and McCann (n.d.).
- 6 See Rita Felski's marvellous *The Uses of Literature* for discussions of transport, enchantment and recognition in acts of reading.
- 7 See Miller (2014); Sands, Stanley and Charon (2008); Charon, Hermann and Devlin (2016).

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2

Three testimonies from those living with pain

Facial pain: Managing facial pain through creativity

Liz Aldous

Prelude: Summer 2009

The summer of 2009 presented me with another challenge: in coming to terms with the development of a very worrying and unexplained facial pain and severe unrelenting toothache. It resulted in numerous appointments at the dentists, antibiotics and root canal treatments, which did nothing to help the agony but actually served to make the situation worse. Eventually, when there was no other option, the decision was made to extract what turned out to be a perfectly healthy tooth. As it happened, at the same time, a very close friend of mine was experiencing almost the same pain herself on the rounds of referrals and appointments. This was some comfort, but also left me feeling that I was in some way hijacking her pain, as she was unable to work and we would regularly talk about the things that in some small way were helping in our desperate pact to have some relief.

The pain continued through the cold winter of 2009, at which point I sought medical advice from a specialist via my partner's private insurance. MRI scans were performed and I received a steroid injection into my right temporal mandibular joint (TMJ) but this had little effect. This served no purpose other than to worsen my already high level of anxiety and the pain heightened to its worst, requiring oral morphine.

I was told I was suffering from a form of neuropathic facial pain and was prescribed yet another medication to help me to manage this. The biting wind and extreme cold weather exacerbated the pain, cleaning my teeth was like an electric shock, opening my mouth was becoming more



Figure 2.1 Deborah Padfield with Liz Aldous, 'Untitled' from the series *Face2face*, 2008–13. Digital Archival Print. © Deborah Padfield

difficult and even having a shower was an ordeal. The pain never left me and, in the evenings, when I tried to sleep, it seemed at its most vicious: the silence of the night and lack of distraction amplified its grip.

It is worth explaining that I was also managing another chronic long-term illness, having been diagnosed as having chronic fatigue syndrome and fibromyalgia in 1989. These illnesses had already managed to rob me of many years of my life, and had affected my career as an occupational therapist and left me unable to fulfil many of my life ambitions and goals. I was therefore very familiar with never feeling well, but this was an altogether different unrelenting and unforgiving pain.

Eventually, via my dentist, I was referred to the Eastman Dental Hospital, where I was first assessed in spring 2010. I was diagnosed as having phantom tooth pain, atypical facial pain and temporal mandibular joint dysfunction (TMJD), now known as chronic idiopathic facial pain. This had been, and continued to be, one of the most distressing times in my life. We had just moved into a new house, I had just gained my foundation degree and we had a lovely new puppy – but I was unable to enjoy any of this. In fact, I was unable to enjoy anything full stop. I read numerous articles about these conditions and tried in my usual proactive

style to find out what I could do to help myself. I was devastated to realise that I now had another medical condition for which there was NO cure and yet something else I would have to learn to live with. I did feel a sense of security from knowing that I was receiving help from the leading specialists in this field, but this was coupled with an overwhelming sense of fear and dread as to how on earth I could manage to cope with this. In the UCL publication 'Easing the pain through art' (Pillay 2011) I explained 'The pain had spread to my neck and ears. I couldn't eat, swim, sing, work, or do any of the things I love. Imagine the worst toothache, earache and neck pain every single day of your life. It makes you very depressed.' I was no longer working as an occupational therapist, but had begun to work a small number of hours at a local charity for young people, who were not in education, employment or training (NEET), where I ran art sessions. I can think of so many times where I wondered how I managed to do this, but with huge amounts of willpower, medications, heat packs, stretching exercises and support from my partner, I managed to continue with this work.

Following my assessment at the Eastman Dental Hospital, I was offered a chance to work on a project called *Face2face*, with photographer Deborah Padfield (then artist-in-residence at UCLH and PhD candidate at Slade School of Art). It was explained that this would not be an art therapy project, but a chance to explore ways to visually communicate facial pain, using photography, and working on a one-to-one basis. Having recently completed my foundation degree, and with my background in textiles and design, this sounded very interesting and I was more than willing to take part. The photographs would help to form the basis of a project piloting a pack of PAIN CARDS to be used as new communication in NHS pain clinics. This proved to be one of the best decisions I ever made and further helped to reinforce my personal beliefs in the power of creativity in helping to manage facial pain.

Face2face

My sessions with Deborah Padfield began in spring 2010. This involved initial sessions at the Eastman Dental Hospital, where I began to work on ideas, collect materials and take images.

My initial concept was using newspaper text and my numerous medications.

At one of the sessions, I placed a small craft peg on my lips, Deborah captured the impromptu image: this is now one of the most

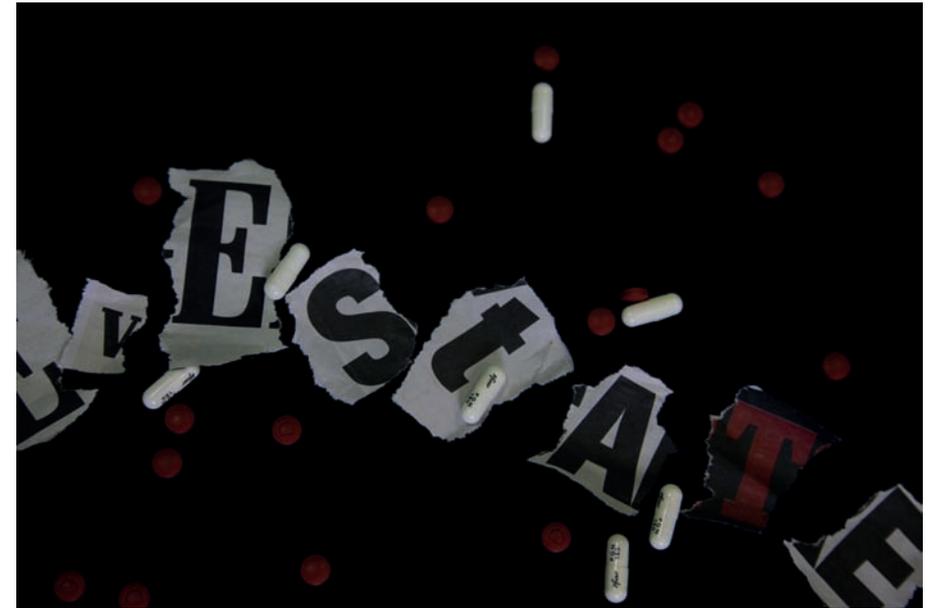


Figure 2.2 Deborah Padfield with Liz Aldous, 'Untitled' from the series *Face2face*, 2008–13. Digital Archival Print. © Deborah Padfield

popular images in the final pack of image cards to which people can relate (see Fig. 2.3).

The ideas further developed, and we travelled to East London to capture the essence of derelict and decaying buildings: the once useful but crumbling buildings strongly represented my pain. My own teeth were grotesquely superimposed over the image, and I quoted 'and again everything is falling down, that's typically what happens when it occurs. Everything goes wrong'. This image is used at the beginning of this chapter (see Fig. 2.1).

I made a small rag doll with my own face upon it, the doll looked lost and small, very sad and very depressed, and no longer strong. This doll was taken to various locations and photographed.

This pictorial journey was always very interesting, and Deborah worked with me, showing great sensitivity, sometimes it was amusing and sometimes very emotional (see Figs 2.4 and 2.5).

Some of the images we produced in this collaboration were used as part of the final set of 54 PAIN CARDS.

The confidence that I gained through working with Deborah reawakened my own interests in becoming more involved in local



Figure 2.3 Deborah Padfield with Liz Aldous, 'Untitled' from the series *Face2face*, 2008–13. Digital Archival Print. © Deborah Padfield



Figure 2.4 Deborah Padfield with Liz Aldous, 'Untitled' from the series *Face2face*, 2008–13. Digital Archival Print. © Deborah Padfield

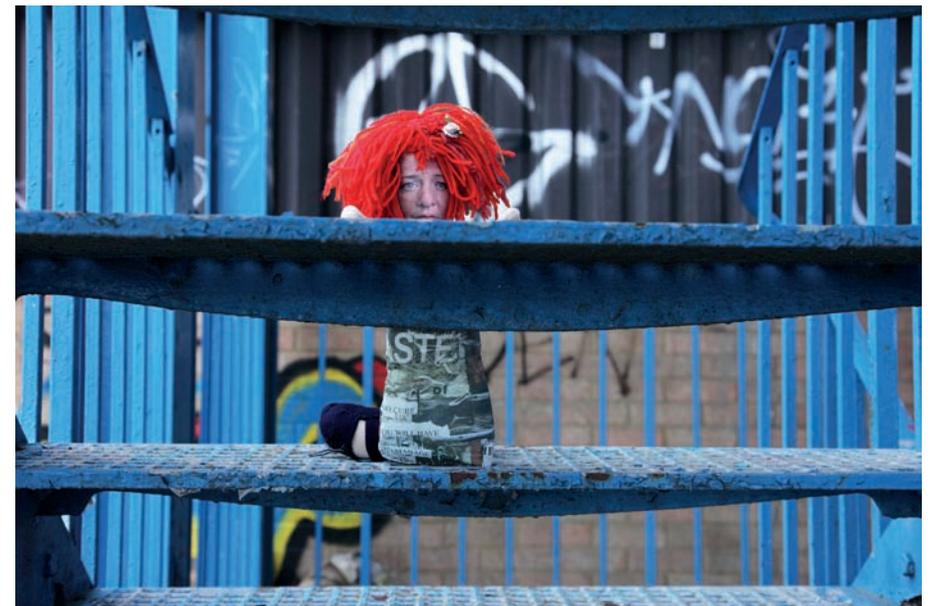


Figure 2.5 Deborah Padfield with Liz Aldous, 'Untitled' from the series *Face2face*, 2008–13. Digital Archival Print. © Deborah Padfield

community arts within Luton, and I became involved in a project called High Town Art For All (a popup group of local artists running a community art space in a disused shop), where I took the opportunity to run and develop a series of community art shops. I was still coping with a huge amount of pain, but being involved in something I enjoyed meant that the distraction was an analgesic.

The small red-headed doll's face changed: she no longer looked sad, I had re-engaged with my creativity and decided to take the bold step to work enough hours that I no longer needed state benefits.

It was around this time that I was asked to be interviewed about my experiences of this project: This was published in February 2011 by UCLH – 'Easing the pain through art' – authored by Deenan Pillay.

As well as focussing on the pain through the art project, my individual sessions with the team's specialists proved invaluable, as did meeting fellow sufferers in the pain management group.

The *Face2face* project as facilitated by Joanna M. Zakrzewska, with Deborah Padfield, allowed me a chance to tell my story, to feel listened to and also to develop my own belief in my ability to identify triggers, reduce negative thoughts and improve my sleep.



Figure 2.6 Deborah Padfield with Liz Aldous, 'Untitled' from the series *Face2face*, 2008–13. Digital Archival Print. © Deborah Padfield

In July 2011, I was invited to attend an exhibition (*Mask:Mirror: Membrane* at the Menier Gallery in South London), where the work Deborah and I had collaborated on was exhibited. Some of the images exhibited were those used on the PAIN CARDS.

It was a chance to share some of my experiences with other sufferers, carers, professionals and members of the public.

The exhibition also provided me with an opportunity to see how I had continued to develop my own coping strategies for dealing with my facial pain, which although still there, had reduced significantly and had less impact on my life.

As an occupational therapist within the mental health services I have been able to use the knowledge and experiences gained from the *Face2face* project within my own work. I encourage my patients and clients to visually express their emotions, feelings of loss and desperation but also of hope and recovery in a creative way. I have done this individually and also within a group setting.

I strongly believe there is so much scope to develop these ideas. To have a set of cards that visually show images of psychological and emotional pain would be of huge benefit within the realm of psychiatry and when completing mental health assessments.

'Encountering Pain' conference

In 2016, I was invited to speak about my experiences of being involved in the project at the 'Encountering Pain' conference at UCL. I was able to contribute by facilitating a workshop as part of the two-day conference. Working with Zakrzewska and Deborah Padfield, I was excited and proud to be part of such an innovative and exciting collaboration, which proved to be the first of its kind and a huge success.

To me it was an event that synthesised the valuable relationship between art and medicine. Also, during 2015, I managed to achieve a lifetime ambition of raising money and volunteering abroad in Greece, helping refugees affected by the war in the Middle East.

Life continues ...

By February 2017, I finally returned to working as an occupational therapist for a local eating disorders charity, having earlier in the year



Figure 2.7 Documentation of the 'Encountering Pain' conference at UCL, 2016. © Nir Segal

volunteered abroad for the third time. In May I was cycling to work for the first time in years, was embracing a relatively pain-free lifestyle and was actively involved in a number of community arts projects. Over the last year, I had considerably reduced all of my medications with a view to becoming drug free. I was seen at the Eastman Dental Hospital in June 2017, where it was felt that I was managing my pain and no further treatment was required: I was discharged.

However, as with any chronic condition, and certainly as per my experience of my other conditions, there is always the potential to relapse. My facial pain returned and brought with it the overwhelming sense of fear and lack of control. I was forced to increase my medications and once again, in desperation I tried to revisit and put in place my well-tested coping strategies. I began to wonder what may have triggered this relapse; had I done something to cause it? I was at a total loss to arrive at any conclusion. This proved to be yet another very challenging and testing time. I was fortunate enough to be able to have a consultation with Zakrzewska. It appeared that my overzealous approach to life meant that I had forgotten to pace myself and was over-committed. In our discussion it was suggested that I should reduce some of my activities and commitments.

Pacing myself has always been difficult for me, but I have learned that this is the only way to prevent relapses both from my ME and facial pain. I have also learned not to fear these relapses and that they do not have to last as long as they once did.

I am grateful to Zakrzewska and Deborah Padfield for their support, kindness and belief in me. There is no doubt that my initial involvement with the *Face2face* project has helped to shape my career and passion for using creativity to manage my own pain.

I have been able to harness my own experiences and have used considerable effort to help others through their problems through creative participatory arts projects across our town. These have earned me recognition: the projects themselves have won various community awards and in December 2016 I was awarded Lutonian of the Year in recognition of my dedication. In early 2018 I was diagnosed with stage II B breast cancer which came as a complete shock. Appropriate treatment was offered, and I made a life-changing decision to not take chemotherapy. This wasn't a quick decision – it was based on 'Predict', a scale which outlines the percentage of life expectancy based on treatment, which for me was only a difference of 6 per cent. Taking my facial pain and existing health conditions into account, physically and emotionally, I would not have been able to cope with it. To this day, I know that for me this was the right decision.

Following surgery and radiotherapy, and knowing the value of art and being creative, I began creating canvases as thank you gifts for all the different people and departments at Mount Vernon Hospital and Luton and Dunstable Hospital which were all gratefully received and proudly displayed.

Following treatment, I returned to work as occupational therapist with the eating disorders charity. I continued to incorporate the use of imagery alongside the cognitive behaviour therapy protocol for eating disorders as a way of encouraging my clients to discuss their relationships with food and emotional states. This proved to be very powerful and not dissimilar to the way in which the PAIN CARDS are used in consultation.

Unfortunately, in the autumn of 2018, following an introduction of a drug to prevent creation of oestrogen as part of the anti-cancer treatment, along with what had been a very stressful period in my life, I started to become unwell and my mood deteriorated. I was eventually admitted to a mental health unit.

While in the unit my medication was changed, and I improved very quickly – too quickly. I had my first experience of what I now know

was hypomania. To me, it was quite amazing that through all of this, my facial pain condition did not flare up, which I would have expected. By the end of the year, I was diagnosed with bipolar affective disorder, which in hindsight had probably gone undiagnosed for more than 20 years.

Due to this diagnosis, I lost my job as occupational therapist with the eating disorder charity, ironically a mental health charity. Although this was highly discriminatory, I felt too unwell to challenge it. I began keeping a daily creative journal of words, images and photographs of my days, knowing how valuable and powerful this can be. I am currently on my fourth journal and continue to update it every day, which I find helps my mood.

On a professional level I am pleased to say that I am employed by another charitable organisation that works with the most vulnerable groups of people in our community, including those with mental health problems, addiction, the homeless and those who are marginalised. This job allows me more scope to use my creativity – given the freedom to initiate and deliver workshops and projects which respond to the needs of those who we support. I plan to take elements of what I experienced from the *Face2face* project in the imagery as a way of communicating emotional and physical distress. This opportunity has allowed me to rebuild my own self-confidence and further proves the value creativity can play in recovery and communication.

Reference

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Visual art is powerful: A patient's perspective

Ann Eastman

I used to joke that I was too busy to be ill. There was a home to run and an all-consuming career as a graphic designer and writer. The career defined my life. Having fought my way through the heavy glass ceiling of a giant multinational corporation, I worked on international communication projects that included writing and making films everywhere from Kenya to Kazakhstan, Sweden to Singapore. After 20 years of enjoyment and fulfilment mingled with stress, I decided to go freelance, studied for an art history degree and then semi-retired at the age of 68 to 'enjoy the roses'.

Retired men are often struck down by heart attacks while playing golf. I was struck down by trigeminal neuralgia while brushing my teeth.

I had never heard of trigeminal neuralgia, neither it seemed had anyone else, including my GP, which perhaps is hardly surprising given that it afflicts a mere 0.01 per cent of the population. Even now, ten years later, apart from meeting fellow sufferers at Trigeminal Neuralgia Association events, I have only come across one other person with it. That makes the condition even more frightening and lonely.

Said to be the most painful affliction known to medical science, trigeminal neuralgia is notoriously difficult to diagnose. What makes the diagnosis more problematic are the periods of remission – some short, others long – and the spasmodic nature of attacks, which means that one might never actually have an attack while seeing a doctor. That situation, plus the absence of any visual symptoms or vital signs creates anxiety; anxiety about being regarded as a hypochondriac, hysterical or possibly even mentally unsound? For all one knows, perhaps that is indeed the case ...

There are no vital signs, blood tests, brain scans or any means whatsoever of diagnosis. The doctor or dentist has absolutely no symptoms or indications to study apart from the patient's narrative, which all too often leads to misdiagnosis or non-diagnosis.

My consultant Joanna M. Zakrzewska is an international authority on trigeminal neuralgia and other complex conditions of facial pain. She collaborated with photographer Deborah Padfield, and they evolved an unusual, and imaginative concept to help resolve that problem of diagnosis. Selected patients participated in the process



Figure 2.8 Deborah Padfield photographed by Ann Eastman, in front of a photographic portrait of Ann, co-created by them for the exhibition *Mask:Mirror:Membrane*, at the Menier Gallery, London, 2011. © Ann Eastman

of co-creating images, which could express and communicate their mental and physical suffering. The resulting images are metaphors for their pain. Printed in postcard format, they are then used as a resource to augment Zakrzewska's diagnostic process. New patients, who are shown the postcards, select the ones that most closely express their own pain. This is a subtle means of initiating and developing the essential two-way communication process between doctor and patient to elicit the vital narrative required for diagnosis. Subsequently a pilot study investigated the use of those images on the impact of patient interaction with pain experts in different fields of medicine.

Visual art is powerful and can undoubtedly transcend language. One of the most familiar examples is artist Edvard Munch's evocative picture *The Scream*, painted in 1893. Although now clichéd, it remains a powerful visual metaphor expressing the artist's acute psychological

pain, without the need to understand Norwegian. Likewise, the imagery of First World War recruiting posters was so powerful they encouraged millions of young men to die for their country, or feel guilty if they were reluctant to do so.

But can images in the context of diagnosis transcend words? The English language is exceptionally rich, but despite that not every patient has the eloquence to convey their misery. However, the process of asking patients to find images that describe their pain is fraught with potential complications: if there is no image they can relate to, what does that mean? What does that say about them? What does that say about their illness? Perhaps they are imagining the whole thing? They might even end up questioning their sanity.

Not all health professionals or clinicians are highly articulate either, or they might not share their patients' language, furthermore they probably have no personal experience of trigeminal neuralgia or similar facial pain. Their knowledge is purely theoretical, so no matter how expert they consider themselves to be, they lack empirical understanding. In such situations a picture might indeed replace a thousand words, making it a powerful diagnostic instrument. However, all powerful instruments need to be used with great expertise.

Visual metaphors can be obscure, and easily misinterpreted. We all process images differently: imagine a photo of mountaineers – it might evoke admiration for their bravery, or contempt for their foolhardiness. Similarly, the colour blue that I see, is probably not the blue that someone else sees, just as being pierced with a needle is agony to some, while to others it's a mere pinprick.

Isolation and despair

The image in [Fig. 2.9](#) could be interpreted as a hermit or an introvert wishing to shut out the world. But actually, it's a visual metaphor for the loneliness of isolation and despair. You are happily getting on with your life, when suddenly the cosmic sledgehammer strikes, as it tends to when there are few cares or problems on the horizon. You are brushing your teeth when suddenly the most excruciating pain makes you scream in agony. Your panic-stricken other half rushes in, begging you to stop – fearing that the neighbours will call the police!

You are in despair due to this wholly inexplicable excruciating pain. What is the cause? Nobody knows, neither your GP who recommends ibuprofen, or A&E at the hospital, where after waiting



Figure 2.9 Deborah Padfield with Ann Eastman, 'Untitled' from the series *Face2face*, 2008–13. Digital Archival Print. © Deborah Padfield

for hours you are dismissed with a hint of scepticism and codeine. The dentist is utterly mystified, all he can detect is a slightly inflamed root. Yet to his consternation, unprovoked agonising stabbing electric shocks emanate from that area, so regretfully he extracts what appears to be a healthy tooth, in the hope that your pain will be alleviated. But when the local anaesthesia wears off – the pain is still there!

Is this a dental variation of phantom limb pain? Googling 'phantom tooth pain' results in various answers, including 'tri-gem-in-al neur-algia'; what the hell is that? The description ominously fits. It's incurable! 'No!' you tell yourself – 'I have *not got that!*'

You return to the GP, but despite 40 years of experience, she has never come across anyone with trigeminal neuralgia and thinks it's highly unlikely that you have it. She prescribes an array of painkillers. They have no effect.

The cosmic sledgehammer

Ten days later the pain disappears as suddenly as it arrived. You forget the horrendous experience, and normal life resumes. But the cosmic sledgehammer has not forgotten you, and you are happily unaware of its shadow hanging over you (see Fig. 2.10). Eight months later, shortly before Christmas, it attacks again. Your GP, who is nonplussed, now considers your suggestion about the cause, and talks about finding an oral maxillary consultant, meanwhile prescribing ibuprofen, codeine, tramadol and finally morphine, all of which have absolutely no effect. You are recommended to return to the dentist for an X-ray – in case a fragment of root was left behind. The dentist is away skiing and his emergency cover contemptuously dismisses the possibility of trigeminal neuralgia. He ascertains that the wrong tooth was extracted, so he takes out its neighbour. After the injection wears off, the unremitting pain is still there.

With the utmost difficulty, pleading with an unsympathetic secretary, you manage to get an emergency appointment with a facial pain specialist, who is not away for Christmas. As you walk into her room the pain is so overwhelming, speech is almost impossible. The diagnosis is 'a classic case of trigeminal neuralgia ...'

Normal life cannot be resumed. The slightest movement triggers paroxysms of tortuous electric shocks across the right side of your face. Your family is in helpless despair. Holidays are cancelled, theatre tickets given away, invitations turned down – a pattern that will become all too familiar.



Figure 2.10 Deborah Padfield with Ann Eastman, 'Untitled' from the series *Face2face*, 2008–13. Digital Archival Print. © Deborah Padfield

The only defence is anti-convulsants that control epileptic fits; you must start on a very low dose over a four-week period until the intensity of the shocks are somewhat reduced. Meanwhile you endure four weeks of unmitigated hell.

Nightmare doors

Now, despite trying to shut it out with displacement activity, fear haunts you. It stalks you while you brush your teeth, wash your hair, crunch buttered toast, make future plans or accept invitations, laugh, relax or sleep ...

Sleep is no longer peaceful; it is haunted by nightmares of struggle to keep heavy doors closed to shut out the agonising pain that threatens you and your family (see [Fig. 2.12](#)). You fight to prevent them from opening and engulfing everything in lava, rocks and stones like a volcanic eruption. Inevitably they burst open and everything surges through.

Drilling into your brain

When the pain attacks it's like a hammer-drill boring into your brain, exploding a tangle of live wires in a junction box inside your skull (see [Fig. 2.11](#)). Health professionals infuriatingly recommend that you



Figure 2.11 Deborah Padfield with Ann Eastman, 'Untitled' from the series *Face2face*, 2008–13. Digital Archival Print. © Deborah Padfield



Figure 2.12 Deborah Padfield with Ann Eastman, 'Untitled' from the series *Face2face*, 2008–13. Digital Archival Print. © Deborah Padfield

‘develop coping skills’ and advise against ‘catastrophising’, telling you that ‘fear makes it worse’.

Sorry, but unless you are one of the rare people with a congenital insensitivity to pain, the prospect of torture *does* generate fear. Despite knowing pain is in the mind, not in the pin-pricked finger, and that it stems from 100 billion electrochemical nerve cells in the brain, and no matter how hard you endeavour to avert thoughts, and concentrate on breathing and so forth – it makes not one jot of difference – *this* pain is *inside your brain*. The stabbing, crackling electric shocks dominate and devastate your existence. When you cannot clean your teeth, face or hair, hardly eat, drink or smile, be kissed or lower your head to read, without triggering paroxysms of anguish – that is catastrophic.

Do you have the ‘coping skills’ to actually survive?

Not for nothing is trigeminal neuralgia known as the ‘suicide disease’.

Doors to paradise

Each horrendous episode is eventually followed by a blissful period of remission, with the heavy doors leading into a paradise garden, passing under an illumination from an exquisite fifteenth-century Book of Hours, celebrating spring and renewal (see Fig. 2.13). You industriously and



Figure 2.13 Deborah Padfield with Ann Eastman, ‘Untitled’ from the series *Face2face*, 2008–13. Digital Archival Print. © Deborah Padfield

joyfully do as much as you can, while you can; phone friends, invite them to dinner, go to museums, theatres, concerts, walks, gardening, exercise, painting and smelling the roses. But you know that you’re on borrowed time. The cosmic sledgehammer will inevitably strike again, although you have no idea when; could be two weeks, two months or two years ... But it *will* come back, and will continue to do so for the rest of your life ...

The self-portrait

This self-portrait expresses how you feel (and it seems to be an image that many other patients can also relate to), although it is allegorical – trigeminal neuralgia is invisible – so a conventional self-portrait would convey nothing (see Fig. 2.14). The unaffected left side is bright and buoyant, while the afflicted opposite side is dark and bare. The sinister claw-like branches of the trigeminal nerve encroach, invading your body and soul, destroying your root structure. The road ahead is overshadowed by apprehension and terror.

Six years later the condition escalates. The cosmic sledgehammer strikes more ferociously than ever: the pain-killing medication that I



Figure 2.14 From the exhibition *Mask:Mirror:Membrane*, at the Menier Gallery, London, 2011. © Ann Eastman

was dependent upon must be ceased due to one of its rare, but serious side effects – profound hyponatraemia – a serum sodium level so low that it can prove to be fatal.

Having reached the end of the pain-killing medication road, one's entire existence is dominated by pain. The only path is neurosurgery. A brain scan had shown a blood vessel compressing the trigeminal nerve, wearing away its protective myelin sheath, similar to the plastic tubing that covers electrical wires. Microvascular decompression (MVD) looked to be the appropriate choice, a procedure that separates the nerve from the blood vessel, preventing further contact.

The dreaded drill

The prospect of neurosurgery is probably more terrifying than any other surgical operation. As Henry Marsh writes in *Do No Harm*: 'All doctors have failures; the problem with brain surgery is, *that failure*, is often very terrible and very spectacular'.

But as a patient one must accept that things *can* go wrong, yet still remain optimistic.

The optimism is challenged when a registrar brings the consent form, bluntly stating 'I have to point out to you that this is major surgery, with a 30 per cent failure rate that includes death ...' and draws an explanatory diagram indicating where the scalp would be shaved, slit, peeled back and the entry hole drilled into the skull ...

The roses return ...

The two-week stay in hospital is not the happiest period of my life, and in a tick-box exercise entitled 'Patient Experience' would score zero out of ten. But when the dressing and the 15 staples are removed, and I can go home, rather wobbly but confident and pain-free – that is definitely ten out of ten!

That was in 2015, the surgery was completely successful, and I feel very fortunate. The road ahead looks bright and beckoning and the roses, which for me symbolise growth and happiness, are beautiful and smell gorgeous.



Figure 2.15 Deborah Padfield with Ann Eastman, 'Untitled' from the series *Face2face*, 2008–13. Digital Archival Print. © Deborah Padfield

... but not only for me

I hope that the concept of using the power of visual images as a diagnostic instrument for recognising trigeminal neuralgia will ultimately become the conventional method of communicating and understanding facial pain, helping those who are isolated, alone and undiagnosed. Perhaps by extension that will create the interest, incentive and funding to research new safe medication specifically for trigeminal neuralgia, providing alternatives to agony, and the risks of surgery, ensuring that every sufferer can enjoy the roses (see [Fig. 2.15](#)).

The beginnings of pain

Alison Glenn

My pain arrived without warning, sharp and stabbing it flashed across my jaw, it was gone as fast as it had appeared and so I continued my meal with friends and thought no more about it.

Over the course of the next few days I began to experience a recurrence of the pain leading me to make an appointment with my GP, who felt that it was most likely dental related and advised me to visit my dentist.

My dentist's thoughts were that I had an infected tooth and redid a filling, however my pain didn't subside and became increasingly severe, and with subsequent visits back to the dentist it was decided that a root canal would be a sensible next course of treatment. It was an unpleasant procedure to go through and I found that my pain intensified afterwards to the point where I could no longer open my mouth. I couldn't eat, talk or touch my face, it was hard to communicate just how severe the pain was and the distress that it was causing me. I had difficulty identifying exactly where the pain was and difficulty describing the pain, often it was a referred pain (referred pain is where pain is felt in another location other than the actual site of the pain). On some occasions it seemed to come from individual teeth whereas at other times it felt as if it was in my cheek or jaw. The pain was having a terrible effect on me and I was feeling extremely low and constantly tearful.

I returned to my dentist who was concerned to see the pain that I was in and the amount of weight that I had lost since a previous visit. He agreed to refer me to an oral specialist. With another visit to my own doctor I was prescribed amitriptyline, however as I had an appointment to see the oral specialist in a couple of weeks after a holiday in France, I foolishly decided to hold off taking the medication so that the specialist could see my symptoms just as they were.

The holiday was a complete disaster, not only did it rain for almost the entire two weeks, I really couldn't function normally, anything touching my lip triggered an excruciating nerve pain, I was unable to open my mouth any more than a few millimetres. I tried to drink soup through a straw but the pain even of the straw touching my lip was intense.



Figure 2.16 Deborah Padfield with Alison Glenn, 'Untitled' from the series *Face2face*, 2008–13. Digital Archival Print. © Deborah Padfield

(Ice cold water with hidden knife blades among the chunks of ice waiting to catch you unaware when least expected, with a sharp, stabbing cutting pain. The eye looking out from the broken glass illustrates the person experiencing the facial pain, trapped in the glass.)

Two points that I experienced were that the pain was only severe on one side of my face, and secondly, I didn't experience pain when I was asleep, which gave me some respite at night.

The search for a diagnosis

My visit to the oral specialist did not, as I had hoped, yield a definite diagnosis. His feeling was that it was most likely a dental problem, though he prescribed carbamazepine and gave me another appointment in a few weeks' time. I revisited my dentist who felt that another tooth with an old filling could be causing the problem, however this time he wasn't happy to carry out the root canal himself and referred me to a private dental clinic to have the root canal carried out by an endodontist.

I started taking the carbamazepine tablets and was amazed at how quickly they relieved my symptoms. I couldn't believe that the pain that I had been experiencing had gone and I was able to open my mouth again, talk and eat. However, going forwards it soon became clear that finding the correct dosage was not easy; too little and the pain was not controlled, and with too much I felt incredibly dozy and out of it and very sleepy. My three secondary school children, a husband who often worked away from home during the week and the necessity to be able to drive on a daily basis made life a challenge.

When I visited the private dental clinic, the endodontist's thoughts were that I didn't have trigeminal neuralgia, which had been mentioned, he felt that I wouldn't be able to talk as well I was able to do. I tried to get across that it was the carbamazepine that was allowing me to function, but this seemed not to register. The root canal was carried out followed by the discussion that if it didn't solve the problem, then there was another tooth that could be responsible for the pain and a root canal could be carried out on that one too.

The pain continued and was controlled partly with varying amounts of carbamazepine. I had a private brain scan done to see if there was an evident problem, but nothing was apparent.

My concern was that there had to be something wrong, how could I be in such severe pain and yet there was not an obvious cause?

I had several more visits back to the oral specialist who suggested that it may be necessary to have all my teeth taken out if we couldn't resolve the pain!



Figure 2.17 Deborah Padfield with Alison Glenn, 'Untitled' from the series *Face2face*, 2008–13. Digital Archival Print. © Deborah Padfield

(The black velvet background represents the darkness of the facial pain. The sole focus is the pain of the knife cutting through the flesh, reflected in the use of the strawberry as the focal point of the piece. The juice trickling down the strawberry conveys the idea that the pain radiates beyond the knife point.)

It was important for me to get another opinion so I changed my dentist, however again I was referred to an endodontist to carry out a root canal. He felt that he could work through my teeth one by one until the source of the pain was discovered. My pain had increased by this stage, sometimes it was like an electric shock, sharp and burning and other times like a knife stabbing into my jaw through the flesh. The effect on my life and that of my family was devastating; I couldn't function normally and lived in fear of the pain striking without warning. I would open my mouth to speak and be unable to close it, finding myself regularly in embarrassing situations. I couldn't plan anything because I couldn't predict how I would be. It was easier to be a recluse and not bother to socialise. All the routine things that we normally do without thinking became the most enormous challenges and hurdles, from washing my face and brushing my teeth, to pushing a supermarket trolley on uneven ground. On bad days at worst my pain could be triggered by even a single hair blowing on my face.

The impact of facial pain

The impact of my facial pain was vast. When pain is chronic and goes on for years it is debilitating and wears you down. It was frightening for my children to see me on occasions in extreme pain. Emotionally it was hard to watch everyone else getting on with their lives and I felt trapped at home, isolated, controlled, often hardly speaking to anyone during the course of the day. I lived in fear of not being able to control the pain.

The diagnosis

After virtually exhausting all routes to get a diagnosis, the endodontist mentioned Joanna M. Zakrzewska, a world-renowned specialist in facial pain, at a London teaching hospital.

I was fortunately given a referral to see the professor who quickly diagnosed me with trigeminal neuralgia. It was a relief to get a diagnosis and to find someone who had such an understanding of what I was going through.

An MRI scan was organised and a meeting with neurosurgeon, Mr NK. The scan picked up clearly that there was compression of the trigeminal nerve and that I would be a suitable candidate for surgery.



Figure 2.18 Deborah Padfield with Alison Glenn, 'Untitled' from the series *Face2face*, 2008–13. Digital Archival Print. © Deborah Padfield

(The apple was used as a reminder of the pain I experienced during everyday tasks such as cleaning my teeth or eating. Despite the apple appearing to be crisp, shiny and appetising, it was filled with needles to represent the pain I knew would strike if I dared to take a bite. Likewise, the toothbrush also represented a simple everyday task that I struggled to complete. The toothbrush is ready to be used, yet is untouched, just like the apple due to the daunting nature of this task.)

Microvascular decompression (MVD) is an invasive procedure with risks but, in my situation, it was worth those risks as I just wanted to get my life back and have an end to the pain.

I was incredibly fortunate to have Mr K carry out my surgery in London and nearly nine years on, thanks to his amazing skill and that of his team, I am still pain-free.

UCL *Face2face* research project

Zakrzewska approached me to ask if I would like to be involved in the UCL *Face2face* research project with artist and photographer Deborah Padfield. The study would use photography to understand patients' experiences of pain and research practitioner-patient communication, exploring how pain may look as a visual image and how the images could go on to help both pain sufferers and professionals.

I did contemplate whether this was something that I could be involved with, given that at the time I was still finding it very difficult to leave the house and was still experiencing a lot of unpredictable pain. However, with a background in design I was very interested in the idea of the project and decided to give it a go – and I am so pleased that I did.

The study involved several parts. In my initial sessions with Padfield I was interviewed about my experiences of pain and we discussed ideas for images to represent the different stages of treatment.

The purpose of the project was not intended as a therapy, but I nonetheless found the experience very beneficial in helping me to accept my situation, understand it better and to look ahead to a future which at times I hadn't been able to see.

Expressing feelings through art and creativity is very therapeutic. I now had the opportunity to be listened to, to spend time focussing on my experience of pain and creating ideas for the images. Spending so much time discussing and thinking about how to communicate that pain in a visual form was a great distraction.

Padfield and I co-produced many images which covered my time before, during and after treatment.

Looking back on creating the images, I appreciate how valuable the entire process was. In particular, having the set stages to focus on and work towards from the initial discussions with Deborah, sharing



Figure 2.19 Deborah Padfield with Alison Glenn, 'Untitled' from the series *Face2face*, 2008–13. Digital Archival Print. © Deborah Padfield

(This image illustrates the emotional aspect that the facial pain creates. Most notably, the feeling of isolation is depicted through the separation of the glass to the outside world. Everyone is getting on with their lives oblivious to your situation. I felt trapped, confined, isolated and controlled by the trigeminal neuralgia. I also wanted to include within this image photos of my children as the impact of chronic pain affected us all as a family.)

my experience of living with and trying to cope with my facial pain and the long search for an accurate diagnosis, which was followed by how I would like to interpret my pain visually.

This was done through time spent creating sketches and collecting items to be used in the photographic sessions, with further meetings with Deborah to put together and create the sets which were then photographed. Deborah was always keen to make sure that the photographs were a true reflection of how I wanted to portray my experience of pain. She was exceptionally empathetic and sensitive in what was a very personal and fairly emotional time.

The following stages were during treatment, my hospital stay and surgery, and lastly, a period in which I was lucky enough to have had a successful outcome to the surgery and was finally pain-free. Again, we followed the same process of producing further sketches and collecting items for the photographs, where Deborah took more pictures for these further stages.

A selection of images from the project were put together as a prototype box of PAIN CARDS to be used between patients and practitioners. The images have proved valuable as an instrument for instigating discussions between the patient and practitioner and in assisting the patient in communicating not only a description of their pain but additionally the impact of their pain on their lives and emotional wellbeing. Having the images as the centre of interest acts as a distraction and enables the patient to be far more open than they would normally be about their own experiences, particularly as in many cases with a clinician who is initially a stranger.

Some of the photos along with images from the other participants in the project were used at an exhibition exploring the concept of pain *Mask:Mirror:Membrane* which took place at the Menier Gallery, London, in July 2011.

In July 2016 I attended and took part in a two-day live event and international conference, 'Encountering Pain' at UCL. Over the course of the two-day event responses to pain and how we encounter pain were explored in a variety of ways, with talks from keynote speakers, artistic expressions, personal presentations from individuals experiencing pain and workshops to encourage the sharing of knowledge, experiences and approaches surrounding pain.

I believe that it is vital to raise awareness of facial pain, as my own findings have shown that not enough was known about the vast range of conditions and treatments available – resulting in it taking too long to receive an accurate diagnosis.



Figure 2.20 Deborah Padfield with Alison Glenn, 'Untitled' from the series *Face2face*, 2008–13. Digital Archival Print. © Deborah Padfield

(After surgery, I was lucky enough to start a new pain-free chapter of my life. This picture represents throwing away the pain and the painful memories that came with it. In this image I wanted to feel and illustrate that I was now in control and could move forwards. The pain controlled me for so many years, I was trapped and lived in fear. The photo shows everything to do with the pain contained within a clear ball, the hospital name band, the strawberry/flesh, the pins/pain, and medication. In the image I am in control and I throw the ball away. The image is taken from a view on the beach in France where my facial pain had just begun and was at its worst. It gives closure to be back at the same location but this time pain-free. I initially had planned and wanted to violently smash the ball to bits with a hammer or kick it away, such was my anger towards the facial pain, however when the time came to produce the image it was enough just to throw the ball away and of course then everything was still trapped inside.)

I am very fortunate to have been one of the participants in the *Face2face* project with Deborah Padfield and Joanna M. Zakrzewska and to have met the other participants. This took place at the *Mask:Mirror:Membrane* exhibition (after we had produced our own images). It has been very helpful meeting other facial pain sufferers and learning of their experiences and coping strategies, as well as seeing their visual interpretations of their pain.

From my own experience I would recommend joining a support group such as the Trigeminal Neuralgia Association (TNA UK) as the support and information is extremely beneficial.

3

Approaches to images

An art therapist's perspective on photographic images of pain used to communicate the experience of pain in medical consultations

Helen Omand

This chapter is written from my perspective as an art therapist contributing to a multidisciplinary arts in health project that researched the effects of images in medical pain consultations: 'Pain: Speaking the Threshold' (PSTT) (Padfield, Zakrzewska and Williams 2015, Padfield 2016, Padfield and Zakrzewska 2018, Ashton-James et al. 2017, Padfield et al. 2018, see also the introduction to this volume). In the chapter I examine the possibilities and limitations of bringing particular ways of thinking about images in art therapy to increase understanding of how images functioned in PSTT. 'Art therapy is a form of psychotherapy that uses art media as its primary mode of expression and communication' (British Association of Art Therapists n.d.), whereas PSTT looked at the use of art in a different context; it studied pairs of doctors and patients in medical consultations, using a pre-existing set of photographic images of pain to communicate the experience of chronic pain. The chapter brings to the PSTT approach frameworks derived from particular psychoanalytic and art therapy theories (Winnicott 1971; Schaverien 1995; Isserow 2008, 2013; Tipple 2003, 2011; Skaife 2008). The writing that follows is based on an earlier exploration of this subject (Omand and Padfield 2019) and will add new ideas about images in the space 'in between' doctor and patient, and use further case examples. I set the theoretical frameworks out, along with reasons for their choice in the literature review below, with the aim of expanding the ways one can view the encounters with images in the pain consultations.

Each of the theorists cited above draws on different theoretical frameworks to understand the relationships between people and art

objects. They provide diverse approaches to thinking about the effect of an art object placed between two people, which I suggest can help appreciate the image's role between doctor and patient in PSTT. In brief: Winnicott uses an object relations framework to develop ideas about transitional objects as existing between self and other in 'an intermediate area of experiencing, to which inner reality and external life both contribute' (Winnicott 1971, 3). Isserow (2008, 2013) compares psychoanalytic theories of early development with child development theory of mind to consider joint attention. He connects this with reflective self-awareness and symbol formation within the triangle of client/art/therapist; 'both patient and art therapist look together at the art object, in an attempt to share the feeling and possible meaning ...' (2008, 24). Schaverien's theorising on 'transactional objects' draws on anthropological frameworks of exchange 'I am suggesting a more direct and, in some ways less complex role for the picture ... as an object through which unconscious transactions may be acted out and channelled' (1995, 127). Tipple (2003, 2011) uses social theories of discourses and art historical ideas of barter 'to examine artwork in relation to the context or social setting' (2003, 58) and Skaife draws on philosophical feminist writing and suggests the meaning of the image is in the 'intersubjective relationship between patient, therapist, world and image' (2008, 51).

In applying some of the thinking generated by these theories I hope to show how using these frameworks can further understanding of the effects of images in the PSTT project. Of course there are also potential difficulties to consider; if theories developed in one context are applied to another we cannot expect identical conclusions to be drawn. However, while caution is needed, I suggest that aspects of the different ways these authors understand the image's role are helpful here, if thought about critically in relation to a new context (Omand and Padfield 2019). Overall, what I found useful in the approaches given here, are the diverse theoretical bases each draws on and the rich ideas these generate in relation to the use of images in PSTT. Overall this chapter will suggest images in this setting may allow for a negotiation of unconscious dynamics between clinician and patient and have the potential to aid communication and empower patients, pointing to avenues for future research (Omand and Padfield 2019).

PSTT, the project I will be considering through these frameworks, was a multidisciplinary arts and medicine project set up by artist and researcher Deborah Padfield and pain consultant Joanna M. Zakrzewska at a leading UK teaching hospital. PSTT was a continuation

from an earlier innovative PHD project *Face2face* (Padfield et al. 2010; Padfield 2011; Padfield, Zakrzewska and Williams 2015) where Padfield, using her own artistic practice in photography, co-created with different pain patients a series of images based on how those patients visualised their pain (examples Figs 3.1–3.6). These images were then offered to 17 pairs of other patients and doctors for use in chronic pain consultations, to select from and use if they wanted. The hope was to aid the communication of the experience of pain, and by using images to expand on limited traditional verbal and numerical rating scales of pain (Hjermstad et al. 2011; Morse 2015). The consultations were videoed with consent of participants (for full method see Padfield, Zakrzewska and Williams 2015; Padfield and Zakrzewska 2017).

The main aim of PSTT was to study retrospectively the videos of that experimental situation. PSTT specifically sought to gather individuals from different disciplines to bring together multiple perspectives and ways of looking at the videos. The team met every term for three years and included linguist Elena Semino, clinical psychologist Amanda Williams, historian Joanna Bourke, social sciences researcher Tom Chadwick, artist and writer Sharon Morris, Deborah Padfield, Joanna M. Zakrzewska and myself as an art therapist. Padfield and I had previously worked together in another capacity, and I was familiar with her process of image-making and the patient group. I was intrigued at the prospect of being part of the team studying the encounters. The psychodynamic thinking I had as an art therapist had given me a particular curiosity about the unconscious processes potentially happening when images were used by PSTT participants.

The possible forms that our investigations of the videos could take was left very open; PSTT was funded by a grant to promote the value of interdisciplinary collaboration and the only outcomes specified by funders were that a team of clinicians, artists and academics would be assembled, interdisciplinary debate and collaboration would be fostered (Padfield et al. 2018) and public awareness increased by a truly interdisciplinary event, the 2016 conference 'Encountering Pain' (Padfield and Zakrzewska 2017). Because the remit was so broad, even pinning down a shared hypothesis about the videos caused much debate. Our differing approaches to analysing the data raised epistemological questions. Team members started by each exploring an aspect of the videos: Williams coded non-verbal behaviour (Ashton-James et al. 2017); Semino analysed participants' language (Semino and Williams 2017); Chadwick and Padfield qualitatively analysed narratives (Padfield, Chadwick and

Omand 2017); Bourke contributed a historical/cultural understanding of metaphors of pain (Bourke 2017); Zakrzewska added a clinician's perspective (Padfield and Zakrzewska 2017) and Morris responded to the theme of chronic illness with a poem.

In an early meeting I was asked to give my 'perspective' as an art therapist. That required a mental readjustment: using fine art in a health context, sometimes positioned as 'arts in health', is not 'art therapy'. After discussion of these clearly different endeavours, we considered what they had in common. Both a specialist pain consultation and a therapy consultation can be seen as bounded clinical encounters, involving one person seeking help from another who is a healthcare professional. There will be a power dynamic associated with this, particularly in a medical setting (Leibmann and Weston 2015). Both the pain consultations and, arguably, any therapeutic encounter, involve communicating complex subjective human experience. Pain as an emotional psychological experience, involves both mind and body (Van der Kolk 2015). Its invisible nature means it is difficult to communicate and for a listener to understand exactly what the other person is undergoing (Padfield 2011). PSTT also shared a broad premise with some aspects of art therapy about the potential usefulness of art for communicating subjective experience: that generally people look for meaning in images; that images can convey something immediately and viscerally; and that images might offer a way of communicating something about a state of mind, or being, to another person in the room. In both endeavours there was an expectation that images could convey feelings in a different way to words, and that this might in some way be helpful.

In PSTT the images were pre-existing digital photographic images, co-created by Padfield with other pain patients based on their experiences of pain. The premise was that new patients at the clinic would be able to identify with these in some way and find sharing them in their consultations helpful. As an art therapist it stood out for me that the patients in the consultations did not make the images, as is standard practice in art therapy. I wondered how patients would express themselves using these photographs. That said, there are exceptions in art therapy literature where art therapists work with images and objects not made by clients (e.g. Case 1996; Brooker 2010), which show how clients powerfully projected meaning onto those objects within the relationship. PSTT was based on the expectation that patients would do just that.

Having set out the premise of this chapter and introduced the project, I will now describe the methodology and literature, and give

four case examples reflected on using art therapy theory. I will finish by considering what the different approaches suggested about the case material and the implications of this for the project.

Methodology

For PSTT methodology see Padfield, Zakrzewska and Williams (2015), Padfield and Zakrzewska (2017), Ashton-James et al. (2017) and Padfield et al. (2018). Videos, transcripts and images were used throughout. An initial thematic analysis (Braun and Clarke 2006) familiarised me with the data and identified particular recurring features and their frequency as avenues for exploration. I became curious about the following aspects of the data: nearly all patients imbued images with highly personal meanings, seemingly using images to convey complex emotional aspects of their pain. I noticed participants often physically handed images back and forth in order to share them, and most spent extended periods in joint attention. In nearly all cases there was frequent looking back and forth between patient, image and clinician. I also observed in the majority of cases clinicians initiated the introduction of the images, however once patients started to use the images, a less 'directive' space seemed to be opened within the traditional medical consultation with its inherent power structures. A process of reviewing and selecting literature began with the aim of expanding understanding of these features.

Case studies were selected as exemplars (McLeod 2011), each typical of the length and content of the data overall. Each is also an example of features identified above to be explored. I reflected on each case example using art psychotherapy theory. In reflecting on these interactions I held in mind Spinelli's phenomenological approach (2005) which emphasises the inseparable relationship between the observed and the observer: the critical eye of the observer constructing meaning must be acknowledged to be part of the context, and others may come to different but no less valid interpretations that will exist in relationship to each other.

Full permission has been given for images and transcripts to be used. The project has ethics approval and UCL Data Protection Registration.¹

Clearly there are power imbalances in research itself and how patients are represented which have been increasingly acknowledged (Zappa 2017). Throughout I have tried to refer to the patients'

words about their chosen images and seen these as key to the images' meaning in this context. It is also worth saying I come to this research as a psychodynamically trained white British female art psychotherapist and my perspective will be shaped by this position. Due to original permission restrictions I could not ask the patients included in the study for their feedback on this research and I would welcome any responses.

Literature

The literature included in this chapter is informed by my psychodynamic training and practice as an art therapist in the UK. It necessarily sits within an ongoing critical dialogue within art therapy about how best to understand our practice that includes many disparate approaches (Hogan 2016; Huss 2015; Rubin 2016). The following literature was developed from work with a range of client groups and settings, and draws on frameworks including object relations and psychoanalytic ideas, child development, anthropology, art history, social theory, feminist theory and philosophy. My focus is on theoretical approaches to the image and their relevance to this new context. Notably, there is a growing body of literature on art therapy with people with physical illnesses, which although beyond my remit, has been reviewed thoroughly in Leibmann and Weston (2015) and Malchiodi (1999, 2013).

Transitional objects, the 'third area' and symbolisation

The seminal ideas of psychoanalyst Winnicott on *transitional objects and spaces* (1971) provide the first way we can think about an art object between two people. Winnicott used his ideas to understand the power of the imaginative and illusionary spaces created in art and culture, but he developed them originally from his work as a paediatrician. In this role he carefully observed mothers and babies relating. He noticed in particular how babies used their first possessions, usually blankets or teddies, and how strong their attachments were to them. Winnicott theorised the baby imbues these possessions with meaning from their internal world, so that it feels to the baby as though the object is fully under their control and is even an extension of themselves. But there is a contradiction – the object contains the stuff of their inner world, it is 'of them', yet *at the same time* it is clearly not part of them: it is 'other',

existing concretely in the external world. Winnicott saw these objects as *transitional*, where inner and outer intersect: 'the intermediate area between the subjective and that which is objectively perceived' (1971, 4).

Winnicott describes a universal tendency that continues throughout life: 'This intermediate area of experience, unchallenged in respect of its belonging to inner or external (shared) reality, constitutes the greater part of the infant's experience, and throughout life is retained in the intense experiencing that belongs to the arts and to religion and to imaginative living' (1971, 19). Winnicott thought that it was in this 'third space' that symbolic thinking developed. For adults, this space might include enjoyment of art or film, in which a midway point between illusion and reality can be appreciated. For example, we might suspend our disbelief when watching a horror film. In the 'third space' it might genuinely feel *as though* the monster is going to come and get us, even though part of us knows it is not real. This entails symbolic thinking, the ability to represent in one's mind an object by a symbol that is not the same as the object. This is as opposed to more concrete thinking where the symbol is seen as the same as the object (Segal 1957). Taken to a psychotic level of concrete thinking in this example, we might actually think the monster is real, call the emergency services and barricade the doors. This would be an example of not being able to think symbolically.

Art therapists Wood (1984) and Waller and Dalley (1992) have drawn on Winnicott's ideas to understand the role of the image as transitional within the triangle formed in art therapy of client–image–therapist. Art therapist Isserow emphasises that this triangle involves joint attention; 'the capacity to look and feel together' (2008, 36), pointing out the work of art therapy involves 'an overlap of coordinated looking, thinking and feeling around the art object' (2008, 35).

Isserow brings together different frameworks to consider joint attention: psychoanalytic theories which suggest the benefits of more sophisticated triadic, as opposed to early dyadic, relating patterns (e.g. Britton 1989; Burhouse 2000); and developmental psychology 'theory of mind' (Baron-Cohen 2000), which describes the ability to acknowledge that another person also has a thinking mind with another point of view, and will see the same object from a different perspective. Isserow suggests triadic encounters with art in the presence of 'a mindful other', art therapist or not, may facilitate joint attention, encouraging joined up triadic relating, reflective self-awareness and symbol formation

(2013, 130). Isserow reminds us ‘Symbol formation lies at the very heart of humanity enabling both inter and intra-personal communication’ arguing that much of art therapy has aimed to encourage it (2013, 122). I suggest his theories provide a way of thinking about the triadic encounters in PSTT and the opportunities they may provide for reflective thinking in the presence of another.

The next approach provides a way to think about the image more concretely in the physical space between participants. Art therapist and Jungian analyst Schaverien (1995) brings anthropological explorations of the transactional use of artefacts within cultures, to understanding images as ‘transactional objects’. She noticed this use of images by clients in art therapy who used images to negotiate control where transference and relationship dynamics remained unspoken. She describes transactional objects as more concrete than Winnicott’s ‘transitional objects’: ‘I am suggesting a more direct and, in some ways less complex role for the picture ... as an object through which unconscious transactions may be acted out and channelled’ (1995, 127). For example, a patient may negotiate control through the image by revealing just part of it, to keep the therapist at bay.

Understanding the image in its social context

Previous theories have understood images as potentially symbolic of the patient’s inner world, or used concretely in exchange. Next follow alternative understandings of images that emphasise the meaning of the image in relation to the social context that surrounds it. Art therapist Tipple (2003, 2011) examined verbal exchanges and artworks in videoed assessments at a centre for children with learning disabilities. Tipple, drawing on Foucault (1984), writes ‘Discourses, or more precisely discursive networks, shape our sense of reality and positively produce the world, in terms of objects and subjects’ (Tipple 2003, 49). Tipple sees the diagnostic encounter as surrounded by discourses ‘social contexts’ that impact upon individual subjectivities. Tipple’s approach intended ‘to examine artwork in relation to the context or social setting within which the child and the therapist endeavour to share their subjectivities’ (2003, 58). Drawing on art historical ideas of barter (Baxandall 1985), Tipple suggests image use became a way for both to continually negotiate role and to propose identity. ‘The art products and images, visual and verbal, are used in this production of shifting identities and

interpretations of the social situation ... power is contested and loss of face is resisted’ (2011, 156). Tipple’s conception of the image in a social frame provides a lens to view the impact of the diagnostic context of PSTT on image use.

Skaife draws on philosophical approaches from Derrida and Irigaray and emphasises the ‘intersubjective relationship between patient, therapist, world and image’ (2008, 51). She criticises some psychoanalytic approaches to art therapy that see the meaning of the image as originating solely from the individual’s psyche, noting the rigid tendencies this can bring to pathologise the client and ignore the impact of their social context. Skaife concludes that a focus on pure psyche ignores embodiment and leads to a neglect of ourselves as physical entities in a particular situation: to gender, race and class, stifling political meaning. She notes the tension whereby the image’s meaning is context dependent, yet something of the original making of the image carries across to new situations. This highlights the complications for PSTT given that the patients using the images did not make them: ‘if presence is always tainted by traces of what has gone before, of the image in previous contexts that cling to it imperceptibly, then there can never be a single, static meaning’ (2008, 48). Using case examples Skaife suggests we can understand an image’s meaning in context by asking what the image’s agency is, or what it brings into the intersubjective space.

Case example A

Patient A, Caucasian, female, in her 80s, lives alone and her chronic back pain keeps her housebound. The clinician is middle-aged, female and Caucasian. Patient A’s chosen images are spread on the table between them. I focus on four images that centre around one aspect of her pain.

Patient A: [points to Fig. 3.1] This one is like a total break. I know I’ve got brittle bones, but ...

Clinician: Mm [looking at image].

The patient trails off uncertainly. Both look at the image, a row of stones curved like vertebrae. A missing stone leaves a gap.

Patient A: [studies Fig. 3.2] What did I chose this one for? What’s that? Loss?



Figure 3.1 Deborah Padfield, 'Untitled' from the series *Perceptions of Pain*, 2001–06. C-type print. © Deborah Padfield, reproduced by kind permission of Dewi Lewis



Figure 3.2 Deborah Padfield with Liz Aldous, 'Untitled' from the series *Face2face*, 2008–13. Digital Archival Print. © Deborah Padfield



Figure 3.3 Deborah Padfield with John Pates, 'Untitled' from the series *Perceptions of Pain*, 2001–06. C-type print. © Deborah Padfield, reproduced by kind permission of Dewi Lewis

[Long pause] Probably I've ... [Said slowly, quietly. Hesitation].

I've lost my ... way to live. I don't know. [looks at Fig. 3.3] Um, I feel as if everything is coming apart and I need screwing up again.

Clinician: Yes (gently).

Patient A: This one [Fig. 3.4] ... it seems that I've got a lot of links that don't connect.

Clinician: Yes.

Patient A: I'm in a lot of pain with my knees and my hips and my back.

Patient A associates the torn chain with disconnection. The clinician later picks up on emerging themes of connection and loss. Having established Patient A is estranged from her son, she asks her to say more about her communication with friends and family.

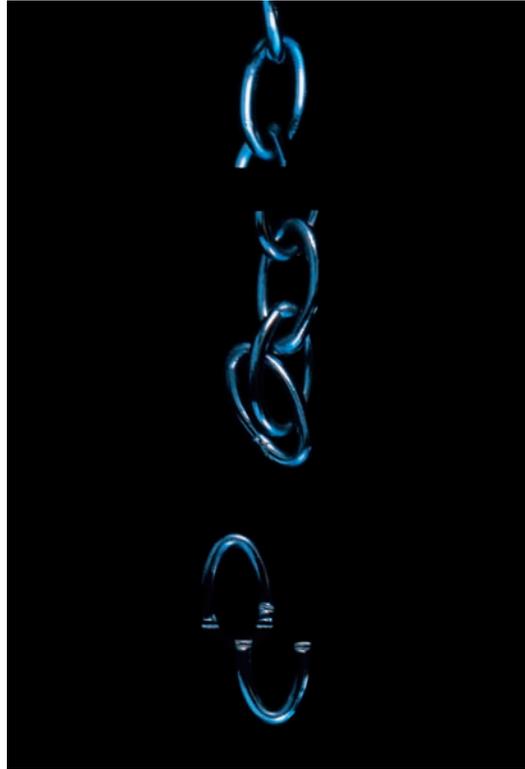


Figure 3.4 Deborah Padfield with John Pates, 'Untitled' from the series *Perceptions of Pain*, 2001–06. C-type print. © Deborah Padfield, reproduced by kind permission of Dewi Lewis

Clinician: Tell me a bit more about ... more about that, what your life is like.

Patient A: Non-existent.

Clinician: Mm. [encouragingly]

Patient A: It only exists when I travel down to spend time with my daughter and my granddaughter on the beach, you know, walking and that. Bless her little cotton socks, she's beautiful. [Laughs. Adjusts position in chair]. You know I love her dearly.

Reflection

Viewing the images as *transitional objects* helps us see them as containing projections from the patient's inner world and yet also existing in reality to be perceived by both participants. The patient's words and images about her pain convey broken structures and disconnection. 'Coming apart' and 'links that don't connect', are ambiguous, perhaps referring to her body and/or state of mind. The images can be

seen to exist in Winnicott's third area, a potential space between participants where experimental ideas, play and meaning-making can take place.

As patient and clinician look back and forth between each other and the images in joint attention, a triangular relating pattern is formed. Isserow's work provides a framework for understanding this as setting the conditions for reflective self-awareness and symbolic thought (2008, 2013). The patient is highly reflective and seemingly uses the images to represent aspects of her pain to herself and to the clinician. Patient A is first uncertain why she picked Fig. 3.2, 'Loss'. We see her looking, and connecting to its meaning for her. We could wonder if she is making links between conscious and unconscious parts of herself, in her hesitation 'I don't know ...'. The feeling of loss seems to become present in the moment; as she reflects with the clinician she sounds sad. 'Lost my way to live' seems profound and complex, encompassing multiple losses, all of which will have a bearing on her experience of pain. Overall something important seems to get communicated about the emotional and relational aspects of her pain, which the clinician asks more about. Here the patient 'comes to life', sounding enthused and sitting up as she talks about what does give life meaning: her relationships. These aspects are also prioritised in her treatment outcome, referral to the pain management centre where options include occupational and psychological therapies and groups, with the aim of helping her have a more social life.

I suggest that theoretical frameworks help us understand more of the effects of images within this encounter as occupying a 'third space', conceived of as real and imagined (Winnicott 1971) and as part of a triadic relationship promoting reflective linking and symbolisation (Isserow 2008, 2013).

Case example B

The patient and clinician are Caucasian, female, in their 50s–60s. They sit facing each other. The patient has jaw pain. She gave one-word explanations of her other pictures, which concerned physical symptoms. She hugs the images against her chest. The clinician asks if she has something to say about her final images.

Patient B: [looking at Fig. 3.5 but keeps image turned inwards so clinician cannot see] This was more about what worried me

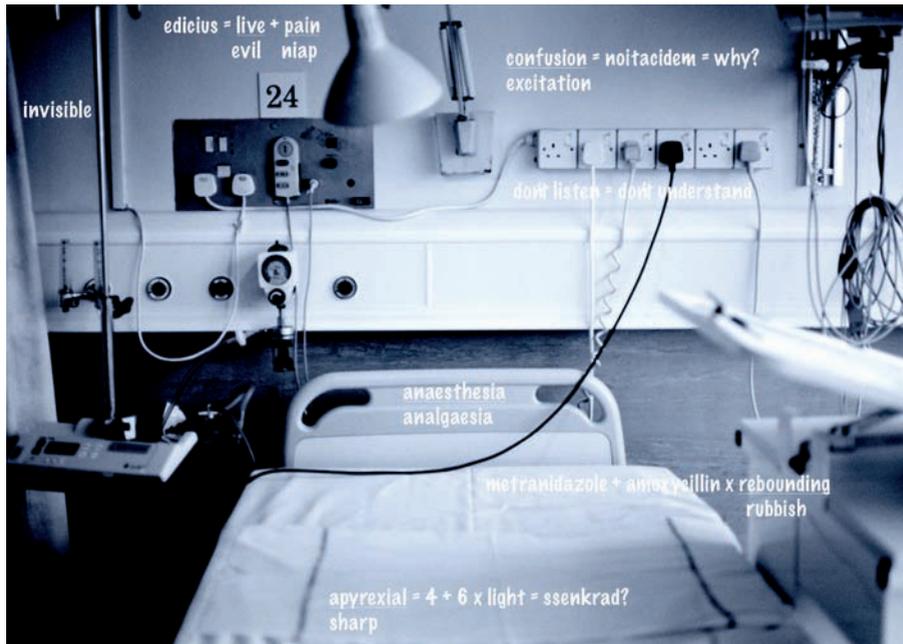


Figure 3.5 Deborah Padfield, untitled from the series *Perceptions of Pain*, 2001–06. Silver Gelatin Print. © Deborah Padfield, reproduced by kind permission of Dewi Lewis

- Clinician: Mm-mm.
 Patient B: That one. [Patient continues looking at image. Does not show to clinician]
 Clinician: And what's that about worry? [She confidently reaches to patient and takes image from her. Places it on the desk between them and touches it. They both look at it] Why ... why is this one then?
 Patient B: Just the thought of ... [Leans towards and also touches image. Both looking]
 Clinician: Of having to go into hospital again?
 Patient B: And anaesthetics and all that kind of thing.
 Clinician: Mm-mm. [Affirming]. Makes notes.

Reflection

The patient seemed reluctant to verbalise her thoughts about the previous images. She was literally keeping the image 'close to her chest', hanging onto it, not offering it to the clinician at first and seeming uncertain. Considering the image as a form of 'transactional object' helps

to see that keeping it to herself allows the patient to control the pace at which she discloses her anxieties and her more vulnerable feelings, which seem harder to share. By reaching over and taking the image, the clinician also uses the card as a transactional object to assert control in, what seems to be here, a reassuring way for the patient who responds by speaking her anxiety, as both show joint attention to the image. In a more symbolic way the image, at this moment, may also stand for the patient's worry. As such the clinician takes the 'worry' from the patient (in the form of the image), and puts it between them on the table, to physically demonstrate that they can look at this together and share it. Using ideas about more concrete transactions or symbolic uses of images lets us see the complexity of how they are used by participants to negotiate interactions.

Case example C

Patient and clinician are female, Caucasian, aged 40–50 years. Patient C has been angry and upset about taking medication to manage pain and the effect it has on her life.

- Patient C: Um, this has to do with my self-identity [Fig. 3.6]
 ...
 Clinician: Ah, okay.
 Patient C: ... being worn away by always having to pain manage and knowing that I have an icky time.
 Clinician: What about that one makes you think about your self-identity?
 Patient C: Because that, that person's face is burning off [forcefully].
 Clinician: Right, okay.
 Patient C: So, for me that's self-identity.
 Clinician: That's interesting, actually, because, um, I did some work with, I think it was her, um, when I'm doing this project, so it helps me identify with that as well.
 Patient C: Yes, because for me, if that's a portrait of a person [makes sustained eye contact with clinician], well you know ...
 Clinician: Yes.
 Patient C: ... I'm a visual ... I work in visuals ...
 Clinician: Visual things as well.
 Patient C: So that's like the burning off of ... and plus my pain is hot.



Figure 3.6 Deborah Padfield with Linda Williams, 'Untitled' from the series *Face2face*, 2008–13. Digital Archival Print. © Deborah Padfield

Reflection

If we consider the discourses that skew the power relations in diagnostic encounters (Tipple 2003, 2011), the clinician's role here is to contribute towards a body of knowledge held about the patient and contribute to a diagnosis within the formalised medical system: a position of 'expert' and decision-maker, a powerful position. The clinician has thus far steered the consultation, and confirmed her role as a professional whose job it is to direct the situation by asking questions 'what about that one ...?'

When both consider Fig. 3.6 together, something interesting happens, which is that the clinician comes out of this role and appears to give more authority to the patient. To a certain extent all the patients in PSTT became 'experts' on their chosen images, but here the clinician goes further, acknowledging that the patient has helped her to think differently about another patient of hers who originally made the image. This reveals more about the clinician, her thought processes, uncertainties and previous work with the project, 'I think it was her ... um'. It seems to have a levelling effect, and empowers the patient who then feels able to openly assert her own expertise 'I work in visuals' drawing on her strengths and knowledge, and taking on a more powerful identity as an expert. Tipple's theories about how participants used images in assessment provide a way of seeing the image here as part of a social interaction, where negotiating its meaning allows for shifts in roles. The subjectivities of participants are formed and re-formed from moment to moment (Tipple 2011).

The potent image that the patient has chosen is of a woman's face seemingly half in flames. The face belongs to the patient who originally co-created the image with Padfield, and we can wonder about its making and the complexities of what it brings into this new relationship. Skaife (2008) suggests the image will retain some intrinsic features from its making but its meaning will shift, a meeting between the image itself, people and environment, in the moment. This brings up the complexity of how we understand images. In Fig. 3.6 *people on fire* might call to mind protest (setting the self on fire) or persecution (burned at the stake). These are my culturally influenced interpretations and others would read the image differently. It would have different significance on a political placard, on the cover of a music album and in a pain consultation. This research is another context where we are making meaning retrospectively from the image.

In the consultation the patient's words about the image accentuate the act: something truly terrible is happening to this woman, 'that person's face is burning off'. Her words to the clinician emphasise horror. In addition to 'self-identity' the image seems to bring something of the patient's previous anger and distress into the room. The violent attack on her identity by pain causes her extreme emotional suffering and this is a key theme that the clinician later picks up on, also reflected in the treatment plan, which includes access to further support. The two look at each other during and after the words 'portrait of a person', which seems to bring the humanness of Patient C's experience and their interaction into the room.

Case example D

Patient D, male, Caucasian in his 20s, has suffered chronic groin pain for several years and undergone many referrals. The clinician is female, Caucasian and middle-aged.

- Clinician: And this one? [They hold Fig. 3.5 (shown above with case example B), between them, each holding an edge].
- Patient D: That's ah, I guess to do with the psychological side. I have been seeing other doctors in hospitals for so, so many years now and, ah, I've had so many tests and it ... I'm, sort of, used to it now but I'm not getting anywhere [sounds fed up].
- Clinician: What, why ... what from that says that to you?
- Patient D: Ah, it's just, sort of the setting.
- Clinician: The setting, yes.
- Patient D: And, sort of, becoming numb to the setting.
- Clinician: Okay.
- Patient D: I guess.
- Clinician: Is it different being here today?
- Patient D: It is, actually. Um well just ... just, ah, you do, [makes eye contact] you do seem very, ah, interested [laughs] and, ah ...
- Clinician: [laughs] Oh, that's quite good.
- Patient D: ... willing to listen and, um, ah, some of these doctors I felt like they've not really given me much time to discuss it or talk about what, what the worries I have in the long term ... they'll talk for five minutes and book a, book a test and that'll be it.

Clinician: Actually, you didn't perhaps expand on what your long-term worries were.

Patient D: Oh, well, just, ah, ah, I hope that I can improve the symptoms ... and, ah, and the sexual problems.

Clinician: Mm-hmm.

Patient D: I'd like to, sort of, make sure they don't get any worse.

Clinician: Yes, okay.

Reflection

Patient D associates Fig. 3.5 with his negative feelings about the 'setting'. He doesn't elaborate on why, but a viewer might notice the image has a bluish tone with clinical white labelling and shows a view down on a hospital bed. In light of Patient D's words I interpreted its tone as cold and dispassionate: the 'patient' is seen through the viewer's gaze as though we have stopped during a ward round to make an examination. Medical equipment and wires surround the bed and the light suggests scrutiny or procedure. There is no body or identifiable human individual in the bed; a person is conveyed only through their role in this setting.

Skaife (2008) suggests what the image brings into the inter-subjective space can be subversive, and it can be seen as having its own agency. Understood like this, the image lets Patient D bring the unpleasant dynamics of 'the setting' into the room for discussion. He uses Fig. 3.5 as a way to voice his reaction to having to endure this; his frustration and upset with 'doctors' generally; his role as patient, 'I've had so many tests'; and depressing feelings of disempowerment 'I'm just not getting anywhere'. Both consider the image. The patient's words 'numb to the setting' seem significant in that it is possible for either clinician or patient to experience overexposure to the medical system, becoming desensitised or 'unfeeling' to the other human person in the clinical encounter, seeing instead only the role or identity of 'doctor' or 'patient'.

Bringing in 'the setting' is like pointing out the invisible discourses or 'frames' (Tipple 2003) that surround their exchange. Having these exposed seems to result in the clinician, in an extremely direct way, asking Patient D's opinion of their encounter in the here and now. We could think the question was leading, in that the clinician wanted to move him away from his negative experiences. However, in asking the question, she makes herself vulnerable to the patient's scrutiny and he now has power to comment on the dynamics, which he does – on how the clinician is performing her role. In doing so something changes,

and it *does* feel different in that moment: they look directly at each other, both laugh slightly self-consciously, and they are able to move from the acknowledgement of the patient's objectified feelings, to a hopeful trusting communication in which he is able to raise serious worries.

Concluding summary and implications

The case material was considered using some markedly different theoretical approaches to images found in art therapy literature. Each theoretical approach drew on diverse frameworks from a range of other disciplines, and it was *how* these author/practitioners had applied these frameworks to understanding aspects of image use in their settings, that proved helpful in thinking about the images in PSTT.

To summarise, considering the images as transitional objects (Winnicott 1971) showed them as forming a middle ground between patient and clinician, where aspects of the patient's self could be explored and thought about. Within the triangle of patient-image-clinician, joint attention took place, bringing potential for symbolisation, insight and meaningful emotional communication about pain with another (Isserow 2008, 2013). As transactional objects (Schaverien 1995) images were objects of exchange being used to negotiate dynamics. Changing the focus to the social context of the exchange, images allowed participants to shift role and identity, which could be formed and reformed in the moment (Tipple 2003, 2011). Finally, the image's meaning can be understood in terms of its contribution to the intersubjective space (Skaife 2008).

The case studies raise questions as to the role of images used by other professions in different settings. The case material suggests to me as an art therapist that the presence of images themselves appeared to be of value; they enabled useful spaces to open up for communication and insight, and for relationship dynamics to be negotiated, potentially empowering patients. There are also possible problems: images can bring up powerful feelings that need responding to sensitively, and if used thoughtlessly may negate the potential for patient empowerment. Clearly images should not be used clinically without carefully considering circumstances: importantly PSTT clinicians were specialists in the complexities of pain and could make referrals for psychological support if desired. Seeing the way PSTT patients used a finite image resource to convey highly personal meanings, led me to wonder how these patients

would have created their own images from scratch, and what these would have looked like. Art therapy could be a suitable referral option for patients who wanted more support.

Overall, I suggest the different theoretical frameworks used expand our understanding of how images were functioning in PSTT. Of course, these approaches are not the only way to understand the encounters, yet they let us see them in ways we have not before. These frameworks also add layers of meaning that co-exist with other qualitative and quantitative findings of the research team (Padfield et al. 2018; Padfield, Chadwick and Omand 2017). In addition, viewing the encounters through these lenses suggests avenues for further exploration: for example, using discourse analysis to examine the transcripts further for the impact of images on participant role and identity; exploring symbolisation; and interviewing participants about how they felt using their images, potentially playing back the videos. Each of the aspects preliminarily explored here could warrant further investigation.

By drawing on approaches other art therapists have taken to understanding images I have suggested some of the ways in which we can view the images used in PSTT. In the PSTT study, images appear to have opened up new spaces between patient and clinician in which dynamics could potentially be negotiated. In these spaces reflection and meaning-making could take place and complex emotional aspects of pain could be communicated.

Note

- 1 MREC Ref: 09/H0801/51. Registered (NIHR CRN Clinical Research Portfolio ID no 7451). UCL Data Protection Registration: (ref Z6364106/2009/5/15, Section 19, Social Research).

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4

Pleurisy I–V

Rebecca Goss

Pleurisy I

At its most acute,
she pictured an orb,

phosphorescent,
in its snare of rib.

It eased to the pressure
of a handstand,

executed
by someone fully grown

upon her chest,
and every cough

discharged small bombs
across her back.

In her most breathless
state, there was a tree –

cankorous and scratching.
Malevolent in its reach

around her frame.
She wanted it uprooted,

hauled outside her body,
just to pick off the lungs

snagged amongst branches.

Pleurisy II

She tried to cancel out

one great sensation
with another –

wanting the weight of him
to counter

what she felt
and as he held her,

flooding her body
with touch –

cautiously urgent
as she tilted for his push,

hurt bloomed
between her shoulders

and it was
the brightest flowering.

Pleurisy III

8am – 1g paracetamol

9am – 400mg ibuprofen (with food)

12noon – 1g paracetamol

3pm – 400mg ibuprofen (with food)

4pm – 1g paracetamol

8pm – 1g paracetamol

9pm – 400mg ibuprofen (with food)

Pleurisy IV

*'When doctors listen to the breath, that's what they want
to hear: an openness connecting breath to the sky ...'*
(Gavin Francis, *Adventures in Human Being*)

She did not spill sky.
Did not open her mouth
and release a piece of firmament.

Something billowed, yes.
It wanted to get out, but its way
was met with rub and thwack.

She dreamt of grace, of breeze.
Taking her out of this bed, and up.

Pleurisy V

My daughter
comes to sit beside me
and read.

I struggle
to complete a sentence
of praise,

head bent, blown.
She strokes my face,
a touch

that defines herself
as mine.
Her lungs expand

and she doesn't
feel them.
The breaths she makes

are clear and young.
She is
studying my fatigue.

This child,
inhaling the space
between us.

She is
present. She is
air.

5

From boardroom to consulting room to jobcentre plus

The bureaucracies of pain

Jens Foell

Conversations about pain

Conversations about pain take place everywhere: within the family, in care-giving situations, in the clinical encounter or in ‘processes of social administration’ as in the assessment of one’s capability to fulfil social obligations, such as working capability assessments. Conversations about pain are also the fundamental building blocks in the medical and social administration of pain. It is a conversation between two ‘social animals’ about the private experience of one social animal. Pain is an emergent phenomenon of the brain and a subjective experience (Tracey and Mantyh 2007). Pain also affects social interactions and influences interpersonal relationships. This is played out in many encounters – between close relatives, in professional encounters with healthcare providers, but also in processes of social administration. I am going to explore this aspect of pain in this chapter and elaborate how this takes place in the world of street-level bureaucracy.

Is persistent pain a thing?

First let us go back to the biopsychosocial model. Current understanding of the pain experience is based on the ‘biopsychosocial’ model (Engel 1977). We teach it to the medical students, to trainee doctors, it is mentioned everywhere. There is a sequence in the amalgamation of letters: ‘Bio’ first, followed by ‘psycho’, with the ‘social’ positioned at the end. The sequence indicates a hierarchy. Siddall and Cousins (2004) describe the position of these factors as primary, secondary

and tertiary, and allocate the environment the role of a tertiary factor contributing to the persistence of pain. The biopsychosocial model is a flexible and elastic model that can incorporate the relevant components of the pain experience in order to make sense of people's predicaments and assign appropriate treatment strategies accordingly. Commonly this 'biopsychosocial' model is opposed to a 'biomedical' model. Mildred Blaxter attributes three doctrines to the biomedical model: the doctrine of a disease-specific aetiology, the position that diseases are generic phenomena across space and time and lastly that they are a deviation from the norm (Blaxter 2010; Boorse 1977) (see Fig. 5.2). Historically the discourse of pain has shifted in the transition to hospital medicine from interpretations of the account of the sufferer in a framework of balance, to assessments of the physical tissues. It moved from issues to tissues, from a system of deranged equilibrium to the local lesion (Jewson 1976). The 'biomedical' model has never been explicitly formulated as theory. Nevertheless, multiple authors have taken positions in opposition to this biomedical model, which is more a dominant but silent set of practices and a way of working than a *model*. The origins of this presumed mind–body dualism are retrospectively attributed to René Descartes. This is a retrograde attribution stemming from debates in US medicine in the early twentieth century (Duncan 2000; Brown 1989). The biomedical model as preference given to the situation of somatic tissues is just *there* as silent dominant discourse – more as a way of doing things (practice) than a way of seeing things (theory). If it is seen as a way of *doing* things it makes sense to analyse how the work of dealing with persistent pain states is allocated between the professions and disciplines, and where this work is carried out. I am talking about the division of labour in the field of health and social care.

In the reality of shared work and patient journeys through a fragmented landscape of health and social care, the biopsychosocial compartmentalisation provides the battleground for allocating or even shifting responsibilities for an unpleasant situation between different protagonists or work spheres (Armstrong 1987).

Fragmentation

An argument can be made for looking at the politics of pain on the various levels of interaction, from consultation room to boardroom, from individual encounter to policy-making for populations. If it is clear whose job it is, who can actually do something about pain that does not

go away, the anomaly, the liminal condition, then it is clearer how to proceed. Healthcare services are increasingly fragmented. Coordinated multidisciplinary working as advocated for treatment in secondary care is the exception, not the norm. The division of healthcare labour relies on the exchange of increasingly granular information, which travels independently of the index person through the system of health and social care. The welfare system in the UK is fragmented in a similar fashion, with third sector organisations and independent providers such as Atos and Maximus carrying out work that has been outsourced by the Department for Work and Pensions (DWP) (McCartney 2012). Within the welfare system, workfare interventions (interventions aimed towards integrating people into the labour market) are carried out by a variety of organisations working on specified contracts as subcontractors. These contracts include key performance parameters like the proportion of clients who re-enter the labour market (return to work). There is an ongoing debate as to whether such sanctions are equally part of the targets in subcontracted work.

The moral aspects of the biopsychosocial model

Conversations about the role of the biological, the psychological and the social components of the pain experience are delicate. They touch moral sentiments. Dysfunctional pain communication can, following Cronen and Pearce's account of interlinked communication patterns, be framed as a 'strange loop' (Pearce and Pearce 2000). Doctors and patients may fall into well-known stereotypes, 'they did not listen' meets 'they do not have insight'. Every frontline healthcare practitioner is familiar with such statements. Many service users report that healthcare professionals have said that the pain is 'in your head'. I doubt any doctor really has said 'it is all in your head'. But I do speculate that this is a response not to what has been said, but to how the recipient felt when something else was said. The authenticity and legitimacy of the pain experience, in particular when no pathological lesion is found that could be accountable for the pain experience, is at stake. The relevant communication content may have been conveyed in the way of phrasing the reply and not in the semantic content of the verbal utterances. Professionals' accounts for the psychological component of the pain experience shifted with time. 'Psychogenic' went out of fashion, but even as late as 2004 Siddall mentions 'conversion hysteria' (Siddall and Cousins 2004; Biro 2010). Waddell's signs of unravelling pain

behaviour in contrast to ‘genuine’ pain have gone, but the scepticism towards a significant psychological component of the pain experience has remained (Waddell et al. 1980). I am guessing it has to do with the moral connotation of the ‘B’, the ‘P’ and the ‘S’ of the biopsychosocial model. At stake in the sequence of the letters is the moral integrity of the person experiencing pain.

One can maintain moral integrity, if the predicament is located in the bio-sphere. It leaves a chance to simply ‘get on with it’. On the contrary it does not give the sufferer agency to change it. It is beyond control, but also beyond the power to change things. The psychosphere, meanwhile, is a comparatively more challenging space. It locates agency in the personality of the patient and comes with a behavioural change agenda. The sufferer has to change something in order to be relieved from his/her predicament. All sorts of programmes exist to accomplish this task, from classic conditioning in behaviourist assumptions to more modern neoliberal strategies of mindfulness (Jackson 2005). The locus of control is in the personality of the sufferer.

If pain is explained as mal-adaptation, it includes the prefix ‘mal’ – a negative or bad way of responding to a situation with pain that never goes away (Borsook and Kalso 2013). This is a difficult starting point for learning to live with pain as the persistent noisy guest, the bothersome and distracting and at times negative intruder into one’s life, a focus of persistent worry (Eccleston and Crombez 2007).

The ordinary consultation/conversation about pain often includes a fierce battle about the locus of control or the accountability for the absence of control.

If the locus of control is situated in the *social sphere*, the situation becomes problematic for both parties in the encounter. It puts both healthcare professional and healthcare recipient into a disempowered situation. Mildred Blaxter describes participants’ responses in lifestyle surveys by stating that ‘causes of health and illness outside the individual’s control – housing, the environment, personal poverty or prosperity – were rarely mentioned, for good or ill, as important in one’s own life’ (Blaxter 1997, 748).

This situation of interdisciplinary care for people experiencing pain that does not go away can be likened to the children’s game ‘Pass the Bomb’ (Rodriguez, Barc and Heyworth 1994) (see Fig. 5.1). In this game a plastic device with an inbuilt random timer for the sound effect of a detonation gets passed around in a team and each player has to accomplish a task at speed and the pass the device. In the shared care for chronic pain the tasks can be ‘refer to Physio’, ‘start Chondroitin



Figure 5.1 Photograph of the game ‘Pass the Bomb’
© Jens Foell

sulphate’, ‘refer to IAPT’ etc., all the usual steps to convert current responsibility into somebody else’s problem, and whoever finds the responsibility in one’s court perceives the situation as an inappropriate dumping ground for predicaments that belong elsewhere. The plastic bomb detonates in your hand. It’s your job. There is no dedicated holding space for people with chronic pain. There is no service with a longitudinal contract to help the ones who cannot get helped. Interventions are geared to be one-off interventions. There are limited resources for treating a chronic condition. So, I am returning to the starting point. The point I want to make is that the order of the letters in terms of sequence and importance indicates a) hierarchy of the nobility of the reason for being in pain and b) that this has consequences for selfhood. Being in persistent pain is often associated with stigma (Goldberg 2017). Pain intensity and pain disability also have a steep social gradient (Bridges 2012). Seen in the context of the social determinants of pain, the model should better be called the ‘sociopsychobiological model’. But where does it leave people, if the main driver for the pain experience is located in the ‘S’ of the biopsychosocial model?

Quintner et al. (2008) suggest locating pain in a *third space*. It is the interpersonal space (Schuetz 1945). This is a space for mutual respect and a space that opens space. It is not a space for a professional career based on the relationship of the specialist with a disease. Mildred Blaxter mentions this attachment dimension for a professional career in her book about health (Blaxter 2010). This space is well known from dealing with people with personality disorders – the locus

of intervention is not the disordered personality, as it is their relationships and attachments that are quite difficult and complicated (Crowell, Beauchaine and Linehan 2009). This does not mean ‘impossible’. With respect, curiosity and imagination a lot is possible, but only in the context of functioning relationships. This is the basis of DBT or dialectical behavioural therapy, which includes relationships in the equation (Robins and Rosenthal 2011).

Illness, disease and sickness

‘Patients suffer “illnesses”, doctors diagnose and treat “diseases” (Eisenberg 1977, 11) (see Fig. 5.2 and Table 5.1). Relatedly, Charles Rosenberg states that

disease is at once a biological event, a generation-specific repertoire of verbal constructs reflecting medicine’s intellectual and institutional history, an aspect of and potential legitimisation for public policy, a potentially defining element of social role, a sanction for cultural norms, and a structuring element in doctor/patient interactions. In some ways disease does not exist until we have agreed that it does – by perceiving, naming, and responding to it. (Rosenberg 1989, 1–2)

Sickness relates to the processes of social administration that regulate the intersection of social functioning, illness and disease (Parsons 1975).

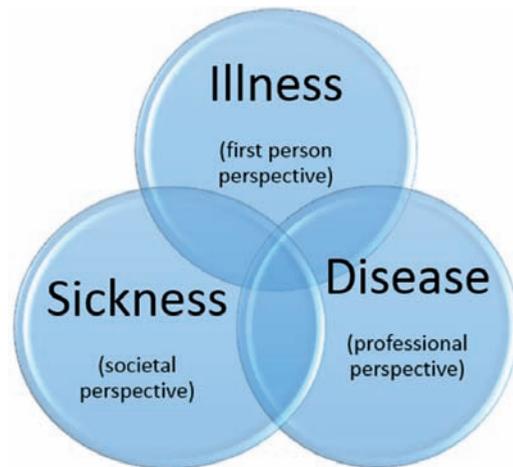


Figure 5.2 Illness, sickness and disease (after Blaxter 2010)

Table 5.1 Illness, sickness and disease (after Blaxter 2010)

	Disease	Illness	Sickness
Field, area, primary agents/ stakeholders	Profession, medical and other healthcare professions	Personal, (experiential existential)	Society, social institutions, health policy-makers, lawyers
Basic phenomena	Physiological, mental, genetic, environmental entities or events	Subjective experience, first-person negative experience, suffering, pain	Social conventions, norms, roles (including social prejudice)
Access to phenomena through:	Observations, examinations, measurements (by the natural sciences and by the use of technology)	Introspection, intuition (phenomenology), interaction (language), mental states (psychology)	Participation, interaction, social (science) studies
Knowledge status	Objective	Subjective	Intersubjective
Altruistic approach	Cure	Care	Resource allocation, justice
Entities to, results in:	Examination, diagnostics, treatment	Attention, support, moral and social excuse, reduced accountability	Economic support and compensation, sick leave, but may also result in discrimination and stigmatisation

Cycle of invalidation

Many people who experience chronic pain describe their ‘journey’ through the healthcare system as a cycle of invalidation or a persisting struggle to demonstrate the legitimacy of their experience. Having to place this experience in the framework of illness, disease and sickness is a difficult task (Young 1982). The presence of externally accessible signs and investigation findings is a prerequisite for the ontological status of ‘disease’.

In illness – the subjective experience in the absence of external markers – feelings of shame, guilt and anger occur frequently (Serbic and Pincus 2017). Loneliness and social withdrawal follow suit (Cacioppo et al. 2011). Hidden distress is part and parcel of the situation (Scambler 2004). The presence of an invisible significant condition that affects the relationship with the past, the present and the future affects relationships and societal obligations with family and (if applicable) work. It makes communication with others difficult. Negative experiences prime the expectation for the next encounter with

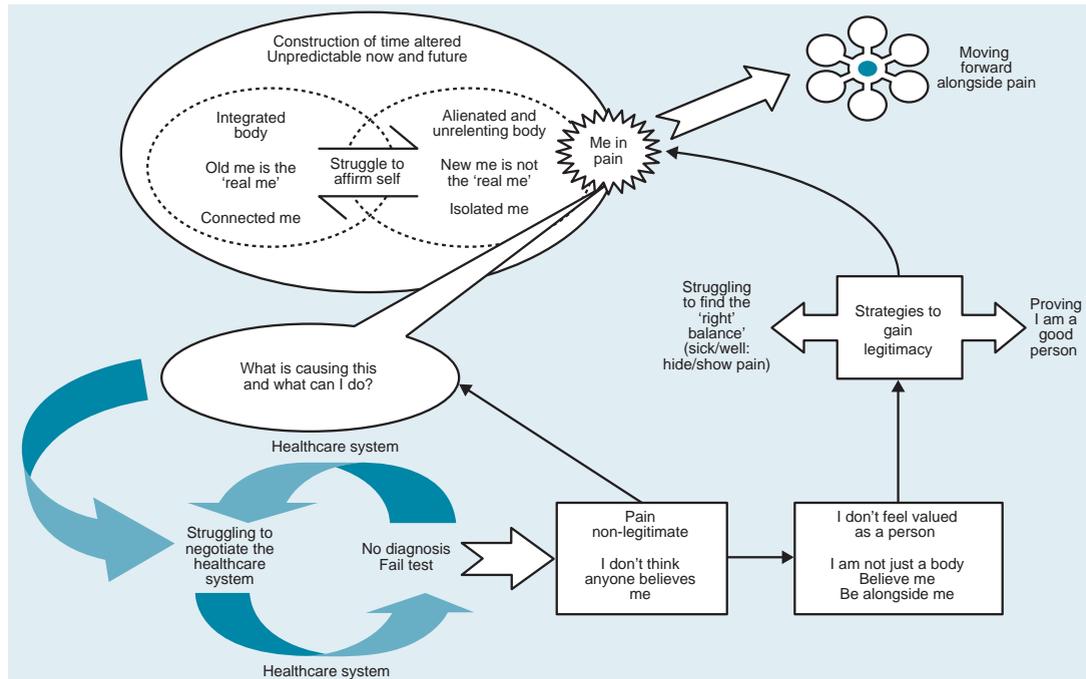


Figure 5.3 Constant adversarial struggle (Toye et al. 2013)

healthcare professionals. This is the nocebo effect, the dark counterpart of the much studied placebo effect (Greville-Harris and Dieppe 2015). Unfortunately bad is stronger than good (Baumeister et al. 2001). This means that for conversations about pain in public encounters there is always baggage: negative experiences from the past affect the present. This loop is well documented for the patient ‘journey’ through the healthcare system (Toye et al. 2013) (see Fig. 5.3).

It makes sense to broaden the scope and look at the welfare system to see even wider and more complicated implications of the same situation. Assessments of structure and function, of impairments and their consequences for activities of daily living and interacting with others take place in the context of eligibility for social housing including positioning on the banding system for prioritisation and for working capability assessments. These assessments are influential in granting access to the most basic needs in life: housing and finances or work. This situation relates to the basic dilemma in interactions with people in pain. Their disability is invisible. Pain is what the patient says. This may not be good enough for the patient (‘nobody believes

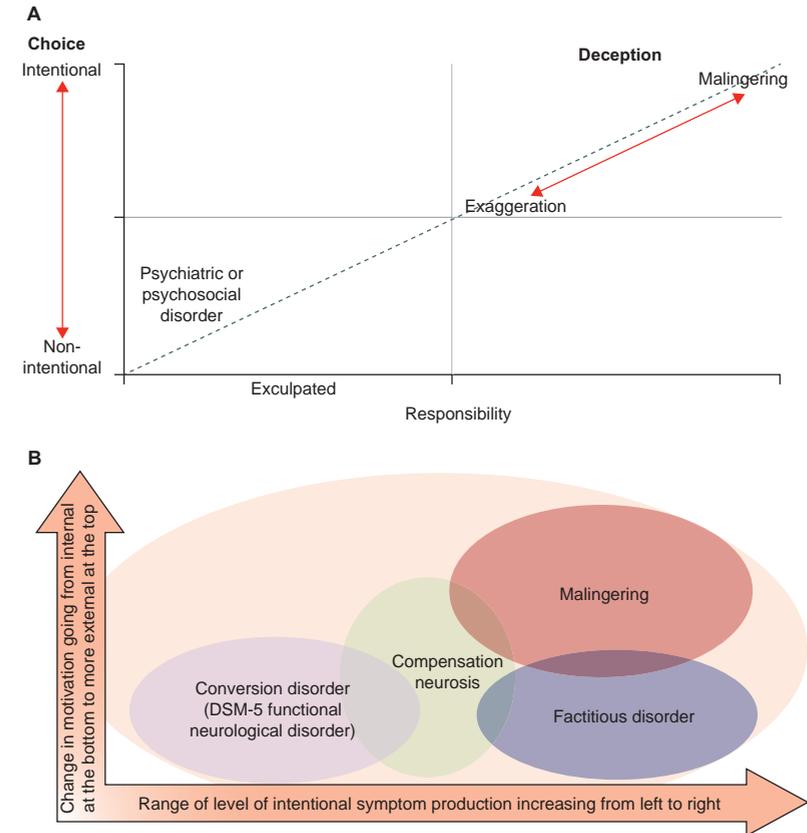


Figure 5.4 Two models of illness deception (A) and compensation neurosis (B) (Bass 2014). Reproduced by permission of Sage Publications (A) and American Psychiatric Press (B). Diagrams show the potential roles of patient choice, intentions and motivation in symptom production and, ultimately, diagnosis. (American Psychiatric Association 2013)

what I am going through’) or the assessor (‘is this genuine?’). Disease-status is necessary for the configuration of the patient’s predicament in processes of social administration, e.g. sickness absence, access to benefits, working capability assessments. The technological validation of the patient’s experience is the missing link in this dilemma (Hofmann 2001). The inability of the assessor to bypass the patient’s subjectivity establishes a space of doubt: is there malingering at play, is this unconscious, is this a matter of performing an experience in order to be believed? (Bass and Halligan, 2014) (see Fig. 5.4).

Targets: Return to work and sanctions

We are talking about pain disability and its rehabilitation. Pain features widely, but only indirectly, in health-related work absence. It is not coded as ‘pain’, it comes either under ‘musculoskeletal conditions’ or under ‘mental health’ (Mansfield 2013; Foell et al. 2014). Pain is what musculoskeletal and mental health conditions have in common, but it is not represented as an entity in its own right, and therefore not independently coded (Arnold et al. 2009). Public sector organisations work to targets, and are paid by outcomes and results. This applies also to workfare services. The people who can easily be brought into the labour market get prioritised over more vulnerable people. The colloquial term for this situation is ‘cherry picking’. Very little is known about sanctions being the subject of targets; but systematic data collection about the variation in practice between jobcentres relating to sanctioning does exist (Domokos and Wintour 2013). While it is known that the *volume* of working capability assessments is included in the specifications for the contract awarded to Atos and Maximus, the DWP has not disclosed whether the working capability assessment *outcome decisions* are also subject to such targets, as leaked information from whistle-blowers suggested (Gentleman 2013). The DWP states in a report ‘the use of sanctions did not seem to have a positive impact on motivation to progress and could damage the relationship between the Work Coach and participant’ (Ipsos MORI 2018, 73).

Fitness certification and the regulation of health-related work absence

The regulation of health-related work absence saw the shift from a deficit paradigm to an asset-based paradigm – from sick note to fit note, from focussing on what can’t be done to focussing on what can be done, from (in-)capacity to capability. It follows the ideology of patients as people who need to be ‘activated’ and the assumptions of a ‘dependency culture’ (Houston and Lindsay 2010). GPs now fill in fit-notes and ought to focus on what people can do, rather than what they can’t (Byng, Wheat and Barnes 2015). The overhauled version of the sick note allows for comments about work adaptations and early return. This positive psychology paradigm should facilitate resilience and a ‘can-do attitude’. Eligibility for benefits such as the employment support allowance (ESA) is assessed by a working capability assessment (WCA). Alongside

physical factors, it includes mental and cognitive and intellectual aspects, called ‘descriptors’. The amount of difficulties is numerically graded and finally added up to a global sum of points. This process has been fiercely criticised. Critiques include the fact that the assessments are outsourced from the DWP to private suppliers like Atos or Maximus. These assessments are standardised and use semi-structured interviews and a decision-making software called LiMA. In his independent parliamentary review of the work capability assessment, Lord Harrington criticises this as involving poor interorganisational communication and a rather mechanistic, protocol-driven, impersonal and opaque process (Harrington 2010).

Templates

The standardisation of health and social care relies on assessment algorithms. Such algorithms may be used as diagnostic tools in diagnostic conversations (triage), as a structure for long-term condition management, as a risk-assessment tool in mental health situations or as an assessment tool in working capability assessments. They provide the data infrastructure for standardised working practices. This has implications for the encounters between mental health professionals and patients – there is a temptation to deliver template-driven care (Seale, Rivas and Kelly 2013). Frontline staff often have to make choices between prioritising what matters for the client and what has to be done according to the template (Launer 2003). Templates are the reification of structured data collection and sets of rules. Frontline workers are often required to ‘work round’ the templates in order to get their job done. Templates can provide data for secondary purposes (billing, surveys, research) and require special techniques from the operators entering data. Experienced users say ‘you internalise the template and integrate it into your dialogue’, but often the template becomes the most authoritative voice in the concert of competing interests (Swinglehurst 2014). Humans are trained to assist the work of computers in the man–machine interface.

Conditionality

Behavioural change is a key goal of the welfare system. ‘Conditionality’ or in other words sanctions have thereby become an essential part of social engineering. Having been originally introduced for the regulation

of worklessness, its outreach has now expanded to lone parents and disabled people. Conditionality, the combination of incentives and sanctions is the vehicle for the movement from ‘welfare to workfare’ (Fletcher 2014). This new face of the welfare state was introduced as ‘jobseekers mandatory activity’ in 2006. Since then the principles have been applied in various other situations where the welfare state interacts with claimants. This intersection deserves more attention: the principles of customer service in industries dealing with commodities have been transferred to public services. At the same time the same public services are regulated with targets and experience a combination of strict top-down control, tight control of service delivery, often coupled with service redesign and job insecurity for the workers. Sanctions became a prominent factor contributing to the rise of foodbanks: as sanctions were widely implemented it meant many claimants lost every source of financial security and became dependent on charitable organisations to provide them with the bare minimum – food. But even this is often rationed and dependent on tightly regulated processes of social administration. Food vouchers from the Trussell Trust are handed out in numbered batches and only a set number of vouchers can be issued per claimant (Garthwaite 2016). Welfare to workfare therefore stands for two developments in public services: managerialism and the rise of penal regimes (Wright 2016). ‘Effectiveness and efficiency’ is not only the title of a landmark publication paving the way for evidence-based medicine, it also describes the process of redesigning public services within the management framework of retail industries or the food industries (Waring and Bishop 2013; Cochrane and Fellowship 1972). But there is an important difference between the two, as in the case of public services the service user is not a purchaser of services or commodities. The service user is in this instance a person whose behaviour needs to be regulated, the person in need of transformation (Dwyer 2018). Public services as people industries are now equipped with the carrot and the stick. And the stick needs to be used (targets for penalty frequencies). The carrot is the use of strategies of self-optimisation and positive health in the context of behavioural change (Friedli and Stearn 2015).

Street-level bureaucracy

Frontline staff navigate the competing interests of clients, organisations and the government. Their job is located at the intersection of enforcement of policies and rules, and the interests of the provider-organisation at

the macro-level, and interactions with clients at the micro-level. This is street-level bureaucracy (Lipsky 2010). Lipsky writes that:

street-level bureaucrats often spend their work lives in these corrupted worlds of service. They believe themselves to be doing the best they can under adverse circumstances, and they develop techniques to salvage service and decision-making values within the limits imposed on them by the structure of the work. They develop conceptions of their work and of their clients that narrow the gap between their personal and work limitations and the service ideal. (Lipsky 2010, xv)

This discretionary space is subject to the often-competing interests of the client, the organisation, top-down directives (including payment incentives) and organisational targets. Frontline staff (education, police, health and social care) need to carefully navigate these conflicting interests while serving clients and employers. This often happens in situations of poor support and/or low control coupled with high demand.

Politics of pain, policies of poverty

Welfare, workfare and healthcare are closely interconnected. Persistent, bothersome pain conditions like chronic musculoskeletal pain are unsurprisingly bound up with mood disorders (see Fig. 5.5). The following section explores the multiple influences and dimensions of this interpersonal and administratively governed space. Clare Bamba writes:

It is unclear how all this will play out, but it seems likely that the deserving/undeserving dichotomy may well reinforce and magnify the existing stigma attached to claims that are based on mental illness and may therefore further increase health inequalities. Either way, it will have important implications for the health professionals involved, as the validity of professional medical certification is being questioned by the government, and healthcare workers will become increasingly involved in regulating the poor. (Bamba 2008, 517)

Pain has a social gradient (Dorner et al. 2011; Bridges 2012). Pain intensity and pain disability are linked to social disadvantage. The

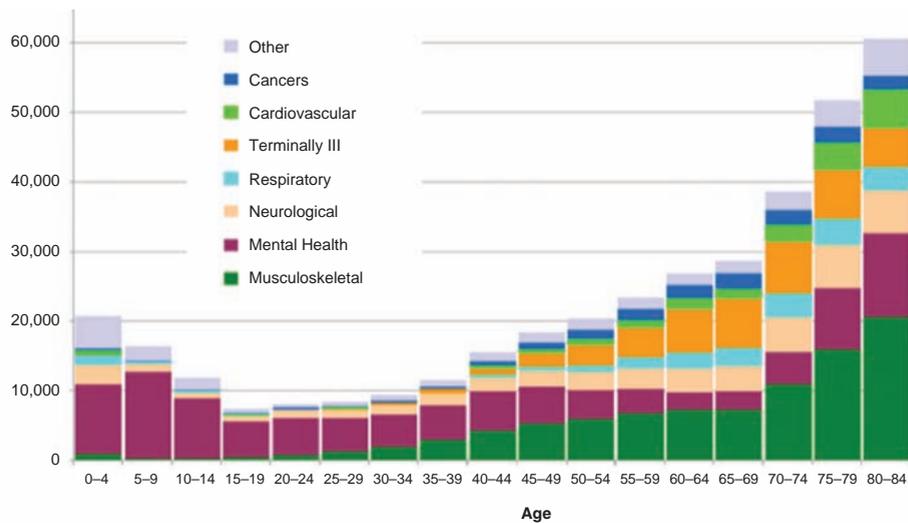


Figure 5.5 Condition descriptors classified by age groups in Disability Living Allowance and Attendance Allowance 2011/12 (DWP)

politics of pain are therefore closely linked to the policies of poverty. In a joint green paper, the Department of Health and Social Care and the DWP ask, ‘what will it take to transform the employment prospects of disabled people and people with long-term health conditions?’ (Department for Work and Pensions and Department for Health and Social Care 2017).

‘I need a report stating exactly what’s wrong with me’ is a common opening statement in primary care consultations about pain and mental health and its associated predicaments. These reports consume a good deal of GPs’ time and are very unpopular in the primary care workforce, but they can also transform patients’ lives for the better. In contrast to the private sector, where professionals working in healthcare and law can earn considerable sums from providing medicolegal reports, GPs are either not paid at all for this service or paid at a very low rate. A common response is to provide a basic, and often perfunctory or even plain wrong ‘summary record’. These summaries include an amalgamation of coded diagnoses in combination with centrally inserted administrative codes relating to the administrative issues as the likelihood of admission or other categorisations relating to service needs.

‘Why do you need this report?’ asks the doctor. ‘I need it for my PIP (personal independence payment) application’, replies the

patient. If the doctor were to give the patient this generic printout it would be fairly meaningless. To write a detailed factual report stating the patient’s situation, the diagnostic labels, their impairments, their activity limitations and their participation restrictions a doctor would need about 45 minutes (of personal time, unpaid, where medicolegal reports by insurance companies are paid by the companies), but as doctors rarely have such time available the resulting reports are highly likely to contain inaccuracies. Disability benefit advisors comment that most of the reports by GPs are inadequate.

This is a problem: such reports could have a huge impact and may be influential in processes of social administration and clarify the medical situation of the claimant. However, they require a great deal of knowledge about the patient/claimant, about processes of social administration, about cut-offs in assessments of physical and social functioning and about the intricacies of welfare administration. Very few doctors know this. And they are placed in the context of legitimising the claimants’ situation. As we have seen, the politics of pain are bound up with the politics of poverty and politics of welfare in the space of social justice. Disability without pathological lesion sits historically in a problematic space (Halligan, Bass and Oakley 2003). This space is governed by assumptions about conscious intentions and agency. There is malingering (conscious deception) on one end of the spectrum and hysteria (unconscious event) at the other end (Kanaan and Wessely 2010). Pain disability without demonstrable lesion is located in the very same place, where the authenticity of the experiences and their consequences are under investigation.

One problem is that the process is geared towards an essentialist formulation (disease) and relational formulations (an analysis of her impairments in the context of her life history and life-world) often disappear in the assessment grid (Litchfield 2013, 2014).

If people present with sleeplessness and low mood, the doctor has to ask what they are thinking about when they are not sleeping. If the doctor is curious, they may hear about debt. Problem debt affects 8 per cent of all households and is far more common in the lowest quintiles (20 per cent (Department for Work and Pensions 2017b)). Many people are too ashamed to volunteer information about their financial situation. Being poor has become a shameful state (Garthwaite 2011). The doctor may be reaching for the next food bank voucher (Garthwaite 2016). There are boxes to tick: ‘Benefit changes’, ‘Benefit delays’.

Financial stability and food security are at the foundation of Maslow’s hierarchy of needs (Maslow 1987). It is the priority.

GPs deal with these matters on a daily basis, particularly if they practise at the Deep End,¹ in deprived areas (Watt et al. 2012). The Faculty of Public Health argues for better mental health for all and relates the mental health of the population to politics and policy: job insecurity leads to housing insecurity, this is a fundamental stressor and exacerbates mental health problems (UK Faculty of Public Health 2017). Every GP is faced with the physiological consequences, but their job does not end here. It is about addressing the causes of these ‘idioms of distress’ (Nichter 2010). And this must be more than suggesting optimising individual adaptation strategies to promote wellbeing (see Fig. 5.6).

Doctors may individually or as communities of action decide to give more attention to these reports as important influences in processes of social administration. They highlight important intersections between illness (what the patient feels), disease (the measurable examination and investigation findings) and sickness (societal response to health-related changes in social participation). If such a report is undertaken properly in collaboration with the patient it can be an important part of the therapeutic partnership.

Pain also affects social interactions. Unsurprisingly, the most common descriptors to be categorised in the working capability assessment in the Work Related Activity Group (WRAG) segment, are ‘adapting to change’ and ‘social interaction’ (Department for Work and Pensions 2017a).

It is noted that social interactions are not core categories in the biopsychosocial assessment of pain, but highly influential in processes of social administration.

Summary

In summary this chapter has argued that:

- The biopsychosocial model builds up a straw man of the biomedical model, but is just a variation of the same theme, as it still operates in the same value system.
- It would be so easy and straightforward if persistent pain could be a *thing*. Pain without a lesion is a condition charged with moral judgement. Persistent pain as a thing, as a *disease in its own right* could shift the pain experience into an amoral space. It could be measured and isolated and categorised. People experiencing pain

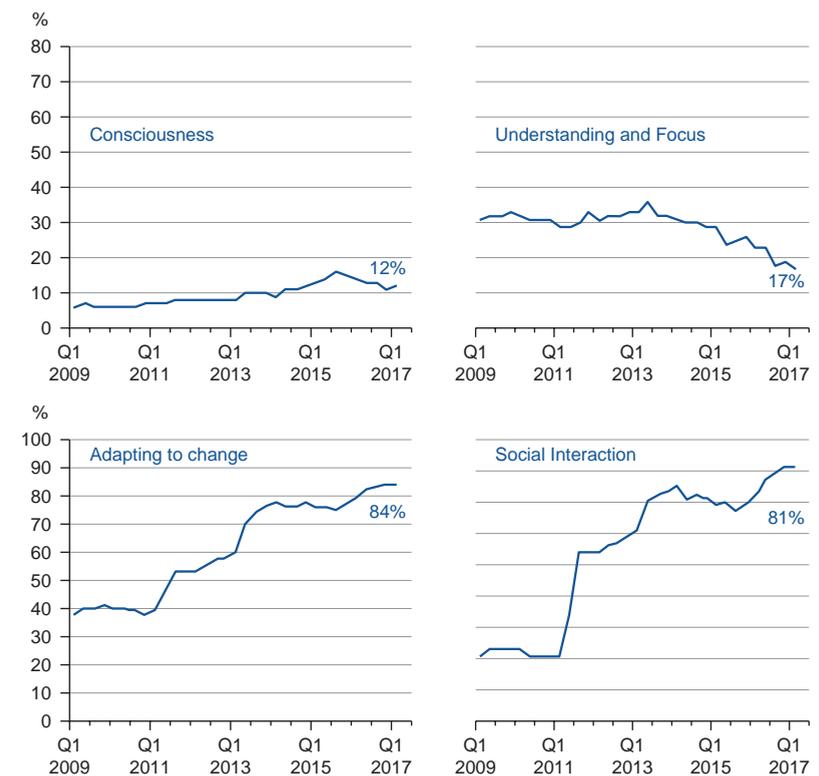


Figure 5.6 Descriptors for allocation to Work Related Activity Group (WRAG) in Employment Support Allowance claims (DWP 2017)

Figure note: The charts show the four main functional impairment categories in which claimants have scored points when assigned to the WRAG, scoring 15 points or more at initial assessment. Receiving 15 points or more is the main reason for assignment to the WRAG at initial assessment, however claimants can also be assigned to the WRAG at reconsideration or after appeal.

‘Adapting to change’ and ‘social interaction’ remained the most common reasons for WRAG allocations in the first quarter of 2017, with 84 per cent of claimants having an ‘adapting to change’ condition and 81 per cent present in the ‘social interaction’ group. Note that claimants can have multiple functional impairments and therefore appear in more than one category.

‘Understanding and focus’ affected 17 per cent of WRAG claimants (with 15 points or more) in the first quarter of 2017. Other reasons for being assigned to the WRAG (with 15 points or more) which aren’t shown here (‘upper limb’, ‘sensory’, ‘continence’ and ‘lower limb’) are less common.

might have less stigma and medical experts could have their careers bound up with a condition just as other specialists have built their career on their relationship to a disease. But, unfortunately, pain is not a *thing*. ‘Pain does not emerge naturally from physiological processes, but in negotiations with social worlds’ (Bourke 2014).

- This is enforced by administrative systems that favour sickness depending on disease, and this disease model forces claimants to build a case according to the disease paradigm to validate their experience. But this is notoriously difficult, and as a consequence decisions are often subject to the discretionary space of street-level bureaucrats (operating in a space with decision rules reified in computer templates and targets), which leads to a high rate of questioning the verdict within the organisation (mandatory reconciliations) and appeals against decisions despite the attempts of organisations undertaking the assessments to provide a standardised service by auditing the assessments. Despite scaffolding the assessments by specific decision-support software, wide variations remain in outcome decisions.
- In conditionality systems there is the opportunity to create a rehabilitation paradigm, but this would require more organised effort from the players in the teams. Unfortunately, it is more often experienced as a dysfunctional system with unconnected parts.
- The steep gradient in health inequalities and social disadvantages puts a spin on encounters about persistent pain. People in pain have both vulnerabilities and resiliencies. A truly rehabilitative approach would invite people as therapeutic partners to invest their assets into the rehabilitation, however many parts of the welfare system operate with essentialist models and invite people to present their vulnerabilities rather than their resiliencies, if the latter minimises the chances to get more support. This has consequences for successful rehabilitation.

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This chapter draws on extended conversations with Jonathan Tomlinson, Amanda C de C Williams, Rhodri Hayward, Pippa Brown, John Launer and Charles Pither.

Note

- 1 <https://www.gla.ac.uk/researchinstitutes/healthwellbeing/research/generalpractice/deepend>.

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6

Living with trigeminal neuralgia

Interview from *Pain Under the Microscope*

Chandrakant Khoda

The following text comprises selected extracts from an interview with Chandrakant Khoda for the film Pain Under the Microscope (Padfield and Omand 2018). Interspersed with it are images co-created with Chandrakant Khoda during the Face2face project at UCLH. The text is included as a stark reminder of the overwhelming nature of pain, its presence and impact on day-to-day living. Although short, it allows us a glimpse of what it is like to live with this level of pain on a daily basis and even when absent, the fear it might return.

I think it is difficult to explain to people exactly what the pain is until they can feel it for themselves. I can't tell people, take this pain away from me. That is not easy. Unless people have been in this pain before, it is difficult to explain. It is very difficult to explain this pain.

When I am in severe pain at home and if the pain is unbearable, to draw my wife's attention I will very often bang my fingers or palms of my hand on the table or just kick my left foot on the side panels, or anything where I can make a noise so my wife can hear me, for example kicking my foot. Basically, anything to draw my wife's attention – this is what I will do. I will just kick with my foot and so it is something like this, I will do this as well – a couple of times (demonstrates kicking on the floor).

This morning I could hardly brush my teeth. That gave me a message that I couldn't shave, as you have probably noticed I haven't shaved my beard much today, as if I did I would not feel comfortable. So, I don't shave until my pain is stopped. Tomorrow, I don't know if the pain might be stopped or it might not be stopped. I take it on a day-by-day basis. It is difficult to tell how I am going to feel tomorrow.

*



Figure 6.1 Deborah Padfield with Jillie Abbott and Chandrakant Khoda, 'Untitled' from the series *Face2face*, 2008–13. Digital Archival Print. © Deborah Padfield



Figure 6.2 Deborah Padfield with Chandrakant Khoda, 'Untitled' from the series *Face2face*, 2008–13. Digital Archival Print. © Deborah Padfield



Figure 6.3 Deborah Padfield with Chandrakant Khoda, 'Untitled' from the series *Face2face*, 2008–13. Digital Archival Print. © Deborah Padfield

When I have got visitors at home or even if my wife is at home I will normally just sit down with my hand on my face like this and try not to speak to anybody and try to leave it there as comfort, because I don't know when the next pain is going to kick in. When I am in severe pain that is what I usually do with my hand, just leave my hand, my palm against my face like this to give myself comfort. Sometimes also in fear, as there is a fear that the pain is going to kick in at any moment. So, I leave my hand there as comfort and then release it like that. When I am in severe pain I will very often go upstairs and lie on the bed as I don't want to talk to anybody, I just want to leave myself to myself because I worry more about the pain then than anything else. I won't want to watch television or listen to the radio or listen to music, I will be sort of like a depressed person. Obviously, I will take my medication and then keep myself to myself.

*



Figure 6.4 Deborah Padfield with Chandrakant Khoda, 'Untitled' from the series *Face2face*, 2008–13. Digital Archival Print. © Deborah Padfield



Figure 6.5 Deborah Padfield with Chandrakant Khoda, 'Untitled' from the series *Face2face*, 2008–13. Digital Archival Print. © Deborah Padfield

Even perhaps the medical professionals struggle to pinpoint exactly what problem I have; I have no doubt about that at all.

*

Life is not normal. You can have medical conditions at any time and you still have to get on with your life.

Chandrakant had successful surgery for TN and is now back working and doing the things he enjoys.

Reference

Padfield, D. and Omand, H. (dirs) (2018). *Pain Under the Microscope*. Revised version. Film.

7

Karuṇā (करुणा in devanāgarī)

Anusha Subramanyam

Pain resists movement and yet it was Anusha's movement at the conference that united all of us through rhythm, gesture and generosity of spirit. For this volume she re-creates images with her body in response to the photographic images from the project, placing them alongside fragments of text reminding us we are all connected in suffering and in hope.

Shredded ties

All that connects me to me, where has it gone? All that ties me within me seems to fall apart. Not sure of where and how I am wired. Something snaps, which is real and yet unreal for others. How did I get heard, who can hear, see, feel the pain? The pain that slowly shreds away myself, me.

Fear fearless

For me these sufferers have to deal with their pain in so many ways. For me they teach fearlessness and compassion to themselves and therefore to all of us.



Figure 7.1 Anusha Subramanyam re-creates images with her body in response to photographic images from the *Perceptions of Pain* and *Face2face* projects. All documentary images. © Nir Segal

Gentle tread

Who walks with me, who sees me? I walk and stumble, I struggle. When I find myself, hold myself, I can see the beauty within, I taste life, I fly, soar in joy. There is light, the sun shines.

Making connections

Connecting and creating compassion within myself I can connect with others. Others help, support and bring my being into wholeness as I hold myself and I am held with others.



Figure 7.2 Anusha Subramanyam re-creates images with her body in response to photographic images from the *Perceptions of Pain* and *Face2face* projects. All documentary images. © Nir Segal



Figure 7.3 Anusha Subramanyam re-creates images with her body in response to photographic images from the *Perceptions of Pain* and *Face2face* projects. All documentary images. © Nir Segal



Figure 7.4 Anusha Subramanyam re-creates images with her body in response to photographic images from the *Perceptions of Pain* and *Face2face* projects. All documentary images. © Nir Segal



Figure 7.5 Anusha Subramanyam re-creates images with her body in response to photographic images from the *Perceptions of Pain* and *Face2face* projects. All documentary images. © Nir Segal

Clarity

Together we bring clarity for pain sufferers and carers. Touching humanity, learning growing.

Karuṇā compassion, compassion for all, for ourselves and for others. In pain and suffering, in joy, in life that is ever present.

Part II

Seeing

8

The photograph as a mediating space in clinical and creative encounters

Deborah Padfield

... problems begin with the reality of putting a person in front of a camera, and the complex dynamics that take place between the sitter, the photographer and the spectator. (Goldstein 2002, 168)¹

This chapter explores ways in which a co-creative practice can address some of the unequal power dynamics between photographer and sitter inherent in the photographic portrait. The *Face2face* project at UCLH, NHS Foundation Trust (UCLH) attempted to produce portraits of pain *with* rather than *of* pain sufferers. Building on an earlier collaboration with Charles Pither at St Thomas' Hospital, *Perceptions of Pain* (Padfield 2003), *Face2face* was a collaboration between an artist (myself) and a pain consultant (co-editor Joanna M. Zakrzewska), with staff and patients from UCLH. It involved working with five core participants from the pain management waiting lists to co-create photographic images reflecting their unique experience of pain, many of whom have contributed to this volume. A selection of these photographs were integrated with a sample from the earlier project, *Perceptions of Pain*, and used to develop a pack of 54 (6" × 4") laminated images. These images, or PAIN CARDS as they became known, were subsequently piloted in pain clinics with patients who had not been involved in making them, and their impact on doctor–patient interaction evaluated. The project is described more fully in the introduction and analysed in [chapters 2, 3, 9, 16, 21 and 22](#), as well as in a range of journal articles (Omand and Padfield 2019; Zakrzewska, Padfield and Ferguson 2019; Padfield et al. 2018; Padfield and Zakrzewska 2017; Ashton-James et al. 2017;

Semino et al. 2017; Padfield, Zakrzewska and Williams 2015; Padfield 2011).

The intention was to enable people with pain to control how their illness and experience was represented to others. The lengthy collaborative process allowed space for complex aspects of the pain experience to emerge, which might not otherwise have been revealed or recognised. Similarly, the dynamics between those viewing the photographs, when placed between clinician and patient in the clinic, and the experiences of those who co-created the original images are brought into play. Such pain narratives might not have found their way into a medical discussion, yet were often central to the intensification, prolongation and/or disabling impact of pain on that person's life. The photograph in this context can be seen as a mediating space navigating between the original experience of the person who co-created the image (validating pain which defies description or logic), that of the person with pain visiting the clinic and selecting the photograph, and that of the person witnessing or treating the pain. The space referred to is both physical and metaphoric. The images bring the physicality of pain sensation directly into the room via the materiality of the image on the one hand, and symbolically as a springboard for discussion of the emotional and social impacts of pain, on the other. They could be seen to be, in anthropologist Alfred Gell's term's, 'relational' (1998), participating in performances of identity construction and relationship building.

This chapter teases out the specificities of photography that make it the most appropriate medium for such work and argues that the use of photographic images and processes can regenerate the language around pain and improve communication in a clinical setting. However, the photographs could equally be used in other settings such as with family members or in further medical contexts such as paediatrics (which might require a new set of images), grief counselling, anger management or with any experience that is intrinsically invisible. It could also be valuable to pilot them in primary care, with non-pain experts and/or in the education of healthcare professionals. There is potential for images to be valuable in differential diagnoses, particularly where the first language of the patient is not the same as that of their clinician, and/or where verbal or spoken skills are impaired, or where it is difficult for someone to answer the question 'what does your pain feel like?'.

The PAIN CARDS were not designed as a diagnostic but as a communication tool, aiming to assign greater agency and expression to the person with pain.

Origins of the project: Why seek a visual language for pain?

Pain = evil; evil = darkness; darkness = pain. (patient testimony from *Perceptions of Pain* [Padfield 2003] while creating Fig. 8.1)

What is this sentiment communicating? What is the image communicating? What is the space between word and image communicating? Could you constrict any of these into a number from one to ten – as pain patients are routinely asked to do in pain clinics and hospital visits? The sense of hopelessness, of isolation, the multi-faceted nature of pain, with its linguistic roots in Western culture's system of retribution and religion, derived from the Latin 'poena' meaning punishment (Goldberg 2017; Biro 2010; Leder 1990), cannot be adequately conveyed through a number. Not only is a number unlikely to capture the complexity and intensity of pain, but the number itself is dependent on the social context in which it is sought. Neuropsychologist Paul Broks, when asked who he thought he was, replied, 'There isn't a single answer to that question, "who am I?" – it will depend on who's asking the question. It will depend on the circumstances, and on who wants to know what about me' (Broks 2009, 80). The same thing could be applied to rating your pain on a scale from one to ten. It will depend on the social context in which such a question is asked, for example: the consequences of choosing a high or low number, what is expected, what is seen as 'appropriate', the speaker's emotional state or what someone feels the number selected represents in that environment. A number is neither neutral nor particularly informative in chronic pain assessment. Alternative means need to be found to cross the divide between those living with and those witnessing/assessing persistent pain, *with* or (to use Andrew Hodgkiss' term), *without* lesion (Hodgkiss 2000).

This is where our work started – in seeking an alternative visual language for pain which could capture its ambiguity and the significance it holds for an individual. The multiple readings photographs give rise to, and their ubiquitous nature within our lives (Sontag 2003), make them a natural medium with which to address this question and reflect on the multifaceted and subjective nature of pain. Pain causes intense crises in meaning-making. People living with pain strive for legitimacy for the experiences which are so real to them and induce so much doubt in others (Scarry 1985; Brown 2008). Chronic pain stigma, though seen as part and parcel of the illness experience, is capable of inducing intense psychosocial harm (Goldberg 2017). Patients report



Figure 8.1 Deborah Padfield with Rob Lomax, 'Untitled' from the series *Perceptions of Pain*, 2001–06. C-type print. © Deborah Padfield, reproduced by kind permission of Dewi Lewis

finding social interactions challenging, in part because of the stigma attached to pain (Nizza, Smith and Kirkham 2018; Toye et al. 2013), indeed Perez-Brumer et al. (2015) go so far as to argue that it is a risk factor for suicide. By the time a patient ends up in a pain clinic there can be a wide gulf between the agendas of patient and clinician (Kenny 2004) and the significance it holds for them both. There is thus an urgency to find a means of crossing that gulf.

Current reductive measures for assessing pain

Difficult and complex experiences of pain, as chronic pain stories so often are, need to be voiced and witnessed in the consulting room and understanding of their multidimensionality increased. These experiences are not easy to fit within the existing reductive framework and measures into which the medical system tries to place them, which often serves to increase the isolation of sufferers, itself increasing pain intensity (Eisenberger 2003).

Most current pain measures commonly used are either verbal or numerical, such as the verbal rating scale (VRS), visual analogue scales (VAS), brief pain inventory (BPI) or the McGill pain questionnaire (MPQ). These can fail to capture an experience as multifaceted as pain and leave patients feeling they have to reduce their baffling symptoms and bewildering experiences to pre-existing formulae or normative patterns in order to be believed.

The pain inventory or McGill short-form questionnaire, a widely used measure, has similar limitations. Its strength is its assumption that it is important to assess not only the *intensity* of patients' pain, but also its *quality* (Deignan, Littlemore and Semino 2013). Its limitations are that it asks patients to constrict their experience within pre-existing formulae, such as the adjectives of others, which, although gathered from real pain patients, were gathered from a distinct community with a distinct vocabulary, not necessarily reflecting the language the majority of patients might actually use, for instance 'lacerating' and 'lancinating' (Bourke 2011a, 2011b; Deignan, Littlemore and Semino 2013). While there are occasions in which the words can be useful in identifying certain types of pain, for example the '*burning*' or '*tingling*' of neuropathic pain, the '*shooting*' of trigeminal neuralgia (TN) and the '*aching*' of muscle pain,² it could be construed as yet another reductive system whereby people have to fit their experience into the shapes and sounds of others.

Origins of using images in pain assessment

Pain drawings are another measure currently in use, often in combination or as part of the MPQ. Here patients are given outlines of the front and back of the human frame onto which they are asked to mark the site of their pain. It is notable that patients regularly extend what could be a routine exercise into an artwork using different colours, shading and symbols such as butterflies, serpents or arrows within the relevant areas of the body (Pither 2002). This reflects the overwhelming desire, noted by Boddice (2014), that those with pain seek to express and communicate it to others through any means possible. Responding to such a drive, Uden, Astrom and Bergenudd (1988) proposed that drawings might elicit information capable of speeding up differential diagnosis. They set up a study evaluating whether markings made on the current pain drawing (body outline) could help. They observed, for example, the specific pattern produced by a herniated lumbar disc in patients suffering from sciatica was different from those made by people with widespread or non-anatomical pain, which was seen to correlate with patients identified with concomitant psychological disturbances. Asserting that the organic process causing back pain is still mostly unknown and that psychological and socioeconomic factors are often present, Uden, Astrom and Bergenudd (1988, 391) concluded that the pain drawing is a useful way of distinguishing quickly between organic and non-organic pain. There are limitations to this, one being that it is almost impossible to divide psychogenic from physiological pain processes, or the mind from the body, and I do not believe it useful to return to this type of dualism. Secondly, Uden's tool offers patients pre-prescribed tools, here symbols/marks instead of words (six different symbols ranging between bars, dots and letters), with which they could mark the pain drawings; and if the symbols were changed or not used, according to the protocol, the drawings were discarded. What, in this context, is drawing doing that words could not have done? Are they not almost standing in for pre-prescribed words or ideas rather than employing the specific material and sensational qualities of images?

Increasing use of images and photographs to elicit narratives of pain and trauma

The health–arts nexus has received increasing attention from clinicians, researchers, health/social care professionals and policy-makers

(Davies et al. 2014) with a growth in networks and centres promoting healing through the arts, such as the Sydney de Haan Research Centre for Arts and Health, Canterbury Christ Church University; Tamalpa UK; the London Arts in Health Forum; Medicine Unboxed; the Association for Medical Humanities; and the newly formed Culture, Health and Wellbeing Alliance, among many others. Visual methodologies are more frequently used within social science health research, and their use is increasing within qualitative research design (Stones 2013; Reavey 2012). There is a current trend towards making visual shareable representations of pain and illness, which are outside the body (Radley 2009). The power of photographs to elicit personal testimony, so that it can be acknowledged, discussed and held, is widely acknowledged in the many photo elicitation and photo voice projects which use photographs and the narratives they call forth to overcome trauma (Bugos et al. 2014; Wang and Burris 1997). These range from Jo Spence's original use of photographs to represent her own illness experience (1986) and the development of phototherapy with Rosy Martin (Martin and Spence 1987; Dennett 2011), to current projects such as social psychologist Alan Radley's project giving cameras to people who were homeless and to in-patients in hospital to record their surroundings and encourage reflection (Radley 2010; Radley, Hodgetts and Cullen 2005; Radley and Taylor 2003), artist Johanna Willenfelt's embodied texts (Willenfelt 2014), artist Davina Kirkpatrick's collaborative practice (see: <http://3d3research.co.uk/fellowship/davina-kirkpatrick/>) that also explores the embodied nature of pain, Pat Walton's (2016) exploration of the experiences of families affected by chronic pain, and images/photographs/films used in the healing process of those affected by war and trauma (Christensen 2018; Denov, Doucet and Kamara 2012; Quaglietti 2018; Lykes 2010). Filmmakers and performance artists have also offered insights into the experience of living with chronic illness and pain, for example Stephen Dwoskin (*Pain is ... and Intoxicated by my own illness*), Bob Flanagan, Martin O' Brien, Laura Dannequin's performance work based on her personal experience of living with chronic pain (2015) and Rachel Bagshaw, who developed and directed *The Shape of the Pain* (2019) in response to her own lived experience.

While there is a parallel growth of online collections of images expressing individual pain, for example Collen's 'PAIN Exhibit' (2005), the online *Exhibiting Pain* exhibition curated by Susanne Main (see Chapter 14) and the Flickr and Tumblr sites examined by Gonzalez-Polledo and Tarr (2014) (see Chapter 13), there is an observable

growth of work exploring visual means of communicating pain in clinical contexts as part of pain assessment.

McMahon et al. (2008) developed a web-based pictogram tool, the Iconic Pain Assessment Tool, known as the IPAT.³ McAuley (2009) developed a toolkit called 'Pain pictures: A better picture of chronic pain' in conjunction with a pharmaceutical company. Stones, Knapp and Closs (2016) and Closs et al. (2015) developed a series of 12 test images 'depicting sensory qualities' of pain to assess their use in differentiating between neuropathic and nociceptive pain. Their study, however, identified the inbuilt problem in assessing images for their 'accuracy' – as it could be argued one of the characteristics of images is their openness to multiple interpretations and that there is no such thing as an 'accurate' or universal image. However, having piloted the tool with a group of students and finding that one image could be associated with over 200 words, they make design recommendations to improve the design of pain pictograms and guide designers of related pictogram work in the future.⁴

Drawing has also been used to express patient narratives in clinical settings, for example Sarah MacLean's pilot study (2009) and the work of Nizza, Smith and Kirkham who studied using participant drawings to stimulate reflection during interviews at three different points in the pain management journey. Nizza, Smith and Kirkham (2018) wrote a longitudinal interpretative phenomenological analysis of changes in sufferers' pictorial representations of pain, following participation in a pain management programme over nine months. The study revealed ways in which pain sufferers gained control over their relationship with chronic pain and showed increased insight and ownership over their progress (Nizza, Smith and Kirkham 2018).

It is worth drawing attention to the specific qualities of art forms, such as photographs, which do something different to pictograms in that they allow the images to evoke emotion, to reach the unconscious and elicit narrative, connecting seemingly disparate elements and finding meaning within those juxtapositions. Words alone, or at least the type of language that abounds in the clinic, relying on more generic descriptions such as pain intensity, location or frequency, are seldom able to produce the type of shared experience as images, relying as these do on shared perception. The person describing their pain and those listening have to refer back to the physical image, colour, lighting, tone and environment depicted in order to make sure they have understood what pain means to that person. This process induces a negotiated dialogue

which, it is hoped, could lead to a more fluid consultation style and improved mutual understanding.

I believe it is through the addition of visual and material dimensions that images can aid communication around pain, not necessarily through the use of visual equivalences but through the specific qualities of form, surface and texture. The photographic 'portraits' of pain co-created during *Face2face* aimed to expand existing metaphors for conveying pain, which currently focus on notions of injury and damage, even when there is no remaining evidence of tissue damage or lesion. The texture and form of the photographs created act on our bodies as well as our perceptions so that both the senses and the mind are drawn into a metaphoric and imaginative space. We don't just *conceptualise* pain's meaning, we *experience* its meaning, bringing us closer to lived experience. Could these visual representations of pain help us formulate a broader definition of pain, such as American physician and writer David Biro (2014) advocates, one that is not dependent on a division between psychogenic and physiological pain, and that highlights aspects of pain experience we need as a society and as individuals to address?⁵

Identity and the portrait

When I refer to 'portraits' of pain, I do not mean portraits in the conventional sense. The images rarely include the face (although they sometimes do) but instead use objects, materials and the relations between them to evoke the internal abstract experience of pain, making it visible and putting the person with pain in charge of how it is seen by others. In this way the co-creative process used is one of collaborative photographic portraiture, with implications for portraiture in its wider sense. Many contemporary artists engage in lengthy processes through which they come to know their sitters. The photography critic Martin Fried describes, for example, the triggering of the shutter for German photographer, Thomas Struth, as 'only a final stage in a much longer process' (Fried 2012, 196). Struth engages his sitters in a series of discussions around how they wish to be portrayed, so that they are not just put at ease, but become 'collaborators in the making of the portraits' (Fried 2012, 196). Similarly, rather than being an object on the other side of the lens the participants in *Face2face* were active collaborators, discovering, revealing and communicating their experience and emotions through the images and image-making processes. I would

argue that although many art forms such as painting, drawing, sculpting and music would also reveal subjective experience, photography is best suited to reveal experience in a way that makes it accessible, tangible and believable to others, for reasons which will be explored later.

In his essay on Mark Gilbert's painted portraits of people undergoing maxillofacial surgery, critic Carl Grenier identifies a shared ownership of identity that develops through the portraiture process. The process makes apparent what Grenier calls a 'communal ownership of identity'. He asserts that though 'initially we might imagine that our identity is simply our possession ... our identity is both in our possession and with those who have an emotional connection to us' (Grenier 2008, 68). Grenier further describes how 'the interplay between our internal identity and external identity is active in each of our lives' and how 'the production of a portrait engages the painter in a new social process and can add a dimension to healing' (Grenier 2008, 68). The portrait, whether painted or photographic is a social process and one in which it could be argued there is an integration of what neuropsychologist Paul Broks calls the minimal (or core) and extended (or narrative) self (2009, 81–3). It is a point or series of points where a strong distillation of the self and/or experience meets the self as evolved over time and in relation with others. Thus, it is an object which is living, which gives birth or shape to the most intense recognition of self and, in the case of the *Face2face* participants, of pain experience and what that signifies. For this reason, it is absolutely essential that participants play an active part in the visual representation of the self so that their experiences and sense of identity are not re-appropriated, as can so often happen during the long diagnostic journeys so many have endured (see Chapter 2).

Grenier observes that:

the viewing of the portrait (by caregivers, friends, spouse or significant others) becomes a potential psychological resource for the patient ... An astute portrait provides a resource for asking meaningful questions. For both the caregiver and the patient, there will be the opportunity to learn about the psychological impact of serious illness, the importance of empathy and the development of an identity that acknowledges the illness. (2008, 68)

While Gilbert's paintings and processes are remarkable, with much evidence to support defining the process as a healing one, Gilbert is working with people with visible facial difference who can receive

too much unwanted attention. In contrast, I am working with chronic pain patients with invisible pain who generally receive little attention, acknowledgement or understanding from others. For this reason a photographic process which 'documents' and validates their experience is a useful medium for legitimising and sharing that experience.

In the *Face2face* project there were two main contexts in which the photograph and the processes of making and viewing played a major interactive role: firstly with the core participants in one-to-one workshops co-creating the images or 'pain portraits', and secondly viewing a selection of these images in the clinic with clinicians and patients who had not participated in making them, but had agreed to use them within their normal consultation. I will discuss both of these, but first the process of co-creation itself.

Co-creating the photographs in one-to-one workshops

The co-creative process brings together whatever technical or visual skills I have with those of the people I work with, interwoven with their intense first-hand experiences of pain and its impact. The aim is that the outcome might be more than the sum of its parts, enabling the photographs to have meaning for each individual co-creator, while also resonating powerfully with those outside the process.

The process is not without its tensions, as it welds together two different visions, two different ways of making images, guided on the one hand by the intense experience that gave rise to them, and on the other by aesthetic decisions which would confer impact beyond the context of their making. These tensions were navigated differently with each individual. Participants brought their own metaphors and skills, for example: painting, collage, music, textiles and design. As with any really living process this did not result in an optimum model but in a recognition that there was *no* optimum model. However, a genuine process of collaboration, of mutual active listening and responding produced images capable of communicating the private invisible experience of pain at the same time as resonating beyond that relationship.

I was incredibly lucky with the people I worked with, several of whom have contributed to this book, documenting the process from their own perspective (see Chapter 2). The process was lengthy and demanded mutual trust and commitment. The option was always there for participants to drop out and remove their photographs at any point in the process, which was a risk for me in terms of time and

input. Equally, participants were sharing highly personal experiences, thus taking their own risks and in need of the safety of knowing they could remove images or themselves from the process if, and when, they so wanted. Notably none of the participants dropped out during a very lengthy image-making process, which lasted between six and 12 months for each person. We worked individually during between ten and 12 sessions, where possible, over the arc of their treatment or management journey – before, during and after treatment. This meant that the photographs reflected different pain intensities, as well as changes participants made in their perceptions, acting as a feedback or way of reinforcing those changes where they existed. It was equally important that, where no change was felt or perceived, the images also reflected this, or that they reflected fluctuations rather than a chronological journey from high to low pain levels. It was imperative that the intensities and pain characters depicted were led by the person living with pain and that no attempt was made to depict artificially ‘positive’ journeys. Nevertheless, the sense of beginning, middle and end, and the length of time the images took to produce addressed the sense of stasis and paralysis which so often accompanies the language and experience of persistent pain. For example, one participant said of the process

Doing this project ... was a road ... there was a beginning, middle and end. This broke the cycle I was stuck in and I just couldn't get out of. Somehow psychologically it took me to thinking ahead, to being more positive and thinking about more positive times. It got me out of the cycle I was in.

The sessions took place mostly in rooms in the hospital (UCLH), but sometimes we went to locations chosen by the participants which held a particular significance for them, such as walking round Hackney photographing buildings as they were demolished, searching across London for litter-filled locations which felt lost, walking round parks or a participant's garden or accosting men drilling in hospital corridors! All sessions, whether on or off site, were audio recorded and transcribed to facilitate the image-making process and ensure that it was always guided by the participants' observations. Sessions usually began by me asking the participant a series of questions about how their pain might be visualised, for example, whether they had any images or metaphors already for their pain or whether there were any colours, materials or environments which reflected the

characteristics or the impact of their pain? I met with all participants who had volunteered to tell them a little bit more about the purpose of the project and what would be involved. I asked them to bring an object to the first session, which represented some aspect of their pain. These ranged from fruit to pins, knives, elastic bands or wires. The objects were used metaphorically, shifting our discussions towards personal rather than collective meaning and providing a starting point for the photographic process. The photographs were taken using a high-end digital camera. I usually pressed the shutter release, but only after the co-creator had the opportunity to check the framing and composition we had negotiated. In subsequent sessions the series of images were uploaded onto a computer and reviewed by me with the participant as we discussed which images were stronger and/or which got closest to their experience. A selection was then made from each session. We would usually end up modifying aspects of some of these images during following sessions, through for example, repositioning the fruit, knives or pins, changing the speed of falling pins, or taking the doll to different sites. I would print the photographs out and bring them to the next session where we could use them as backgrounds, superimposing different objects on top of them such as teeth, balls or shadows. They would be further deconstructed and reconstructed in between sessions, either by the participant through printing, painting, stitching or collaging, or by myself through editing in Photoshop or the darkroom. As the images evolved, they brought out the unavoidable relationship between personal narrative and pain experience. The process impacted on the language we used, observing and recognising components of the images and thus of pain experience that we were scarcely aware of when we started. Although the experiences people were drawing on were intensely personal and painful there was much laughter as well as tears. I had attempted to keep my own experience of pain out of the process, but I inevitably learned a lot through the insights and courage of those I worked with, as they reflected on theirs.

Some of the metaphors people brought were immediate, such as, exposed wires or rotting fruit (see [Figs 8.2](#) and [8.3](#)), but some were harder to realise than others. For example, the shadow sandwich was a beautiful and striking metaphor through which to describe experience but difficult to give photographic form to. Through the process of trying, we were stretched photographically, and almost through the limitations of my technique and the struggle to give form to the formless, an original and poignant series of images emerged, which would never



Figure 8.2 Deborah Padfield with John Pates, 'Untitled' from the series *Perceptions of Pain*, 2001–06. C-type print. © Deborah Padfield, reproduced by kind permission of Dewi Lewis



Figure 8.3 Deborah Padfield with Chandrakant Khoda, 'Untitled' from the series *Face2face*, 2008–13. Digital Archival Print. © Deborah Padfield

have materialised had I created them on my own (see [Figs 8.4–8.8](#)). The process of collaborative image-making brought forth nuanced descriptions of the impact and qualities of this individual's pain. Looking at the photographs we finally produced, she described how they are:

... just a way of explaining that you really don't feel like the person you were at all ... there's almost no relationship, there's such an emptiness inside of you 'cause you just feel completely burned, like there's an empty shell ... muffled like you have no voice, there is no mouth, no one can hear you.

It was significant that the bread she brought with her to make a shadow sandwich was mouldy, in fact she had propagated it in her room to achieve this effect, arriving with it several weeks after we first started working. Visually this gave it an impression of being some sort of geological formation or landscape with a subtle beauty. Conceptually it seemed closer to photographs others had produced of decay, for example, rotting apples or demolished buildings, suggesting a negative process with concomitant violence and destruction of the self being signified. The final image, resembling a silhouette on a postage stamp, threw up further questions around identity. This series of images gave rise to a multitude of responses from people from a range of occupations and backgrounds when viewed in an exhibition, as opposed to the clinic, such as:

- The image is a representation of how the patient sees herself and also how she feels others perceive her.

- Pain is a powerful emotion and if present on the face it is so much more devastating. It results in loss of identity, the patient feels that her own life has gone, and pain has now taken over her identity.
- The portrait is absent, it is specialised through shadow ... Are these the hands of the artist, of the doctor, of the patient, I cannot tell? All subjects converge.
- A shadow is by definition indistinct, poorly delineated and transient. In language, 'shadow' is often used metaphorically to suggest diminished abilities, power, strength or beauty, as in 'a shadow of his/her former self'.
- I see the images in terms of the relationship between you [Deborah] and the patient as well as the journey of her treatment.
- This is haunting and insubstantial ... It suggests the soul within, rather than the substantive body. Its posture suggests that the soul is not at ease but it is difficult to tell clearly what the source of their anxiety is.



Figure 8.4 Deborah Padfield with Linda Williams, 'Untitled' from the series *Face2face*, 2008–13. Digital Archival Prints. © Deborah Padfield



Figure 8.5 Deborah Padfield with Linda Williams, 'Untitled' from the series *Face2face*, 2008–13. Digital Archival Prints. © Deborah Padfield

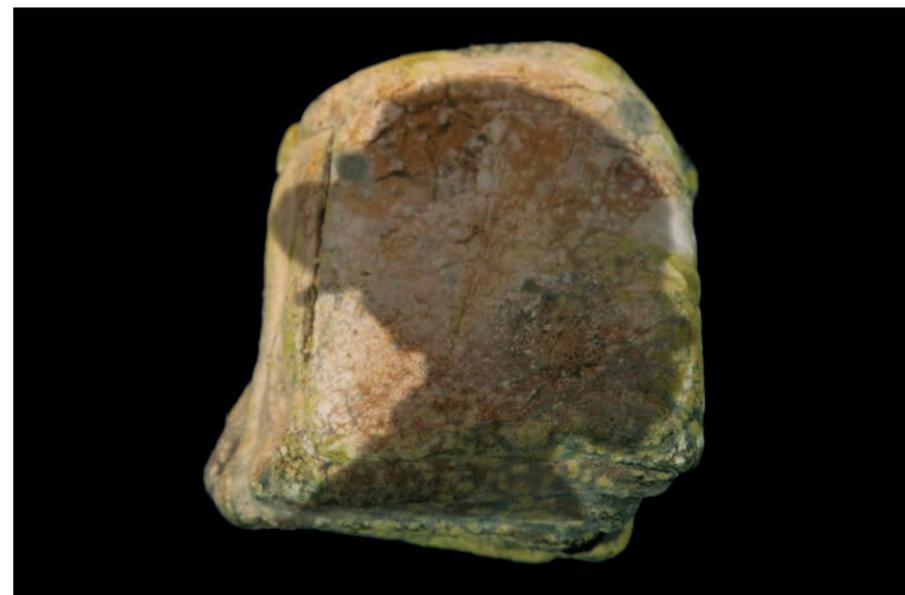


Figure 8.6 Deborah Padfield with Linda Williams, 'Untitled' from the series *Face2face*, 2008–13. Digital Archival Prints. © Deborah Padfield



Figure 8.7 Deborah Padfield with Linda Williams, 'Untitled' from the series *Face2face*, 2008–13. Digital Archival Prints. © Deborah Padfield



Figure 8.8 Deborah Padfield with Linda Williams, 'Untitled' from the series *Face2face*, 2008–13. Digital Archival Prints. © Deborah Padfield

These are a reminder of the multiple readings photographs can arouse and that it is this very quality that allows them to resonate in the clinic and have meaning for other patients not involved in their production, providing a space to negotiate new meaning. This is a good place to pause and consider the specific qualities of photography that make it the medium which best serves our purpose. It is not that other mediums could not give expression to inner pain. Ann Eastman's paintings demonstrate that painting can be very effective, as are the collages of Liz Aldous and the drawings of Alison Glenn, or the myriad online collections of images in a range of formats by people with pain, such as those collected by Susanne Main (Exhibitingpain.wordpress.com) and Mark Collen (<http://painexhibit.org>). However, I believe there are specific characteristics of the photographic medium which make it the most appropriate for making the subjective hidden experience of pain, credible, tangible and sharable.

Why the photograph? Could another medium have worked as well?

The overwhelming cry from people with pain is that it makes them feel out of control, 'Your whole life stops when it is so bad, the pain is so severe that it comes out of nowhere and it is a feeling of being out of control' (*Face2face* participant). Being in control of the lens rather than objectified by it, not only returns a sense of personal agency but also a sense of control over how the self and illness are represented to others, as demonstrated so successfully by photographer, feminist and activist Jo Spence in the 1980s. In her film *Time and Light* for ILEA in 1987 she states:

Going into hospital is pretty traumatic and upsetting. You have no power at all and one of the ways I had symbolic power was to photograph what was happening to me. In hospital you are completely infantilized and any right to make any decisions is taken away from you. You have no power at all. (Spence et al. 1987)

Although medical practice has changed considerably since the 1980s there is still an inherent power inequality built into the doctor–patient relationship. Putting those with pain in control of the photographic gaze rather than remaining as passive recipients of a medical or technological gaze makes them active participants in the representation and understanding of their condition, challenging the loss of control so many people with chronic illness experience. In the earlier project,

Perceptions of Pain (Padfield 2003), one of the participants said that when she woke up in the night and felt out of control because of the pain she would start imagining how she would visualise it and make it into a photograph, and that made her feel more in control of it.

Alongside this sense of control is the distance that the photograph offers: a physical distance whereby the experience is captured within an object outside and separate from the body; distance in time from the moment the photograph was taken, and the psychological distance which allows the creator/viewer to stand back and observe what has hitherto been invisible and hidden. The writer and critic Susan Sontag (1978, 2003) speaks often of the dangers of photography aestheticising the pain of others, and the ubiquitous nature of images of trauma which numb us to the intensity of the pain depicted through the distance we have from the original experience. However, within this project, it was precisely the distance the photographs created from the original event, pain, that allowed people to talk about deeply personal experiences. In placing an inner invisible experience in the external world the photograph could be seen as becoming a transitional object, as Helen Omand describes in Chapter 3, navigating between the internal world of the person with pain and the external dialogue and interaction happening around them.

Another distance created is the gap between what people intend to show and what they actually reveal, the gap Sontag identifies between the 'intention' and the 'effect' (Sontag 1978, 78–9) or perhaps that which produces Barthes' *punctum*' (see next section) and allows the unconscious to play an essential role within both the image-making and the image-viewing processes. Identifying aspects beyond conscious control and bringing them into consciousness through the image-making process can play a part in a return of agency and conscious control, so that the person living with pain is not left feeling helpless and at its mercy. Creative and imaginative processes draw on the less conscious part of ourselves, bringing forth observations and feelings which surprise us (Townsend 2015).⁶ This can have a cathartic effect but needs to be handled sensitively, which is why I think it imperative for all artists working in healthcare settings to have psychological supervision. This not only keeps the artist safe, but also those with whom they are working.⁷ This was no less true when other patients used the images in the pain clinic. It is not only humanities literature but medical literature which is beginning to articulate the benefits of images and creativity to health and wellbeing, through its access to the subconscious and the way that it provides an 'additional manner of expression and therefore

an opportunity for psychological exploration and communication' Christenson (2013, 250). In the short report *Creative Health: The arts for health and wellbeing* by the All-Party Parliamentary Group on Arts, Health and Wellbeing Inquiry (2017), Grayson Perry alludes to the way the arts help us access parts of ourselves which fly 'beneath the radar ... returning with stories from the unconscious'. In the same report Sir Michael Marmot describes how 'enriching the mind through creative and cultural activity, can mitigate the negative effects of social disadvantage', advocating that 'creative health' should be studied by all those commissioning services.

Perhaps more importantly than any of these is the capacity we still confer on photography to document, to provide proof that a person, moment or event has existed. In this way, despite all the paradoxes digital photography throws up, challenging notions of 'reality' and 'authenticity', alongside our contemporary awareness that a photograph is largely constructed and manipulated by the photographer, we still associate it with an ability to document 'authentically'. Sontag observes how a 'fake painting ... falsifies the history of art' whereas 'a fake photograph ... falsifies reality' (1978, 86). Conversely this gives the photograph a unique ability to validate and authenticate the baffling and subjective experiences it depicts, making these real and believable to others. It allows this trace of the imaginative process to reveal to us what has hitherto been concealed from sight, but which contains an essential truth within it.

The ambiguity of many photographs and the multilayered and multiple readings they can evoke, as described earlier in relation to the shadow (interestingly commanding both positive and negative associations), makes them particularly versatile when reviewed by other patients in the clinic. It allows individuals to project what they need to talk about onto the photograph, triggering nuanced discussion of facets of experience which might not otherwise be revealed in a medical encounter.

The photographs resonate through the surface arrangement of forms, colour, composition, the light in which they are photographed, the relationship of objects depicted (as well as awareness of those omitted), through texture and material qualities, but also through the ability of the photographic image to become a symbol, to signify beyond its own frame, to use photographic theorist Roland Barthes' terminology, 'connoting' rather than only 'denoting'. In *Camera Lucida*, Barthes (1980) identifies the ability of photographs to reflect beyond the limits of their frame, to look beneath what is apparent. The

photograph is not an exact 'copy' or a literal 'representation'; it is a construct, it has an author, it involves selection and framing. Barthes moved away from his initial position that photographs only denote, to one where he acknowledges they also connote, describing this as the '*punctum*'⁸ and it is this *punctum* or 'pricking' that allows the images in our context to reveal what was not necessarily consciously known or recognised (Barthes 1980, 26–7). In this way the photographs create an environment for relevant emotional disclosure.

The materiality of the images plays a large role both in the process of creation but also in the review process, the handing back and forth of the photographs, giving them agency and making them 'relational'. Additionally, the fact that they were co-created with those living with pain, gives them legitimacy. The images are a materialisation of pain – a translation into a visible form. There has been a process leading to them. Alan Radley describes how photography is more than a medium, 'it is a way of making known and shaping experience' (2010, 270). So perhaps the fact that pain sufferers were involved in producing the photographs helps validate the cards to other sufferers when offered to them in the clinic.

Viewing the images in the clinic and interplay between viewer and image

Reviewing in the clinic is the other context in which the specificities of the photograph play a major role. As described earlier, a selection of the images produced during *Face2face* were integrated with images from the earlier *Perceptions of Pain* project to form a pack of 54 laminated PAIN CARDS. Ten different clinicians from UCLH offered to pilot these cards in their consultations, each offering two clinics using the images and two without images, as a control group, resulting in 38 recorded consultations (Ashton-James et al. 2017). The conditions were the same for both groups and the primary goal was pain assessment.

Patients who had not been involved in making the images were given the pack of cards in the waiting room before their consultation and asked to pick out any that resonated for them, take them into their consultation and use them as triggers to help them talk about their pain. Very little guidance from the researchers was given to either patient or clinician on how to use the images in order for participants to be free to use them when and how they wished. The consultations were filmed (with informed consent), and clinician and patient

asked to complete post-consultation questionnaires independently. This provided a unique body of material which we were subsequently able to bring a distinguished multidisciplinary team together to analyse. Detailed results can be found in chapters 3, 9, 16 and 21 of this volume. To summarise, the images appeared to affect the verbal as well as the non-verbal language, eliciting description of the emotional impact and components of pain and improving clinician–patient affiliation. What became apparent from observing the consultations was that the space between clinician and patient became far more active with greater non-verbal interaction and a more conversational rather than interrogative style of verbal communication. The hope is that this can influence a more negotiated relationship during the rest of the consultation, which the non-verbal analysis, led by Amanda Williams appears to corroborate (see Chapter 9).

The aspect which concerns us here is the role the specific qualities of the photograph played in these interactions.

Returning for a moment to Barthes' *punctum* allows us to consider that which creates meaning for the viewer as not necessarily the result of the photographer's intention, but as dependent instead on the viewer's perception, on the associations and meanings they bring to it. In other words, the *punctum* 'pricks' because of the relationship between the *photograph* and the *viewer* (Fried 2012), not necessarily because the photographer has shown something to the viewer but because the viewer has perceived something, or in the clinical context, 'projected' something onto it, which they need to talk about. The image calls forth in Barthes' words, 'the pressure of the unspeakable which wants to be spoken' (Barthes 1980, 19).

In the photographs produced during *Face2face* the '*punctum*' is not always accidental and has not been solely achieved as a result of the relationship between the image and the viewer. On the contrary, it has often emerged from a lengthy process and out of complex exchanges between me and the participant. Nevertheless, those elements which 'prick' or elicit deeper psychological meaning for someone with pain are frequently only recognised when viewing the final photograph – even for the maker. One participant remarked: 'I didn't realise until I saw the photograph, but it is about having the inner and the outer experience at the same time. It is because you have inserted the collage between my face and my hand. It is about touch' (Padfield 2003, 113). Another patient observed: 'Seeing the photograph made me realise what I had done to myself'.⁹

When the images are selected by other patients not involved in making them and viewed in the clinic, another process of 'pricking' or

‘resonating’ is enacted as the photographs unravel different meanings for different people. The very act of choosing and handling the images are acts of agency, moments of decision, of recognition of the significance of one emotion or sensation over another, in relation to a multifaceted and multisensorial experience which changes over time.

The challenge in representing chronic pain is that the wounds felt are seldom visible. They frequently fluctuate and are elusive, arousing doubt not just in the listener (Scarry 1985) but in the person with pain themselves. This is why giving them form, making them tangible, sharable and visible to others becomes critical. It is also important to remember that photographs do not just allow us to recollect experience or to elicit narrative – they also create it. The photographic theorist John Tagg suggests that the production of images ‘animates’ rather than discovers meaning (1980), so that meaning is not only constructed and revealed during the co-creation process but other meanings are constructed and revealed during the process of selecting and viewing images in the clinic. This is why it is not only vital both that pain sufferers play an active role in the co-creation process, but that they play a central role in the interpretation of the images in the clinic.

The multiple readings photographs facilitate allow interpretations to intersect or conflict with those of the original sufferer who co-created the image. However, when viewed in the clinic it is the person who selected the image whose interpretation is paramount at that moment. The subjectivity of interpretation parallels the subjectivity of pain itself. It is worth noting that just as pain is temporal, so too photographs are time-based. They resonate in relation to the past as well as the present and possibly the future. Evidencing the different ways in which individuals construct meaning through images provides a glimpse of how significance and meaning are conferred on pain experience. The process demonstrates the need for a flexible and negotiated dialogue capable of interweaving multiple interpretations in the clinic. Your ‘pain’ is not the same as my ‘pain’ (Bourke 2011b) and does not carry the same significance. Images make this explicit in a way which language sometimes doesn’t. If we speak the same language, we can imagine we mean the same thing by particular words, but in the clinic this is often not the case (Marshall and Bleakley 2013) and a baggage of knowledge, interpretation and culture lie behind the words used, creating chasms in meaning between patient and clinician. Through drawing attention to the multiple interpretations an image evokes, it becomes possible to see how photographs encourage dialogue so that participants recognise the chasm in meaning that may (or may not)

exist between them – moving them to ensure they are understanding each other accurately. In our study, Clinician H continually referred back to the image to check he was understanding what the patient was trying to communicate. The art psychotherapist Helen Omand describes in Chapter 3 how the images encourage negotiation and create triadic as opposed to dyadic relations, becoming a mediating space where meaning is created, unravelled and dissected. Language is not a neutral conveyor of facts (Wetherell, Taylor and Yates 2003). Images therefore allow the language that emerges around them to become invested and coloured by patients’ experiences, bringing pertinent experience and signification into the consulting room and into the clinician–patient interaction at many levels.¹⁰

Concluding thoughts

By physically and materially bringing pain into the clinician–patient encounter and into the medical consulting room, photographs can collapse distinctions between physiological and psychological pain, so removing the urgent need for legitimacy that drives so many people experiencing pain in a dualistic culture. American physician and academic David Biro argues for an expanded definition of pain, to that advocated by the IASP, redefining it as: ‘the aversive feeling of injury to one’s person and the threat of further potentially catastrophic injury’ (2014, 61). He argues this would reduce semantic confusion around pain, and provide a better framework for managing patients, encouraging new ways of treating them by removing a distinction between actual and perceived damage, between physical and emotional pain. Williams and Craig (2016) argue for expanding the IASP definition of pain to include social components. These calls have been heard and in 2020 the IASP changed its definition of pain for the first time in four decades (Raja et al. 2020).

Physical and emotional processes undoubtedly intersect within pain experience. The language we evolve to communicate pain has to rid itself of a duality between physical and emotional (and perhaps social) pain, in a way such as Biro’s and Williams and Craig’s redefinitions of pain might permit. Participants in the *Face2face* project frequently report that they have been changed by ‘pain’, that their lives and identities have become fragmented. If this fragmentation, loss of the old and remaking of the new self is understood through purely psychological analysis, then the body is marginalised. It is within the body that pain is ‘remaking’

people and affecting the constructs of their subjectivity and intersubjectivity. Note the subtitle of Elaine Scarry's seminal book on pain, *The Making and Unmaking of the World* (1985) and Berenike Jung's framing of pain as 'constructing' the world (Jung 2019, 2). The philosopher Elizabeth Grosz (1994) provides a useful redefinition of subjectivity with which we can approach pain and the image. She theorises the body as part of the construct of subjectivity rather than something affected by it. In a similar way, the photograph acts as a physical object while also signifying subjective experience. The image has been projected onto a surface which is torn, etched or stitched in a way that parallels how narrative and experience are etched into our bodies. Can such a corporeal conception of subjectivity bring us closer to the lived experience of pain, removing the need for distinction between psychological and physical suffering? Could photographs of pain placed between the person with and the person witnessing pain re-energise the language around pain, to give agency and legitimacy to those who too often suffer in silence and live with ambiguity and fear? Is there a place within NHS programmes for embracing such a tool capable of bringing to the surface the myriad aspects of pain experience, reflecting and legitimising its paradoxical nature?

Napier et al. (2014) argue that ideas about health vary widely across cultures and should not be defined merely by measures of clinical care and disease. This applies even more so to beliefs around pain, which are intensely personal as well as culturally constructed. If the way pain is conceived changes the way it is experienced (Bourke 2014) then the next step in this journey is to build on the current interest in images as a means of communicating pain and co-create photographic images with people living with pain in a wide range of cultural contexts. There is value in exploring whether it would be possible to develop a transcultural pack of PAIN CARDS or if there need to be distinct packs for specific cultural contexts. Doshi in Chapter 18 and Khetarpal and Singh in Chapter 19 begin to explore these ideas. This indicates work for the future, but for now the challenge is to introduce photographic measures capable of capturing the 'multivariant dynamic nature of pain experience' (Goldberg 2017) into the space between the one with and the one witnessing pain, recognising that both pain and caring for those who experience it, are essential components of being human.

... For the medical humanities and interpretive social sciences, care-giving is a foundational component of moral experience. By this I mean that care-giving is envisioned as an existential quality of what it is to be a human being. (Kleinman 2008, 23)

Notes

- 1 Referring to artist Thomas Struth's family photographic portraits.
- 2 These words are also found in other pain screening questionnaires such as Pain Detect (Bennett et al. 2007).
- 3 For further discussion of the IPAT, see Laloo and Henry (2011).
- 4 Pictograms have also been explored as ways of catalysing discussion among minority ethnic groups in Palliative and End of Life Care in the South-East of England by the Learning Alliance for Palliative Care and End of Life (LAPCEL). The pictograms were developed from drawings made with minority ethnic groups and academic researchers from LAPCEL, formed in North Kent and Medway to raise awareness about how to get quality of life at the end of life for diverse communities. For further information contact: education@ellenor.org.
- 5 Following calls from many, including Williams and Craig (2016) to expand the definition of pain, the International Association for the Study of Pain (IASP) has recently changed its definition of pain, for the first time in four decades, to include social experience (Raja et al. 2020).
- 6 For further discussion of the creative process and its parallels with the psychoanalytic process, please see Townsend 2019.
- 7 Christenson (2013: 250–2) citing Moss and O'Neill (2009) also argues for the need for artists who are not trained as art therapists to receive training in important skills for medical settings 'such as those associated with infection control, blood borne pathogens, confidentiality and appropriate boundaries'.
- 8 'A Latin word exists to designate this wound, this prick, this mark made by a pointed instrument: ... This second element which will disturb the *studium* I shall therefore call *punctum*; for *punctum* is also: sting, speck, cut, little hole – and also a cast of the dice. A photograph's *punctum* is that accident which pricks me (but also bruises me, is poignant to me)' (Barthes 1980, 26–7).
- 9 For images see Padfield 2003, 43.
- 10 This is further complicated with non-English speakers and when translators are used. Zakrzewska has used the PAIN CARDS in her clinics with non-English speakers in order to try to get an understanding of the character and type of their pain. This needs further study.

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9

How images change non-verbal interaction in chronic pain consultations

Amanda C de C Williams

Pain, defined as 'an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage' (IASP 1979), is challenging to assess and to communicate. Yet knowledge of its meaning for the individual with persistent pain is important, if not essential, for the clinician trying to understand the pain and arrive at the best treatment options. There are various rating scales, uni- or multidimensional, but most people with pain do not find these effective in expressing their pain (Stenner et al. 2015). Nor is their interpretation easy and clinicians tend to bring unconscious biases to interpreting patients' communication of pain, whether in a formal pain scale or spontaneous verbal or in non-verbal expression (De Ruddere et al. 2013; Tait, Chibnall and Kalauokalani 2009). Furthermore, none of these ratings encourage emotional disclosure by people with pain about the effects of pain on them and on their lives.

Description of pain in a clinical setting is always a social as well as a clinical interaction (Schiavenato and Craig 2010), and social context affects expression of pain, verbally and non-verbally. Many processes are involved in this complex interaction (Craig 2015). Both the person in pain and the clinician, caregiver or other observer are subject to intrapersonal and interpersonal influences. Intrapersonal influences cover anything from biological endowments to personal history, and interpersonal influences consist of multiple social and physical contextual factors. For the clinician, intrapersonal influences also include sensitivity, knowledge and judgement biases, as well as professional training. These influences affect the way that pain is encoded and expressed (or suppressed), and how it

is interpreted by the clinician or other observer (Craig 2015; Goubert et al. 2005). In a recognition of the gap between the routine methods for assessment of pain and associated problems, and the multiple interacting influences described here, Deborah Padfield developed photographic images of pain, co-created with people with pain, and experimented with their use by other people with pain in clinical settings (see the Introduction and Chapter 8 on the photograph as a mediating space).

Study of pain images in consultations

Patient and clinician ratings

Thirty-eight patients consented to take part in the study, of whom 17 used images they chose from Deborah Padfield's set in their first consultation in a Pain Management Centre, while 21 control patients did not. All assessments were videotaped, and afterwards patients and clinicians were asked to complete a series of questions about their experience (Padfield, Zakrzewska and Williams 2015); the ten healthcare professionals who took part in the consultations, all with expertise in pain, completed these questions after each consultation. Unexpectedly, there were no significant differences between those patients who did and those who did not use images during their consultations in ratings of communication of pain, clinician's understanding, rapport with the clinician, arriving at a treatment decision, confidence in the treatment plan or overall satisfaction. The most likely explanation for this is that almost all patient ratings were high: 5/6 or 6/6, giving too little variation on which to test for differences.

Clinician ratings were a little lower, and further exploration of the within-consultation data showed that in the group that used images, the higher the patient rating, the lower the clinician rating, and vice versa. Why should that happen? It could be a finding within the range of random variation, but one hypothesis was that, in each consultation, either doctor or patient took more control over the content and process of the interaction, and that whoever was more in control rated aspects of the interaction higher, while the interaction partner rated it lower. We decided to attempt to answer this question by examining the non-verbal behaviour of patients and doctors during consultations.

Patient and clinician behaviour

All consultations were sampled, taking one minute of every five (Capella 2014), whatever the length of the consultation. Two researchers, both with a background in psychology, noted patient and clinician behaviours that constituted rapport. These behaviours were classified, consistent with a substantial body of literature on interpersonal interaction (Kiesler and Auerbach 2003; Mast 2007; Tickle-Degan and Rosenthal 1990), including in medical encounters, as affiliation behaviours, and dominance or submission behaviours. Affiliation behaviours are positive behaviours (e.g. smiling, nodding, looking at the other, leaning towards the other, reducing the distance such as by moving the chair towards the other, taking up a symmetrical posture such as legs crossed, arms on lap, laughing together, speaking gently, offering something, such as tissues); and negative behaviours (e.g. frowning, turning away, showing impatience, increasing distance from the other) (Kiesler and Auerbach 2003). Dominance behaviours included looking at the other only when speaking, speaking while doing another task, asymmetric postures, big gestures, postural expansion, leaning away from the conversational partner, interrupting and speaking loudly; submission behaviours included fidgeting, self-manipulation, such as twisting hair in fingers, avoiding the other's gaze, postural constriction, speaking quietly, speaking in a higher voice and stuttering. Positive affiliation and dominance together can constitute behaviour that engages the other; positive affiliation with submission is deferential; negative affiliation with dominance is critical and diminishing of the other; and negative affiliation and submission appears as withdrawal from the encounter (Moskowitz and Zuroff 2005; Schermuly and Scholl 2012; see also Ashton-James et al. 2017).

The methodology and the findings can be read in detail in Ashton-James et al. (2017). Again, we found no overall differences between consultations with and without images in the number or pattern of affiliation behaviours of patients. However, in consultations with images, clinicians showed *more positive affiliation* behaviours towards patients, and the pattern was different across the course of the consultation from those without images. In particular, there was a rise in clinicians' affiliation behaviours over the last third of the interview in consultations with images, and a drop in their affiliation behaviours over the same segment in consultations without images. The same clinicians carried out consultations both with and without images, so

the difference was in the interaction, not a matter of different personal styles among clinicians.

In a typical medical consultation, the doctor tends to be dominant and the patient submissive, although these behaviours may not be very marked. We found no effect of having images on the number of dominance behaviours by clinicians, but there was a difference in pattern. A surprising difference was in patient dominance behaviours: in the consultations with images, patient dominance rose across the course of the interaction, while in non-image interviews, it tended to decrease. The fact that images affected clinicians' behaviour much more than patients' behaviour was intriguing, and suggested that images might make a difference not to *patient communication* of pain but to *clinician empathy* to patients' communications. That is, pain images may facilitate rapport between patient and clinician by improving clinicians' understanding of the patient's pain experience; this promotes clinician affiliation towards the patient.

In order to examine in more detail what was happening in the consultations, we analysed the interrelationship of patient and clinician behaviour within each consultation. Recall that the images were used as and when the patient wished, for a specific section of the consultation, not throughout, so we could compare times when they were the subject of discussion and times when they were not. In consultations with images, we found far more *correspondence* between patient and clinician affiliation behaviours than in consultations without images, that is, that sections with many patient affiliation behaviours also showed many clinician affiliation behaviours, and sections with few patient affiliation behaviours also showed few clinician affiliation behaviours. Further analysis demonstrated that clinician affiliation tended to *follow* patient affiliation behaviours rather than preceding them, a very unusual pattern for medical consultations and more characteristic of relatively egalitarian interactions. Within the image consultations, clinician, but not patient, affiliation behaviours were more evident when images were actually visible (i.e. under discussion). At this point, we could only test our tentative hypotheses about what was happening by listening to the content of discussion; again, two independent researchers viewed and scored the videotapes. They found more emotional disclosure by patients in consultations with images than those without.

Summing all this up provides the following preliminary findings about using images in consultations. We certainly found evidence in some, but not all, non-verbal behaviour for better rapport when images were used in consultations, where rapport is indicated by clinician

affiliation behaviour that is more frequent and more responsive to patients' behaviour. We did not find more patient affiliation behaviours in consultations with images; the difference in patient behaviour was rather in more frequent dominance behaviours and in emotional disclosure, an unexpected combination. Overall, it seemed that the images influenced both clinician and patient behaviour, in different ways, but that nevertheless seemed to add up to a more equal and open discussion with greater understanding. This takes us some distance from our original notions of images facilitating patients' communication of pain, and that communication eliciting greater empathy from clinicians and does not bear out our hypothesis about control (dominance) and satisfaction. However, the findings seem worth pursuing if they tell us how to increase rapport in medical consultations, since rapport consistently predicts better outcomes (Henry, Holmboe and Frankel 2013; Kelm et al. 2014).

Having described at some length the outcome of our analyses of the videotapes, but in somewhat abstract terms of 'affiliation' and 'dominance', below I give several excerpts from two consultations in order for the reader to gain a more nuanced understanding of the behaviours and interactions.

Consultation excerpts

Consultation 1. The doctor sits at the desk facing the computer and the patient's notes, while the patient sits at 90 degrees to him, facing his shoulder. The doctor crosses his legs and often jiggles his foot (this can indicate impatience) when the patient is talking. When he turns more towards her and listens to her history (which is complicated), she leans in and the doctor stops jiggling his foot: he looks attentive and the patient opens up about her family difficulties. For a while they take symmetrical postures during a series of exchanges. This gives way to a more animated section when they talk over each other at times, but also laugh together twice. Her account of her life and what she believes to be the causes of her pain becomes ever more complex and concerns family difficulties rather than pain; the doctor shows signs of impatience and then cuts across her narrative with some factual questions about smoking and other health-related habits. Half an hour into the consultation, he attempts a provisional diagnosis, but she disagrees with it and returns to an ever more confusing and detailed account of her pain and associated problems.

Eventually he asks her if she chose some image cards, and she presents the first, which she uses to elaborate on her pain being sharp, 'like a knife' (gesturing cutting). He half-turns away from her to write something down. She presents another card, and talks about 'burning' pain, repeating herself several times and then saying, 'Sometimes I can't take it no more'. The doctor continues to look at the card, and then points to another that she has chosen. A few cards later she states 'I feel lost – I don't know what to do'; she sits up, attentive, as if expecting a question; the doctor turns away to write again.

This excerpt includes moments of empathy, in which doctor and patient are responsive to one another, and a range of affiliative behaviours, but other moments when the patient's emotional disclosures elicit no response, acknowledgement or further questioning, and the patient withdraws temporarily.

Consultation 2. The patient starts the interview in a fairly closed posture, slightly leaning back (away from the doctor) in her chair, with her arms crossed in front of her, but the doctor angles her chair so that she is facing the patient across the corner of the desk, and sideways on to the computer and notes. The doctor leans towards her, and the patient gradually unstiffens and takes a more open posture: their positions are increasingly symmetrical as the consultation progresses. When, after the patient has given an account of the history of her pain, the doctor asks her what she believes is the cause; the patient explains briefly and the doctor acknowledges it without agreeing, then gives a somewhat different explanation that the patient receives in silence.

The patient has been invited to use the cards whenever she wishes at the outset of the consultation, but is prompted some way into the interview to talk about her choice. She holds the cards and presents them at her own speed, taking much longer over some than others, moving on when she is ready. The doctor looks intently at them, listens, nods, interpolates 'OK' or similar encouragements to continue. For the first card, which the patient puts down on the corner of the desk between them, she states that it is 'Electrical – I often think of pain as electrical because when the pain machine [TENS] is on I think that disperses electric charge that causes pain'. During this, the doctor pulls her chair closer and

looks at the image, but the patient is already looking at the next card, which she holds facing her, not visible to the doctor.

The patient does at one point refer to self-harm, and the doctor asks quietly about how serious that is; the patient answers by talking more specifically about how she feels. The doctor hardly writes at all (which raises the question of how well the consultation is recorded); a couple of times, early in the interview, she uses the computer to find information, but angles it so that the patient can also read the screen, and the space between patient and doctor feels shared. There are moments of silence when they hold one another's gaze after the patient has made a particularly sensitive disclosure, and the doctor's questions about the disclosure are very quiet, tentative and mostly draw the patient out.

These excerpted descriptions are not intended to identify one doctor as better than the other, and both show disjunctions in the communication or gaps in understanding as well as episodes of rapport and openness. They demonstrate the dynamic interactions that occur between the two interaction partners, and between what is said and the behaviour of speaker and listener. An emotional disclosure by the patient can elicit empathic encouragement to say more, or a distancing behaviour that can leave the patient uncertain whether her words were heard, and even more uncertain whether their meaning was understood. People with pain almost always have frustrating and distressing encounters with medical and other clinical staff in their pain histories, and can be particularly sensitive to apparent lack of interest (which might indicate disbelief about the pain or the seriousness of its impact), and to explanations of cause that do not make sense to them in terms of their beliefs and experience (Smith and Osborn 2007; Werner and Malterud 2003).

Visual imagery in communication

Visual imagery is often assumed to be a fast route to emotional influence, as in advertising (Houts et al. 2006; Joffe 2008), and vivid imagery is certainly more emotive and more memorable than text alone, although some unpleasant imagery evokes avoidance and so does not convey messages effectively (Joffe 2008). Mental imagery that arises from internal processes rather than external sources is also thought to be

integrally connected to emotion, as in flashbacks associated with post-traumatic stress, but there is relatively little evidence of this, perhaps strongest for the association of mental imagery with anxiety rather than with other emotions (Holmes and Mathews 2005). The use of visual imagery in medicine, outside art therapy, has been the subject of little research, including in pain.

A study of spontaneously drawn pictures of pain, by people with a variety of chronic pains, identified three main themes from the images: the nature of pain (its location, time course and sensory qualities); pain as an attacker (often represented by monsters or weapons); and the impact of pain on the individual's life (Phillips, Ogden and Copland 2015). The authors comment that 'Overall, the expressive content of the images reflected a sense of attack, helplessness, isolation and fear' (2015, 406). It is noticeable, though, that many of the pictures that contributed to the 'nature of pain' theme used metaphors such as flames for hot pain, or lightning for shock-like pain. All had parallels in spontaneous verbal descriptions of pain, using the same metaphors to describe the quality of pain (Jensen et al. 2013), so the advantage of the drawing is unclear. Further, many patients wrote explanations on their drawings, suggesting that they did not trust communication by visual images alone.

Another study used simple pictorial representations of sensory pain qualities (such as hot, cold, prickly, shock-like, etc.) for two different types of pain, and found surprisingly little agreement in how they were described (Closs et al. 2015). Their subjects were nurses, familiar with pain, and design students, familiar with visual representations. Only two of the 12 representations of pain, for 'cold' and 'stabbing', exceeded the 70 per cent identification criterion across the sample, and several achieved less than 30 per cent agreement. This is rather disappointing for icon-like representations that are intended to be universally understood, and underlines the idiosyncratic nature of interpretation of any communication, verbal or visual (Craig 2015).

Empathy and rapport

What is empathy? There are many definitions, and multiple overlaps with related constructs (Cuff et al. 2016). It has both cognitive and affective components, but their relationship remains unclear (Goubert et al. 2005); it may be that affective empathy is more automatic and is then modulated by cognitive empathy or perspective-taking (Lamm, Batson and Decety 2007), often, but not always, leading to a behaviour

directed towards the target of empathy. One of the most widely accepted models is that of Preston and de Waal (de Waal and Preston 2017; Preston and de Waal 2002), who describe 'empathic accuracy', dependent on the empathiser's attention, motivation and personal experience, and its distinction from helping, which can arise from many sources other than empathy. They define it as 'emotional and mental sensitivity to another's state, from being affected by and sharing in this state to assessing the reasons for it and adopting the other's point of view' (de Waal and Preston 2017, 498). They base their understanding in mammalian behaviour and human neural pathways (de Waal and Preston 2017). Applying this to a medical context raises questions about what we expect of clinicians. It is possible to take another's perspective in an unempathetic way, but clinicians are expected actively to engage with the patient's perspective, not necessarily to 'adopt' their viewpoint. Similarly, clinicians are encouraged (and taught) to feel some emotional resonance with their patients and to understand their emotional states (which can be done without taking the other's perspective), instead reading behaviour and context (Cuff et al. 2016), rather than to 'share' those emotional states.

Empathy for pain in humans is based on recognition of activation of some areas of the brain that are also involved in processing the individual's own pain: these are by no means identical networks, but there is substantial overlap (Goubert et al. 2005). This activation essentially draws on the individual's beliefs, impressions, own experiences and many other personal variables. This 'top-down' aspect of empathic processing interacts with the 'bottom-up' characteristics of the stimulus – the patient, his or her account and behaviour – that of course cannot be conceptualised without awareness of the context, in this case, the clinical context with its expectations of behaviour and its power distinctions. There are many systematic differences in stimulus characteristics, such as sex and ethnicity, that affect empathy (Drwecki et al. 2011; Tait, Chibnall and Kalauokalani 2009); empathy also varies with context, and so has become a major target for improving doctor-patient interactions.

There is a large literature on teaching communication skills and clinical competencies to medical students and to qualified doctors, with empathy commonly recognised as a desirable quality because of its association with better outcomes from the consultation: patient satisfaction, patient adherence to treatment plan and a more efficient interaction (Henry, Holmboe and Frankel 2013; Kelm et al. 2014; Maguire and Pitceathly 2002). The interventions often use direct methods of skills

teaching, often verbal strategies such as open questioning (Stepien and Baernstein 2006), and arguably somewhat neglect non-verbal behaviours known to influence patient ratings of empathy (Kraft-Todd et al. 2017). Other interventions use indirect methods such as exposure to narrative and creative arts and humanities to encourage taking others' perspectives (Batt-Rawden et al. 2013). Ideally, outcomes of the interventions are judged by observing genuine doctor–patient interactions (Batt-Rawden et al. 2013; Henry, Holmboe and Frankel 2013), including feedback from the patient (Kelm et al. 2014). Many studies, regrettably, rely on self-rating by the individual who has received training (Kelm et al. 2014) with fewer on observer ratings. Interventions do bring about the desired changes immediately after training, but their maintenance is rarely assessed (Batt-Rawden et al. 2013; Henry, Holmboe and Frankel 2013; Kelm et al. 2014) although they are intended for lifelong practice. In medical students, follow-up indicates that the skills decline over time (Maguire and Pitceathly 2002).

The version of empathy taught to medical students and doctors tends to emphasise perspective-taking over emotional sharing, whether by direct or indirect methods. Emotional skills may be harder to operationalise, train and assess, but are essential to avoid the practice of good communication skills without emotional engagement, and empathy might be conceptualised more in the process of consultation than according to its quantifiable components. It is common for the patient to make tentative or oblique references to emotional concerns, 'empathic opportunities' that the clinician may or may not respond to, with or without evident empathy: this largely determines whether the patient discloses more or moves away from emotional topics (Eide et al. 2004; Morse, Edwardsen and Gordon 2008). The dynamic of taking the perspective of the patient, and sharing his or her emotions, runs counter to the tendency towards scepticism about the extent or authenticity of patients' pain (Kappesser and Williams 2010), when internal and external pressures emphasise not giving 'freeloaders' access to valuable (and sometimes restricted, as for many opioids) health and welfare resources.

In the excerpts above, and in our overall analyses, the experienced clinicians showed many empathic responses in their verbal and non-verbal behaviour, as well as some missed opportunities and failures of rapport. That is to compare it with an ideal of empathic responding, but the medical consultation must also achieve a diagnosis or formulation of the problem and a treatment plan to which the patient freely agrees. These can emerge from empathic interactions, but take greater skills than simply empathising with the patient's

sensory and emotional descriptions of pain, potentially very satisfying in the short term but also, potentially, leading nowhere. Finding ways forward with chronic pain requires more than understanding the patient's pain experience.

Conclusions

Images had several effects, directly and indirectly, on the content and process of the pain consultation. They gave patients the central role in explaining their pain experience, and most if not all, used image cards to explore emotional dimensions as well as to elaborate on sensory descriptions. Use of the cards relegated the clinician more to the role of listener, although some offered their own interpretations of the cards. That listening in itself, with some open questions or encouragement to the patient to extend an initial explanation of what the image meant, may have been powerful in building and deepening rapport. It might not have occurred if the patient had, without cards, embarked on emotional disclosure.

That reading of our findings takes no account of the content of the images, other than that they were emotionally engaging and held the attention of both patient and clinician. But perhaps the content of the images, combined with the patient providing context and elaboration, had direct effects on clinicians' emotions, so that not only were they taking the patient's perspective but also aligning in affect. During consultations, the images were always additionally described verbally, and in some cases those accounts were quite prosaic, often sensory, descriptions of pain (as in the 'electrical' pain description in consultation 2). The images clearly cannot produce emotional disclosure independent of many contextual and personal factors.

Although the images had been co-created with one set of patients, they clearly had resonance with the patients in this study, suggesting that the images do have wider relevance. They also had resonance with the clinicians, but this might not be the case for healthcare staff with less expertise in pain. We urgently need better ways to facilitate empathic interactions between doctors and patients, particularly in the area of chronic pain where there is so much scepticism and uncertainty, and, while we are far from understanding how they do so, these images do appear to provide a recognised opportunity for emotional disclosure by the patient and to improve rapport.

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Picturing pain

Suzannah Biernoff

Capturing pain

What does pain look like?¹ Charles Darwin's *The Expression of the Emotions in Man and Animals* includes the following list of physiological signs:

When animals suffer from an agony of pain, they generally writhe about with frightful contortions; and those which habitually use their voices utter piercing cries or groans. Almost every muscle of the body is brought into strong action. With man the mouth may be closely compressed, or more commonly the lips are retracted, with the teeth clenched or ground together. There is said to be 'gnashing of teeth' in hell; and I have plainly heard the grinding of the molar teeth of a cow which was suffering acutely from inflammation of the bowels With man the eyes stare wildly as in horrified astonishment, or the brows are heavily contracted. Perspiration bathes the body, and drops trickle down the face. The circulation and respiration are much affected. Hence the nostrils are generally dilated and often quiver; or the breath may be held until the blood stagnates in the purple face. (Darwin 1872, 69–70)²

There are some major obstacles to the study of emotional expression, however. The facial movements involved, Darwin notes, are often 'extremely slight, and of a fleeting nature'. We perceive subtle differences in expression from moment to moment, yet cannot say with any certainty what has changed (1872, 17–18). This difficulty

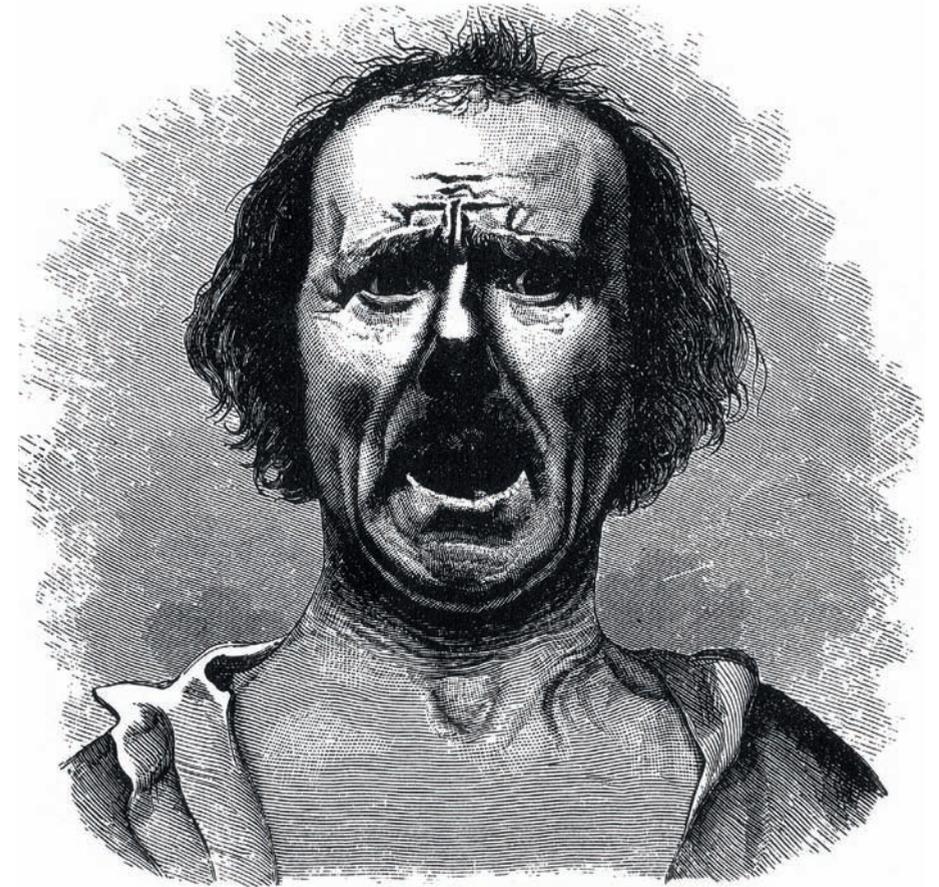


Figure 10.1 'Horror and Agony. Copied from a photograph by Dr Duchenne', from Charles Darwin's *The Expression of the Emotions in Man and Animals* (Fig. 21). Creative Commons Licence

is compounded by the fact that our own feelings are apt to cloud our judgement and memory: when we witness 'deep emotion' in others, he ventures, 'our sympathy is so strongly excited, that close observation is forgotten or rendered almost impossible' (1872, 13).

In order to capture such mercurial and transient phenomena, Darwin turned to the relatively new medium of photography, using a selection of images from a series published a decade earlier by the French neurologist, Guillaume-Benjamin-Amand Duchenne. In the original prints, Duchenne's experimental apparatus is visible: he used electrical probes to identify the muscles responsible for specific facial expressions. When he was preparing the illustrations for his own book,

Darwin instructed the engraver to omit the electrodes and hands of the operator visible in the original prints. This has the effect of making the expressions look more natural, but it also evades the question of whether the experiment itself was painful. As Darwin remarks, this particular man, a shoemaker by trade, had impaired sensation in his face. Because of his insensitivity to pain, Duchenne had been able, in his own words, to ‘stimulate his individual muscles with as much precision and accuracy as if I were working with a still irritable cadaver’ (Duchenne 1990, 43). What we see here is not pain, in other words, but its artful simulation – Duchenne refers to his method as ‘art’, and quotes Buffon’s description of the human face as a ‘living picture where the emotions are registered with much delicacy and energy’ (1990, 2). To complicate things further, when Darwin showed the photograph to his colleagues and family friends, 10 out of 23 people identified the expression not as pain, horror, or agony, but as extreme fright (3), anger (6) or doubt (1) (Darwin 1872, 305–6).

Researchers at the University of Cambridge recreated Darwin’s parlour experiment online and summarised the responses of 18,000 participants in pie charts. The results for our example are extremely varied, ranging from ‘angry’ (the most common response) to ‘shocked’ (the second largest group), ‘surprise and horror’, ‘fearful’, ‘outraged’, ‘disgust’, ‘aghast’ and ‘confused’. Only about 7 per cent of respondents associated the expression with pain. There are a number of plausible explanations for this marked lack of agreement: a changing historical repertoire of emotions (the authors of the Cambridge experiment note that the top response to Darwin’s image of ‘deep grief’ was ‘bored’); the enduring problem of categorising feeling, both physical and emotional; and the difficulty of identifying emotions – especially complex ones – from static images. Duchenne’s photographs and Darwin’s engravings do not provide us with any of the contextual clues we normally use to gauge how others are feeling. Voice, movement, narrative and social context: all of these are absent.

Pain, of course, is not usually thought of as an emotion (which may also explain why the participants in the online ‘Emotion Experiment’ did not *see* pain). Nor is it generally included in the universality hypothesis of facial expressions, which focusses on the six basic emotional states of happiness, surprise, fear, disgust, anger and sadness.³ In what follows, I take it as given that the expression of pain is not universal. What I am concerned with is how we ‘picture’ pain collectively – or more correctly (for there is no generic ‘we’) how ideas and images of pain shift and change in relation to social and political contexts

as well as medical practices and priorities. There has been considerable scholarly interest in the social and cultural history of pain in the last two decades. Highlights include, in chronological order: Lucy Bending’s *The Representation of Bodily Pain in Late Nineteenth-Century English Culture*; Robert Mills’s *Suspended Animation: Pain, pleasure and punishment in medieval culture*; Esther Cohen’s *The Modulated Scream: Pain in late medieval culture*; Javier Moscoso’s *Pain: A Cultural History*; Jan Frans Van Dijkhuizen’s *Pain and Compassion in Early Modern English Literature and Culture*; John Yamamoto-Wilson’s *Pain, Pleasure and Perversity: Discourses of suffering in seventeenth-century England*; Joanna Bourke’s *The Story of Pain: From prayer to painkillers* (which traces the idea, practice and treatment of pain in the English-speaking world since the eighteenth century); Rob Boddice’s *Pain and Emotion in Modern History* and *Pain: A very short introduction*, and Berenike Jung and Stella Bruzzi’s *Beyond the Rhetoric of Pain*. All of these books complicate Elaine Scarry’s seminal account of pain in *The Body in Pain* (1985) as something that destroys language, erodes the bonds of sociality and ultimately ‘unmakes’ the world of the person in pain.

Bourke opens her book with the question ‘What is pain?’ One answer, offered by the Victorian physician Peter Mere Latham, is that pain is simply ‘what is spoken about as “Pain”’ (in Bourke 2014, 3). Someone who says they are in pain ‘is in pain’. Most scholars within the humanities – and many clinicians – would accept Latham’s definition. It foregrounds the perspective of the sufferer and allows for the discursive nature of pain. There is a problem though: Latham assumed, not unreasonably, that pain was *something*: something spoken about, something suffered. This tendency to think of pain as a thing or an ‘it’ – independent of the sufferer and the observer – is misleading (Bourke goes so far as to call this common assumption an ontological fallacy) (2014, 5). In Scarry’s book, for example, it is *pain* that has agency, not the person who suffers pain. According to the literary theorist Geoffrey Galt Harpham, Scarry:

treats as ... a baseline of reality, what is in fact a combination of sensations, dispositions, cultural circumstances, and explanations, a phenomenon involving body, mind, and culture. [Scarry] has, in other words, misconceived the character of pain precisely by giving it a character, by treating it as a fact – a brute fact, the first and final fact – rather than as an interpretation. (Harpham 2001, 208)



Figure 10.2 Wolcott's Instant Pain Annihilator (c. 1863). Library of Congress, Washington D.C. Creative Commons Licence

Rather than taking pain as a 'brute fact', Bourke suggests, we would do better to think of it as an event. The questions then become rather different: 'how have people *done* pain and what ideological work do acts of being-in-pain seek to achieve?' (2014, 8). One very common way to 'do' pain is to objectify it using metaphor, to imagine pain as a thumping hammer, a knife, a red-hot poker, a crushing vice, an electric shock, a ligature, an army of ants, a gnawing beast or a host of demons, as in a nineteenth-century advertisement for Wolcott's Instant Pain Annihilator (Fig. 10.2).

Social, literary and iconographic histories of pain, however, have shown that pain is as much a cultural phenomenon as a physiological one. To reiterate Harpham's criticism of Scarry, pain is not a brute fact but an interpretation: a compound of body, mind and culture. The implications of this for clinical practice and medical humanities are profound. As well as asking about the severity of a patient's pain, or its precise character (in order to make a diagnosis or offer appropriate pain relief) one would want to know how an individual's pain was negotiated socially (in hospital, at home or in the workplace) and what their pain meant to them.

The pictorial, verbal and gestural languages that people use to communicate pain are, for the most part, conventional. There are 'cultural scripts' for being in pain, and sticking to the script means that you are more 'likely to generate a desirable response in terms of medication, care and compassion' (Bourke 2014, 17). Studying the

visual cultures of the past gives us access to some of the most enduring cultural scripts in human history. These scripts (ways of behaving and feeling) are context-specific, of course, but they also vary according to gender, class and age: children and adults are expected to 'do' pain differently, as are men and women. The pain-scripts I will focus on here have specific histories, but their influence can still be detected in attitudes towards illness and suffering. They are: beauty and ugliness as symptoms of moral value (or its deficit), the Christian iconography of sacrifice and the masculine ideal of stoicism.

None of the images reproduced in this chapter show straightforward pictures 'of' pain, but they can all be seen as ways of performing or 'doing' pain. Because I will be focussing on visual sources, questions of aesthetics (specifically to do with beauty, ugliness and visual pleasure) emerge that have tended to be overlooked in the scientific and historical literature on pain. This is important because aesthetic judgements are not confined to discourses on art: they have very real social, political and economic causes – and effects. Ugliness, in other words, is not just an aesthetic category: it is a social one. 'Abominations of the body' is the first of Erving Goffman's three categories of social stigma (the other two are 'blemishes of character' and the 'tribal stigma' of race, nation and religion). 'By definition', he writes, 'we believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances' (1990, 15).

Our bodies are visibly and aesthetically marked by class, ethnicity, sexuality, ability and disability, but they are also marked by illness, injury and ageing. These markers matter in clinical medicine and public health just as much as they matter in visual culture. *Ugly* suffering can provoke anger or guilt (in this sense ugliness has positive value in anti-war art). *Beautiful* suffering, however, is more commonly used to elicit compassion or pity – and charitable donations. These affinities between physical appearance and emotional response warrant closer attention. Historians of art and visual culture have the potential to elucidate the ways in which images (both scientific and artistic) exceed simplistic notions of illustration, documentation and expression, and become embodied.

Darwin and Duchenne acknowledged that science can be artful in its methods, but Darwin was less convinced of the illustrative value of fine art to scientific enquiry. In the introduction to *The Expression of Emotions*, he admits having hoped to 'derive much aid from the great masters in painting and sculpture', but says that his search proved

fruitless. ‘The reason is’, he speculates, ‘that in works of art, *beauty* is the chief object; and strongly contracted facial muscles destroy beauty’ (Darwin 1872, 15). Pain and anguish are disfiguring, and art is concerned with the expression of beauty. This passing comment bears closer scrutiny, not least because in the art historical canon of Darwin’s day – which encompassed the classical tradition and the Christian iconography of suffering – there seems to be no shortage of pain-in-art.

In order to understand the problem of picturing pain – its unexpected elusiveness where one most expects to find it – I have risked ranging more widely than is usual in academic art history. My point of departure is familiar enough: the famous *Laocoön* now on display in the Vatican Museum; but some of the subsequent detours (through eighteenth-century social caricature, twentieth-century medical portraiture and abject art) are less well trodden. My aim is not to provide a chronological survey of images of pain – which would need a book – but to raise questions about pain and representation that are relevant to medical humanities and clinical science.

Beautiful pain, ugly pain

Found at the baths of Titus in Rome in 1506, the Greek sculpture known as the *Laocoön* group influenced the course of both Renaissance art and eighteenth-century classicism, and occupied some of the greatest German intellectuals of the eighteenth and nineteenth centuries (Herder, Moritz, Schiller, Goethe, Hegel, Schopenhauer and Schlegel all wrote about it).⁴ In his book *Laocoon’s Body and the Aesthetics of Pain*, Simon Richter argues that classical aesthetics is fundamentally concerned with the body in pain because it is through pain that beauty is demonstrated. ‘Pain reveals’, he argues. It is ‘the origin of beauty’ (Richter 1992, 31). The *Laocoön* is also significant, Nigel Spivey points out, because it is one of the earliest naturalistic depictions of human emotion we have (the date is still a matter of debate, but it was made by three Greek sculptors before 70 BCE, when Pliny the Elder recorded it in his *Natural History*) (Spivey 2001, 28).

The sculpture shows the Trojan priest and his sons succumbing to the great sea serpents that the goddess Athena has sent to destroy them during the siege of Troy. Art history students usually encounter the group via the commentaries of two eighteenth-century scholars: Johann Winckelmann (1717–68), regarded as the father of German Classicism;

and his antagonist, the philosopher Gotthold Lessing (1729–81). For Winckelmann, writing in the 1750s, the central figure exemplifies the ‘noble simplicity and quiet grandeur’ of Classical Greek sculpture.⁵ *Laocoön*’s struggle is dignified and ennobling, Winckelmann argues: ‘Just as the depths of the sea always remain calm however much the surface may rage, so does the expression of the figures reveal a great and composed soul even in the midst of passion’ (quoted in Richter 1992, 44). This is *beautiful* pain – *silent* pain – the embodiment of Stoic philosophy.

Lessing saw the sculpture very differently, as an object lesson in the superiority of poetry over painting and sculpture.⁶ Words do not have to resemble what they signify in order to be understood, he reasons, but painting and sculpture are constrained by the necessity of resemblance (he is, of course, writing about figurative art: modernism turns this formula on its head). To convey horror, an artist must *show* us horror. And for Lessing, like Darwin, the graphic depiction of pain or suffering was invariably ‘disfiguring’ (he also describes it as ‘belittling’ – *verkleinernd*) (Spivey 2001, 31). Comparing the sculpture to Virgil’s telling of the story in the *Aeneid*, Lessing insisted on the difference between *seeing* pain (in visual art) and *hearing* it voiced (in a poem).

The ugly (*das Hässliche*) and the disgusting (*das Ekelhafte*) occupy three full chapters of Lessing’s essay on the *Laocoön*. Here he makes a distinction not only between painting and poetry, but also between painting as ‘an imitative skill’ and painting as ‘a fine art’ (a distinction that would have been obvious to both Darwin and Duchenne). Anything – so long as it is visible – can be imitated, but art ‘restricts itself only to those visible objects which awaken our pleasure’ (Lessing 1962, 127). The separation of art from craft or skill, and also from science, resulted in new hierarchies of representation in the eighteenth century. Art – as the preserve of beauty, taste and moral instruction – required that the human body be idealised or treated allegorically. Science, by contrast, increasingly turned to images of unvarnished and even visceral realism that privileged ‘the mark of truth’ over the delights of the imagination (Kemp 1993).

It should be clear by now that beauty and visual pleasure are slippery concepts. Aristotle had famously argued in *De Poetica* that even unpleasant objects and emotions become pleasing in imitation. Lessing countered that ugliness was an exception. When fear, terror, melancholy or compassion are depicted in a painting, for example, we do not confuse the representation – an expression of melancholy, for example – with our own sadness. Ugliness and disgust, though, are

‘always real and never imitations’ (Lessing 1962, 127). The sight of a disgusting object – Lessing later gives the examples of a harelip, a mole on the face and a complete lack of eyebrows – has no equivalent in poetry, in which meaning is revealed gradually, rather than in an instant (1962, 131). In the visual arts, he elaborates, ‘ugliness exerts all its force at one time and hence has an effect almost as strong as in nature itself’ (1962, 128). In short, ugliness ‘offends our eyes, contradicts the taste we have for order and harmony, and awakens aversion irrespective of the actual existence of the object in which we perceive it’ (1962, 127).

In his own compendium on ugliness, Umberto Eco observes that the response to beauty is often (or ideally) one of ‘disinterested appreciation’, whereas ugliness provokes ‘a reaction of disgust, if not violent repulsion, horror, or fear’ (2007, 16). As the following terms from Eco’s book attest, the emotional and visceral response to ugliness carries with it a moral judgement. To be ugly is to be:

repellent, horrible, horrendous, disgusting, disagreeable, grotesque, abominable, repulsive, odious, indecent, foul, dirty, obscene, repugnant, frightening, abject, monstrous, horrid, horrifying, unpleasant, terrible, terrifying, frightful, nightmarish, revolting, sickening, foetid, fearsome, ignoble, ungainly, displeasing, tiresome, offensive, deformed and disfigured. (2007, 16)

Ugliness is not just beauty’s other. It is, wrote Karl Rosenkranz in his 1853 treatise on the aesthetics of ugliness, the ‘hell of beauty’ (quoted in Eco 2007, 16). *Laocoön’s* creators had a dilemma: obey the rule of beauty or represent the disfiguring effects of pain. Lessing sets out the problem:

The demands of beauty could not be reconciled with the pain in all its disfiguring violence, so it had to be reduced. The scream had to be softened to a sigh, not because screaming betrays an ignoble soul, but because it distorts the features in a disgusting manner. Simply imagine *Laocoön’s* mouth forced wide open, and then judge! Imagine him screaming, and then look! From a form which inspired pity ... it has now become an ugly, repulsive figure from which we gladly turn away. For the sight of pain provokes distress; however, the distress should be transformed, through beauty, into the tender feeling of pity. (1962, 17)

The focal point of this passage is the gaping cavity of *Laocoön’s* mouth. It testifies to the inescapable muteness of visual art (Virgil’s hero ‘lifts high

his hideous cries to heaven, just like the bellows of a wounded bull’) and also to all that the classical body disavows: the body’s materiality, its unpredictable passions and dark, uncharted depths. Lessing’s reaction is interesting for another reason, though; it makes pity reliant on beauty, not absolute beauty, perhaps, but the *ameliorating* effects of beauty. Does ugliness preclude compassion? A meaningful answer would need to historically contextualise both ‘ugliness’ and ‘compassion’ – something that is beyond the scope of this chapter – but there is evidence from different historical periods to suggest that compassion, pity, sympathy (and empathy, a more recent addition to the vocabulary of humanitarian feeling) are thoroughly entangled with aesthetic concerns (Schweik 2009).

Bourke quotes an article published in 1896 in *The London Hospital Gazette* (Bourke 2014, 192–3). The author is a second-year medical student at The London Hospital, which served the immigrant population and working poor in the area of East London around Aldgate. The scene is a surgical-dressing room, with ‘Jews, Turks, and Heretics mingl[ing] together in one seething mass of injured and diseased humanity’. A ‘child of Israel’ in a far corner of the room provokes a ‘feeling akin to loathing’ (this patient – an ‘uncanny object’ – is not even accorded the status of a sentient being). Elsewhere in the treatment room ‘a puny, wizened, shrivelled up little fellow of doubtful nationality’ protests when an orderly approaches him with gauze to dress his wound. Groaning and rocking ‘to and fro on the couch’, he says he cannot ‘bear it’ then ‘slink[s] away amid the smiles of the stalwart Britons standing around’. The intern, known to us only as E. M. P., finds relief in the ‘pleasanter sight’ of two ‘fair haired little English boys ... wearily, but patiently waiting their turn’. The stoicism and physique of a ‘fine British working man’ (‘well developed – what a chest’) are also noted approvingly. Asked by the surgeon if he is ready – scalpel in hand – the workman ‘cheerily’ replies ‘all right, sir’ and, firmly holding the back of a chair, draws a ‘deep breath’ and is ‘silent – motionless – till all is over’.

E. M. P.’s attitude towards his immigrant patients was not unusual. ‘Indeed’, notes Bourke, ‘it took until the 1980s for the routine underestimation of the sufferings of certain groups of people to be deemed scandalous’ (2014, 192). Witnessing another’s pain does not necessarily or automatically excite sympathy. E. M. P.’s denial of his patients’ humanity – his visceral disgust in the face of their suffering – is indicative of the presence of stigma. In contrast, his white, working-class patients perform the cultural scripts expected of them: their

stoicism is no doubt deeply ingrained, but it is also instrumental in eliciting care. Erving Goffman described stigma as one of the ‘primal scenes of sociology’, an experience likely to be uncomfortable for both parties (1990, 24). The vignette in *The London Hospital Gazette* could serve, just as well, as a primal scene of medical humanities, illuminating the performative nature of suffering as well as the contingency of feeling.

Imitatio Christi

The vocabulary of suffering and stoicism discussed so far has its roots in classical philosophy and aesthetics, but Christian theology has an equally longstanding investment in pain. In *The Modulated Scream*, Esther Cohen emphasises the *positive* significance of pain in the European Middle Ages. ‘Suffering was not to be dismissed, vanquished, or transcended: suffering was to be felt with an ever-deepening intensity’ (Cohen 2009, 4). The possible reasons for this are various and include the frequency of famine, war and plague, and a reorientation of religious practice around emotive and bodily experience beginning in the eleventh century and culminating in the Baroque. Focussing on the period between the thirteenth and fifteenth centuries, Cohen argues that pain was *productive*: ‘it was used – by inquisitors (who used it to elicit confession); by physicians (who used their patients’ descriptions of pain as the basis of diagnosis); by the devout (whose sufferings brought them closer to Christ)’ (2009, 5).

Beginning in the thirteenth century, visual experience played an increasingly important role in both public religious life and in private devotion (Belting 1990; Biernoff 2002). Dramatic re-enactments of biblical stories; the exhibition of relics and other sacred objects; the elevation of the host within the mass; the production of devotional images: all of these developments point to a new ‘need to see’ (Belting 1990, 80). If the unrepresentability of God had previously been taken as proof of his divinity, the daily possibility of seeing the Virgin and Child, participating in a Passion play, or beholding the suffering of Christ came to ‘fulfil the postulate that reality attains to full existence and is proven only in visibility’ (Belting 1990, 82).

In the account of her 16 ‘showings’ or revelations (completed in around 1393), the anchoress Julian of Norwich mentions that she prayed for ‘a bodily sight’ of Christ’s Passion, ‘in which I might have more knowledge of the Saviour’s bodily pains’ (1978, 178). Julian’s

‘compassion’ is not to be confused with modern humanitarianism, which seeks to alleviate the suffering of others: to end pain (Merback 1999, 20). Her desire to be identified with Christ in his suffering, death and resurrection has its biblical precedent in the words of the Apostle Paul: ‘I have been crucified with Christ; it is no longer I who live, but Christ lives in me’ (Gal. 2.20). Paul, however, speaks of an interior transformation. Julian’s *Imitatio Christi* involved a bodily mnemonic: the transcription of Christ’s every pain onto her own flesh. Julian’s text is a virtuoso performance of pain, yet the ‘expression’ of pain (as Darwin understood it) is absent from medieval art.

Faces, in the art of the Middle Ages, could signify virtue or vice, but the emotions or ‘passions’ were located in the body, not the face. Indeed, it was the absence of a theory of physiognomy that allowed for such a rich tradition of the grotesque in medieval culture (Skinner 2014). The energetic (and at times gleefully obscene) face-pulling and contortionism that goes on in the margins of medieval manuscripts is nothing to do with the language of emotion. The grotesque faces of demons and the grimaces of the damned register evil or sin, not feeling. Christ’s beauty and serenity would have been read as an index of his divine nature, not a barometer of his physical or emotional torment. In Christian art of the Renaissance the face remains a site of transcendence. Even when the bodies of saints and martyrs are dismembered, pierced with arrows or twisted in agony, their serene faces look beyond the earthly realm, beyond pain, beyond death, to eternity (Fig. 10.3).



Figure 10.3 *Martyrdom of Saint Sebastian* (circular illustration). Oil painting. Wellcome Collection. Creative Commons Licence

The face of the crucified Christ is allowed to register suffering (it is theologically necessary that he is seen to die a real death). But Christ's face must still be beautiful, and the exceptions to this rule (look at Holbein's cadaverous entombed Christ in the Kunstmuseum, Basel) are truly shocking.

In *Illness as Metaphor* (1991) Susan Sontag speculated on the lasting impact of Christian portrayals of suffering on modern attitudes towards illness and disease. 'Our very notion of the person, of dignity, depends on the separation of the face from body', she writes, 'on the possibility that the face may be exempt, or exempt itself, from what is happening to the body' (Sontag 1991, 126). When the face is disfigured by pain, injury or disease, its ability to 'perform' endurance, patience or serenity is compromised. This might help to explain why some illnesses – and certain kinds of injury – are more easily romanticised, and some more stigmatised, than others. 'What a truly luminous sight it is to see a young girl or a young man on their deathbed, victims of consumption', Rosenkranz exclaims in his treatise on ugliness; and conversely, how 'nauseating' the eruptions and deformities that accompany tertiary syphilis (quoted in Eco 2007, 256). Lessing, too, uses examples of facial disfigurement to illustrate his theory that ugliness – even in a painting or a sculpture – provokes disgust. If there is beauty in suffering, it seems it is selectively bestowed.

Henry Peach Robinson's *Fading Away* (Fig. 10.4) exemplifies Victorian attitudes to tuberculosis (still, in 1858, called consumption, and like syphilis, a common and incurable disease). The tragic but lovely subject of Robinson's composition is certainly luminous: she is not so much fading away as becoming lighter. Her slight figure seems composed of an ethereal substance altogether different from that of her three companions. An older and a younger woman, presumably mother and sister, are absorbed in their silent bedside vigil. The man looking out of the window with his back to us is harder to place – is he the girl's father or suitor? – but it is easy to guess the poetic significance of the setting sun that draws his gaze. Less obvious to the casual observer is the fact that this intimate domestic scene has been produced from five separate negatives. *Fading Away* is what was known at the time as a combination photograph. It is also completely staged: the young woman is a model, while her companions have been dressed and arranged by the photographer.

The fictitious nature of *Fading Away* was not a problem for nineteenth-century viewers. Robinson wanted his work to be seen as art, not as documentary photography, so he made the image look like a painting and exhibited it with lines from Percy Shelley's poem



Figure 10.4 Henry Peach Robinson, *Fading Away*, 1858. Albumen silver print from glass negatives. Creative Commons Licence

Queen Mab ('Must then that peerless form ... As breathing marble, perish!'). What bothered critics was a nagging doubt about the tastefulness of Robinson's subject matter. *The Photographic Journal's* reviewer declared: '*Fading Away* is a subject I do not like, and I wonder Mr. Robinson should have allowed his fancy to fix on it; it is a picture no one could hang up in a room, and revert to with pleasure' (quoted in Coleman 2005, 118). To represent illness, or to picture pain, is to become entangled in questions of beauty, pleasure and taste.

Treating pain

With one exception (Fig. 10.2, the advertisement for Wolcott's Instant Pain Annihilator), the images discussed so far have been variations on the theme of beautiful or ennobling suffering. Historians of medicine, however, will be quick to point out that there are plenty of pictures – often made for commercial or pedagogical purposes – that illustrate the alleviation of pain. An easy way to see a representative sample is to type 'pain' into the Wellcome Collection's image search tool. What is perhaps surprising is that the portrayal of medical treatment

in these popular prints and in advertisements so often occurs within, or borrows from, the tradition of caricature, in which ugliness and illness are metaphors for moral decay and social disorder. So, we have images of headache, toothache, gout and dental extraction, indigestion, pain relief (including the first use of ether as an anaesthetic in 1846) and even hypochondria, illustrated in *Punch* with the caption:

‘I’ve got such a pain in my heart doctor – just here’.
‘But your heart isn’t *there!*’
‘Ah! Then that’s what’s the matter – it’s *moved!*’⁷

In all these cases, pain is something to be *treated*, whether pharmacologically, surgically or (in the case of gout) by cutting down on brandy, stout and steak and kidney pies. In the case of the sick poor, social reform was part of the cure, ‘sickness’ being understood as a collective malady as much as an individual one.

Lucy Bending has shown that Christianity and medicine offered two ‘dominant, though conflicting’ paradigms for understanding pain throughout most of the 1800s (Bending 2000, 4). By the close of the century however, developments in medical science, especially physiology, had begun to dislodge the idea that pain was necessary and instrumental (either as a form of punishment or a means of atonement). Advances in pharmacology and clinical medicine also play a part in this story: casting doubt on the ‘naturalness’ and inevitability of pain by approaching it as a bodily phenomenon that could be treated either surgically or chemically (Bending 2000, 52).

The process of secularisation that Bending describes was disrupted, however, by the resurgence, during the Great War, of an unmistakably Christian ideology of suffering. It is also complicated by the persistence of stoicism as a masculine ideal. The wounded were expected to exhibit fortitude, to make light of their pain and at the end, to die quietly. ‘I’ve got a motto’, went the words to a popular music-hall song: ‘always merry and bright!’⁸ We think of injury and convalescence as passive states – to be a *patient* is ‘to receive medical treatment’ – but what comes across in the letters, diaries and memoirs of the war-wounded is the performative effort involved.

Indeed, pain is conspicuously absent from the images reproduced in my book *Portraits of Violence*, which takes as its starting point Henry Tonks’s intimate drawings of facial casualties, made between 1916 and 1918 (Biernoff 2017). Although partly about the representation of facial

injury – in portraits, press photographs and medical records – one of the aims of this project has been to explain the *unrepresentability* of certain kinds of injury, and certain kinds of pain, in the public sphere. In Britain, during and after the First World War, facial injury was written about in the press, but almost never shown outside the professional context of clinical medicine. Tonks worked with the plastic surgeon Harold Gillies: some of the portraits were reproduced in Gillies’s 1920 textbook, *Plastic Surgery of the Face*, but they were never intended for public consumption. Although images like those in Private Kearsley’s case file record devastating injuries (Fig. 10.5), they are in a profound way not ‘about’ pain.

The wartime culture of stoicism and trench humour goes some way towards explaining the absence of pain in Tonks’s portraits, and in the medical photographs of the same patients, but it is not the only factor. There is a sense, in the drawings, of a surgeon’s eye at work – not just because these are drawings of patients before and after surgery, but because Tonks himself trained as a surgeon before becoming an artist. In his memoirs, he admits having ‘often wondered ... what the figure looks like to anyone who has not this knowledge [of anatomy]’ (Tonks 1929, 230). He would not have been insensitive to a patient’s physical pain or psychological distress, but it was not his primary concern.

The diagrams Tonks produced as a graphic record of Gillies’s operations capture the surgical gaze (and touch) in the most economical form possible. The injury is abstracted from its human context, certainly from any suggestion of pain or suffering. To borrow a phrase from the Royal Academy’s first professor of anatomy, the obstetrician and surgeon William Hunter (1718–83), they possess ‘a kind of necessary Inhumanity’.⁹ As drawings, they have more in common with tailors’ patterns than portraits, and for Gillies and Tonks their purpose was indeed pedagogical as well as documentary.

The powers of horror

Henry Tonks’s drawings of facially injured soldiers are seen today as some of the most poignant and honest images to come out of the First World War. At the 1995 Venice Biennale several of the portraits were included in Jean Clair’s themed exhibition *Identity and Otherness*: a show that filled the Palazzo Grassi and the Museo Correr in St Mark’s Square with images of ‘the century of atrocities’ (Graham-Dixon 1995). Tonks’s small studies of facial casualties took their place alongside



Figure 10.5 *Portrait of Private William Kearsley*, by Henry Tonks, c. 1917, pastel. RCSSC/P 569. 36. © Museums at the Royal College of Surgeons

canonical works by Otto Dix, Max Beckmann and Jacob Epstein, while in the British Pavilion Jake and Dinos Chapman revisited Goya's *Disasters of War*. Two decades on, and a century after Tonks made them, the portraits of Gillies's patients have become war art for the twenty-first century. They have an uncanny ability – as good portraits do – to make the absent present and revivify the past, but their legacy is also a product of the 1990s and that decade's embrace of horror

and ugliness as aesthetic and political tools. What Tonks regarded as too disturbing for public consumption is art, now, precisely because of its power to disturb. The final part of this chapter will consider the re-emergence of pain under the umbrella of abject art and what it means to think about suffering stylistically.

In the 1980s and '90s the English translation of Julia Kristeva's *Powers of Horror* (originally published in French in 1980) became one of the key texts associated with the 'corporeal turn' in the humanities and social sciences: an intellectual trend that drew inspiration from various sources, most notably feminist theory and the writings of Michel Foucault. The renewed theoretical interest in the body was, in part, a response to the inexorable post-war expansion of consumer culture with its progressive commodification of almost every facet of everyday life – and every aspect of embodiment. However, by the late 1980s there was a more immediate reason to focus on the body and bio-politics, and that was the AIDS crisis. Writing in 1991 of the pervasive 'politics of anxiety' in Britain, the sociologist Bryan Turner observed that 'for a great variety of reasons ... the 1990s already have, more in a medical than in a chronological sense, a terminal quality' (Turner 1991, 24–5). In avant-garde art of the period, on both sides of the Atlantic, the image of the diseased, fragmented, disfigured or dying body seemed to assume an apocalyptic significance: a tendency that crystallised in the Whitney Museum's 1993 exhibition *Abject Art: Repulsion and Desire in American Art* and in Norman Rosenthal's controversial Royal Academy shows, *Sensation* and *Apocalypse*, in 1997 and 2000 respectively.

The glossary entry for 'abject art' on the Tate Collection website provides this definition for visitors:

It can be said very simply that the abject consists of those elements, particularly of the body, that transgress and threaten our sense of cleanliness and propriety. Kristeva herself commented 'refuse and corpses show me what I permanently thrust aside in order to live.' In practice the abject covers all the bodily functions, or aspects of the body, that are deemed impure or inappropriate for public display or discussion.

As Nicholas Chare notes in the introduction to his book on the aesthetics of abjection, by the mid-1990s 'abject' was a term applied to any art with 'visceral pretensions' – and there was a lot of it around (Chare 2011, xvii). In the UK, the transgression of the 'clean and proper' body became one of the hallmarks of Charles Saatchi's collection of young

British artists. Chris Ofili (whose own work is in the Saatchi collection) described typical 'Saatchi art' as 'one-off shockers. Something designed to get his attention' (quoted in Stallabrass 2006, 207). If Kristeva was often revered (and sometimes maligned) as the high priestess of abject art, Saatchi was its most prominent financier, as well as a publicity genius. Chare's book is not cultural history, and it steers clear of the more banal and cynical examples of abject art. Instead, he makes the case for a more nuanced engagement with the concept of abjection itself, as well as its cultural expression.

Most people do not read beyond the opening chapters of *Powers of Horror*, where the passage quoted in the Tate glossary appears. Certainly, few definitions of abjection refer to the later sections on the writer and physician Louis-Ferdinand Céline, whose virulently anti-Semitic pamphlets are the subject of Chare's first chapter. The point is that the abject, in Céline's prose-poetry, cannot 'be said very simply' (as the Tate glossary entry would have it) to consist of corpses, disease, decay, waste, flesh, filth, viscera, skin and so on. To reduce the abject to a checklist of cultural taboos is to miss the point that, for Kristeva, abjection (like pain) is fundamentally implicated in both subject-formation and the development of language. Through Céline's writing, Kristeva explores the violent poetics of abjection, its dark 'musicality' and rhythm, its *style*. It is this attention to style, Chare argues, that her critics and followers have overlooked, and it is the problem of style – *how* to show or speak horror – that Chare's book addresses. These debates may seem distant from the central concerns of medical humanities, but they answer a need – articulated persuasively by Angela Woods – to think about health and illness 'beyond narrative' (Woods 2011). If pain is something we do or perform (and not just a brute fact) then *how* it is performed – and how it is interpreted – are critical.

So the singer and composer Diamanda Galás evades the 'threat of beautification' by 'becoming' rather than 'describing' horror and Paul Celan's late works are similarly composed of a 'language of the lifeless', to use Primo Levi's phrase (Chare 2011, 62, 69). They leave no room to breathe or reflect. These are poems that are meant to be spoken and heard; sensed rather than narrated or made sense of. '*Hör dich ein mit dem Mund*', Celan writes: 'listen your way in with your mouth'. To 'mouth' Celan's poems or to be 'fucked up' by Galás's vocals is to take leave of the symbolic and enter the realm of the semiotic. In *Desire in Language* (1980, 157) Kristeva argued that the semiotic dimension of language has its origins in the 'rhythms, intonations, and echolalias

of the mother-child symbiosis'. The symbolic aspect comes later, as the child internalises the linguistic structures, such as grammar and syntax, necessary for intelligible speech. The semiotic is always present, though. It is the bodily and affective 'lining' of signification, but also the place where meaning collapses. The symbolic 'clothes' language, fashions it into a social artefact.

Following this train of thought, there is another way to conceptualise the relationship between pain and representation – not in terms of communication and understanding (content, in other words), but in terms of aesthetics and style. Chare opens his Preface with Scarry's description of the violent unmaking of the world:

To witness the moment when pain causes a reversion to the pre-language of cries and groans is to witness the destruction of language; but conversely, to be present when a person moves up out of that pre-language and projects the facts of sentience into speech is almost to have been permitted to be present at the birth of language itself. (Scarry 1985, 6; Chare 2011, xvii)

Like Scarry, he is fascinated by the disintegration of language *in extremis*, a process of 'unwording' that he extends to the visual languages of painting and photography as well as to speech and writing. Thus, Francis Bacon's *Study after Velázquez* (1953) is described as 'painting as unwriting' (Chare 2011, 49). In the process of returning the body to nerve and flesh, Bacon enacts 'a journey back towards the psyche's beginnings, a journey into the night' (Chare 2011, 55). Bacon's painterly facture finds its vocal parallel in the performances of Galás in which words cease to be the 'contours for thought' and become instead something terrible and inhuman and palpable. 'Eviscerated' of sense (Chare 2011, 60), language becomes something that is felt rather than understood. To define such expressions as 'visual art' or 'music' is to miss their appeal to other senses (notably touch) and their insistent, sometimes overwhelming, materiality.

Kristeva's account of abjection does not map perfectly onto the experience, representation or witnessing of pain. Disgust and a fear of contagion are symptomatic of the abject, the presence of which is also marked by cultural taboos. Both pain and abjection, however, are limit experiences: at their most powerful, they threaten a loss of self or consciousness and make us face 'the limits of the human universe' (Kristeva 1982, 11). There is also a parallel between the ontological status of pain, as Joanna Bourke sees it (as an event, not a thing) and

Kristeva's insistence that the abject is not an object. 'When I am beset by abjection', she writes, 'the twisted braids of affects and thoughts I call by such a name does not have, properly speaking a definable *object*' (Kristeva 1982, 1). Elsewhere, she calls the abject a 'composite of judgment and affect, of condemnation and yearning, of signs and drives' (Kristeva 1982, 10). Like pain, abjection is something we both experience and 'do'.

Conclusion

Given the peripatetic nature of this text it seems appropriate to finish with some reflections rather than any definitive conclusions. The first is that images are cultural and epistemological artefacts. They are different from the lived experience of pain, whether one's own, or another's. This sounds obvious, but is often overlooked: painting, sculpture, medical illustration and photography never simply represent or record pain or injury (as Darwin thought): they make it meaningful and useful; they prescribe and they normalise, but they also have the potential (as in abject art) to reimagine and resist. In the *Laocoön*, pain is a proving ground. In Christian images of the saints and the Passion, suffering is both instrumental and exemplary. In pharmaceutical advertising, pain is something that can be relieved if you buy the right product. Portrayals of the piteous poor are lessons in the politics of sympathy, and gout provided satirists with a visual shorthand for hedonistic excess.

Representations – however convincing or seemingly unmediated – are not reality. Nevertheless, as Bourke reminds us, the cultural scripts we use for pain play a part in constituting that pain: they influence how it is experienced subjectively, as well as how it is negotiated socially. The anthropologist Michael Kimmel uses the term 'retrojection' to describe the process by which cultural forms – images, metaphors, gestures – 'come to be felt inside the body' (Kimmel 2008, 99, 101). So, the questions we need to ask about the visual cultures of pain are not just the obvious ones: how has pain been represented; what does it look like? Such questions invite the kind of art historical survey I set out, at the start, to produce, but this seems inadequate if the goal is to understand how cultural artefacts, like altarpieces or advertisements, come to be 'felt inside the body'. How do images work, in specific contexts, as ways of 'doing' pain? Simply surveying pictures of pain also fails to address the undemocratic nature of representation: the fact that some pains are represented, and others are deemed unrepresentable.

A further question we might want to ask is: when is suffering *not* shown, and why? If pain is absent from the visual culture of modern medicine, for example, what purpose is served by its absence?

Finally, images are not just cultural and epistemological artefacts – legible things, the bearers of knowledge and ideology and cultural capital – they are also aesthetic objects. Classical aesthetics dictated that pain, in art, should be ameliorated by beauty. Idealised, pain reveals and instructs; it inspires fellow feeling. Beauty, according to this formula, was a prerequisite not only for art, but also for the stirrings of sympathy in the beholder. But if the eighteenth century saw the emergence of 'spectatorial sympathy' as a cornerstone of moral philosophy, it was spectatorial *pain* that preoccupied artists, curators and theorists by the end of the twentieth century (Halttunen 1995, 307n.8). 'You are about to see videos which will make you suffer', warned the French performance artist Orlan as her 'surgery-performance' (one of nine operations between 1990 and 1993) was broadcast live to audiences around the world (quoted in Hirschhorn 1996, 126). In art, pain can be staged, anthropomorphised, faked, inflicted, performed, referred or signified. And pain is never just *what* is spoken of, but *how* it is spoken. In its attention to the aesthetics of pain and the poetics of illness, medical humanities has the potential to go beyond the limits of narrative.

Notes

- 1 An earlier version of this chapter appeared in A. Whitehead et al. (eds) (2016) *The Edinburgh Companion to the Critical Medical Humanities*. Edinburgh: Edinburgh University Press.
- 2 Detailed commentary on Darwin's *Expression* can be found in Boddice (2016), Dixon (2003), Gross (2010), Leys (2010) and Rees (2014).
- 3 For a critique of the universality hypothesis see Jack et al. (2012).
- 4 Duchenne reproduces a photograph of the head of the *Laocoön* in *Human Facial Expression*, Figure 70, and quotes Winckelmann's analysis on p. 98.
- 5 Winckelmann's *Gedancken über die Nachahmung der Griechischen Werke in der Malerey und Bildhauer-Kunst* was published in 1755, shortly before he left Dresden for Rome. Dresden was famous for its collection of casts of antique statues, and it was here that Winckelmann encountered a plaster copy of the *Laocoön*.
- 6 Lessing's essay of 1766 was titled *Laokoon: Oder über die Grenzen der Malerey und Poesie* (*An Essay on the Limitations of Painting and Poetry*). Quotations are from E. A. McCormick's 1962 translation (Lessing, 1766).
- 7 A hypochondriac tells her doctor that she has a pain in her heart while clutching the wrong side of her chest. Reproduction of a drawing after Beauchamp, 1932, Wellcome Library, London, ICV No 11813.
- 8 'So the resolute men fight on, suffering, tormented, maimed; but their teeth are set and the light in their eyes is high, and never does their agony debase them'. 'Laughing in the Face of Pain' (1916).

- 9 The expression ‘necessary inhumanity’ comes from Hunter’s introductory lecture to students, c. 1780, St Thomas’s Hospital Manuscript 55, Royal College of Surgeons, 182 verso.

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Making charcoal for drawing

Onya McCausland

Introduction

Onya McCausland's contribution to the conference was a collaborative drawing session that developed methodologies which liberated drawing from visual conventions by focussing on tangible sensation and the imagination. The workshop sought to examine equivalences for transmitting experience through gesture and line; a search for resemblance, rather than representation. Using collaboration and dialogue the session explored how gaps between words, meanings and marks on paper can open cracks into new experiential insights. It emphasised the interaction between subtle tangible sensations through a combination of shared communications and imagination rather than depending on optical perception alone.

On burning

Burning is 'polysensual' ... it involves sight, sound, taste and smell, as well as the sensation of heat on the skin. Fire is a palpable medium, with the action feeling its way into the future through reports recorded through words, sounds, images – the legacy of after-glow. To experience burning with only one sense is to spark in the imagination another four registers of perception. (Le Feuvre 2014, 4)

Burning, a most ephemeral act, gives way to the most enduring material – charcoal is a conduit for language, and drawing enables

the material to speak. Drawing is a direct way of tuning in to internal sensations, as gesture, action and touch are materialised and give tangible form to invisible sensations and thoughts. The internal experiences of the body can be expressed and discovered through the act of drawing, as knowledge of the body is tapped to find a new language of and for the body. The intimate and unmediated sensation that occurs between mind, body-gesture and material is particular to drawing and is what maintains drawing as a radical act of thinking, feeling and seeing. In my own experience of the clinical setting I found that I wave my hands about – limited by my capacity to find the precise words – I am drawing in space, trying to convey a feeling, a sensation that is new to me, and therefore on the outer edge of my linguistic capacity. I use drawing to try to confront the paradoxical impasse between language and experience. What follows is an account of preparing a drawing that began with experiencing the transformation of its material.

Sitting at a table in my studio, I have a large chunk of charcoal the size of a fist beside me. It looks like a piece of coal, less oily, with clearly visible striations of woodgrain running across it. The tight rings of the original oak tree have carbonised into thinly layered brittle plates. It is



Figure 11.1 Charcoal clamp, Cannop Hill Forest of Dean Sculpture Trail. October 2015. © Onya McCausland

light in weight. Running my hand over it makes a sound that resembles polystyrene.

The charcoal came from the Forest of Dean where it had been an oak tree for over 300 years. Then it was cut down and turned into a sculpture which stood in the sculpture trail for 29 years (Magdalene Jetalova's *Place*). In 2015 the oak sculpture was chopped into pieces, stacked into a mound covered with turf to make a traditional 'clamp', where it was burned to make charcoal on the top of Cannop Hill, where the sculpture and tree had once stood.

After the frenzy of the fire-starting, things settle down, and a new pace is established by the charcoal burners who have gathered. They take turns to walk round the mound. Looking for breaches in the turf skin and patching them up, while keeping five or six 'vent' holes open by poking a long stick through into the body of the mound. Changes in the colour of the smoke signal internal changes. White steam releases moisture, like sweat, slowly becoming tinged with yellow as sulphurous tar residues burn off, finally the smoke turns blue when the wood is charred – carbonised and ready to combust. The vents are sealed, and new ones opened further down the mound/mountain/body (see Fig. 11.1).

The huge smouldering earth-covered mound is full of heat. Thick coils of smoke pour through the holes in the turf. The vents hold the burn in balance – letting in just enough air evenly spaced around the form to maintain the steady heat but prevent combustion. For three days and two nights the mountain of oak steams and breathes like a giant, sleeping animal. A heat source without emitting light. It feels alive. Occasional breaches in the skin expose the inferno inside – the charcoal minders are always alert to the danger of collapse, pacing around, checking all the time. No sleep. By the third day the mountain/animal has changed, it has become deflated and tired, more lumpen, less animate. The last traces of bluish white steam exhaling through the leathery turf skin.

The decision about when to break open the burn is taken collectively by the burners. The deflated, exhausted mound is doused with water, then torn apart with forks and rakes, exposing the hissing and steaming interior. During this violent and dangerous transition, small fires break out on sudden exposure to oxygen, immediately they are doused with water. Dark red embers glow through the pile of dense black coals in a scene of devastation. Hundreds of cracked and fragmented shards of shiny looking lumps of coal spread out around the core in a circle. The mass of energy is finally dissipated and quiet (see Fig. 11.2).



Figure 11.2 Heap of burned charcoal on Cannop Hill, Forest of Dean Sculpture Trail. October 2015. © Onya McCausland

The huge heap of charcoal made by the burn was so visually and physically related to coal that my first urge was to return it to the ground – where it 'belonged' – and where its life began in the form of an oak tree – a form of burial, a culturally symbolic and literal act of



Figure 11.3 Charcoal measure, Cannop Hill, Forest of Dean Sculpture Trail. March 2016. © Onya McCausland

transformation also connected with burning. It is like coal only much lighter in weight, dense but brittle, soft and very black. It is very dry, has surprisingly little smell now and is completely black like the inside of a coal mine. The 'coal measures' underlying the forest are a record of a geological cycle of transformation, and their exploitation as fossil fuel a record of our relationship with the earth. The burn brought these two material realms together: the geological and the human.

This transformation of one material form into another demonstrates a concerted effort between people. The care and nurture of the body of the charcoal mound by the charcoal burners demonstrates a fine balance between knowledge and tacit experience; the process cannot be understood theoretically. Rather it is tested through touch and sensing, watching and feeling – adjusted and adapted until its form is discovered. The drawing I eventually made came unexpectedly as the process of burning developed. An Ordnance Survey map of the forest's coal mines revealed the hidden grid structure of the cavities left by extraction, and the skeleton-like 'walls' of coal left in the ground, to support the roof – directly beneath the site of the burn. It was as if the processes we had collectively enacted, the days spent on the hill preparing, the nights living with the burn had filtered downwards into the interior of the hill, had drawn up and revealed the hidden constructed geological depths 100ft underneath our feet (see Fig. 11.3).

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12 The art of pain and intersubjectivity in Frida Kahlo's self-portraits

Minae Inahara

Introduction

Frida Kahlo was a renowned Mexican artist who created striking paintings, most of them self-portraits, reflecting her lived experiences, often of pain and sorrow. Kahlo contracted polio at age six, which caused her right leg to be thinner than her left leg. Later in her life, she was involved in a car accident that left her paralysed. Due to her health problems Kahlo was left with reproductive problems and chronic pain. In this chapter, I shall argue that Kahlo's paintings can serve as a resource for those who want to better comprehend the experience of physical pain. Her self-portraits are a medium through which she visualises pain and the effect of pain on her own lived body.

As a pain sufferer, I can feel the pain and sorrow expressed in Kahlo's paintings; through them, I can reflect upon the lived experience of pain from the perspective of other pain sufferers. Kahlo's paintings, I believe, can help me and others understand what it is like to feel pain. In this chapter, I shall therefore attempt to connect Kahlo's paintings to the concept of intersubjectivity and explore the significance of self-portraits for Merleau-Ponty's notion of the body as expression. When Merleau-Ponty writes of a 'body as expression', he wants to emphasise that the body is not a 'mechanism' that can be used as a 'tool' or an 'instrument'. For Merleau-Ponty, the body is primarily the way that a human being interacts with the world, an interaction that is both embodied and expressive.

Kahlo's work braids and interlaces the mind and the body, the self and the other in order to create her own self-representations.

Highly diverse in composition, her oeuvre explores her own subjectivity and lived experiences of being a woman with disability and in pain. Constructed from a bricolage of her lived experiences, Kahlo's paintings capture her complexity. This complexity, I suggest, interrogates her sociocultural beliefs, codes and expectations that reinforce the depictions of her identities as a woman (daughter, mother, lover and wife), a Mexican woman and a woman with disability and pain. Her paintings offer opposites and dualities – the mind and the body, the self and the other, the public and the private, the powerful and the powerless and the gazing and gazed.

In creating artworks that remain mysterious while exploring the meaning of embodiment, Kahlo's works reveal that the fixed subject does not exist. Before I discuss Kahlo's paintings, I shall explain Merleau-Ponty's notion of the body as expression. I shall also explore three paintings of Kahlo to show how they reflect a complex concern with the normative, but also offer a phenomenological insight into vulnerabilities, while both representing and deconstructing identity.

The body as expression

Merleau-Ponty's work overcomes the dichotomy in the Western philosophical tradition between body and mind. Merleau-Ponty integrates the philosophical problem of body and mind by turning to lived experience. *The Phenomenology of Perception* offers an extended analysis of the significance of embodied consciousness and the primacy of perception for understanding the specificities of lived experience. By means of his phenomenology of expression, he paves the way to leave behind the conventional mind–body dichotomy. Merleau-Ponty develops a philosophy of expression in which embodiment, intersubjectivity and a background of a shared world are interwoven. In *The Phenomenology of Perception*, Merleau-Ponty states:

We have seen in the body a unity distinct from that of the scientific object. We have just discovered, even in its 'sexual function', intentionality and sense-giving powers. In trying to describe the phenomenology of speech and the specific act of meaning, we shall have the opportunity to leave behind us, once and all, the traditional subject–object dichotomy. (2002, 202)

The art critic and philosopher Jonathan Gilmore summarises Merleau-Ponty's notion of the body as expression:

One's body is simultaneously seeing and seen, and when it sees itself, it sees itself seeing, just as it can touch itself touching. This capacity of the body to be both its own subject and object leads Merleau-Ponty to describe the self as constituted non-transparently and non-autonomously, as both object and subject. Thus, against the notion of unified subject that serves as the transcendental guarantee of unity of the world, Merleau-Ponty introduces ways of speaking of a decentered self: one that is not immediately present to itself. (2005, 300–1)

Merleau-Ponty develops a phenomenological notion of the embodied self who is living, emotional and makes use of bodily expression (including speech) as a tool of communicating with others in a community. Merleau-Ponty's notion of the 'body as expression' questions the fixed distinction between the body and the mind. Merleau-Ponty introduces the concept of 'embodied subjectivity' to philosophy, the idea of a unified body and mind. To do this, he offers the body not in scientific, naturalistic or mechanistic terms, but as the phenomenological notion of the lived body. The lived body, for Merleau-Ponty, is ambivalent, since it is both physiological and psychological. The expressive body needs its physiological features in order to be expressive, but these expressive characteristics cannot be experienced simply by attending to the body's physiology. Thus, the lived body is the living subject that is both a mind in the body and a body in the mind. Merleau-Ponty states:

the psycho-physical event can no longer be conceived after the model of Cartesian physiology and as the juxtaposition of a process in itself [the body] and a cogitatio [the mind]. The union of soul and body is not an amalgamation between two mutually external terms, subject and object, brought about by arbitrary degree. It is enacted at every instant in the movement of existence. (2002, 102)

The body which Merleau-Ponty explores is not the objective (biological and medical) body in its materiality, but the subjective (lived) body in its dialogue with others and the world.

Following Merleau-Ponty I see, with regard to my own physical disability, the way in which my body is seen and evaluated by others

often has a strong impact on the way in which I experience my own condition. Others have an influence on me, and the gaze from others shapes who I am. My lived body expresses my subjectivity, but these expressions gain their meaning from intersubjective relations. In fact, the expressive body is not the outside sign of private inner hidden sensations, but a significant carrier of emotion that others can recognise. The body is also a site for the inscription of sociocultural norms, which I incorporate into who I am and which mediate the emotional meaning with which my expressive body is imbued.

Since the moment of my birth, I have been encultured into classifications which were not of my own construction and I have been initiated into the community (whether that community is one of sex, nationality or disability – the list is not exhaustive). These are what Merleau-Ponty (1993, 125–6) calls *instituted* meanings which precede me. Although I do not completely identify with the classification of my body by virtue of its sex, race (skin, hair and eye colours), voice, posture, ability, age, size and so forth, these are all constitutive of who I am. I cannot institute such a meaning. Since I have not established the classifications into which I was born, there are always characteristics of myself which are somehow beyond me, but which yet are part of myself. When I am recognised and classified as a disabled, Japanese, heterosexual, middle-aged and married woman, I am in the process of becoming a particular embodied subject. However, Merleau-Ponty insists that such instituted meanings are never stable and cannot be all-encompassing. They leave room for creative acts of *instituting* meaning in which new expressive possibilities come into being. The other's reaction to me can lead me to react against it and point out its failure in unfolding who I am, by saying 'it is not me!'. This can lead to new creative acts. In Kahlo's paintings we can see how she uses the instituted meanings operative in her society, but also reinvents them to yield new creative forms.

On intersubjectivity: The body, pain, emotions and art

We have to understand the process of being a subject, which acknowledges the intensity of both the self and the other in relation to one another. I suggest that expression is something that appears in any communication between the self and the other. When I see the expression of pain, for example, I do not see the pain as separate from its expression, but, rather, the pain is embodied as a particular

expression. When I see the body in pain, I do not see the pain as something separate from the body. The pain is expressed as a specific embodiment. The recognition of the other's body in pain is a recognition of embodied intersubjectivity and a rejection of any mind–body dualism. I argue that bodily expressions can be perceptible, not veiled, and yet there are conditions in which we might find them difficult to interpret, or we might misunderstand them. What happens in the process of perceiving bodily expressions is an understanding of a particular gestalt, recognition of a particular movement of the body, for example, the body in pain. This is a way of reading a body. We can be taught to read bodies so that we can detect sensations, emotions and thoughts in their public manifestations. Such expressive content can be noticed without paying specific attention to the material features of the bodies. We are rather attending to the expressive contours which such material features make possible. As Kathleen Lennon, a philosopher of mind and body who often writes about the body and affectivity, explains:

Firstly, for bodily expressions, we learn to detect the emotional quality of the expression without detecting a *physiological* character and then attaching significance to it. There may indeed be no coherent unity at the physiological level, and certainly not one that is available to those detecting the emotion. Secondly, if we wanted to teach someone what joy is, we would do so by initiating them into this recognitional practice, a practice anchored in a body in context and within patterns of response of others to that body. (2012, 39)

Lennon argues that we are aware of the bodily processes (physiology) in terms of what it expresses, such as expressions of anger, pain and other emotions. I shall apply this notion of bodily expressions to my analysis of Kahlo's work, in the hope of further developing the concept of embodied intersubjectivity. David Cockburn (2009), as a philosopher of mind who often uses the ideas of Ludwig Wittgenstein in his work, gives more emphasis to the roles of linguistic expression in the understanding of emotions. However, Cockburn sees that language cannot be understood in abstraction from our other bodily expressions and their role in communication. Like Lennon, Cockburn discusses bodily expressions to problematise certain types of dualism, not just the mind–body dualism but also a possible dualism between two different types of bodies, a dualism between the 'body as mechanism' and 'body as expression'. Cockburn and Lennon draw attention to the fact that

one's emotional reaction to bodily expressions of others reveals the quality of being an embodied subject to us.

Both Lennon and Cockburn apply Merleau-Ponty's (and also Wittgenstein's) phenomenology to develop a concept of bodily expression as an ambiguity, since it is simultaneously interpretation and creation, both instituted and instituting. When examined from the perspective of phenomenology, the expressive content of Kahlo's paintings is derived both from her cultural anchorage and her artistic creativity. She creates works which can be read intersubjectively, so that the content of her often painful lived experience can be communicated to her audience.

Kahlo's art of lived experiences

Kahlo's art shows her questioning the normal, the legitimate and the dominant through an exploration of her own embodied subjectivity. Kahlo was concerned with death and the vulnerability of her body. Her childhood and teenage years were afflicted by polio, which affected her right leg, and a traumatic bus accident which she was involved in as a teenager, in which a pole cut through her back and her vagina, resulting in many operations and health complications. Her work can be seen as a creative enquiry into her life, death, pain, disability and suffering, in which she is communicating the nature of living in/through a body such as hers. This enquiry is made through the mediation of art and thereby her experience of living is transformed through her art. She expresses her emotions with her brush and paints, and her paintbrush functions like a walking stick for a person with a disability, that is, as an extension of the body. Thus, her paintings are extensions of the expressive modes of her own body. In the following sections, I analyse three of Kahlo's paintings to explore her embodied subjectivity.

Henry Ford Hospital (1932)

The work *Henry Ford Hospital* (1932) relates to a miscarriage that Kahlo experienced. In this painting, Kahlo portrays herself in Henry Ford Hospital, lying on a bed naked with a haemorrhage. Her body is distorted, and her feelings of helplessness and sadness are expressed in the painting (Burrus 2008). The pain shows in the way in which she paints her body, but also in the objects with which she surrounds her body and the colours and tones of the painting. Kahlo employs such

techniques to creatively expand the expressive possibilities of the body. The work is a reflection of what Kahlo felt when she lost her child. She expresses another side to the experience of motherhood: the loss of a child rather than the birth.

There are six objects around her body: 1) a foetus, which is the son she and Diego longed to have, 2) an anatomical model of female reproductive organs, 3) an orchid which looks like a uterus, 4) the pelvis which caused the miscarriage, 5) the medical appliances which were used on her and 6) the snail (a symbol of time). Lennon (2011) refers to the painting in the following way:

In Frida Kahlo's picture, *Henry Ford Hospital*, the horror of the medicalisation, and resultant objectification of the body, may impact more easily on those whose bodies have been in the hands of gynaecologists or other surgeons. However, we need to take care here with the way in which we see the communalities as working. It is not the case that some process of simulation takes place in us, from which the content of Frida's emotional state can be gauged. We do not imagine what kinds of emotions would make such depictions appropriate for us, and then see these as lying behind the painting. The process is rather that some elements of shared experience *facilitates* the reading of the painting, and *enables* the *immediacy*, which is involved in grasping expressive force. Such conditions may causally enable grasp of expressive content, but they are not constitutively required for it. (2011, 294)

Thus, Kahlo lends her body to the world, giving expressive content to feelings that are present in lived experience and allowing the viewers to grasp the content of those feelings. We can apply Merleau-Ponty's phenomenology of perception to understand Kahlo's artworks. This is not a matter of imagining hidden sensations but is rather detecting characteristics of the embodied self in the image that is presented to us. A pain is never merely a pain but always a pain of something. It might be the opposite of what Scarry (1985, 162) suggests, that pain is not "of" or "for" anything'. However, we must also recognise the 'intentionality' of pain, that pain always has an 'object'. The experience of pain is always of a pain at some particular location, but whether that location is spatial or temporal, or that the pain is physical or emotional, the location of the pain, is ultimately beyond our grasp. It is therefore impossible to capture the pain of a miscarriage, without recalling that it is a pain, a loss of a child, and without indicating that this pain

has a certain perceptible quality, a certain weight and also without contrasting it against the pains which are involved in the norms of motherhood.

Merleau-Ponty observes that there are many similarities between phenomenology and art. There is a connection between thinking and painting in the case of Kahlo. For her, painting is thinking. Both perception and artistic expression are thoroughly bodily affairs. I have come to realise in Kahlo a fascination with the realm where the self and the world fuse in an embodied encounter. Kahlo's body on the bed at Henry Ford Hospital expresses her embodiment, without a division between self and other, what she was trying to express through her art; her consciousness and mine, I feel are unified. Kahlo's paintings reflect my own belief in the importance of the unity that should exist between self and other, subject and object in philosophy, whether that philosophy is metaphysics, ethics, politics or aesthetics. Since, like Kahlo, I do not see the world from a fixed position, bodies and objects are to be seen from angles not normally perceived together. The painting renders visible the experience of miscarriage in my lived encounter with the depicted female body.

My Birth (1932)

This radical image of the female body is very different from the traditional representation of the female nude. Painted shortly after Kahlo's miscarriage and her mother's death, this picture relates to two deaths, a birth and possibly a rebirth (Burrus 2008). None of the three figures visible in the painting seem to be alive. The mother's head is covered by a white sheet, and it can be interpreted variously as Kahlo's own mother, as Kahlo herself and as other mothers elsewhere. The bed can also be seen as a coffin. In place of the dead mother's veiled face, Kahlo portrayed the face of the *Virgin of Sorrows* (*Mater Dolorosa*) in a picture above the bed. The *Virgin of Sorrows* was originally made by the seventeenth-century Spanish sculptor, Pedro de Mena, and expressed sadness, tragedy, pain and suffering through the tearful face. The image of the *Virgin of Sorrows* recreated by Kahlo looks at the dead body on the bed seen as a coffin. In *My Birth*, the Virgin on the wall looks on the room but is unable to save the situation.

The birth echoes both Kahlo's miscarriage and her own birth. However, the painting can also suggest the 'rebirth' of Kahlo herself after her traumatic experiences. Thus the painting remains ambivalent, and offers its viewers a way to grasp her experiences of extreme bodily

and psychological pain. She felt there were no words that could explain the sorrow she felt over the deaths of her mother and her child or the childhood memories she recalled.

In this painting, Kahlo seems to subvert the normative (patriarchal) manifestations of motherhood and femininity ascribed to the classical images of female nudes and the Madonna. Kahlo depicts the bloodied act of childbirth, which is, as Julia Kristeva (1982) writes, 'the abject': that which we are socially forbidden from looking at. According to Kristeva, the abject refers to the bodily reaction (horror, vomit), induced by the loss of the distinction between subject and object, or between self and other. One thing that causes such a bodily reaction is the corpse (which traumatically reminds me of my own embodiment and vulnerability). However, as Kahlo depicts, the genitalia can elicit the same bodily reaction. Kahlo allows the genitalia to take centre stage in the painting, and reclaims the act of childbirth from the realm of taboo. The image of the abject body can be seen as a site of subversion whereby the mother's body is displayed as ambivalence and a complexity of two embodied subjectivities. Kahlo deploys a weaving of multiple images in a shift from the personal to the female experience of pain and suffering. By covering the face in the painting, Kahlo makes the image become anonymous and asks the viewer: 'Who could that be?'. Kahlo's expression of female embodied subjectivity makes the viewers reconsider their own bodies and subjectivities.

The Two Fridas (1939)

Shortly after her divorce from Diego Rivera, Kahlo completed this self-portrait of two different manifestations of herself (Burrus 2008). On the right side, is the person who was respected and loved by Diego: the Mexican Kahlo in Tehuana costume (Burrus 2008). In her hand she holds an amulet bearing the portrait of Diego as a child. On the left side, is a rather more European Kahlo in a lacy white Victorian wedding dress, the image of herself that Diego abandoned (Burrus 2008). The hearts of the two women lie exposed, a device Kahlo often used to express her pain. The divorced Kahlo's heart is broken while the married Kahlo's heart is whole. From the amulet that she is holding springs a vein that goes through both hearts and is cut off by the surgical pincers held in the lap of the divorced Kahlo. In her misery, she stops the flow of blood from Diego, but it keeps dripping, and she is in danger of bleeding to death. She holds her own hand, as if she were her only companion.

In this image, Kahlo acquires the power both to act and represent at once, through the possibility of self-portrait. This self-portrait speaks to the viewers of the way in which Kahlo is both the subject and the object of a process of divorce. I maintain that her self-portrait is both a portrait of herself and of a mirror image of herself. A mirror image has established a left–right reversal; even if Kahlo employs a double mirror to modify for this, the element of her whole self is lacking in the mirror. Kahlo sees both sides: the married and the divorced, as she is beyond the binary between the married self and the divorced other, she is both the self and other, that she knows, thus she can detach herself from the work and yet portray herself.

Kahlo's painting is ambivalent: she is herself both the viewing subject and the viewed object. She looks into herself and the image of her own making. Kahlo lived with her pain despite medical intervention. She also expressed physical pain and psychological trauma through her depictions of her body. Kahlo's artwork is therefore a kind of autobiography, in which she expresses and brings into question her experience of living with pain as a woman.

Concluding remarks

By reading Kahlo's paintings, I have come to realise that Kahlo is her body in the world. Merleau-Ponty (2002, 231) writes: 'I am my body, at least wholly to the extent that I possess experience, and yet at the same time my body, as it were a "natural" subject, a provisional sketch of my total being'. Likewise, Kahlo's use of her body captures her whole lived world, a life full of enthusiasm and passion. I have paid most attention to Kahlo's practice of painting her body in so far as it makes manifest the seen and unseen of her world. By lending her body to the world, Kahlo changed the lived world with her paintings. Kahlo's work offers us a dynamic interpretation of her own embodied subjectivity capable of resistance, change and transformation.

I have argued that Kahlo's art parallels Merleau-Ponty's phenomenology in being a strategy to 're-achieve a direct and primitive contact with the world' (Merleau-Ponty 2002, vii). Kahlo's paintings, much like Merleau-Ponty's phenomenology, are an intensification of perception in that they are not only a regeneration of what has happened in the world of perceiving, but are also a way of expanding such a world. Kahlo's self-portraits, I have argued, interweave the experienced past and the painted present of Kahlo herself, of Kahlo and her viewers

as well as of different cultures (the Western and the native Mexican, and the male and the female) (Inahara 2012). I suggest that the paintings of Kahlo, in particular those which I have analysed above, are bodily expressions that are both more ambivalent and more primordial than the expressions of verbal language.

I have found in the phenomenology of Merleau-Ponty a model for what Kahlo presents as the female body, which seeks to account for the complex processes of lived experience: the embodied relationship to the self, to others and to the world. I have argued that Kahlo's work exemplifies a phenomenological model of femininity and pain that is both unique and singular but also transformative.

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Frida Kahlo's Artworks

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- My Birth* (1932). Private collection of Madonna Louise Ciccone.
- The Two Fridas* (1939). Museum of Modern Art, Mexico City.

The thing about pain

The remaking of illness narratives on social media

Elena Gonzalez-Polledo and Jen Tarr

‘That’s the thing about pain’, Augustus said, and then glanced back at me. ‘It demands to be felt’. (Green 2012, 54)

Introduction

Expressions of chronic pain in social media are becoming a growing archive that can be accessed from anywhere in the world (Ernst and Parikka 2013). This archive conveys multiple experiences of what it means to live with pain and brings them to the public domain. Focussing on the new roles of social media in the emergence of new forms of pain expression, mediated chronic pain narratives are transforming traditional models of illness experience. Studies of pain expression through photography, such as Padfield’s (2003, 2011; Ashton-James et al. 2017), and of disability in the digital age (Ginsburg 2012) attest to how the creative process involved in communicating pain through multiple media has the potential to transform the experience of pain by shifting its locus from within to outside the body.

In the social sciences, however, the experience of pain and illness is still primarily analysed through a narrative paradigm. In particular, illness narratives are co-authored by patients and doctors in the clinical process of understanding the aetiology and prognosis of pain, and have been understood as key forms of communication through which people in pain make sense of the complexity of the illness experience and possibilities for healing (Kleinman 1988, 1995). Hurwitz, Greenhalgh and Skultans (2004) highlight the role of narrative in shaping illness

experience, implicating narrative’s structural elements, conditions and functions in the link between illness and subjectivity (Williams 1984; Mattingly and Garro 2000), linking particular forms of illness expression to cultural senses of subjectivity and identity (see also Jackson 2005; Aldrich and Eccleston 2000; Skultans 2007). Approaches to illness narratives have fallen short of addressing the complexity of pain experience and expression because, although illness narratives often derive functionality from their analytical use in clinical and caring relations (Frank 1995; Bury 2001), they collapse multiple temporal, social, psychological, physical and emotional dimensions of pain. Experiences like pain often also fall outside the ability of narrative to adequately account for them.

As the field of narrative medicine has expanded in the last decade (Charon and Montello 2002; Charon 2006; Jurecic 2012), story-making has gained a central role in defining the method and purpose of the social science of health and medicine (Hyden 1997; Hyden and Brockmeier 2008; Charteris-Black and Seale 2010). Yet what counts as a narrative or story is changing. Payley (2009) argues that narratives can be placed on a continuum of high and low narrativity (a ‘narrativity ladder’). A narrative must contain more than one event, make claims about causal connection and have a central character. To progress to the ‘high narrativity’ of a story, it must also have an ending which is prefigured by earlier events. Simpler low-narrativity expressions can also be understood as narratives if they have the elements above.

Narrative theorists have long questioned how and to what effect expressions that defy traditional notions of medium can be considered narratives (Grishakova and Ryan 2010). Ryan (2010) develops the concept of ‘intermediality’ by looking at non-digital media, arguing that while verbal language remains the most powerful mode of signification and representation, it has traditionally relied on non-verbal communicative forms such as sound, gestures and facial expressions, which add pragmatic and cognitive dimensions to the narrativity of a story, and which extend narrativity to images, painting, architecture and music.

Flickr and Tumblr: Key differences

Flickr is designed around the photostream (van Dijck 2011) where users produce original content which they may tag, organise in sets or add to groups. What becomes visible about chronic pain on Flickr

depends on how one accesses the images: as part of a photostream, they will appear in the order they were uploaded, while as part of a user's sets they can be ordered in whatever way the user chooses. Sets allow users to stream images into a narrative structure. However not all images are part of sets, and sets are not the only way to find or view images. Flickr's homepage streams both 'interesting' images which have been 'favourited' often, and 'most recent' images (van Dijck 2011, 409; Lee Antoniadis and Salamatian 2010). Tagging images makes them searchable by keyword, meaning they may be encountered out of context, near other images with the same tag. Users are likely to encounter each other's images individually rather than as part of sets, particularly if a user is searching the Flickr database rather than looking through sets of a specific user. It is also possible for users to curate other users' images into a 'gallery' of up to 18 images, so that images can be used to tell a story not envisioned by their creators. However in both groups and galleries, the identity of the image's creator is preserved by inclusion of usernames.

Tumblelogs are made of content which is often ambiguous, fragmented and multimodal. The Tumblr stream interface, however, facilitates dynamics of appropriation, mimesis and repetition that link users through the interface's main functions (reblogs and likes), and sometimes through the addition of text notes to content. The key content type in Tumblr are memes, which often depict variations of humorous everyday descriptions of chronic pain experiences (Shifman 2013). Chronic pain memes often deploy a range of messages over gifs or animated scenes depicting popular film and television scenes. Simple talking memes describe everyday encounters, the meanings and implications of living with chronic pain or with a particular chronic illness. Alongside their explanatory value, they circulate in a network that provides support for users (who often remark on the social support received). Although many of these characteristics have been found to be central to other social media (Dean 2010; Berry, Kim and Spigel 2010), Tumblr uniquely draws on abstract depersonalised expressions built on provocation, humour and sarcasm. The process of real-time transmission shifts the centrality of individual profiles to networks of content where 'imitation and remixing become the pillars of participation' (Shifman 2013). Here the platform's architectural affordances, in suggesting the types of content that can be uploaded, and the types of interactions allowed (adding text notes, liking and reblogging) both suggest and limit possibilities of interaction (Papacharissi 2011).

We draw on Galloway's (2014) work on changing practices of mediation, modelled through the figures of Hermes, Iris and the Furies

as representatives of hermeneutics, iridescence and symptomatics, three steps in communication, each a succession to and evolution of the previous. Flickr shares some characteristics with Galloway's description of immanent or 'iridescent' communication associated with the Greek messenger goddess Iris, counterpart to Hermes (2014, 46): it has immediacy, and is meant to communicate experientially rather than hermeneutically. It is often also unidirectional, as images may not be seen, commented upon or favourited by other users, and even if they are, two-way communication does not necessarily ensue. Galloway writes that in iridescent communication, which he associates with images, 'It is simply a question of being present at hand to tell. Once relayed, the telling is already consummated' (2014, 45). As we show, a similar dynamic is at work on Flickr.

Tumblr mirrors the 'symptomatics' mode of fragmented, dispersed and multiple communication, which no longer aims to represent or show reality. This mode of communication, as Galloway writes: 'demonstrate[s] that truth is not inside or even outside the real, but simply alongside it, nipping at its heels' (2014, 61). For Galloway, these symptomatics take the shape and temporality of the Furies of mythology: a swarm, an assemblage, or a network. Furious communication does not necessarily have a single centre, but gains commonality as a system and negotiates excommunication not as a critical 'in between', but in 'massively distributed forms of communication that exceed normative – and human – forms of communication' (2014, 80).

Narrative immediacy and iridescence

While structural elements of illness narratives persist on Flickr in sets, captions or comments, the images often stand alone, ambivalent in meaning. Flickr images seek to communicate in three ways: they *make pain visible* by highlighting aspects of the experience of living with pain or portraying a person as being in pain; they appeal to empathy by *making pain felt* using similes or metaphors ('the pain is like *this*') and/or trying to evoke the pain viscerally; or they *make chronicity visible* by building a sequence of images around pain, often through '365 projects', photo journals in which people take and upload one photo every day for a year. This last aim is most similar in structure to offline and text-based narratives.

The semiotics of images made by people with pain are striking. They tend to use black and white, and a sparing use of colour to highlight areas of pain. Red is the most common colour used, followed

by blue. There is a tendency to over- or under-expose images, as well as the use of blur and effects of Photoshop or PhotoBooth software to render images with grainy, cracked or rippled surfaces. Common visual signs, including similarities in ‘references, forms, colour and metaphor’ were also noticed by Padfield in her work creating photographs with people with pain; suggesting ‘a generic iconography for pain’ (2011, 249) of which these are elements.

Images aiming to *make pain visible* are often self-portraits, with facial expressions used to convey the experience of pain. These are frequently black-and-white or low-contrast images. Those focussed prominently on the head often refer in the title or caption to migraine as the source of pain. Grimaces, holding the head or silent cries are common in these images. Aside from migraines, images from people with other kinds of pain show bodies that are contorted, prone or vulnerable, again often in black and white or muted tones. In some, the semi-nude body is balled up, only the spine visible, as if blocking off the more vulnerable chest and face, or images are framed to fragment the body itself, with the painful part abstracted from the rest of the body, suggesting ambivalence and/or disinvestment in it.

Other images make visible the material aspects of a sufferer’s daily life. These may have to do with medication, and pictures showing the number of pills taken are common. Unlike pain, medication has visibility, and the quantity of pills shows some objective measure of the pain. While the person may not ‘look sick’, as users note, medication is a material reality of their suffering and stands for the effort that goes on ‘behind the scenes’. In contrast to images of people with pain, pills are often brightly contrasting and stand out against the background. This plays on the iconography of ‘taking pills like candy’ where medication is framed to appear abundant and appealing.

Images where the aim is to *make pain felt* tend to focus on modifications to the image, through standard photographic practices and image manipulation. The effect of pain is evoked through blurred edges, cracked surfaces or the appearance of being immersed under water or wrapped in a web of gauze. Among migraine sufferers, images often attempt to express something of the experience of migraine itself, as well as drawing an implicit simile: the pain is *like this*. Drawings and collage images seem to be particularly common among migraine sufferers, who also produced abstract patterns and used more colour than other users, in part as a reference to visual disturbances experienced by many as part of migraine. These images evoke disturbance of norms, showing something outside everyday experience.

Other images attempt to illustrate what the pain feels like, suggesting the sensory experience of *having* pain. This is less about finding a source for comparison than about evoking the pain viscerally. Jilly999’s image ‘hand pain’ is an example of this.¹ In it, an X-ray style image, the ‘objective’ measure of anatomy produced in the clinical encounter, is given a radical ‘subjective’ twist through the colouring of red and purple, electric streaks issuing out from the hand itself suggesting nerve pain and the addition of nails stabbing into the spaces between the digits. The red colour also suggests heat or a burning sensation.

Immediacy is central to Flickr. The default, photostream setting is chronologically based and loads newest images first. An ongoing series such as a 365 project allows a more sustained, less fragmented narrative structure to appear. What these series show is the passage of time: chronic pain and chronic illness don’t simply cause severe suffering in an instant, but are part of an extended daily struggle. For instance, in a series from a 365 project by user Snowflakesarewhite, ‘spoon theory’² is illustrated literally by showing how many ‘spoons’ (units of energy) are used during daily activities such as showering and having breakfast. The caption on the image *216.365 8:30 AM shower*,³ for example, refers to the energy it takes to stand up in the shower, to lift her hands above her head to wash her hair and deal with the effects of the heat and humidity. The photographer’s feet and painted toenails contrast with the muted blue-grey of both spoons and tiles, suggesting that spoons are shed like water, down the drain.

Some images appear in photostreams as a literal temporal and narrative disruption, accompanied by a comment to the effect of ‘this is why I haven’t been posting many photos lately’, and disclosing the condition or illness causing the pain. Others are part of sets related to the experience of chronic pain or disease. Some users use Flickr primarily to document and express elements of pain and illness, but more commonly they are elements within wider projects where pain periodically shifts from background to foreground.

On Payley’s narrativity ladder, individual images have low narrativity: they may contain a central character and an event but rarely more than one. Sets and 365 projects contain more than one event, fulfilling two narrative criteria, but rarely contain causal claims or relationships. Rather, following Galloway, these three types of visual pain communication are an ‘iridescent’ form of communication in the sense that they *appear*, and by appearing and bringing to visibility certain

aspects of the pain experience, their work is done. They maintain some elements of narrative, by documenting an event or having a central figure, but are no longer ‘illness narratives’ per se. Neither are they ‘chaotic’ in Frank’s sense, although they lack structure and are outside of words. They appeal and refer directly to experience and immediacy. A Flickr photostream is ‘fleeting, malleable, immediate, and contains a type of liveness in its initial appearance’ (Murray 2008, 157). In Galloway’s model, iridescent communication *tells*, yet it ‘is contentless’: it is affective and illuminating, but does not interpret or discuss. Flickr users with pain do exchange comments on photos, but it is not their primary form of engagement and many images receive no comments. To ‘favourite’ an image is not to engage in sustained discussion but merely to mark affective success: something has been transmitted. Although non-narrative in structure, Flickr images continue to communicate something about pain.

Tumblr: Narrative symptomatics

While Flickr relies on single users where images belong to one person, narrative fragments in microblogging platforms such as Tumblr are inherently relational. Every chronic pain blog we analysed brings together elements that relate to pain and chronic illness in a broad sense. In Tumblr, a social network particularly popular among young people, these messages are not primarily textual, nor do they necessarily share a physical or historical proximity. Instead they bring together heterogeneous elements and find unconventional forms of narrativity.

Multimodal expressions offer unique features compared to text. For example, as on Flickr, we found that Tumblr bloggers upload graphic accounts that illustrate moments of pain, such as photographs of their bodies, hospital stays, taking medication or suffering side effects. These photographs fit in with a type of coping narrative that shares features with Frank’s quest narrative: they illustrate an effort to come to terms with diagnosis and the need to reach out for support. However, Tumblelog archives suggest that posting frequency, themes and content types vary greatly over time. This reflects Ressler et al.’s study of text-based illness blogs (2012), where the researchers surveyed bloggers’ motivations and found that sharing the experience of illness with others (82 per cent) and learning about illness and illness patterns to be among the top reported reasons to blog about illness. Ressler et al. found that, over time, the form of bloggers’ involvement

shifted from the diary form to a method of advocacy, an opportunity to develop relationships of support and mentorship, a practice intended to reach out and connect and sometimes a way to vent frustrations and conflicts that relate to experiencing pain and disability. Tumblelog archives similarly suggest an evolution of themes in time. Over time, chronic pain-related content is diluted in streams of content, disassociating expression from the temporality of an illness narrative that eventually resolves (Ricoeur 1991; France et al. 2013). Rather, chronic pain tumblelogs are structured in loops of recurrent improvement and flare-up and offer temporal structures that result from fragmented temporalities; for example, through the superposition of multiple conditions and the use of perception altering pain medication. These temporalities provide a new socio-narratological context whereby chronic pain narratives perform new functions. No longer primarily oriented towards accessing health services, these narratives only partially follow narrative conventions, sometimes conveying details of everyday experience through figuration, fragmentation, abstraction, metaphor or simile, but profoundly reconfiguring understandings of the function and form of narrative in significant ways. As in Flickr, many posts attempt to conceptualise or represent pain, but more often they bridge experiential worlds by developing new grammars that will trigger new social relations and associations (for instance, linking pain to aesthetic or desirable images, critically reporting about everyday frustrations by using conceptual terms, jokes or sarcastic statements). It is the social engagement that happens after content is posted (that a post is reblogged or liked) that matters, and from this standpoint we conceptualise the type of mediation in Tumblr as *symptomatics*. This mode of communication does not aim to represent reality but is rather sceptical of any essential truth as Galloway highlights, ‘reveal[ing] the structured absences, contradictions and misunderstandings’ (2014, 39), ‘complicating’ any simple reading of chronic pain. Here, what matters is not so much the representation of chronic pain within an individual story or the negotiation of what it means between two people, as the circulation of multiple expressions in the system, their appropriation and resonance with other expressions raises issues beyond the exegetic or hermeneutical framework, reading for what isn’t necessarily already there, but ‘should’ be.

While on Tumblr content posted by users whom we assume are individuals is the most common, there is also a host of textual content under chronic illness and chronic pain tags that refers to educational material and fundraising initiatives, offering coping or

support narratives for users with specific conditions or aims to raise awareness. Yet these photographs and memes acquire new meaning as they are reblogged by users on the platform and embedded in individual profiles, and as the original content is modified with 'notes' or support messages that reframe the original message, adding new significance. Participants are linked within the platform by following each other's blogs, and the material they post is variously produced, appropriated, modified and reposted by other users, to the extent that aesthetic, medium-determined and communicative patterns emerge as a result of the sharing function.

As technological mediations make visible and connect new dimensions and temporalities of living with chronic pain, we found that the more personal visual narratives, those that depict more accurately a single person's experience, gather lower note counts than generic content that resonates with chronic pain experience. For instance, we retrieved four iterations of a meme that captures the line from John Green's novel *The Fault in Our Stars* (2012) with which we began this paper: 'that's the thing about pain: it demands to be felt'.⁴ The different note counts they accrued were an indication of how aesthetic expression makes relevant new relations that reconfigured and shaped the message, raising questions around the kind of dynamics of imitation at play (Tarde and Parsons 2010; Aunger 2002). This type of referentiality may indicate that communication about pain through this network does not address a general audience, instead seeking to generate resonances with others who share the experience of pain. In fact, the difficulty of 'fitting in' with mainstream narratives and particularly medical discourses is often elaborated upon as a form of excommunication built on stigma, isolation and exclusion.⁵ In its network form, the circulation of pain expressions on Tumblr refers to chronic pain, but in doing so sceptically and with multiple simultaneous voices links to wider 'clues' that reveal structural contradiction, paradoxes and absences.

Among the chronic pain blogs we follow on Tumblr, memes and gifs often contain elements that put pain experience at a distance from the communicative act they perform. These posts relate to issues of inequality, discrimination and a perceived lack of structural support from healthcare professionals and often offline social networks: in short, they relate to pain itself as a form of difficult communication that often fails to be negotiated, resulting in exclusion and silence. Humour and provocation become the new symptomatics of these problems, pointing to the wider question: 'should chronic pain have politics?'.⁶

Memes such as the Chronic Illness Cat, which cover all forms of chronic pain, or other disease-specific memes,⁷ critically describe everyday situations of living with pain, making them matter in new ways. Often these memes are also provocations that point at the systemic shortcomings of health services and cast new light on the context, structure and conceptual limits of pain. By positing their messages outside the realm of 'real' chronic pain measurements and interventions, posters become witnesses whose testimony contains clues of the politics of chronic pain, the values that 'should' sustain the community. Real-time interaction differentiates microblogging about chronic pain from other social networks and at the same time highlights the constitution of the social network as what boyd describes as 'networked publics': at once a space constructed by networked technologies and an 'imagined community of people, technology and practice' (2014, 5). In this context, the processes of transmission, modification and transformation that users engage in while using these networks become a crucial area of enquiry (Hartley, Burgess and Bruns 2013) that shift the centrality of individual expression to sharing, liking and reblogging dynamics, situating pain experience predominantly as a collective form.

Conclusion

Flickr fragments illness narratives and emphasises immediacy and telling over dialogue or discourse. Tumblr however further dissolves these narratives, through reblogging functions that eliminate not only the multiple events and causal structure Payley (2009) argues are an integral part of narrative, but also the main character, whose experience and story is shared rather than unique. Despite losing all the narrative structures required to sustain them as 'illness narratives' per se, both Flickr and Tumblr expressions continue to communicate something of the lived and felt experience of pain, through visual and multimodal means.

Our research reveals how digital forms of pain expression open up new possibilities of imagination, action and advocacy not bound by the dynamics and the 'rules' of offline social relations (Baym 2010). Our analysis raises new questions about the implications of social media in the making of online landscapes of pain expression, where pain can no longer be merely understood as an incommunicable substance that debilitates and hinders an individual's body and social life. Rather,

pain communication is reconfigured as 'iridescent' or 'symptomatic' communication; by making aspects of the pain experience visible, or by networks of voices engaging and reinterpreting pain in networks of multimodal communications.

What develops through Tumblr, and to a lesser extent through Flickr, are 'networked narratives' (McNeill 2012, 78). Social media is therefore part of the act of configuring pain expression, as much as the users themselves are. To this assemblage of users and social media we should also add the materiality of pain itself, and its specific qualities and temporality: pain itself acts and enacts particular relations based on its qualities (Gilmore 2012, 92).

There are reasons that both pain clinicians and the general public can benefit from more in-depth engagement with chronic pain in social media (Ressler et al. 2012). Padfield et al. (2010), in a survey of pain clinics, found that photographic images were useful in clinical consultations, improving communication and clinicians' understandings of patient experiences (Ashton-James et al. 2017; Padfield et al. 2018). Their set of 54 images was created together with one artist, and the expansion of the range of images available through a large-scale resource like Flickr could enable more patients to find visual representations of their pain to assist them in explaining its affective dimensions to clinicians. Tumblr content is often more overtly critical and political, and would perhaps be harder for many clinicians to hear. However, such content often neatly encapsulates the feelings of people with pain, and the frequency with which various expressions are reshared could provide insights into how common particular experiences are. Further, one of the problems raised by the clinical encounter is the need for brevity, and the succinct encapsulation offered by Tumblr content may help here as well.

Our primary interest however has been in chronic pain expression beyond the clinical encounter, and here Flickr and Tumblr offer opportunities for people without pain to better understand the experience of having pain. By remaking illness narratives in fragmented, immediate and networked forms, they become, perhaps, easier for others to understand. The widespread popularity of social media also enables wider distribution of messages about pain, potentially challenging excommunication and ableism. Social media can also enable new types and forms of networks and interactivity, effectively remaking both our understandings of pain and illness communication.

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Notes

- 1 See <https://www.flickr.com/photos/jilly9/3107067124/in/faves-111438760@N03>.
- 2 'Spoon theory', by blogger Christine Miserandino, has become an internet shorthand for the experience of living with a chronic illness, having to think constantly about the number of 'spoons' as units of energy that are used up by daily activities: <http://www.butyoudontlooksick.com/wpress/articles/written-by-christine/the-spoon-theory>.
- 3 See <https://www.flickr.com/photos/irisslootheer/9076655728/in/faves-111438760@N03>.
- 4 See <http://cherrybam.tumblr.com/post/38751746221>; <http://hellunder-thesea.tumblr.com/post/73996169830>; <http://hellyeahjustlikethat.tumblr.com/post/75174632442>; <http://erica-san.tumblr.com/post/20251842568/thats-the-thing-about-pain> (accessed April 2014).
- 5 See <http://feathers-oars-blades.tumblr.com/post/85431561824/fibro-bro-happy-fibromyalgia-awareness-day>; <http://aww-tistic.tumblr.com/post/85431869324/iffhavethespoons-every-time-i-search>, or <http://spottydotdy45.tumblr.com/post/81083206814> (accessed April 2014).
- 6 See, for example, three common types at <http://palewansickly.tumblr.com/post/83012413428/when-youre-filling-out-a-form-and-it-says-list-your>; <http://megsmiracles.tumblr.com/post/81846270007>; and <http://communicatingchronicpain.tumblr.com/post/74855855949/via-nikki-wiser> (accessed April 2014).
- 7 See <http://chronicillnesscat.tumblr.com/>; <http://potsproblems.tumblr.com/>; <http://ehlersdanloszebra.tumblr.com/> (accessed April 2014).

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Exhibiting pain

The role of online exhibitions in sharing creative expressions of chronic physical pain

Susanne Main

Exhibiting Pain is a PhD research project that explores the benefits of sharing and viewing online creative works which represent life with chronic physical pain. These works were created by people who choose to express their pain creatively. Here, I provide a narrative overview of the project, the motivations of the creators in sharing their works and the motivations of visitors in viewing them. In addition, I will provide a descriptive summary of the effect that sharing these works online had for both creators and audience members.

Why exhibit pain?

Having previously considered the role of creativity in communicating chronic pain, I have argued that creative methods may help to communicate the experience when language fails, or is lost (Main 2014). Building on this, I developed *Exhibiting Pain* to examine the potential of online exhibitions to increase understanding of life with chronic physical pain, as well as using them as a means to collect research data. In addition, an aim of the project has been to explore further the potential for creative methods in helping to communicate the lived experience of chronic pain.

I believe that exhibitions of creative works enable voices to be heard, allowing the person's pain to be witnessed and recognised by audience members. They also ensure that a visitor can engage with multiple voices and experiences, gaining insight into the nuances of the subjective experience of living with chronic pain. A range of works, varying in content, style and focus, featured in *Exhibiting Pain*.

Exhibiting PAIN

Using creativity to express chronic pain



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Background & Aims:

This PhD research project explores the potential for using creative methods to aid communication of the chronic pain experience. It also considers the benefits of sharing such creative works online.



Method:

People with chronic pain, who use creative methods to express it, shared their works in online exhibitions which were hosted using two forms of social media software (WordPress blog and Facebook). A thematic analysis was carried out on the data, which consisted of audience responses to individual works and the exhibitions as a whole, collected via questionnaires and in online group discussions.

Key findings from qualitative data:

Creators of the exhibits	Audience members with pain	Audience members without pain
Hoped to reduce isolation for others with pain by sharing their works	Reduced isolation knowing others empathise	Viewed works through an interest in learning more about the impact of pain in order to support friends/family
Pleased to find others who use creativity to manage and express pain	Resource to explain their pain	Surprise that the works focused less on symptoms than psychosocial effects e.g. pain's invisibility and stigma
Sharing works helped them to feel heard and their pain validated	Inspired to try creative methods to manage and express their pain	



Conclusions:

Using creative techniques as part of a **multi-modal approach** to **communicating chronic pain** is effective in sharing the subjective experience.

The sharing of creative works, and discussions surrounding these, fosters a sense of **community** and **belonging**; it helps people to feel that their experience is being recognised.

Both exhibition sites continue to be used by visitors, but not for research purposes, as they provide a valuable **resource** and source of **support**.

susanne.main@open.ac.uk @sueam80 Exhibitingpain.wordpress.com Exhibiting Pain

Figure 14.1 Main's poster for the 'Encountering Pain' conference 2016. © Susanne Main

This variety enabled as many people as possible to engage with the content.

The decision to host the exhibitions online was to ensure a global reach for contributions of works and audience members, also ensuring that it was free to host and participate. It also allowed for ease of access at times and places of convenience to visitors. Using social media and blogging platforms that people were familiar with and may have been using already increased the likelihood of engagement. Hosting the exhibitions online proved popular, in part because it was easy to visit and revisit the works at visitors' convenience. This format ensured that the visitor had control over how long they spent viewing a particular work or had the ability to click away from it quickly.

Recruitment of creative works

A call for creative works by people who live with persistent physical pain was promoted across social media, through personal networks and with the aid of Mark Collen, former CEO of the PAIN Exhibit website (2018).¹ Consequently, those who submitted works to exhibit did so by volunteering their existing work (also choosing to use a pseudonym if they wished). Featuring works which were not created for this research project was important to me. Had works been made specifically for *Exhibiting Pain* there would have been a particular audience or purpose in mind which would likely affect what was presented and how. I was interested to know what people wish to creatively express in the daily context of living with their pain.

Research method

A WordPress blog page was established and featured the creative works, together with a feedback form for visitors. Audience members could also post comments on individual works if they wished to and these would be visible to anyone visiting the site. The feedback forms consisted of seven questions which could be completed and submitted anonymously. In addition, a Facebook group was established to host the same works. This was done using 'closed' group settings which ensures that the content of the group is only visible to those people who are members (membership has to be requested and then approved by the administrator of the group).

Gathering audience responses to the works, and using them to facilitate discussion, allowed for topics to be discussed relating to the interpretations of works, the intentions in creating and sharing them, the motivations in viewing them and the perceived benefits of such exhibitions – both for those with pain and those without. Creators were able to share in discussions in the Facebook group, which proved popular.² They could receive feedback and read interpretations of their works, often obtaining such feedback for the first time. In addition, participants encountered others who use creativity to express and live with pain.

The works stimulated discussions about pain experiences, metaphors used, communication of pain and the benefits of creative pursuits. As the Facebook group developed, discussions also featured comments from participants about the benefit of being in the group, seeing and sharing works and participating (or reading) the accompanying comments. As such, the research provides insight into the social support to be gained from the group and from the experience of sharing and viewing creative works about pain.

Curation

Curatorial decisions were kept to a minimum as it was my intention that the creators should retain control over the content they exhibited (within appropriate ethical guidelines and boundaries of the research), including the accompanying text and title. This ensured that the creator had autonomy over the expression of their pain experience, sharing what was most important to them at the time. Creators took different approaches to the inclusion of accompanying text, or not. I intervened on one occasion where I advised that some text would be helpful for an abstract work, in order to engage viewers more effectively.

Representing pain

Creators were asked why they represent their life with pain creatively. While some had completed the works as part of art therapy or college art projects, others spoke of art being their natural form of language. Some creators also commented on the ability of a visual form in helping people to understand what is being felt or described. In thinking about the communicative element of these works, some creators commented that they hoped to make people aware of invisible illnesses, such as

chronic pain, adding that other people do not see them when they are alone and in tears and this can cause difficulties believing the pain experience. Others mentioned that the expression through art helped them accept their circumstances and provided a sense of achievement.

Intended audience

Creators were asked if they had a particular audience in mind when creating their works. Most answered 'no' or stated that they created the pieces for themselves. Some mentioned that they thought of others who also live with pain in the hope of reducing their sense of isolation. Having works created specifically for this research/exhibition would, I believe, have led to an element of conscious self-presentation, possible moderation or exaggeration of features of the individuals' experience that they wished to reveal or believed should be presented. While this is still relevant in the creative expression of the chronic pain experience, it would likely have not allowed for an examination of the natural or spontaneous expression.

While most creators wrote of not consciously having an audience in mind for their pieces, they did choose to share them in this public online gallery and, in the case of many, their own personal websites or elsewhere. This suggests that the creative expression of pain as a cathartic outlet may be beneficial but that the sharing of the works provides an additional benefit.

Viewing pain

A number of creators chose to join the Facebook group, responding sometimes to interpretations or comments on their own works and those of others. There was interest in the diverse focus given to the expression of pain in the works. Some audience members remarked that they had expected to see a greater focus on the symptoms and physiology involved and were surprised by the large number of works without this emphasis. There was also surprise expressed that many works were more positive and optimistic than anticipated. A creator commented that the work produced was likely to depend on the level and type of pain being experienced at that time, and how they were handling it. This sentiment may be extended also to the choice made by the creator in terms of which work to share in the research exhibition

and the text accompanying it. Additionally, audience responses to the works may have been influenced by the same factors.

Audience members remarked that viewing the galleries can be emotionally difficult as the works stimulate empathy. However, audience members stated that viewing the works was worthwhile and frequently expressed gratitude to the creators for sharing these. This demonstrates that the audience motivation in viewing works may be linked to a wish to understand and support people with pain. Those who live with chronic pain noted their gratitude to creators for sharing their works which helped to reduce their feelings of isolation, discovering there are others who empathise. They also remarked that the exhibitions provided a resource to help them to explain their own pain to friends and family.

Interpretation

Creators commented they didn't like their works being interpreted. It was felt in the Facebook group that there wasn't a need for the works to be interpreted, with members noting that the artwork had done its job if it elicited an emotional response. However, if the creative works are intended to express or communicate something particular about living with pain, the need to interpret the work would seem inherent to this process. Other creators commented that when their work is interpreted, they find themselves to be misunderstood. However, the desire to share the works publicly was clearly greater than concerns about (mis)interpretation as creators had submitted their works for this research project, aware that it was examining interpretations and responses to the pieces.

The issue of interpretation led to a discussion regarding the accuracy of viewer understandings of a work. While a concern was expressed by creators about being misunderstood, their overriding emphasis was on the audience's emotional responses to the works. However, audience members without chronic pain were conscious of the need to avoid getting something so important 'wrong'. They expressed awareness of emotional responsibility in interpreting works of this nature. Some creators were interested in the process of having their works interpreted, engaging with this out of curiosity to know how their representation of pain had been understood.

Audience members expressed differing levels of engagement with the titles and texts accompanying the creative pieces. While

those audience members who identified themselves as artists were less concerned with the accompanying text, other audience members expressed a preference for it to ensure an ‘accurate’ understanding. This demonstrates again the sense of responsibility felt by viewers of the gallery and the belief that there is a particular message that the creator wished to communicate. Audience members who have chronic pain were less concerned with whether their interpretations were ‘accurate’ but engaged with works in a way that helped them to feel less isolated.

Abstract works, particularly those without text, engaged viewers far less, receiving fewer return visits on the WordPress site and little engagement in the Facebook group. Additionally, the perceived level of skill involved in the works had an impact on how some audience members engaged with them. Sometimes works were rejected due to stylistic preferences and a concern was raised that the level of pain experienced by the creator may be underestimated if the creative work lacks detail or refinement.

Diagnostic images

Discussion took place in the online Facebook group about whether creative works about pain might help the diagnostic process. Stories were shared of a creator’s doctor liking their work so much they hung it in their examination room. Other patients of the clinician stated that it depicted what they were trying to put into words. Another noted that their reason for depicting their pain creatively was to explain their pain and its location. Participants raised the possibility that if they had been asked to draw it by a doctor it may have sped up the diagnostic process. Possible concerns about the misinterpretation of creative works were seen to relate most to whether the pieces were being used for diagnostic purposes.

Sharing pain

When asked about their experience of sharing the creative works, creators noted that they valued doing so, stating that it validated their experience, connected them to others and helped them. One audience member (who has chronic pain) expressed surprise at their level of interest in the research and how helpful it had been, proving thought-provoking and inspiring. Reading others’ insight of the pain experience

was invaluable for some people. It was also stated that it was important for those who live with chronic pain to have a voice. Another noted that the effects of pain on mind, body and spirit cannot be described, only experienced. Audience members asserted that viewing a creative work about pain provides the chance for the viewer to experience it. A non-pained audience member stated that the exhibition provided a meaningful way of engaging with the difficulty of conveying pain.

Concluding thoughts

At the time of writing, the thesis for this PhD project is being constructed and I am developing ideas for how to build upon the successes of the project. *Exhibiting Pain* has demonstrated that the sharing of creative works online, with like-minded people, has been helpful for those who have had the opportunity to do so. It has fostered a sense of community and belonging, breaking down feelings of isolation. While the Facebook group and WordPress gallery site do not function as support groups, there is an underlying element of providing a form of advocacy and reducing the sense of not being believed or understood. Those without pain have found it possible to engage with the works as both artistic pieces and as a means to better understand the experience of living with chronic pain. The use of exhibitions and online formats has therefore provided a globally accessible resource for people to engage in seeking to better understand the experience of living with chronic pain, whether or not they personally live with the condition.

Notes

- 1 ‘PAIN Exhibit’ is a website established in 2012 by former CEO, Mark Collen. It was created to use artworks to raise awareness and understanding about chronic pain and give a voice to those living with it. *Exhibiting Pain* is the research study described in this chapter. I have drawn on the verb ‘exhibiting’ to emphasise this aspect of the research data collection technique and because of the way in which people often feel they must actively exhibit their pain for it to be seen.
- 2 The term ‘creator’ is used to describe those people who shared their creative works in the *Exhibiting Pain* research galleries. This word was used as it encompasses those who do not identify themselves as ‘artists’ and is inclusive of all types of works.

References

- Main, S. (2014). 'Picturing pain: Using creative methods to communicate the experience of chronic pain', *Pain News*, 12(1): 32–5.
- PAIN Exhibit, Inc. (2018). 'Pain [Exhibit.org](http://painexhibit.org): A non-profit art exhibit'. Available from: <http://painexhibit.org> (accessed 21 September 2018).

Exhibiting Pain website addresses

WordPress: <https://exhibitingpain.wordpress.com/>

Facebook: <https://www.facebook.com/groups/exhibitingpain/>

Part III

Speaking

15

'Me' and 'my pain'

Neuralgia and a history of the language of suffering

Joanna Bourke

In 1978, Susan Sontag published one of the most cited books on ways of speaking about illness. In *Illness as Metaphor*, she argued that the act of giving pain a meaning is 'punitive' (Sontag 1978, 3). Metaphors can inflict additional suffering on the sick; they are part of the disease. Witnesses to the suffering of others need to be especially vigilant against the seductions of metaphor. There is no purpose, reason or function to suffering, only blind effect.

Sontag was writing *Illness as Metaphor* shortly after having been given a cancer diagnosis. However, 14 years earlier, she had published a less well-known short story entitled 'Man with a Pain' (1964). In it, Sontag also reflected on the difficulties of finding words to describe pain. Published in *Harper's Magazine*, the story revolves around an unnamed man living in Manhattan whose pain is invisible to others, yet excruciating to himself. She tells us that the 'man with a pain' has become 'stiff and awkward by misery', as well as by the inability of his friends and acquaintances to understand what he is going through. Chronicity is the enemy. He confesses to having

eaten his pain and slept in it and papered his walls with it and jammed it into the morning paper, alongside the earthquakes and broken peace conferences. He is so tightly wrapped, swathed, and buttoned into his pain. He is embalmed in it, like a mummy. A tight cylinder of pain, he rolls down the hill into a vale of numbness. (Sontag 1964, 74)

In the face of this overwhelming tsunami of chronic pain, language eludes him. He makes an attempt to talk to a friend but when he 'hauls

the sorrow up out of his throat', it 'comes out in bits and pieces. Poor shriveled thing. It doesn't come out whole, because it doesn't come out as a scream' (Sontag, 1964, 72). Worlds of sociability have been eradicated.

In his extreme suffering, Sontag's 'man with a pain' nevertheless attempts to think about the crushingly *present* nature of bodily pain. He does so by drawing on the metaphors that, a decade and a half later, Sontag would disparage in *Illness as Metaphor*. He mused:

Either the wound is a contract (then there is a date of termination, when all obligations are cancelled) or it is an inheritance (then it's his until he can bequeath it to someone else) or it is a promise (then he must keep it) or it is a task (then he may refuse it, though he will be fired) or it is a gift (then he must try to cherish it before exchanging it) or it is an ornament (then he must see if it's appropriate) or it is a mistake (then he must track down the person in error, himself or another, and patiently explain matters) or it is a dream (then he must wait to wake up). (Sontag 1964, 73)

None of these figurative ways of understanding his pain help him. Sontag insists that 'whether contract, inheritance, promise, task, gift, ornament, mistake, or dream ... he is injured, he is in pain' (1964, 73).

Sontag does not provide readers with a diagnosis for her 'man with a pain': after all, the only thing that matters to him is the presence of that reified agent ('pain') that transforms everyday objects and surroundings into adversaries and creates a disconnection between 'me' and 'my body'.

Throughout her story, though, there is a throbbing headache or neuralgia. Historically, these forms of suffering have spawned rich metaphorical languages to aid in communication. Although Sontag is usually quoted for her disdain of metaphors for pain, she does admit that 'one cannot think without metaphors'. Sufferers in the past regularly had recourse to the three most prominent metaphors for pain: that is, pain is a dog that bites, a knife that stabs and a fire that burns. In 1816, for example, neuralgia was described as a feeling of 'a heated knife' that was 'piercing or screwing into the flesh' or like 'hot pincers ... tearing or twisting it from the bone' (Murray and Mott 1816, 19).¹ In 1890, a patient with a frontal headache described it as 'of a bursting character, as of the eyes were being thrust out' while a sailor complained that his headache threatened to 'unship the top of his head' (Dunlop 1890, 417). A patient known only as Alice A. experienced her headache as

'something about an inch long ... moving about in her throat'. It was 'as though the top of her head were being pricked and being moved up and down' (Bulstrode 1901). Time and again, sufferers evoked an image of neuralgia as an 'arch-fiend' that 'comes to visit us' (C.N. 1911, 9; Anonymous 1809, 226), a 'powerful electric shock as if somebody was jabbing me with a red-hot knife',² or a feeling of being 'hammer[ed] ... to death' (Cooper 1951, 18).

As Sontag argued, many of the metaphors people draw upon to talk about their headache are ones she believed people should 'abstain from or try to retire' (1978, 93). For example, Christians in mid-nineteenth-century Britain might claim that their neuralgic pain was a 'test of my spiritual state' (Carey 1851, 172, 195, 197, 199), or punishment for 'sins of presumptuous vanity or self-seeking pride' (Smyth 1914, 198). Even secular commentators could argue that pain 'stands sentinel to our vices' (*Dental Review* 1859, 705).³ Since nineteenth-century medical thought was clear that there was no pain without lesion, pain was a 'useful monitor', as the author of *On the Pathology and Treatment of Some Forms of Headache* put it in 1883. It was 'warning the individual to stop the mischief which is occurring before it is too late' (Brunton 1883, 329–30). Such language implies fault in the sufferer.

Sontag is also aware that ways of speaking about pain are highly gendered. Her 'man with a pain' fears that his suffering renders him weak and womanly. He recognises that he needs to act like a man, but is repelled by the harshness of his voice as he dictates letters to his secretary. In very important ways, he realises that pain engenders disorder. The 'man with a pain' feels as though he has been 'felled by a tree but he didn't see why he should fall down'. He admits feeling pregnant 'but didn't see why this entailed giving birth' (Sontag 1964, 72). In other words, normal rules of nature are disrupted: bodies feel as though crushed by trees, but remain upright; men have the impression of being swollen in pregnancy.

Gendered presentations of neuralgia and 'the headache' also appear routinely in historical accounts. As one male sufferer woefully acknowledged in 1852, when men 'writhed' with headache pain, they were both 'unmanned and unmanly' (Smyth 1914, 198). In fact, though, the neuralgic sufferer was usually portrayed as a woman. The predominantly female constituency in the world of neuralgia is *implicit* in many accounts. For example, the cover of a book entitled *The Localization of Headaches and Sick-Headaches* (Hewston 1897) showed the profile of a woman; commentators warned sufferers to ensure that their long hair was 'dressed loosely' lest the affliction rendered

them bald (*Daily Mail* 1913, 9; *Daily Mail* 1921, 9); the affliction was blamed on tight lacing. But in many accounts, this gendering was made explicitly. For example, advertisements for headache cures promised to provide the 'Rich, New Blood that a weak woman's system wants' (*Daily Mail* 1909, 11). The advertisement for Dr Williams' Pink Pills for Pale People bragged about how they had transformed a woman whose headache made her 'quite unstrung' into a 'bonny, healthy girl' (*Daily Mail* 1908, 7). Most advertisements picture female headache sufferers with their heads held in their hands, their sewing crumpled in their laps, or with an agonised face, with a male physician treating them.⁴ These advertisements routinely promised to give women freedom, beauty and health, as well as a loving husband and/or male child.⁵

The gendered nature of these representations of headache is highlighted in the more unusual commentaries addressing both sexes. Take the 1908 advertisements for Dr Williams' Pink Pills, an over-the-counter pill for neuralgia. Both male and female mill workers are pictured, but while the man's head is described as 'spinning round as fast as the gear wheels' (a masculine, mechanical metaphor), the women operatives are said to 'turn faint and weak' and see everything 'as though a mist'.⁶ Nearly half a century later, the author of 'Migraine headache said result of too much thinking', used similar imagery. For him, male sufferers kept 'grinding the gears between his ears', while female sufferers were described as 'leak[ing] energy' by 'knitting in crowded trains, in theatres, while shopping, writing, watching the television, and even in bed before dropping off to sleep' (Greiger 1954).

Female sufferers were also much more likely to be pathologised. Time and again, physicians noted that headaches were due to 'a certain impressionability of the sensorium', which was typically 'exhibited by neurotic young women' (Corning 1894, 56). This meant that 'the prospects of recovery are more favorable in men than in women' (Corning 1894, 82).

From the 1960s, headaches became signs of 'psychological disturbance', but with significant differences according to sex. As Harold Merskey (the physician in psychological medicine at the National Hospital for Nervous Diseases in Queens Square, London) observed in 1968, while around 7 per cent of men he saw in his general practice suffered from headaches, nearly half of men rejected by the military on psychiatric grounds suffered from them (Merskey 1968, 297). When he turned to female sufferers, he portrayed them as sexually disordered. Merskey observed that:

the most typical psychiatric patient with pain is a married woman of the working or lower-middle class, possibly once pretty and appealing, but never keen on sexual intercourse, now faded and complaining, with a history of repeated negative physical examinations and investigations, frank conversion symptoms in up to 50% of cases in addition to the pain, and a sad tale of a hard life. (1968, 301)

Very different visual and linguistic metaphors can be observed in discussions about men. Rather than being sexually 'frigid', the archetypical male headache sufferer was generally said to be a high-performing businessman, scientist, physician or politician. This can be seen in advertisements for headache relief,⁷ as well as in medical texts. One physician even coined the diagnosis 'political headache', since it afflicted politicians who worked in demanding environments and failed to get enough sleep (Eccles 1895, 331). There were also headaches caused when scientists did too much 'brain work'; when men dashed from a 'rich but hurried meal' to sit in a 'crowded theatre, gazing over the glare of the footlights'; and when men, 'over-pressured' by 'the whirl, bustle, and hurry of these latter days', failed to get enough rest (Eccles 1895, 334).

In this way, male headache sufferers were part of a broader trend of blaming modernity for rendering brains 'overfull of blood' (*Daily Mail*, 1913, 9; *Daily Mail*, 1911, 9). This argument was particularly prominent in late nineteenth- and early twentieth-century debates. In 1883, for example, T. Lauder Brunton argued that headache was a disease of civilisation. The first sentence in his chapter on headaches asserted that 'of all the kinds of pain which inflict humanity, or at least civilised humanity, there is perhaps none which causes a greater amount of misery than headache' (Brunton 1883, 329, my emphasis). Another prominent physician, writing in 1895, claimed that the 'conditions of everyday life' were 'conducive to the development of headache'. One of the chief culprits was 'rapid means of communication' (Eccles 1895, 328). A writer in 1895 explained that neuralgia was caused by 'overwork of the brain in mental exercise, and overexcitement by emotional extravagance' (Eccles 1895, 330). In former times, he explained, life moved at a slower pace. In the fin de siècle, however, 'the successful man of business, the prosperous practitioner, and the rising politician' were all alike engaged in the attempt to practice a feat, aptly, though perhaps vulgarly, expressed as 'putting a quart into a pint pot' (Eccles 1895, 336). It was a theme echoed by the author of *A Treatise*

on *Headache and Neuralgia* (1888 and repeated in the 1894 edition). He observed that headaches and neuralgia were most common in the ‘great towns of the Atlantic seaboard’. This was due to ‘the nervous exhaustion and strain incidental to the irregular mode of life and competition of the great cities’. He warned that ‘these head-pains so often the precursors of impending nervous bankruptcy’ (Corning 1894, 7). In this way of thinking, the male body was a financial system: when depleted it ‘not infrequently drive[s] the victim to suicide or the madhouse’ (Corning 1894, 7). As the author of ‘Migraine headache said result of too much thinking’ explained, headache was:

the price brainy people pay for thinking too much. Brainwork requires enormous amounts of body energy ... and the man who keeps grinding the gears between his ears is ‘paying time and a half for mental overtime’ as far as his energy reserves are concerned. When energy reserves are depleted, the migraine headache comes like a safety valve to change body chemistry and help restore a normal balance. (Greiger 1954)

Sontag’s ‘man with a pain’ fits within this tradition. He had ‘the misfortune to live in the fastest city in the world. The city is under him, and stands tall around him. Lights turn red, then green. The subway throbs beneath his shoes’ (Sontag 1964, 72). It was no wonder he suffered.

The languages used in discussing neuralgia have also changed dramatically over time. In my book *The Story of Pain: From prayer to painkillers*, I showed that figurative languages for *all* kinds of pain were progressively stripped from clinical textbooks. The introduction of diagnostic classification systems, changing medical technologies and shifts in medical training rendered patients’ descriptions of pain more peripheral to the healing process.

This eradication of emotive, descriptive language in clinical texts on pain can be seen in texts concerning neuralgia and headache. The timeframe for this shift varies widely, beginning in the mid-nineteenth century but not being fully completed until the mid-twentieth century. The earlier medical texts frequently adopted evocative languages when discussing facial and head pain. For example, in 1816, John Murray, in *An Essay on Neuralgia*, described the affliction as feeling like ‘a heated knife, or a sharp instrument was piercing or screwing into the flesh ... as if red hot pincers were tearing or twisting it from the bone’. Murray acknowledged that the ‘severity’ of the pain might ‘overcome the stoutest resolution, and force forth loud and involuntary

screams of anguish’ (Murray and Mott 1816, 18–19). In *A System of Surgery: Pathological, diagnostic, therapeutic, and operative* (1859), Samuel David Gross included detailed descriptions of pain, including the information that the pain of neuralgia was ‘sharp and lancinating, often darting through the parts with the rapidity of lightning, or like an electric shock’ (1859, 73).⁸ In different editions in the 1880s and 1890s, J. Leonard Corning’s *A Treatise on Headache and Neuralgia* speaks of neuralgia in terms of ‘the prick of red-hot needles’, ‘being lacerated with a saw’ and ‘as if electric sparks were projected along the course of his nerves’. The patient ‘suffers the most excruciating agony’. It was not surprising, Corning continued, that the patient might ‘be completely prostrated or even driven to suicide, or the mad-house’ (Corning 1894, 63–4, 68). In *A Treatise on Neuralgia* (Hurd 1890), E. P. Hurd noted that patients told him that their ‘skin seems to be detached, as though they were being scalped’ or they ‘complain[ed] of being tortured by a leaden cap, or by an iron band’ (1890, 2). Hurd observed that neuralgia caused a ‘lancinating pain, paroxysmal in character, described as boring, burning, stabbing’. It might begin as ‘dull and contusive’ but ‘soon becomes more intense, darts up and down one of the main trunks’ (1890, 40). As a pain surgeon to the London Hospital advised in 1905, physicians needed to pay attention to the ‘extreme suffering’ obvious in their patient’s ‘countenance’ and observe how the patient would ‘violently grasp at the skin’ during each ‘spasm of pain’, attempting ‘to tear it away’ (Hutchinson 1905, 32–3).

Crucially, unlike later clinical texts, clinical discussions of neuralgia in the nineteenth and early twentieth centuries also paid significant attention to gesture and inarticulate vocalisations. They conjured up a visual presence of contorted features and inarticulate groans. Neuralgia was portrayed as *imploring* physicians and other witnesses using distinctive gestures, confronting them to ‘bear witness’ and act. ‘When the paroxysm comes on’, one physician observed, the sufferer’s:

whole body is convulsed from the excess of agony; the eyes are intensely closed; and tears trickle down the cheek; the mouth is distorted, and, with the whole cheek, quivers; the body unconsciously waves backwards and forwards, and the foot of the distressed side is involuntarily moved in conformity with the flexure [*sic*] of the body. (Murray 1816, 19)

Despite ‘the stoutest resolution’, the sufferer in 1816 lets forth ‘loud and involuntary screams of anguish’ (Murray 1816, 18). Another patient

could not help ‘involuntary screeching’ (Rowland 1838, 10). In Richard Rowland’s *A Treatise on Neuralgia*, when the patient becomes aware of an approaching attack, the:

utmost horror is often manifested in his countenance; he implores assistance from those around him; or, endeavours to summon up all his fortitude to resist the attack, pressing the seat of the disorder with all his might, and sometimes throws himself on the ground, totally overcome by the agony which he undergoes. (1838, 8–9)

In *Pain and Anaesthetics*, Mott claimed that the ‘anguish of neuralgia’ made the ‘most heroic and stout-hearted men shed tears like a child’ (1862, 5). As a surgeon observed in 1914, physicians only had to observe the ‘pinched features, the knotted brow, the rolling eyes with widely dilated pupils, the ashen countenance’, to know that they were witnessing pain. The patient’s hands might be ‘alternately clenched and opened, grasping wildly at surrounding objects or persons’, or they might be ‘pressed firmly over the painful area’, but, in either case, there would be ‘cries and groans ... bodily contortions and writhings’ (Finney 1914, 15). In 1938, the pain surgeon René Leriche explicitly acknowledged that witnessing the contorted face in agony was an irresistible call to sympathy and to action. He described a consultation with a man suffering from trigeminal neuralgia. He instructed readers to:

Look at him: while you are speaking to him, there he is listening to you, calm, normal, perhaps a little preoccupied. Of a sudden, he becomes rigid: the pain is there. His face becomes screwed up. There is depicted in it a terrible expression of pain, of grievous pain. His eyes are closed, his face is drawn, his features distorted. And immediately he lays his hand on his cheek, presses it against his nose, sometimes rubbing it vigorously; or, more frequently, he remains rigid in his pain, which appears to bring everything in him to a stop. In fact, everything is arrested for the moment, and you yourself are pulled up short, not daring to make a movement, and even restraining yourself from speaking. (Leriche 1939, 30–1)

For Leriche, the inimitable expressions of agonising pain were communicative in two senses. On the one hand, they served as a unidirectional message from the sufferer to his physician, thus aiding diagnosis. On

the other hand, Leriche believed that gestural languages were transmittable, in the sense that *witnesses* to pain were unwittingly compelled to freeze in horror. Both kinds of bodies communicated the inarticulate, yet unmistakable, language of distress. In all these examples, the emphasis was on the patient’s expressive responses to suffering and her demand for sympathy. In other words, these descriptions were not intended to represent *pain* as such, but were rather portraits of an active sufferer beseeching witnesses for help.

This focus on the face was partly due to the fact that physicians in this period were influenced by ideas about facial expressions as a universal language. They were part of God’s design. As Sir Charles Bell put it in his influential *The Anatomy and Philosophy of the Expression as Connected with the Fine Arts* (1806), the deity had created the human body as an expressive instrument to aid communication between humans. Unlike the faces of animals, in whom there were no ‘expressions’, only ‘acts of volition or necessary instincts’, human muscles enabled both speech and expression (Bell 1865, 89, 121). In his words, the human face was a unique and ‘special apparatus, for the purpose of enabling him to communicate with his fellow-creatures’: it was a ‘natural language’ (Bell 1865, 121). Even more secular versions of this ideology – that of Charles Darwin, for instance, in his 1872 classic *The Expression of the Emotions in Man and Animals* – believed that facial expressions revealed a truth that was impossible to totally conceal or, indeed, fake (Darwin 1899).

There is very little of this richly figurative and expressive language in later twentieth-century medical texts, which simply refer to ‘headache’ and its ‘management’. Indeed, rhetorical flourishes by physicians were increasingly sidelined, even discouraged. For clinicians, the person’s misery was reduced to its separate component parts (nervous, visceral, chemical, neurological and so on) within the physiological body. Increasingly, as I argue in greater detail in *The Story of Pain*, complex and elaborate pain narratives by patients became suspect: they indicate that the patient was malingering or seeking financial compensation.

Even the enlightened use of lists of adjectives provided, for example, in different versions of the McGill pain questionnaire do not petition witnesses to respond to suffering. Because the questionnaire’s primary purpose was diagnostic (that is, helping the physician to diagnose whether the patient was suffering from trigeminal neuralgia rather than atypical facial pain, for example) the actual pain descriptors were less important than their statistical distribution.⁹ In other words, the use of pain descriptions were regarded as themselves being

metaphorical, revealing *to the clinician* an inner biological, chemical or neurological ‘truth’ which could be then use to read the interior or subjective body.

When the imploring face eventually returned to medical texts, as it did from the late-1970s onwards, it fulfilled a very different function to the earlier texts. Renewed interest in facial expression was largely influenced by psychological research emerging from the work of Paul Ekman and his collaborators. They claimed that facial expressions of the ‘core emotions’ were universal: anyone could interpret the ‘face of pain’ when they saw it (Ekman and Friesen 1978; 1973; Ekman, Friesen and Tomkins 1971; Ekman 1990). However, while earlier physicians had assumed that the facial expression of pain would elicit sympathy, these commentators argued the opposite. Indeed, F. J. Keefe and J. Dunsmore argued that ‘conscious efforts to communicate pain through guarded movements, facial expressions, or extreme ratings of pain’ actually ‘upset and even enrage clinicians’ (Keefe and Dunsmore 1992, 7). Prkachin and Craig (1995) cite research that purports to show that pained faces are counterproductive in clinical encounters. Prkachin and Craig observed that:

Clinicians, adjudicators, insurance investigators, and family members often propose that the financial or social consequences of pain displays, rather than the experience of suffering, represent their true sources. (1995, 198)

This was why clinicians should be aware of ‘nonverbal leakage’ in pained facial expressions or the ‘display of signals that betray the true underlying state’ (Prkachin and Craig 1995, 198).

This is not to deny that the earlier physicians who focussed on patient descriptions of pain or who responded to the entreating face were therefore more empathetic witnesses and healers. After all, people they regarded as lesser humans (for example, the poor as well as racial and other minority groups) were not accorded the same sympathetic witnessing. Even Peter Latham – generally a highly empathetic physician – admitted that ‘education and the better habits of civilized life render men more rationally attentive to their internal sensations’. For all intents and purposes, ‘the stupid and half civilized’ proffered useless pain stories (Latham 1837, 76–7). Their faces were also less capable of being ‘read’. This can be illustrated by looking at Paolo Mantegazza’s *Physiognomy and Expression*, published in 1904. Like many of the physicians I have looked at in this chapter, he believed

that ‘sobs, loud complaints, all forms of groaning, are useful, because thereby we excite in those who listen to us a compassion which may be of aid to us’ (Mantegazza 1904, 92). He also believed that these facial expressions were universal, even existing among the ‘most savage peoples’. Indeed, he quipped, he would have reproduced a photograph of ‘two Maori idols’ who portray the ‘two fundamental images of pleasure and pain’ in his book ‘had not two large fig-leaves been necessary to conceal certain details of these coarse wooden statues’ (Mantegazza 1904, 110). At the same time, however, Mantegazza had a highly racialised and gendered understanding of facial expressions. He believed that differences in the way people expressed their pain ‘become greater in proportion as we rise in individual and ethnical [sic] rank’ (Mantegazza 1904, 127). Men and women also responded differently. In his words:

The man who suffers protests against pain; he utters threats and imprecations on nature and on God. The closed fist stretched towards heaven is the virile expression of some very intense pains. In the woman, on the contrary, the compassionate form prevails, and the groan is the most habitual form of expression. The woman who suffers, prays and performs acts of charity; the man most frequently blasphemes and menaces. (Mantegazza 1904, 127)

Mantegazza’s sympathy is with the active male sufferer, not the passive female one. What Mantegazza’s words remind us is that whether physicians gaze deeply into the eyes of other sentient beings, listen carefully to patient narratives, or studiously analyse biometric data, they can still end up denying the ethical claims being made by that suffering person. Whatever their stance, witnessing pain makes political claims. This was understood by pioneering British psychiatrist Henry Maudsley. In *The Pathology of Mind* (1895), he argued that the ‘exaggerated expression[s]’ of pain (including ‘the pain is just as if a thousand knives were driven into his brain, or a saw were sawing it’) were:

endeavours, by their strong colouring, to excite in the minds of others a proportionate feeling of the really ineffable misery of the strange and bewildering sensations. (Maudsley 1895, 172)

They were attempts ‘not to convey ideas, but to express feelings that are inexpressible’ (Maudsley 1895, 172). In other words, expressions of

pain – whether verbal or facial – were not so much attempts to actually describe the sensation, but were more bids to elicit sympathy for pain in witnesses to that suffering. They were attempts to bring witnesses to the pain of others closer to the bedside of the suffering humanity and closer to an understanding of this area of experience normally so inaccessible to language. They brought pain and the world together, while still acknowledging that pain is ugly and unique to each individual. As with Sontag’s ‘man with a pain’, suffering is not a ‘contract, inheritance, promise, task, gift, ornament, mistake, or dream’: the person is simply ‘in pain’ (Sontag 1964, 73).

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Notes

- 1 See also ‘Glasgow Royal Infirmary – Ward Day Book, Female Surgical, Ward 10’, in Greater Glasgow NHS Board Archive HH67; Moffatt (1877) and Young (1815).
- 2 See also Miller (1968).
- 3 Pain as a sentinel is often used: see Spender (1877); ‘The Value of Pain’, *Sander’s Magazine of Physical Culture* (1 November 1906), 562; Sieveking (1854).
- 4 Some examples can be found at *Burnley Express* (1 February 1908), 3; *Lancashire Evening Post* (2 August 1916), 4; *Daily Record and Mail* (7 February 1918), 5; *Newcastle Evening Chronicle* (11 April 1918), 3; *Rochdale Observer* (4 March 1919), 9; *Portsmouth Evening News* (25 November 1921), 3; *Yorkshire Evening Post* (19 October 1922), 4; *Lichfield Mercury* (22 January 1926), 3; *Sevenoaks Chronicle and Kentish Adviser* (20 September 1929), 5; *Yorkshire Evening Post* (1 March 1934), 4; *Hartlepool Northern Daily Mail* (14 April 1937), 6; *Yorkshire Evening Post* (9 June 1937), 11; *Lancashire Evening Post* (10 June 1937), 9; *Derbyshire Times and Chesterfield Post* (28 May 1937), 3; *Kirkintilloch Herald* (1 May 1943), 3; *Sussex Agricultural Express* (27 August 1943), 3; *Larne Times* (25 May 1944), 4; *Rochdale Observer* (20 May 1944), 4; *Aberdeen Weekly Journal* (14 September 1944), 2; *Biggleswade Chronicle* (31 May 1946), 6.
- 5 Some examples can be found at *Sevenoaks Chronicle and Kentish Adviser* (20 September 1929), 5; *Burnley News* (21 September 1929), 15; *Sheffield Independent* (17 September 1929), 7; *Taunton Courier* (25 September 1929), 5; *Burnley Express and News* (7 July 1951), 6; *Aberdeen Evening Post* (17 August 1951), 4; *Portsmouth Evening News* (15 July 1952), 5.
- 6 This advertisement was repeated in many other newspapers and editions.
- 7 For example, see the businessmen addressed in *Lancashire Evening Post* (4 October 1916), 4; *Sheffield Independent* (2 November 1934), 12; *Falkirk Herald* (3 April 1948), 7; *Larne Times* (11 November 1948), 4.
- 8 Samuel David Gross was the trauma surgeon immortalised in Thomas Eakins’ painting *The Gross Clinic*, 1875, held by the Philadelphia Museum of Art.
- 9 For an example of this process, see Melzack, R. et al. (1986).

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16 Language and images in pain consultations

Elena Semino

Introduction: A linguist's perspective on visual images in pain consultations

What happens when people with chronic pain have the opportunity to use visual images when speaking with a doctor? In this chapter, I take a linguistic perspective on this question by analysing 17 specialist pain consultations in which patients had the opportunity to use visual representations of pain in interacting with the consultant. As explained elsewhere in this volume (see Introduction and [Chapter 8](#)), these images were co-created by Deborah Padfield and chronic pain patients in two previous projects: *Perceptions of Pain* (Padfield 2003; Padfield et al. 2010) and *Face2face* (Padfield 2012; Padfield, Zakrzewska and Williams 2015; Ashton-James et al. 2017). The images were then reproduced as a pack of 54 cards, and made available in the waiting room of a specialist pain clinic in London. Patients were encouraged to look through them and, if they wished, to take into the consultation any of the cards that they thought would be helpful. The 17 patients involved in the consultations I will analyse accepted this opportunity by selecting a few cards and taking them into the consultation.

As a linguist, I approached these consultations with a particular set of questions, expectations and methods. The main question I aimed to answer was: what difference, if any, do the PAIN CARDS (images) make to the language used in the consultations?

Answering this question would then feed into a discussion with other members of the project team on the implications of any differences for a better understanding of the experience of pain and an assessment of the potential usefulness of the PAIN CARDS in communication about pain, particularly in clinical settings.

Concerning expectations, my previous work on the PAIN CARDS themselves had shown that they mostly involve metaphorical representations of the experience of pain and of its impact on people's lives, including particularly their identities (see Deignan, Littlemore and Semino 2013). An analysis of the verbal testimonies that accompanied the images included in Padfield's (2003) *Perceptions of Pain* revealed rich and creative interactions between verbal and visual metaphors for different aspects of people's pain experiences. This is consistent with a large body of research on metaphor that has both theorised and shown the central role that metaphor plays in communication and thinking about subjective states such as emotions, illness and pain itself (e.g. Kövecses 2000; Semino 2008; Loftus 2011; Charteris-Black 2012; Semino et al. 2018).

As far as methods are concerned, linguistics provides well-established frameworks and tools for both qualitative and quantitative computer-aided analysis. The former may involve a detailed investigation of the personal stories that people tell in particular contexts; the latter make it possible, for example, to identify all instances of particular words in large data sets, or to compare word frequencies in different data sets.

In this chapter, I begin to provide an answer to the question above by applying a combination of these methods to the language used in the 17 consultations involving the PAIN CARDS. In the next section I discuss the results of a computer-aided analysis of the language used in the consultations. I then go on to present a qualitative analysis of metaphors and narratives in a particular interaction, before drawing some conclusions.

The PAIN CARDS and verbal communication

Answering the question of what difference, if any, the PAIN CARDS make to the interaction between patients and consultants is inevitably a matter of comparison. This, however, leads to a further question: what kind of comparison would be appropriate to identify as reliably as possible any difference that the availability of the cards potentially makes?

An examination of the video recordings of the 17 consultations showed that it was possible to identify the parts of the interactions where the cards were actively used, that is, where they were explicitly talked about. In some consultations, this was one single stretch of

interaction. In other consultations, this involved several stretches of interaction. For the purposes of the verbal analysis, therefore, I extracted the relevant parts of each consultation from the transcripts of the video recordings and combined them into a single data set which I will refer to from now on as 'Card Data'. The rest of each consultation was then combined into another data set which I will refer to as 'Rest Data'. That made it possible to carry out a comparison that would address my original question above, or, to be more precise, a specific version of that question: what are the linguistic differences between the parts of the consultations in which the PAIN CARDS are actively being used and the rest of the consultations?

I will begin with a quantitative approach to these differences, in terms of volume of talk and relative frequencies of words and types of words. I will then take a qualitative approach to one particular extract from a consultation (see also Semino, Zakrzewska and Williams 2017).

Volume of talk: Who speaks more?

One particular linguistic difference between Card Data and Rest Data is to do with the extent to which consultants and patients occupy the conversational 'floor'. In simple terms, this can be measured by calculating how many words consultants and patients speak, and comparing the relevant figures. Table 16.1 provides word counts for patients and consultants in Card Data and Rest Data.

Overall, consultants speak more words than patients, but the difference is very small (67,212 words as opposed to 64,080). However, there is a contrast between Card Data and Rest Data in relative amounts of talk. Overall, patients speak more words than consultants in Card Data (8,463 words as opposed to 5,188), whereas consultants speak more words than patients in Rest Data (6,2024 words as opposed to 55,617). This difference is statistically significant at $p < 0.0001$. These

Table 16.1 Word counts for patients and consultants in different sections of the consultations. © Elena Semino

Data section	Word counts		
	Patients	Consultants	Total
Card Data	8,463	5,188	13,651
Rest Data	55,617	62,024	117,641
Total	64,080	67,212	131,292

differences apply also at an individual level: while not all individual patients talk more than the relevant consultant in Card Data, in all cases the amount of words uttered by patients as opposed to consultants is relatively larger in Card Data than in Rest Data.

An observed difference such as this is not easy to interpret, however. On the one hand, the relative proportion of talk in interaction is one of the ways in which ‘asymmetries’ of power in society generally and institutional settings in particular can manifest themselves in interaction (e.g. Thornborrow 2002, 27). For example, Edelsky’s (1981) analysis of five informal university meetings found that men had longer turns than women in the parts of the discussions that were primarily developed by one person, as opposed to the more open and collaborative parts of the discussions. However, generalisations on amount of talk and power asymmetries are problematic, as there are differences between different types and contexts of interaction. For example, in a job interview, the applicant is likely to speak more than the interviewers, but the balance of power is skewed in favour of the latter. In addition, there are also differences in how interlocutors interpret and act on their perceptions of themselves and others in any particular interactional setting (see ten Have 1991 on ‘asymmetry’ as a partly negotiable aspect of doctor–patient interaction).

Having said that, it is still noteworthy that the active use of the cards in the 17 consultations coincides with a proportional increase in patients’ amount of talk. At a basic level, this is simply because patients explain why they have selected each card, that is, how each card relates to their experience of pain. Consider, for example, the following extract from a consultation involving a male patient and a female consultant:

- Consultant: [...] And this one?
 Patient: That’s a quite, quite, quite, ah, abstract again. But, um, ah, I guess to do with the psychological side. I have been seeing other doctors in hospitals for so, so many years now and, ah, I’ve had so many tests and it ... I’m, sort of, used to it now but I’m not getting anywhere.
 Consultant: What, why ... what from that says that to you?
 Patient: Ah, it’s just, sort of the setting.
 Consultant: The setting, yes.
 Patient: And, sort of, becoming numb to the setting.

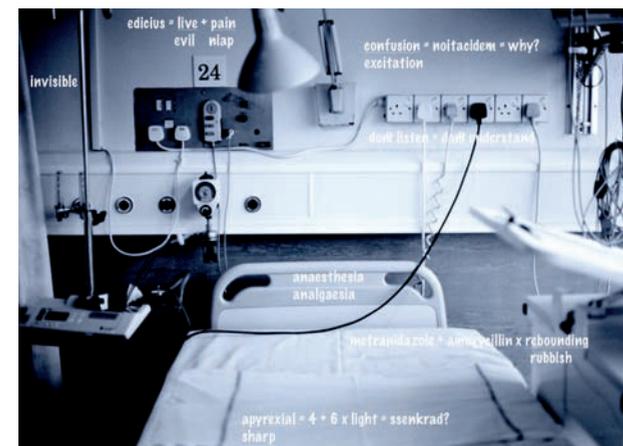


Figure 16.1 Deborah Padfield, ‘Untitled’ from the series *Perceptions of Pain*, 2001–06. C-type print. © Deborah Padfield, reproduced by kind permission of Dewi Lewis

Here the patient describes the significance of the card (see Fig. 16.1) in response to a prompt from the consultant, which takes the form of an elliptical question: ‘And this one?’ This is typical of the 17 consultations generally: it is usually the consultant who decides at what point the PAIN CARDS are brought into the consultation and who tends to move the discussion on from one card to another. On the other hand, the patient responds with a 54-word explanation of how a particular card captures an important aspect of his experience of living with chronic pain. Crucially, that aspect is explicitly described as ‘the psychological side’, and what follows provides more detail on what this means. The card captures the feeling of having become used to seeing many doctors over a long period of time, without the pain being relieved. This lack of success is summarised by the metaphorical expression ‘I’m not getting anywhere’, which relies on a conventional association between lack of forward movement and lack of positive change. The consultant then asks for further clarification, and the patient’s explanation includes another metaphorical reference to an emotional experience, or, rather, a lack of emotional response to being in a hospital (‘becoming numb to the setting’).

As this short extract suggests, the relative increase in patient talk when the PAIN CARDS are actively being used does not coincide with a change in the structure of the interaction: the consultant still controls the interaction by encouraging the patient to show her the cards and asking questions about them. However, the opportunity to explain the

significance of the cards does not just enable the patient to occupy more of the conversational floor, but also to gain more control of the topic, in that selecting the cards and explaining their significance gives him the opportunity to decide which aspect of his overall pain experience to discuss. Topic control is another aspect of interactions that can be a manifestation of asymmetries of power. In that sense, the PAIN CARDS seem to give patients the opportunity to shift the balance of conversational power in their favour, at least to some extent.

In the next section, I will pursue in more detail an analysis of differences in the kind of language that is used around the PAIN CARDS, and what this may suggest about the role of the cards in the consultations.

Frequencies of (types of) words: What is being talked about?

In the previous section, I started from a consideration of *how much* patients and consultants talk in Card Data and Rest Data relative to each other, and ended with a consideration of *what* they talk about when the PAIN CARDS are actively being used. I have suggested that the cards appear to give the patients the opportunity not just to occupy the conversational floor for longer, but also to control the topic, at least in terms of what aspect of their experience of chronic pain is being talked about. To pursue this further, in this section I make use of the computational tools I alluded to above to compare the words used in Card Data and Rest Data.

The method I employed is drawn from corpus linguistics – an area of research at the interface between linguistics and computer science which involves the use of tailor-made software to study digitally stored collections of texts (‘corpora’) that are usually too large to explore by hand or eye alone (McEnery and Hardie 2011). Among other things, corpus linguistics provides ways of comparing two different data sets in terms of the relative frequencies of the words they contain, and of the areas of meaning, or ‘semantic domains’ that the words belong to. This is a way of identifying what is distinctive about one data set as opposed to another in terms of vocabulary and, broadly speaking, topics.

I used the online software Wmatrix (Rayson 2008) to compare Card Data and Rest Data. A distinctive feature of this software is that it has a tool that allocates each word to a semantic domain: for example, the word ‘pain’ as a noun is allocated to the semantic field ‘Disease’. I

used this tool to compare Card Data with Rest Data. The tool counts the occurrences of words within each semantic domain in both data sets, and then produces a list of semantic domains that are used much more frequently or ‘overused’ in, in my case, Card Data than Rest Data. The overused semantic domains are rank-ordered by a measure of statistical significance called ‘log likelihood’, which is based on the amount of evidence that a particular difference exists between the two data sets (Dunning 1993). It is then possible to decide what cut-off point to adopt as an appropriate level of statistical significance in considering overused semantic domains. For the purposes of this chapter, I adopted as cut-off point the log-likelihood value of 6.63 (which corresponds to $p < 0.01$), and carried out the comparison separately for patients and consultants. In the rest of this chapter, I will focus on a comparison between the language used by patients in Card Data and the language used by patients in Rest Data.

Some of the overused semantic domains in this comparison are to do with words that refer to the cards themselves (e.g. ‘picture’ and ‘card’), and that the software allocates to semantic domains such as ‘Arts and crafts’ and ‘Paper documents and writing’. The overuse of other semantic domains, by contrast, seems to be due to the topics that the cards are used to bring up, rather than references to the cards themselves.

Table 16.2 provides a selection of overused semantic domains in Card Data as opposed to Rest Data for patients, with examples of words that the software subsumed under each domain. The semantic domains are listed in decreasing order of log likelihood value.¹

Five of these semantic domains contain expressions that are used metaphorically by patients to describe the particular quality of their

Table 16.2 Selection of overused semantic domains in the patient section of Card Data as compared with the patient section of Rest Data.
© Elena Semino

Semantic domains	Examples of words	Log likelihood
Temperature: Hot/on fire	burning, hot, fire,	31.78
Anatomy and physiology	face, arm, back, head, mouth	18.33
Violent/angry	stabbing	15.17
Electricity and electrical equipment	electric shock, electrical, electric	13.57
Thought, belief	feel, think, feeling, feels	11.49
Constraint	tight	7.76
Degree: Maximisers	all, literally, completely	7.26
Temperature: Cold	cold, cool	6.73

pain. In particular, they describe their pain in terms of hot and cold temperature ('Temperature: Hot/on fire' and 'Temperature: Cold'), the experience of electric shock ('Electricity and electrical equipment'), inability to move freely ('Constraint') and damage to the body via penetration with sharp objects ('Violent/Angry'). For example, in the extract below a particular card (see Fig. 16.2) is used by a patient to describe her pain experience metaphorically in terms of a combination of excessive heat and penetration via a pointed object:

- Consultant: And then, and then you, you showed me, can you maybe just tell me a little bit again what, what these pictures all mean to you? [Lays out pictures]
- Patient: Sometimes I forgot but you know ...
- Consultant: Yeah?
- Patient: ... this one she said to me like a knot, like a knife is sharp, innit?
- Consultant: Is it feels like sharp sometimes?
- Patient: Yeah I feel that inside, I feel that, that sore, that burning I got ...
- Consultant: Yeah.
- Patient: ... that burning I got is really sharp.

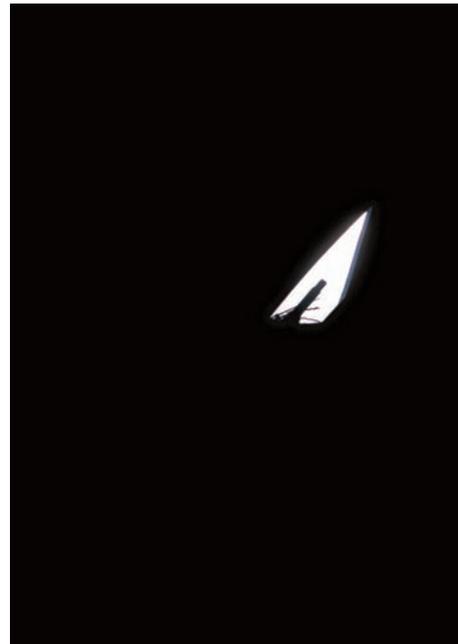


Figure 16.2 Deborah Padfield, 'Untitled' from the series *Perceptions of Pain*, 2001–06. C-type print. © Deborah Padfield, reproduced by kind permission of Dewi Lewis

- Consultant: Mm-mm.
- Patient: And er sweat and the er hot flushes I got is really sharp.
- Consultant: Mm okay.
- Patient: You know sometimes, sometimes I can't take it no more, I can't take that, that heat on my body.

The overuse of the semantic domain 'Anatomy and physiology' is linked to the higher frequency of description of the quality of pain, as patients mention the body parts in which the pain is felt. Similarly, the overuse of the semantic domain 'Degree: Maximisers' is due to the use of expressions that emphasise the intensity and/or appropriateness of descriptions of the felt experience of pain. In the extract below, for example, the adverb 'literally' precedes a figurative description of pain via a simile:

- Yes, that picture I've picked because it's literally, you could ping an elastic band ... I'll be fine, ping the elastic band and that could, like, start. It could start from nowhere, in other words.

The overuse of the 'Thought, belief' semantic domain, on the other hand, is only partly explained by the higher frequency of metaphorical descriptions of pain sensations in patients' utterances in Card Data as opposed to Rest Data. This semantic domain is primarily represented by the verbs 'think' and 'feel' with the pronoun 'I' as subject, that is, expressions of the patient's subjectivity. Table 16.3 provides the 'concordance' of 'feel' in the patient section of Card Data, that is, a list of all instances of 'feel' in the data with the immediately preceding and following text.

The table shows that 'feel' is used to introduce three aspects of the experience of pain: the quality of pain sensation, usually via figurative expressions (e.g. 'I feel as if I'm on fire'); the impact of the pain on the person's daily life (e.g. 'to feel that there are some things I'm not able to do any more'); and the emotional consequences of chronic pain, also often involving figurative expressions (e.g. 'I feel lost, I don't know what to do'). For example, the patient quoted on pages 276–7 (a non-native speaker of English) uses a particular card (see Fig. 16.3) to introduce an aspect of her life that is not directly related to the pain but that nonetheless causes negative emotions, namely the fact that her children and grandchildren do not visit her as often as she would like.

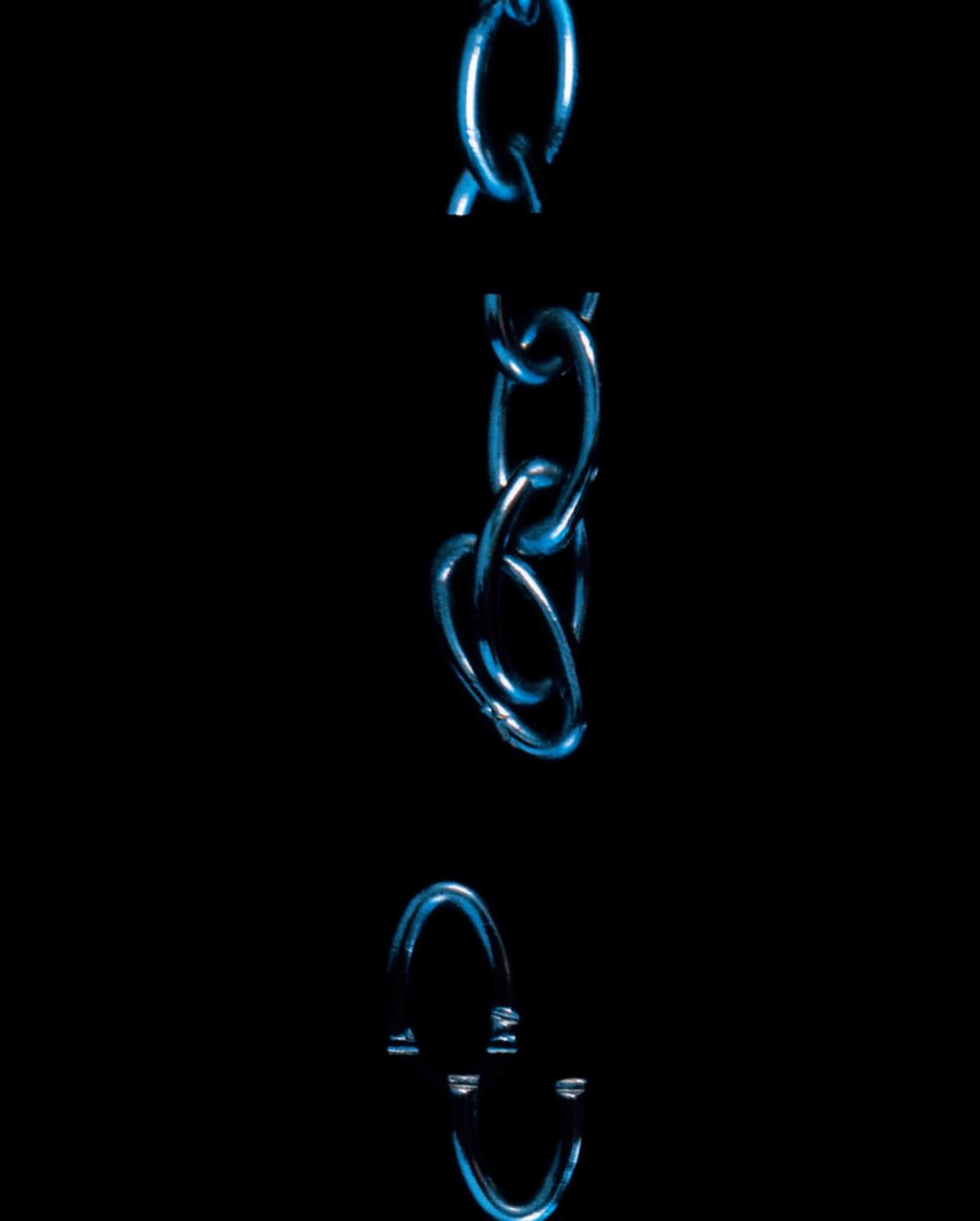


Figure 16.3 Deborah Padfield with John Pates, 'Untitled' from the series *Perceptions of Pain*, 2001–06. C-type print. © Deborah Padfield, reproduced by kind permission of Dewi Lewis

Consultant: Yeah [writes]. Okay and this here?
 Patient: And this one it's like a gap, innit?
 Consultant: Yeah.
 Patient: Some, something, sometimes I feel a gap between my family.
 Consultant: Yeah. So you feel a gap between, so you feel this, this generation gap yeah?
 Patient: Yeah because they try to, to, to like erm keep away from me because they say they haven't got no time, they're busy, they've got problem, all this problem.
 Consultant: Yeah.
 Patient: I feel a gap.

Table 16.3 Concordance of 'feel' in Card Data for patients. © Elena Semino

qb; because it s like the pain is so severe I [Points] um, this one, well, I	feel	as if I m on fire. This one [points]
through me. It s stabbing. Um, this one I	feel	as if everything is coming apart and I knew sc
tes another card] because it, I always	feel	like I want to be cemented up & not cemented
m not that old. 00 : 11 : 52 And, um, and to	feel	tense, not only here [indicates left lo
because [rubs left arm] I do n't God, take it off, it 's because you can not	feel	that there are some things I m not able to do
, I can wear them now, because I just ca n't	feel	on that [rubs left leg] ... on m
b; a belly and it 's just, I just	feel	and then it dawned on my, oh, that 's true.
uspices of this consultation really. So they	feel	it. [Shrugs]. And I 've done the
nother picture on desk], um, is how I	feel	bloated every time ... [00 : 45 : 35 &r
[00 : 08 : 32] And that 's what I rning &; but it 's like a numbness &; but you	feel	slightly clumsy to introduce them but they are
ing it is taking tablets every single day and	feel	, I do n't like [?] all these but
t is far worse than the left. And that one I	feel	when I like, [unclear] a lot of p
at definitely, sort of, clicks there. I do	feel	hot to touch ... [Touching left side o
and go to work, really. I say it because I	feel	that you can't ... and I do n't know if that
rk, really. I say it because I feel &; &; I	feel	in my arm and hands sometimes [shows car
	feel	internally &; &; like it s pushing, you know
	feel	&; &; I feel &; yes, I say it flippantly beca
	feel	&; yes, I say it flippantly because for me it

arge that causes my pain. Um, this is how I	feel	when a cosmetic company wants to book me on a
have to, it s your job. Um, mechanical. I	feel	like I have a mechanical, like, the way my b
ink it s like, it s like, dirty. Because I	feel	like, for someone who bothers to put grown fl
pain point of view but from how it makes you	feel	, you can t really speak, um, as a person wh
Um, that s a reflection of how I, kind of,	feel	about [laughs] now in terms of med
, so, then it s, kind of, it can make you	feel	quite tense, um, the pain & & it can certa
ectric shocks in the face. You can sometimes	feel	warm with it in the face & & um, but not ne
ot, like a knife is sharp, in n it? Yeah I	feel	that inside, I feel that, that sore, that b
sharp, in n it? Yeah I feel that inside, I	feel	that, that sore, that burning I got & & th
trong, like, I eat something like fruit, I	feel	that sharp in my teeth right & & and I have
e out. I just use my denture to eat. This I	feel	a cold in my hand. I had a cold in my hand,
d, I, I have to wear gloves, I had to & I	feel	cold and when, when I wake up in the morning
? Oh tablets, oh no, that s all very <>, I	feel	I don t want them. I don t want them, nothin
nt them, nothing to do with me. Oh lost, I	feel	lost, I don t know what to do. Yeah or loss
r loss. I ve been trying, trying, trying I	feel	lost. And this one it s like a gap, in n it
ap, in n it? Some, something, sometimes I	feel	a gap between my family. Yeah because they tr
, they ve got problem, all this problem. I	feel	a gap. Yeah I do but they don t come, like i
art of them <you know not going to come. I	feel	the burning in my mouth, it s just like a fir
s like a contraction. Literally, you could	feel	it building, building, building, it peaks a

Overall, therefore, a computer-aided comparison of patient language in Card Data and Rest Data shows that, when the cards are actively being used, patients tend to talk more about what their pain feels like and about their subjective states. The emotional disclosure associated with the latter pattern is particularly notable, especially in view of the fact that it is not limited to statements that involve words such as ‘feel’. For instance, the extracts quoted on pages 272 and 276-7 both involve references to emotional states. In Example 1, the ‘psychological side’ of living with chronic pain is mentioned explicitly. In Example 2,

a lengthy description of what the pain feels like is followed by a statement about the emotional consequences of that pain: ‘You know sometimes, sometimes I can’t take it no more, I can’t take that, that heat on my body’. While there are no explicit references to suicidal feelings, the expression ‘can’t take it no more’ can suggest extremes of negative physical and emotional experiences that undermine one’s will to carry on living.

In the next section, I will discuss in more detail a particular extract where both emotional disclosure and indirect references to suicidal feelings occur in a patient’s explanation of the significance of a particular card.

Metaphors, narratives and emotional disclosure in talk around a particular PAIN CARD

In the previous section, I took a quantitative computer-aided approach to the question of what differences the use of the PAIN CARDS make



Figure 16.4 Deborah Padfield with Liz Aldous, ‘Untitled’ from the series *Face2face*, 2008–13. Digital Archival Print. © Deborah Padfield

in the consultations from a linguistic point of view. In this section I complement that analysis with a detailed discussion of a particular extract from a consultation. This extract exemplifies some of the patterns that were revealed by the computer-aided analysis, but also enables me to show how the PAIN CARDS can be used to introduce metaphors and narratives that shed light on the person's lived experience of pain and its consequences.

This extract occurs just over half an hour into a consultation involving a female patient. The patient shows a PAIN CARD showing a rag doll sitting on the London tube (see Fig. 16.4) and the interaction below follows:

- Patient: This is when I'm completely like a rag doll, when I'm so exhausted I can't walk and I just want to go oh, it's my I've had enough days, you know. When you go ah God, what's the point of living and stuff. [Replaces card on desk]
- Consultant: Yes, yes it's a sort of a, quite a dark sort of image, isn't it, and I think that, and again, you get a sense I get of this, of you kind of feeling that you're, I'm trying very hard not to put words into your mouth, but kind of a feeling that the pain sort of depersonalises you in some way.
- Patient: Yes, yes, well you're like, you just don't, I kind of lie a lot to my friends, you know.
- Consultant: Yes, yes ...
- Patient: And I hate, I hate doing this, but I'm permanently like, permanently making up excuses for not going places. I don't want to say I'm in pain, because it's like oh God, change the record. I hear myself saying it [points to self] so I'm constantly going and I'm making up all these stories like, oh, I forgot, somebody's calling or I've got, I've got to do this or, and it's all lies.
- Consultant: Yes.
- Patient: I'm in too much pain to go out, or I just haven't got the strength to get up out of bed.
- Consultant: Okay.
- Patient: [Leans forward and picks up card] I'm feeling maybe there's a bit of shame as well, it's, you know. [Replaces card on desk]

Consultant: Yes.

Patient: I mean I've got such lovely friends, but I lie to them all the time.

The patient uses the image of the rag doll in the PAIN CARD as inspiration for describing herself via a simile ('when I'm completely like a rag doll'). The following explanation clarifies the basis of the similarity: there are times when the person is so exhausted that, like a rag doll, she cannot walk. This description of the impact of the pain on the person's daily life is immediately followed by an account of the emotional consequences of the restrictions caused by the pain: 'it's my I've had enough days, you know. When you go ah God, what's the point of living and stuff'. As with some of the patients involved in previous extracts, this person articulates a feeling that the pain sometimes undermines the very point of the person's existence, therefore potentially suggesting suicidal thoughts.

After the consultant's response and self-conscious rephrasing of the patient's emotional disclosure, the patient goes on to make another personal statement about a behaviour ('I kind of lie a lot to my friends'), which she says she 'hates'. This behaviour is then demonstrated by means of a narrative of regular occurrences in the person's life where she invents excuses for turning down invitations to social occasions. The excuses are made up to avoid telling the truth about her pain, as she imagines that this would receive an unsympathetic response ('because it's like oh God change the record'). However, the patient describes this strategy disapprovingly as 'all lies' and then explicitly mentions the negative emotional consequences of her situation: 'I'm feeling maybe there's a bit of shame as well'. The final utterance in the extract summarises the cause of this feeling of shame through the contrast between 'such lovely friends' and '[lying] to them all the time'.

In other words, this patient uses a particular PAIN CARD as a springboard for a figurative description and a narrative that introduce three aspects of her life with chronic pain: a negative self-perception due to physical limitations; a habitual experience that highlights the negative impact of the pain for her social relationships and social life; and the negative emotional consequences of the pain for how she perceives herself as a friend and for her assessment of the worth of her life as a whole. While one cannot state that these aspects of the person's experience would not have been mentioned without the PAIN CARDS, the findings of my quantitative analysis suggest that this kind

of openness about the negative emotions associated with pain is more frequent when the cards are actively being used than in the rest of the consultations.

Conclusions

In this chapter I have used a combination of quantitative and qualitative linguistic analysis to explore the difference that the availability of visual representations of pain can make to the language used in specialist pain consultations. I have shown that, when the PAIN CARDS are actively being used in the 17 consultations I have analysed, patients:

- speak relatively more than consultants;
- provide more figurative descriptions of the quality of their pain;
- talk more about their subjective states, particularly the negative emotions caused by living with chronic pain.

A close analysis of extracts from the parts of the consultations where the cards are actively being used has shown that emotional disclosure on the patients' part often extends to potential allusions to suicidal thinking and may involve narratives of personal experience that demonstrate the causes of negative emotions and self-perceptions.

Overall, the linguistic analysis presented in this chapter has provided evidence for how the use of the cards can have effects that can be seen as desirable in clinical interactions: a reduction in the power asymmetry between patient and doctor, at least as manifested in terms of volume of talk and control of the topic; and greater opportunities for the verbalisation of lived experiences of pain generally and emotional disclosure in particular, which may make it easier to address the totality of the person's needs and challenges within the therapeutic relationship. Given the low cost of the PAIN CARDS as a clinical intervention, this suggests that they should ideally be more widely considered as a possible tool to improve clinical interactions about chronic pain.

Note

- 1 I also took into account the size of the difference between two data sets, via a statistical measure known as LogRatio. The LogRatio range for the semantic fields in Table 16.2 ranges between 0.48 for 'Anatomy and physiology' and 2.48 for 'Temperature: Hot/on fire'.

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17

The tree, spring and well

Sharon Morris

The London plane

I can't breathe –
thick white motes of pollen
shed by London planes
stick in my throat,
their hairs, abrasive.
Outside the hospital they stand
attached to intravenous drips:
my pulse quickens
in that place of madness,
where everything
is like everything else
each part inseparable from its whole
and I could step off the planet
in our descent
entropic,
into that inert
gospel sea of dark velvet.
I am searching for friends
in the long-fallow system, fields
at rest
in the seasonal flow
of things, I believe
inviolable.

Hospital

In the hospital a woman is dying:
in the hospital a woman is born:
the Thames coils grey, shiny,
around the black tower of Guy's.
Ice plasma shoots through my arm.
I stand on the edge of a cliff. *Don't
jump!* and I turn, take the stairs
down to the medicine man who
holds the turtle of the world; I fall
on the floor as if drunk. A nurse
takes my wrists, counts one, two,
three, four and breathe –
but my nostrils fill with sand,
my body turns to stone; living
my life backwards in an endless
dying, I wait for your return,
listening to her coughing and
the rabbi's whispered voice,
until all sound is one rhythm
and the river a river of light.

Water glass

New blood rushes through me
opening each vein and artery,
colder than my blood, branching
from my arm, successive; I wait
for the sharp needles to strike
my heart and thorn at my lips.
I am broken down as though
this plasma is water glass, silicate
used for preserving eggs and
hardening artificial stone. Shards
of glass under my fingernails fall
away, revealing fine new skin.

Next year I will listen to the sap
rise from the root, rustling to each
branch, to the leaves and finally
the bowers of flowers and fruit.

from *Gospel Oak* (London: Enitharmon Press, 2012)

18

Challenges in managing pain in India

Preeti Doshi

Introduction

Pain is a subjective sensation and it can be quite a challenge to ascertain its severity in the absence of an objective tool with which to measure it. Creating a good rapport by communication is an essential key in pain assessment. This can be particularly complex in a country like India with colossal diversities of languages, ethnicities, religions, cultures and beliefs. Progress in acute pain management over the past three decades has demonstrated that effective pain relief can be achieved with a range of inexpensive drugs and treatments, yet the vast majority of patients in less developed areas of the world have little or no access to even the most limited of therapies that could alleviate their suffering from acute or chronic pain.

Pain statistics in India

There remains a paucity of systematic epidemiological studies published from developing countries including India about statistics on pain or its management. With a considerable increase in life expectancy in the past decade, India has witnessed an unprecedented rise in the ailing population, who are struggling to get adequate treatment for pain (National Research Council 2012). Studies from the developing world that focus on pain tend to come from the better-resourced, mainly urban centres, and are unlikely to represent the real situation in rural clinics, where conditions are largely unreported but are expected to be considerably worse.

According to the Global Burden of Diseases (GBD) survey, low-back pain (LBP) and migraine were among the top five medical conditions resulting in years lived with disability in the Indian population in 2013 (IHME 2013). In India, around 100,000 patients with cancer or HIV-AIDS die every year with inadequate pain treatment (Human Rights Watch 2011). A telephonic survey conducted in eight cities of India in about 5,000 individuals revealed point prevalence of chronic pain as 13 per cent, with 30 per cent of the patients having to go without treatment and 56 per cent reporting unsatisfactory treatment. The majority (68 per cent) of respondents were treated for pain with over-the-counter (OTC) drugs, and most (95 per cent) were taking non-steroidal anti-inflammatory drugs (NSAIDs), which are known to have many adverse effects if taken on a long-term basis without medical supervision (Dureja et al. 2014).

The main aim of this chapter is to give a perspective on different factors which are thought to contribute to the management of pain in developing nations like India. A multitude of factors make the implementation of pain management modalities difficult, as described here.

Lack of awareness

First and foremost, there is inadequate awareness about the consequences of untreated pain. Next, there is a lack of awareness about the pain management options available at various levels in society. This is not just among the lay population but also among healthcare professionals, right from primary care physicians, hospital doctors and paramedical staff, to government officials and policy-makers.

We try to create patient awareness by highlighting any newer treatments in print or digital media and distributing information brochures. There has been an improvement in levels of awareness over the past decade and active requests are being made by patients for getting their pain controlled after surgery or during chronic illnesses.

Another concern stems from the lack of awareness about the use of irrational and inappropriate multidrug prescriptions in India. NSAIDs are the second most commonly prescribed drugs in India (Patel et al. 2005). Rampant polypharmacy, coupled with lack of awareness has had a huge impact on analgesic efficacy and presents tolerability issues (Shalini and Joshi 2012).

Communication and language barriers

India is the world's second-most populous country after the People's Republic of China and home to 17.5 per cent of the world's population. It has a massive and ever-growing population of 1.35 billion, spread across 28 states and nine union territories. Different languages in various geographical regions makes communication difficult in India. People communicate in nearly 114 different languages with 22 being official languages. There is still a significant proportion of people who only communicate in their mother tongue. If a clinician or healthcare worker does not use the same language as the patient, it can lead to an inaccurate interpretation of pain. In India, there is a huge rural population where even the same language has some unusual words which may be sometimes difficult to understand. Patients are often asked to rate their pain on a scale from 1–10: mild (1–4), moderate (5–6), and severe (7–10). Sometimes images of smiling and frowning faces are used as visual aids to help both doctor and patient convey what the numbers signify. To make it simple for illiterate and rural populations, we also have a Rupee scale or 100-point pain assessment scale comprising 0–100 points, paralleling the currency (1 rupee comprises 100 paise).

It is equally challenging to address pain in patients with cognitive decline or difficulties in expressing pain for other reasons.

Cultural beliefs

As in many other cultures, in India pain is an expected and accepted part of everyday life. People of many faiths and cultures came to India as invaders, tourists, refugees or seekers of spiritual peace and wisdom, but ultimately, they were all assimilated into its vast cultural unity and heritage. Throughout its long history, Indian people have been deeply religious and spiritual, and have exhibited unique character in multiple facets of life as depicted in Fig. 18.1.

The great saints, preachers and philosophers have always been an integral part of composite and common Indian heritage and culture. The Vedas, the Gita, the Ramayana, the Qur'an and the Bible are held in great respect by people of different sections and classes of the country. The belief in karma, or repercussions for actions and errors of judgement in past lives is strong. This leads to the misconception that pain is a part of the suffering attributed to one's past deeds.



Figure 18.1 A traditional Indian dance form called Bhangra from the northern state of Punjab. Photographed by Preeti Doshi in 2015 in Mumbai, during the cultural evening programme for an interim meeting of the World Society of Stereotactic and functional Neurosurgery. © Preeti Doshi

This not only delays seeking medical advice but also poses a barrier to accepting it. In some cultures where evil spirits are believed to cause illness and pain, patients talk about their suffering as punishment. Stoicism exists in many Indian religions (Green et al. 2003). Stoicism in the face of pain is common among Buddhists, who believe acceptance of suffering leads to spiritual growth.

An understanding of the impact of culture on the pain experience is important in assuring effective and culturally sensitive patient care.

Behaving in a dignified manner while being in pain is considered very important in Indian culture, and a person who is assertive or complains openly is considered to have poor social skills. This often results in underreporting and chronification of pain.

Superstitions and myths

In rural areas superstitions frequently overrule the implementation of proper medical management, and patients in pain are subjected to

age-old traditional treatments like branding. They also believe in special herbal topical creams or *lep* (a local term) which have doubtful efficacy and can sometimes even be harmful (Bateman, Chapman and Simpson 1998). There are many spiritual leaders called tantrics who often claim to have a solution for every ailment. This may actually deter patients from seeking the correct medical assistance.

There is a prevailing notion in the Indian population that allopathic medicines have many adverse effects and should be avoided as far as possible. Patients have reservations about common interventions for back and neck pain such as epidural steroid injections. They often believe herbal or ayurvedic treatments are safer and work on the root cause to cure the problem. As a result, these are more widely accepted in spite of a high failure rate. In this process they often get exposed to toxic minerals found in many of these ayurvedic products. Some believe in naturopathy and dietary restrictions like avoiding sour foodstuffs which are believed to worsen joint pain. Gold-standard analgesics like opioids (even if genuinely required) are avoided due to the fear of habit formation/addiction. Misconceptions regarding the regulations governing opioid use also exist (Wolfert et al. 2010). Many individuals, including some medical practitioners, think that taking opioids is only justified in a dying patient. Very often the relatives may resist administration of opioids too out of concern that the patient may think they are nearing death.

Patient acceptance of drugs and techniques for pain management

The literature on the variability in pain tolerance or thresholds shows that it is not necessarily a geographic phenomenon but more of an individual one, and is influenced by many factors, not least context. Patients and relatives are often reluctant to agree with the drugs prescribed by the pain specialist such as opioids for the fear of risk of tolerance and addiction. Financial barriers could also result in reduced adherence to treatment, as many patients do not have health insurance and have to pay out of their own pockets for medical care. Even patients who have health insurance cannot cover all the treatment costs. This sadly applies to many cancer patients where 60–90 per cent suffer pain in the terminal phase of their illness. They hardly have any funds remaining to treat pain (particularly for implantation or neuromodulation techniques), having spent their funds for other

initial 'curative' and expensive therapies like oncosurgery, chemotherapy, radiotherapy and others. Most Indian patients do not accept advanced implantable pain therapies. This is for various reasons, including the high cost involved in implantation and maintenance. It can also be attributed to the unrealistic expectation of the patient, such as complete and lifelong relief.

Competing priorities for different diseases

Developing countries are passing through disease pattern transitions in which many infectious diseases like malaria, tuberculosis, gastroenteritis, arbovirus infections, hepatitis, acute respiratory infections and viral haemorrhagic fevers have not yet been completely controlled. The lifestyle diseases of the developed countries, like coronary artery diseases, hypertension, diabetes, obesity, cancers, degenerative neurological and other system diseases, have also made their appearance. Due to the burden of infections, malignant disorders, cardiac and nervous diseases and trauma, the meagre financing earmarked for health (1–2 per cent of GDP) of countries like India is largely prioritised for these conditions (Ghosh 2016). Being both invisible and perceived as non-life-threatening, pain always takes a back seat.

Lack of optimum healthcare infrastructure

The perceived poor quality of government healthcare directs people to private healthcare facilities. About 80 per cent of doctors and 60 per cent of hospitals belong to the private sector. But the population below the poverty line cannot afford treatment at private hospitals. Healthcare infrastructure is often poorly developed in rural areas where the majority of India's population lives. There is a lack of structured pain management services in most government-run or public hospitals and rural locations.

There is poor pain management for acute, trauma and labour pain, leaving aside chronic pain which has worse repercussions. The lack of obstetric services in India results in the unmeasurable suffering of mothers, most of whom have no access to basic medical care, let alone analgesia. The situation in many rural hospitals is likely to be that no analgesia is available to women with either normal or complicated labours. Acute pain is treated sub-optimally, leading to the emergence of chronic pain. Palliative care and hospice care facilities are very

scarce. There are, however, a few dedicated hospice centres, such as India's first hospice, Shanti Avedna Sadan, an institution that takes care of advanced terminally ill cancer patients. It offers the specialised care of a hospital together with the love of a home. Monitoring of pain as a fifth vital sign (which can make pain more visible) is only implemented in a few tertiary-care private hospitals. The concept of a dedicated pain nurse is almost non-existent.

Pain education, which is recognised as being essential in medical and nursing schools at undergraduate level, is not available at this level, nor at postgraduate level in India.

There have been ongoing proactive efforts over the past decade to overcome many barriers and to improve these facilities for the benefit of patients. The Indian Society for the Study of Pain (ISSP), which is a multidisciplinary national body (an Indian chapter of the International Association for Study of Pain comprising nearly 2,000 members), has recently launched a structured one-year fellowship programme to train doctors in pain management and certify them as Fellows of the pain academy after an exit examination. My centre, namely Jaslok Hospital and Research Centre in Mumbai, is a tertiary-care hospital with availability of most super-specialities and various unique speciality clinics in addition to pain clinics such as a spasticity clinic, pelvic floor clinic and paediatric rheumatology clinic, while also being an accredited centre for a Pain Fellowship programme. At the time of writing we do not have any structured training programmes for nurses who actually form the first contact points with the patients.

Cognitive and behavioural therapies are essential for chronic pain management and yet at present are scarcely available in India.

Access and availability issues for drugs and technology

In India, the availability of drugs and varying formulations is a major problem. We do not have the desired concentrations, formulations or varieties of useful drugs for pain management. Drugs used for specific pain types, like ziconotide or 8 per cent Capsaicin patches for neuropathic pain, are not currently available in India, limiting adequate pain control. Preservative-free drugs like steroid formulations (for epidural or intrathecal space administration) are not freely available or of questionable quality, creating safety concerns.

The need for palliative care is expanding due to the ageing of the world's population and the increase in the rate of cancer in

developed and developing countries. The World Health Organization (WHO) estimates that more than 60 per cent of the 14 million new cancer cases worldwide in 2012 occurred in developing parts of the world (WHO 2015). Incidence of pain in advanced cases of cancer is 60–70 per cent. Lack of preventive strategies, poverty, illiteracy and social stigma are the biggest causes of patients presenting in advance stage of their disease. A huge gap remains between demand and current palliative care services in developing nations such as India. In spite of being home to one-sixth of the world's population, less than 1 per cent of India's population has access to pain relief and palliative care (Rajagopal 2015). It is paradoxical that in spite of being one of the largest opioid exporting countries, a very small fraction of opioids are available for medical use within India.

Opioid availability has been made difficult by bureaucratic laws. At present, morphine and Fentanyl are the two main opioid drugs available. Useful compounds like oxycodone, hydromorphone and methadone can be of immense help in specific situations. The choice of opioids in the Western world is vast, making therapy more versatile and patient-centric. In 1985, the draconian Narcotic Drugs and Psychotropic Substances (NDPS) Act came into existence (Joranson, Rajagopal and Gilson 2002). In the 13 years which followed the enactment of the NDPS Act, morphine consumption in the country fell by an alarming 92 per cent – from around 600kg to a mere 48kg. In 1997, India's per capita consumption of morphine ranked among the lowest in the world (113th of 131 countries). During the same period, global consumption of morphine had increased by 437 per cent. Various societies were formed for encouraging palliative care. Many activists struggled together for the same cause for years and fought to provide a very basic human right. The year 2014 saw a landmark action by the Indian Parliament, which amended the NDPS Act, removing many of the legal barriers to opioid access. Due to the untiring efforts of healthcare activists like M. R. Rajagopal from Kerala (who founded the NGO called Pallium India), the Medical Council of India (MCI) in 2010 accepted palliative medicine as a medical speciality and announced a postgraduate MD course in the subject. In addition to implementing the establishment of palliative care services, the National Program in Palliative Care (NPPC) had recommended undergraduate medical and nursing education which is yet to be implemented.

Lack of standardised uniform practices and national guidelines

Another barrier to implementing good pain management is the absence of any national guidelines on treating different kinds of pain. We do not have any consensus on practice of pain interventions. Just to give an example, epidural steroid injections (ESIs) play an integral role in the algorithm for non-surgical management of chronic spinal pain. ESIs are also considered the most common intervention in the armamentarium of a pain physician globally, with significant diagnostic and therapeutic utility (Doshi and Makwana 2009). The use of ESIs varies in different centres and different states according to several factors, such as training, resources, perception of patients and referring physicians. There are several centres which continue to practise blind injections of epidural steroids with lack of desired outcomes, yet if image-guided injections were given the outcomes would be better.

Lack of penetration of insurance services

Indian insurance companies do not accept most pain management interventional procedures as being eligible for reimbursement. Severe refractory pain – which may mandate implantation of advanced pain therapy implants like spinal cord stimulators, cranial or peripheral nerve stimulators or intrathecal drug delivery pumps – cannot be offered to many deserving patients. The reason is that these devices are expensive as they have to be procured from countries like the US and are not affordable for most of the population. Insurance companies do not approve reimbursement for these devices.

Conclusion

To conclude, pain management in developing nations like India still remains a major challenge. As efforts to spread awareness about pain management are increasing, we hope to improve the quality of care and reduce suffering in patients with pain of any kind.

The following measures are among those needed to take this objective forward:

- a) Pain awareness should be enhanced at all levels.
- b) Pain medicine should be recognised as an independent speciality.
- c) Pain education should be made mandatory in medical and nursing schools.
- d) Pain should be considered not just as a symptom but projected as a neurological disease.
- e) Healthcare professionals should be more vigilant to monitor and treat pain at the earliest time point to prevent chronification.
- f) The attitudes of healthcare leaders and policy-makers must change to improve resources for pain care.
- g) National guidelines and uniform protocols should be customised for optimum pain management.
- h) A team approach should be promoted, and all related disciplines involved to optimise pain management.

Since the experience of pain is heterogenic in nature, a 'one size fits all' approach may not be the ideal way to manage pain. In short, an individualised approach to treatment based on the genetic, cultural, social and behavioural aspects of the patient may help in the optimal management of pain across different clinical settings (Kim and Dionne 2009).

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Disabled lives with an undercurrent of pain

A Hindu perspective and first-person testimony

Abha Khetarpal and Satendra Singh

Living involves pain. No one can negate the fact that pain is an inherent part of human life. In particular, the lives of people who live with a disability are likely to have an undercurrent of pain.

Since physical disability can bring atypical physique, the medical model considers disability to be a *part* of an individual, as opposed to the social model of disability which says people are disabled by barriers in society and not by impairment or difference. According to common medical perception, both disability and pain originate in the human body. However, if we take a closer look we find that pain and disability are both subjective experiences of life, not objective facts of the body, and are mediated by many factors. Two individuals with the same kind and same degree of pain and/or disability may experience it differently. Both are often related not only at the physiological, neurobiological, psychological and behavioural levels, but are also inextricably intertwined on the social, cultural and economic planes.

Sometimes pain and disability become both the cause and effect of each other. This chapter explores the relationship between pain and disability.

At the physiological and neurobiological levels

Pains leads to disability

Sometimes pain leads to disability and reduces quality of life. At other times disability causes pain.

Chronic pain can lead to disability in patients with low-back pain, arthritis, whiplash injury and fibromyalgia to name just a few conditions. In such cases the relationship between pain and disability is not distinct. Pain has emotional and behavioural consequences, as does disability. Psychopathological symptoms and depression add to disabling conditions. There is a complex interplay of factors such as self-doubt, emotional distress and negative beliefs (Fisher and Johnston 1998).

Disability leads to pain

Physical disabilities result in physical pain due to tissues and nerve damage, stiffness or muscle spasms, for example phantom pain in amputation, neuropathic and nociceptive pain in multiple sclerosis, overuse and biochemical pain in post-polio syndrome and muscular dystrophy, neurogenic and visceral pain in spinal cord injury, as well as pain associated with multiple fractures in osteogenesis imperfecta.

At the psychological and behavioural levels

Most Hindus approach their experiences with pain, in terms of understanding and coping with it, differently from many in the West. They consider suffering, whether physical or mental, a natural result of inappropriate actions – karma. Disability and pain never occur randomly. They occur in response to negative and unfavourable behaviour in the past. Some embrace suffering as a positive way to progress on the spiritual path. Acceptance is a central concept of the Hindu tradition. Most Hindus believe acceptance of pain and detachment from any struggle will help them surrender to the Almighty. A man with no hands might accept his condition by consoling himself that this is God's way of stopping him riding a bike so that an accident could be prevented (Chandrakumari 2017).

Suffering is seen as a part of living until one finally attains *moksha* or salvation. Hindus are taught not to blame circumstances but accept the current situation as a result of our soul's actions. So, the threshold for tolerating suffering and pain is quite high. Our current pain and suffering compensate for the debt incurred for past negative actions. Hindu philosophy believes that though the body may be impacted by pain or disability, the self or the soul remains unharmed by anything (Whitman 2007).

Often, patients with chronic pain turn to religious or spiritual practices as a means of coping. One can alleviate the fallout of past karma and improve present and future karma by good deeds. But the law of karma sometimes leads to adverse effects by arousing feelings of guilt because of past misconduct, crime or offence. However, it can also be comforting and enable an individual to accept their condition with composure and calmness. Equipose and surrender to the will of God also help people cope with disability. For Hindus, the true solution to suffering lies in detachment, renunciation and the absence of desires.

Disability also involves caregivers, a rehab team and family members. For them and other people around the disabled person, supporting persons with disability gives them an opportunity to gather good karma for their next life. Disability then becomes a warning sign for the non-disabled to be humble, respect others and perform charitable acts.

Thus, Hindu religion and philosophy convinces and consoles disabled people about their pain and desperation. This psychological defence mechanism makes their lives easier. But the problematic aspect of such beliefs concerns not the disabled, but the non-disabled who blame the disabled person for their condition. Many prejudicial practices against the disabled often have such doctrinal justification (Press Trust of India 2015).

In choosing to suffer as reparation for a karmic debt, a believer might fast to please the Gods, turn to unconventional treatments for their body parts or refuse steps to alleviate pain. Enduring pain, problems and miseries is then taken as an obligatory duty and sacrificial offering to God.

According to Hindu philosophy, one must accept both pleasure and pain as the 'play' or *leela* of God. Though this does not eliminate pain, it does help an individual to handle pain in a more comfortable way. Only a true devotee will accept the most severe pain and suffering as the play of God. People are taught to believe that God plays multiple roles and takes on all human forms, and so even the most unbearable pain is given by God in order to test their endurance. As Swami Vivekananda says: 'What we want is neither happiness nor misery. Both make us forget our true nature; both are chains, one of iron, another of gold; behind both is the *Atman* (Spirit)' (Pett 2012, 443). Unfortunately, Hinduism does not give an answer to why there is suffering, but teaches its followers how to live with it.

Cognitive and emotional factors significantly impact on experiences of pain in many conditions. People with disabilities need to adjust not

only in their own families but also to confront cross-cultural issues. Every now and then we sense negative attitudes in society towards all persons with disability. Disabled peoples' way of life and living becomes different, absorbing a lot of emotional pain while enduring the process of adjustment and readjustment. Disability threatens their concept of self as a member of society, which constantly perpetuates the ideology of normality. Because of various barriers, especially attitudinal ones, in the sociocultural framework, persons with disabilities frequently face negative emotions.

The pain of negative emotions

Disability and disabling conditions not only result in physical pain but also emotional pain. Pain, distress and suffering are interconnected and sometimes overlap, especially in the case of persons with disabilities. For them life can be a rollercoaster. Their level of impairment often gets intrinsically linked to their emotional and cognitive characteristics.

On the other hand, negative emotions may cause not only emotional pain but become a reason for physical pain as an individual becomes emotionally vulnerable. Loss of life purpose, decrease in self-esteem, sadness, worthlessness, anger, frustration and loneliness may lead to depression, which can lead to psychosomatic as well as physiological pain. A vicious circle is formed, and all the factors get intermingled, complicating the sufferer's life further in many different ways. According to some psychoanalytic frameworks, psychosomatic disorders have physical symptoms that originate from mental and emotional causes. For instance, constantly overcoming obstacles causes headaches, neck pain is caused by resentment that hurts and upper back pain is caused by not feeling or being appreciated or by fear of love. Research emphasises the role that negative emotions play in the psychology of disabled people and in turn it may affect the way in which they experience their physical impairment (Park, Faulkner and Schaller 2003). Emotional pain may create more havoc than physical pain as the former can directly affect emotional health. Sometimes chronic illness, disease or disability is not a problem; living itself becomes a problem with the baggage of social and emotional pain which disability carries with it.

Let us now turn to examine how some negative emotions cause painful experiences in the lives of persons with disabilities.

Pain of injustice

From misdiagnosis to blatant cruelty, persons with disabilities suffer various kinds of injustice. Persons with mental disabilities are the worst hit. The pain of injustice creates further disconnection. There is a constant violation of even basic human rights like the right to movement, the right to have meaningful relationships, the right to have a means of livelihood, the right to choose and the right to privacy. They are confronted with frequent aberrations of status or rank and challenges to equity norms. Not only this, we can find contempt for the disabled even in our everyday language. Sometimes the language that is used is full of pejorative metaphors about a group of people. Words like 'retard', 'dumb', 'handicapped', 'crippled' and 'imbecile' are used as metaphors in our everyday speech and damage the self-esteem of persons with disabilities, which in turn can have real-life consequences. In Lind and Tyler's words, 'if losses are perceived as undeserved, it is possible that individuals will experience their life situation as unjust' (Sullivan et al. 2009, 238). Unfair rules, poor treatment by family or friends, or increased workload result in feelings of injustice. Sexual and domestic violence against women with disabilities is pervasive (Martin et al. 2006). Perceptions of injustice can result in more severe pain, the persistence of post-traumatic stress disorder and more functional limitations (Sullivan et al. 2009). There is an internal turmoil throughout the situation of unfair treatment. The increasing incidence of disability hate crimes evidence the gross injustice faced by persons with disabilities.

Anger intensifies but is in turn suppressed, or in other words the tendency to keep anger 'bottled up' increases with every single act of injustice. Both the escalation of anger and the coping mechanisms adopted are associated with more negative pain outcomes.

Pain of discrimination

Discrimination is a form of social injustice, and a violation of the principle of equality. Various barriers faced by persons with disabilities constitute different forms of discrimination. Whether it is in education or employment, persons with disabilities suffer the most. Discrimination can cause significant psychological pain. Anger due to frustration has the risk of being pathologised into mental illness. Stereotyping by media and ableism are the root causes of discrimination. 'Micro-aggressions' or subtle forms of discrimination can cause confusion and a sense of inferiority. In the absence of 'reasonable adjustments' to combat such

blatant forms of discrimination, persons with disabilities feel left out and hurt.

Whether an individual with a disability goes to a grocery store, a cinema, a shopping mall, a pub or a government office, people harbour an inherent bias, considering the person mentally incompetent. Whether one wants to drop the kids off at school, take public transport or attend a function, one cannot enter the premises because everywhere there are those discriminatory stairs. This is architectural discrimination at its worst. Even if an individual with a disability has a modified vehicle, it is very common to see non-disabled individuals park their vehicles in 'accessible' parking spaces.

Pain of guilt and worthlessness

There is a psycho-ethical struggle with guilt because of an inability to play specific roles during the lifetime. For instance, a person with a disability might be unable to carry out the role of a father, a mother, a son or daughter as per sociocultural norms. Guilt can lead to painful consequences, and remorse and anguish can start nibbling at the conscious mind. Self-condemnation sets in. Pain gets embedded in the psyche. It takes a lot more energy to store pain than it does to confront it. The pressure, strain and effort of locking the doors of an emotional repository take their toll in physical terms.

Pain of rejection

Rejections are the most common emotional wounds that persons with disabilities sustain in their daily lives. Studies have shown that physical pain is aggravated by social rejection (Chow, Tiedens and Govan 2008). Physical disability leads to maladjustment of the disabled person due to inaccessibility and various other barriers. Rejection comes in the form of exclusion of the individual from almost every sphere of life activity, whether it is political or economic participation, a loving relationship or long-term friendship. The individual with a disability feels rejected and left out of mainstream life. Disability of any kind has the effect of cutting the person off from society and compels the individual to bear the painful sting of rejection from an unaccepting world. Social rejection has the potential of inflicting a great amount of psychological damage. Often disability slurs are used. People with disabilities are portrayed as evil, broken, dangerous, pitiful and tragic. Rejection is most common in the area of forming loving and sexual

relationships. People with disabilities are often treated as asexual, undesirable and even freaks.

What can be more painful than when families and societies defeminise women with disabilities? Only a person who has experienced an acid attack can imagine the pain and sufferings of survivors. Physical wounds might heal or people might learn to live with their scars, but the mental and emotional trauma devastates them. Their burned skin, lost organs, lost eyesight makes them deviant in the eyes of others. The pain of rejection and their inability to get absorbed into the mainstream become the greatest hurdles in their lives.

The Rights of Persons with Disabilities Act 2016 also addresses acid attack victims, and for survivors, there is a long and painful journey to rehabilitation and reconstruction. For them rejection comes in various forms, sometimes even at beauty salons. Marriage and romantic relationships for many of them remain a distant dream. Body images, whether from disability or from anxiety disorders, become distorted due to deformities and use of assistive devices. Even the individuals themselves distance themselves from their own self and from their body due to inferiority complexes and not having 'ideal' and 'perfect' bodies.

Pain of isolation and loneliness

We all know that loneliness hurts. Humans are fundamentally social beings who require social interaction. Indeed, if stable, positive interpersonal relationships are not maintained, people suffer both physically and psychologically (Baumeister and Leary 1995; Cohen 2004).

The absence of social connections causes pain. Social Pain Overlap Theory (SPOT) proposes that social pain and physical pain share the same neural structures (Eisenberger and Lieberman 2004). Social pain is 'the distressing experience arising from the perception of psychological distance from close others' (Eisenberger and Lieberman 2005, 112). This is what really happens to a severely disabled individual. The 'othering' of people with disabilities is deeply ingrained in the majority of our society (Leary et al. 1998). The attitudinal barrier of 'us' versus 'them' draws a sharp line. The absence of inclusion and accessibility can leave them isolated from mainstream society. People carry several extra burdens of disclosing their disability, especially when their disability is invisible. They have limited community facilities and opportunities to engage in social activities. There is an absence of friendship and meaningful loving relationships. Many relationships don't get past the first date.

Relationship of pain, disability and gender

Body defects and personality are often related. Physique even decides the criteria of class and caste distinctions and thus also carries social significance. Even common variations carry negative impacts on personality formation.

Women with disabilities remain doubly marginalised due to their gender and disability. It has been seen that disabled women are more vulnerable to domestic violence and sexual abuse (United Nations Population Fund 2018). In conservative families and cultures, women with disabilities grow up as an object to be hidden from the world. Families don't want to disclose their disabilities. Thus, they remain uncounted, unseen and unheard. Studies show that most of them remain unemployed, underemployed and uneducated. The pain of injustice, isolation and rejection is thus increased. Social and psychological distancing cause greater psychosocial problems which remain largely neglected, leading to depression, stress, lowered self-esteem and social isolation (Nosek et al. 2003).

As far as men with disabilities are concerned, especially those who rely upon assistive devices, it is difficult to attain the image of a macho man who is independent, dominant, well built with an athletic body; these are some of the characteristics linked with masculinity in our society. This stereotyping threatens to have a harmful impact on the psyche of disabled men, questioning their very position in mainstream society.

Growing up as a woman with disability in India: A personal testimony

Half of my polio life I have lived without the slightest flicker of a barrier-free world. Growing up in the 1980s and '90s, people with disabilities were invisible. Inaccessibility and exclusion gave a feeling that you are unwelcome. The daily routine was suffused with this discrimination, which is nothing less than social oppression. How could I feel accepted?

I was taught that success for me meant hiding my limitations. I was trained to overcome my physical shortcomings and in due course it all became a part of my identity. Childhood was lonely without age-appropriate activities. School applications were rejected not because I had a low IQ level but because of the school authorities' unwillingness

to provide accessible infrastructure. During my teens, tough rehabilitation therapies formed a major part of my daily routine. The implicit message that I received during those therapies was that I was deficient and abnormal and in order to become 'normal' I would have to 'overcome' my disability. But I was aware that my disability and the deformity of body wouldn't be 'fixed'; the therapies were just meant to keep things from getting any worse.

Throughout my life I have felt a continued pressure to succeed, if not excel, in the mainstream. I realised that reduction of activity could immensely affect an individual's role in the family and society. There were alternate bouts of anxiety and depression. Being a polio survivor, I can easily affirm that pain is strongly related not only to anxiety but also associated with depressive conditions.

During adolescence and early adulthood, I found my braces to be a kind of cage. Every day I was chained and bolted inside a bizarre exoskeleton that circumscribed my sexuality. I had to struggle with my body image when I had to wear those full-length bilateral callipers with a Milwaukee brace attached to them to manage the curve of my spine. With developing breasts and hips, it was all very painful as they used to jerk achingly against the brace. To accommodate the new growth either the screws had to be adjusted or new measurements had to be taken by male technicians who plastered the naked body.

The brace became the most noteworthy physical object of my entire being. With those huge and heavy braces my disability became significantly visible and I used to become an object of pity as soon as people on the street stopped and turned back to look at me. Sometimes prejudiced, sometimes dismissive, their constant gaze manifested everything. I used to have mixed feelings of horror and anger. It was as if I were alone against the whole world.

Being used as a living case study for medical students gave me a constant feeling of being isolated and separated from my peers. My deformed body parts were frequently photographed as I was an 'interesting case'. As a growing teenager I had to stand unclothed in front of male doctors as an example for their 'studies', absolutely ignoring my existential experience. Girls curve their backs to look sexy. But if they curve it too much, it is considered deformity. I had scoliosis and a Harrington rod was implanted in my spine. This has left a giant seam-scar running up my back for the last 38 years. I had always wondered whether my struggles with body image, physical pain and depression could fit into a perfect person's profile. I did not fit the stereotypical framework of being 'good looking'. Quite often the pricking

pain of rejection by the opposite sex brought a feeling of psychological distress. Until middle age I had to wear that 'involuntary chastity belt' and had to resist my natural urges and impulses. All this caused a whole lot of psychological pain.

I was not able to carry out gender-specific roles as expected by the dominant culture. I internalised that guilt which, I now realise, was immensely painful. Disability is often seen as a 'deficit', and women with disabilities are not able to fulfil the criteria of 'ideal bodies' present in the dominant culture. We thus lament the loss of the dream of the 'body perfect' and 'a perfect life'. Some of us go through the difficulty in having others identify us as 'female'. The same happened to me.

Being a disability rights advocate at present, I still have to bear the brunt of widespread discrimination prevalent throughout society. There is a definite distaste about disabilities in our society, which shows an intense obsession with the body beautiful. We are worshippers of youth and vitality, and therefore the disabled remain dehumanised and marginalised in our society.

Double discrimination against women with disability

Emotional pain that remains invisible becomes a part of people with disabilities, particularly women who are sexually confined and abused. There are numerous examples where girls and women with disabilities have had to suffer silently.

When girls with disabilities reach puberty, family members look for ways to shield them from sexual exploitation and unwanted pregnancy. The deafening social silence regarding hysterectomies or abortions after abuse calls for contemplation. One such incident became public in Pune, India, when forced hysterectomies were conducted on women with psychosocial disabilities (Sreedharan 2013). The practice continues in certain places, with parents surreptitiously forcing daughters to have hysterectomies without their informed consent.

I recently met a girl around 30 years old who has spinal muscular atrophy. Her uterus was removed by her parents when she was in her teens just to manage her periods. In yet another incident, a girl in her early 20s who is a polio survivor was pressurised into living a life in a religious institution so that she could remain close to God and improve the karma of her present life. Another hearing- and speech-impaired girl was raped in a prison van by two policeman in Kolkata. When an activist approached the police station, the officer in charge

refused to register the case, stating that ‘deaf girls are more sexually active and the victim started this so it cannot be treated as a rape’ (Masoodi 2014).

As a doctor with disability: A personal testimony

While growing up in medical school, I ignored the lived experience of being disabled and avoided talking about ableism or calling myself ‘disabled’. There was a denial of disability. I was content and grew up with this identity and the medical model of disability (Singh and Gupta 2016) substantiated it. It took me years to extricate myself from this internalised prejudice. This was how our medical curriculum was fostering ableism unintentionally, and medical students like myself harboured the pain of guilt and worthlessness discussed above.

I finished my medical studies and Master’s and joined as faculty in the constituent medical institution of the University of Delhi. The tipping point was when I applied for the same faculty post under the Ministry of Health and I was rejected because of my disability. This time I realised that I could stand up for my rights even though I could not walk. The pain of discrimination activated my disability identity. I faced discrimination in employment, fought and my success opened up 1,674 faculty posts for doctors with disabilities (Nagarajan 2015). By fighting discrimination actively and channelling the pain of my discrimination I was able to bring policy change and reforms.

This marked my eureka moment, which also gave birth to my disability rights activism (Singh, 2017). I realised that people only have impairments, it’s society which makes us disabled through its barriers, which may be physical, a lack of information or the barrier which I faced – attitudinal. I championed the social model of disability and fought many battles to dismantle physical barriers; a directive was passed by statutory bodies to make all medical institutions accessible (Bhatnagar 2013), and all information and communication services (from hospitals to elections) accessible to visually and hearing disabled people (NDTV 2014).

There was a turnaround in my approach. The same issue which I ignored in my medical studies, and which my co-author faced during medical examinations, was now a glaring ethical violation for me. To respect autonomy and maintain the confidentiality of patients with disabilities, I petitioned against the unethical practice of affixing

photographs showing disability in disability certification. The practice was stopped as a directive was passed to withdraw such discriminatory proforma in medical examinations (Perappadan 2014).

Nothing about us, without us

The social model was massively important in the British disability movement, as it enabled the identification of a political strategy (barrier removal) and considered disabled people as the real experts on their lived experiences. However, the majority of the time, these real experts are not consulted, which leads to the pain of injustice. The Medical Council of India (MCI), in a major overhaul, revamped its entire medical curriculum into competency-based medical education in line with global standards. However, it still focussed heavily on the medical model of disability. This prompted me to lead a collaboration ‘Disability-inclusive Compassionate Care’ with Bucksbaum Institute at the University of Chicago to frame disability competencies for health professional educators. We consulted the real stakeholders – doctors with disabilities, disability rights activists and health professional educators – to frame 52 disability competencies, which were further refined to 27 disability competencies after getting pan-Indian feedback from the disability community (Salian 2019). This was a move away not only from the medical but also the social model of disability, as we proposed competencies in line with the Convention on Rights of Persons with Disabilities. Wearing my activism hat, I was successful in a major overhaul as MCI dedicated seven hours of disability competencies, following our human rights model of disability, into the foundation course of the new medical curriculum (Bhuyan 2019) and it was adopted across 530-plus medical institutions in India in August 2019 (Gohain 2019).

The journey is ongoing; I challenged MCI’s guidelines on disabled learners in the medical profession (Singh 2019). At the time when the General Medical Council of the UK came up with *Welcomed and Valued* to help disabled learners in medicine (General Medical Council UK 2019), MCI framed guidelines to debar learners with certain disabilities from becoming doctors. Leading a group of 75 doctors with disabilities, I was able to amend some of them (Vibhute 2018). For the remaining, I have the support of the international community as well as the Disabled Doctors Network UK, Doctors with Disabilities Australia and the US Association of Academic Physiatrists (Nagarajan 2019). This is a critical time in the disability movement as international linkages are supporting

the human rights of people with disabilities by breaking geographical boundaries.

Conclusion

We cannot separate pain and disability. We need to share pain. We need to understand the unseen, unspoken and unheard. To truly abolish all barriers that burden people with disabilities, we must bring about change. By changing attitudes and behaviour, communicating effectively, respecting diversity and becoming empathetic and ethical we can embrace this brokenness.

Representing the unrepresented is in essence a form of advocacy. It involves awareness of the pain of guilt, rejection, discrimination and injustice. To quote John Green (2014, 311), 'the marks humans leave are too often scars'. Pain nourishes courage. Pain can make you or break you. By encountering pain, by embracing our disability identity and by moving away from medical to social and human rights models of disability we can effect change. We can introduce reforms and policy changes. At least in India we are starting to achieve this.

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20

Acute pain is sexy and chronic pain is not

Language, communication and transformation

Jennifer Patterson

Introduction

Experiences, physiology, diagnoses and representations of pain are complex and layered. Pain is narrated in language that is influenced by environments, intersected by time, place and culture and is historically gendered. It is always expressed, listened to and treated through particular ways of thinking about bodies, health and illness. Thinking about and expressing pain translates sensory experience into language. In translation, pain is often reified, becoming 'a thing', rather than an experience. This gives it agency, while the 'telling' that places it in the past, present or future changes its temporal nature. Language and metaphors translate pain experiences into communications, none of which are neutral or separable from the contexts that produce them. Pain is represented and understood differently between individual people and across cultures, always in the context of the dominant medical culture. Thus, how we think and talk about pain is influenced by general cultural beliefs, and medical ones that include physiology and even traditional pain-relieving medicines. These contexts generate layers of meanings that intersect with those of individuals' patient and personal identities (and roles) through the national, individual, local and familial cultures of which each person is formed.

Patients of different genders, ethnic identities and languages require a more critical, personalised and self-referential investigative approach to research and practice for two main reasons. The first is that reflective self-critical examination offers a healthy political starting point for any consideration of something of which one is a part. The

second is that biomedicine and biomedical perspectives are themselves Western cultural products.

Of Irish origin with a background in art history and French, I research medical humanities, mainly teach applied social sciences and am also a complementary therapist and medical herbalist. Patients and their narratives are therefore central to my work. My interdisciplinary background employs Western critical and cultural constructions, usually from a feminist standpoint. I do not assume to speak for other individuals, or cultures, although some of this may resonate. Good health and care are fundamental human rights and the cultural framework of Western biomedicine challenges indigenous and traditional methods that can in local contexts, provide successful interventions for pain. By employing the interdisciplinary approach outlined in this chapter, I believe we can work more effectively and inclusively with pain and people who live in pain.

This chapter explores how meaning is made and how aspects of interpretation, translation, metaphor and intertextual communications operate within visual and verbal languages. It discusses how and why some patients make and use pain metaphors to describe how they feel and whether language might therefore carry the potential for changing experience. This examination contributes clinical tools for use in medical and nursing education that promise improved listening and communication, and offer a framework of insights from language-based perspectives on pain.

Contexts and methods

Pain is sexist, demonstrating a gender gap, with more women than men experiencing chronic pain. Women's pain is taken less seriously, with longer waiting times for treatment (Fenton 2016). Women are given less medication and there is greater variability in treatment, while more pain studies are carried out on men than on women (Fenton 2016). Research demonstrates that gender variations in the same treatment speak not only of societal and cultural attitudes and the lack of correction in health and medical education (Bendelow 2000), but also of a negation of different pain experiences. This embedded bias requires a creative feminist approach, influenced in particular by the works of Luce Irigaray¹ and Julia Kristeva.²

The Western cultural history of sado-masochism conflates representations of sexual desire and cultural desires involving identity,

religious ecstasy power games and their implications, with acute pain (Weinberg and Falk 1980; Hopkins 1994; Braidotti 2013; Carlström 2019). Why is this, when images and discourses of chronic pain are largely hidden, ignored, responsible for illness and disability, misunderstood and often shameful?

Exploring this complex question demands a complex approach, with sustainable grounding in reviewing (deconstructing) and recycling cultural information. The individual and psychosocial nature of chronic pain is reflected here using applied critical theory in the form of a creative and adapted feminist *bricolage*, a form of purposive DIY.³ Employing this qualitative perspective reflects the tensions between the quantitative measures associated with medical sciences versus the experiences and real lives of patients.

It is some time since the work of Michel Foucault (1963) illuminated the inherent institutional power dynamics within patient/professional/institutional relationships, and their impact on individuals as they frame institutional roles and health discourses.⁴ The culturally different worlds of individuals, patients and professionals meet in complex, layered illness experiences. The real-life identities, inhabited spaces, scenes and situations and role-based performances of various actors are social constructs.⁵ They change through a wide range of sociocultural (ethnicity, class, gender), personal and familial identity-based intersections, indicating their potential flexibility.

All this talk about people and pain takes place within the wider contexts of what we believe and think about our lives and our bodies. The underlying assumption that as human beings we all have bodies that get ill and that particular illnesses require similar forms of treatment, is a biological perspective that has successfully underpinned and driven Western medicine for 100 years or more. The biomedical model of healthcare and illness has led to huge population health improvements, especially from national perspectives (Wade and Halligan 2004). This is the model whose 'seductive disruptive technologies' (Greenhalgh 2001, 39) held power in the relationship between professionals and patients. Awareness of its limitations has, however, been slowly growing, especially with reference to the psychosocial dimensions of illness, accepted for some time in health psychology and complementary therapies (Engel 1989; Sheridan and Radmacher 1992; Wade and Halligan 2004). Furthermore, the democratising influence of knowledge readily available via the internet is also changing the balance. Tensions in the shift from a singular biomedical worldview to pluralist biopsychosocial models of care align with patient demands

and economics.⁶ Economics and patient-centred approaches form the NHS framework for training interventions to improve communication problems between healthcare professionals focus on illness and disease management on the one hand, and patients and their lives on the other (Dwamena et al. 2012). Similar systemic epistemological tensions operate between biomedicine and science on the one hand, and disciplines within the humanities and social sciences on the other.

Experiences, sensations and consciousness

If pain is a bodily experience in time, its persistence over time is complex, multidimensional and culturally related to the ontological experience of being in a body.

Pain is translated, discussed and exhibited through visual and verbal communications, and expressed through body and posture with recognisable specificity (Walsh, Eccleston and Keogh, 2014). For Elaine Scarry (1985), it is ultimately also inexpressible, yet something we communicate and something that communicates to us. For Joanna Bourke, pain is not an independent agent or an ontological entity, it is an event – ‘chronologically flexible and culturally complex’ (Bourke 2014, 17). In discussion with my 13-year-old son about the peculiarities of a single word describing sensations ranging from headaches to injuries, I asked what he thought pain was. ‘It’s a construct’, he said. And from a linguistic perspective, this is important. ‘Pain’ is a broad term, a word for a sensation or experience with a periodicity that is individually and culturally constructed through communication into meaning, subject to a wide range of influences, and linked in time and space to a body. Its meanings are also powerful communications that can themselves be taken on, embodied, even affecting sensations.

‘Acute’ and ‘chronic’ are standardised medical definitions. The former is usually sudden and always self-limiting, resolving in time, while the latter is persistent over time and longer term: three months or more. As a sensation, pain has a fluidity that suggests its more verbal nature, yet it commonly masquerades as a noun, perhaps to ensure its cultural importance or because of it (Bourke 2014).⁷ Whether acute or chronic, pain occurs as a result of something. As a temporal signifier its expression represents (momentarily or continuously) the past in the present. Pain onset has always been associated with an imbalance or something wrong (transformed in some religions into a

spiritual gift, promising a better time in another world) and therefore a conundrum requiring detection, diagnosis and treatment, usually medical or spiritual. Yet, as a felt experience, pain can be viewed as a communication from another entity: the embodied mind.

Pain can also be experienced when part of the body, such as a limb, is missing, yet thinking or cognition and arguably ‘re-cognition’ brings it into consciousness. Whether pain exists in a body without a conscious mind is a contemporary debate that goes back to the divisions of mind and body derived from sixteenth-century Cartesian dualism.⁸ However, the deductive philosophical processes that form the basis of Western rational biomedicine and thinking about bodies today, may be based upon a mistaken division of body and mind as separable entities rather than just materially different in form.⁹

Popular discourse on pain typically suggests it is something that makes us human, which raises questions of consciousness. As we learn more about sentient animals, so we start to question what we know about communication, intelligence and consciousness. Technology has changed our understanding of embryonic development and our knowledge about when a foetus feels pain. Thus, new technologies change both our knowledge and our thinking about consciousness and also what we believe about pain being felt.

Metaphors often combine physical and psychological pain. Pain is to be endured (stoicism); overcome or conquered (heroics); it destroys (victim) or it makes you grow and/or question life’s purpose (transformation). A common inference that pain is punishment and that life is hard in the West is derived from historical Christian ideologies, sometimes with the idea that suffering involves the cognitive recognition of pain (Bourke 2014; Dedeli and Kaptan 2013). For Aristotle, pain was an emotion in opposition to pleasure, experienced in relation to living a moral ethics of behaviour. This position indicates a fusion of mind and body at odds with later Cartesian mind–body dualism and the concept of a mechanistic body.

While pain may be a reminder of the vulnerability of the body, for many the concept of a humanising or learning benefit is also, correctly, perceived to be romanticised and offensive. In her analysis of women’s holocaust narratives, Loew (2011) discusses how as a survivor, Beuber-Neumann argues precisely the opposite. Her experience of the camps witnesses that an excess of pain removes all individual and collective human rights. Persecution, war and genocide cut through mainstream norms. Cultural pressure in the affluent contemporary Western world turns pain into something else. So, while there is nothing romantic

about chronic pain, cultural associations in literature, music and the arts also present pain-relieving drugs that cause out of body experiences as a means of creativity and escape from reality.

So far, this chapter has attempted to show how pain has been constructed in different ways at different times in mainstream Western culture, its relationship with societal beliefs, consciousness and moral concepts. It has mentioned gender and pain, and that altering perceptions of pain suggests that other management strategies will work for some people. Research shows that for chronic pain patients, having a belief system or commitment to spirituality can be both helpful and unhelpful for managing pain (Dedeli and Kaptan 2013). This research highlights a number of pain and spirituality experiments, including the positive influence of meditation practices and neurological processing differences in brain imagery when viewing religious images. Such research suggests the need for healthcare professionals to incorporate understandings of patients' beliefs, attitudes and spiritual identities or ways of life for more effective healthcare. A biopsychosocial approach to pain is therefore important.

Physiology

So, what about sex? The immediate physiology of acute pain is the same as that of orgasm but, importantly for a predominantly visual culture,¹⁰ acute pain *looks* exactly like orgasm.¹¹ Adventure sports, excitement and orgasm all trigger similar chemical signalling (Komisaruk, Beyer-Flores and Whipple 2008). Sex, death and altered states of consciousness are inextricably connected in the cultural history of pain-relieving drugs. The traditional painkiller *Atropa belladonna* (deadly nightshade) was used cosmetically to enlarge the pupils of women's eyes, making them appear desirable (Harris et al. 1985–2020). Medicinal pain-killing herbs are strong poisons with a culture embedded with gender stereotypes, myths and stories (Carter 1996). *Hyoscyamus niger* (henbane) is traditionally associated with witches, flying and sexualised out-of-body experiences.¹²

Anaesthetics inhibit the sympathetic nervous messaging system or work on the cardiovascular system (Neukirchen and Kienbaum 2008; Lambert 2011). Many herbal pain-relieving drugs (analgesics) cause loss of consciousness or death in large doses and were historically used in mainstream medicine as anaesthetics. Several are associated with spiritual and shamanic work and creative inspiration.¹³ Morphine,

today's strongest pain-relieving drug, laudanum and heroin all come from the opium poppy traditionally used for pain relief by ancient civilisations.¹⁴ Addiction to opiates is well known to have a neurological basis in the brain conflated with medicinal applications (Hickman 2010; Robinson and Berridge 1993).

As part of the wider neuro-endocrine system, the nervous system hints at the relationship between chemical messaging and consciousness and between pain and perception as thought. The death of Socrates recounted by Plato, and depicted by the French artist Jacques-Louis David, exemplifies the correlation between nervous system paralysis, living consciousness and death.¹⁵ Condemned to die, Socrates chose the nervous system poison hemlock (*conium maculatum*) to allow him to observe the transition between life and death as his body became paralysed.¹⁶

Candace Pert's (1997) 'psychoneuroimmunobiological' research on mind-body cellular communication has demonstrated that the emotions communicate with the immune system via neuropeptides (known to mediate behaviour and mood) and their receptors. Like drugs, emotions generate ligands attaching to receptors that act to shape our memories and thinking; they simultaneously activate circuits creating a 'constellation of body changes that occur with each shift of subjective feeling' (Pert 1997, 145). This changed her thinking as a scientist and has a range of implications that run in a counter-current to the biomedical paradigm. It means that we must take responsibility for how we feel, for our food and physical exercise and be proactive in our healthy habits since these things affect body chemistry (Stojanovich and Marisavljevic 2008). Living by what we believe is an ethical habit, typified by Socrates. Language can help us change our behaviours and thinking can help change our physiology.

A wide range of psychological and emotional stressors from fear and work-related stress through to physical ones – lack of food, water or extreme temperature changes – act within the nervous system as psychosocial pain triggers or contributory stimuli. Effective, successful mitigation has been demonstrated through cognitive-behaviourally informed treatment (CBT), psychological interventions in chronic low back pain¹⁷ and practice-based evidence (Morley, Williams and Hussain 2008). Research on mindfulness as an effective chronic pain management strategy similarly demonstrates that changing thought patterns have positive outcomes for pain (Kabat-Zinn 1982; Kabat-Zinn, Lipworth and Burney 1985; Morone, Greco and Weiner 2008; Zeidan et al. 2010). Changing the story is a way of changing thinking.

Languages of pain: Narrative

We make sense of our world by telling stories about it in visual and verbal languages. Narratives, the form and content of language, offer diagnostic and transformative potential for changing the whole system that is an individual, their pain, illness, experience, identity and lived life.

As a doctor and then as a patient, Arthur Frank (1995, 1) discusses how illness interrupts an individual's life story, constituting both 'a loss of destination and map' and a change of identity, potential alienation and the necessity of generating a new narrative as a way of 'thinking differently'. Frank's work identifies four broad types of story: restitution, chaos, quest narratives and testimony.¹⁸

Restitution is the belief in bodies as mechanisms that can be fixed, repaired or cured. Promoted through images of cured, happy and clean patients, it organises compliance. The promise of restitution sits behind the social control model of institutional healthcare offering cure, sometimes in relation to affordability. However, while creating a temporary performance of 'being ill', it does not represent the experience of being ill. Instead it mythologises illness as a temporary blip in the project of restoration to a previously healthy state. A lack of patient agency projects expertise and responsibility for one person's body onto another. As Foucault indicated, patient reality is distanced through an objectification of the sick body by 'the medical gaze' or increasingly today, by the alienating technological gaze of internal diagnoses (Greenhalgh 2001). In this model, self and current experience are separated in much the same way as the mind and body are distinct in the Cartesian model. An imaginary future is presented, located in previously embodied knowledge. The former model has benefits (patients become better, healthcare professionals and patients are heroic) and limitations (when its viability runs out there is nothing to fall back on; commodification and affordability of care and repair; increasing desperation and the continuing search for cure when there is none). In terms of life experience and timelines, its dependence on projecting the past into the future means that living in the moment as a conscious act cedes place and there is a potential void, since when restitution is no longer viable everyday life recedes.

The chaos narrative is presented as a metaphor of a hole that cannot be sutured, where the body is in decline and cannot be repaired. This is a space where the tidy timeline proposed by the restitution narrative is no longer valid, where telling, listening and hearing become difficult or impossible. There is a loss of time, of control

and of making sense of life with financial knock-on effects and other difficulties.

I am struck by the different experiences of two close friends unexpectedly diagnosed with cancer this year, attending the same hospital. One, whose cancer was successfully removed, saw her necessary treatment broadly as positive. It was extremely painful but structured; everyone was helpful and problems were tackled and resolved. The high potential for a cure was supported by all for a positive outcome (a restitution narrative). The other had difficult experiences, with each diagnosis being worse than expected (a litany of chaos). Notes, appointments and updates went missing. Treatment felt chaotic. The cancer grew during chemotherapy. Plans had to be abandoned, reinvented. Trying to make sense of colliding worlds is hugely difficult, indeed surreal. Without the possibility of a cure, nobody can say how fast 'terminal' is. Symptoms are mainly invisible, except from what is now experimental treatment. Her specialist nurse did not believe she was terminally ill and was unable to make conversation that communicated understanding for how she might feel. It would be easy to blame individual characters. However, from non-scientific observations while attending clinics, she faced challenges by not fitting a mainstream sympathy model based on the discussion of symptoms and experience of these as illness and wellness indicators. This model is an anti-narrative wherein care feels inhuman.

Conscious knowledge, learning from the experience rather than recovering from the illness, sits at the heart of quest narrative.¹⁹ For Frank, this is represented by 'Nietzsche's dog', the invented name for Nietzsche's pain. Frank's narrative typologies of quest, heroics and testament are problematic here. They refer to patriarchal traditions in medicine and require revision, especially on account of the patient-healthcare professional power dynamics already in play and of the heroic doctor model.²⁰ Journey narratives are not always quests. 'Quest' is a gendered patriarchal concept culturally embedded and psychoanalytically loaded. Conflated with notions of masculine power and success, its mapping of encounters and territories to be encountered and overcome on the way to a obtaining the quest object proves problematic when faced with uncertainty (Patterson 1993).

Frank defines 'testimony' as a pedagogy of suffering taught through illness stories to healthcare students, related to medical ethics and clinical relationship education. Bearing living witness as a communicative body offers value to caregivers and guides others through

overwhelming situations. Testimony follows a narrative ethic in relation to the effect of stories on our lives. It is also a social ethic in response to illness that foregrounds vulnerability and pain. As Charon affirms, it is one that has much to teach about the coherence, conflict and complexity of difficult moral and ethical decisions.

Deborah Lupton's (2012) work considers lay people's perspectives on their collapsing social worlds. These include physical changes from medical treatments such as radical surgery, the messiness of decaying and dying bodies, sexual challenges in disruptive disabilities and the labour of daily life amid embodied cancer crises. Meanwhile, bringing illness events together to form a coherent narrative is also a form of labour; a cultural brokerage undertaken by healthcare professionals. Lupton cites Reeve as establishing the centrality of emotional and embodied contexts for the formation of narrative and articulation of illness experience (Lupton 2012, 90). Such narratives create cohesion in maintaining, recreating and reforming patients' identities.

In language terms there is a chicken-and-egg question about whether thought or language comes first. This is a useful starting point for thinking about pain sensations. Experiments on pain's social aspect – whether it exists if it has never been felt – lead at one extreme into the theoretical-practical impasse of the possible non-existence of pain. 'Pain' is, of course just a catch-all word that describes sensations with physical, emotional or spiritual origins and visible and invisible sources. The etymology of the word 'pain' from the old French *peine* – or suffering, identifies it as something thought of as part of the human condition, given a religious context, retaining a weighty cultural history of religious and moral overtones.²¹ Bourke (2014) discusses representations including the personification of pain, whereby images depict small demons inflicting pain. The loss of agency accompanying such narratives implies patient helplessness. Chronic pain, like illness, disrupts an individual's life narrative. A loss of agency in a pain situation is mirrored by taking on the role of a patient, a further loss of agency within the power dynamic of the clinic. Thus, we create narratives that frame our identities and consciousness about ourselves and the world in which we live. We can recreate them in language, but also through employing other conscious and creative procedures.

Descartes' letters to Elisabeth of Bohemia in the 1600s suggest that family difficulties may have affected her health (including Charles I of England, her immediate sibling, familial problems and financial crises). Her reply looks to the wider issues of her place in the world;

her emotional susceptibility in being female (a gender issue), which she employs as a way of exploring rational embodied differences (Shapiro 1999). Frank's narratives group together internalised patterns in relation to institutional, individual and patient roles (stoic, pessimistic, optimistic; compliant, abandoned, agentic). These seem to represent stages of illness experiences, defining and creating stories and identities bound by illness. Sensitive storytelling the narrative of illness is therefore one way of considering wider challenges, of grieving, letting go and of changing what we think and know about situations. Talking therapies, psychotherapy, art or drama therapy, creative collage, writing and guided meditation, for example, offer patients ways of creating new and changing worlds. Such practices actively and creatively encourage the exploration of other realities, supporting new ways of creating changes in identity.

Languages of pain: Form – communication, intertexts and agency

We do not tell stories in a vacuum, we do so to communicate.

Until very recently, the patient's voice and language were subordinate in clinical settings. The clinician traditionally has particular frameworks for categorising pain, a range of other diagnostic possibilities (including access to different forms of knowledge and technology) and represents answers and solutions to pain. This is a paternalistic form of care. Patient utterances take the form of narratives, verbal and non-verbal responses to questions, prompts, silences and reactions to clinical examination. Recorded as a case history, patient communication is changed, becoming interpreted text. Recognition of physician care in the consultation has been changing, and many clinicians give power to the patient suffering pain. Such care is a partnership-like communication and necessitates several levels of understanding. The way a patient describes their pain may say more about them than about their pain. How what they say is understood may also say more about the person listening than about the pain. The democratisation of knowledge in the form of information available over the internet sparks a more equal conversational approach. All these features highlight the need to revalue the art of medical practice – its creativity, insight, understanding of language and of narrative.

Since patients describe pain through language and metaphors, it is useful to build critical art- and literature-based disciplines into health practice and research. Such disciplines have developed expert

theoretical perspectives on the ways in which words and images function and the networked plurality of meanings produced by reading. They offer broad and complex micro- and macro-level readings of historical and cultural linguistic entanglement. Embedded as they are with Western culture, such readings open space for other readings and cultures.

Thus, communications in a clinical context are both a performance of roles and a process of bringing things together to fit; a system of defining and refining. Psychoanalyst and linguist Julia Kristeva (1969) has called this plurality of cross-referencing 'intertextuality'. Her work is particularly useful and relevant regarding the communication between analyst and analysand, a parallel to that of patient and clinician. Intertextuality has a strong philosophical genealogy of substitution and imitation charged with dynamic power relations from Plato (*Ion*) onwards (Worton and Still 1991).

Rita Charon's (2006) work honours patients, doctors and their stories in a way that is completely different to the institutional or consumer-led management of patient experience. My experience of attending her teaching seminars is above all one of attention to textual detail that sparks multiple outcomes, all driven by improving care for patients in ways that matter to them and to healthcare professionals as people. Aiming to improve the close listening skills of healthcare and medical professionals, narrative-based analyses highlight language and narrative patterns; turning points, changes in structure, shape, metre and direction. They facilitate difficult practitioner conversations in a safe setting. Her experience in general medical practice sits behind Charon's innovative work in the US and that of Trish Greenhalgh and Brian Hurwitz in the UK (1998).

Case study

Some years ago, a young woman came for complementary therapy. She was undergoing bowel cancer treatment at a local hospital. Her narrative emerged in fragments. Hiding feelings towards her young son that upset her, she felt very afraid and also guilty. Her son was about five. She was terrified that she didn't really love him. Her story included passions and uncertainty in married life, financial worries, a change of identity and career that had come too soon and complete terror about how to cope

with her illness. She was easily tired, emotionally out of sorts and could not do all the things she wanted to do. She felt she must be a terrible mother. Guilt created a block that left her unable to face, digest and make sense of her emotions. She no longer knew who she was. Her dreams were full of disembodiment, unhappiness, absence and drifting. A detailed timeline with a case history of symptoms and clinical diagnoses revealed that her cancer had probably developed during pregnancy, something that is not uncommon. Seeing the guilt block in the context of the illness timeline made sense of her emotions and started a process of talking and changing things. Working with a psychotherapist, she was able to recover her sense of self. Today, she is happy in her family life and fully recovered from cancer.

I chose this example of working with communication because it is very clear. The patient intuitively knew (as many patients do) what the problem was but couldn't 'see' it. Her narrative involved short stories about everyday and wider life events (social, personal, familial, professional), updates and processing of this over time; symptoms of pain and aspects of her illness, diagnosis and treatment; sensations and emotions; metaphors and dream stories, as well as my observations of gaps, silences, emphases, descriptions, linguistic parallels and questions for checking I understood. She needed space to be heard and help in making sense of everything. Above all, she did not need interpretation, which would have further removed agency over her narrative and caused potential damage. Her emotions held the key, and what she couldn't say came through in dreams. For my patient, retelling dreams gave clues to terrifying emotions she could not speak about, or consciously feel. She was a shadow, a pale outline, wandering through empty houses. She was grieving, she was terrified and her ghostly image represented how frightened she was of dying. Regaining agency over her story and attending to the emotions supported her physical recovery.

'Close listening' educates the clinician or practitioner-listener to hear better. In so doing they gain a more nuanced understanding of a case, find out what matters to a patient and are better able to support what they are experiencing. Patterns, emphasis and turning points in patient narratives present what patients believe about their illness; what is entangled with it and sometimes what will help effect or blocks

change. Since the patient is the embodied expert, noticing and exploring such beliefs not only honours their expertise but returns agency to the patient. Bringing conscious attention to what they are saying can often effect a transformative experience. Importantly it repositions the healthcare professional in respect to the patient's life, rather than their illness. This affirms the patient's individual identity. As stories are individual, this form of healing demands a different approach to care; one taught through narrative (Charon 2006).

Close listening practices also enable safe spaces for professional and personal reflection, nurturing resilience by supporting an interface which is often ignored. Healthcare professionals talked through resonances from stories and poems of critical incidents, personal feelings, aspects of their own illnesses and those of loved ones – things they had not had time to fully process and that fed professional practice. Supporting the intersection of professional and personal identities involves opening the heart and this enables working with compassion towards self and others.

The aim of communication is to share or tell someone something. But if pain is a communication, who is talking and to whom? Consider for the moment that the sensory experience of pain is a communication from the body. Just as there is an aspect of communication, there also is one of translation, and of form, in the voicing of pain. This is even more pertinent when it comes to detailing what this sensation is or 'feels like'. The 'is' of pain is therefore an embodied communication, an individual's conscious recognition of the sensation, indivisible from an existential process. Much of my work as a therapist involves a process of decoding what my patients are telling me. A large percentage 'know' through the telling of pain or illness what they are saying, but have not brought it into conscious awareness and processed whatever needs to be done to change the story or the metaphor. Working in this way is highly individual.

Languages of pain: Content – codes, images and metaphors

Pain language verbalises sensations that can have physical, emotional or even spiritual origins. One means of communicating a felt sensation is to translate it into something meaningful or recognisable to others, using a culturally shared or meaningful image. Through this process pain is sometimes personified so that it is given agency. Pain becomes

represented as a causative agency outside of the body, such as the small torturing devils historically associated with Western religious pain culture (Bourke 2014), or it is given specific meaning by being allied to another sensation, such as a pinprick or the stabbing of a knife.

The nineteenth-century philosopher Friedrich Nietzsche's transformation of his pain into a dog is creative and transformative. However, Nietzsche was looking for something to vent his mood and like his mood, this pain accompanied him everywhere; it literally and figuratively dogged his steps. This strategy enabled him to use communication to change the relationship and gain an embodied understanding. However, because he made the pain into a dog, it had a certain will of its own as well, appearing as and when it wished; it was reified and had agency. Yet, making communication possible enables an agency that is more complex than it would seem since it works both for the pain and for Nietzsche. It is not by chance that Frank (1995) cites Nietzsche, since his modern ideas on emotions, pain and cognitive states are in dialogue with Classical Greek philosophy and Socratic concepts of pain as an emotive state within a moral ethics of consciousness.

Serendipitously, a Greek taxi driver taking me to the airport last year was an unemployed teacher of Classical Greek and Latin. He confirmed the etymology of the word 'metaphor' to be a very literal form of 'trans-fer' or carrying across of something, moving a cigarette package across the dashboard to demonstrate how he was literally taking me from one place to another (meta-phor). In language the use of metaphor has a particular effect. It is a way of taking something from one place to another to better express, define or communicate what is meant by something else. But language is not neutral. So, in a pain metaphor, the meaning that is carried across is contextually mediated as linguistic or visual within an embodied experience. Language often functions as a signpost indicating something that cannot be fully expressed.

Arthur Kleinman (1988) is a psychiatrist and anthropologist who works with illness and pain within wider contexts of promises, expectations and operational realities. The fictional case of Antigone Paget is an amalgam of common patient stories, an exemplar of the wider frustrations of life lived within cultural and traditional social expectations (88–9). Through this case and others, he describes patterns of illness in relation to realities of life and the lack of agency and choice, displaying a particular sensitivity to class and gender intersections.

Antigone Paget's chronic pain is 'sharp, hot, aching, tight, nagging, punishing', the result of a car accident. It is located in a 'large lump of

muscles, nerves and tendons bunched together' that goes into excruciating spasms (Kleinman 1988, 89–90). Self-descriptions of obedience, being stiff-necked and crucified relate her back pain to an inner pain, a buried hurt of frustration of desire in the absence of a fulfilling life. She is stuck in an impasse where pain mediates familial and economic conflict. The narrative work lies in listening through the patterns of entanglement and a negated possibility of opening up to a painful choice that the patient is ultimately unable to resolve. Kleinman uses the story to indicate the need for a doctor's work to include bearing witness and to argue for treatment of physical and emotional pain, for the emotional therapeutic work of grieving and remoralisation. For Antigone Paget, this is a struggle for freedom, self-actualisation and fulfilment literally 'tied up' in gender-based obligations and personal and professional frustration in the face of societal expectations. Kleinman moves with compassion and empathy between close detailed listening and empathetic broader societal understandings in which to locate and work with embodied narratives, especially those that relate to chronicity.

Becoming a knowledgeable listener requires compassionate listening, practice, patience and observation. Words embedded in the content of a story hold clues for something that needs to be decoded. Decoding the relevance of this for the teller is critical, as critical as sitting face to face and sharing breath as human beings during the consultation.

Clues to embodied emotions are different across cultures and pertain to different parts of the body. In French, 'indigestion' is a liver crisis whose pains can be burning or sharp. In some cultures, words and phrases describe mental/emotional experiences as physical harm to the body. For example, someone might say they are 'heartbroken', felt 'a knife turning in my heart', 'stabbed in the back' because of grief, cruelty, rejection or betrayal; while feeling 'gutted' can mean disappointed. Equally an unpleasant experience might 'turn the stomach' be 'stomach churning' (fearful) or leave a 'sour taste'. Other turns of phrase include being 'sick and tired of everything', 'fit for the knacker's yard' or having 'a burden to bear'. In each case it is the meaning (and damage) these hold for the patient that is key.

While a number of metaphors commonly describe pain sensations, they are not detailed enough to correlate with medical diagnoses. Pins, needles, knives and blades are sharp, slice, stick and prick. Pain eats, bores, gnaws. As images and metaphors hold clues for patient emotions, clearly, they are medically important in a wider embodied worldview.

Incredibly, modern scientific knowledge is starting to confirm some general Ancient Classical and also Eastern understandings of what we call 'embodiment'. Current research into pain and emotions, such as that of Candace Pert, sits at the intersection of modern and ancient knowledge about what being human means. There is a caveat from the sociocultural mainstream that removing pain is 'often unattainable ... [and that] it is important to realise that not all "pain treatments" are equally efficacious, and that questions must be asked regarding specificity – "which therapies, for which patients, and for what purposes?"' (Tunks, Bellissimo and Roy 1990, 2). However, there is also much that can be achieved through narrative diagnosis and medicine to support people with chronic pain.

Conclusion – diaries are written to be read ...

A word, an image and a piece of written or spoken text is a communication through language. 'Narrative' comes from the Latin, *narrare*, to tell, while the 'text', *texere*, to weave, is the result or product of the telling that emerges from processes of meaning-making. The text has arguably no meaning without someone looking, reading or listening to it. Relationally dependent, it also has a special relationship with time and philosophy. Its existential reality depends on its being experienced, within a time and experience-based ideology of perceptions and beliefs about the world. The success of CBT and mindfulness therapies in the management of chronic pain indicates the potential that changing thought processes has for changing pain experiences. Since experiences are communicated through language, it follows that changing language has the potential for changing these experiences.

Meaning exists during reading on a range of levels, through the way that words and images work. It is at once individual and communal and never neutral. Each person engaged in the process of meaning-making employs culturally mediated conscious and unconscious references. Language offers the potential for transforming chronic pain in individually different and complex ways, working together with patients and stories that necessitate careful attention, detailed listening, attention to patterns of form, metaphor, symbols and emotions, and wider understandings of the attitudes, limits and restrictions of the society in which we live.

Notes

- 1 I am indebted to Irigaray in my thinking for ideas about objectification and mirroring in her PhD work through to those on difference, visibility and phenomenology in relation to othering, and on shared breath in her later work.
- 2 I am indebted to Kristeva for her work on relationships in clinical encounters.
- 3 I adapt here Lévi-Strauss's (1962) notion of 'bricolage' in chapter 1 of *La Pensée Sauvage* as a methodology. This comprises the use of whatever materials are available, including less usual ones, as a different form of knowledge-making. See also Derrida's (1967) critique 'La structure, le signe et le jeu dans le discours des sciences humaines', published in *L'écriture et la différence*. The same volume contains Derrida's critique of Foucault on the *cogito*.
- 4 Indeed, Foucault relies on constructs of the feminine which are themselves inherently gendered (and therefore problematic) thereby replicating philosophical power structures rather than creating new forms (Braidotti 2013).
- 5 The chapter draws pragmatically and more generally on social theory throughout although with the emphasis on a linguistic and humanities focus. It is also influenced by Bakhtin and dialogic feminism in its consideration of voice and language.
- 6 Gradual recognition that Virchow's model of cellular abnormality does not underpin all models of illness led to the World Health Organization's (2001) biopsychosocial international reclassification of health and disability. While this embraces a model which is less pathology-driven and less reliant on biology, from a sociocultural perspective it still assumes an equality between what is experienced (subjective) and what is observed (physical and pathological). It does not consider cultural and gender characteristics that, from lay sociocultural perspectives, could be demonstrable for pain as inequitable discriminatory practice.
- 7 For a discussion of pain reification, see the Bourke's introduction to *The Story of Pain*, Bourke (2014).
- 8 Descartes' (1596–1650) *cogito ergo sum* ('I think, therefore I am') answers the question of 'how can I know that I exist?' And places knowledge and understanding of the world within a subjective independent mind.
- 9 See Shapiro (2007) for Descartes' discussion on the *cogito*, understandings and misunderstandings.
- 10 The 'way that we think in Western culture is guided by a visual paradigm' has been recognised for some time (Jenks 1995, 1). Work by John Berger and a range of feminists demonstrated the general non-neutrality of the eye, a further contributor to tensions between the rule of measure (as that which is perceptible by the senses) and the reality of lived lives.
- 11 Deadly nightshade (*Atropa belladonna*) is a medicinal herb traditionally used since ancient times for pain relief whose phytochemical constituents (scopolamines, atropine alkaloids) act on the central nervous system. It gets its name (*belladonna* or 'beautiful lady') from its use by women during the Renaissance to make their pupils widen attractively (as if in orgasm).
- 12 Other members of this family (tomatoes, strawberries, peppers, potatoes) are often implicated in allergic reactions.
- 13 In the EU and UK unsafe plants are subject to a range of prohibitions and restrictions, and like other pharmaceuticals available only through prescription by qualified practitioners and subject to maximum dosage regulation (<https://www.gov.uk/government/publications/list-of-banned-or-restricted-herbal-ingredients-for-medicinal-use/banned-and-restricted-herbal-ingredients>).
- 14 Laudanum is tincture of opium. Authors and poets including Thomas de Quincey and Samuel Taylor Coleridge exoticised it in their writings.
- 15 Jacques-Louis David (1748–1825), *Death of Socrates* (1787). Metropolitan Museum of Art, New York. Catharine Lorillard Wolfe Collection, Wolfe Fund, 1931. Available online https://commons.wikimedia.org/wiki/File:David_-_The_Death_of_Socrates.jpg. David's neoclassical style, the composition and Socrates' dramatic pose referenced leadership in individual moral choices when the state is unjust, in pre-revolutionary France. Socrates' upward-pointing finger indicates his engagement with moral ethics and emphasises the action of the poison, working from the legs upwards.

- 16 Ironically, as health professionals will be well aware, SOCRATES (site, onset, character, radiating, alleviating, time, exacerbating, severity) is the mnemonic for the main pain assessment framework learned in case-taking skills. See <https://www.medistudents.com/en/learning/osce-skills/other-skills/patient-history-taking/>.
- 17 See Hoffman et al. (2007) for a meta-analysis of randomised controlled trials (RCTs) on this subject.
- 18 Biomedical and legal institutions and cultures identifying positive masculine traits embed patriarchal and paternalist language frameworks and values.
- 19 See *Death of Socrates* (note 15).
- 20 See Brownmiller (1975).
- 21 In French, one is in pain, or can cause pain, which can also read as distress. Being *in* pain is a state that can be physical, emotional, spiritual, diffuse (suffering, distress, annoyance) or specific (also *mal*, sore, hurt).

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Intellectual empathy as conflict resolution in the interdisciplinary team

Tom Chadwick

Our bodies are delicate things, painstakingly tuned into the pain sensation. As children we learn through pain about ourselves and our limits. There I am, four years old, squatting down to inspect the sun-baked tarmac of our school playground and concluding with an exploratory prod of my tiny index finger that the heat had softened it sufficiently that I might safely practice my superman dives. A short run up, a flawless take-off, body arching gracefully through the air, a moment of elation in zero-gravity equilibrium. Thud. Wailing. Scene close. I gave up on the dream of flight that day.

We learn quickly that pain is a part of living. There will always be splinters and wasp stings, headaches and heartstrings. As we grow, our relationship with our pain matures and we develop our own pain wisdom. We learn the rules of pain and become skilled at avoiding it where we can. We no longer weep over a grazed knee because we understand that the pain is temporary. We know to expect it, just as we know that it soon will pass.

But when pain becomes chronic, it breaks these rules – its cause is unclear, and its end is unknown. As our own pain wisdom falters in the face of chronic pain, we seek the help of experts and in doing so we give our pain away to them. For all the wonders of modern medicine, patients commonly report feeling disempowered as their pain slips from the grasp of their own wisdom and into the world of medical expertise. When patients speak of the common psychosocial symptoms of chronic pain – despair, isolation, depression and the myriad other ways that chronic pain can destroy a person's sense of self and self-worth – they sometimes feel the issue is dismissed as inconsequential or unimportant in medical settings. Most doctors

lack the training or resources to engage with such patient concerns. They focus on developing diagnoses and treatment plans to cure pain rather than working with patients to help them understand and manage their own pain in the context of their own lives. These decontextualised cures are all too often dismissed by patients as unconnected to their lived experience of chronic pain. This is a classic rift in chronic pain – both parties look at the same problem from different points of view and see very different things there. The result: patients don't feel heard and doctors feel powerless to help. Chronic pain is a divisive and complicated creature. It needs to be understood from multiple points of view if we are to make some headway in patient care. The perfect candidate, then, for interdisciplinary work.

In what follows, I give my account of working within a diverse circle of disciplines that came together to further our understanding of the patient–doctor dynamic in chronic pain consultations – psychologists, poets, patients, clinicians, artists, art therapists, statisticians, doctors, photographers, historians, linguists and others. Just like patient and doctor, the team was united by a desire to improve the lives of those who suffer from chronic pain. Just like patient and doctor, we all viewed chronic pain from our own perspectives.

Again and again we were asked the question – how did you do it? How did you manage to work successfully with so many different disciplines holding so many conflicting points of view? Drawing on one-to-one interviews with my colleagues in the team, and three years' worth of meeting minutes, I reflect upon the process, not the final result, with a view to better understanding how apparently discordant paradigms can collaborate productively. I do this in the hope that others can learn from our mistakes and our successes, and that interdisciplinary knowledge can continue to make us wiser in our lives and in our suffering.

The interdisciplinary team in context

The team grew quite organically from the original three – artist, poet, facial pain specialist. Additions were made as and when they encountered people whose perspectives might bring something new and insightful. I remember it well – a room full of people chattering politely over flamboyant canapés balanced on flimsy paper plates. I scan the room from the doorway, seeking a welcoming face, an open circle,

and caught the eye of my future friend and colleague, Deborah Padfield. The conversation came naturally – filmmaking collectives in Peru, the etymology of pain in India – our ideas overlapped excitedly, even where we disagreed. A week later I joined the team.

‘Interdisciplinary’: something of a buzzword now in art and science. Funding is invariably contingent on ‘innovation’ and ‘collaboration’, boxes that must be ticked in order to stand a chance at laying your hands on the cash. Unfortunately, the complexity of conducting truly interdisciplinary work means that ticking that box is as close as many research teams ever get. Those I talked to all spoke of interdisciplinary projects they had encountered that had been abandoned when the team discovered that their methods were incompatible, their worldviews irreconcilable.

We faced these same challenges. Despite its growing popularity, to step into interdisciplinary work is a radical act. You are deliberately making life more complicated by entering into inevitable disagreements of method and practice. Again and again, our own team meetings were tense with disagreement and misunderstanding. Scientists puzzled over the empirical value of metaphor while artists grappled with the real-world relevance of *p*-values and confidence intervals. Clinicians would cautiously present the results of their analyses, with charts and tables showing that our efforts had not increased levels of patient satisfaction. In the same meeting, artists would enthusiastically share their observation that patients’ used more metaphorical and emotional language, evidence that our work was helping. This was often the form that our interdisciplinary disagreements took – multiple disciplines viewing the same data and arriving at incompatible conclusions. Our resemblance to the patient–doctor dynamic was uncanny.

Reflecting back on one of these debates, in which Anna (artist)¹ felt her practice was being constrained by other disciplines in the team, she noted:

I just feel really frustrated. I can’t see – why would you not be led by what is in the material [video footage of chronic pain consultations]? It’s got all these secrets to yield why would you want to lose that? It feels very restraining and constricting ... Science forms hypotheses before analysing material. Artists look at material and find and make connections between things ... that’s what I want to investigate further. If I come at it with preconceptions, what’s the point? I want to see with an open mind, reflect on material you have rather than trying to pre-guess it.

Meanwhile, another colleague expressed her frustration at what she saw as colleagues ‘going beyond the data’, making broad claims about patient experience, that our work was making doctors more empathic, without the evidence to back up these claims.

It is this kind of classic conflict that brings so many interdisciplinary projects to a premature close – insurmountable differences of opinion leading the team into a tedious spiral of in-fighting and sesquipedalian name calling. These moments can lead us to retreat further into the comfort blanket of our own discipline. There were many occasions when our team left a three-hour marathon meeting feeling frustrated, disheartened and steadfastly back in our own corner. Sometimes damage was done, constructive criticism became too concentrated or personal, or one discipline held the only dissenting voice in an otherwise harmonious room. This discord was tough, but it was never the end of us. The team remained intact and the project pushed on. For the most part, we worked through our conflicts, not by splitting off into cliques to work safely with those we agreed with, not by going along with the most dominant voice, but by other more collaborative and more egalitarian means.

A recipe for empathy: Respect, humility and informality

The stories of interdisciplinary conflict resolution in our team have a common thread running through them, which I term ‘intellectual empathy’.² Now, ‘empathy’ as a concept is not without its critics (see Weller and Jowsey 2020) and the term itself is remarkably unstable. Coined by psychologists translating from the German word *einfihlung* (in-feeling) in 1909, empathy has since assumed such a multitude of meanings that it is now a somewhat ambiguous term (Lanzoni 2018). I use empathy simply to describe what we sometimes saw happening in our team: the practice of sitting in intellectual discomfort together, actively listening to each other presenting ideas and insights (even as they make your whole profession recoil in methodological horror) and responding with open curiosity and humility. The point is not to abandon one’s own discipline, it is to temporarily make space for ideas that lay beyond it. The point is not to all agree, it is to step into a new habit of mind, one that makes space for creative collaboration. Intellectual empathy describes the willingness to *try* to identify with and understand another person’s position – it is a goal towards which it is useful to strive, not a location at which we can ever truly expect to arrive.

For our team, intellectual empathy was the result of three important relational practices that came to characterise our team. One, professional and human respect. Two, the assumption of good will. Three, viewing informal relationships as central to success. Here I unpack each of these approaches to navigating interdisciplinary conflict and explore how they combine to generate a useful paradigm for complex interdisciplinary problem solving.

Professional respect and human respect

Respect. The word arrived quickly and predictably in my interviews with the team. This was unsurprising of course – respect is a term so commonly used in any conversation about how humans might better get along with each other that it has become something of a truism to suggest ‘we just need to respect each other’. Perhaps the word has lost some of its meaning through overuse. Certainly, those I spoke to struggled to explain exactly what they meant by ‘respect’, even as they professed its unrivalled importance. What does the *practice* of respect actually look like here?

There was a commitment from the team, not just to the work and the research but also to each other ... I think there was a respect for each other’s skills and expertise, and just as people that kept us going. There were moments where if I hadn’t had as much respect for those individuals I would have probably left the project at points, well I certainly would have got much angrier. But because I respected the people then I would try and understand and think my way round it ... So when they’re saying x, y, and z I was absolutely sure they were not saying it just to be bolshie or difficult ... I felt from the benefit of their research and skills which were considerable ... they could bring something to it that I knew I couldn’t bring.

It was also respect for them as human beings. It’s essential. It’s a human respect that cares enough to want to not damage those other human beings. And there’s a certain trust in them that they don’t want to damage you. Therefore, if they’re saying something challenging, it’s not because they want to trash you ... they’re saying it because they genuinely want their research to be as good as possible. That helps me go along with them much further than I would otherwise ... it does help me get over where there are real clashes of views.

This passage reveals something of the complexity of respect in practice. Beyond simply ‘giving due regard’ to another’s point of view (the classic dictionary definition of respect), this passage identifies three principles of respect: one, the assumption of good faith from your colleagues in moments of conflict; two, intellectual humility; and three, the importance of the human within the professional. Let’s take each in turn.

When disagreement occurs in the team, as it so often does, it is assumed to be motivated by each person’s professional commitment to ‘making the research as good as possible’, and not by private hostilities between particular people. The assumption that any criticism of your ideas is made in good faith allows you to interrupt the auto-piloted defence mechanism we are so adept at employing in moments of conflict, and to embrace these difficult new ideas as opportunities. This does not mean deferring to another’s ideas at the expense of your own. It means keeping in mind that while the idea sounds ‘woolly’ and ‘imprecise’ to you as a scientist, or ‘rigid’ and ‘unimaginative’ for you as a poet, it is being put forward by a well-respected practitioner whose work you admire and who has had great successes in the past. It is likely to have some value that you can’t see yet. This approach leaves open the possibility for progress. It might be that the idea turns out to be unworkable, or that it opens up a whole new field of research. We cannot know in the very moment of conflict, but by embracing the conflict as an opportunity to find out, we might be pleasantly surprised.

Implicit in the quote above is also a message about intellectual humility in the practice of respect. The speaker is aware of the limitations of their own discipline and so embraces the possibility that others might plug the gaps or ‘bring something to it that I knew I couldn’t bring’. Acknowledging the limitations of one’s own discipline opens up the possibility for embracing new perspectives and expanding one’s own practice.

Finally, the speaker insists that respect must extend not only to the professional opinion being given but also to the person giving it. This is an ‘essential ... human respect’ that takes seriously the human need for care, and trust even in professional settings and relationships. The idea that a successful interdisciplinary team attends to both the professional *and* the human in their colleagues was echoed by all of those that I spoke with.

The professional is personal

Following the more fractious meetings, in which disagreements became heated, those involved often reached out to one another outside the meetings to try to clear the air. 'It's important to let the informal relationship grow with the professional one', Karim (scientist) says, 'people don't talk about the importance of the informal side of working relationships'. Continuing to work together without acknowledging moments of conflict can lead to 'horrible tensions', which can ultimately undermine the group and distract them from their goals.

Much of the conventional wisdom of professional culture teaches us to keep some emotional distance from our colleagues so as to avoid personal issues interfering with our work. There is wisdom in this, but if followed to the letter we risk missing the valuable contribution that human relationships can make to our work. This is especially important in interdisciplinary circles where conflict is so common. This work is necessarily social. The clue is contained in the word itself: interdisciplinary. 'Inter-', a prefix meaning to be 'between', 'among' or 'in the midst of' something. When we speak of a discipline, we also speak of the people that come attached to that discipline. Poets are the people of poetry, just as statisticians are the citizens of statistics. With disciplines come people and with people disciplines. In this sense, 'interdisciplinary' is synonymous with 'interpersonal' – both denote a state of being between, among or in the midst of other people and their ideas.

Building professional relationships with these people is important, of course, but it is rare that one's profession and one's personal life share no common ground. Our professional pursuits are often motivated by our personal experiences and private lives – think of the police officer once bullied at school, the civil rights lawyer once a child under apartheid rule. Our professional façade may falter when a colleague criticises our work and we find we are personally offended. This is because our work is a part of us – our identities, self-worth, egos and aspirations are all bound up in it. Our personal and our professional selves bleed into one another, they are never fully separate. When we work together with others, we do not just encounter their disciplinary selves, we also encounter their human selves – their sympathies, insecurities and imperfections. This is especially likely in the interdisciplinary setting where disagreement and conflict are so common.

In order to move through interdisciplinary conflict, we must recognise this overlap between discipline and person. A sustained professional critique of a colleague's work may eventually be experienced

as a personal attack. When this happens, we step out of professional discourse and into something murkier. The professional approach to navigating these moments is often to try to gloss over them altogether, or to work through them within the confines of professional language. This can leave unresolved tensions behind, which simmer and undermine your future work together. But, by taking seriously the idea that interdisciplinary relationships are also personal relationships, conflict can be navigated informally and without the pressure of the rest of the team bearing witness. Many an email was exchanged to check in and apologise if any upset was caused, sometimes followed by a coffee to talk through what happened. These gestures, which take seriously the humanity in our work, helped us to not only move past conflict, but to move *through* it, keeping the team intact and moving forwards.

Intellectual empathy as conflict resolution

So, what are we moving forwards into? Intellectual empathy. If we practice respect, if we assume good faith, if we acknowledge our own shortfalls and if we encounter one another as professionals *and* humans, then we are well equipped to work together across boundaries of method and epistemology. The team described the above as a pedagogical rite of passage which eventually opened up into a space in which you could question what you think you know – 'If everyone is doing that, I think there's a certain amount of un-comfortableness that you have to have to then really go further and succeed'.

Sitting in critical and respectful discomfort with one another was an experience echoed by everyone I spoke with. It was described as the subtle intellectual craft of silencing the dismissive voice without discarding the critical one.

I'm having all these thoughts, *why would you do that!?* ... and I'm having to really suppress them when different disciplines were talking ... I respected them as people and without that respect I don't think I would have been able to quieten those voices.

As we mature into our disciplines, we learn to pre-emptively dismiss familiar opposing views. We see a familiar theme emerging in another's ideas and we drop it neatly into the box of things we disagree with. By silencing the dismissive voice, we can learn to actively engage with

another's view before then bringing in our own critique. We may still disagree, but we have at least understood the internal logic of the other and how they have arrived at their conclusions. This can be a much more productive space from which to move forwards.

The team gave a number of examples of instances where their immediate reaction to an idea being presented was sceptical, but through the practice of intellectual empathy they came to understand and even embrace the idea. Speaking about her reaction to the suggestion that we invite Anusha Subramanyam, a dancer and choreographer, to perform in response to the images of pain, Karim says:

When Anna first told me about the dance, I thought, 'oh my god it's expressive dance' you know, 'god help us' [laughter]. But it was fabulous, it was so moving, really lovely! ... I'm perfectly used to thinking one thing but holding off on acting it because I'd only close off things that I then really enjoy ... The scientist bit says, 'oh for god's sake', and then the bit that isn't just totally dominated by that says 'oh, wait and see'.

Likewise, later in our interview the same speaker recounted her response to a colleague's idea for a new article using an approach she had many concerns about: 'I didn't want to outright challenge it because maybe it's not interesting to people what I'm interested in. So, I tended to listen, and I may have listened quite critically but what I heard I thought did persuade me'.

Perhaps one of the most successful examples of interdisciplinary working came in the form of our paper entitled 'Can images of pain enhance patient-clinician rapport in pain consultations?' (Ashton-James et al. 2017).

For months a number of the artistically inclined members of the team had been presenting their belief that the PAIN CARDS were having a significant impact on the non-verbal behaviour of patient and doctor. Their evidence for this were cherry-picked moments of video footage where doctor and patient leaned in together to study a particular image, or else passed images back and forth in a gesture interpreted as sharing and mutual understanding. For the scientists in the room, this unsystematic approach to the data was reprehensible. A number of heated discussions ensued concerning the importance of scientific method for drawing such conclusions. The artistic rebuttal to this was that all knowledge is subjective, so a subjective exploration of the data has its value.

The resulting compromise was a painstakingly rigorous process of counting, categorising and scoring the non-verbal behaviour of doctors and patients along a scale of affiliation and dominance, comparing the treatment group (with images) to the control group (without images). Along the way, there was concern among the artists in the group that affiliation and dominance were not something that could be counted, or that through randomly selecting segments of video the interesting moments might be lost. Nevertheless, we found that in the treatment group doctors displayed more affiliative behaviour over the course of the consultations, and that patient and doctor affiliation behaviours were more reciprocal than in the control group (Ashton-James et al. 2017). I asked Anna about her initial scepticism towards counting non-verbal gestures and reducing subtle human behaviour to numbers on a graph:

That's the interesting thing. I think through a method of counting it [the article] has arrived at something much more interesting, it's arrived at something that excites me ... You've gone through the process of counting and numbers and you've arrived at something that you could have arrived at through perception but you couldn't have *proved* it through perception.

To my mind, this is one of the team's best examples of true interdisciplinary work. It may read as a scientific journal article, but its origins were in artistic enquiry, later translated into a scientific approach. A scientist's stem to an artist's seed, and a paper about which the whole team were enthusiastic.

Our interdisciplinary achievements were built upon the patient practice of intellectual empathy. No one ever called it this explicitly, I have borrowed the term from the disciplines of pedagogy and the philosophy of knowledge. It is important to acknowledge that this was not our only tool, and it was not always successful. There were times when interdisciplinary understanding was impossible, and we chose to break into teams that could more easily work together. Sometimes a particular discipline did overshadow others and pragmatic compromises were made in order to get our work published, our funding extended. That said, at the centre of our work together was a dedication to intellectual empathy and all that this entails – being grounded in respect, disagreeing in good faith and adopting humility that recognises our own weaknesses and seeks the help of others to

move forwards. Interdisciplinary work is painstaking at times, but when practised with patience, curiosity and care, it can be an intellectual pleasure, extending the reach of our knowledge, making us wiser in our lives and in our work towards improving the lives of others.

Picture the scene: you're standing on a balcony looking down at 200 people gathering for lunch, attendees at the conference you helped organise. Lively chatter fills the hall and laughter rings out above the noise. But something feels wrong. You turn to your colleague for reassurance, asking, 'does anything seem strange to you?'

'Oh yes, it's wonderful isn't it?'

'What is?'

'Well, it's all wrong isn't it?'

'What do you mean?' you groan, panic mounting.

'Well look!' she implores, pointing.

'The poets are ignoring each other. The scientists are all mixed up chatting to the patients and the artists and everyone else'. She turns to you, smiling. 'This isn't how a conference is supposed to be.'

Notes

- 1 All names have been changed to retain the team's anonymity.
- 2 The term is borrowed from philosophy and pedagogy and is closely associated with the work of Johann G. Herder (see Forster 2002) and more recently Maureen Linker (2014) and Carolyn Calloway-Thomas (2010), among others.

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Part IV

The future

Visual images

Implications for clinical practice

Joanna M. Zakrzewska

Background to the creation of PAIN CARDS

David Biro (Biro 2010), a clinician and patient, realised how difficult it is to talk about pain due to our lack of language. This resulted in his wonderful book, *The Language of Pain: Finding words, compassion and relief*. As a clinician working with patients who have chronic facial pain I, like Biro, realised how difficult it was for my patients to tell me the story of their pain and its impact. Equally it is difficult for clinicians to appreciate the reality of the pain as there are currently no biomarkers to help validate the diagnosis. I looked for ways I could overcome these problems and came across a technique a psychotherapist was using with victims of torture – metaphors. Metaphors are symbolic and a profound means of communicating complex information, observations, reflections and feelings in ways which can implicitly connect to the listener. Metaphor, among other things, enables people to speak of the unspeakable, is deeply effective, integrates the cognitive and the emotional, creates a safe place and provides a means by which patients can help themselves. We find metaphors in phrases, poetry, images, dreams, stories and objects.

With the help of a psychotherapist, a dental student carried out a small project to see if the use of known works of art could assist patients to articulate more congruently not only the character and intensity of the pain but the accompanying emotions. Although the patients' emotions do not exist in the art, the power of art is that as a metaphoric embodiment of expression, it evokes and connects to both subjective and collective emotions in others. Aristotle said that metaphor was a natural human

ability supporting the notion that everyone connects to art/images in some way across class, age and cultures. The American philosopher Khatchadourian (1980) postulates that art brings order to the human world and can bring people together – we may become more sensitive to ourselves and others. This notion is echoed in the recent report *Creative Health: The arts for health and wellbeing* in which Grayson Perry, an artist, writes ‘Making and consuming art lifts our spirits and keeps us sane. Art, like science and religion, helps make meaning from our lives and to make meaning is to make us feel better’ (All-Party Parliamentary Group on Arts, Health and Wellbeing 2017, 12).

A picture can help engage patients in deep and revealing conversations as shown by Wikstrom in her work with elderly people in nursing homes:

Reading a painting is a complex procedure that allows the onlooker to perceive far more than is represented. One aspect of the complexity of a painting is the reality of times, places and people interacting with the onlooker. Another aspect of complexity is the diversity of languages that are expressed in a painting. It could be an imitation of nature, a self-expression of the artist or it can speak for itself. Consequently, a painting can be a challenge for the onlooker to search for the language described by the artist. (2003, 184)

Different paintings evoke varied emotions in people. Some induce negative emotions and others positive ones which can contribute to wellbeing. Pain is both an evolutionary and psychological factor of our existence and, therefore, it is not surprising that it is the dynamics of pain which are at the centre of some of the world’s finest art. It seemed appropriate, then, to explore the use of paintings as metaphors for people’s pain, particularly in those with facial pain, which probably results in more complex biopsychosocial effects than pain in other parts of the body. This is because the face represents some of the most important functions of life: eating, drinking, sex, emotional expression, talking, touching and being identified.

The small project showed us that patients responded to this methodology and it created an improved relationship between the doctor and patient, which Wikstrom (2001) also found with the nurses.

I was therefore looking to expand the project when I came across Deborah Padfield’s images at a British Pain Society conference and it struck me that they were potentially the new tools to use with my

patients. Many of my patients were keen to help create new images which would express their perception of facial pain and so we were able to start our project, *Face2face*. The images co-created by the patients and Padfield were made into PAIN CARDS as these were more versatile than an A4 folder of images.

Clinical use of the PAIN CARDS

I explored the use of the PAIN CARDS in a variety of settings. In my face-to-face clinical consultations, especially when seeing non-English-speaking patients, I find it useful to show them some of the PAIN CARDS to help them give me a more detailed description of their pain. However, using images can change the dynamics of the consultation just as Pearce et al. (2012, 2009) have shown that computers do. Interdisciplinary interpretations of video recorded pain consultations with the use of the PAIN CARDS have made me reflect on my own pain consultation. It has made me appreciate the importance of the desk space between myself and the patient and how this can be effectively utilised for the sharing of information. The space enables material to be personalised and amplifies the patient’s voice when making decisions.

Our facial pain unit runs pain management sessions with groups of patients who have persistent facial pain, and it is during these that we use the PAIN CARDS. Up to 54 PAIN CARDS are put out on a table and patients are asked to choose a card that resonates with them either because it describes the character of their pain or it reflects the impact of pain on their lives. Patients then explain their choices, and many have commented on how it reduces their isolation when they realise that others have similar experiences (Zakrzewska, Padfield and Ferguson 2019).

Many of the images, understandably, are dark and convey negative emotions. However, as Rita Charon so eloquently says, pain physicians need to accompany their patients and hold out hope and this can be done through visual imagery. Part of the *Face2face* project included the visual journeys of six of our patients through a facial pain programme. Although not everyone had a positive outcome in terms of becoming pain-free, the images do change over time and show how patients were able to improve their knowledge and understanding of pain. The project helped some to focus on their situation, looking at it with a fresh eye and perspective. The experience of being involved in the *Face2face* project was a platform for further communication, including acting as

an advocate or voice for the wider community. The patients took part in the writing of this book, in our conference and in a Wellcome exhibition entitled *In Pursuit of Pain*. The independent evaluator of this section of the project, Gemma Moore, also showed how it impacted personal wellbeing:

One of the most significant benefits from participating in *Face2face* is from the ways it enhanced self-confidence and self-esteem. This was expressed in different ways by those interviewed. The results suggest that the project has helped those involved to acquire knowledge, skills and confidence. Some of those interviewed noted a change in their relationships with others and relate this to being involved in this project. Others noted 'comfort' in knowing that their involvement was part of a larger network of activities and people. It was clear that the project had affected the patients' overall outlook on life and some commented on how they were more positive and hopeful about the future ... Through a range of activities, i.e. the co-creation of images, exhibitions, PAIN CARDS, *Face2face* has embodied values of collaboration and participation in its approach and it is this approach which has encouraged learning, raised awareness of facial pain and improved personal well-being.

As we all know, an image is worth a thousand words, and so the use of images for teaching and presentations at conferences have made healthcare professionals more cognisant of the characteristics of chronic pain and its impact. The public's knowledge of chronic pain is poor, and these images have been used to further draw attention to the suffering that accompanies pain through public exhibitions, such as *Mask:Mirror:Membrane* and in events such as the Wellcome Collections night spectacular *In Pursuit of Pain*.

The future use of the PAIN CARDS

Making these images available to more healthcare professionals may encourage a new way of communicating with and supporting patients with chronic pain. However, as one patient reflecting on the project says:

Images and ideas are powerful, but they can also be volatile. I mean you are dealing with fear: the fear of pain, the fear of the anguish from the pain: there is no pain worse than that of trigeminal neuralgia. Nothing can help, there is no project, not one therapy, there is nothing that can help when you are in that situation, when you have that pain, it takes over completely. The process of articulating pain and asking people to articulate their pain is a volatile thing and I am not sure that has been thought about, has it? For instance, if you don't see something there [in the cards] that you can relate to: What does that mean? What does that say about you? What does that say about your illness? It is a volatile situation, asking those questions or opening those doors, you may end up questioning yourself – your actual sanity. People with pain are on the edge and many [clinicians, therapists] who are in positions to provide support haven't experienced it themselves; they don't really know. So I think there needs to be caution with the cards and the images. It is a dangerous, but powerful tool. Powerful if effective, and powerful in a dangerous way if not.

The images need to be culturally sensitive and will be affected by context, so work is needed in different communities and varied settings.

The current pack includes 54 PAIN CARDS and, although this number is useful in a group session, it is too large a number to use in a one-to-one consultation. If patients could see these on an app prior to coming to a pain consultation and preselect their key images this may make their use more manageable.

As the patients and I have pointed out, there is a need for more hopeful images to be included to show that improving self-management of chronic pain can result in positive benefits. These same techniques could be used to develop cards which could be used with children, patients with mental health issues or other disabilities.

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23 What is the pain experience and how can we control it?

Perspectives from neuroscience

Kirsty Bannister and Anthony H. Dickenson

Pain is a complex personal experience and involves many signalling and modulatory systems that encompass peripheral pain signals that can be altered by complex circuits in the brain. The relation between injury and pain is complex and not linear, so we can experience severe pain with minor physical insults or the opposite, low levels of pain despite major injury (Colloca et al. 2017; Bannister, Kucharczyk and Dickenson 2017). This chapter examines the ways in which messages coming from peripheral pain sensors can be amplified or suppressed by the central nervous system and looks at the mode of action of analgesics and how they interact with neural signalling. Acute pain is a key survival signal and so people who cannot sense pain suffer from serious injury as their warning signals are lacking. Once pain becomes chronic, a whole series of events are established in the nervous system that take over one's attention. These events are inescapable and are detrimental to our quality of life.

Why we feel pain

When we sense that any part of our body is in danger of being harmed, or has been damaged in any way, we can experience pain. If we touch a hot surface our hand recoils automatically. If we cut our finger while chopping food, we instantly drop the knife and clutch the injured digit. Our body knows automatically when to move away from a painful stimulus. Occasionally it is not possible to escape acute pain. For example, if we absentmindedly wipe our eyes while chopping a chilli pepper excruciating pain ensues and we must wait for the pain to stop.

Nonetheless in all scenarios we are instantly aware that something hurts, that we are in pain.

Our bodies are full of pain sensors called nociceptors that can be activated by a wide range of stimuli including thermal (a hot stove or freezing ice), mechanical (a sharp knife) and chemical (capsaicin, the pungent ingredient found in chilli peppers, wasp stings etc.) stimuli (Basbaum et al. 2009). There is no denying that the presence of a fully functional pain perception system works to our advantage in terms of the survival of the species; it is imperative that we recognise an external, damaging threat and react accordingly. However, the advantage of this critical warning system loses its value when it becomes persistent. The switch from an acute to a chronic pain state is no longer advantageous to our survival and in fact is wholly detrimental. For now, we are being harassed and chased every day by a stimulus that we cannot escape.

Why pain can be disadvantageous

Humans and even very primitive organisms are able to survive because they have developed systems that provide a warning of potential or actual damage to themselves, allowing movement away from a painful stimulus. Some of these systems work by telling us where the pain is and how bad it is. For example, a pain signal travels from the periphery when nociceptors are activated and is relayed to the cortex. This allows us to locate the pain (ouch, my hand hurts!) and describe its intensity (it hurts a lot!). Other systems activate muscles that enable us to move away from a painful stimulus. In addition, the affective motivational aspect of pain is conveyed when the pain signal is relayed to the limbic brain. This ancient part of the brain is where emotions are processed and this is why chronic pain often goes hand in hand with co-morbidities such as anxiety, fear, anger and depression. These two separate arms of the pain experience are discussed in further detail shortly.

While our knowledge surrounding the underlying mechanisms of pain, and indeed pain relief (analgesia), has improved greatly in the last three decades, we still do not fully understand the pain perception experience in total. When chronic, the function of pain becomes rather unclear. To disseminate the sequence of events that result in a chronic pain disease, we can first consider the two main categories of pain, although many types exist. *Nociceptive* pain refers to a pain type where tissue is damaged as a result of trauma, surgery or a disease such as arthritis.

In these instances, the damaged tissue releases chemicals which sensitise and, at higher levels, activate pain sensors. *Neuropathic* pain is generated as a result of a disease or lesion that causes nerve injury. In theory, since a loss of afferent input accompanies a neuropathic insult, we might expect to experience numbness only. But in reality, patients experience pain as well. In the normal situation ion channels act to generate and transmit electrical impulses in nerves, an important process in our pain perception pathway, and vital for the sense of pain and therefore the removal of one's self from harm's way. But, in neuropathy, ion channels act abnormally, and electrical impulses are transmitted unnecessarily by the nerves in the absence of tissue damage (Colloca et al. 2017).

Entirely different treatments are required for the two pain types discussed. It is logical and preferable to treat nociceptive pain at a peripheral source which will require blocking the actions of pain-producing chemicals in the damaged area. With injury to the nerves, however, we may experience both numbness and pain that arise due to changes in peripheral nerves, spinal cord and brain systems that act to enhance, amplify and prolong pain. Treating the peripheral cause of pain, the abnormal electrical events in the nerve in this instance, can provide adequate pain relief but there are additional targets as now there can be central nervous system abnormality.

Not all pains fall into these two simple classifications. Lower back pain and cancer pain are commonly comprised of both nociceptive and neuropathic pain underlying molecular mechanisms. Vitality, treatment must target both sets of mechanisms for a successful therapeutic outcome. Tissue heals reasonably quickly and efficiently, so we recover from trauma and surgery correspondingly well. In contrast nerves have a very limited capacity to fix themselves and as such neuropathic pain often is chronic. If tissue and nerves are damaged after major surgery a persistent post-surgical pain state can ensue, driven by ongoing peripheral and central neuropathic events despite the fact that the tissue and resultant nociceptive pain are long gone. Finally, there are pains which are more widespread than nociceptive or neuropathic pains which are mostly restricted to the damaged tissue or nerve. Examples of these pains are fibromyalgia and irritable bowel syndrome. Here the pains are widespread and diffuse and often accompanied by mood and sleep disturbances. It is likely that these pains arise from disorders of central limbic brain structures including areas that modulate pain (Phillips and Clauw 2011). Minor or normal peripheral inputs arrive in the central nervous system where

the ability to control these inputs may be compromised, and instead the brain may set in place mechanisms that enhance pain. Headache and migraine are not actually due to tissue damage but rather due to an abnormal production and/or release of various pain chemicals into the blood vessels and nerve endings in the scalp and brain membranes accompanied by changes in the brain.

There is, therefore, clearly a difference between how nociceptive or neuropathic pain originates in the periphery. But, once the information from the pain sensors passes along the sensory nerve, which connects the periphery to the spinal cord, common central mechanisms are activated. These include central sensitisation, a process whereby the spinal cord amplifies and expands the incoming pain message before sending it to the brain. The brain has two key areas concerned with pain. Outputs run from the spinal cord to the thalamus and on to the somatosensory cortex where an imprinted 'map' of the body allows us to localise and rate the pain intensity, this being the sensory component of pain. In addition, parallel pathways run the pain

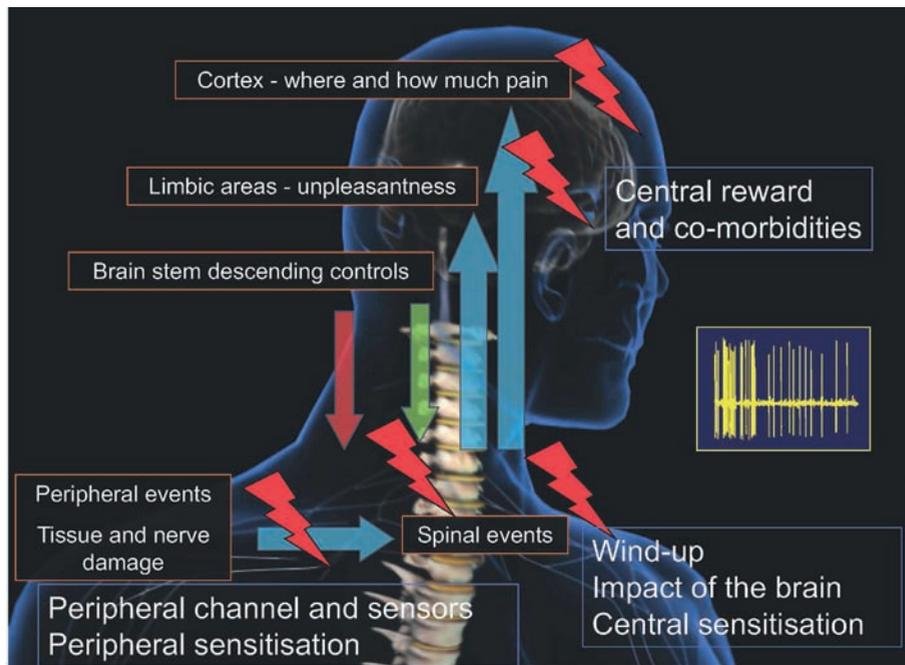


Figure 23.1 The peripheral, spinal and brain areas involved in the processing of painful messages. Inputs into the spinal cord activate ascending pathways that generate the sensory and emotional components of pain at higher centres and thereafter, descending controls can further modulate spinal activity. © Kirsty Bannister and Anthony Dickenson

message from the spinal cord to the limbic brain containing areas such as the amygdala, cingulate cortex and insula. These areas establish the emotional aspects of pain and the co-morbidities. In turn, the brain will signal back down to the spinal cord through descending controls. In this manner, thoughts and emotions can turn pain 'up', meaning that we feel worse pain, or we may distract ourselves, set up coping strategies and reduce our pain. We will explore these axes of pain perception in more detail.

Nociceptive pain

When we damage a part of our body or tissue in some way, for example by spraining an ankle, nociceptors send a pain message to the brain to ensure that we do not cause further damage to the injured part of our body. For example, we may now hop! The endogenous local chemicals that are released into the damaged area sensitise the nerve endings so that any stimulus becomes more painful. For example, placing weight on the injured ankle would now hurt a lot. The chemicals also act on local blood vessels to cause swelling. Although it may not seem like it at the time, this is an important part of our eventual recovery as it allows immune cells to leak out of the plasma and prevent infection. An example of peripheral sensitisation is sunburn caused by UV radiation, or, to put it simply, by sunbathing for too long. An otherwise innocuous warm shower feels very painful on sunburned skin, and the touch of clothing is now unpleasant and even painful. As the tissue heals, the pain and swelling dissipate (and a tan develops!). With a much more serious disease state such as osteoarthritis, the damage is to cartilage which has low ability to heal and thus often a chronic pain condition ensues.

Peripheral events

As mentioned, the first stage in the transmission of acute pain (caused by grabbing something hot for example) involves the activation of specialised sensory receptors called nociceptors. Nociceptors are present on a set of peripheral nerves called C-fibres, found in our skin, muscles and other parts of our body. Nociceptors are multimodal as they can sense and respond to a variety of painful stimuli, including strong pressure or a pinch (mechanical stimuli), hot and cold (thermal stimuli)

and chemical (for example the aforementioned capsaicin ingredient found in chilli peppers). This is because a nociceptor is not a single entity. Instead, it is made up of a number of receptors and channels and this means that they can sense and respond to different modalities of painful stimuli. Capsaicin evokes a sensation of burning pain as it activates a particular receptor that is our heat sensor. We have a huge range of channels and receptors that allow peripheral nerves to respond to many stimuli and, importantly, send messages (electrical signals) from the periphery through the spinal cord to the brain (central nervous system), where they reach our consciousness and let us know that we are in pain (Basbaum et al. 2009; Dubin and Patapoutian 2010).

What happens when tissue is damaged?

Locally the damaged tissue releases a cocktail of chemicals, including a group of chemicals called prostaglandins. These will cause the injured area to become inflamed (red and swollen), and the nociceptors in that area become particularly sensitive to other stimuli. Prostaglandins do not normally activate nociceptors directly, but instead work by reducing the threshold required to activate C-fibres, such that they now respond to lower-intensity stimuli. This is why we might feel pain when we apply even light pressure on an inflamed finger, or we feel excruciating pain when we get into a hot bath after being sunburned. In this way, by feeling more pain in the injured area, we can take action to avoid damaging it further.

Non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen relieve pain by blocking the formation of the prostaglandins. This leads to a reduction of inflammation and sensitivity of the injured area. The precise mechanism of action of the NSAIDs relates to an inhibition of enzymes responsible for the formation of the prostaglandins. The enzyme in question is cyclo-oxygenase (COX), which has two isoforms, COX-1 and COX-2. The main action of the NSAIDs is to block COX-1. However, COX-1 is a constitutively expressed housekeeping enzyme with physiological functions that include preservation of the stomach lining, where prostaglandins serve a protective role. As such, inhibiting COX-1 can cause gastric side effects. In contrast COX-2 is expressed only in inflamed areas following tissue damage. Newer painkillers, called COX-2 inhibitors, preferentially block only this isoform. These analgesics are just as efficient at reducing pain, but positively lack the potential side effects (i.e. stomach problems) of the older NSAID medicines.

As well as prostaglandins, other chemicals including bradykinin and serotonin (also called 5-hydroxytryptamine or 5-HT) accumulate in damaged tissue, playing a part in the sensitisation and the activation of C-fibres during inflammation via activation of their relevant nociceptors. Serotonin is well known for its pain-inducing actions in migraine and headaches. Pharmacologically, the triptans modulate the actions of serotonin and so are useful as analgesics in headaches, but not other pains. Migraine appears to be a complex mixture of disordered central processing that cumulatively leads to the auratic and visual changes associated with migraine, as well as nausea and sensitivity to light and the abnormal release of chemicals in the periphery. In total, this equals pain (Dubin and Patapoutian 2010; Bannister, Kucharczyk and Dickenson 2017).

Neuropathic pain

The nature of the pain that arises from a nerve injury is unlike an everyday pain. Neuropathic pain can be spontaneous, meaning present in the absence of a peripheral stimulus, or it can be triggered by a stimulus. Spontaneous pain is notoriously difficult to manage and can be either constant or intermittent (episodic). Most patients with neuropathic pain describe having both a constant burning pain and an intermittent shooting or electric shock-like pain. For neuropathic pain, patient's pain triggered by stimuli is often allodynic. That is, peripheral stimuli which do not usually cause pain (cooling, gentle touch, movement or pressure), now evoke pain. In other situations, stimuli that are normally painful are now perceived to be even more painful, and this is known as hyperalgesia. People with neuropathy also often report abnormal sensations like crawling, numbness, itching and tingling (Colloca et al. 2017).

The symptoms of neuropathic pain are similar despite the many causes of nerve injury. Apart from direct trauma or damage, neuropathic pain occurs in approximately 20 per cent of patients with diabetes or shingles, and it can also occur after HIV infection and surgery. It is also one of the most difficult painful symptoms to control in many cancer patients. The pain of neuropathy itself is produced by changes in the nervous system as a result of the nerve injury. These changes make the nervous system hypersensitive, both in the periphery (all nerves outside of the brain and spinal cord, including those in the torso, and arms and legs) and centrally (nerves in the brain and spinal cord). In order to understand how nerve and tissue damage cause changes in the

nervous system and neuropathic pain, we must first take a look at the pain processes that occur in the periphery.

What happens when nerves are damaged?

When a nerve is damaged people experience neuropathic pain. This pain is often long lasting (chronic) and includes both negative symptoms (sensory loss and numbness) and the positive symptoms of allodynia (pain from previously non-noxious stimuli), hyperalgesia (heightened pain sensitivity to previously noxious stimuli) and ongoing pain, which is unlike pain experienced when other sensory systems are damaged (crawling and tingling). Given that a nerve has been damaged these negative symptoms make sense. The positive symptoms, however, are harder to explain and strongly suggest that there are changes within the nervous system that are unnecessarily excessive, as the system attempts to compensate for the sensory loss caused by the nerve injury. Neuropathic pain is thought to begin in the periphery, within the nerve itself. Unlike acute pain or pain caused by tissue damage, the first events of neuropathic pain are independent of peripheral nociceptor activation.

When a nerve is damaged, a number of changes occur in the nerves in terms of activity, properties and transmitter (chemical) content. Damaged nerves generate ongoing pain impulses in the absence of stimulation because of the accumulation and clustering of certain types of channel (called sodium channels) around areas of nerve damage. There is also evidence that the receptors that sense and respond to mechanical stimuli (strong pressure or a pinch) become highly sensitive to stimuli. This aberrant activity can then start to spread rapidly to parts of the central nervous system. As well as these changes, injured nerves may now become oversensitive to chemicals released from other nerves, leading to their activation. This can cause spontaneous pain and prime the spinal cord to have exaggerated responses to stimuli, which themselves have greater effects due to increased sensitivity of the peripheral nerves (Colloca et al. 2017).

A lot of the information about the changes in the periphery that occur following nerve damage has become known relatively recently. This has helped us understand why medicines that block sodium channels, like the epilepsy treatment carbamazepine or the local anaesthetic lidocaine, are helpful in controlling neuropathic pain. There are many different types of sodium channels that can generate the

electrical events in nerves and neurones. Certain sodium channel types in particular are linked to pain. In the future, drugs that block these channels may become very useful novel drugs lacking the side effects of present analgesic agents. Unfortunately, for a small population of individuals, rare inherited disorders of pain result from abnormal sodium channel function.

Reaching our consciousness

Tissue and nerve damage activate peripheral nerve fibres in different ways but both cause electrical signals to run into the spinal cord, at which point chemical messengers take over and allow the message to be passed onwards from nerve to nerve, until the final pain messages reach our consciousness (the brain). However, this is not as straightforward as it sounds. Once the pain signal reaches the spinal cord, various mechanisms operate to further amplify and prolong the stimulus. Networks of C-fibres in the periphery convey pain signals as electrical signals to the spinal cord. When a pain signal reaches the spinal cord, the central nervous system (comprising nerves in the spinal cord and brain) takes over from its peripheral counterpart. Various mechanisms operate to ensure that we are aware of the magnitude of the pain and that we experience the emotional aspects of pain, like anxiety and fear. Two systems are of prime importance in pain within the central nervous system; the excitatory system and the inhibitory system. The excitatory system enhances pain signals to ensure that they remain strong sufficiently for the journey onwards to the brain. The inhibitory system controls pain signals to reduce pain. The excitatory system predominates in most conditions, which is why an absence of pain after trauma is a rare event confined to short periods of time on the battlefield or in a sports event since the inhibitory controls that may be able to dampen pain, become overwhelmed.

The excitatory system

Nerves carrying pain signals from the periphery such as the skin, converge at an area of the spinal cord called the dorsal horn. Here the pain signals switch from being electrical in nature (driven by action potentials) to chemical. The chemical messengers that take over are called neurotransmitters. There are several different types of

neurotransmitter, but most of the nerves arriving in the dorsal horn of the spinal cord contain the excitatory neurotransmitter glutamate. The neurotransmitters are released following the opening of voltage-gated calcium channels in the spinal cord, and they activate (or *excite*) nerve cells in the dorsal horn. In this way, they are involved with passing the pain signals onwards to the next nerve in the spinal cord and so on until the signal finally reaches the brain. This process involves thousands and thousands of nerves scattered throughout the circuitry.

Gabapentin and pregabalin are frontline analgesics for the treatment of neuropathic pain, despite originally being discovered as anti-convulsants. They are believed to work by interacting with an accessory subunit on overly active voltage-gated calcium channels. Ultimately, they reduce the amount of transmitters released into the spinal cord in response to pain signals. This results in less activation of the nerves that send pain signals to the brain, and in this way the pain is dampened. However, due to a widespread population of voltage-gated calcium channels throughout the nervous system these drugs can produce side effects including sleepiness, dizziness and thought problems.

In total, a complex network of neuronal circuits can change spinal sensitivity to pain signals that arrive from the periphery. Regulation of this sensitivity by pathways that link to the brain can in turn link the level of spinal cord sensitivity to the behavioural and environmental context of the pain experience. This far-reaching effect of neuronal projections within the pain circuitry is mediated by the neuronal contact with areas in the brain that cause fear, anxiety and the stressful response that pain generates. En route the nerves can also reach parts of the brain that control sleep, appetite and our attention to the outside world. Social interactions, the normal rewards that everyday life can bring, and concentration abilities can suffer greatly in the presence of chronic pain. If it is possible, employing coping and distraction strategies can allow an individual to reduce this amplification and thus positively influence the pain experience leading to reduced pain (Garland 2012; Colloca et al. 2017).

Other pain-enhancing pathways

The pathways mentioned thus far are not the only pathways in the central nervous system that can make pain signals increase. When the specialised nerves in the periphery that convey pain signals are stimulated greatly over and over again, for example when we

experience persistent pain, an amplification and prolongation of the response to the pain signal by the nerves in the dorsal horn is generated. This means the pain gets worse and worse even though the painful stimulus stays the same. This phenomenon is called ‘wind-up’. We can demonstrate wind-up in individual people. If you put a painful heat stimulus (a hot rod for example) on the hand of someone ten times, they will feel more and more pain with each application even though the intensity of the heat remains the same throughout the test. This is wind-up, and it means pain felt after the tenth heat stimulus seems much more painful than that experienced after the first application. Because of wind-up a relatively minor peripheral pain stimulus can cause severe pain that often lasts longer than the stimulus. Wind-up occurs when a receptor on nerves in the dorsal horn called an N-methyl-D-aspartate (NMDA) receptor becomes activated by the chemical transmitter glutamate, itself released in response to pain signals. When NMDA receptors are activated, a higher number of nerves in the dorsal horn become activated per painful stimulus. Repetitive episodes of wind-up can cause a phenomenon called long-term potentiation (LTP), which is similar to memory. When LTP occurs, the spinal cord becomes hypersensitive to incoming pain signals. It ‘remembers’ a peripheral pain stimulus as being more intense than it actually is. As a result, greater pain messages are sent to the brain and incoming pain messages are translated into allodynia, where sensations that do not usually cause pain like cooling, gentle touch, movement or pressure, now evoke a painful response.

NMDA receptor activation in the spinal cord plays a predominant role in the sensitisation process involved in many persistent pain states, like inflammation and neuropathic pain. There are a number of drugs that can block the activation of the NMDA receptor, including the licensed medication ketamine. Ketamine is potent but often not used because it has unacceptable side effects, altering cognition and causing dissociation from the outside world (Bannister, Kucharczyk and Dickenson 2017).

The inhibitory system

Just as there are neurones in parts of the central nervous system that can amplify pain signals, there are also certain parts that can inhibit or ‘muffle’ incoming pain signals to reduce the amount of pain that we feel. The amount of pain we feel can be reduced by the production of

endorphins and enkephalins, which are morphine-like substances that occur naturally in the body. Stress, excitement and vigorous exercise are some of the ways in which we can stimulate the production of endorphins. This is why an athlete may not notice the pain of a fairly serious injury until after the sports event has finished. Pain-relieving opioid medications, such as morphine, work by mimicking the action of naturally occurring endorphins. Specifically, opioids act in the brain and dorsal horn of the spinal cord. In the spinal cord opioids may act pre-synaptically and post-synaptically to reduce the level of pain that we are experiencing. Firstly, they may reduce the amount of chemical excitatory neurotransmitter released from the nerves carrying pain signals from the periphery (C-fibres) such that the nerves in the dorsal horn are less excited by incoming painful messages. Secondly, opioids may block nerve signals generated in the spinal cord such that the pain message is not passed on to the next nerve and so on. This results in a situation whereby the pain message fails to reach the brain, or our consciousness.

Opioids like morphine can provide excellent pain relief in patients where the pain is acute, but they may be less effective if the pain syndrome is neuropathic in origin, as in the case of phantom limb pain where pain signals seem to arise from amputated limbs. That said, it is now accepted that at least some patients do obtain pain relief with morphine following nerve injury. Opioids can be given by the spinal route and so target the pain systems directly. However clearly this is not a convenient approach for patients who need to self-administer at home, and so they are most often given by mouth or injection, and patches can also be used. Opioids are very effective at accessing the brain and subsequently producing an analgesic response, but it comes at a price. The receptors for morphine are not confined to the parts of the nervous system involved in the transmission of pain. Activation of opioid receptors in sites of the brain separate to those involved in the transmission of pain lead to sleepiness, cognitive problems, nausea and respiratory depression. There are many opioid receptors in the gut and opioid medication can cause constipation. In common with many drugs, opioidergic side effects often mean that effective doses (for pain control) cannot always be achieved.

There is another important inhibitory system in the brain that can alter activity in the spinal cord. Long pathways connect the brain to the spinal cord and these so-called descending controls run from limbic and brain stem systems (Ossipov, Morimura and Porreca 2014). The chief neurotransmitters in these descending modulatory pathways are

the monoamines: noradrenaline and serotonin. Overall, the brain is able to switch pain up or turn it down by changing the levels of these neurotransmitters in the spinal cord (Bannister and Dickenson 2016). On a basic level, if the concentration of noradrenaline increases, pain reduces, whereas in contrast serotonin predominantly enhances or facilitates pain. Examples of drugs that increase the levels of the monoaminergic neurotransmitters are anti-depressants. Thus, they can also be used to control pain, even though a patient may not be depressed.

It is possible to gauge activity in the descending inhibitory systems by a simple test. One pain can inhibit another, and this is effective in most healthy subjects. However, the ability of one pain to inhibit another is lost in many different pain conditions and as such a pain condition can spiral such that events like wind-up are now more likely to occur. This loss of inhibition by the brain of spinal cord pain transmission has been noted to relate to persistent pain and is seen in patients with osteoarthritis, neuropathy, migraine and fibromyalgia. Loss of this control allows excitatory signals to dominate. By monitoring the balance of excitatory and inhibitory descending controls that exist in pain patients, clinicians can tailor a particular drug treatment to the pain mechanisms in that individual, rather than using random treatments that may or may not work to alleviate the pain (Bannister and Dickenson 2016).

Conclusions

On the whole, our understanding of the basic mechanism of pain transmission and analgesia is satisfactory. We know that hyperexcitability (when our body is particularly sensitive to pain) can occur following both peripherally and centrally driven events. We are also beginning to understand the complex links between pain and emotions. Many of the events that cause pain are invisible, hidden deep in our peripheral nerves, spinal cord and brain; and although invisible we know that they are real. The drugs used to treat pain have logical mechanisms and we understand the targets. As we come to an improved understanding of the complexity of pain and its emotional and cognitive impact, developing techniques to cope with and distract from pain may become another important way of learning to live with pain. Many experts feel that movement and exercise are also beneficial in helping to control pain.

Although we know more about pain than many other diseases and disorders of the nervous system, there are still many areas where our understanding of pain remains inadequate. For example, there is clearly

a huge range of events in the central nervous system that can transmit and alter pain. Genetic make-up may partly explain the varying levels of pain experienced by people after an injury and their transition from acute to chronic pain. It may also affect an individual's susceptibility to neuropathic pain after nerve damage and analgesic effectiveness. The future holds promise. In order for pain to be better controlled, the knowledge we have of the mechanisms of pain needs to be translated into therapy. Rest assured, there are many pre-clinical and clinical specialists working towards the advent of bigger, better, more effective analgesics and therapies.

Glossary

Allodynia	a consequence of changes such as central sensitisation whereby non-painful stimuli such as touch and cold are now perceived as painful.
Central sensitisation	a process in the spinal cord where repeated painful inputs result in neurones becoming more sensitive to subsequent stimuli.
Cortex	specifically, the somatosensory cortex where pain messages reach consciousness and maps of the body in the correct allow us to locate our pain and rate its intensity.
Cyclo-oxygenase (COX)	an enzyme that causes the production of prostaglandins, the target for drugs such as aspirin and ibuprofen.
Endorphins and enkephalins	naturally occurring opioid transmitters with weaker actions than morphine.
Glutamate	the major excitatory transmitter in the nervous system.
Hyperalgesia	where painful stimuli are more painful than they should be.
Limbic brain	parts of the brain that deal with emotional responses to the outside world – pain inputs into these areas is presumed to produce anxiety and mood changes.
Long-term potentiation	a more prolonged version of wind-up.
Neuropathic pain	pain arising from damage to sensory nerves and neurones caused by trauma, diabetes etc.
Nociceptive pain	pain arising from tissue damage such as trauma, surgery and arthritis.
Nociceptors	specialised sensors found throughout our bodies that respond to painful stimuli.
Opioids	drugs that act on opioid receptors – morphine is a prime example.
Wind-up	the spinal neuronal events underlying central sensitisation.

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Reflecting on ‘Encountering Pain’

Giskin Day

The poet Emily Dickinson wrote, ‘After great pain, a formal feeling comes’. We rely on experts – both by training and by experience – to formalise their insights by describing, discussing, exchanging and disseminating narratives about pain so that we can learn from them.

In my role as an educationalist in the medical humanities, an abiding concern that is raised time and again by the medical students I have had the privilege to teach has been: ‘How do I retain my humanity in the face of the suffering of others without succumbing to burnout myself?’ There is no simple strategy to resolve this tension. Medical education, though, surely has an obligation to ensure there are opportunities for healthcare students to explore, articulate and reflect on the balancing act between the clinical detachment needed for professionalism and the personal connection that frames the clinical encounter. Pain is one of the very best topics for exploring these issues. It opens up dialogues about ways of communicating about intangible sensations. It invites discussion of issues such as stigma, health inequalities, touch, diagnosis, medical error and also what constitutes good, sensitive care.

The health humanities have much to offer in this regard. One of the central tenets of the discipline is to foster a better understanding of embodiment – the relationship between physical sensations and emotions that reflects the lived, subjective experience of being-in-the-world. One of the characteristics of pain is that it is a particularly individual sensation, a feature that makes it a fiendish phenomenon to analyse. However, narratives of pain are sharable and beneficially so. The contributors to the ‘Encountering Pain’ conference, and to this volume of scholarship, have thoughtfully and generously shared their

stories – often personal and emotional – so that we all might better understand pain and how to address the suffering it engenders.

My reflections have been shaped by a book recommended to me by Jonathan Tomlinson at the ‘Encountering Pain’ conference: *The Renewal of Generosity* by sociologist Arthur Frank (2004). According to Frank, an act of generosity is epitomised in the offering of consolation. Generosity begins, he argues, in welcome: ‘To guests who suffer, the host’s welcome is an initial promise of consolation’ (2004, 2). This consolation promises that sufferers will feel less isolated, less stigmatised. The ‘Encountering Pain’ event created such an atmosphere of hospitality. Everyone, suffering or not, felt both welcome and consoled by the event, and all that preceded and followed it. We felt embraced by a community invested in better understanding pain, and reassured by the manifest evidence of a community that cares about those with pain and is actively working to help alleviate suffering.

The greatest challenge facing medicine in the twenty-first century, according to Frank, is not devising new treatments, as valuable as those may be, but resolving how to increase the generosity with which medical skill is offered. As a model for how to do this Frank proffers the concept of the ‘dialogical stoic’. Drawing on the writings of the Roman philosopher Marcus Aurelius, he interprets ‘stoicism’ not as the shunning of pleasure, but as the practice of freeing oneself from the thinking capacity of the intellect, which is in our control, and the body to which uncontrollable misfortunes occur. The mind is not separate from the body, but it does have the capacity to choose how to understand what is happening to the body.

Those who suffer from chronic pain are stoics because they have to find an intellectual way of dealing with intense suffering in order to carry on. Liz Aldous, Alison Glenn and Ann Eastman all speak eloquently to this in their patient testimonies (Chapter 2). Their stories have in common the difficulty of negotiating a system that prioritises clinically generated evidence over patients’ first-hand accounts of suffering. The absence of a lesion to account for pain continues to challenge the paradigm in Western medicine that insists on the verification of patient narratives by empirical evidence. Patients’ accounts relate how infuriating – and demoralising – it is for those in pain to be told that scans or test results are ‘normal’. There is nothing normal about chronic pain. The use of ‘normal’ seems a way of explaining pain away rather than admitting that medical imaging is inadequate to the task of explaining pain. Patients’ aversion to the word ‘normal’ may be baffling to those who routinely deliver scan results who do not intend to

cause offence. But ‘normal’ is a loaded term, weighted with assumptions about ‘acceptable’ tolerances and the collectivisation of data. We need to find different ways of talking about the relationship between pain and medical technology: words do matter. Awareness needs to be raised about how the language around pain can compound suffering. This is an important concept that medical education needs to do more to address.

Rita Charon is an advocate for the type of narrative attentiveness that understands how language can exacerbate suffering. She argues that a moral response to the talk of pain has never been more urgent. Charon is acclaimed for pioneering the concept of ‘narrative medicine’, an approach that champions the telling of and attentive listening to stories as being at the heart of humane medicine. She talks of pain being an unremitting central dilemma. Witnessing pain can lead to re-traumatisation of the listener – pain becomes a reciprocal, intersubjective event. By developing narrative competence – an appreciation for time, space, metaphor and the non-verbal communication suggested by gestures and bodily signals – clinicians can improve their capacity for listening to the talk of pain. This is an act that involves both imagination and humility – two qualities that can sometimes seem in short supply in medical institutions.

Medical education is central to shaping moral responses to pain. By encouraging medical students and healthcare professionals to engage with narratives about pain through a variety of media – verbal, visual, kinaesthetic, aural, poetic and prosaic – they can develop their imaginative capacities. We must consider patients with pain with generosity, not as irritants who cannot be helped but as stoics ready to engage in dialogue. The very act of engaging in attentive listening and careful communication may help sufferers to feel better. Good dialogue is fundamental to treatment plans that have any chance of success.

Metaphor’s role in conferring meaning

Pivotal to good dialogue and narrative attentiveness is an engagement with metaphor. Metaphors are crucial for understanding the meaning – or meaninglessness – of pain, as so many of the chapters in this volume testify. Metaphors have an independent operational force, reasons Joanna Bourke. Bourke has contributed greatly to cultural and social understandings of pain, through her intellectual activism, helped by her excellent book *The Story of Pain* (Bourke 2014). To highlight changes in how pain has been interpreted over time, she quotes a

nineteenth-century physician in claiming that pain was the ‘protector of voiceless tissues’, the ‘prayer of a nerve for healthy blood’ (2014, 226). The metaphor of prayer became a trope through which pain acquired positive meaningfulness. This challenges us in a secular age: human cultures do not want to face up to the meaninglessness of pain, which is why pain in the absence of a lesion is so difficult to accept. Bourke convincingly argues that we need to embrace negativity as a generative force rather than something to be eschewed. In so doing, we can acknowledge the influence of prevailing culture on the body and how people in pain attach meaning to experience.

Elaine Scarry’s *The Body in Pain* (1985, 11) is often criticised for its insistence that pain entails a shattering of language: ‘Physical pain’, she says, ‘does not simply resist language but actively destroys it’. However, an often-overlooked but important aspect of Scarry’s thesis that she then goes on to develop is that ‘shared objectification’, through creativity, is capable of restoring articulation to the experience of pain: ‘[T]he poet projects the private acuties of sentience into the sharable, because objectified, poem, which exists not for its own sake but to be read: its power now moves back from the object realm to the human realm where sentience itself is remade’ (Scarry 1985, 307). For Scarry, the poem is a fulcrum between projection and reciprocation. It is precisely this reciprocal relationship, between poet and reader, between the capacity for feeling pain and the horror of feeling nothing at all, that gives the use of metaphors – verbal and visual – their power.

Specific metaphors emerge as helpful ways to conceptualise pain. The tree was an image that emerged strongly through many of the artists’ work at the ‘Encountering Pain’ conference as a particularly powerful emblem in dealing with pain. Liz Aldous, an artist who suffers from facial pain, took the tree as her totem of healing. She facilitated a relaxing workshop in which participants narrated their journey, either through designing fabric leaves or purely enjoying the experience of being creative with art materials. Implicit in the tree metaphor is the narrative of growth. For all that pain can restrict and constrict, it can also be productive in developing coping mechanisms and new ways of living. Sometimes, the creative avenues that patients are exposed to, primarily because of their experience of pain, have been life enhancing.

Growth and tree metaphors are also evident in Rebecca Goss’s poems on pleurisy (Chapter 4). Describing the pain of pleurisy as ‘explicitly unkind’, Goss reconstitutes her experiences into affective, enthralling poems. The tree metaphor that lends itself so well to healing and growth, is here malicious. In the poem ‘Pleurisy I’, Goss writes,

‘In her most breathless / state, there was a tree – / cankerous and scratching, / malevolent in its reach / around her frame’.

Sharon Morris, educator, visual artist and poet often uses trees in her work as a way of connecting lived experience and the natural world. In her poem ‘Water glass’ (Chapter 17) she focusses on renewal. The final stanza reads: ‘Next year I will listen to the sap / rise from the root, rustling to each / branch, to the leaves and finally / the bowers of flowers and fruit’. This is a welcome reminder of the sensation that is intellectual and social growth. It rewards those that tell – and attend to the telling – of stories of pain.

Pain is often described as ‘productive’ in that it warns of damage or protects the body against further harm. But suffering from chronic pain can be a very disempowering, unproductive experience. The role of the arts in re-empowerment is a strong theme in therapeutic approaches to pain. In the negotiation of everyday life, most of us can often switch our focus: we can indulge our bodily sensations or forget about our bodies for a time and treat them as mere husks for our sentient brains. For sufferers of pain, bodily sensations continually interrupt and disrupt this negotiation. Embodiment is insistent and unpleasant. Engaging with the arts can distract from pain, but the arts can also be a means of focussing on pain and articulating it in unconventional and dynamic ways. The arts are particularly successful at highlighting this distracting–focussing duality, and also enacting it in creative work. For example, Anusha Subramanyam’s expressive dance (Chapter 7) epitomises why the verb ‘moving’ is applied to emotions as well as physical action. The language of South Indian dance reminds us that gesture is a rich source of paralinguistic communication. It is a powerful demonstration of how the arts provide new insights into the dynamics of pain.

Research

Credible research is integral to the intellectual underpinnings of pain studies as a discipline. One of the main prompts for the ‘Encountering Pain’ event was to consolidate collaborative research on the value of images and image-making for pain management. This three-year multi-disciplinary project, entitled ‘Pain: Speaking the Threshold’, evaluated Deborah Padfield’s ground-breaking work in co-creating images with pain patients (Chapter 8), which has led to innovations in approaches to pain consultations. Joanna M. Zakrzewska (Chapter 22) uses the pain images printed on cards in pain consultations: patients select image

cards that they feel correspond most closely to their own experiences and may use them whenever they feel it is appropriate. Zakrzewska endorses their value in facilitating discussion around pain and her findings are borne out by research into the impact of the cards on the discourse within consultations.

Elena Semino has analysed the linguistics of these consultations (Chapter 16) and discovered that only when the cards are used do patients speak more than consultants. She also found that the level of personal disclosure increases with the use of the cards. The word ‘feel’ was used more often by patients in consultations in which the cards were deployed. The use of the images helps clinicians to become more aware of the emotional landscapes of patients’ pain.

While Semino analysed linguistic elements of pain consultations, Amanda C de C Williams has researched how using the images changes non-verbal interactions (Chapter 9). By noting patient and clinician behaviours that constitute rapport, Williams and researcher Tom Chadwick show that using images promotes ‘affiliation behaviour’ by clinicians in response to patients. Clinicians tended to follow rather than precede patients’ behaviour. There are many useful lessons to emerge from this research, not least that patients have specific expectations about what constitutes a good consultation. Patients want the opportunity to discuss concerns and prefer to be presented with a range of treatment options. The qualities that Williams found were valued most highly in a clinician include expertise in ‘delivering bad news’; the ability to give a patient their full attention; and honesty. These are important lessons that deserve more attention in educational settings.

Research on pain is complex. Pain resists easy quantification or even qualification. The dedication, commitment and indeed passion, of the research team are evident. This research is an affirmation of the use of images in consultations. It could potentially have a transformative effect on the shape of pain consultations.

Healing spaces and places

The use of images in social, rather than clinical, spaces is a fascinating area of research. Although photography has long documented and catalogued painful symptoms, in the past this has contributed to stigma by giving the impression of danger – so many ways of describing pain involve violence, like ‘stabbing’, ‘sharp’ and ‘hammering’. The information age has meant that digital networks of patients and their

carers share images. These practices often humanise and socialise pain through associating it with positive affiliation signifiers. Elena Gonzalez-Polledo and Jen Tarr's work (Chapter 13) shows how image sharing on social media offers opportunities for those with pain to come to new understandings of their own narratives and to share them with others. Digital communities are actively contributing to raising awareness, and social acceptance, of certain conditions, and in so doing, have invoked a new visual and verbal semiotics of pain communication. Online exhibitions of creative works exploring pain are shown by Susanne Main (Chapter 14) to be helpful to both exhibitors and viewers, not least because they provide a sense of advocacy around the credibility of pain experiences.

Pain and its management demand exquisite cultural sensitivity. Stoicism, while necessary for coping with pain, can be a barrier to patients being motivated to seek appropriate treatment. Preeti Doshi speaks of the challenges in managing pain in India, where Buddhists accept suffering as an aspect of spiritual growth and it is often culturally frowned upon to complain openly about pain (Chapter 18). There may also be a cultural aversion to some forms of treatment, such as a conceptualisation of the body as 'fragile', making some patients unlikely to follow recommendations for exercise. It makes pain management programmes particularly challenging when healthcare practitioners and patients lack a shared conceptual basis for approaching pain. Patients with different cultures and languages from their healthcare providers face additional hurdles in accessing care. Being attuned to cultural sensitivities in pain management is something that practitioners are aware is important, and how to best to take these into account in treatment programmes is an evolving area of research.

Being given the opportunity to voice pain is a privilege afforded to all too few. We recognised that those of us attending the 'Encountering Pain' event were privileged to be present and able to actively participate. Those who suffer too acutely to be able to leave their homes or even their beds have voices that are difficult to hear in academic scholarship, but also in treatment settings. Jens Foell, a general practitioner who works in an area with a high level of recipients of welfare benefits, reminds us in Chapter 5 how difficult it is to negotiate the politics of pain through what he aptly names 'street-level bureaucracy'. He highlights the contradiction between patients needing to simultaneously persuade medical professionals of their impairments in order to legitimise sickness certification, while disability assessments are couched in the rhetoric of working capacity. As Foell points out, doctors

called upon to certify disabilities tend to be unaware of the minefield of bureaucracy that claimants need to negotiate. As part of a conscientious response to addressing pain, medical education and professional development programmes need to devote much more attention to awareness of the systemic obstacles faced by patients in need of support.

Conclusion

I began this chapter by referring to Emily Dickinson. Many of her poems are explicit about the link between the capacity to receive pain and the seemingly contradictory ability to experience pleasure. It makes sense that we require the ability to experience pain in order that the pied nature of joy might be discovered. Dickinson wrote several poems in which pain is dealt with very directly. Within many of her poems are oxymorons, such as 'sweet torment' and 'sumptuous despair'. Mackenzie (2000, 56) describes the use of oppositional devices in Dickinson's poetry as 'self-inflicted textual wounds'. These, she argues, become sites for pleasure in a Barthesian sense, as Barthes claims in *The Pleasure of the Text* that 'what pleasure wants is the site of a loss, the seam, the cut, the deflation, the dissolve of which seizes the subject in the midst of bliss' (Barthes 1975, 7). The result, according to Mackenzie, is that Dickinson's 'pain provides the paradoxical power that generates her artistic and spiritual potential' (2000, 59). This artistic and spiritual potential was indeed realised at the 'Encountering Pain' event, and given legacy in this volume, through the nexus of theory, experiment, creativity, philosophy and psychology.

The word 'encounter' first entered the English language in the thirteenth century. It originally meant the 'meeting of adversaries' from Old French *encontre*: 'meeting; fight; opportunity' (Online Etymological Dictionary n.d.). How apt! At this *meeting*, we wrestled, *fight*-like, with intellectual, social and cultural concepts of pain. What emerged was a new *opportunity* for increased understandings of the ways in which we can communally make sense of pain.

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Afterword

Communicating chronic pain

Jonathan Wolff

As Dean of the Faculty of Arts and Humanities at UCL the time of the landmark 'Encountering Pain' conference, and as a political philosopher who researches issues of justice and health, I am honoured to have been invited to add my reflections to this extraordinarily rich and innovative volume. For academic researchers, health conditions are often rendered very abstract, in terms of loss of quality adjusted life years (QALYs), or performance on some sort of scale or measure. Issues of resource allocation encourage us to look for the universals underlying different conditions, leaving their underlying phenomenology neglected. Yet for the individual the phenomenology and what, if anything, can be done to alleviate it, fills their life in a way in which, as Padfield and Zakrzewska (2017) suggest, resists easy reduction. Charts, scales and measures might tell us that one pain is worse than another, or that, in some sense, it is more or less 'serious' (and hence more or less deserving of resources) than some other condition. But we are unlikely to capture the essence of what it feels like to be in pain by such means. The more that can be done to understand the experience of pain, the more chance we will have of finding ways of managing or mitigating it.

The key theme of the conference, and of this volume, is the idea of communication, which requires a communicator, a mode of communication and an audience. In the case of chronic pain, the act of communication is impeded by the absence of a standard or agreed mode of communication. This can cause immense frustration on one side and impatience or even disbelief on the other. The innovation of the book is to open up the issue of the mode of communication regarding pain, inspired by Deborah Padfield's own work as an artist and image-maker. Having co-created a set of PAIN CARDS with patients, she has made the

first step towards creating a universal new language for expressing pain in its multiple forms.

One central question regarding the images that some patients and clinicians have found so helpful is how they function. Do they allow patients to form thoughts they could have expressed without the image – for example that there is a ‘gap’ in a family – or do they provide a form of communication for which we have no words, and, perhaps, could have no words? Joanna Bourke (2017) shows how pain has been communicated in words by those with a particular literary facility, yet even in the evocative examples she gives we seem to run up against limits. We run out of verbal metaphors very quickly. Any alternative form of communication is an extremely exciting prospect.

The idea of communicating something that cannot be expressed in verbal form may seem surprising but in fact it is a familiar part of life. Following Gilbert Ryle (1949), philosophers sometimes distinguish between ‘knowledge that’ and ‘knowledge how’. ‘Knowledge that’ is knowledge that can be put into the phrase ‘This person knows that p’, such as that Jakarta is the capital of Indonesia. But not all knowledge takes that form. Knowing how to swim is a form of knowledge that cannot be reduced to a set of sentences or communicated in written form. True, some things can be passed on verbally, but the idea that someone could learn to swim simply by studying a swimming manual seems absurd. ‘Knowledge how’ can be passed on, but in the form, in this case, of physical training. Knowing how something feels may be a further category of knowledge. It can sometimes be expressed in words, especially to those who have had the same feeling before. Art, poetry and music are often used to evoke new feelings in people, in ways we might not fully understand. But communicating how something feels to someone who has never felt it, and without wishing for them to feel it, may well require a different set of tools.

In the work by Elena Semino, Joanna M. Zakrzewska and Amanda Williams, we see how the PAIN CARDS have been used in practice. One key role seems to be that they enable a conversation that, in principle, could have taken place without the cards but, in fact, would not have done. The cards seem to give the patients a form of permission to talk about matters that they may have otherwise felt were inappropriate in that clinical setting. They prompt conversations far beyond the description of pain. I’ve already mentioned family, but other examples involve a sense of identity and a sense of loss. If a patient is asked why they have chosen a particular card then, in principle, nothing is excluded as a possible topic of conversation. Arguably this moves the

person suffering from chronic pain away from their assigned role as a patient in a pain clinic, with the restricted scripts available to anyone playing that particular role, to a human being with a full range of emotional and intellectual responses. This, in turn, appears to bring the clinician out of his or her assigned role too, responding to the patient in a warmer, more human fashion. Much of our socialisation as human beings is to learn how we are expected to behave on particular occasions. Yet this can also constrain and limit us in damaging ways. In this respect, the PAIN CARDS can liberate patient and clinician from the limitations of those roles that we have inadvertently created.

What is the effect of placing everything in such a potentially unrestricted context? Critics will say that it is a distracting waste of time and resources, focussing attention away from what should be the main business of finding clinical methods of managing pain. Those more sympathetic will see it as a way of finding new routes to tackle problems that have proven to be intractable by traditional means. Both sides make empirical, testable claims about the most effective – and most cost-effective – ways of tackling chronic pain. The next step should be to carry out those tests in a way that meets accepted standards of high-quality evidence. It will be a challenge to design an experimental protocol, and the cost of doing so on a significant enough scale to be meaningful would be formidable. But the potential benefits are immense.

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Figure 25.1 'The Ash, Yr Onnen: Summer, yr haf', from 'For the Ash: I'r Onnen', *The Moon and a Smile*, Glynn Vivian Art Gallery, 2017. Giclée archival print. © Sharon Morris

Index

Page numbers in **bold** refer to tables and boxes; page numbers in *italics* refer to figures; 'n' after a page number indicates the endnote number. Photographs from *Face2face* are the co-creative work of Deborah Padfield and participants of the project. To avoid repetition, page numbers for these photographs are given under participants' names only.

- Abbott, Jillie: *Face2face* series, 'Untitled', 133
- Abject Art: Repulsion and Desire in American Art* (1993 exhibition, Whitney Museum, New York), 207
- abjection, 208
 abject art, 196, 207–8, 210, 227
 pain and, 209, 210
- ableism, 240, 304, 310
- acute pain, 318, 320, 359
 as key survival signal, 355
 opioids as pain relief, 366
 switch from acute to chronic pain as detrimental, 14, 356
- aesthetics
 beautiful/ugly pain, 195, 196–200, 202–3, 211
 beauty and ugliness, 9, 196, 197–8
 images as aesthetic objects, 211
 ugliness as social category, 195, 199
see also art; picturing pain
- Aldous, Liz, 6, 46–56, 165, 371
Face2face, 48–53, 55, 56
Face2face series: 'Untitled', 47, 50
Face2face series: 'Untitled', 49
- Face2face* series: 'Untitled', 49, 50
Face2face series: 'Untitled', 49, 51
Face2face series: 'Untitled', 52
Face2face series: 'Untitled', 90
Face2face series: 'Untitled', 281
- facial pain, 46–8, 53, 54–6
- High Town Art For All, 52
- the tree metaphor, 373
see also Face2face
- allodynia, 361, 362, 365, 368
- analgesia, 294, 356, 367
see also pain relief; medication
- analgesics, 14, 320
 distraction as analgesic, 52
 effectiveness of, 368
 neural signalling and, 355, 360–1, 363, 364, 366
see also medication
- Aristotle, 197, 319, 349–50
- art, 2, 374, 381
 abject art, 196, 207–8, 210, 227
 art/medicine relationship, 53, 166–7
 communicating pain and, 3, 8–9, 13
 emotions and, 350, 381
 'Encountering Pain' conference, 53

- art (*cont.*)
 health–arts nexus, 152–3, 350
 intersubjectivity: the body, pain, emotions and art, 222–4
 pain in modern art, 9
 phenomenology/art similarities, 226, 228–9
 power of, 59, 349–50
 role in re-empowerment, 374
 war art, 195, 206
see also aesthetics; picturing pain
- arthritis, 301, 356, 367, 368
 osteoarthritis, 359, 367
- art therapy, 81, 84, 100–1
see also PSTT
- Ashton-James, Claire E., 179, 344–5
 Atos, 113, 120, 121
- back pain, 23, 89, 152, 293, 330
 low-back pain, 290, 301, 321, 357
 nociceptive/neuropathic pain combined in 357
 upper back pain, 303
- Bacon, Francis, 209
 Bagshaw, Rachel, 153
 Bamba, Clare, 123
 Bannister, Kirsty, 13
 Barthes, Roland, 167–8, 377
punctum, 166, 168, 169, 173n8
 Baxandall, Michael, 88
 beliefs and spirituality, 11, 302, 320, 325
 Bell, Charles, Sir, 263
 Bending, Lucy, 193, 204
 Berger, John, 332n10
 Biernoff, Suzanne, 8–9, 204
 biomedicine, 316, 318, 319
 biomedical model, 112, 126, 316, 317–18, 321
 biopsychosocial model, 111–12, 126, 317–18, 320, 332n6
 moral aspects of, 113–16
 as sociopsychobiological model, 115
 Biro, David, 155, 171, 349
 Blaxter, Mildred, 112, 114, 115
 Boddice, Robert Gregory, 152, 193
- body
 ‘abominations of the body’ as social stigma, 195
 act of drawing and, 215
 bodily expressions, 223–4, 229
 body/mind interaction and effects on pain, 321, 331
 ‘corporeal turn’, 207
 disability and, 306, 307, 308–9
 as expression, 219, 220–2
 images of pain, 234
imitatio Christi, 201
 intersubjectivity: the body, pain, emotions and art, 222–4
 markers of, 195
 pain as communication from the body, 327
 pain expression and, 318
 as part of the subjectivity construct, 172
 physical appearance/emotional response link, 195
 ‘retrojection’, 210
 as site for inscription of socio-cultural norms, 222
see also embodiment; face; mind–body dualism
- Bourke, Joanna, 9, 83–4, 199, 210, 318, 324, 381
 ‘cultural scripts’ for being in pain, 194–5, 199, 210
The Story of Pain: From prayer to painkillers, 193, 260, 263, 372–3
- boyd, danah, 239
- brain
 addiction to opiates and, 321
 areas concerned with pain, 358–9, 358
 brain scans/imagery, 57, 68, 72, 320
 in children, 23
 consciousness of pain, 363, 366
 cortex, 356, 358, 359, 368
 empathy for pain and, 185
 enhancing/reducing pain signals, 366–7
 limbic brain, 357–8, 359, 366
 limbic brain, emotional aspects of pain, 356, 359, 364, 368
 pain and, 16, 18–19, 20, 21, 24, 27, 28, 111, 355, 360
 pain as ‘drilling into your brain’, 63
see also central nervous system; pain, neurobiological perspective
- bricolage, 13, 220, 317, 332n3
- Brison, Susan J., 44n3
- Broks, Paul, 149, 156
- Brunton, T. Lauder, 257, 259
- Bruzzi, Stella, 193
- Buddhism, 292, 376
- bureaucracy, 7
 street-level bureaucracy, 123, 128, 376–7
see also healthcare system; welfare system; workfare
- cancer, 33, 55–6, 255, 290, 327–8
 in developing countries, 296
 narratives and, 323
 neuropathic pain, 361
 nociceptive/neuropathic pain combined in cancer pain, 357
 pain management, 293–4
 terminal cancer, 293, 295, 323
- CBT (cognitive-behaviourally informed treatment), 55, 321, 331
- Celan, Paul, 208
- Céline, Louis-Ferdinand, 208
- central nervous system, 25, 27, 355, 368
 chronic pain and central nervous system changes, 3, 362, 367
 descending controls, 359, 366, 367
 enhancing/reducing pain signals, 363
 excitatory system, 363–4
 inhibitory system, 14, 19, 363, 365–7
see also brain; pain, neurobiological perspective; spinal cord
- Chadwick, Tom, 13, 83, 169, 375
- charcoal: making charcoal for drawing, 214–18
- body and the act of drawing, 215
 burning, 214
 burning charcoal, 216, 218
 burnt charcoal heap, Cannop Hill, Forest of Dean Sculpture Trail, 216–17, 217
 charcoal, 214, 215–18
 charcoal clamp, Cannop Hill, Forest of Dean Sculpture Trail, 215, 216
 charcoal measure, Cannop Hill, Forest of Dean Sculpture Trail, 217, 218
 drawing, 215
- Chare, Nicholas, 207–8, 209
- Charon, Rita, 1–2, 5–6, 13, 16, 326, 351, 372
- children, 336
 exaggerating pain, 23
 infants, 23, 24, 25, 26, 87
 pain processing development, 23–4
- Christianity
 Christian ideology of suffering, 196, 204, 319
 Christian theology and positive significance of pain, 200–1, 204
 iconography of sacrifice: *imitatio Christi*, 9, 195, 196, 200–3
- chronic pain, 1, 33, 336, 371
 central nervous system changes and, 3, 362, 367
 challenges of, 3–4
 challenges in representing chronic pain, 170
 chronic pain sufferers as stoics, 371, 372
 chronification of pain, 292, 298, 355, 368
 communicating chronic pain, 380–2
 definition of, 3, 18
 diagnosis of, 3
 disability and, 301
 dismissed as unimportant in medical settings, 336
 ethical challenges raised by, 2, 7
 gender gap, 316

- chronic pain (*cont.*)
interdisciplinary work needed to deal with, 337
lack of public knowledge on, 352
lack of training to engage with, 336–7
as neuropathic pain, 357, 362
patient–doctor dynamic
in chronic pain consultations, 336–7
in social media, 230, 237, 238–9, 240
Sontag, Susan: ‘Man with a Pain’, 255–6, 257, 260, 266
switch from acute to chronic pain as detrimental, 14, 356
see also chronic pain, impact of; *Exhibiting Pain*; pain
chronic pain, impact of, 74–5, 193, 277, 301, 336, 364, 374
anger, 356
anxiety, 19, 46, 57, 356
attack, sense of, 184
depression, 336, 356
fear, 63, 75, 76, 132, 136, 184, 353, 356
helplessness, sense of, 184, 324
impact on the family, 63, 74, 75–6, 75, 153
isolation, 10, 19, 59–61, 75, 75, 136, 184, 238, 249, 278, 336
loss of control, sense of, 54, 76, 165, 277, 336
self and self-worth, 336
stigma, 115, 149, 151
Clair, Jean: *Identity and Otherness* (exhibition), 205–6
classical tradition of suffering and pain, 196, 197, 200, 211, 329, 331
Cockburn, David, 223–4
Cohen, Esther, 193, 200–1
collaborative action/practice, 6, 7, 13, 14, 338
collaborative research, 374
team approach, 298, 337–9
see also intellectual empathy; interdisciplinarity
Collen, Mark: *PAIN Exhibit* (website), 153, 165, 246, 251n1
communicating pain, 3, 13, 152, 194
art/artistic expressions, 3, 8–9, 13
communicating chronic pain, 380–2
complexities/challenges of
expressing pain, 38–9, 132, 177, 183, 231
conversations about pain, 6, 111, 113, 114, 118
culture and, 231, 315
expression of pain is not universal, 192
language and, 3, 6, 7, 10, 11, 12, 26
metaphors, 39–40, 349
pain as communication from the body, 327
quality of pain, 184, 277
social interaction, impact on the expression of pain, 177–8
through multiple media, 230
ubiquitous representations of pain, 34
see also language; pain expression; visual images of pain
communication, 380
in clinical contexts, 325–6
communication skills, 40, 185–6
effective communication, 5
embodied communication, 327
good dialogue, 372
power asymmetries in, 272, 274, 284
topic control, 274
see also nonverbal interactions
compensation neurosis, 119
consolation, 371
control
chronic pain and sense of loss of control, 54, 76, 165, 277, 336
locus of control, 114
topic control in communication, 274
Corning, James Leonard, 258–9, 260, 261
Craig, Kenneth D., 171, 173n5, 264
Creative Health: The arts for health and wellbeing (2017 report), 167, 350
creativity, 14, 76, 325, 377
benefits in exploration and communication process, 166–7, 244, 247
pain management and, 46, 48, 52, 55, 56, 373
‘shared objectification’ through creativity, 373
culture
communicating pain and, 231, 315
cultural scripts for pain, 194–5, 199, 210
cultural sensitivity and pain, 376
expanding cultural notions of pain, 12
health and, 172
images as cultural and epistemological artefacts, 210
India, cultural beliefs, 291–2, 292, 376
India, cultural and linguistic diversity, 11, 289, 291, 376
Japanese culture, 15
pain and, 172, 318, 320, 324
pain as cultural phenomenon, 194
‘retrojection’, 210
social and cultural history of pain, 193
Dalley, Tessa, 87
Dannequin, Laura, 153
Darwin, Charles, 9, 210
The Expression of the Emotions in Man and Animals, 190–2, 191, 195–6, 263
David, Jacques-Louis, 321, 332n15
Day, Giskin, 14
DBT (dialectical behavioural therapy), 116
Department of Health and Social Care (UK), 124
Department for Work and Pensions (UK), 7, 113, 120, 121, 124
depression, 301, 303, 307, 308, 336, 356
Derrida, Jacques, 89
Descartes, René, 112, 319, 324, 332n8
De Waal, Frans B. M., 185
diagnosis
chronic pain, 3
diagnostic classification systems, 260
facial pain, 73–4, 76, 80
factors interfering with the listening for pain, 40
gestures of agonising pain aiding diagnosis, 262
misdiagnosis/non-diagnosis, 57, 304
narrative diagnosis, 331
pain, diagnosis of, 13, 349
PAIN CARDS and, 78
trigeminal neuralgia, 57–9, 61, 69–70
visual images of pain and, 59, 69–70, 149, 152, 250
Dickenson, Anthony H., 13
Dickinson, Emily, 36, 370, 377
disability
2016 Rights of Persons with Disabilities Act, 306
acid attack victims, 306
advocacy for, 311–12
anger, 304
barriers, 304, 305, 306, 310, 311, 312
body and, 306, 307, 308–9
chronic pain and, 301
disability certification, 310–11
disability identity, 12, 307, 310, 312
disability without pathological lesion as problematic, 125
emotional pain and, 303, 309
family and, 302, 304, 306, 309
gender/pain/disability relationship, 307
human rights model of disability, 311–12
intersubjective relations and, 221–2
Kahlo, Frida, 220, 224
medical model of disability, 300, 310, 311
mental disabilities, 304
mental illness, 304

- disability (*cont.*)
 men with disabilities, 307
 pain disability, 115, 120, 124, 125
 pain/disability relationship, 300–3, 312
 self-esteem, 303, 304, 307
 social model of disability, 300, 310, 311
 as subjective experience of life, 300
 women with disabilities: sexual and domestic violence against, 304, 307, 309–10
see also disability, pain of negative emotions; India: disability and pain
- disability, pain of negative emotions, 303–6
 pain of discrimination, 304–5, 307–8, 309, 310–11, 312
 pain of guilt and worthlessness, 305, 309, 310, 312
 pain of injustice, 304, 311, 312
 pain of isolation and loneliness, 305, 306
 pain of rejection, 305–6, 309, 312
see also disability
- diseases, 294
 headache as disease of civilisation, 259–60
see also illness, disease and sickness
- ‘doing’ pain, 194, 195, 208, 210
- Doshi, Preeti, 11–12, 172, 376
- Duchenne, Guillaume-Benjamin-Amand, 191–2, 195, 197, 211n4
- Dunsmore, J., 264
- Dwoskin, Stephen, 153
- Eastman, Ann, 6, 57–70, 165, 371
Face2face, 58
Face2face series: ‘Untitled’, 59, 60
Face2face series: ‘Untitled’, 62
Face2face series: ‘Untitled’, 64–5
Face2face series: ‘Untitled’, 66
Face2face series: ‘Untitled’, 67
Face2face series: ‘Untitled’, 68
Face2face series: ‘Untitled’, 69
 neurosurgery, 68
 self-portrait, 58, 66
- trigeminal neuralgia, 57–9, 61, 63, 67
see also Face2face
- Eastman Dental Hospital, 47, 48, 54, 349
- Eco, Umberto, 198, 202
- Edelsky, Carole, 272
- education and training, 12, 14, 260, 316
 empathy: training/skills for, 185–6
 India, 12, 295, 296, 311
 lack of training to engage with chronic pain, 336–7
 listening: training/skills for, 40–1, 43, 326, 372
 medical education, 316, 370, 372, 375, 377
 pain education, 295, 298
 qualities valued in a clinician, 375
 testimony, 323–4
- Ekman, Paul, 264
- Elisabeth of Bohemia, 324–5
- embodiment, 89, 207, 331, 370, 374
 embodied communication, 327
 embodied emotions, 330
 embodied intersubjectivity, 223
 embodied mind, 319
 embodied relationship to the self, 229
 embodied subjectivity, 221, 222, 224, 227
 health humanities and, 370
 Kahlo, Frida, 220, 223, 226, 227
- emotional pain, 53, 330
 disability and disabling conditions, 303, 309
 physiological/psychological pain distinction, 20, 152, 171
- emotions
 art and, 350, 381
 embodied emotions, 330
 emotional aspects of pain, 101, 359, 363
 emotional disclosure by patients, 180, 181, 187
 emotional expression, 190–2, 196
 emotional skills, 186
- emotions/immune system communication, 321
- face and body in medieval art, 201–2
- facial expressions based on six emotional states, 192
- limbic brain, emotional aspects of pain, 356, 359, 364, 368
- pain as emotional experience, 14, 192, 319
- pain/emotions links, 14, 18, 20–1, 171, 301, 363, 367
- physical appearance/emotional response link, 195
- visual images of pain in consultations and emotional disclosure, 180, 181, 187, 279, 281–4
see also chronic pain, impact of
- empathy, 184–5
 affective empathy, 184
 in clinicians/doctors, 185–6
 cognitive empathy, 184
emföhlung (in-feeling), 339
 empathic accuracy, 185
 intersubjectivity, 36
 for pain in humans, 185
 skills and training for, 185–6
 witnessing the pain of others, 199, 263, 264, 265–6
see also intellectual empathy; rapport
- ‘Encountering Pain’ (2016 international conference, UCL), xxxv–xxxvi, 1, 14, 53, 54, 78, 83, 139, 214, 346, 352, 370–1, 373, 376
 artistic and spiritual potential, 377
 collaborative research, 374
 communal sense-making of pain, 377
 communication as key theme of, 380
Exhibiting Pain poster, 245
 hospitality and consolation, 371
Encountering Pain: Hearing, seeing, speaking (book), 15, 352, 370–1
 aims, 2, 15
- communication as key theme of, 380
 interdisciplinary approach, 2, 15
 structure, 5–14
 endorphins, 365–6, 368
 enkephalins, 365–6, 368
 ethics, 2, 7, 324
- ethnicity
 racialised understanding of facial expressions, 265
 underestimation of ethnic groups suffering, 199, 264
- Exhibiting Pain* (PhD research project and online exhibition), 244, 245, 251n1
 abstract works, 250
 benefits for creators and audience, 247, 248, 249, 250–1
 creators, 247, 251n2
 curation, 247
 diagnostic images, 250
 empathy, 249
 Facebook group, 246, 247, 248, 249, 250, 251
 intended audience, 248
 interpretation, 247, 248, 249–50
 online exhibitions and chronic pain, 244, 246, 251, 376
 recruitment of creative works, 246
 representing pain, 247–8
 research method, 246–7
 sharing pain, 250–1
 viewing pain, 248–9
 why exhibit pain?, 244–6
 WordPress gallery, 246, 250, 251
- face
 facial expressions, gendered understanding of, 265
 facial expressions and demand for sympathy, 262–3, 264, 266
 facial expressions as universal language, 263, 264, 265
 facial injuries, representation of, 204–5
 focus on the face for descriptions of pain, 263–4

- face (*cont.*)
- important functions of life and, 350
 - in medieval art, 201–2
 - see also* body; facial pain
- Face2face, 3–4, 7, 10, 12, 83, 351
- arts and health research project, 3, 76
 - co-creative process, 147, 155, 157–65, 168, 352, 374, 380
 - digital photography, 159, 167
 - identity and the portrait, 155–7, 160, 164
 - images and meaning, 164–5
 - impact on participants, 53, 55, 78, 148, 154, 165, 351–2
 - locations, 158
 - metaphors, 159
 - multiple readings of photographs, 149, 164–5, 167, 170
 - origins of, 149–51
 - pain narratives, 148
 - participants, 147, 156–8, 351
 - photographic workshops, 4, 157–65
 - photography as mediating space, 148
 - portraits of pain, 147, 155
 - the *punctum*, 169–70
 - viewing the images in the clinic and viewer/image interplay, 157, 167, 168–71
 - why the photograph?, 165–8
 - see also* Aldous, Liz; Eastman, Ann; Glenn, Alison; Khoda, Chandrakant; Padfield, Deborah; PAIN CARDS; Williams, Linda; Zakrzewska, Joanna M.
- facial pain, 4, 46–8, 69, 71, 74–5, 351
- complexity of, 350
 - creativity, power in managing pain, 48, 52, 55, 56
 - diagnosis, 72–3, 74, 76, 78
 - evocative language for its description in early medical texts, 260
 - impact of, 74
 - management of, 46, 48, 53, 54–5, 72
 - see also* face; trigeminal neuralgia
- family, 181, 249, 381
- chronic pain, impact on family, 63, 74, 75–6, 75, 153
 - disability and, 302, 304, 306, 309
- feminism, 13, 207, 316, 332n5
- feminist *bricolage*, 317, 332n3
- fibromyalgia, 25, 47, 301, 357–8, 367
- Fitzgerald, Maria, 6
- Flanagan, Bob, 153
- Flickr, 153, 240
- Flickr/Tumblr comparison, 231–3, 236, 239, 240
 - immediacy, 233, 235–6, 239
 - iridescent communication, 233, 235–6
 - photostream, 231–2, 235, 236
 - see also* social media: remaking of illness narratives
- Foell, Jens, 7, 376–7
- Foucault, Michel, 88, 207, 317, 322, 332n3–4
- Francis, Gavin, 108
- Frank, Arthur W., 14, 236, 322–4, 325
- The Renewal of Generosity*, 371
- Fried, Martin, 155, 169
- Galás, Diamanda, 208–9
- Galloway, Alexander R., 232–3, 235–6, 237
- GBD survey (Global Burden of Diseases), 290
- Gell, Alfred, 148
- gender-related issues
- chronic pain, 316
 - disability/pain/gender relationship, 307
 - facial expressions, gendered understanding of, 265
 - female medical students and perception of pain, 23
 - female pain-sufferers as being pathologised, 11, 258–9
 - gender variations in the same treatment, 316
 - metaphors, gendered use of, 257–9
 - neuralgia, gendered presentations of, 257–9
 - pain descriptions as highly gendered, 11, 257
 - sympathy and gender, 265
- generosity, 14, 15, 40, 139, 371, 372
- Gilbert, Mark, 156
- Gillies, Harold, 205
- Gilmore, Jonathan, 221
- Glenn, Alison, 6, 71–80, 165, 371
- Face2face*, 76–80
 - Face2face* series: ‘Untitled’, 71
 - Face2face* series: ‘Untitled’, 73
 - Face2face* series: ‘Untitled’, 75
 - Face2face* series: ‘Untitled’, 77
 - Face2face* series: ‘Untitled’, 79
 - facial pain, 70, 71, 75–6
 - facial pain diagnosis, 72–3, 74, 76, 78
 - trigeminal neuralgia, 75
 - see also* *Face2face*
- Goffman, Erving, 195, 200
- Gonzalez-Polledo, Elena, 376
- Goss, Rebecca: ‘Pleurisy’ I–V (poems) 7, 104–10, 373–4
- Green, John, 230, 238, 312
- Greenhalgh, Trisha, 230–1, 317, 326
- Grenier, Carl, 156
- Gross, Samuel David, 261, 267n8
- Grosz, Elizabeth, 172
- Harpham, Geoffrey Galt, 193, 194
- Harrington, Malcolm, Lord, 121
- Hartman, Geoffrey, 35
- headache, 256, 303
- abnormal production and/or release of pain chemicals, 358
 - as disease of civilisation, 259–60
 - evocative language for description in early medical texts, 260–3, 264
 - metaphors for, 256–7, 259–61
- modernity and, 259
- serotonin and, 361
- as sign of ‘psychological disturbance’, 258–9
- see also* migraine; neuralgia
- healthcare professionals, 2, 298, 318, 322, 326, 327
- cultural sensitivity, 376
 - engaging with narratives of pain, 372
 - illness narratives and, 324
 - India: pain management challenges, 290, 376
 - need for understanding patients’ beliefs, spiritual identities, ways of life, 320
 - negative experiences with, 113, 118, 238
 - PAIN CARDS and, 148, 352
- healthcare system
- constant adversarial struggle, 118
 - cycle of invalidation, 117–19
 - fragmentation of, 7, 112–13
 - fundamental changes needed in, 37–8
 - GPs’ reports on patients’ pain and disabilities, 124–5, 127
 - India, 294–5
 - politics of pain, policies of poverty, 123–7
 - templates, 121–2, 128
 - see also* welfare system; workfare
- health humanities, 370
- health inequalities, 128, 370
- Hewetson, Henry Bendelack: *The Localization of Headaches and Sick-Headaches*, 257
- HIV-AIDS, 290, 361
- Holocaust survivors, 35
- humane medicine, 372
- humility, 302, 339, 341, 343, 345–6, 372
- Hunter, William, 205, 212n10
- Hurd, Edward Payson, 261
- Hurwitz, Brian, 230–1, 326
- Husserl, Edmund, 36–7, 42
- hyperalgesia, 361, 362, 368

- IASP (International Association for the Study of Pain), 171, 173n5
- identity
- disability identity, 12, 307, 310, 312
 - Face2face*, 155–7, 160, 164
 - illness narratives and, 324
 - pain and, 2, 315
 - PAIN CARDS, 270
 - self-identity, 95, 98
 - PSTT*: images and identity, 100, 101
- illness, disease and sickness, 116, 116, 117, 118, 127, 128
- illness deception models, 119
- India
- access and availability issues for drugs and technology, 295–6
 - barriers, 291, 293, 295, 296
 - changes in the Indian medical education system, 12, 311
 - chronic pain, 290, 294, 295
 - communication and language barriers, 291
 - competing priorities for different diseases, 294
 - cultural beliefs, 291–2, 292, 376
 - cultural and linguistic diversity, 11–12, 289, 291, 376
 - disability and pain, 11, 290
 - a doctor with disability, 310–11
 - double discrimination of women with disability, 309–10
 - forced hysterectomies, 309
 - growing up as a woman with disability, 307–9
 - healthcare professionals, 290, 376
 - Hindu philosophy/religion, 301–2
 - inadequate pain treatment, 290
 - karma, 291, 301–2, 309
 - lack of awareness, 290
 - lack of optimum health care infrastructure, 294–5
 - lack of penetration of insurance services, 297
- lack of standardised practices and national guidelines, 297
- pain management challenges, 11–12, 297–8, 376
- pain statistics in India, 289–90
- palliative care, 294–6
- patient acceptance of drugs and techniques for pain management, 293–4
- paucity of systematic epidemiological studies on pain, 11, 289
- polypharmacy, 290
- population, 11, 291
- prejudices against the disabled, 302
- recommendations, 297–8
- spirituality, 302
- suffering, 301–2
- superstitions and myths, 292–3
- visibility/invisibility, 307, 308
- see also* disability
- intellectual empathy, 13, 346n2
- collaboration, 338
 - as conflict resolution, 343–6
 - empathy, 339–40
 - good will/good faith, 340, 341, 343, 345
 - humility/intellectual humility, 339, 341, 343, 345–6
 - informality, 340, 342
 - interdisciplinarity, 337–9
 - interdisciplinary conflict, 339, 340, 342–3, 345
 - the professional is personal, 342–3
 - respect: professional and human, 340–1, 343, 345
 - teams, 337–9, 344
 - see also* interdisciplinarity
- interdisciplinarity, 1, 2, 7, 11–12, 14, 316
- challenges of, 338–9
 - chronic pain, interdisciplinary work needed for, 337
 - interdisciplinary care for people experiencing pain, 114–15
- PSTT*, 83, 169
- see also* collaborative action/practice; intellectual empathy
- intersubjectivity, 36–7, 372
- the body, pain, emotions and art, 222–4
 - disability and intersubjective relations, 221–2
 - embodied intersubjectivity, 223
 - Kahlo, Frida, 219, 224
 - locating pain in a *third space*, 115–16
 - pain as intersubjective event, 35–8, 372
 - PSTT*, intersubjective relationship, 82, 89, 100
 - social negotiation of pain, 194
- intertextuality, 326
- Irigaray, Luce, 89, 316, 332n1
- irritable bowel syndrome, 357–8
- Isserow, Jonathan, 82, 87–8, 93, 100
- Julian of Norwich, 200–1
- Jung, Berenike, 193
- Jung, Nike, 172
- Kahlo, Frida, 219–20, 228–9
- art of lived experiences, 224–7
 - bodily expressions, 223, 229
 - disability, 220, 224
 - embodied subjectivity, 224, 227
 - embodiment, 220, 223, 226, 227
 - Henry Ford Hospital* (1932), 224–6
 - instituted meanings, 222
 - intersubjectivity, 219, 224
 - My Birth* (1932), 226–7
 - pain, 219, 220, 224, 228
 - Rivera, Diego, 225, 227
 - The Two Fridas* (1939), 227–8
 - see also* Merleau-Ponty, Maurice
- Keefe, Francis J., 264
- Khatchadourian, Haig, 350
- Khetarpal, Abha, 12, 172
- Khoda, Chandrakant, 6, 132
- Face2face* series: 'Untitled', 133
 - Face2face* series: 'Untitled', 134–5
 - Face2face* series: 'Untitled', 136
- Face2face* series: 'Untitled', 137
- Face2face* series: 'Untitled', 160
- trigeminal neuralgia, 132, 136, 138
- Kimmel, Michael, 210
- Kirkham, Jamie A., 154
- Kirkpatrick, Davina, 153
- Kleinman, Arthur, 172–3, 329–30
- Knapp, Peter Raymond, 154
- 'knowledge that'/'knowledge how', 380
- Kristeva, Julia, 207–10, 227, 316, 326
- language
- communication of pain and, 3, 7, 9, 10, 25
 - the healing word, 43–4
 - images vs words, 59, 152, 154, 229
 - limitations of language to describe/talk about pain, 38–9
 - pain and, 3, 11, 20, 21, 151, 315, 325, 372, 373
 - paradoxical impasse between language and experience, 215
 - physical/emotional pain distinction, 20–1
 - therapeutic value for pain, 12
 - see also* communicating pain; communication; language, communications and transformation; metaphors; similes; visual images of pain in consultations (linguistic approach)
- language, communication and transformation, 315–16, 331
- beliefs and spirituality, 320, 325
 - body/mind interaction and effects on pain, 321, 331
 - case study, 326–7
 - changing language, potential for changing pain experiences, 331
 - consciousness, 319, 320, 329
 - contexts and methods, 316–18
 - creativity, 325
 - critical theory, 317
 - experiences, sensations and consciousness, 318–20

- language, communications and transformation (*cont.*)
 feminism, 316, 332n5
 feminist *bricolage*, 317, 332n3
 languages of pain: content – codes, images and metaphors, 328–31
 languages of pain: form – communication, intertexts and agency, 325–7
 languages of pain: narrative, 322–5
 physiology, 320–1
see also language
- Laocoön* (Greek sculpture), 196–7, 198–9, 210, 211n4, 211n5
- LAPCEL (Learning Alliance for Palliative Care and End of Life), 173n4
- Latham, Peter Mere, 193, 264
- Laub, Dori, 35
- Lennon, Kathleen, 223–4, 225
- Leriche, René, 262–3
- Lessing, Gotthold, 197–9, 202–3, 211n6
- Levi, Primo, 208
- Levinas, Emmanuel, 37
- Lévi-Strauss, Claude, 332n3
- Lipsky, Michael, 123
- listening for pain, 38–40
 attentive listening, 5, 372
 authentic listening, 35
 close reading and close/radical listening, 41–3, 44n5, 326–7
 compassionate listening, 330
 factors interfering with, 40
 the healing word, 43–4
 ‘listening understanding world’, 15
 pain as intersubjective event, 35–8, 372
 the telling of pain and the listening for pain, 38–41
 training/skills for listening, 40–1, 43, 326, 372
 traumatisation of the listener, 35, 372
see also witnessing the pain of others
- Lomax, Rob: *Perceptions of Pain* series, ‘Untitled’, 150
- The London Hospital Gazette* (1896), 199–200
- Lupton, Deborah, 324
- McAuley, Kit, 154
- McCausland, Onya, 8–9, 214
- MacKenzie, Cynthia J., 377
- MacLean, Sarah, 154
- McMahon, Émilie: IPAT (Iconic Pain Assessment Tool), 154
- Main, Susanne: *Exhibiting Pain* (exhibition), 153, 165, 376
- Mantegazza, Paolo, 264–5
- Marcus Aurelius, 371
- Marmot, Michael, Sir, 167
- Marsh, Henry, 68
- Martin, Rosy, 153
- Martyrdom of Saint Sebastian* (painting), 200, 203
- Mask:Mirror:Membrane* (2011 exhibition, Menier Gallery, London), 53, 58, 80, 352
- Maslow, Abraham H., 125
- Maudsley, Henry, 265
- Maximus, 113, 120, 121
- meaning, 331
Face2face: images and meaning, 164–5
 instituted meanings, 222
 photographs as meaning-making objects, 7
see also pain and meaning
- medical humanities, 12, 172–3, 194, 200, 211, 370
- medical illustration, 210
- medication, 234, 236, 237, 316, 366
 allopathic medicines, 293
 anaesthetics, 94, 320
 anticonvulsants, 63, 364
 antidepressants, 367
Atropa belladonna, 320, 332n11
 carbamazepine, 72, 362
 COX-2 inhibitors (cyclo-oxygenase), 360
 epidural steroid injections, 293, 297
 gabapentin and pregabalin, 364
 ibuprofen, 61, 107, 360, 368
- India: access and availability of drugs, 295–6
- India: polypharmacy, 290
- ion channels and, 362–3, 364
- ketamine, 365
- monitoring the balance of excitatory and inhibitory descending controls, 367
- NMDA receptor (N-methyl-D-aspartate) and, 365
- NSAIDs (non-steroidal anti-inflammatory drugs), 290, 360
- over the counter drugs, 290
- painkillers, 61, 67, 71, 107, 360
- pain-relieving drugs, 320
- paracetamol, 107
- side effects, 68, 236, 360, 363, 364, 365, 366
- triptans, 361
see also analgesics; pain management; pain relief; opioids
- Melzack, Ron, 26
- mental health, 56, 124
 headache as sign of ‘psychological disturbance’, 258–9
 mental disabilities, 304
 mental illness, 304
 politics and policy, 126
- Merleau-Ponty, Maurice, 37, 224, 225, 226, 228–9
 the body as expression, 219, 220–2
 embodied subjectivity, 221, 222
The Phenomenology of Perception, 220–1
- Merskey, Harold, 258–9
- metaphors, 3, 8, 10–11, 315, 325, 349–50
 absent in clinical textbooks, 11, 260
 as clues for patient emotions, 330
 combining physical and psychological pain, 319
 communicating pain and, 39–40, 349
 ‘doing’ pain and, 194
 emotional pain, 21
 etymology, 329
- gendered use of, 257–9
 for headaches and neuralgia, 256–7, 259–63
 languages of pain: content – codes, images and metaphors, 328–31
 negative impact on the sick, 255, 257
- PAIN CARDS, 270
- pain as a dog that bites, a knife that stabs, a fire that burns, 256, 276–7
- pain as a sentinel, 257, 266n3
- petitioning witnesses to respond to suffering, 263
- role in communication and thinking about subjective states, 11, 270, 349
- role in conferring meaning, 372–4
- Sontag, Susan and, 11, 255, 256, 257
- tree and growth metaphors, 373–4
- ugliness and illness as metaphors for moral decay and social disorder, 203–4
- visual images of pain in consultations (linguistic approach), 275–6, 279, 281–4
 visual metaphors, 8, 59, 184, 270
see also communicating pain; language
- Middle Ages, 200–2
- migraine, 23, 234, 260, 290, 361, 367
 abnormal production and/or release of pain chemicals, 358, 361
 serotonin and, 361
see also headache; neuralgia
- Mills, Robert, 193
- mind–body dualism, 8, 112, 152, 155, 171–2, 223, 319
 Christian iconography, 202
 Merleau-Ponty, Maurice and, 220–1
 physiological/psychological pain distinction, 19–20, 152, 171
- mindfulness, 114, 321, 331
- minority groups: underestimation of suffering of, 199, 264
- mirror neuron theory, 15

- Miserandino, Christine: 'Spoon theory', 235, 241n2
- Moore, Gemma, 352
- Morris, Sharon, 11, 83, 84
- 'The Ash, Yr Onnen: Summer, yr haf', 406
- 'The Ash, Yr Onnen: Winter, y gaeaf', xxxiv
- 'Hospital' (poem), 287
- 'The London plane' (poem), 286
- 'Water glass' (poem), 288, 374
- Moscoso, Javier, 193
- Mott, Valentine, 256, 260–1, 262
- Munch, Edvard: *The Scream* (painting), 58
- Murray, John, 256, 260–1
- Napier, David, 172
- narrative medicine, 1, 231, 372
- Narrative Medicine (Columbia University, New York City), 41, 42–3
- narratives, 231, 331
- chaos narrative, 322–3
 - healthcare professionals, 324
 - illness narratives, 230–1, 324, 325
 - intermediality, 231
 - languages of pain: narrative, 322–5
 - narrative-based analyses, 326
 - narrative diagnosis, 331
 - narrativity ladder, 231, 235
 - 'networked narratives', 240
 - non-verbal communicative forms
 - and story narrativity, 231
 - pain narratives, 148, 230, 237, 370, 371, 372
 - patients' narratives, 9, 10, 12, 58, 154
 - quest narrative, 322, 323
 - restitution narrative, 322
 - suspicion on patients' pain narratives, 263
 - testimony, 322, 323–4
 - types of, 322–4
 - see also* social media: remaking of illness narratives
- neck pain, 293, 303
- nervous system, 27, 321
- sympathetic nervous system, 15, 320
 - see also* central nervous system
- neuralgia, 256
- gendered presentations of, 257–8
- gesture and inarticulate vocalisations associated with, 261–3
- metaphors for, 256, 257, 260, 261–3
- see also* headache; migraine
- neurons, 27, 28
- excitatory neurons, 29
 - inhibitory neurons, 28, 29
 - nociceptive/pain neurons, 27–8
 - pain pathways and 28, 29
 - see also* pain, neuroscientific perspective
- neuropathic pain, 357, 361–2, 365, 368
- a chronic pain, 357, 362
 - opioids as pain relief, 366
 - treatment, 357, 362–3, 364
 - see also* pain, neuroscientific perspective
- neuropathy, 357, 361, 367
- Nietzsche, Friedrich W., 323, 329
- nightmares, 63
- Nizza, Isabella E., 154
- nociception, 18, 25, 36
- nociceptive/pain neurons, 27–8
 - nociceptors, 356, 359–60, 361, 368
 - see also* pain, neuroscientific perspective
- nociceptive pain, 154, 301, 356–7, 359, 368
- treatment for, 357
 - see also* pain, neuroscientific perspective
- nonverbal interactions, 169, 372
- affiliation behaviours, 179, 180–1, 182
 - dominance behaviours, 179, 180, 181
 - negative behaviours, 179
 - nonverbal communicative forms and story narrativity, 231
 - patient and clinician behaviours, 179–81
 - positive behaviours, 179
 - submission behaviours, 179, 180
 - see also* visual images of pain in consultations (nonverbal interactions)
- 'normal', 371–2
- O'Brien, Martin, 153
- Ofil, Chris, 208
- Omand, Helen, 6–7, 166, 169, 171
- opioids, 36, 293, 296, 368
- addiction to, 33, 293, 321
 - India, 296
 - mechanism of action, 365–6
 - morphine, 46, 61, 296, 320–1, 365–6, 368
 - side effects, 366
- Orlan (Mireille Suzanne Francette Porte), 211
- Padfield, Deborah, 8, 58, 338, 350, 374, 380–1
- 'Encountering Pain' conference, 53
- Face2face*, 3, 48–9, 53, 58, 76, 78, 83, 147, 374, 380–1
- photography, 147, 178, 234, 240
- PSTT*, 82, 83
- see also Face2face; Perceptions of Pain*
- pain, 2
- criminal pain, 34
 - culture and, 172, 318, 320, 324
 - diagnosis of, 13, 349
 - disability/pain relationship, 300–3, 312
 - fundamental to the human condition, 26, 172, 300, 319, 324
 - legitimacy of, 149, 171, 172
 - pain disability, 115, 120, 124, 125
 - pain without lesion, 115, 127, 257, 371
 - as part of living, 301, 336
 - psychosocial triggers, 321
 - referred pain, 70
 - as shaped by past experiences, 21
 - social and cultural history of, 193
 - social pain, 306
 - a universal phenomenon, 38
- see also the entries below related to pain; chronic pain; communicating pain; emotional pain*
- pain, definition/description, 171, 173n5, 177, 193
- as biological sense, 26
 - as a construct, 318, 320
 - as cultural phenomenon, 194
 - as emotional experience, 17–18, 192, 319
 - as an event, 194, 318
 - as intersubjective event, 35–8, 372
 - as neurological disease, 298
 - peine*, 324, 333n21
 - as physiological phenomenon, 194
 - physiological signs of pain, 190–2
 - punishment/poena, 149, 204, 257, 292, 319
 - as subjective experience, 300, 370
 - as a thing, 127, 193, 315
 - as 'what is spoken about as "Pain"', 193
- pain, neuroscientific perspective, 12, 16, 355, 367–8
- acute pain, 355, 359
 - analgesics and neural signalling, 355, 360–1, 363, 364, 366
 - benefits of, 17, 18, 355, 356, 374
 - central sensitisation, 358, 368
 - disadvantages of pain, 356–9
 - emotional aspects of pain, 359, 363
 - excitatory system, 363–4
 - glutamate, 364, 365, 368
 - inhibitory system, 363, 365–7
 - injury/pain relation, 355
 - ion channels, 357, 362–3, 364
 - long-term potentiation, 365, 368
 - mechanistic approach, 17, 22, 24, 26
 - neurotransmitters, 363–4, 365, 366–7, 368
 - noradrenaline and serotonin, 366–7
 - noxious input, 18, 20, 21, 22, 24, 26, 27, 28, 36, 362
 - pain as emotional experience, 17–18

- pain, neuroscientific perspective
(*cont.*)
- pain/emotions links, 14, 19, 21–2, 363, 367
 - pain-enhancing pathways, 363–5
 - pain pathways, 18, 20, 21, 23, 24, 26, 28, 29, 356, 357, 358–9, 363
 - ‘pain’ reflexes, 18
 - peripheral, spinal and brain areas involved in pain messages processing, 358
 - peripheral events, 359–60
 - physical/emotional pain distinction, 18–19
 - prostaglandins, bradykinin, serotonin, 360–1, 368
 - reaching our consciousness, 363
 - sensory aspects of pain, 358
 - stimuli, 18, 356, 359–60, 361, 362, 365
 - switch from acute to chronic pain as detrimental, 14, 356
 - therapy, 14, 368
 - what happens when nerves are damaged?, 357, 362–3
 - what happens when tissue is damaged?, 356–7, 360–1
 - why we feel pain, 355–6
 - wind-up, 365, 367, 368
 - see also* brain; central nervous system; neuropathic pain; nociception; nociceptive pain
- Pain: Speaking the Threshold. See PSTT*
- PAIN CARDS, 26, 53, 240, 374–5
- advantages of, 26, 78, 80, 272–3, 281, 284, 375, 381–2
 - background to the creation of, 349–51
 - clinical use of, 13, 351–2, 381
 - as communication tool, 148, 381–2
 - diagnostic process, role in, 58
 - future use of, 352–3
 - healthcare professionals and, 148, 352
 - identity and, 270
 - impact of, 13, 270, 351–2
 - limitations, 13, 353
- metaphorical representations of pain experience, 270
- as method of discussing pain, 13
 - origin of, 4–5, 48, 52, 78, 147, 168, 269, 351
- pain assessment, 168
- recommendations for use in clinical consultations, 284, 352–3
 - transcultural pack of, 172
 - used with non-English/non-native English speakers, 173n10, 277, 351
 - see also Face2face; PSTT*; visual images of pain; visual images of pain in consultations (linguistic approach)
- pain clinic, 151, 166, 269, 375, 382
- pain expression, 230, 238, 239–40, 315, 318
- see also* communicating pain
- pain management, 6, 12, 13, 289, 380
- beliefs and spirituality, 320
 - cancer, 293–4
 - coping and distraction strategies, 364, 367, 374
 - creativity, power in helping to manage pain, 48, 52, 55, 56, 373
 - cultural sensitivity, 376
 - decontextualised treatments, 337
 - diet, 293
 - facial pain, 48, 53, 54–5, 73
 - mindfulness, 321
 - naturopathy, 293
 - ‘one size fits all’ approach, 298
 - see also* India: pain management challenges; medication; pain relief
- pain and meaning, 4, 6, 155, 177, 255, 315, 318
- Christian theology and positive significance of pain, 200–1, 204
 - deep problems of meaning, 33–4
 - Face2face*, 164–5
 - images/photographs as meaning-making objects, 7, 93, 97, 101
 - metaphors, role in conferring meaning, 372–4
- semiotics of images made by people with pain, 233–4
- visual images of pain in consultations: semantic domains, 274–6, 275, 277
- see also* meaning
- pain measure/assessment, 380
- BPI (brief pain inventory), 151
- challenges in, 177, 289
 - current reductive measures for assessing pain, 38, 151
 - India: Rupee scale, 291
 - MPQ (McGill pain questionnaire), 151, 152, 263–4
 - PAIN CARDS, 168
 - Pain Detect* questionnaire, 173n2
 - rating scales, 3, 23, 36, 149, 177, 291
 - Ron Melzack’s scale, 26
 - SOCRATES (site, onset, character, radiating, alleviating, time, exacerbating, severity), 332–3n16
 - using images in pain assessment, 152
 - VAS (visual analogue scale), 151
 - VRS (verbal rating scale), 151
- pain medicine, 1–2, 298
- pain processing development, 24
- pain relief, 33, 320
- advertisements for, 194, 194, 203–4, 258, 259
 - ayurvedic treatments, 293
 - herbal treatments, 293, 320, 332n11, 332n13
 - indigenous and traditional methods, 316
 - neuropathic pain, 357
 - see also* analgesia; medication; pain management
- pain threshold, 34, 40, 301, 360
- variability in, 24, 293, 368
- Pain Under the Microscope* (film, 2016), 15, 132
- Paley, John, 231, 235, 239
- Pates, John
- Perceptions of Pain* series: ‘Untitled’, 91
- Perceptions of Pain* series: ‘Untitled’, 92, 280
- Perceptions of Pain* series: ‘Untitled’, 161
- patient-centred care, 296, 318
- patient–clinician interactions, 8, 171, 349, 375
- in chronic pain consultations, 336–7
 - detachment (professionalism)/personal connection balance, 370
 - PAIN CARDS, 382
 - paternalistic form of care, 325
 - photography, improving patient–clinician interaction, 8, 148, 240
 - see also* empathy; PAIN CARDS; rapport; visual images of pain in consultations (linguistic approach); visual images of pain in consultations (nonverbal interactions)
- Patterson, Jennifer, 12
- Pearce, Christopher, 351
- Perceptions of Pain* (Deborah Padfield, 2003), 4, 147, 149, 270
- impact on participants, 166
 - ‘Untitled’, 89, 90
 - ‘Untitled’, 91
 - ‘Untitled’, 92, 280
 - ‘Untitled’, 93, 94, 98–9, 272
 - ‘Untitled’, 150
 - ‘Untitled’, 161
 - ‘Untitled’, 276
- Perry, Grayson, 167, 350
- Pert, Candace, 321, 331
- phantom pain, 301
- phantom limb pain, 61, 319, 366
 - phantom tooth pain, 47, 61
- phenomenology, 36–7, 85, 220–1, 224, 332n1, 380
- phenomenological insight, 220
 - phenomenology/art similarities, 226, 228–9
- photography, 3, 6–7, 34, 375
- improving patient–clinician dialogue and interaction, 8, 148, 240
 - pain experience and, 172

- photography (*cont.*)
 photo elicitation, 153
 photographic portrait, 147
 photographs as meaning-making objects, 7
 phototherapy, 153
 photo voice, 153
 use of photographs to elicit narratives of pain and trauma, 152–5
see also Face2face; Perceptions of Pain; PSTT; visual images of pain
- physiognomy, 201, 264–5
 pictograms, 154, 173n4
 picturing pain, 196, 210–11
 abject art, 196, 207–10
 beautiful/ugly pain, 195, 196–200, 202–3, 211
 Christian iconography of sacrifice: *imitatio Christi*, 9, 195, 200–3
 cultural scripts for pain, 194–5, 199, 210
 disfiguring pain, 9, 196, 197, 198
 images as aesthetic objects, 211
 images as cultural and epistemological artefacts, 210
 powers of horror, 197, 205–10
 questions of beauty, pleasure and taste, 203
 spectatorial pain, 211
 stoicism, 195, 197, 199–200, 204–5
 treating pain, 203–5
 ugliness and illness as metaphors for moral decay and social disorder, 203–4
see also aesthetics; Laocoön
- Pillay, Deenan: ‘Easing the Pain through Art’, 48, 52
 Pither, Charles, 147
 Plato, 321, 326
 Pliny the Elder, 196
 politics, 7, 376
 bio-politics, 207
 politics of pain, policies of poverty, 123–7
- poverty, 33, 123–7, 294, 296
 Preston, Stephanie D., 185
 Prkachin, Kenneth M., 264
PSTT (Pain: Speaking the Threshold), 4–5, 168–9, 374
 aim of, 82, 83
 arts in health project, 81, 82
 art therapy literature, 86–92
 art therapy/*PSTT* distinction and similarities, 81, 84
 case studies, 85, 89–100
 effects of images in, 82, 100–1, 169
 images and identity, 100, 101
 images: potential to aid communication and empower patients, 82
 images as transactional objects, 7, 88, 95, 100
 interdisciplinarity, 83, 169
 intersubjective relationship, 82, 89, 100
 methodology, 85–6
 research team, 83–4
 subjectivities, 88, 97
 transitional objects, the ‘third area’ and symbolisation, 86–8, 92–3, 100
 triadic/triangular encounters, 7, 87–8, 93, 171
 understanding the image in its social context, 88–92, 100
 videos, investigations of, 83, 168–9
see also PAIN CARDS
- psychiatry, 53, 258–9, 334
 psychoanalysis, 7, 37, 81–2, 87, 303
 psychotherapy, 81, 85, 325, 328, 349
Punch (British weekly magazine), 204
The Pursuit of Pain (Wellcome Collections exhibition), 352
- Quintner, John L., 115
- Radley, Alan, 153, 168
- rapport
 patient–clinician interactions, 8, 375
- visual images of pain in consultations, 180, 181, 182, 186–7
see also empathy
- rehabilitation, 120, 128, 306
 Ressler, Pamela Katz, 236–7
 Richter, Simon, 196, 197
 Ricoeur, Paul, 37
 Robinson, Henry Peach: *Fading Away* (painting), 202, 203
 Rosenberg, Charles, 116
 Rosenkranz, Karl, 198, 202
 Rosenthal, Norman, 207
 Rowland, Richard, 262
 Ryle, Gilbert, 380
- Saatchi, Charles, 208
 sado-masochism, 316–17
 Sartre, Jean-Paul, 37
 Scarry, Elaine, 9, 172, 209, 225, 318
The Body in Pain, 193, 373
 Schaverien, Joy, 82, 88, 100
 Semino, Elena, 10, 83, 169, 375, 381
 self-portraits, 234
see also Kahlo, Frida
- senses
 ‘movement’, 13
 pain as a basic biological sense, 26
 ‘the sense of the other’, 15
- shadow, 61, 159, 164, 167, 328
 Shelley, Percy: *Queen Mab* (poem), 203
 Siddall, Philip J., 111–12, 113
 similes, 233, 234, 237, 277, 283
 Singh, Satendra, 12, 172
 Skaife, Sally, 82, 89, 97, 99, 100
 Skultans, Vieda, 230–1
 Smith, Jonathan A., 154
 social care, 112, 113, 121, 123, 152
 social media, 246
 social media: remaking of illness narratives, 239–40, 376
 chronic pain in social media, 230, 237, 238–9, 240
 images aiming to make pain visible/felt, 234
 images suggesting the sensory experience of having pain, 235
- ‘iridescent’/‘symptomatic’ communication, 240
 liking and reblogging, 232, 239
 ‘networked narratives’, 240
 ‘networked publics’, 239
 reasons to blog about illness, 236–7
 tumblelogs, 236–7
see also Flickr; Tumblr
- social pain, 306
 social sciences, 172–3, 207, 230, 316, 318
 Socrates, death of, 321, 332n15
 Sontag, Susan, 11, 34, 166, 167, 202
Illness as Metaphor, 201, 255–6
 ‘Man with a Pain’, 255–6, 257, 260, 266
 metaphors, 10–11, 255, 256, 257
 Spence, Jo, 153, 165
- spinal cord
 dorsal horn, 29, 363–4, 365, 366
 neurons in, 29
 NMDA receptor activation in, 365
 pain pathways, 29, 358, 358, 360, 363
see also central nervous system; pain, neurobiological perspective
- Spinelli, Ernesto, 85
 Spivey, Nigel, 196
 Stein, Edith, 37
 stigma, 123, 195, 238, 375
 ‘abominations of the body’ and, 195
 chronic pain stigma, 115, 149, 151
 social stigma, 195, 199–200, 296
 stoicism, 197, 199–200, 292, 319, 371, 376
 chronic pain sufferers as stoics, 371, 372
 ‘dialogical stoic’, 371
 as masculine ideal, 195, 204
 wartime culture of stoicism, 204–5
see also picturing pain
- Struth, Thomas, 155
 subjectivity, 172, 300
 embodied subjectivity, 221, 222, 224, 227
PSTT, 88, 97

- Subramanyam, Anusha, 7–8, 139–40, 140–2, 143, 374
- suffering, 372
- Christian ideology of, 196, 204, 319
- classical tradition of, 196, 197, 200, 211, 329, 331
- Hindu philosophy/religion and, 301–2
- minority groups, underestimation of suffering of, 199, 264
- petitioning witnesses to respond to suffering, 263, 265
- suicide, 63, 151, 260, 261, 281, 283, 284
- symbols, 87, 152, 167, 225, 331
- symbol formation, 82, 88
- sympathy, 323
- facial expressions of pain and, 262–3, 264, 266
- gender and, 265
- ‘spectatorial sympathy’, 211
- witnessing the pain of others, 191, 199, 266
- symptoms, 38, 303, 323, 328, 375
- chronic pain, 18, 336
- language and, 39
- neuropathic pain, 361, 362
- trigeminal neuralgia, 57–8, 73
- Tagg, John, 170
- teeth
- extraction of, 46, 61, 218
- phantom tooth pain, 47, 61
- root canal treatments, 46, 70, 73, 74
- see also trigeminal neuralgia
- threshold. *See* pain threshold
- Tipple, Robin, 82, 88–9, 97, 99, 100
- Tolstoy, Leo: *The Death of Ivan Ilych*, 35–6
- Tomlinson, Jonathan, 371
- Tonks, Henry, 204–7
- Portrait of Private William Kearsley*, 205, 206
- trigeminal neuralgia, 57, 76, 132, 136, 138, 151, 353
- diagnosis, 57–8, 61, 69–70
- MVD (microvascular decompression), 67–8, 76
- neurosurgery, 67–9, 76, 138
- painkillers and, 61, 67
- remission, 57, 67
- as the ‘suicide disease’, 63
- see also facial pain; teeth
- Trigeminal Neuralgia Association (UK), 57, 80
- Tumblr, 153
- Flickr/Tumblr comparison, 231–3, 236, 239, 240
- memes, 232, 238–9
- narrative symptomatology, 233, 236–9
- textual content, 237–8, 240
- see also social media: remaking of illness narratives
- Turner, Bryan, 207
- UCLH (University College London Hospital NHS Foundation Trust, UK), 3, 5, 8, 48, 147
- the unconscious/unconscious nature, 82, 83, 88, 93, 119, 125, 154, 166, 167, 177, 331
- University of Cambridge: Darwin Correspondence Project: Emotion Experiment, 192
- Van Dijkhuizen, Jan Frans, 193
- Virgil, 197, 198–9
- visual imagery, 201
- in communication, 183–4, 350
- images as aesthetic objects, 211
- images as cultural and epistemological artefacts, 210
- images as tools in clinical practice, 11, 13, 350–1
- mental imagery, 183–4
- visual metaphors, 8, 59, 184, 270
- visual images of pain, 3–4, 25–6, 38
- advantages of, 26, 39, 53, 155, 240, 352
- diagnosis and, 59, 69–70, 148, 152, 250
- a generic iconography for pain, 234
- icon-like representations, 184
- images aiming to make pain visible/felt, 234
- images suggesting the sensory experience of having pain, 235
- images vs words, 59, 152, 154
- limitations of, 12, 152, 154, 353
- online collections of images
- expressing individual pain, 153
- pain assessment and, 152
- semiotics of images made by people with pain, 233–4
- themes: nature of pain, pain as attacker, impact of pain, 184
- use of images and photographs to elicit narratives of pain and trauma, 152–5
- see also communicating pain; PAIN CARDS; photography
- visual images of pain in consultations (linguistic approach), 269, 284, 375
- Card Data/Rest Data, 271–2, 274–5, 275, 277, 278–9, 279
- concordance of ‘feel’ in Card Data for patients, 277, 278–9, 375
- conversational floor, 274
- corpus linguistics, 274
- frequencies of types of words: what is being talked about?, 274–81, 275
- metaphors, 275–6
- metaphors, narratives and emotional disclosure, 279, 281–4
- PAIN CARDS, 269
- PAIN CARDS, advantages of, 272–3, 281, 284
- PAIN CARDS and verbal communication, 270–1
- patient talk, increase in, 272–3, 375
- power asymmetries in communication, 272, 274, 284
- semantic domains, 274–6, 275, 277
- research expectations, 270
- research methods, 270, 271, 274–5
- research questions, 269, 270, 271
- volume of talk: who speaks more?, 271–4, 271, 284
- see also PAIN CARDS
- visual images of pain in consultations (nonverbal interactions), 8, 178–87, 344–5, 375
- affiliation behaviours, 8, 179, 180–1, 182, 345, 375
- consultation excerpts, 181–3
- emotional disclosure by patients, 180, 181, 187
- empathy and rapport, 180, 181, 182, 186–7
- patient and clinician behaviours, 179–81
- patient and clinician ratings, 178
- patients’ dominance behaviours, 181
- see also nonverbal behaviours; visual images of pain
- Vivekananda, Swami, 302
- vulnerabilities, 128, 220, 224, 227, 319, 324
- Waddell, Gordon, 113–14
- Waller, Diane, 87
- Walton, Pat, 153
- war, 33, 34, 53, 153, 319
- anti-war art, 195
- First World War, 59, 204–5
- war art, 195, 206
- welfare system
- capability assessments, 119, 121
- conditionality, 122–3, 128
- condition descriptors in Disability Living Allowance and Attendance Allowance, 124
- fragmentation of, 7, 113
- from ‘welfare to workfare’, 122
- politics of pain, policies of poverty, 123–7
- see also healthcare system; workfare
- WHO (World Health Organization), 296, 332n6

- Wikström, Britt-Maj, 350
- Willenfelt, Johanna, 153
- Williams, Amanda, 8, 14, 83, 169, 171, 173n5, 375, 381
- Williams, Linda
Face2face series: 'Untitled', 96, 97–8
Face2face series: 'Untitled', 159, 160, 162, 163
Face2face series: 'Untitled', 163
Face2face series: 'Untitled', 164
- Winckelmann, Johann, 196–7, 211n5
- Winnicott, Donald Woods, 82, 86–7, 88, 93, 100
- witnessing the pain of others, 5, 34, 36, 172
 empathy, 199, 263, 264, 265–6
 gestures and sounds of agonising pain, 262–3, 265
 metaphors and, 255
 petitioning witnesses to respond to suffering, 263, 265
 reciprocity, 35, 372
 sympathy, 191, 199, 266
 witnessing oneself witnessing, 35
see also listening for pain
- Wittgenstein, Ludwig, 223, 224
- Wolcott's Instant Pain Annihilator (pain relief advertisement), 194, 194, 203
- Wolff, Jonathan, 5, 14
- Wood, Mary M., 87
- Woods, Angela, 208
- workfare, 376–7
 descriptors for allocation to WRAG in Employment Support Allowance claims, 127
 fitness certification and the regulation of health-related work absence, 120
 from 'welfare to workfare', 122
 health-related work absence, 120
 jobcentres, 120
 politics of pain, policies of poverty, 123–7
 return to work and sanctions, 113, 120
 sick note, 120
 work capability assessment, 121, 126, 376
see also welfare system
- writing, 325
 creative/responsive writing, 41–3
- Yamamoto-Wilson, John, 193
- Zakrzewska, Joanna M., 13, 55, 58, 76, 374–5, 380, 381
 'Encountering Pain' conference, 53
Face2face, 3, 53, 58, 76, 147
 PAIN CARDS used with non-English speakers, 173n10, 351
PSTT, 82, 83, 84

...in any form can feel like being compressed in a shrinking iron box in which one is entirely alone. Serious pain dominates every conscious moment, and into dreams as well. Pain comes in many forms, sudden, like painshock, or slow and intensifying, with many distinctions in between.

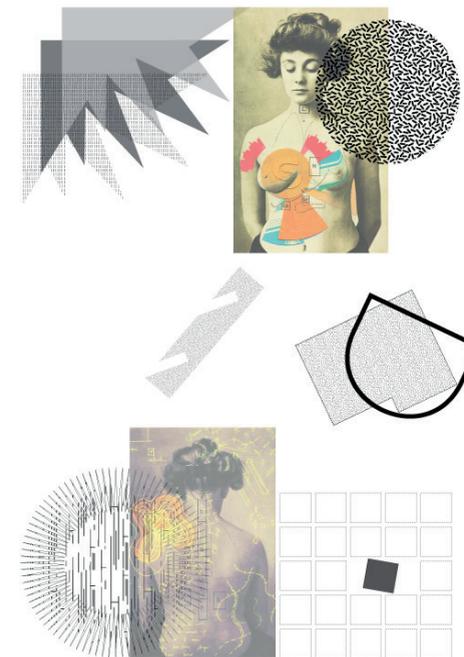
Graphic images and photographs are the most descriptive ways of illustrating different kinds of pain to anyone with imagination, and so much more helpful than asking a person to pick a number from 1 to 10. All schools should have these paincards. They transcend language and culture differences, and behavioural differences of all kinds.

Living with pain, stepping on from encountering pain, is unique to each individual. If people can understand what causes it in its different forms, it should be possible to endure and overcome much of it – just as one tries to explain it to children as they grow to learn about pain.

The importance of pain conferences/seminars/workshops is the sharing of experiences. This can diminish the awful sense of isolation brought on by pain. Encouraging feelings of identity with others, and then the ability and courage to discuss and explore ways of reducing pain in so many forms.



...is an individual experience, it can be all consuming and yet invisible, and when you are in pain you are the only one that can really communicate that pain. So encountering pain makes you vulnerable to miscommunication, because you need to communicate something that could be quite complex, when your ability to articulate your need for relief is compromised by the nature of your pain.



...was something I was already interested in before attending the UCL conference via my work with LSE Communicating Chronic Pain project so I was curious to see how creativity and art making was being used to support people encountering pain within and beyond academic and health care communities.

What it has enabled me to be and do is be a deeper listener and supporter for my Dad who has facial neuralgia. I am more able to connect with him and empathise with him knowing that's my contribution to his various efforts to bring some relief to his situation. The sessions about the co-design process and testing of the pain cards really inspired me and have given me a wider frame of reference and language. The results in the patient/consultant relationships bringing back more patient support is a real breakthrough.

...led me to helping others in pain.

...is the neuronal gathering of a symptom that reminds you to live across the moments and into them after it ends.

...is the understanding of our possibility to become one with the universal psyche.



...I shake you by the hand
Pleasantries aside, I ask you to leave
but you have settled in for the night,
and day,
and years,
they go by
but you still stay.
I have a new self now,
my faithful friend and I,
never parted
Never departed

...on every street corner, pain will be lurking, buried or alive, emotional or physical and we should never underestimate the pain that a loved one may be carrying, or indeed, the stranger who pushes past us to be first on the bus.

Figure 25.2 Compilation of images and texts from 'Encountering Pain' conference delegates. See Figure 0.1 for thanks and acknowledgements.

'This is a majestic volume. Visually striking, intellectually challenging, and experientially transformative, this book promises to change how everyone encounters pain.'

– **Rob Boddice**, *Freie Universität Berlin*

What is persistent pain? How do we communicate pain, not only in words but in visual images and gesture? How do we respond to the pain of another, and can we do it better? Can explaining how pain works help us handle it? This unique compilation of voices addresses these and bigger questions.

Encountering Pain shares leading research into the potential value of visual images and non-verbal forms of communication as means of improving clinician–patient interaction. It is divided into four sections: hearing, seeing, speaking, and a final series of contributions on the future for persistent pain. The chapters are accompanied by vivid photographs co-created with those who live with pain.

The volume integrates the voices of leading scientists, academics and contemporary artists with poetry and poignant personal testimonies to provide a manual for understanding the meanings of pain, for healthcare professionals, pain patients, students, academics and artists. The voices and experiences of those living with pain are central, providing tools for discussion and future research, shifting register between creative, academic and personal contributions from diverse cultures and weaving them together to offer new understanding, knowledge and hope.

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Deborah Padfield with Linda Williams,
'Untitled' from the series *Face2face*,
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