***In Extremis***

In the photographic work, *The House of My Father*, a papery house held together by pins, rests in the palm of a hand. The house is made of human skin; a remnant from one of many operations that the artist, Donald Rodney, underwent as a result of sickle cell anaemia. If Rodney’s fragile fabrication reminds us that skin is our last dwelling place, it also brings us to the playful and painful accommodations of the racialised debilitated body. Another twist to Fanon’s pathology-inspired idea of race-making as ‘epidermalisation’1. In the history of the visual archive and post-colonial critique, it is disabled, ageing and infirm bodies that remain marginal.

For nearly twenty years now, haunted2 by unacknowledged realities, I have been researching the worlds of dying migrants3. The foreigner in need of care is a figure that reappears throughout the Abrahamic religions and continental philosophy4 as the test of the moral worth and making of a community. More recently, writers such as John Berger5 and Hanif Kureshi6, have parodied capitalism’s repression of the migrant worker’s vulnerability and finitude: “they do not age: they do not get tired: they do not die”, Berger writes. For Kureshi, the migrant “is impossible to kill or finally eliminate…because there are waves of other similar immigrants just over the border coming right at you”.

And what of the real? The aged or incapacitated migrant wheeled into a church or temple, lumbering with her walking frame into a doctor’s surgery, being led by the hand around the supermarket, watching the world go by from a park bench or filling the hospital ward with too many visitors and her care home unit with too much stuff?

In the UK, we are at a point of historical transition. As new waves of migrants “come at us”, those who migrated from Ireland, Eastern Europe and the Commonwealth in the 1950s and 60s, are ageing and dying. At times of diasporic debility, different scales, times and frontiers of life intermingle.There is the ‘perverse subsidy’7 of migrant labour that underpins our care systems, resulting in devastating care deficits in low and middle-income countries. There are the uneven circuits of big Pharma - 90% of the world’s morphine is consumed by 10% of us8. And there is the diasporic body itself.

For Harshini’s mother, it was dementia that unearthed a “distributed perception”9 not tied to a single time or place. Telling her family “I am going to the fields”, she would wander off from her house in Leicestershire believing that she is ambling in the rural village in India that she left many years ago. “Even today, although she is not aware of what she is doing with her hands, without a mala…her fingers are still working as if she is praying”, says Harshini. With language and self-consciousness lost, Harshini’s mother, now in a care home, is living on the edges of her life. She is not quite in the here and now, not quite a Hindu, not quite the mother Harshini knew. It is only the phantom mala beads and the ‘foot anarchism’ of the new ‘desire paths’10 that she carves out as convenient shortcuts between England and India, that flicker with the rythmns of a past life.

These are stealthy migrations, underneath the skin. The body stays in place and summons distant places, people and times to it. As thinking and perception are rearranged, difference does its work from inside the body. In this sense, diasporic debility is queer in the way that Gayatri Gopinath describes it, as being marked by “the failure of generation, and the losses and desires associated with normative genealogies of belonging”11. New questions emerge. Not so much, ‘Who are you?’, and in the case of migrant bodies, ‘Where are you from?’, but “*When* are you?

When are you?

In England and Wales, those racialised as being ‘black and ethnic minority’ amounted to about 707,300 residents aged 65+ in 2009, with numbers estimated to rise to over 1.3 million by 202612. These populations are ageing and dying in successive waves, mirroring patterns of migration and settlement. According to estimates by the All Party Parliamentary Group on Dementia, in 2013 there were nearly 25,000 people with dementia from black and minority ethnic communities in England and Wales. The number is expected to increase by nearly seven times to over 172,000 people by 205113.

Under the sway of institutional multiculturalism, the care needs of these elders have been translated into such matters as diet, religious observation and ethnic customs. A lifeline to some, this mapping of need by culturalist categories is always already missing a beat. As Stuart Hall has reminded us “since the colonized subject is positioned in relation to cultural narratives which have been profoundly expropriated, he/she is always ‘somewhere else’”14.

She is always somewhere else.

At the end of a life, changing biochemistry, neurology and hormones thicken this “somewhere else”, with bodily symptoms showing the intimacy between cultural and biological life. Neuroscience research on “social pain”15 – the pain of marginalisation – is providing evidence of the theoretical claims made by feminist and postcolonial scholars about how social inequalities and injustice hurt16 and how unspoken trauma can be passed on from one generation to another17.

With disease or impairment – changes of sight, hearing, taste, muscle memory, face and motion – can bleed into and tinker with cultural emblems and unzip cultural hybridities. Second languages are lost with dementia. For others, the spiciness or colours of once familiar food on a plate might trigger nausea. Voice synthesizers flatten accents or impose vocal ethnic and gender transitions. The usual culturalist indexes slip and slide. There is more room for play and misrecognition.

The protagonist in Andrea Levy’s semi-autobiographical novel, “Every Light In The House Burnin’”, is Mr Jacob, who sailed to England in 1948 on the Empire Windrush. The novel follows Mr Jacob and his family over 20 years, chronicling his demise from cancer and his desultory journey through the National Health Service. It is a rabbi who administers to Mr Jacob on his deathbed in a hospital ward. His surname, together with his repeated calling out to ‘Lazarus’ in bouts of terminal delirium, gave the impression that he was Jewish. “They got you a rabbi, Dad” Levy writes, “God knows where you’ll be now”18.

Mr Ali’s turn to Judaism came when he was admitted into a hospice. In an interview, his wife tells me that he ate the Kosher options on the menu. In matters of the gut, Kosher food seemed closest to the spirit of Islamic prescriptions and without the inflammatory spices of the halal dishes. Pakistani-born Fatima relished the opportunity to try out British vegetarian food, whilst English patients chose the halal options when they craved a curry19. Such deathbed conversions produce hundreds of inventive and opportunistic mixes. People step out of and across cultural nationalism and life-long habits, sometimes becoming foreigners to themselves and their loved ones.

Just as impairment can cut into and sever cultural and national allegiances, there are other external forces at work, heaping pressure on diasporic identifications. “*Living the Dream*”20, a poem by Ash Sharma donated to my “Case Stories” archive on social pain21, transports us to a final journey from the Midlands to India and the scattering of a father’s ashes into the mighty Ganges. It is an ancient ritual, now shamelessly profane and commercialized. Any seductive fantasy of homecoming dissolves into angry flotsam, muddying what psychoanalysts see as the fluid borders between grief and grievance22. Our people are no less exploitative of vulnerability than others, ““Is this all he’s worth?”/ Holy men with calculators/ Standing guard on the river’s edge, soiled with foreign currencies./ Ashes escaping in the torrent/ Holding back the rage and sorrow.”

Is this all he’s worth?

Despite initiatives to document and archive these far-flung coordinates of diaspora, a sort of dementia impedes our efforts. As Arjun Appadurai observes, “Migration tends to be accompanied by a confusion about what exactly has been lost, and thus what needs to be recovered or remembered”22. With the rise of the online archive, Appadurai sees memories as being actively made through diverse connections that are not reliant on kinship, nation or face-to-face relationships. This is the archive as “*intervention*”, returning to its “more general status as a deliberate site for the production of anticipated memories by intentional communities.”

How do we want to intervene in the remembering of our elders and our dead? What communalities do we wish to foster? If queer postcolonial writers, such as Jabir Puar23, are correct in suggesting that we have given far too much attention to capacity, language, linear time and disabled exceptionalism in our critical engagements, taking postcolonial concerns to the everyday life of the luncheon club, the care home and the hospital is long overdue. Here, in the sideboards bulging with whatnot, in music, in the sociality of the communal meal, in the ornate rhythms of a syringe driver pumping morphine, are many other facets to Donald Rodney’s epidermal home-making that both help and hurt.

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**Notes**

**1. Frantz** Fanon, *Black skin, white masks.* Second Edition. (London: Pluto Press, 1986).

2. Yasmin Gunaratnam, *Death and the Migrant: Bodies, Borders, Care*, (London: Bloomsbury Academic, 2013).

3. For the sociologist Avery Gordon, haunting is a social rather than supernatural phenomenon. It signifies the spectral presence of “fugitive knowledge from below and outside the institutions of official knowledge production”. Avery Gordon, *Ghostly Matters: Haunting and the Sociological Imagination*, 2nd ed, (Minneapolis, MN: University of Minnesota Press, 2008), xviii. Writing with regard to the Korean diaspora, Grace Cho, sees haunting as a trope for how “unspeakable and uncertain” diasporic histories can be dispersed across place, time and generation. Grace Cho, *Haunting the Korean Diaspora: Shame, Secrecy, and the Forgotten War*, (Minneapolis, MN: University of Minnesota Press, 2008), 40.

4. See Alphonso Lingis,*The Community of Those Who Have Nothing in Common* (Bloomington: Indiana University Press, 1994),12.

5. John Berger and Jean Mohr, *A Seventh Man*, 2nd ed., (London and New York: Verso, 2010), 68.

**6.** Hanif Kureshi, The migrant has no face, status or story, *The Guardian* (30 May 2014). Available online: <http://www.theguardian.com/books/2014/may/30/hanif-kureishi-migrant-immigration-1>

7. Maureen Mackintosh, Parvati Raghuram and Leroi Henry, A Perverse Subsidy: African Trained Nurses and Doctors in the NHS, *Soundings* 34,(2006):103–113.

8. Pain and Policy Group, Opioid consumption data (2010). Available on-line: <http://www.painpolicy.wisc.edu/opioid-consumption-data>

9. Gilles Deleuze and Felix Guattari, *Anti Oedipus: capitalism and Schizophrenia*, (Minneapolis: Minneapolis University Press, 1983).

10. Nicholas Crane, *Two Degrees West: An English Journey*, (London: Viking, 1999).

11. Gopinath, Archive, Affect, and the Everyday: Queer Diasporic Re-Visions. In Janet. Staiger, Ann Cvetkovich, and Ann Reynolds, eds, Political Emotions: New Agendas in Communication, (New York, NY: Routledge, 2010), 165-192, 167.

# 12. Natalia Calanzani*,* Jonathan Koffman andIrene J Higginson, Palliative and end of life care for Black, Asian and Ethnic Minority groups in the UK: demographic profile and the current state of palliative and end of life care provision (2013). Available online: <http://www.scie-socialcareonline.org.uk/palliative-and-end-of-life-care-for-black-asian-and-ethnic-minority-groups-in-the-uk-demographic-profile-and-the-current-state-of-palliative-and-end-of-life-care-provision/r/a11G0000001893YIAQ>

13. House of Commons, All Party Parliamentary Group on dementia, Dementia Does Not Discriminate: *Experiences of Black Asian and Minority Ethnic Communities in the UK* (2013). Available online: <http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=1186>

14. Stuart Hall, Minimal Selves. In Homi K Bhabha, ed. Identity—the Real Me (ICA Documents 6), (London: Institute of Contemporary Arts, 1988), 44–46, 44.

15. Neuroscience research suggests that there is structural correspondence between physical and social pain in their sharing of the same somatosensory substrates. Naomi Eisenberger, Broken Hearts and Broken Bones: A Neural Perspective on the Similarities Between Social and Physical Pain. *Current Directions in Psychological Science*, 21 (2012): 42–47.

16. For examples, see Yasmin Gunaratnam, Morbid Mixtures: Hybridity, pain and transnational dying, *Subjectivity*, 7(2014): 74-91.

# 17. Brian Dias and Kerry Ressler, Parental olfactory experience influences behavior and neural structure in subsequent generations, *Nature Neuroscience*, 17 (2014): 89–96.

18. Andrea Levy, *Every Light in the House Burnin’*, (London: Headline, 1994).

# 19. Yasmin Gunaratnam, Eating into multiculturalism: hospice staff and service users talk food, ‘race’, ethnicity, culture and identity, *Critical Social Policy*, 21 (2001):*287-310.*

20. Ash Sharma, Living the Dream (2013). Available online: <http://www.case-stories.org/ash-sharma>

21. The Case Stories project was the basis of a British Academy (Mid-Career) Fellowship (MD120033). See: http://www.case-stories.org/

22. See Lita Crociani*-*Windlanda and Paul Hoggett, Politics and Affect, *Subjectivity*, 5 (2012): 161–179.

23. Arjun Appadurai, Archive and Aspiration. In Joke Brouwer and Arjen Mulder, eds, *Information is Alive: Art and Theory of Archiving and Retrieving Data*, (Rotterdam: Naj Publishers, 2003): 14-25, 17.

24. Jasbir K. Puar, Coda: The Cost of Getting Better. Suicide, Sensation, Switchpoints. GLQ, 18(2011): 149–158.