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Advocating for diamorphine: Cosmopolitical care and collective action in the ruins of the ‘old British system’

Fay Dennis

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ABSTRACT

Britain was the first country in the world to prescribe diamorphine (pharmaceutical-grade heroin) to heroin users as a treatment for opioid dependency. Known and admired internationally as the British System, Britain has a somewhat more ambivalent relationship to its own invention. Where patients were once prescribed diamorphine and other injectable opioids on an unsupervised basis, new patients are no longer initiated in this way and those existing ‘old system’ patients are under threat. Carrying out ethnographic research at an advocacy service for people who use drugs, I explore this threat as an onto-epistemological concern and the advocates’ work to sustain these ‘old’ ways of knowing and being with diamorphine as a collective matter of care and action. Accounting for advocacy as a non-objective ‘emboldening’ of the individual to speak, the advocates draw our attention to the inequity of knowledge production and the collective act of speaking in an environment that is increasingly hostile towards these patients. As neoliberal political economies interact with stigmatising forces against people who use drugs, the article highlights the advocate’s work as essential in allowing these patients’ concerns to be heard where a threat to their prescription becomes a threat to their very way of living.

KEYWORDS

Advocacy; care; cosmopolitics; diamorphine prescribing; heroin dependency

Introduction

A small and dwindling but significant number of patients are in receipt of injectable opioid treatment on an unsupervised basis. These patients usually receive a prescription regularly and pick up, sometimes very large, doses of medicines from community pharmacies. [. . .] They should not be confused with the kinds of acutely high risk, heavily-using and chaotic patients who can respond positively to ‘supervised’ injectable treatment as shown by research in the UK and other countries. It is not clear how many new patients have been started on this ‘old system’, unsupervised injectable opioid treatment [. . .] but it is likely to be a very small number. [. . .]

Where there is clear evidence of benefit, treatment should continue and be improved for these patients.

– Clinical Guidelines on Drug Misuse and Dependence, Department of Health (2017)

The UK has a complex history of prescribing injectable opioids, in particular, diamorphine, as a treatment for opioid dependency. This can be seen divided into an old, unsupervised system, where patients take their prescription home, and a new, supervised system, where patients inject their prescription under controlled conditions in a clinical setting, often as part of a scientific trial. While the most recent Clinical Guidelines (above) designate a space for both, in my ethnographic work at an advocacy service for people who use drugs, we received frequent calls from patients who were having their old-style prescriptions threatened, reduced or withdrawn completely. Advocacy is understood here as an onto-epistemological (of knowing and being) matter of care (Puig de la Bellacasa, 2017), for enabling subjugated others to speak and be heard, in which it is more than an act of supporting the pre-existing individual (to be known), but an intimate engagement in sustaining this life (Stengers, 2015). This article explores the advocate's work of 'emboldening', translating and caring for these ways of being and knowing with diamorphine in the 'ruins' (Stengers, 2015). This is different to the way advocacy is usually understood in health settings as 'a combination of individual and social actions designed to gain political commitment, policy support, social acceptance and systems support for a particular health goal or programme' (World Health Organization, 1998, p. 5). Rather than a combination of what is known as 'political cause' and 'individual case' advocacy, which view individuality as human-centred and autonomous (Carlise, 2000; O'Gorman et al., 2014), the advocacy witnessed here takes individuality as always assemblic, blurring political/ethical causes and individual cases – giving space for advocates and the substances they advocate for to get involved in how life can be for these people. Drawing on Isabelle Stengers' 'cosmopolitical proposal' 'that there is no knowledge that is both relevant and detached' (Stengers, 2005, p. 1002), advocates 'become activated' (Criado & Rodríguez-Giralt, 2019) in learning from or, as Stengers (2005; 2015) puts it, 'composing with' (see below) people who use diamorphine and the diamorphine itself. Thus, and in following Criado and Rodríguez-Giralt (2019), and others (Rabeharisoa et al., 2014; Rodríguez-Giralt, 2011; Rodríguez-Giralt et al., 2018), agency and activism is always made up of a network of human and nonhuman entities. And as such, non-human objects can become a cause for thinking and care. This article explores these more-than-human ways of knowing and caring (with the substance) as a form of collective action against an increasingly inflexible and hostile 'new' system of opioid prescribing.

Understanding 'speaking' as a collaborative act, and appreciating the non-innocence of care in this domain (Murphy, 2015), enables us to see how 'old system' patients get silenced and the relational work that is needed for them to speak. Speaking is then translated into 'being heard'. To be heard, the advocate plays a crucial role in knowledge production, turning patients' embodied matters of concern (around the destructive potential of reducing/removing diamorphine for their vitality and livelihood) into matters of fact (such as, convertibility, cost-effectiveness and dose) for 'expert' consumption. The advocate draws our attention to the role

of diamorphine as not only a care preference or legal right, but an entangled substance for living, and a flexible technology for challenging moves to supervised regimes. Therefore, this article asks: What happens, if like the advocates, we follow diamorphine as a cause for care? That is, a cause for our attention and support, to take seriously as an ethico-political mode of maintaining life. What happens if, instead of following calls for scientific progress and evidence, we follow diamorphine and see what it does if left alone to be taken into patients' lives? How might an attentiveness to this flexible diamorphine ask questions of our current modes of care, and propose new kinds? In order to attend to these questions, it is first necessary to look at diamorphine's complex history.

The 'British system' of diamorphine prescribing: From 'old' to 'new'

Britain was the first country in the world to prescribe injectable heroin, known pharmaceutically as diamorphine, to heroin users, forming a key component of what is now known as the old British System. The British System took a medical approach to opioid dependency, using the 'addict's' drug of choice to stem their illicit use and improve health (Strang & Gossop, 1994). It was legitimised in 1926 by the Departmental Committee on Morphine and Heroin Addiction who found 'the supply of morphine and heroin [. . .] to persons suffering from addiction to those drugs [. . .] as medically advisable' (Departmental Committee on Morphine and Heroin Addiction, 1926, p. 2).

In the 1960s, this British System, however, came under increasing scrutiny, particularly from the United States who viewed heroin use as a moral (rather than medical) issue. The Ministry of Health implemented a number of changes, including that heroin could only be prescribed by a doctor with a licence from the Home Office at a specialist clinic. In the years following, from 1968 to 1978, the percentage of people being prescribed diamorphine who were in treatment for opioid dependency dropped from 60–80% to 9% (Stimson & Oppenheim, 1982, p. 114). The 'old' system suffered another blow in 1999 when the new Clinical Guidelines highlighted its limited use and warned against starting new patients (Department of Health, 1999, p. 57). Consequently, where in 2000 there were approximately 500 diamorphine patients (Metrebian et al., 2002), this has now nearly halved to 280 (Gregory, 2019), representing just a fraction of those in treatment, who mostly receive oral methadone or buprenorphine (approximately, 150,000) (UK Focal Point, 2017).

'The only way you can [start patients on diamorphine] is by trialling it with different population groups'. As this advocate in my study points out, the only way patients have been able to access diamorphine in recent years is through a clinical trial of what has been called Heroin-Assisted Treatment (HAT). This new HAT system arose from persistent calls to medicalise and evidence diamorphine prescribing (e.g. Strang & Gossop, 1994, 2005, p. 217; Strang et al., 2005, p. 13; Zador, 2005), but at the same time works to replace the flexibility that marked the practice's identity and success (e.g. Stimson & Metrebian, 2003). Ironically, it is this very evolution towards an evidence-base for diamorphine that has triggered its demise as an unsupervised and take-home medication. These new trials require patients to come into the clinic, usually twice a day, to inject diamorphine under supervised conditions that dictate the route, dose and

frequency of administration (see Brooks, 2019; Strang et al., 2010). As diamorphine has become increasingly evidenced through clinical trials, it has become something else entirely, silencing the ‘old’ informal and situated care structures.

Therefore, for the remainder of this article, I will argue through the accounts of advocates and patients for the continuation of these flexible and hidden modes of caring with diamorphine as not merely a form of supporting individuals’ rights (to care) and services’ responsibilities to these rights (‘duty of care’), but a form of collective action and living.

Methods and approach

The research presented in this article is based on an ethnographic project, drawing on participant observation as a volunteer at an advocacy service for people who use drugs, as well as interviews with the three advocates and additional interviews with ten patients who are currently or have previously been prescribed diamorphine.¹ My research question was concerned with how people who use heroin are cared for in contemporary UK society, especially considering rising opioid-related deaths (Office for National Statistics, 2019). The advocacy service was one such care site. Participant observation took place one day a week (10am-6pm) over a nine-month period (Sep 2018-May 2019). Field notes were written up immediately and analysed alongside the interview transcripts using thematic techniques.

My approach is informed by feminist Science and Technology Studies scholarship, and in particular, Isabelle Stengers’ (2005) cosmopolitical proposal and Maria Puig de la Bellacasa’s (2017) concept of ‘matters of care’, with the latter being tempered by Michelle Murphy’s (2015) cautionary tale on the noninnocence of care. I will only introduce these works briefly as they get fleshed out through the findings in the discussion section.

The cosmopolitical proposal starts from the position that there is no objective, utilitarian knowledge. For Stengers:

As for the cosmopolitical perspective, its question is twofold. How to design the political scene in a way that actively protects it from the fiction that ‘humans of good will decide in the name of the general interest’? How to turn the virus or the river [or here, diamorphine] into a cause for thinking? But also how to design it in such a way that collective thinking has to proceed ‘in the presence of’ those who would otherwise be likely to be disqualified as having idiotically nothing to propose, hindering the emergent ‘common account’? (Stengers, 2005, p. 1002)

Moving through this quote clause by clause, it highlights, for my purposes: the need and role of the advocate in a non-innocent landscape of decision-making; the nonhuman actor, in this case, diamorphine, as a ‘cause for thinking’; and the often-ignored subjugated ‘idiot’, here, the person who uses opioids, in the emergence of a ‘common account’. But where, in Stengers writing, she talks about the representational work of the cosmopolitical diplomat –

where the [d]iplomat’s role is [. . .] above all to remove the anaesthesia produced by the reference to progress or the general interest, to give a voice to those who define themselves as threatened, in a way likely to cause the experts to have second thoughts (Stengers, 2005, p. 1002-1003)

– the advocate, I will suggest, goes further still.

The advocate inevitably starts from a place of non-innocence where some people are less able to speak and be heard than others. Therefore, advocates do not simply work from the non-objectivity (and representational potential) of knowledge production but the subjugation of certain ways of knowing. Removing ‘the anaesthesia produced by the reference to progress’, in this case, evidence-based diamorphine, advocates are sceptical of recent moves to Heroin-Assisted Treatment. Like in Murphy’s (2015) study of seemingly progressive reproductive care, care is exposed as a sticky and inequitable terrain where some ways of knowing and being are more possible than others. Advocacy as care work is more than a concern, but an affective-obligatory mode of attention to neglected things and peoples: ‘we must take care of things in order to remain responsible for their becomings’ (Puig de la Bellacasa, 2017, p. 43). Speaking up for people who use opioids, advocates become affected by them and their substances, collectively enabling otherwise threatened ways of living.

Interweaving these concepts in the following sections, I will attend to three stages of what I call cosmopolitical advocacy as a form of collective action and care. I will end with a discussion of how these practices question current modes of care and provoke new ones.

Findings

The cosmopolitical advocate; a different kind of advocacy and politics

[Advocacy here is] having someone to come on their side, who understands how the system works, and understands the issues, can really just kind of embolden them, and give them a sense that they’re not-alone.

In this concise summary from one of the advocates, Neil² pinpoints advocacy as a non-objective, translational, embodied and collective emboldening of the client. A key point of departure from mainstream advocacy services like the National Health Service (NHS)’s Patient Advice and Liaison Service (PALS) is a recognition of the non-innocence of care that targets and silences people who use drugs as a stigmatised group. Therefore, taking ‘speaking’ as an onto-epistemological concern (at once, a matter of being and knowing), advocacy – speaking with and up for others – becomes a mode of politics (of who and what gets empowered). For Neil then, talking about this relationship, ‘it gets complicated because there is no clear link between advocacy and activism, in that sense’. This is a smaller, more intimate and situated mode of doing politics than say ‘cause advocacy’, with Neil saying, ‘we have to be a bit distant from that’. ‘Composing with’ (Stengers, 2005; Stengers, 2015, see also, Hoppe, 2019; Tola, 2016) and ‘becoming activated’ (Sánchez Criado & Rodríguez-Giralt, 2019) by people who use drugs and the drugs themselves – the understanding of ‘the issues’, inevitable side-taking and collective emboldening that Neil alludes to – I call this more-than-human and non-innocent advocacy, cosmopolitical advocacy.

First, I will say more about the silencing and non-innocence of care which means an advocate is needed (rather than a diplomat, say). Second, I will explore advocacy’s cosmopolitical work of emboldening where one’s agency to speak is always a collective act of knowing and being.

Third, I will attend to how these shared and embodied matters of concern are translated into ‘fact’ for persuading ‘experts’ to pay attention.

Silencing

The silencing of diamorphine patients takes many forms, but all are reliant on an insidious form of stigma which becomes amplified by a neoliberal competition over resources. According to the advocates this includes clients 1) having a reputation for drug-seeking behaviour, which means other reasons for resisting the removal/reduction of diamorphine cannot be believed, and 2) being told that they are ‘lucky’ – rather than deserving – and thus should not be surprised if their prescription is withdrawn.

Starting with the first point, people who use drugs where dependency is a factor are commonly labelled as addicts, but addiction, as we know, carries more meaning in contemporary society than most medical diagnoses. Where autonomy and rationality are sacrosanct, it marks a loss of self-control (Sedgwick, 1993, c.f., Fraser, 2017; Dwyer & Fraser, 2016). And it is against this backdrop that the advocates say opioid patients are not believed by their care providers. ‘Sadly, when we’ve done work, I’ve heard them say, “Oh, yes, but they are an addict. You can’t just automatically believe what they say”’ (Lisa). For Lisa, this is what makes diamorphine patients an easy target for budget cuts: ‘it always starts with the most vulnerable people, doesn’t it? Because you can get away with it . . . Because they won’t be believed’. For example, in one case (explored further below), a patient’s daily diamorphine prescription had been reduced from 500 ml to 120 ml and the doctor was trying to reduce her again. The patient explained how she was in withdrawals and could not cope with a further reduction, but these pleas were dismissed as drug-seeking. Furthermore, attempts to resist and be heard are seen to simply reinforce this identity as a ‘pushy’ drug-seeker, which served to further silence her.

They were saying, ‘She’s very pushy and aggressive.’ I’m like, ‘She’s been withdrawing for a couple of weeks, because you won’t give her meds. If you gave her the right meds and she wasn’t withdrawing, maybe her response would be [different]’. (Tony)

A second way diamorphine patients are silenced is through a narrative that they are lucky. As aforementioned, very few people are now prescribed diamorphine in the UK. Patients are made aware of this frequently and made to feel lucky, which means they are more likely to succumb to pressures to reduce or end their prescription:

It’s used as a massive stick to beat people with. Because services will say, “Oh, do you realise how lucky you are, to be one of the very few people in the country still?” That really kind of makes people belittled and makes them feel oh, okay, I should pipe down and just do as I’m told here. (Neil)

This ‘luckiness’ of course relies on an undeservingness – they are only ‘lucky’ because they are not deserving of care like other patients. For example, Lisa frequently refers to the diabetic patient who would not be harassed in the same way. Speaking rhetorically about a case in which a patient was offered a ‘relaxation in pickups (to reduce how often they visited the pharmacy for their prescription) if they reduced their dose’: ‘Why would you need less insulin because you weren’t going to pick it up every day? You wouldn’t!’. This ‘luckiness’ also works to isolate diamorphine patients from each other. They were made to feel like they were existing

under-the-radar and thus operated in these silent ways, with one patient saying: ‘I just slid in quietly’, ‘people don’t ask, we don’t say’.

Furthermore, within a competitive care environment where drug-treatment budgets are no longer ‘ring-fenced’ (Advisory Council on the Misuse of Drugs, 2017), people who use drugs, as Neil puts it, become ‘low hanging fruit’ (see also, Hamilton, 2019; McCluskey, 2019). Therefore, in these changing times, defined by ever divisive patterns of stigma (where ‘addicts’ are unbelievable and underserving) and a political economy open to moral judgements (e.g. Stevens, 2019), advocacy is needed to embolden these subjugated peoples and modes of living with drugs.

‘Emboldening’

Having explored some of the ways diamorphine patients are silenced, this section and the next will attend to the advocate’s work of enabling patients to speak and be heard. The advocates discuss their role to ‘embolden’ the individual, so they feel able to ‘fight’ in an arena that constantly feels untenable: ‘It’s a really brilliant illustration of the power dynamic. “What’s the point of fighting? You’ll lose anyway”’ (Tony). Individuality here is not a starting point but an achievement, where speaking is an act of collective agency. Emboldening someone to speak is cosmopolitical work that involves the interaction of the human (patient, family) and nonhuman (technologies, substances) in constituting agency. I will now look at some of these interlaced entities.

Lisa notes how ‘the patients themselves are often too frightened to let us advocate so we often advocate behind the scenes by coaching the person’. Advocating is not done for people (as an external force) but with them as part of them.

Frequently, people will decline us getting involved on their behalf and will prefer to have regular consultations with us about what they want to do. They are worried that it’ll be worse for them [. . .] – ‘how dare they stand up for themselves, go outside the agency, seek advice’.

Lisa continues, ‘we’ll help them to try to phrase it in the best possible way by just sending an email’. Here, this small, backstage work of crafting emails is essential where attempts at a ‘constructive’ conversation can be quickly turned into a complaint. For Tony: ‘They see it in a, “You’re having a go at me,” sense, as opposed to actually, “This is a constructive attempt to look at a problem in a different way”’. By turning an attempt to look at a problem differently into a complaint, negotiation is shut down, becoming a bureaucratic matter, and crucially, it is the complainer who becomes ‘the problem’ (e.g. Ahmed, 2017). The advocates therefore try to avoid such procedures that operate to further silence the patient.

Cosmopolitical advocacy happens with the substances in question. That is to say, unlike other services, the advocates talk about the intimate ways in which they have learnt from the substances they advocate for in a way that allows them to know what it might be like to have doses and regimes changed: ‘PALS wouldn’t know what methadone [the most commonly prescribed opiate substitute] was. You really need to know so much about the medication in order to advocate for people’ (Lisa). Unlike PALS, the advocates here have lived experience of substances (professional and personal) and know how integral substances are to people’s

lives, enabling them to advocate from this embodied knowledge (explored further below in terms of ‘becoming activated’).

Emboldening is a relational act that also involves a bolstering by-proxy through the family who can become blinded by a narrative of addiction that focuses on negative behaviour and encourages ‘tough love’.

We can advocate for the person who’s using drugs by the way we talk to their parents or relatives so that we can continue to have this theme of people being respected and being understood and having feelings. (Lisa)

This is about challenging dehumanising practices so the patient can be seen as a son/brother/partner etcetera: ‘not just being some arsehole who can’t manage their money and is sleeping in the porch. They’re still that son that you had whose sister died. Usually there’s something pretty difficult in somebody’s history’ (Lisa). Making ‘addicts’ human again (that is, where humanity is always collective) is an important part of allowing them to exist in very material ways, for this man, to continue living with his parents rather than being made homeless. Lisa notes: ‘It’s the drugs and behaviour that get focused on and you understand why’. These ways of knowing are more possible than others. It takes an attuned listener to disentangle and mediate these ways of knowing (addiction) to encourage the family to recognise the son.

The more you listen to people, not talk, the more you hear the complexities that have led to the current situation. You might get a mother who’s so fed up but [. . .] the more you listen, you find out that actually there’s something like that in the history. They realise that actually that is what the problem is but they’ve forgotten it because it’s always, “I’m afraid he’s going to set fire to himself”, or, “He’s got an injecting leg injury”, or, “It smells”. (Lisa)

It is through such collaborative problem-making – approaching a problem differently with others, as Tony says – that the person can be heard and be.

Finally, I want to look briefly at this ability to listen as a process of ‘becoming activated’. The advocate is very much involved in this emboldening in how they register what is going on and play it back to the relative. This is not a neutral act, but one only made possible by becoming-with people who use drugs and the drugs themselves. As Stengers writes:

It is not an ‘objective definition’ of a virus or of a flood that we need, a detached definition everybody should accept, but the active participation of all those whose practice engaged in multiple modes ‘with’ the virus or ‘with’ the river.

All the advocates had a long history of becoming-with drugs, that is not necessarily to say by consuming them, which would only be one such embodiment, but by learning from them in various capacities of research and practice (of when and how they are taken and to what effect – the feelings, thoughts and actions they make possible), their users and associated stigmas. Through this deep, embodied knowing, the advocates shared their clients’ frustration over how little some ‘experts’ (care providers) knew: ‘From my own history, I knew way more than these people knew, and it just annoyed me’ (Tony). ‘I would never stay quiet. I would always have to pick people up. I would even stand up at meetings and openly say things’ (Lisa).

Given the dispersed nature of agency and individuality, we have seen how emboldening ‘one’ ‘to speak’ requires a network of practices, people and things. In the next section, I will look at how being heard by the expert in acts of advocacy requires a further set of translations.

Translating

Where the previous sections explored the sociomaterial silencing and subsequent cosmopolitical emboldening of diamorphine patients as subjugated peoples, here, I want to look at the collective work involved in patients ‘being heard’ by the care provider that requires translation. As a volunteer at the service, my field notes record one morning that focused my attention.

Today I was tasked with compiling an ‘evidence table’ for ‘the continuation of injectable diamorphine’. [T]here have been many calls to the helpline from people having their diamorphine prescription threatened [. . .]. [I had] to get to grips with these cases – read the complicated case notes, reflect on my phone conversations with the clients, speak to other workers – and turn their concerns into something concrete, namely, through external sources. I was to translate this experiential, embodied and shared knowledge into something more meaningful and palatable for the expert audience we were trying to convince. I was to turn matters of concern into matters of fact.

From answering helpline calls, and reading clients’ letters to care providers, I knew the importance of diamorphine in clients’ lives. Clients pleaded for the continuation of their prescription, sharing intimate details of their reinvigorated lives away from the criminal underworlds that put themselves and family at risk, describing how old-system diamorphine gave them the stability and flexibility (not tied to a clinic) to enter education, employment and improve their health. They rebuilt connections and made lives for themselves, very much with diamorphine. Therefore, I was shocked to see the cold responses from those professionals in charge of their care who ignored such vitalism. Diamorphine was not simply a pharmaceutical preference for these patients but had been life-making and sustaining for the last two decades (or more). As one woman I interviewed said, ‘it was the making of me’:

[Morphine] was the best thing that happened to me, I was thriving [. . .]. It was the making of me. I was going on holiday, I was going to see my mum, I was going to do other things [she names attending courses and even lecturing on them], and then everything went to pot, I don’t know what happened. It was not good the way that the carpet got taken from under my feet. (Sofia)

Diamorphine, and then slow-release morphine, gave Sofia the foundations (to use her carpet imagery) to do things that others take for granted, which meant its removal had world shattering consequences. When I met her, Sofia had started using illicit heroin again and, for the first time, drinking alcohol excessively.

In a ‘factish’ (Stengers, 2010) domain, where embodied more-than-human concerns, like where changes to a prescription could be the un/making of somebody, rarely matter, they had to be translated. Next, then, I attend to this translational work that turned complex ways of being and knowing with diamorphine into matters of 1) ‘convertibility’ 2) cost-effectiveness and 3) dose.

In some cases, where injectable diamorphine was being threatened, patients were told this would be replaced with oral formulations of other opioids. Painting these as ‘convertible’ violently neglects the specificity of these medicines, how they are consumed and taken into the body, and how their patterns of use and feelings have become enfolded into the recipient’s life.

It’s poorly understood, the transfer. There doesn’t seem to be any equation that always works. There’s such a psychological component to it as well. You just can’t say, “10mg of IM [intramuscular] diamorphine is equal to 30mg of Oramorph.” (Lisa)

The sensory and embodied experience of injecting, for example, is drastically different to consuming substances orally. The substance does not only get absorbed into the body differently but relies on a completely different set of practices, apparatus and relations between the drug, brain, body and environment. A set of connections, as we see below in Erik’s and Sofia’s return to illicit heroin, that can easily falter if not treated with care. The advocates knew these drugs were not convertible but had to translate this into the expert’s terms. Compiling the table, I was tasked to find studies that ‘evidence’ the problem of ‘switching’ opioids and their different absorption rates.

Speaking to the integral role of diamorphine in their lives, patients were terrified of returning to their ‘old lives’ if their prescription was removed. Therefore, a second translation was concerned with patients fears of having to return to an illicit market, which posed a threat to their employment and ability to look after themselves and family. These are very real fears as Tony highlights in pointing to the rapid loss of life following the closure of diamorphine clinics in the late 1990s (Gregory, 2019; Hari, 2015). These fears were translated into matters of ‘cost-effectiveness’, ‘retention rates’ and ‘efficacy’. As Neil comments: ‘it’s costly, but it’s efficient at keeping people engaged with services, keeping their stability, allowing them to develop their independence, and, you know, be productive members of society, and all that’. With a cynical nod to the simplicity of these translations – ‘and all that’ – the studies in the table were used to evidence diamorphine as more cost effective over time than the criminal and health cost implications of returning to illicit heroin.

Where the entire diamorphine prescription was not threatened, another issue and matter for translation was dose reduction. ‘I’ve heard many practitioners say, “They won’t notice the reduction.” “Really?!”’ (Lisa). For one distressed client I spoke to on the helpline, this happened with no warning. She had just collected her prescription and noticed the missing diamorphine ampoules (20 mg a day). Through tears and gasping breath, she explained to me how she could not cope with yet another reduction. Here, we had to translate her embodied knowing into something meaningful to the prescribing doctor, into a matter of dosing and tolerance. As noted above, this involved careful negotiation around an issue that regularly came up, that patients knew more than their doctor about how their bodies had become-with diamorphine in ways that might challenge professional opinion.

Drawing on his own experience, Tony says: ‘It’s really hard to know why you don’t go, “Actually, you’re talking rubbish, because I used to be on three times that dose, and it didn’t even touch the sides”’.

Patients and advocates, with their embodied knowing, regularly became frustrated with doctors who refused to accept the dose needed to avoid withdrawals and, even more, 'thrive'. For example, Sofia, introduced above, says:

I was asking again to go back [to her previously higher dose], but my doctor, said, 'okay, I can give you 20mg'. 'You know what you can do with your 20mg! You think, just because you have a couple of letters after your name, you think you know it all, you actually don't!'

And one man, Erik, who had started using illicit heroin since the diamorphine trial he was enrolled in had ended, even spoke of a surprising temptation to give up his morphine prescription because the doctor knew so little about it:

The amount of times I've said, 'I feel like I want to change back to methadone [a common substitute with less similar effects] because at least then they know what they're prescribing' [. . .] [F]or doses and things, when I tell them about my tolerance, it doesn't seem to wash, it doesn't seem to register with them. [. . .] they're scared to prescribe it [morphine], like, to up and down it.

Due to the silencing explored above, and a privileging of facts over concerns, the flexibility needed to experiment with different doses are ignored: 'You're battering your head against a brick wall when you're telling doctors over and over the same thing and no-one's listening' (Erik). Frustrated with this distrust, lack of knowledge and sub-dosing, Erik is tempted to give up his prescription altogether.

Here, I see this translational work from matters of concern to fact as a 'matter of care' for it works with and mediates what patients are saying and living into something more acceptable and operational for health professionals with duties of care. In other words, it gets involved and makes a difference in what it means to live with old-system diamorphine in a new system that works to collapse it. Next, then, I turn to where this cosmopolitical advocacy takes us in terms of sustaining these ways of living with diamorphine.

Discussion

A cause for care: Caring with diamorphine in changing times

In this paper, I have explored advocacy as a more-than-human and onto-epistemological matter of care in terms of being heard, where not being heard has potentially devastating effects, with patients returning to illicit markets and injecting practices that risk their health, employment and family life. I have paid attention to how this silencing occurs and the sociomaterial work of advocacy in 'emboldening' the individual and translating knowledge in this non-innocent domain. In this discussion, I take up Stengers cosmopolitical proposal, to look speculatively at the kinds of care that such interventions might have. And particularly how, if given a chance, diamorphine could be a cause for care. That is, how does diamorphine ask questions of our current modes of care, and what new modes of care does it make possible?

In these changing times, witnessed as a change in systems of prescribing, made possible by violently entangled social, economic and material forces, which leaves diamorphine patients

silenced ('people don't ask, we don't say'), advocacy acts as a kind of collective agency or activism that allows these subjugated ways of being to be heard (by family members, care providers) and exist. Becoming affected or activated, this is not a distanced attempt at decision making but an embodied pursuit of care in sustaining life (Puig de la Bellacasa, 2017). In their collective agency with diamorphine, as well as other 'things' (seen in the construction of emails), advocates slow down reasoning, enabling problems to be looked at differently – a position that treatment services sometimes try to shut down by turning advocacy attempts into complaints.

Involving 'things' in our 'common accounts', diamorphine responds to the "“cosmopolitical” question: how, by which artefacts, which procedures, can we slow down political ecology' (Stengers, 2005, p. 1001). How might diamorphine 'slow down the construction of this common world, to create a space for hesitation regarding what it means to say “good”?' (Stengers, 2005, p. 995). For this, flexibility is key. Therefore, the advocates, as we have seen, are not only advocating for diamorphine, but diamorphine as a flexible technology. As one patient-activist put it:

It goes back to flexibility [. . .], a realisation that if you feel that you have it [diamorphine] [. . .], you don't have that worry over not knowing where that next fix is coming from. It completely changes the playing field. It's like a different drug altogether [. . .]: 'Okay, that's fine, I won't use, I'll have it when I get home'.

This is no longer a drug that 'fixes' her to certain places, people and times (like the clinic or drug dealer), but allows her to do things, in her case, enjoy a successful career and full life, knowing that diamorphine is waiting for her at home. Therefore, it is unsurprising that this patient, like Tony, is incredibly scathing of the new supervised Heroin-Assisted Treatment (HAT): 'you can't do it supervised, it will just ruin it all!' (see also Fraser, 2006, for a similar criticism of methadone programmes). Like with the inflexible and underdosed morphine Erik is tempted to give up, the drug becomes something else, so HAT trials tell us very little about the drug that the patients and advocates in this study know and advocate for.

Lifting this amnesia of progress (Stengers, 2005, p. 1003), which has literally meant people have forgotten 'old system' diamorphine (with one media outlet reporting: 'Drug addict to make history and become first person in UK to receive publicly-funded heroin' (ITV Report, 2019; see also Hymas, 2019; Dalton, 2019), this flexible diamorphine questions our current care practices in many ways. First, it challenges an idea that medications should be taken in one go, at a specific time, and with a certain continuity. Erik talks about his preference for 'staggering' doses and desire to 'up and down' it in finding a dose that works. Flexible unsupervised diamorphine moves with and enables life rather than having to be fitted around, curtailing what somebody can do (much like the more mainstream opiate-substitution programmes, see for example, Bourgois, 2000; Fraser & Valentine, 2008). Second, the diamorphine here is prescribed on a maintenance basis, which contests reduction targets in the name of progress and recovery (National Health Service, National Treatment Agency for Substance Misuse, 2012). Third, it is injected, disrupting a focus on oral consumption and an assumption that different formulations and routes are interchangeable. Lastly, diamorphine asks new questions of how we care for people who use opioids by drawing attention to

availability. Subject to shortages, it asks providers to plan for supply issues. But rather than learning from this in terms of exploring pharmaceutical production, the advocates see it being used as an excuse to withdraw diamorphine altogether: 'So, diamorphine appears to be subject to shortage of supply. This is often used as a reason to get people to stop being on diamorphine, just in case there's another shortage' (Lisa).

As we move towards a treatment system increasingly defined by patterns of stigma and political economy that cast diamorphine patients as unworthy of care, all the while propagating the value of objectivity that silences these processes, it is not surprising that advocates call to slow down reasoning. Pushing against the medicalisation and evidencing of diamorphine that pursues a drug-free utopia (promised by our current recovery-based policies and Heroin-Assisted Treatment), flexible diamorphine can change the political scene in more emancipatory ways, affording the freedoms (where individuality is always collective) to live relationally meaningful lives with diamorphine. Therefore, where this diamorphine is threatened, the fear we hear in patients' (and advocates') voices is a fear for their very freedom.

Notes

1. Ethical approval was granted by the university and NHS ethics boards. All names are pseudonyms and some details in participants' accounts have been altered to preserve anonymity. For confidentiality reasons, the patient accounts used here are not the same patients who are being advocated for.
2. Pseudonyms are used throughout.

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