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ORIGINAL ARTICLE

The social life of HIV care: On the making of 'care beyond the virus'

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Abstract Treating care as an effect of material implementations, we use qualitative interviews with people living with HIV in London, most of whom are migrants, to explore care practices linked to clinical treatment delivered as part of the 'cascade of HIV care'. We consider how HIV care is done, and what HIV care does, drawing on assemblage theory. We ask how is care affected by the situations in which it is enacted? and what contingent forms of care does the HIV care cascade potentiate? A prime actor in the care assemblages revealed in our study is immigration, from which multiple uncertainties flow, including access to vital resources such as housing and income. Yet we also found that clinical HIV care is worked-with in practice to afford multiple forms of care. Here, viral care is translated into matters of vital concern to produce care which extends 'beyond the virus'. Practices of care beyond the virus afford social protection, including through making-up social relations and networks, and novel modes of sociality. Friendship connections, community organisations and HIV clinics are among the key actors involved. Being attuned to how HIV care is made to matter helps generate new ways of knowing and doing care.

Keywords Care · Care practices · HIV · Social life · Assemblage · Qualitative

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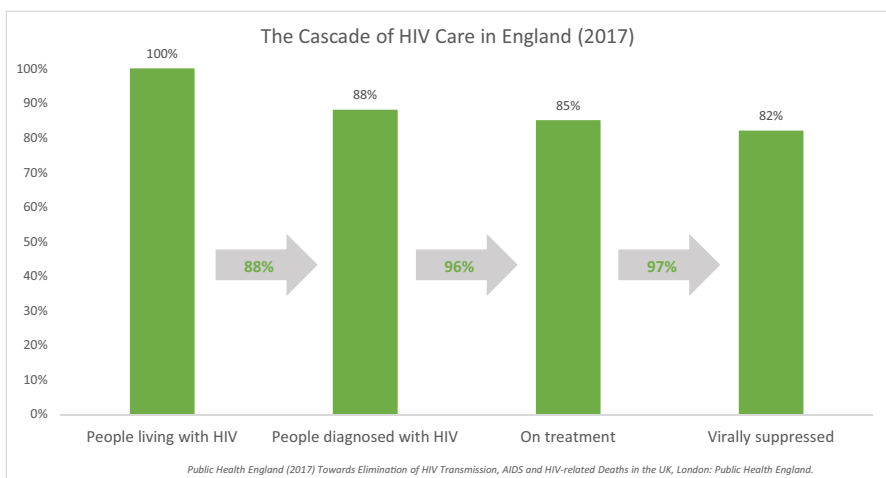[3] Graduate Institute of International and Development Studies, Geneva, Switzerland

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Introduction

The figures of the 'cascade of care' and 'care continuum' feature prominently in the field of HIV care. The cascade of care is a clinically informed surveillance framework for generating stepwise epidemiological estimates regarding the process of engaging people into HIV care, including measures of intervention access, adherence and outcome (Mugavero et al. 2013; MacCarthy et al. 2015; UNAIDS 2014). It promotes key metrics in relation to the numbers or proportions of people diagnosed and undiagnosed, as well as in and out of treatment, and their public health implications. Importantly, this care cascade frames 'treated HIV' as the defining end-point and ultimate measure of effect on health, in a process of sequential, largely biomedical, care engagements—from HIV testing, to HIV diagnosis, to linkage with antiretroviral HIV treatments (ART)—which are sufficient to bring about a state of viral undetectability through viral suppression (Paparini and Rhodes 2016). Figure 1 illustrates an example of the cascade of HIV care. Based on surveillance data in England to 2017, this indicates that 88% of the estimated number of people living with HIV are diagnosed, of whom 96% are treated, of whom 97% achieve viral suppression (Public Health England 2017). Not only has the cascade of care become a primary knowledge-making practice of HIV health, but it also infuses how care is governed in relation to other conditions, most notably hepatitis C (Linas et al. 2014). In a context of discourses promising viral elimination afforded by ground-breaking biomedical treatments for HIV and hepatitis C (Granich et al. 2009; Rhodes 2018), the cascade of care is mobilised as a technical solution to delivering biomedical promise.

The HIV care cascade enacts particular forms of patient and care expectation, and these infuse how care is delivered and experienced (Paparini and Rhodes 2016). The constitution of good, exemplary or poor care, for example, is produced relationally, including through the material relations which make up the cascade of

The Cascade of HIV Care in England (2017)

Public Health England (2017) Towards Elimination of HIV Transmission, AIDS and HIV-related Deaths in the UK, London: Public Health England.

Fig. 1 The cascade of HIV care (England 2017)

HIV care (Flowers 2010; Thomas et al. 2010; O'Daniel 2014; Nguyen et al. 2007). Care pathways afford a logic for navigating disease and delivering clinical care, also making care subject to administration, audit and measurement (Berg 1997). And these practices also foster a discipline, including by defining health narrowly according to clinically observable outcomes and subjugating patient experience relative to scientific expertise (Berg 1997; Llewellyn et al. 2018). The cascade of HIV care enacts a particularised, seemingly singular, trajectory of HIV health organised in relation to a linear account of how a virus is acted upon by a series of biomedical interventions. This cascade of care gives primacy to care as a matter of *viral* control.

While clinical care pathways constitute a disease and make it navigable, this is largely "according to parameters that unfold outside the lives of patients" (Llewellyn et al. 2018). Accordingly, the clinical care cascade may be viewed as offering an illusionary or virtual sense of singularity, since the multiple practices, as well as alternative logics, that characterise how health and care is materialised in practice are neglected or go unnoticed (Mol 2002, 2008). Multiple actors combine to situate the different possibilities of HIV care in practice, including how patients and their forms of care are afforded. Previous work, for example, maps an entanglement of material–social relations in HIV care, involving bodies (Persson 2004; Persson et al. 2003); technologies, including pharmaceuticals, treatments and tests (Rosengarten 2009; O'Daniel 2014; Race 2001); care systems, including the locations and spaces of care (Biehl 2007; Nguyen 2005); narratives and inscriptions, of which discourses of care expectation are a part (Michaels and Rosentgarten 2013); social and friendship networks (Moyer 2014); laws, regulations and policies, which enable as well as ration care opportunities (Rhodes et al. 2009) and material and other resources (Reynolds-Whyte et al. 2006; Marsland and Prince 2012). How HIV care is done, and what HIV care does, is thus a function of the particular material–social assemblages in which care is enacted, wherein multiple human and non-human actors combine to afford the care possible. Attending to care as a matter of practice, by focusing on how care is situated locally and materially, helps notice forms of care, and things that make up care, that might otherwise go unnoticed (Puig de la Bellacasa 2011; Buse et al. 2018). The virtual singularity of the cascade of HIV care masks the alternative cares in practice (Mol 2008). Focusing specifically on the case of how people living with HIV, most of whom are also migrants, engage with ART and HIV care, leads us to explore how HIV care possibilities are enacted relationally as a matter of social life. Our analysis is guided by two related questions: how is HIV care affected by its assemblages and situations? and what forms of care does HIV care potentiate? Taken together, we seek to notice forms of care related to HIV that might otherwise go unnoticed or neglected in the biomedically infused cascade of care accentuating viral control.

Our focus on the ways care is materially enacted illuminates how HIV care is accommodated in relation to social life and matters of vital concern which extend beyond those of treating the virus itself. This shift of focus—from matters of viral to vital concern—helps notice the multiple logics of care related to HIV in practice (Mol 2008). This more-than viral care is a form of "relational extension" generated from attachments with materials of HIV care that affect how social relations are

done, and "through which world-making is accomplished" (Latimer 2018, p. 380). It involves *movement*, wherein universal matters of fact that situate HIV care as a viral concern are transformed through the ways in which the cascade of HIV care is worked on and tinkered with in practice (Mol et al. 2010). Rather than following a single path, as imagined by the simplifying figure of the care cascade, actors tinker as they go, generating situated opportunities for the care that matters, extending care relations beyond the standard of care (Llewellyn et al. 2018). In our study, immigration emerges as one of the key dimensions of the care needed, possible and enacted.

Treating HIV and migrants in the UK

Immigration and ethnicity are important dimensions of HIV health in the UK, and especially London, as large proportions of people living with HIV are migrants, particularly from sub-Saharan Africa, and HIV disproportionately affects Black Africans compared to other ethnic groups (Kirwan et al. 2016; Baylis et al. 2017). Black African and migrant people are also more likely to present to clinical care with late diagnosed or undiagnosed infection (Kirwan et al. 2016; Harris and Khatri 2015). Although clinical HIV care is not refused as a result of immigration status, the latter affects rights to residency, work, social housing, access to public funds and benefits, as well as access to health care beyond HIV. Black African and migrant people living with HIV in the UK are disproportionately affected by poverty and homelessness (Ibrahim et al. 2008; National AIDS Trust 2014; Terrence Higgins Trust 2014), and face "extreme social and financial exclusion" (Baylis et al. 2017). Vital life resources—access to work, housing and a basic income—are especially precarious for people whose immigration status is uncertain, such as those 'undocumented' and seeking asylum. Access to HIV care through National Health Service specialist clinics and voluntary sector community organisations constitutes a significant resource of material and social protection in such uncertainty (Baylis et al. 2017). The care afforded through such specialist HIV services enables access to care which extends beyond the immediacy of HIV health (National AIDS Trust 2017).

HIV care services in the UK are in flux, with organisational shifts altering the capacity of specialist services to provide care beyond the immediacy of HIV health. One key actor is the Health and Social Care Act of 2012, which precipitated the fragmentation of HIV care commissioning between the NHS, now primarily responsible for delivering treatment, and Local Authorities, now primarily responsible for delivering testing, diagnosis and prevention (Baylis et al. 2017). In addition to local challenges of implementing integrated HIV care through such divided commissioning, social support services fall in between these commissioning divides, with no clear legal framework of delivery (Baylis et al. 2017). Social support services, which are largely delivered through community-based organisations, have become a matter of local discretion subject to funding contingencies. Given the "alarming trend for cutting or completely decommissioning HIV support services", with recent average annual cuts in expenditure for HIV support services estimated at 28% for England, HIV care which extends beyond the clinical is under threat (National AIDS Trust 2017). There are claims, for instance, that over a quarter of Local Authorities in

England have cut their contracts for HIV care by at least 50% in recent years (National AIDS Trust 2017), and that 40% of HIV community organisations surveyed in 2015 faced budget cuts in the previous year resulting in staff reductions, with a third facing closure, as an effect of rationing measures (Dalton 2016).

This rationing of HIV service provision combines with a particularly delicate climate of access to health care for migrants. The connection between HIV and immigration has fed a hostility against people living with HIV, particularly asylum seekers, fuelled by xenophobic media coverage and discourses of 'health tourism' enacting migrants as a burden on health and welfare systems (Tyler 2010). The UK Government's public commitments to reduce rates of migration have combined with increased surveillance efforts via the linkage of personal data across public institutions, including with health services, to identify the undocumented and unwanted, feeding a state of precarious citizenship among migrants as well as fears of deportation and arrest at the point of accessing health care.

Approach

With our primary interest being access to ART, a key threshold in the cascade of HIV care (Mugavero et al. 2013; MacCarthy et al. 2015), we treat HIV care engagements as effects of their practices of implementation. Rather than assuming a single, prior and stable knowledge of HIV care, we assume care objects and effects to be emergent, contingent and multiple expressions of material practices (Latimer 2018; Buse et al. 2018). A relational ontology calls attention to *movement* in the *becoming* of a *multiverse* of care as an effect of its translations and transformations. This attention focuses on the care that is done according to its situation, helping to "illuminate different imaginaries of care to those that dominate healthcare environments" (Latimer 2018, p. 380). We therefore explore how migrants living with HIV respond to their situation and the multiple human and non-human actors making up their HIV care possibilities—such as, treatment technologies, clinics, community services, friends, laws, policies, discourses—to enact care as a matter of situated becoming. This approach makes apparent how pathways of HIV care are open to navigation and production in multiple ways, giving rise to variable practices of care which extend beyond the clinical. Here then, HIV care is investigated as an object in-the-making, and this helps make visible forms of care that might otherwise go unnoticed in the imaginary of the HIV care cascade. To this end, we approach our analysis as a way of 'thinking with care' (Puig de la Bellacasa 2011, 2012) at once to situate HIV care as a matter of vital concern and to generate different ways of knowing and generating care.

Following Puig de la Bellacasa (2011, 2012), we envisage care as an affective state, a material vital doing and an ethico-political obligation. Puig de la Bellacasa draws on Tronto and Fisher's description of care to include "everything we do to maintain, continue and repair 'our world' so that we can live in it as well as possible", where "that world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life sustaining web" (Tronto 1993, p. 103). Care then is concomitant to life, for it makes life liveable: "Care obliges us

to constant fostering, not only because it is in its very nature to be about mundane maintenance and repair, but because a world's degree of liveability might well depend on the caring accomplished within it" (Puig de la Bellacasa 2012, p. 198). By presenting 'matters of fact'—here, the virtual singularity of the clinical HIV care cascade—as 'matters of concern'—as embodied practices made to work socially— we can appreciate how care is assembled as a matter of social life (Puig de la Bellacasa 2011; Latour 2005). This shift in staging care as a matter of material doing and vital concern can be treated as an intervention of ethico-political becoming, for it generates new ways of knowing what care matters. This is part of a "speculative commitment to think about how things would be different if they generated care" (Puig de la Bellacasa 2011, p. 96).

In re-assembling HIV care as a contingent effect of practices, we seek to describe how multiple actors (human and non-human) entangle together in an assemblage to produce care limits and potentials. Assemblages accentuate care as "heterogeneous, contingent, unstable, partial and situated" (Ong and Collier 2003, p. 12), helping to notice the multiple effects at work in how care is done (Mol 2008). Rather than biomedical technologies, such as ART, simply 'acting on' people moving along a viral care pathway—as if treatments, people, viruses and care pathways come into relationship as separately bounded objects with essentialised attributes—care transformations and potentials are produced by entangled interactions between the multiple bodies of an assemblage (people, technologies, organisations, discourses) which have the capacity to affect and to be affected in relation to one another step-by-step (Deleuze and Guattari 1987; Duff 2014, p. 106; Fox and Allred 2017). As the bodies making up the care assemblage encounter one another, they move and change, through their partial connections and incorporations, to affect new bodily arrangements in the assemblage. DeLanda describes this as a "double determination" in which "assemblages emerge from the interactions between their parts, but once an assemblage is in place it immediately starts acting as a source of limitations and opportunities for its components" (2016, p. 21). Whereas HIV care pathways trace how the assumed bounded objects of patient and virus move in space and time in a linear trajectory point-to-point, an assemblage of care imagines an ontology of becoming in which actors entangle to produce "movement by which the line frees itself from the point, and renders points indiscernible" (Deleuze and Guattari 1987, p. 294). We thus treat HIV care practices as a dynamic of changing assemblages, and the conditions of possibility these generate (Latimer 2018). We approach HIV care as malleable rather than fixed, multiple rather than singular and relational rather than linear, to explore how the care materialised in practice interferes with that imagined by the figure of the cascade of clinical care.

Methods

The analysis here is made through 29 qualitative interviews with Black African and Black Caribbean men living with HIV in London, most of whom are migrants to the UK. Our broad aim was to investigate the social relations of the HIV cascade of care (Mugavero et al. 2013), especially access to ART. Our specific focus here is how

care assemblages enact care, including those practices of care that extend beyond the biomedical. We focused our recruitment purposively on people and situations theorised to be especially vulnerable to care disruption or disengagement. We did this as a way of exploring the situated nature of care engagement, including how care is enabled in conditions of constraint. Following consultations with community and other experts in London, we focused our recruitment towards Black African and Black Caribbean men, who have received little research attention to date, and who have been evidenced elsewhere to be disproportionately affected by HIV and by social-material inequalities affecting their HIV care (Ibrahim et al. 2008; Kirwan et al. 2016). The study was undertaken in close collaboration with community and clinical partners, and received approval from the London School of Hygiene and Tropical Medicine and Camberwell and St Giles' Ethics Committees. This research was undertaken as part of the National Institutes of Health Research Health Protection Research Unit (NIHR HPRU) in Blood-Borne and Sexually Transmitted Infections.

Participants ($n = 29$) were recruited between 2015 and 2017 via three London HIV clinics ($n = 15$) and three community organisations ($n = 14$). Most recruitment at community organisations was at one project via its lunch club, where the researcher, SE, had regular presence. Those recruited at HIV clinics were referred to us via clinic staff. All interviews were audio recorded, with consent, for later verbatim transcription, and all bar five took place at recruitment sites. All participants were given a small cash reimbursement, and all names used in this analysis are pseudonyms.

Participants averaged 44 years old (ranging from 21 to 82 years), with most describing themselves as Black African (19), and the remainder, Black Caribbean (4), Black British (3) or Mixed Heritage (3). Most were born in Sub-Saharan Africa (19). Most were migrants to the UK (23), with three having migrated in the last five years, and 10 in the last 10 years (with 13 having been in the UK for more than 10 years). Despite having been in the UK for long periods of time, for many their immigration cases remained unresolved. While nine had British citizenship, and three citizenship elsewhere in Europe, and 10 had secured indefinite leave to remain in the UK, six were in the process of seeking asylum, had temporary asylum or were undocumented (one person's UK citizenship status was unclear). A minority had paid work (8), with 20 either unemployed or not permitted to work given their citizenship status and one retired. Most (21) had received their diagnosis of HIV over five years ago. Most had consistent and ongoing engagement in HIV care (23), although for six their engagement in HIV care had been inconsistent. Most (24) had accessed care or social support from community-based organisations, and for 16 this was consistent and ongoing.

Our approach to analysing interview data treats narration and discourse as *practice*; not merely as language or as representation, but as enactments with material form and effects (Bacchi and Goodwin 2016; Fox and Allred 2017). This enables analyses of phenomena as patterned networks of social relations and events. Further, rather than narrowing our attention to delineating representations made through narrative, we approach our qualitative data with a focus on noticing the interplay of human and non-human effects in the care assemblages being enacted

through the interview accounts (Fox and Allred 2017). Rather than treating things for what they are, or for what they are represented to be, we are also focusing on what knowledge-making practices can do (Bacchi and Goodwin 2016). We noticed how accounts at once enacted forms of HIV care as an accommodation to everyday life situation and as an affordance of life potential. We became attuned to how HIV care both affects and is affected by its assemblages of production, and this helped us notice the making of 'care beyond the virus' linked to shifts in the practice of care from a matter of viral cascade to a matter of vital concern.

Assemblages of HIV care

We begin our analysis with two cases mapping HIV care as a dynamic of situated assemblages in which immigration features as one of the key actors. While the figure of the cascade of HIV care envisions health and care in a biomedical relationship shaped by a stepwise trajectory of clinical intervention, the care situated in practice in these cases is materialised in alternative ways.

Godfrey's situation

Godfrey is East African and 44 years old. He is living in the UK without legal documentation. He is one of the eleven people we interviewed who had experienced periods of disengagement from ART. Godfrey's account emphasises disease as something which is felt. Like many in our study, Godfrey came to know this feeling as HIV unexpectedly when seeking help for his unexplained sickness. There was nothing beyond the mundane in this: "I was sick. I just went there. Just like a normal thing, you go to hospital. I went with my partner. It was just a normal thing¢ Godfrey initiated ART upon his clinical diagnosis. His HIV care is accomplished through an unpredictable mix of heterogeneous elements.

Godfrey's care situation changed shortly afterwards, with him withdrawing from ART. Various elements make up the assemblage affecting his treatment disengagement. First, he feels well. Godfrey questions the biomedical evidence before him indicative of his illness: how can he be declared sick when he feels so well? His account positions health as contingent, as something affected in the space between what is felt, embodied on the inside and what is told, known by technologies on the outside. These oscillations between different ways of knowing move Godfrey to enact a subjectivity of denial in relation to his changing care trajectory away from ART:

> This is a thing in the blood. You can't see it. Not many people believe in things when we can't see them. Being told that you've got something in your blood which you can't see, and it's untreatable, you can't have treatment for it, then you're sort of like, 'hang on, it can't be me'… Some people are still believing, thinking 'No, no, no, no, I think the machine was wrong. I don't believe it's correct with the result. I don't think it's me'.

Second, ART makes Godfrey feel more ill than he felt without it: "I had one tablet which I was taking at that time which made me feel very weak and dizzy". The treatment materialised in practice is affected as a multiplicity of lived conditions: "They are saying it is working, but the way it is working is worsening my situation". Godfrey is moved to stop this apparent treatment: "I stopped the medicine. On no treatment, you are feeling much better than when you've than it. So, you say, 'Hang on, how am I continuing to take this thing?'".

But this mix of elements in the assemblage—clinical tests, medicines, treatment promises, embodied feelings—are not the only actors affecting translations in clinical care. There are other matters of concern, especially Godfrey's capacity to work. The actualised ill-effects of treatment affect Godfrey's capacity to work (and what this in turn affords to self and health though identity and income) disrupting his survival. Here, treatment blocks rather than affords. Only eight of the 29 participants in our study are in paid work. Most are desperate to work but are unable to do so given their uncertain immigration status. In this situation of financial precarity, Godfrey is not alone in deflecting treatment so as to sustain a capacity to work. Godfrey is moved to protect his vital concerns:

> It was the side-effects and my work pattern which was really affecting me. I didn't feel well to go to work, and I didn't want to stop going to work. So, I decided, 'Hang on, this thing is affecting me, I'm not going to take it tomorrow… don't feel well, I'm not taking this thing'.

There are additional reasons why Godfrey's situation is compelling as an illustration of how heterogeneous elements in an assemblage enact care as a practice with contingent effects. Godfrey works as a health professional at the same hospital where he was diagnosed and treated. He embodies partial connections with multiple knowledges in relation to HIV health as patient and expert. The flows of affect produced in the shifting bodily arrangements of his care assemblage at once incorporate, and are incorporated by, him. Godfrey thus instantiates the translations emerging from his care assemblage, for they flow through and from him. He affects, and is affected by, his care relations in ways that transform care from a device of clinical intervention (through ART) to a matter of everyday concern, extending care relations beyond the biomedical and technical. When assemblages of care change, subjectivities also alter (Duff 2014).

Treatment, health and care in Godfrey's situation are clearly not immutable but dynamic. This is accentuated by further movement enacted in the care assemblage which returns Godfrey to ART. A new becoming of felt sickness, following Godfrey's resistance to taking treatment, prompts a revisioning in his constitution of health. Multiple elements combine (Godfrey, clinicians, CD4 machines, blood tests, graphic imagery, felt sickness, discourses of moral responsibility), and Godfrey re-incorporates medical expertise as a means to care:

> I went back for another check-up. They said, 'your viral load is still increasing, are you sure you're taking our medicine?'. I said, 'To be quite honest I take it when I feel I need to take them. Sometimes I don't take them'… They showed me a graph, which shows the levels of CD4 count and

how the medication works. I quite understood it. And I said, 'I should be concentrating on this now because rather than get on the bad side of it, because otherwise I am cheating myself'.

Following the sequencing of care assemblages making up Godfrey's situation reveals how the relational shape of care transforms according to its particular moments of expression, and how these produce attachments which either maintain or change care subjectivities (Torronen and Tigerstedt 2018; Duff 2014). Godfrey's care relations move from potentiating clinical care attachments, to blocking and destabilising these, to once again affording their potential. In this latter version, Godfrey enacts a new, more biomedically infused, moral responsibility in relation to his adherence as a good patient. He revises his previous performances of health as 'mere representations': "You assume, you *say* you're fine, but you *are* not". His clinical care is re-incorporated as a vital concern of healthy subjectivity:

> They advised me that if you keep on forgetting your tablets or doing it purposely then it means you are doing yourself a *bad thing*… You've just *damaged yourself*… You would have damaged your system already… So, it's really *up to you* to think about it, but that's the way it is.

Lucas's situation

Lucas is West African, and 46 years old. He was diagnosed with HIV two years ago. A constellation of actors are at play in materialising his HIV care: friends, carers, landlords, work, language, stigma, disclosure, hospitals, treatments, community support. But an especially important figure is immigration. Lucas has outstayed his visitor's visa. His life in the UK is "tough" regarding access to work, basic needs and care. This is especially so given his fear of arrest linked to his illegal status:

> When we travel from Africa to here, you have so many siblings, your family, everybody, so it was tough. So, I was trying to make my way through it in a legal way… For about eight months to a year I wasn't able to eat well.
> Because of the immigration status it was very hard for me to go to the hospital… Going to the hospital was tough. […] I phoned one of my friends. I've known him for a long time, and he said you can go to the walk-in. But for me to go to the walk-in, I was scared because if I go to the walk-in and they start asking me… Because we're going to sit down and talk about this immigration.

Lucas felt his health deteriorating. He came back from work one day feeling very "dizzy", with his body very "weak". He had no doubt that "something was going on". His immediate response was to seek help from a friend—someone he had known from school-days back home. As he notes above, his friend advised him to seek help from a walk-in clinic, especially given his general practitioner (GP) being so far away from where he lived. But Lucas "was scared" given his illegal status. His friend takes care of the immediate situation, chaperoning him to his GP. His GP

sent him home, with Lucas feeling unable to communicate effectively just how ill he felt. Again, his friend acts as chaperone, bringing him home.

Like others in our study, Lucas's engagement in hospital care results from a crisis of illness. His sickness worsens and he collapses. His flat-mate calls an ambulance. Lucas's friend again offers support. Lucas is in a coma. This, alongside his broken English seriously limits what can be communicated in the absence of an interpreter being made available. Lucas does not know what is going on. His friend acts as interlocutor. His friend's intervention is critical to enabling Lucas' moment of care engagement, otherwise lost in translation. This extends to his friend translating the meaning of his diagnosis:

> I don't know what happened… He [doctor] mentioned my name but I couldn't hear… I couldn't talk… So, I was asking, using my hand, asking 'What happened?'. [My friend] told me what happened… He saw by the way I responded that I didn't understand what he [the doctor] was telling me… Things were very bad… Within two, three, weeks I changed. My face changed. My body changed. Everything changed. I became like this. […] My friend told me, that he saw that the way he [doctor] was talking to me, the thing, the word he was saying to me that I hadn't understood. So, he explained to me, and he says you are not, "positive" does not mean that it is good.

Following his diagnosis and crisis of illness, Lucas is referred to Hospital A for longer-term care. While there, in a stark illustration of enacted stigma, he is evicted by his landlord from his home:

> When I was in the house, the ambulance came, and it picked me up to the hospital. I was in the hospital and they transferred me to Hospital A… It's purposely for HIV people… I was in the Hospital A for four months. I was there, and the landlord told me that he doesn't want me in the house… because he was scared.

He comments on the phone call he received from his landlord while in hospital:

> I can't stand. I can't see. When I'm walking, I'm shaking. I can't do anything, and they phoned me at the hospital… He says, 'I don't want you, to see you, in the house again. Don't come back. I will take your things'. I said, 'Why are you taking my things? Even if you don't want me, let me come'. And he says, 'No, I don't want you to step here'.

Care opportunities for Lucas are narrowing. This is no simple access to a free-flowing cascade of HIV care. His access to resources—health, housing, citizenship, capacity to communicate and negotiate—are beyond reach. The assemblage in which Lucas' HIV care is enacted is rapidly losing capacities as relations and connections are foreclosed. Having lost his home, Lucas feels stripped of resources. He feels shamed, shunned by those he knows, who have come to suspect him of having this illness. His HIV is materialised by living social stigma:

> You come out [of hospital], and you don't have anybody… My life was very, very, very, very tough… They [friends] all ran away./I came out. I call

everyone. Their phones are off. One picked up the phone, and I say 'Hello, can you hear me, can you hear me?', I introduced myself and they cut the phone.

If I board a bus and I see a friend I know. He will say maybe 'Hi, hello', but the moment he sees me, the first or second stop, he will get off… He doesn't want to be associated with me… Either they think maybe you have AIDS or they think 'What happened to you? Your body has changed all of a sudden'… So, I even stopped taking the bus. I don't even have the money to take a bus, so I walk to the hospital.

Once again, it is friendship care which enables some protection for Lucas. A friend who he has helped in the past find work, and whose wife he happened to help regarding her migration to the UK, telephones:

I listened to the voicemail, and he says 'Where are you? I have been calling you for almost a month, I can't find you'… I phoned him… I told him I'm on the streets… I told him I lost where I was living… He said, 'I heard you were ill, and somebody told me you were in hospital, in err, err, Hospital A'. You see, 'Hospital A', because when they get to know it's Hospital A they know that it is HIV. I said, 'No, I wasn't in Hospital A, I was in Hospital B, but I'm out now'. He said, 'OK, come'… They opened the door… They saw a different body. They asked me 'What has happened?' I can't talk, I can't say… If I tell them, they will never let me in.

His friends offer him an open door, a place to stay. But the creation of this care relation is itself subject to social constraints. Lucas is careful to diffuse any associations of his hospital stay with 'Hospital A' for what this might reveal about the illness he has. His access to a temporary home depends upon it: "If I tell them, they will never let me in". What follows is an account of how Lucas protects his fragile access to friendship care through risk-managing any deductive disclosure of his HIV. His adherence to ART depends on it:

They wanted to know. When a call came [text reminder to take his ART], they wanted to know. I couldn't take my medication… I'm always hiding. And my friend is, 'Why are you here? Why are you in there? You're doing this, and you have to come and sit with us!'. I'm trying to disassociate myself a bit, and they don't understand… They want to help me to be like a family.//I have to try to hide it. I have to lie. I say, 'I have to take a walk'. I can't stay in the room all the time.

Lucas has to pretend. He pretends he takes long walks when in fact he leaves the house to take medicines or to make hospital appointments. He pretends his illness is something other than HIV. All these strategies serve to accommodate his fragile care relation. Importantly, this problem of managing deductive disclosure in relation to HIV treatment occasionally results in doses being delayed or missed: "I was having a problem and I can't take it, at times I used to forget".

In the assemblages in which Lucas finds himself, HIV care engagements are fundamentally precarious. It is a case of working-with, and muddling through, especially in light of how immigration and stigmas combine to affect the care Lucas

may potentially receive or participate in. The pockets of care enacted in the face of such fragility are affected by matters unnoticed in the figure of the clinical care cascade: temporary housing, friendship connections, chance meetings, phone calls. The presence of clinical modes of care in Lucas's trajectory derives its power of acting in relation to other elements of vital care concern in an assemblage. Of note is how attachments related to friendship are maintained, from one event to another, in ways that serve to actualise a care that matters and to moderate how care might otherwise be destabilised.

Social life as a matter of HIV care

We now turn to working across the interview accounts to trace the social life materialised through practices of HIV care, including through the possibilities of care that clinical HIV care affords. We show how HIV care makes up social life through delineating four forms of materialisation: care beyond the virus; care affording social relations; care affording open society and new sociality and making a social life in care. Of particular note is how HIV care becomes transformed, from a care bounded in relation to a virus to one grounded in practices beyond viral care.

Care beyond the virus

A striking feature of participants' accounts is how they enact a version of HIV care which extends beyond narrow biomedical concerns linked specifically to caring for oneself in relation to a virus. Care beyond the virus was something realised through engaging with community-based organisations, but was also a critical feature of the care practiced by HIV treatment clinics. The clinic-based care most valued by Lucas, for instance, was that linked to his immigration and everyday life concerns. And similarly, the care most vital for James was the support he received when adopting his sister's children after her death from HIV complications:

> He [clinician] asks me about my immigration status. If I ask him to write anything [letters of support], he will do it, because he saw me when I was in difficulties… When I go to the hospital he asks about my immigration, where I am living, he wants to know everything about me. [Lucas]

> I think that was the roughest time of my life here in UK. It was really rough. You know, lawyers, what happened, everything. When she passed away, the good thing is, I think probably I had good, good support. A lady who was working in [CBO A]. She was the one who really helped me through it, getting a lawyer, everything. [James]

Vital life concerns—such as those linked with immigration, housing, work, money, food and family—situate how care needs are materialised. Viral care becomes a *resource for making* vital care in relation to matters of immediate survival (Lucas above), at the same time enabling social protections in the face of disruptions (James above). The HIV clinics and community organisations referred to in

interviews enable a protected space where HIV can be made visible and known, which can contrast with efforts on the outside to hide or remove HIV from everyday interactions with others (see below).

The care beyond the virus that HIV care affords also serves to maintain engagements in biomedical HIV treatment. Abbas, for example, describes how his coming to terms with HIV was intimately bound up with his drug use. His intense drug use in the four-to-five years between his diagnosis and eventual re-engagement with HIV care was "big escapism". He was "using more and more and more, and running and running and running, but not getting anywhere". Like Godfrey earlier, a crisis of felt sickness prompted him to seek treatment. The care beyond the virus he experiences following this re-engagement affects a sense of recovery which is pivotal also to securing his biomedical care engagement. These turning points for Abbas are materialised through care practices which connect intimately to him and his vital matters of concern. This is a practice of care with a strong current of affective flow that directly mediated Abbas's capacities to produce HIV care relations. He describes of one such care moment at the community service offering him help to treat his drug use:

> There was one time when I spoke openly about it to my whole group of peers. I remember the build up to it. I was terrified. I was in bits crying, and I was shaking, and I just didn't want to do it. And once I'd done it, I was crying and shaking because I couldn't believe the way I was held. I was overwhelmed with, um, gratitude. I was really touched to be honest with you, to have a room of full grown up big men, hardened criminals so to speak, that were able to just accept me, understand me… That helped me move forwards… It was a turning point for me. [Abbas]

Care affording social relations

A critical feature of care beyond the virus is the social relations it enables. One striking instance is the constitution of HIV clinics as "home" in which HIV consultants and carers become "family" or "friends". In both clinics and community-based organisations, carers are transformed into personal connections through vital relationships, beyond mere figures of biomedical transaction. Anton, for instance, captures this sense of networks of affective care, which extend beyond the carers and consultants to other service users:

> You *feel* like at home. You *feel* it like a family. When you go there you *feel* you are at home, because you are associating with the people who are HIV like you. [Anton]

A sense of home is obviously unbounded by physical location, and here, constitutes a haven, a place of relative security and belonging. Being migrants to the UK, most were either a long way from "back home", had no more than temporary living arrangements or were living in situations which felt insecure in a context of risk-managing their everyday life with HIV (as with Lucas above). Although friendship

care was pivotal in times of crisis (as we have seen), the clinics—and community-based organisations—are also enacted as sources of friendship, and as familiar and trusted refuges. They are relatively stable spaces of social connection in lives otherwise (for many) characterised by the unfamiliar and unforgiving. Spaces of HIV care delivery in this way sustain important *practices of belonging*. Many first made contact with their clinics and consultants in a state of illness crisis, and this situates a particular materialisation of care engagement, fused with affect, a sense of gratitude and even dependency. The social connections afforded through HIV care engagement may become among the most profound, as well as stable and ongoing, that people who are experiencing uncertain immigration into the UK have. HIV consultants become friends, *for life*:

> The doctor, the nurses, they are my friends. Even the doctor who is looking after me at the moment, I told him, I will never ever go to any doctor unless you are around. I would never go to anyone else, because he knows me. He knows me. I know him. / He is my friend. I will never leave him, because he took care of me. Now he is a friend of mine. [Lucas]

While immigration is clearly a force in the situating of the HIV clinic as a space of belonging, it is important to note that HIV care also constitutes these effects for those for whom immigration is less vital. Thomas, for example, has known his consultant for over a decade. Born in the UK, his care is entangled less with immigration and more in relation to his diagnosis when very young and his "growing up with HIV". His consultant helps him make a pathway for life. Again, the clinic and the consultant potentiate a sense of belonging, biography and social protection. Indeed, Thomas's HIV consultant becomes "doctor of absolutely everything":

> She was like my mum. I saw her every month. I was her youngest patient at the time, and she was really good./Like she called me the first night I took my meds, and she called me like every day for a week just to make sure I was OK. She was much more than an HIV consultant. She was my doctor for absolutely everything. [Thomas]

Care beyond the virus thus orientates towards matters of vital concern with affective and material effects. Small things, such as support with food and small grants to pay the bills, are afforded high value, and these entangle with survival support through legal advice, access to medical and welfare expertise, social support and help with housing. But it is the sense of social connection—and the relations that sustain it—affected by such care that appears most vital. Emmanual suggests that what these places of care have afforded him is "social interaction". Care enabling a sense of social relation is generative, at once producing care, as James explains:

> They do help a lot. They do help financially, with advice. They help people with benefits, housing, a lot with filling forms, those kind of things… But to me, I find that, going there, it's almost like coming here like meeting a person, others who have been in worse situations than you. And if you're talking to

them they are able to give you their experience of what they have gone through, and you learn a lot from that. [James]

Care affording open society and new sociality

There are two prime effects of the experience of care as enabling of social relations. The first we are calling 'open society'. Spaces of HIV care—the clinics and community-based organisations—become safe havens for their enabling of openness. Unlike day-to-day life outside these spaces, HIV care spaces enable freedom, a release, from having to hide one's HIV status, from having to present the self in a particular (non-HIV) way. They potentiate a multiverse of enacted subjectivities and expressions of self. Care engagement enacts a more-open society, in contrast with that cast as closed:

> You even see patients taking their medication in front of others… They are comfortable because we are the same./You don't disclose, it's so difficult. But whenever you go to a group, which is for HIV people, you have no problem [disclosing] at all. [Anton]
> It's all very free down here. I'm very free, and I've come to realise that there are a lot of free people here. [James]

Importantly, this is a *more*-open society, for it is inseparable from its relation to the 'outside', with the space of HIV care made up through its incorporations with other spaces of HIV experience. Anton locates this sense of more-open society inside his particular assemblage of relations as a migrant from Africa. He says that "If we're African, we have to be a little bit careful". Earlier we noted how Lucas enacted his friendship care (and HIV disclosures) within certain limits. These are the 'generous constraints' of HIV care (Gomart 2002). Such pockets of care beyond the virus are not without their situated rationing. Anton emphasises pervasive HIV stigma as an everyday material effect of 'African life': "That's African life, no two ways about it, that's the way *we are*". This enactment of Africa-stigma as if it is a stable and easily identifiable object speaks to the perceived limits of hope for change. In Anton's envisioning, HIV care spaces potentiate openness, including in HIV disclosures, *except* with other African people, for here they entangle with the outside: "If he's African? No, no, no! He asks me [if I am HIV], and I say 'No!'. Don't say it [HIV], just go!".

Second, the social connections afforded by care—in this case, an effect of community-based organisations—enables what we can describe as a 'new sociality'. HIV care spaces make up connections between people that they otherwise could not make, and in affective and communicative forms that otherwise might not be possible. This new sociality is forged (as with Lucas above) through the sharing of experience and care, linked indirectly to, and extending beyond, HIV, and thus not limited to a 'biosociality' of HIV positive status and linked stigma (Rabinow 1996). This is an affective flow of care beyond the virus. James, for example, makes connections through his time spent at the community-based organisation which

evolve into a sense of sociality which feels altogether different to that generated by his presence in other assemblages:

> It's an opportunity to meet new people. You are meeting people, making new friends and everything. It's good… And when we go down the pub, there's a pub in Xxxxx. We are sitting down, watch football, talk just openly, even at times distributing leaflets there with condoms and everything./We just used to meet down there and everything, talk, because they have a computer there, games. Yeah, used to go down there, and then we started 'Why don't we just move it to, extend a little bit more?'. Now what I understand is it's much easier talking in a pub than talking like to a party of people of my community. [James]

Making a social life in care

The transformative effects of HIV care in making social life become explicit in their organisation of daily life. It was common for people to organise their day-to-day lives around their scheduling of care interventions. This care giving and receiving was enacted by some as a form of "work", a "job" to be done, with a "schedule". It opens up a biography and sense of career trajectories made through care. For Simon, care engagement was a "full-time job". For others too:

> Tuesday I go to [CBO A]. Then Wednesday I go to [CBO B]. So Thursday I can go to [CBO C]. Friday I go to [CBO C] as well, for the men's group. Saturday I go to [CBO 4]. Busy week. It keeps you active. [Anton]

> [CBO 1] I had the outings. [CBO 2] I go to have lunch, therapies. I have [CBO 3]. They used to do it at the [CBO 4] until last year… I like lunch there on a Thursday… I go to a place called [CBO 5]. We've got a choir there… [CBO 2] for lunch and a bit of chit chat, I'm part of the furniture there… Except for the weekends [when I] might try and chill out, re-charge my batteries. [Peter]

Few of the study participants are in paid work (see above). The absence of paid work, and the 'free time' this affords, is enabling of care engagement as a force for socially organising life. Those in regular paid work tended to hone their engagement around the receipt of clinical and biomedical care. Enacting care beyond the virus as a practice of work and doing appears contingent upon the time–space available in the absence of paid work. For instance, we noted earlier how Godfrey valued his capacity to work, with his (dis)engagement from ART affected by this. He emphasises his stopping of ART as a way to continue working given the debilitating side-effects his treatment was generating. He interrupted his HIV treatment until such time as his health deteriorated rapidly, leading him to seek help in crisis. After having re-engaged with HIV treatment, he separated from his wife, a relationship which enabled him legal status in the UK. In consequence, his immigration status changed, with his entitlement to work ending. No longer able to work, Godfrey was unable to maintain the costs of his housing. He became homeless. His HIV care

engagement became a primary everyday focus, affording a safety net. His expanding care engagements evolved into a life of care. He looks to make a future career in care:

> I haven't got a job. I haven't got anything to do, I'm just here myself. I wasn't going [to CBOs] because I was working at the time. So, when I stopped, I had more time now to come to the group... I have got more time, plenty of time to do these things... Actually, I'm thinking of forging ahead with a career in the HIV area. [Godfrey]

Discussion

We have understood the social life of HIV care as an effect of assemblages of social, affective and material relations. This has enabled us to trace how care is incorporated in practice. One key actor in the care assemblages described here is immigration, which shapes how HIV care is worked-with. We find that the multiverse of HIV care moves from accommodated versions of biomedicine to re-assembling clinical care as more-than biomedical. This produces modes of *care beyond the virus*. We note how clinical HIV care engagements afford alternative forms of care which extend beyond the virus to potentiate care as a matter of everyday life concern. Whereas the cascade of HIV care narrows attention on viral clinical control, separated from its situated incorporations and extensions, care beyond the virus accentuates the social life of care afforded through its networks of social relations.

Translations and transformations

Understanding care as a matter of shifting assemblages and material practices leads us to consider care-making as works of translation and transformation. We have mapped how HIV care is affected in its becoming multiple. This becoming is characterised by the translation of vital matters of concern which transform 'care of the virus' into 'care beyond the virus'. In the moment of its making, care is *working-with* biomedically infused versions of viral care as well as *working-from*, and beyond, constituting care as more-than biomedical, as an altogether *different thing*.

The case situations of Lucas and Godfrey proffered examples of this translation of care practices. In the case of Lucas, social conditions shaped his various clinical interactions regarding diagnosis and treatment, performing practices of translated biomedicine. A key feature of Lucas' care assemblage was immigration, which in combination with social stigmas and other elements, limited his agency to engage with clinical forms of care. At the same time, the care that matters in Lucas's situation derives its power of acting from friendship attachments, which despite their weak ties, maintain their presence through shifting care assemblages that hold together a care in practice. The care produced in Lucas's assemblage is a practice of working-with and working-from biomedical care.

The case situation of Godfrey also accentuates HIV care as a practice in motion, situated in relation to matters of vital concern. After an initial encounter with a biomedically infused mode of HIV health, in which clinical diagnosis and ART both feature, various elements in this assemblage combine to block clinical care, potentiating a subjectivity of treatment resistance and an alternative care beyond the virus. Events then shift again producing new assemblage relations which re-incorporate clinical care through a return to ART, re-enacting a mode of 'healthy' subjectivity in relation to patient responsibility linked to treatment adherence. A 'singular–multiple' (Law 2004) of HIV health is performed here, with Godfrey enacting diffracted versions of health and care contingent on his situation. A capacity to work to survive, for instance, emerges as a vital matter of concern in his assemblage of health, particularly when deflecting clinical care opportunities. Once deflected, clinical treatment is relegated to the edges of how Godfrey constitutes his health. All the while it is deflected, clinical care is performed as an absence to care, as a relative harm, rather than worked-from into a practice of care. In other words, clinical care is not resourced as a 'thing' within Godfrey's care assemblage until felt sickness (among other things) redefines Godfrey's sense of need for treatment. Godfrey's situation moves between multiple performances and object transformations in HIV health (for instance, health as a matter of virus or not) and in HIV care (for instance, care as a matter of clinical treatment or not).

The case studies of Lucas and Godfrey perform care as an effect of shifting interactions between heterogeneous elements in an assemblage of care. By exploring the various translations and transformations which make up different forms of care from one assemblage to another, we can appreciate how different subjectivities of care are produced (Duff 2014). Importantly, this noticing of the care that is materialised in practice invites concomitant appreciation of the alternative and diffracted practices of HIV care that are produced in social life beyond those of a clinical care cascade. Shifting our focus from care as a matter of viral clinical cascade to a matter of vital everyday concern generates a different way of knowing care that may also potentiate a more caring way of doing (Puig de la Bellacasa 2012).

In the field of science and technology studies, translation is used as a metaphor of communication and travel, of making connections, between two different things. It is at once an invention, or transformation, brought about by the making-up of connections *and* a movement in apparent convergence which delimits previous object differences (Callon 1984). And thus, translations make up objects, such as different forms of HIV care, as singular–multiples (Law 2004). HIV care, in its incorporation of multiple modes or practices of care—from the viral to the vital— expands care practices beyond those delimited by a virtual biomedical singularity. HIV care is thus a coordinating mechanism for holding together a multiverse of worked-with and altered cares in practice. This coordination is crucial for it enables clinics and carers to maintain the *necessary* (biomedical treatments and clinical care) while producing *more* (care beyond the virus) in the name of the *same*, and despite the apparent staying power of a biomedically infused care cascade. Yet reifying HIV care and its cascade *as if* singular and stable maintains a sense of viral control through the promise of technical intervention. It generates simplification in

an otherwise messy, complex and precarious world of living with HIV in a context of immigration and social marginalisation.

Conclusions: care beyond the virus as the care that matters

Care beyond the virus concentrates caring on immediate vital matters of concern, which for our participants linked to everyday survival in relation to immigration problems, housing, work, money, food, family and for some, drug addiction. HIV care is enacted in a way that is *made to matter*, through its movement from *care of the viral to care of the vital*. A care-in-the-making deflects attention from the 'fact' of what care *is* to a 'concern' for what care is enabled to *do* (Latour 2004). Thinking with care as a matter of concern thus speculates on how things could be different (Puig de la Bellacasa 2011, p. 100).

While we are hesitant to draw out conclusive patterns given the idiosyncrasies of the care assemblages described above, we find clinics, community-based organisations and friendship to be among the key forces affording care beyond the virus. Here, HIV care is transformed from a biomedical order of governance to a practice of vital care that far exceeds the virus to encompass social relationships that express new modes of sociality, and new ways of living beyond the virus. The HIV clinic enacted as a home and space of belonging, made up of affective relations with carers constituted as family and friends, is a prime instance of this new mode of sociality and the vital care it expresses. This mode affords a practice of care beyond the virus specifically attuned to a condition of travel linked to participants' experiences of immigration and the insecurity, uncertainty and disruption this produces. Similarly, community-based organisations emerge as key actors in the enabling of caring spaces that cushion some of the experience of stigma and social exclusion experienced outside the assemblages of care described here, while affording new links to communities 'back home'. Critically, the space of community-based organisations afforded a sense of new sociality giving rise to expressions of new modes of friendship care. We note friendship care as a particularly vital effect in the assemblage of care beyond the virus, enacting a safety net in precarious life conditions (Mills 2017). We thus find that HIV care interventions perform care beyond the virus when they afford spaces of engagement which are "off the map" and "unbounded", in this case by biomedical care (Deleuze and Guattari 1987; Andrews et al. 2014). We conclude that HIV care enacted as care beyond the virus is doing much more than accommodating or translating biomedical care in relation to matters of vital concern since it is *producing* social life itself (Appadurai 1986). This becomes explicit when the doing of everyday life is consciously made-up around HIV care opportunities which afford care beyond the virus.

Being attuned to how HIV care is made to matter in relation to vital concerns has practical as well as ethical implications for it invites reflection on how particular versions of care come to matter and how particular assemblages of care are more 'response-able' than others (Barad 2003). Our noticing of how particular assemblages enable a capacity for care beyond the virus emphasises fundamentally the power of acting linked to social practices of care (Deleuze and Guattari 1987).

This seems to us to be especially apposite given current shifts in the organisation of HIV care in the UK, which perform a rationing of social care provision (National AIDS Trust 2017; Baylis et al. 2017). Because the social care experienced in the assemblages of health described here extends beyond the virus to matters of concern, the risk of their being removed in either organisational or social practice is feared by both care receivers and providers (National AIDS Trust 2017). The rationing of care beyond the virus risks further medicalising care as a matter of viral cascade, undoing the social, affective and material care relations, which are most vital to people living with HIV. Undoing care beyond the virus also risks disabling how social care supports biomedical care. As we have seen, care beyond the virus is at once a more-than biomedical care that *also* secures biomedical care engagement. This tells us of the importance of protecting what expresses and materialises the care that matters through investments in social care provisions, including through clinic and community-based networks and through self-help and social network interventions.

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Compliance with ethical standards

Conflict of interest All authors have no declarations or conflicts of interest.

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