THE UNIVERSITY of EDINBURGH

Edinburgh Research Explorer

The stories we tell: qualitative research interviews, talking technologies and the 'normalisation' of life with HIV

Publisher Rights Statement:
NOTICE: this is the author's version of a work that was accepted for publication in Social Science and Medicine. Changes resulting from the publishing process, such as peer review, editing, corrections, structural formatting, and other quality control mechanisms may not be reflected in this document. Changes may have been made to this work since it was submitted for publication. A definitive version was subsequently published in Social Science and Medicine, 131, April 2015. 10.1016/j.socscimed.2015.02.041

General rights
Copyright for the publications made accessible via the Edinburgh Research Explorer is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy
The University of Edinburgh has made every reasonable effort to ensure that Edinburgh Research Explorer content complies with UK legislation. If you believe that the public display of this file breaches copyright please contact openaccess@ed.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.

OPEN ACCESS

The stories we tell: qualitative research interviews, talking technologies and the 'normalisation' of life with HIV

Abstract:

Since the earliest days of the HIV/AIDS epidemic, talking about the virus has been a key way affected communities have challenged the fear and discrimination directed against them and pressed for urgent medical and political attention. Today, HIV/AIDS is one of the most prolifically and intimately documented of all health conditions, with entrenched infrastructures, practices and technologies – what Vinh-Kim Nguyen has dubbed 'confessional technologies' – aimed at encouraging those affected to share their experiences. Among these technologies, we argue, is the semi-structured interview: the principal methodology used in qualitative social science research focused on patient experiences. Taking the performative nature of the research interview as a talking technology seriously has epistemological implications not merely for how we interpret interview data, but also for how we understand the role of research interviews in the enactment of 'life with HIV'. This paper focuses on one crucial aspect of this enactment: the contemporary 'normalisation' of HIV as 'just another' chronic condition – a process taking place at the level of individual subjectivities, social identities, clinical practices and global health policy, and of which social science research is a vital part. Through an analysis of 76 interviews conducted in London (2009-10), we examine tensions in the experiential narratives of individuals living with HIV in which life with the virus is framed as 'normal', yet where this 'normality' is beset with contradictions and ambiguities. Rather than viewing these as a reflection of resistances to or failures of the enactment of HIV as 'normal', we argue that, insofar as these contradictions are generated by the research interview as a distinct 'talking technology', they emerge as crucial to the normative (re)production of what counts as 'living with HIV' (in the UK) and are an inherent part of the broader performative 'normalisation' of the virus.

Key words: United Kingdom; HIV; Qualitative Interviews; Illness Narratives; Normalisation; Confessional Technologies.

1. Introduction

Bolstered by the success of antiretroviral drugs (ARV), HIV has slowly been reframed in global health policy as a 'manageable' condition (McGrath et al., 2014). In a bid to boost the uptake of ARVs and counteract the enduring stigma faced by those affected by the virus, healthcare practitioners, activists and patient groups have been largely supportive of the discursive 'normalisation' of HIV as 'a disease like any other' (Moyer & Hardon, 2014: p.263). More recently, however, social science research has shown that numerous issues undermine the ability of people living with HIV to actualise this 'normalcy', including: socio-economic hardship, treatment side-effects, stigma and discrimination, concerns about infectivity and criminalisation (see *Medical Anthropology*, 2014, 33(4)). This is the case not only in countries where access to treatment is scarce (Rhodes et al., 2009; Mattes, 2014; O'Daniel, 2014), but also where it is widely available (Squire, 2010; Mazanderani, 2012; Persson, 2013).

Here, we contribute to the growing body of research on the putative normalisation of HIV in two key ways. First, drawing on 76 semi-structured qualitative interviews conducted in London during 2009-10, we explore underlying tensions in people's experiential accounts of living with HIV in which the virus is simultaneously framed as *both* 'normal' *and* 'exceptional'. Second, drawing on Vinh-Kim Nguyen's work on 'confessional technologies' (Nguyen, 2010; 2013), we foreground the relationship between research interviews, wider storytelling practices in the field of HIV, and the discursive normalisation of life with the virus. More specifically, we argue that while the findings of semi-structured interviews are often used by social scientists to challenge the enactment of HIV as 'just another' chronic condition, these same interviews form part of the on-going reproduction of the very normalisation they critique. Building on this, we critically reflect on the influence that extant

practices of storytelling have on social science research and, *vice versa*, how the stories we as researchers are told and, in turn, retell in our presentations and publications, can inadvertently reinforce what comes to count as 'living with' HIV.

The paper is based on two projects conducted in the UK in 2009 and 2010. Project A, carried out by author two, focused on multiple forms of discrimination in the lives of people with HIV in the UK. Project B, carried out by author one, investigated how HIV positive women originally from sub-Saharan Africa, but based in the UK at the time, use the internet in relation to their health. Each project had different substantive foci and associated methods, but both relied heavily on one-off, semi-structured interviews with people living with HIV (35 from Project A and 41 from Project B).

While conducting these separate projects we discussed our emergent findings on a number of occasions. Our interest was raised by the unexpected similarities we found *within* and *between* the two separate datasets we were working with. Although the specific contents of the interviews differed, many of the accounts participants gave of their experiences of living with HIV converged around particular themes (including ones we never sought to elicit) and drew on similar narrative styles, imagery, metaphors and analogies. Significantly, neither project had an initial focus on the 'normalisation' of HIV; nonetheless it emerged as a core theme in both. Furthermore, even the atypical narratives we identified echoed each other, with participants speaking in similar ways when contrasting their individual 'lived experiences' to what they presented as a 'normal' life with HIV. Thus, even the more idiosyncratic voices in our datasets coalesced into collective, albeit peripheral, narratives.

When we compared our respective 'top line' findings to published material on living with HIV in the UK, we found that many of the commonalities we had noted in our interviews, including the overarching emphasis on normalisation, were replicated in medical and social information about HIV available on websites, in community groups, magazines, the 'grey' literature produced by agencies and charities and, importantly, extant UK academic publications (e.g. Squire, 2010; Flowers, 2010; Terrence Higgins Trust, 2011). Since most research on people's experiences of HIV in the UK is based on a relatively small population, accessing a handful of health and community services, often in the same locations (mostly London and other large urban centres), these commonalities are perhaps not surprising. Still, the degree of coherence in the way 'life with HIV' was narrated across our two studies was remarkable in light of the many differences in participants' backgrounds, including gender, ethnicity, socio-economic status, nationality, sexuality and how long they had been living with HIV.

Prompted by these similarities, we looked more closely at the style and content of the experiential narratives in our studies. We began to question the interview process itself – and our role in it – as the context for the production, not just the collection, of such narratives. How could we account for some of the near-identical 'stories' in our respective fieldwork? To what extent were the accounts we were recording informed by and contributing to broader discourses of contemporary HIV, especially, given its prominence in our interviews, the normalisation of the virus? What was the relationship between the semi-structured interviews we conducted and other ways of 'telling HIV', such as the practices of sharing personal stories in community support groups so often mentioned by our interviewees?

This paper is the result of our attempts to answer these questions. Below, we provide an overview of the role played by talking technologies in the history of HIV/AIDS activism,

treatment and care – a field that is itself constantly being (re)constituted through the sharing of personal experiences. Next, we outline our specific case studies and methods. In section four, we discuss the different ways wider discourses on the normalisation of HIV permeated the experiential accounts of living with HIV we recorded. In section five, we examine the tensions and contradictions haunting these discursive enactments of life with HIV as 'normal'. Finally, we bring the findings of the two previous sections together, treating the research interview not as a reflection of people's ability or lack thereof to enact life with HIV as 'normal', but as forming part of its wider discursive normalisation.

2. 'Silence=death': talking technologies in a changing pandemic

Since the syndrome that became classified as AIDS was first recorded amongst primarily gay men in the USA and Western Europe in the early 1980s, HIV/AIDS has been, simultaneously, an epidemic of a 'transmissible lethal disease' and one of 'signification' (Treichler, 1987, p. 32). As such, the 'war on AIDS' has never been waged solely against a viral pathogen – it has been a fight over the multiple meanings attached to it. Exemplified by the AIDS Coalition to Unleash Power (ACT-UP) slogan 'silence=death', one of the key ways early AIDS activists intervened in this 'epidemic of signification', in order to challenge the fear and discrimination leveraged against them, was through getting people affected by the virus to *talk* about their experiences (Epstein, 1996). Building on pre-existing gay community networks, activist groups developed a complex assemblage of practices and technologies, such as anonymous phone lines and support groups, designed to actively encourage people to share their experiences (Nguyen, 2010).

People had, of course, talked about their experiences of illness long before the arrival of AIDS, but never before on such a large or politicised scale. During the 1980s-90s the sheer quantity of people writing and speaking about HIV/AIDS outstripped that of any other disease (Jurecic, 2012, p. 2), and played a central role in shaping the biomedical and public health response to the epidemic (Berridge, 1996; Epstein, 1996). As the epicentre of the epidemic shifted from 'key risk groups' in North America and Western Europe to a generalised pandemic across the African continent and beyond, an emphasis on talking became institutionalised as part of the global 'fight' against AIDS (Nguyen, 2010, pp. 24-30).

Today, a belief in the transformative power of talking, of sharing 'your' story, remains at the heart of HIV activism, treatment and care; yet the contexts in which these stories are

produced have changed radically. Unsurprisingly, the talking technologies developed by gay community activists in relatively liberal Western democracies in the 1980s have had variable, often unintended, consequences when deployed in different environments in the context of global inequalities. However, despite their ubiquity, work that critically examines *talking*, as opposed to *bio*, technologies remains rare.

Nguyen's ethnographic research in Burkina Faso and Côte d'Ivoire is an exception to this (Nguyen, 2010; 2013). Drawing on Foucault's notion of 'technologies of the self' (Foucault, 1998), Nguyen has conceptualised the practices he focuses on – namely peer-support, counselling, participatory research, and public testimonials – as 'confessional technologies' (Nguyen, 2010; 2013). As confessional technologies, these ways of talking about living with HIV do not simply represent a pre-existing self, but rather turn the self into a 'substance' that can be worked on, thereby creating new selves and subjectivities (Nguyen, 2010; p.8). This resonates with Arthur Frank's, also Foucault-inspired, conceptualisation of illness narratives as 'care of the self' (Frank, 1998). Both Frank and Nguyen argue that illness narratives (in the case of Frank) and confessional technologies (in the case of Nguyen) are *performative* of the very subject(s) they claim to provide unmediated access to.

What makes Nguyen's work particularly notable is that he not only highlights how sharing experiences contributes to the creation of new forms of self and selfhood – something now widely acknowledged in medical sociology and anthropology – but draws attention to how, in the context of the politically unstable and economically poor West African countries where he conducted his research, sharing your story in the 'right' way with the 'right' people became a means of gaining access to the scarce life-saving anti-retroviral treatments distributed by international aid agencies – literally a form of triage into therapy (Nguyen, 2010). Thus,

paradoxically, techniques premised on human rights and aimed at empowering people living with HIV enacted new forms of differentiation in which talking about yourself became a matter of life and death (Nguyen, 2010; p.9).

Nguyen is not alone in adopting a performative approach to knowledge practices in relation to HIV (see Rosengarten, 2010). But, as the 'confessional' talking technologies he focuses on are so closely aligned and, in some cases, directly overlap with the methods used in social science research, his work is especially relevant here. It prompts epistemological and ethical questions about the use of interviews as a means of accessing people's experiences of 'living with' HIV, and moreover, connects social science methods to wider practices of experiential storytelling in the field of HIV activism, treatment and care.

Taking Nguyen's work as a starting point, this paper explores the relationship between semi-structured research interviews and the contemporary 'normalisation' of HIV in the UK – a country with one of the most established and effective HIV treatment and care programmes in the world. Rather than simply applying Nguyen's take on 'confessional technologies' to a different socio-economic context, we draw on his understanding of the performative aspects of talking about HIV to analyse the discursive effects of the research interview on the normalisation of HIV.

3. Research context and methods

There are approximately 100,000 people living with HIV in the UK, of which just over 20% are unaware of their status. Of those estimated to be living with HIV, around 40% are men who have sex with men, and 32% are African-born heterosexual men and women (Aghaizu et al, 2013). Since 1996, Antiretroviral Therapy (ART) has been freely and universally available through the UK's National Health Service (NHS), with the majority of those diagnosed receiving treatment and care at specialist public sector centres (hereafter 'clinics'). However, even within a functioning healthcare system with free HIV care, those directly affected by the virus continue to experience HIV in radically different ways. Gender, age, sexuality, ethnicity, socio-economic and migration status not only structure the social aspects of HIV in uneven ways (Dodds et al, 2004; Ibrahim et al, 2008; Doyal, 2009), but affect health outcomes, particularly in relation to rates of late-diagnosed and undiagnosed HIV, which are significantly higher amongst African men and in people over 50 (Aghaizu et al, 2013).

Project A

Project A was concerned with what remains unknown about the experiences of different people living with HIV in the UK, including those who do not fall into the two most-at-risk populations – Africans and men who have sex with men. These gaps in our knowledge are related, in part, to the tendency to categorise people living with HIV in research studies into discrete groups, based on the standardised procedures of epidemiological classification.

Qualitative research about the experiences of discrimination amongst a mixed group of people living with HIV in the UK was carried out to assess whether a different methodological approach to the operationalisation of social categories could elicit new and/or different findings about HIV discrimination in the UK. The study adopted five social

categories identified from a critical review of available literature on living with HIV as especially relevant to the analysis of this topic: sex/gender, race/ethnicity, class, citizenship and sexuality.

Between December 2009 and December 2010, a total of 35 people were interviewed, each in a single session of one to two hours. After relevant ethics approval was obtained (South West London Research Ethics Committee 10/H0806/57), the majority of participants (23) were recruited through three different voluntary organisations for people living with HIV, and a further 12 participants were recruited amongst patients attending an NHS HIV clinic in North East London. All participants consented (in writing) to take part in the interview. Most of the interviews were audio recorded and transcribed verbatim, whilst notes were taken for participants who preferred not to use the recorder. Based on a multi-levelled (individual, interpersonal and structural) approach to discrimination (Krieger, 1999; Campbell et al, 2007), interview questions were asked about reported episodes of discrimination, perceptions of discrimination, perceptions of peers' experiences and the impact of discrimination on feelings of self.

Project B

Project B explored how women originally from sub-Saharan Africa but living in London used the internet in relation to their health. The project studied internet use as part of 'everyday' life with HIV, focusing on its relationship to wider healthcare practices and information sources. A mixed-methods approach was used, combining qualitative interviews with 41 women from 13 different sub-Saharan countries; six interviews with people working in the provision of information and support to people affected by HIV; and two focus groups held at community organisations. Additionally, a content analysis was undertaken of relevant

websites (blogs, charitable organisation websites, and online services or platforms mentioned by interviewees) and documents (patient information booklets, magazines, policy documents).

Research participants were recruited primarily from three clinics in East London (One of the sites coincided with that used by Project A. We have taken this into consideration in the analysis.) Information sheets were provided to clinic attendees and potential participants were given information about the project by a physician, a nurse or the researcher. Interviews took place mainly in a clinic room, or in a few cases in interviewees' homes. Interviews lasted on average one hour, were audio recorded and transcribed verbatim unless participants expressed concerns over privacy, in which case simultaneous notes were taken. Ethical approval was provided by the Outer North East London Ethics Committee (08/H0701/75). Interviews were semi-structured with questions focused on how interviewees used the internet in relation to their health. This emphasis on internet use was contextualised in relation to broader experiences of living with HIV.

Combined analysis

In 2014, we analysed the similarities we had noted between our interviews in more depth. First, we each revisited our data, focusing on how interviewees articulated experiences and perceptions of HIV. Then, over a series of meetings, we jointly reviewed our respective findings, drawing out themes common to both data sets. We situated this process in relation to the broader body of literature about living with HIV in the UK.

We found that the commonalities we had noted in interviewees' descriptions about living with HIV tended to cohere around three broad themes: normalisation, biomedicalisation, and

discrimination. Moreover, we confirmed the prevalence of what we refer to as the 'normalisation narrative', in which interviewees contrasted what HIV *had been* in the early days of the epidemic to what *it was now*, stressing that with access to appropriate treatment it was possible to live a 'normal' life with HIV in the UK. There were, however, a few striking cases where interviewees challenged this. Furthermore, when we combined our analyses, a number of re-occurring contradictions within the prevailing narrative enactment of 'life with' HIV as 'normal' became apparent. This prompted us to reflect on the peculiar combination of adherence *and* resistance in the broader discursive normalisation of HIV evident in our interviews.

4. 'Better than suffering from cancer': the 'normalisation' of HIV in experiential accounts of living with the virus

In our interviews, the 'normalisation' of HIV emerged as a two-fold process. On the one hand, individuals spoke of adjusting to the trauma and disruption of an often unexpected diagnosis, and, with the passage of time, integrating HIV into their life. This required numerous cognitive, emotional and practical adjustments, such as learning to adhere to complex biomedical regimens, taking responsibility for their health, and progressively finding ways to live without being dominated by their condition. At the same time, HIV was presented as a condition that was being normalised at a wider societal level, which, if successfully 'managed', had a minimum impact on people's ability to engage in those activities that define 'normality' (e.g. having work, stable relationships, and children).

The trajectories towards 'normality' that interviewees spoke of were crucially premised on the availability and success of ART. The biomedical underpinning of the normalisation of life with HIV was evident in multiple ways, including: detailed descriptions of participants'

health in clinical terms, frequent references to the biomarkers of CD4 count and viral load, pharmaceutical drugs and treatment regimens. This is exemplified in the quotation below:

> *Living with HIV for me is about how I manage the disease, how I make it work for me. In a lot of ways [living with HIV] is about knowing what your counts are all the time and understanding what those counts are, and also doing that you're doing nothing to pass it on and making sure you take your tablets every day, it's all part of managing it. It is always there but I think if you manage it well, you're on top of it...* [Project A; a gay British man]

Thus, biomedical practices and clinical rationalities were positioned as key enablers for a 'normal' life with HIV, often juxtaposed against previous bouts of serious illness:

> In project A, a heterosexual man from Ghana described the period around his initial diagnosis by saying: '*Because the doctors at that time think I have it* [HIV] *long time, it had developed in me like losing my memory, that's why they found out in hospital. My CD4 count was less than 20, I almost died.*'

> In project B, a heterosexual woman from South Africa described her experiences of diagnosis in a similar way: '*I was in the hospital for about 5 months because I had... my nerves stopped working so half of my side was paralysed. And I think my CD 4 count was something like 24, something like that. It was very low because I couldn't speak. I had paralysis so I couldn't speak.*'

While the challenges of adhering to medication were mentioned (particularly the 'pill burden' and side-effects), the general tone was optimistic, with interviewees pointing out that, although not perfect, the medication had improved radically over time:

In project A, after speaking about a traumatic year of self-destruction post diagnosis a heterosexual man from Nigeria said: *'I started my medication a year later…and ever since nothing has ever gone wrong.'*

In project B, a heterosexual woman from Uganda said: *'At the moment my health is good. I don't worry too much. In 1996 I was on fifteen pills and I am now on one.'*

Examples such as these not only permeated our datasets, but shared striking similarities with accounts from radically different contexts. For example, in a paper on the normalisation of HIV in north-eastern Tanzania, Dominick Mattes (2014) provides the following quotation from an interview with a woman living with HIV:

These medicines have really helped me. And they keep helping me because I have strength, I can do my work: Today I got up, I washed all my clothes! It's not like back when I was sick all the time and I could not even wash up. [The medicines] give me strength, I feel like they help me very much. (Mattes, 2014, p.277)

In addition to drawing on their own experiences to illustrate the normalisation of HIV, interviewees referenced wider discourses of normalisation (primarily provided by clinicians, activists and community members). One of the most common examples of this was when HIV was compared to other serious health conditions, such as diabetes (a comparison frequently used in medical consultations and information leaflets) and cancer:

Doctor [name] used to say to me it's not about the HIV, anything can happen, people die from car accidents, people die from cancer, you could live for another 20, 30, 40 years with HIV, you know. It is even better than those suffering from cancer. And that got me thinking because

I have an aunty who had cancer and she suffered terribly before she passed. I thought well you know mine is not the worst of case. [Project B; a heterosexual woman from Nigeria]

Beyond its biomedical underpinnings, a shift from 'dying from' to 'living with' HIV was articulated in psychological and ethical terms that resonated strongly with wider discourses of 'positive' living (Levy and Storeng, 2007; Watkins-Hayes et al., 2012). Frequent references were made to eating healthily, exercising, avoiding drugs and alcohol, and, importantly, learning to cope with stressful situations and developing a positive attitude. The language used to express this attitude, and the ways it was conjured up and maintained, varied, often along the lines of therapeutic self-analysis (mostly for gay men) or faith and prayer (mostly for African participants) – but the overall message was fairly homogeneous. Of course, individual journeys to positive living (facilitated by church communities or support groups, counsellors or pastors, self-help techniques or prayer) and challenges towards such acceptance ('lifestyle' issues, problematic substance use, discrimination, poverty) were different. But a positive outlook was deemed absolutely crucial to adjusting to and, eventually, integrating HIV into one's life:

In project A, as a British Caribbean heterosexual woman explained: '*I can't be wasting my energy on negative crap…I used to react to everything, I was volatile, paranoid and I never took anything from anybody but I turn the other cheek a lot now. HIV does not define who I am but makes me want to think a lot about how I live my life.*'

In project B, a heterosexual woman from Zimbabwe described how through reading the information she received from healthcare professionals she realised that: '*[I]f you took the medication then you can stay healthy as long as you live positively, and you live a healthy life,*

you eat healthily and you look after yourself well, then you will be fine and I've experienced

that for the past six years.'

While interviewees did speak about considerable suffering, trauma and loss, for the most part their accounts of living with HIV (at least in the UK) were suffixed with a final message of triumph over adversity. However, as discussed in the next section, despite its prevalence, this framing of HIV as 'normal' was fraught with contradictions and tensions. Moreover, paradoxically, this was evident even within those interviews that, for the most part, endorsed an overarching narrative of normalisation.

5. 'HIV is no barrel of laughs': the tensions, challenges and contradictions of living a 'normal' life with HIV

There are, understandably, disconnects and tensions between people's narratives of living a 'normal' life with HIV and what actually happens in individual circumstances as HIV affects emotional, physiological, material, sexual, psychological and political lives in uneven ways (Doyal, 2013). These disconnects were evident in our interviews. Often in the same breath as emphasising that HIV was a manageable condition, interviewees spoke of the difficulties of adhering to medication, multiple co-morbidities, complex side-effects and on-going health problems. For example:

> In project A, a heterosexual man from Spain described how he feels some mornings: *'I wake up and I feel like an old man and I tell myself "you need to eat, you need food" because sometimes I can't do anything, sometimes for two or three days I'm in a crisis...'*

> In project B, a heterosexual woman from Zimbabwe talked about depression as a side-effect of her medication: *'Because the medications, one of then, it was Sustiva I think that was causing the depression. Because it causes depression, it causes nightmares; it causes a lot of things.'*

In addition to health complications, immigration issues, financial concerns, unemployment, precarious living conditions, and anxieties about providing for dependents, posed major challenges to living a 'normal' life with HIV – both in our own interviews and those undertaken by others (e.g. Doyal, 2009; Squire, 2010; Moyer and Hardon, 2014). Also prominent were high levels of stigma and discrimination that people with HIV still fear and experience (Dodds et al, 2004; Anderson et al, 2008; Elford et al, 2008; Doyal, 2009). Project A was explicitly about discrimination, so it was unsurprising that this was a major theme of

the interviews. Project B, however, was not particularly focused on this issue, yet discussions on stigma and discrimination featured in every interview. People spoke of being rejected by partners, friends and family, of constantly hearing people say 'ignorant' things about HIV, and of media bias. The awareness of negative social perceptions of HIV was also evident in interviewees ensuring to present themselves as responsible and moral citizens (see also Goffman, 1963; Rhodes et al., 2013). For example, although neither of us asked interviewees how they had acquired the virus, they often mentioned their sexual relations and practices, stressing that they were not promiscuous (see also Mattes (2014) and, in relation to other illnesses, Frank (1997)):

> In project A, a heterosexual, man from Zimbabwe spoke of his difficulties in the early days of his diagnosis: '*[It was] a struggle, because people wouldn't want to share anything with me, they fear I would pass what I've got to them, there was a lot of talk that I used to sleep around, that I sleep with prostitutes, that's why I've got what I've got.*'

> In project B, interviewees also discussed issues around promiscuity, as illustrated in this quotation from a heterosexual woman from Zimbabwe: '*It's not that you are promiscuous or anything. I didn't get it through promiscuity. I don't know what happened, because I had my partner.*'

The many ways in which discrimination formed part of people's narratives about 'life with HIV' might seem to be in stark contrast to representations of HIV as 'normal'. However, narratives of discrimination are themselves a core part of the historical discourse of HIV (Parker and Aggleton, 2003). Thus, as performative utterances, these accounts of discrimination simultaneously *both* reinforce *and* contradict the normalisation of HIV as just another chronic condition. Furthermore, just as narratives of discrimination co-exist with and

participate, in ambiguous ways, in narratives of normalisation, interviewees' accounts of life with HIV were 'haunted' by previous, marginal and recalcitrant understandings, experiences and stories about the virus (Decoteau, 2008). These 'ghosts' took various forms, but for many of our interviewees the one they most struggled to exorcise was an image of the virus as a lethal killer (Flowers, 2010). This was particularly heightened for people who had witnessed family and friends die of HIV-related illnesses, or migrants whose access to ART was contingent on them staying in the UK:

> In project A, a heterosexual woman from Uganda speaking of her continuing difficulties in finding a partner said: *'The men that I would meet, trying to be in a relationship, you tell them 'I'm HIV' and then the next thing you don't see them... I put myself in their shoes, how would I react? Possibly I'd react the same, because in those days HIV was like a death sentence...'*

> In project B, a heterosexual woman from Uganda who had seen her aunt die of AIDS related illness said*: 'I can see it; I know exactly how I am going to die. So I try not to read about what other people go through as it will haunt me.'*

Thus, people whose health 'fails' to keep up with the biomedical depiction of HIV as just another chronic condition or those who are simply unable to perceive the virus in this way risk being 'left behind' in the wake of the biomedicalised and normalised trajectory of contemporary HIV (Squire, 2010). As a result, they can experience further stigmatisation, exacerbated by an inability to adhere to the more recent normalised version of HIV, even when they themselves might partially subscribe to it. This manifested in our studies in various ways. For example, a few interviewees who were unable to adopt a 'positive' perspective on living with HIV said they felt unwelcome in community groups. Others, especially those who had been living with HIV for a long time, observed that, whilst their health was declining, the

'normalisation' of the virus had legitimised cuts to the welfare they depended on. However, the majority of our research participants (with a few rare exceptions), neither completely endorsed nor rejected the possibility of living a 'normal' life with HIV. Instead, as illustrated in the quotation below, they actively grappled with reconciling two versions of life with HIV – as 'normal', on the one hand, and a 'death sentence', on the other:

> *HIV is not a killer but it's not a barrel of laughs either…public opinion has found its own level but that's dangerous because nobody is checking if that level is true or untrue. Many people think that now there's the tablets, everything's fine and others think AIDS is a death wish and if you get it you'll be dead in days.* [Project A, gay British man]

6. The research interview as talking technology: the narrative enactment of new 'norms' of living with HIV

In the above two sections we focused on the way discussions on the normalisation of HIV permeated our interviews while being, at the same time, beset with challenges, contradictions and tensions. This, as argued elsewhere (Squire, 2010; Persson, 2013; Mattes, 2014), is indicative of the gap between the biomedical, activist and policy enactment of HIV as 'normal' and people's lived experiences. However, if the research interview is viewed as performative, rather than representative, of people's experiences of living with HIV, these apparent contradictions can be simultaneously seen as an artefact of the research interview as a particular type of talking technology, embedded in and shaped by the wide array of talking technologies operating within the field of HIV research, treatment and care in the UK.

As is common research practice in the UK, our interviewees were recruited primarily in clinics and community groups; potential participants were often introduced to the research

project by healthcare practitioners or staff in HIV community organisations. Consequently, many of the interviewees had already shared their experiences of HIV, and were familiar with the kinds of experiential narratives circulating in information booklets, educational material, magazines, on the internet, within face-to-face and online HIV community groups. Moreover, many of them were aware that these accounts, like the ones recorded in our research projects, tended to follow a particular form. For example, in Project B a woman (originally from South Africa but resident in the UK for many years) gave the following response to the question of whether she attended community groups: *I used to do, but I found it tended to be, you know, something like Alcoholics Anonymous. You hear the same thing over and over again.'*

The reference to Alcoholics Anonymous is prescient as this association is a particularly striking example of how the culture and ideology of a support group can shape the stories shared by its members (Steffen, 1997). But this is also the case in relation to HIV community groups, where 'confessional' talking technologies (Nguyen, 2010) and 'framing institutions' (Watkins-Hayes et al., 2012) encourage people to speak about themselves in particular ways. This clearly affected the narratives we collected in our interviews: other people's accounts of 'living positively' with HIV were often invoked as evidence of 'normal', healthy and productive lives with HIV.

Thus, when participants spoke about their return to normality post-diagnosis, they not only appropriated and reproduced extant discourses on the normalisation of HIV: they situated themselves within this discourse, enacting a hopeful future with HIV in which, with appropriate medical assistance, they were individual agents for change in their own lives who were ultimately responsible for their own wellbeing. The enactment of HIV as 'normal' in our interviews was, therefore, crucially, normative. As such, the accounts of living with HIV we

recorded did not simply reflect a wider process of normalisation (successful or otherwise), but were used as opportunities by interviewees to produce new norms, or 'regimes', of living with HIV (Lakoff and Collier, 2004).

However, while there were many connections and overlaps between the stories participants told us in research interviews and those they heard or shared in other situations, taking part in an interview is clearly not the same as sharing experiences in peer groups, therapy sessions, clinical appointments, or public testimonials. It is a distinct communicative context that elicits its own type(s) of narratives and themes. Over the past decade there has been an increase in research mapping people's experiences of the UK epidemic. Often closely allied with charitable organisations, clinicians and epidemiologists, this research has been geared towards building a scientific 'evidence base' about behaviours, needs and experiences to aid the design of HIV-related policies and service-delivery (e.g. Prost et al, 2008; McKeown et al, 2012; Weatherburn et al, 2013). This policy-and-delivery emphasis has had a significant impact on the types of studies carried out, the academic disciplines involved, and the frameworks deployed, but also, we argue, on people's perceptions of the role of social science research and its potential implications for policy and practice.

In both our projects a substantial number of interviewees mentioned that they had taken part in previous studies and were familiar with social research, while others explicitly said they took part in research in order to contribute back to community groups, the health care system and clinicians who had helped them. Furthermore, participants' responses were sometimes constructed as messages that we, as researchers, would transmit to decision-makers in powerful positions. Interviewees, therefore, adopted the discourse of 'positive living' whilst at the same time detailing a significant array of immediate material problems that troubled the

very same narrative. These political undercurrents in interviewees' accounts of the challenges to living a normal life with HIV – particularly around issues of welfare, poverty, and the threat of deportation to countries with scarce ART provision – became evident only when we combined our analysis.

The performative aspects of the research interview as a talking technology in our studies thus encompassed the (re)production of ideas surrounding normalisation as well as the dissemination of commentaries on the individual, social and systemic obstacles to 'realising' normalisation. However, rarely did these amount to actual critiques of the paradigm of HIV as 'just another' condition, showing the predominance of the normative effect of cumulative discursive practices surrounding normalisation, which include the research interview itself. Looking at research interviews from this perspective – as talking technologies that work towards the production of what comes to count as a normal or valid life with HIV – demands that we not only explore what is being (re)created in these accounts, but that we also ask questions about what is not said or, indeed, remains unheard. Clearly there is no one correct way to go about doing this, but a starting point would be to adopt more varied approaches to sampling and analysis: thinking beyond the 'most at risk' groups that continue to be the main focus of inquiry of much HIV research – for the UK, gay men and African communities – to include other 'groups' according to age, ethnicity, gender, class or other social categories in a variety of combinations as pertinent to each study; extending recruitment beyond clinical and community group settings; paying particular attention to the anomalous and contradictory accounts that might be overlooked in thematic analyses; and conducting combined and secondary analyses on the rich archive of narratives already collected.

In research on another highly 'storied' medical condition – breast cancer – Kertsin Sandell (2008) has termed the silenced and marginal stories that challenge standard narratives of breast reconstruction 'stories without significance'. In HIV, there are undoubtedly numerous such stories. Many people cannot or choose not to share their experiences of living with HIV in any setting. Some accounts are silenced due to structural inequalities, language barriers, poor health or simply because they are not 'loud' enough to be heard. In contrast, we argue that the stories narrated in research interviews are 'stories with significance'. This is not simply because they are explicitly articulated, heard, recorded and reproduced, or because of the significance researchers, policy-makers, funders, patients and others attribute to them, but, crucially, because these accounts, alongside others, play a role in shaping what comes to count as 'life with' HIV in the 'post-AIDS' era. As such, they form part of the performative articulation and (explicit or implicit) legitimation of the distinctive norms of this particular form of life in the wider social context.

7. Conclusion

HIV is increasingly framed in biomedical and health policy discourse as a chronic condition, with people with HIV being told that with the help of ART they can live a 'normal' life with the virus. Our analysis of experiential accounts of living with HIV reveals that even in the UK, a country with a high standard of HIV care, people's ability to enact this promised normality is fraught with challenges and contradictions. This echoes the findings of social scientific research conducted in other contexts and regions of the world, but it also significantly builds on it. While extant research has highlighted the differences between how HIV is framed in biomedical and policy discourse versus people's experiential accounts, the emphasis has typically been placed on how people with HIV are simply *unable* to enact the

promised normalcy. We, in contrast, have drawn attention to how such experiential narratives *both* contradicted *and* reproduced the wider discursive normalisation of HIV.

While this may seem paradoxical, drawing on Vinh-Kim Nguyen's work on 'confessional' talking technologies, we have argued that insofar as these contradictions are generated within the research interview as a distinct talking technology, they emerge as crucial to the normative (re)production of what counts as 'living with (normalised) HIV' (in the UK). Moreover, while Nguyen focused on how 'confessional' talking technologies create new forms of selfhood (Nguyen, 2013) and subjectivities with immediate material effects (Nguyen, 2010), our analysis has instead drawn attention to how the research interview as talking technology plays a role in the enactment and legitimation of new norms of 'living with' HIV which are fundamentally premised on the success of ART and individual responsibilisation.

The specifics of the argument presented here are intertwined with the history and broader field of HIV research, activism, and care. However, an emphasis on encouraging people to talk about their experiences of illness is in no way limited to the HIV pandemic. The media savvy ways of talking about illness pioneered by the early AIDS activists have been adopted by people affected by many different health conditions. Social science research methods are increasingly being appropriated and used within healthcare settings, patient organisations and policy discourse (Moreira et al., 2014). More attention must therefore be paid to the implications of asking people to share their experience in contexts, such as HIV, that are already teeming with experiential accounts and in which the practices of sharing experiences have been shaped by very specific socio-political histories. For not only do wider practices of

storytelling shape the accounts we as social scientists collect; in reproducing these accounts we form part of the performative (re)production of different modes of 'living with' disease.

8. References

Aghaizu A., Brown A. E., Nardone A., Gill O. N., Delpech V. C. & Contributors. (2013). *HIV in the United Kingdom 2013 report: data to end 2012*. November 2013. Public Health England, London.

Anderson, M., Elam, G., Gerver, S., Solarin, I., Fenton, K. & Easterbrook, P. (2008). HIV/AIDS-related stigma and discrimination: accounts of HIV-positive Caribbean people in the United Kingdom. *Social Science & Medicine*, 67(5), 790-98.

Berridge, V. (1996). *AIDS in the UK: the making of policy 1981–1994*. Oxford: Oxford University Press.

Campbell, C., Nair, Y., Maimane, S. & Nicholson, J. (2007). 'Dying twice': a multi-level model of the roots of AIDS stigma in two South African communities. *Journal of Health Psychology*, 12(3), 403-416.

Decoteau, C. L. (2008). The specter of AIDS: testimonial activism in the aftermath of the epidemic. *Sociological Theory*, 26(3), 230-257.

Dodds, C., Koegh, P., Chime, O., Haruperi, T., Nabulya, B., Sseruma, W. S. & Weatherburn, P. (2004). *Outsider status: stigma and discrimination experienced by gay men and African people with HIV*. London: Sigma Research.

Doyal, L. (2009). Challenges in researching life with HIV/AIDS: an intersectional analysis of Black African migrants in London. *Culture Health & Sexuality*, 11(2), 173-188.

Doyal, L. (2013). *Living with HIV and dying with AIDS: diversity and inequality in the global pandemic*. Farnham: Ashgate.

Elford, J., Ibrahim, F., Bukutu, C. & Anderson, J., (2008). HIV-related discrimination reported by people living with HIV in London, UK. *AIDS and Behaviour*, 12(2), 255-264.

Epstein, S. (1996). *Impure science: AIDS activism and the politics of knowledge.* Berkeley: University of California Press.

Flowers, P. (2010). HIV transitions: consequences for self in an era of medicalisation, in: Davis, M., Squire, C. (Eds.), *HIV Treatment and Prevention Technologies in International Perspective*. Palgrave Macmillan, Basingstoke, pp.109-125.

Foucault, M. (1998). *The history of sexuality: the will to knowledge,* Volume 1, New Ed. London: Penguin Books.

Frank, A. (1997). Illness as moral occasion: restoring agency to ill people. *Health:,* 1(2), 131-148.

Frank, A. (1998). Stories of illness as care of the self: a Foucauldian dialogue. *Health:,* 2(3), 329-348.

Goffman, E. (1963). *Stigma: notes on the management of a spoiled identity*. London: Penguin Books.

Ibrahim, F., Anderson, J., Bukutu, C. & Elford, J. (2008). Social and economic hardship among people living with HIV in London. *HIV Medicine*, 9(8), 616-24.

Jurecic, A. (2012). *Illness as narrative*. Pittsburgh: University of Pittsburgh Press.

Krieger, N. (1999). Embodying inequality: a review of concepts, measures, and methods for studying health consequences of discrimination. *International Journal of Health Services*, 29(2), 295-352.

Lakoff, A. & Collier, S. J. (2004). Ethics and the anthropology of modern reason. *Anthropological Theory,* 4(4), 419-434.

Levy, J. M. & Storeng, K. T. (2007). Living positively: narrative strategies of women living with HIV in Cape Town South Africa. Anthropology & Medicine, 14(1), 55-68.

Mattes, D. (2014). Caught in transition: the struggle to live a "normal" life with HIV in Tanzania. *Medical Anthropology*, 33(4), 270-287.

Mazanderani, F. (2012). An ethics of intimacy: online dating, viral-sociality and living with HIV. *BioSocieties*, 7(4), 393-409.

McGrath, J. W., Winchester, M. S., Kaawa-Mafigiri, D., Walakira, E., Namutiibwa, F., Birungi, J., Ssendegye, G., Nalwoga, A., Kyarikunda, E., Kisakye, S., Ayebazibwe, N. & Rwabukwali, C. B. (2014). Challenging the paradigm: anthropological perspectives on HIV as a chronic disease. *Medical Anthropology*, 33(4), 303-317.

McKeown, E., Doerner, R., Nelson, S., Low, N., Robinson, A., Anderson, J. & Elford, J. (2012). The experiences of ethnic minority MSM using NHS sexual health clinics in Britain. *Sexually Transmitted Infections*, 88(8), 595-600.

Moreira, T., O'Donovan, O. & Howlett, E. (2014). Assembling dementia care: patient organisations and social research. *BioSocieties* 9(2), 173-193.

Moyer, E. & Hardon, A. (2014). A disease unlike any other? Why HIV remains exceptional in the age of treatment. *Medical Anthropology*, 33(4), 263-269.

Nguyen, V.-K. (2010). *The republic of therapy: triage and sovereignty in West Africa's time of AIDS.* Durham: Duke University Press.

Nguyen, V.-K. (2013). Counselling against HIV in Africa: a genealogy of confessional technologies. *Culture, Health & Sexuality*, 15(4), S440-S452.

Parker, R. & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social Science & Medicine*, 57(1), 13-24.

Persson, A. (2013). Non/infectious corporealities: tensions in the biomedical era of 'HIV normalisation'. *Sociology of health & illness*, *35*(7), 1065-1079.

Prost, A., Elford, J., Imrie, J., Petticrew, M. & Hart, G. J. (2008). Social, behavioural, and intervention research among people of sub-Saharan African origin living with HIV in the UK and Europe: literature review and recommendations for intervention. *AIDS and Behavior*, 12(2), 170-194.

Rhodes, T., Bernays, S. & Janković-Terzić, K. (2009). Medical promise and the recalibration of expectation: hope and HIV treatment engagement in a transitional setting. *Social Science & Medicine,* 68(6), 1050-1059.

Rhodes, T., Harris, M., & Martin, A. (2013). Negotiating access to medical treatment and the making of patient citizenship: the case of hepatitis C treatment. *Sociology of Health & Illness,* 35(7), 1023-1044.

Rosengarten, M. (2009). *HIV interventions: biomedicine and the traffic between information and flesh*. Seattle: University of Washington Press.

Squire, C. (2010). Being naturalised, being left behind: The HIV citizen in the era of treatment possibility, *Critical Public Health*, 20(4), 401-27.

Steffen, V., 1997. Life stories and shared experience. *Social Science & Medicine*, 45(1), 99-111.

Treichler, P. A. (1987). AIDS, homophobia, and biomedical discourse: an epidemic of signification. *AIDS: Cultural Analysis/Cultural Activism* 43, 31–70.

Weatherburn, P., Keogh, P., Reid, D., Hammond, G. & Jessup, K. (2013). My Care, I care: A study of what people with HIV value about HIV NHS services across London. London, Sigma Research, available at: http://www.sigmaresearch.org.uk/projects/hiv/project54

Watkins-Hayes, C., Pittman-Gay, L. & Beaman, J. (2012). "Dying from" to "living with": Framing institutions and the coping processes of African American women living with HIV/AIDS. *Social Science & Medicine*, 74(12), 2028–2036.

Terrence Higgins Trust. (2011). *21st Century HIV: Personal accounts of living with HIV in modern Britain*, 2011. London, Terrence Higgins Trust. Available from: http://www.tht.org.uk/get-involved/Campaign/21st-century-HIV