

'There's no pill to help you deal with the guilt and shame': Contemporary experiences of HIV in the United Kingdom

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Abstract

The experience of living with HIV, in the global north, has changed significantly over the past 20 years. This is largely the result of effective biomedical methods of treatment and prevention. HIV is now widely considered to be a long-term condition like many others – it has been argued that HIV has been ‘normalised’. Drawing on online qualitative survey data, with respondents aged 18–35 years, diagnosed with HIV in the past 5 years, this research explores contemporary subjective experiences of being diagnosed, and living, with HIV in the United Kingdom. The data reveal ambiguous experiences and expectations, as the ‘normative’ status of HIV exists alongside ongoing experiences of fear, shame and stigma – maintaining its status as the most ‘social’ of diseases. In rendering HIV ‘everyday’, the space to articulate (and experience) the ‘difference’ which attaches to the virus has contracted, making it difficult to express ambivalence and fear in the face of a positive, largely biomedical, discourse. In this article, the concepts of normalisation and chronicity provide an analytical framework through which to explore the complexity of the ‘sick role’ and ‘illness work’ in HIV.

Keywords

chronic illness, contemporary experiences, HIV, normalisation, qualitative

Background

In ‘When Plagues End’, published almost 20 years ago, Sullivan (1998) reflects on ‘normalcy’ and ‘the ebbing of AIDS’ in the immediate aftermath of ‘the good news from the laboratory’ – the increasingly effective, life-altering, introduction of combination anti-retroviral drugs in the mid-1990s (p. 79). The possibilities for life, and survival, changed what it meant to live with HIV and AIDS. Living, he commented, ‘is about the place where the plague can’t get you ... now I live in the knowledge of its existence. So will an entire generation’ (Sullivan, 1998: 84).

Drawing on a qualitative online survey, undertaken in 2015–2016, this article explores the ways in which the promise of a ‘normal’ life offered by the early iterations of anti-retroviral therapy (ART) has undergone subtle, but nonetheless profound, shifts as promise and possibility have become real expectations. As such, the experiences of the contemporary generation of people living with HIV might be as different from those reflected in Sullivan’s work as the generation he refers to was different from the preceding one. My key objective is to understand contemporary experiences of young people in the United Kingdom living with HIV. The work centres on the primary question: Is living with HIV different now and in what ways? Related objectives consider

the ways in which HIV is ‘normalised’, how it is increasingly perceived and experienced as a long-term chronic condition (LTC) and its ongoing legacies.

In 2015, 6095 people were newly diagnosed with HIV in the United Kingdom, while 88,769 people were living with diagnosed HIV (Public Health England (PHE), 2016). The majority of adults with HIV are aged 35–49 years and there is a growing number of older people seeking HIV-related support. According to PHE (2016), ‘one in three (29,960; 34%) people accessing HIV care are now aged 50 years or over. This compares to one in seven (7,310/51,449; 14%) a decade ago’ (p. 7). The ‘graying of HIV’ (Chambers et al., 2014) has thus become a central focus of recent research, specifically, the medical and social uncertainties associated with unchartered territory (Beuthin et al., 2015; Meyers and Lawrence, 2013; Owen and Catalan, 2012; Rosenfeld et al., 2014, 2015). It is this generation to whom Sullivan (1998) referred, people who have not only glimpsed the possibilities of ART but also have embraced its benefits and possibilities.

The documented experiences of older generations of people living with HIV provide important historical and theoretical points of reference for this study which, by distinction, focuses on young people up to 5 years post-diagnosis. Here, the concepts of normalisation and chronicity in HIV are invoked to provide an analytical framework for the data which reveals that ‘old’ narratives, steeped in despair and distress, sit alongside expressions of productivity and possibility; the experience of HIV as a chronic illness which is articulated as highly manageable is clear, but so too is the primary challenge of living with a ‘social diagnosis’. The drive to normalisation of HIV over the past 20 years not only highlights the prominence and legitimacy of HIV as a chronic condition but also signals the challenge of articulating continuing ambivalence and fear in the face of the positivity of biomedical discourse.

Normalisation

The bio-medicalisation of HIV, through the sustained provision of ART, has created the possibility for what is now referred to as the normalisation of HIV – in the global north, it is regarded by many, certainly among those working in the HIV field, as a chronic disease no different from any other. Moyer and Hardon (2014) argue that this drive to normalisation derives from a range of sources, including AIDS activists challenging stigma and discrimination, health practitioners, health administrators and policymakers aiming to integrate systems of care and support and international donors retreating from funding demands (p. 263). Biotechnical intervention in preventing and treating disease more generally has thus had the capacity ‘to turn people with HIV into regular unremarkable citizens, just like anyone else’ (Squire, 2010: 407) and has shifted the focus, at all levels of intervention, from ‘dying from’, to ‘living with’, HIV (Watkins-Hayes et al., 2012). This shift draws on a seemingly unproblematic correlation between ‘decreased mortal threat with improved quality of life’ (Wong and Ussher, 2008). The biomedical markers of ‘normality in HIV’, such as reduction in the virus to undetectable levels in the blood and the impact on significantly lowering infectiousness, have contributed to a dominant clinical narrative of normalisation. Flowers (2010) argues, ‘the normalisation of HIV has crystallised a singular, dominant, medical construction of HIV infection’, reducing the ‘HIV positive person to a disease vector’, overshadowing and dismissing the continued psycho-social consequences of living with HIV (pp. 109–110). This leads to the ‘misplaced assumption that, post ART this [being diagnosed with HIV] is not such a terrible event after all’ (Flowers et al., 2011: 1388). Persson (2013:

1065) similarly questions whether it is possible to transform the lived experience of HIV into a normative one in which the HIV body ‘reimagined and reinhabited as non-infectious and harmless’ and suggests (drawing on Squire (2010) and Flowers (2010)) that there are aspects of living with HIV which resist the normalisation process, resulting in dissonances between biomedical rhetoric and people’s embodied experiences (Persson, 2013: 1066). This is echoed by Moyer and Hardon (2014) who demonstrate that there is no simple link between ‘biomedicalising HIV and normalising the social and economic realities of the disease’ – a link, they suggest, that is set to cement further with the scaling up of treatment as prevention (TASP) programmes (p. 267). Mazanderani and Paparini (2015) also point to the gap between ‘the biomedical, activist and policy enactment of HIV as ‘normal’ and people’s lived experience’ and, in doing so, they demonstrate the contradictions of simultaneously experiencing normalcy and exceptionalism for people living with HIV (p. 71). The tensions between ‘normalisation’ and the historical legacies of HIV, including its enduring stigma in mainstream society, are reflected in the accounts presented in this article. Respondents’ narratives generate the question – What space exists in policy, practice and research for alternative, complementary or competing views to that of normalisation?

Chronicity

While the emphasis on the normalisation of HIV focuses attention on dominant biomedical and public health discourses, it is also the everyday experiences of living with a condition for which there is no cure which lies at the heart of being HIV positive. In this respect, Beuthin et al. (2014) argue, ‘the day-to-day- experiences, realities, and challenges of [particularly older] affected individuals remain largely invisible’ (p. 612). They suggest that the growing body of scientific enquiry on the longer term physical impacts of HIV and ART needs also to make visible the everyday challenges, and daily work, of chronicity. The biographical work in constructing, reconstituting and repairing self and identity in living with HIV and other LTCs (now well-documented) constitutes a critical dimension of people’s everyday lived experiences (Bury, 1982; Carricaburu and Pierret, 1995). Persson et al. (2014) specifically refer to the contemporary epidemic as one of complexity. They refer to the changing nature of HIV and its growing ‘comorbid capacity’, the resultant invocation of multiple medical specialities, multifarious treatments and changing needs (p. 13). The work of managing chronicity is thus expanding for both practitioners and patients. In addition, Moyer and Hardon (2014: 267) suggest that managing ‘continuous uncertainty’ is an ongoing dimension of life with chronic diseases, particularly HIV – disruption due to illness, medication and socioeconomic circumstances, requires work, recognition and an acknowledgement that, even following the commencement of HIV treatment, people return to a life, ‘which is anything but ‘normal’ – a life which is immersed in illness (Charmaz, 1991: 73).

Tackling the everyday complexities of HIV remains a task of confronting the legacies of stigmatisation, contamination, danger and damage, making the efforts of normalisation and work of chronicity particularly challenging. As Persson (2013: 1068) states, ‘studies across time and cultures show that an HIV diagnosis retains the power to generate self-stigmatisation, what Goffman (1963) termed a ‘spoiled identity’, or more recently described by Flowers et al. (2006) in relation to HIV as a ‘viral identity’

(p. 120). It is this ongoing stigma which compounds and generates the complexity and uncertainty which characterise contemporary experiences of living with HIV.

In reworking the concept of ‘illness careers’, Grue’s (2016) analytical metaphor, ‘Illness is work’, identifies the physical and ontological effort involved in chronic illness: physical symptoms are exhausting, as is the ongoing relationship with health services, employers, family and friends – work which may require providing justification, of both symptoms and experiences. These efforts ‘are not minor or casual. They can be demoralising, exhausting, and a cause for despair. Structuring them as work may be a strategy for providing meaning where little meaning is apparent’ (Grue, 2016: 409). The notion of ‘illness work’ can be further incorporated into contemporary health policies including self-management, but a growing burden of symptoms and treatment indicates that people living with chronic illnesses, and their caregivers, often face great demands from the healthcare system in (self) managing their conditions (Mair and May, 2014). This includes recording clinical data, managing complex drug regimes and navigating complicated administrative systems, requiring time, skill, resources and the mobilisation of capacity (Boehmer et al., 2016; May et al., 2014). Living with the everyday chronicity of HIV can encompass much of this complex illness work – in a context where HIV is simultaneously positioned as ‘normalised’ and not.

Methods

This was a small-scale qualitative study which aimed to understand, first, what it means to receive and live with a diagnosis of HIV in contemporary UK society and, second, how the social experiences of living with HIV have/have not changed in the light of biomedical developments. The predominant method of data collection was an online survey, structured around open-ended questions. A website, ‘Positively Different’ was linked to the survey. It introduced the research, its aim and objectives and the researchers. It addressed ethical questions around participation and provided details of ethical approvals obtained (University Ethics Committee, University of Hull) and provided a national list of support and information organisations.

The increased use of online research in health and social sciences is reflected in literature which assesses its utility and limitations (Bryman, 2012; Graffigna and Bosio, 2006; Jones and Wooley, 2015; Price and Walker, 2015; Tates et al., 2009). Notwithstanding the potential for online research to exclude some social groups by virtue of limited Internet access and (non)familiarity, it can provide an avenue to access hard to reach groups, particularly in the context of stigmatised illnesses (Price and Walker, 2015). It offers anonymity, although it has been noted that some participants may underestimate the possibilities for identification by inadvertently revealing personal details. The website provided a cautionary note for respondents in this regard (in accordance with British Psychological Society (BPS) (2017) guidance). Internet research also creates the possibility of achieving geographic spread. This was one of the aims of this study, as much HIV research in the United Kingdom customarily takes place in large metropolitan centres. Internet research demands relatively little time from participants, there are no time constraints and the method may reduce interviewer bias. Conversely, the limitations of using non face-to-face techniques are well known – there is no opportunity for follow-up, clarification or use of verbal cues, potentially limiting the depth of data collected particularly on sensitive subjects. The use of online

data does not allow for the opportunity to tease out ambiguity in the language used by respondents and there may be high attrition rates.

Using the Bristol Online Survey (consent assumed), the questionnaire ran from September 2015 to May 2016. In addition to the website, a Facebook and Twitter account publicised the research. Contact was made with 63 HIV-related organisations, across the United Kingdom; 21 offered to directly support the project and circulated the link to the research through their own social media. Twitter helped expand contact with a variety of organisations and individuals, sexual health agencies and clinics, academics and researchers in the field, LGBT organisations and radio stations with an interest in HIV/LGBT issues. This recruitment strategy was informed by the demographic profile of HIV in the United Kingdom. PHE (2016) estimated that 101,200 people were living with HIV in the United Kingdom in 2015, of whom 69% were men and 31% women (pp. 7–8). Two in five people were living in London. A total of 47,000 gay/bisexual men and 19,600 heterosexual men and 29,990 heterosexual women were estimated to be living with HIV. Of those diagnosed (87% of the 101,200), 96% were receiving HIV treatment, of whom 94% had a suppressed viral load. In 2015, an estimated 2500 people who inject drugs (PWID) were living with HIV in the United Kingdom.

In total, 40 surveys were completed by individuals who met the criteria for inclusion (young people, between 18 and 35 years, in the United Kingdom, who had received a diagnosis in the previous 5 years). While not generalisable, the sample provides a starting point from which to develop further research. In coding the data, two responses were excluded – one a duplicate and the other incomplete. In addition to the survey, two respondents indicated that they wished to be interviewed. Topics covered in the online survey and interview guide included the following: reactions to diagnosis and how they have changed over time, decisions around disclosure, impact and effects of diagnosis, support accessed, social effects of living with HIV and experiencing HIV as a chronic illness. All responses to the open-ended questions in the survey (14 out of a total of 21 questions), and interview data, which were transcribed verbatim, were coded and thematically analysed by two researchers (Braun and Clarke, 2006).

Participants

The majority of respondents were between 27 and 35 years (72%) with 21% between 23 and 26 years and the remainder were in the age group of 18 and 22 years. About 79% described themselves as White British; 86% of respondents identified as gay men; and 14% as heterosexual women. No respondents identified as intravenous drug users. Geographic spread was interesting, as responses were obtained from all four UK nations. Notably, 14% of respondents came from Northern Ireland. The largest category came from London (36%), with a broad geographic spread across the rest of the United Kingdom. About 40% of respondents were diagnosed within the past year and the remainder were evenly spread evenly across the remaining age categories (1–5 years).

Results

The data demonstrate three core themes: old narratives, new knowledge; chronicity, manageability and the impact of HIV on everyday life; HIV as a ‘social diagnosis’ and the

'pressures to normalise'. The first section here focuses on respondents' initial responses to their diagnosis and reflections on their subsequent experiences.

Old narratives: new knowledge

The overwhelming response to diagnosis (irrespective of time since diagnosis, age, sexuality and gender) was a combination of fear, anxiety, shock, terror, distress, numbness, regret, anger, shame, disappointment, loss, grief, isolation and mortality. One respondent said,

Immediately I just felt like it must be wrong, it can't happen to me, this only happens to promiscuous sluts having BB [bareback] chem sex every weekend ... I felt dirty, infected, unclean and scared of the future and what people, friends and family would think of me. [I] thought that would be the end of any future plans to have a relationship, get married, have a family. After leaving the clinic, after finding out, I walked around London for about 3 hours feeling completely numb. (Male, diagnosed in the past 6 months)

The immediate sense of needing to confront an unexpected, alternative, life trajectory is reflected in these statements:

... my predominant memory is being in shock and not really taking anything in. The first real memory I have after being told is standing outside the clinic, knowing my entire life would be different from now, with no-one to go to or know what to do. (Male, diagnosed 2–3 years ago)

I dreaded telling people and I was disappointed in myself that I contracted HIV. I was angry, very very angry, which caused my existing depression and self-esteem issues to come back. (Male, diagnosed 4–5 years ago)

Shock, devastation, shame, guilt. (Female, diagnosed 4–5 years ago)

These responses resonate with existing studies capturing people's responses to diagnosis in the pre-HAART era (Flowers et al., 2006), very much reflecting established historical narratives. So, despite biomedical developments and 'normalcy discourses', the initial devastation of being diagnosed with HIV was clearly evident in each person's response. Moreover, the legacy narratives (of a 'spoiled identity') associated with HIV and AIDS are amply evident here, whereas a chronic illness/'ordinary' narrative is less apparent, suggesting the limited public reach of normalcy discourses. Experiences of guilt, shame and fear of disclosure suggest that the discourse of 'normalisation' is not matched in mainstream society, where ignorance around HIV continues to prevail. The public discourse on HIV remains one of risk, perpetuated, in part, through silence around HIV, while the promise of normalcy, through treatment, is the dominant narrative in HIV medicine, policy and practice. As Persson et al. (2016) argue,

... society's knowledge about HIV lags behind the extraordinary strides in biomedicine, which have transformed the virus – and what it means to live with it – beyond all recognition'. (p. 210)

The period following initial diagnosis, however, presents a different picture. Respondents reflected that they felt that they were assuming greater control over their lives due to having information, access to treatment, knowledge and understanding.

They articulated a strong sense of empowerment in this context. They spoke of responding well to treatment and of absorbing, particularly biomedical, aspects of their diagnosis into their lives:

I'm no longer scared of HIV, but it's still a significant part of my life. (Male, diagnosed 3–4 years ago)

I've definitely come to terms with it. On treatment now and undetectable. I'm more knowledgeable about HIV and I take more of an interest in my own health. My family have come to terms with my diagnosis and I'm getting to a place where I'm comfortable with my sexuality. (Male, diagnosed 3–4 years ago)

A man, more recently diagnosed, described his diagnosis as

The consciousness – it's like a balloon floating high from the top of my head.

He carried the analogy through, saying,

I accept it. I know how the virus can be harmless with medical treatment. The balloon above my head will hopefully float higher and higher, until the day I won't be able to see it anymore. The wire will still be linked to my head, but the weight will be lighter. ... After all, I'm not surprised I got infected ... I live it as a fair punishment of Life, a tyrant with fair rules but still a tyrant. I walk with my tail between my legs ... (Male, diagnosed 6 months–1 year ago)

Embracing the possibility for successful treatment (and health) offered through biotechnical intervention is a critical dimension of living with HIV in the contemporary period and a central element of biographical (re)constitution following diagnosis. Taking control of one's health (taking medication, eating healthily, doing regular exercise) was a key dimension of living with HIV. Indeed, seeing the promise of the 'balloon of HIV' lift with intervention is emblematic of the 'normalising' possibilities of biomedical treatment, yet, the 'strings' of HIV remain attached. They are attached not only because of the ordinary everyday consequences of living with an LTC but also precisely because of the continuing negative (not ordinary) psychosocial context of HIV.

The respondents in this study were astute, cautious and strategic about disclosing their HIV positive status. Although 39% of respondents said that they spoke publicly and widely, the remaining 61% told few/very few people and did so on the basis of trust or a 'need to know' basis. Although a few respondents said, following disclosure, that people's initial response was quite often one of shock and distress, most spoke of having a supportive, caring and affirming response from the selected groups of people to whom they disclosed their HIV status. The simultaneous experience of being cautious and considered about disclosure, in ways which might not be the case with other chronic conditions, yet, encountering an affirming, 'ordinary' response, again reflects the ongoing duality of 'old' or lingering narratives and new knowledge and possibilities.

The impact of HIV on everyday life – competing and concurrent narratives

The everyday lived experiences of HIV, since the development of effective biomedical intervention, are contradictory, competing and fluid. Narratives of control,

introspection and empowerment sit side by side with mental distress, ill-health and the everyday interference and burden (both physical and psychological) of living with a chronic condition (Persson, 2013, 2014; Squire, 2013). The overarching narratives of the young people in this study continue to reflect this historical ambiguity (a seemingly inescapable consequence of medicalisation, normalisation and stigmatisation). However, there is also an evident thread which typifies the increasingly mundane nature of chronicity – of everyday illness. There is, moreover, a sense of acceptance which underpins people's illness experiences and trajectories – evident in respondents' use of the 'language of chronicity'. The increasing mundanity and everyday, unexceptional, nature of the management of HIV in this data are not dissimilar from that alluded to by Persson et al. (2016) in the context of serodiscordant couples when the respondents in their study referred to the 'insignificance and manageability of HIV and the safety and validation provided by recent developments in biomedical science' (p. 199).

Certainly, the power of medication and its place in underpinning the everyday inconsequentiality of HIV is particularly evident in the language of 'simply getting on with it':

It does not affect my life that much. I can do everything I previously did ... If I adhere to the medication, my life expectancy is the same as anyone else's. (Male, diagnosed in the past 6 months)

It hasn't really [changed my life] ... all I do differently is take 3 tablets a day. I've been to the doctors for check-ups and blood tests, other than that, nothing has changed. (Male, diagnosed in the past 6 months)

Nonetheless, the daily routine of chronicity was initially challenging:

It's [medication] just the norm now, but getting used to it was a difficult few months as I seem to be like a guinea pig, allergic to everything. (Female, diagnosed 4–5 years ago)

... with my first round of drugs, they were food dependent as well, which meant that I had to decide my meal time every day and it was very intrusive. (Male, diagnosed 3 years ago, Interview 1)

The hardest part was trialling various medications at the beginning of treatment. I had very negative side effects. I would go to bed at night experiencing terrible night terrors, sweats, chronic diarrhoea and sickness plus my mental and physical health became very poor. (Male, diagnosed 2–3 years ago)

The consequent daily integration of medication was a constant dimension of managing chronicity, particularly in the context of the co-morbidities which characterise many LTCs, including HIV. And, as with any LTC, ongoing anxiety about fluctuations and bodily changes are part of daily living:

If I am getting sick, there is always going to be that little voice in my head that's thinking, oh shit, has something gone wrong? (Male, diagnosed 3 years ago, Interview 1)

The daily challenge and generativity of living with an incurable condition and the ontological battles it provokes are captured by this respondent:

If I'm being honest, like I go, I go most days without really thinking about it other than you know, I have to take my drugs, but I don't ... that's become so habitual I don't actually have to, you know, link that in my mind with a painful experience every day. It is more episodic for me, in terms of when I struggle. I think I am a much stronger person for having gone through it, I think like I, whilst if you could, you know, wave a magic wand and take it away from me I absolutely would, you know, have it gone from my life, I mean, of course I would, but in terms of me and my character and what I am able to deal with and how I am able to approach situations and my kind of, my outlook on life and positivity, excuse the pun, it's, it's actually made me better, like you know what I mean, like it's, yeah, because I've had to man up and deal with it, I've learned a lot from it. (Male, diagnosed 3 years ago, Interview 1)

Other people, similarly, 'took control over their lives', as their HIV status became an integral part of their identity:

It has made me more self-reflective and focused on self-care and the pursuit for authenticity. (Male, diagnosed in the past 6 months)

Making the decision to start ART to protect my husband felt like taking back control and enable me to see it positive – pardon the pun. (Female, diagnosed 4–5 years ago)

It's been positive for me. My life style has changed for the better. I have lost weight (due to eating more healthily) and I look after my emotional well-being better now than I did before. (Male, diagnosed 4–5 years ago)

My HIV has ultimately come to empower me. (Male, diagnosed 4–5 years ago)

Yet, the routine daily process of living with, and managing, HIV is evidently burdensome and wearing – there is no escape from the critical markers of well-being/illness: medication, testing and monitoring constitute a continuous, if integrated, backdrop:

Some days I have a sobering realisation that I have a virus that will stay with me until I die. (Male, diagnosed in the past 6 months)

If I don't take my meds I will get very sick very quick, I know this and I will be taking them forever, making it a long term illness. It's like cancer, I take my pills and I can stay in a kind of remission, I stop and it takes over again. (Male, diagnosed 1–2 years ago)

Take it one day at a time – T count higher and viral load okay. (Male, diagnosed 6 months–1 year ago)

Mental distress, self-rejection and social isolation also characterised living with HIV, compounding pre-diagnosis difficulties:

I feel better than when I was first diagnosed. I have started to try to come to terms with this. However, I do not see why someone else would want to be with me, how can I expect someone else to love me when I do not love myself? I feel unattractive and unsexy. I do not like to look in the mirror, as I do not recognise the person looking back. I do not like to be left alone with my thoughts, as I constantly worry ... I have placed a lot of emphasis on being alone, which I cannot change. I would like to find love and have a family, but cannot take the chance of being rejected ... (Female, diagnosed 4–5 years ago)

These narratives suggest that contemporary experiences of living with HIV remain kaleidoscopic, if increasingly conventional: they reflect a daily life that is variously ordinary, complex and challenging. Life lived with HIV, in a contemporary UK context, is inescapably about managing the limiting discourse (or complexity) of normalisation and the increasing focus on the management of chronicity. Moreover, the evident power of normalisation, a critical effect of biomedicalisation, to enable a productive life as citizens, workers, employees and sexual subjects cannot be underestimated and is amply evident in the narratives above. Yet, one additional dimension of chronicity in HIV is its social consequences, which were far less ambiguously experienced.

'Social diagnosis': the pressures to 'normalise'

Respondents were not asked directly about stigma, rather, what social effects they experienced living with HIV and whether they perceived and experienced HIV as being the same as living with any other long-term chronic illness, as suggested by the normalisation discourse. The motivation in doing so was to elicit an open response, rather than to foreground 'anticipated' or 'expected' experiences. Notwithstanding this, with very few exceptions, respondents said that HIV remains, as it has throughout the past three decades, a 'social diagnosis' – perhaps more so than a medical one, given that the biomedical experiences of HIV have, in their terms, been managed. Respondents indicated that the social aspects of living with HIV were, without doubt, the most challenging part of the condition. These manifested themselves as isolation, experiences of mistrust, fear of dating and forming relationships because of fear of rejection and stigma (both felt and enacted).

The tension between biomedical normalisation and ongoing stigma clearly highlights the social complexity of living with HIV: a complexity which is not readily accounted for within a narrow biomedical discourse. This is summed up clearly by this respondent, who states that a 'social diagnosis' is not one that can be treated so easily:

I feel that an HIV diagnosis now, given treatment is available, is more of a social diagnosis than a medical one – you can take medication to treat the physical aspects of the disease, however the social aspects are much more engrained and influence a lot of life's interaction and consequently take a lot of 'inner-work' to come to terms with – there's no pill to help you deal with the guilt and shame. (Male, diagnosed in the past 6 months)

The majority of respondents were of the view that the social dimensions of HIV distinguished it very clearly from other chronic conditions. They felt strongly that other LTCs were not shameful or stigmatised (although type 2 diabetes and obesity are increasingly regarded as such (Lupton, 2013)), and most respondents suggested that other conditions generated more sympathy:

Other chronic illnesses are viewed sympathetically on the whole, HIV is not. (Female, diagnosed 4–5 years ago)

There are enormous negative social connotations associated with HIV which can have profound effects on people with HIV. There aren't many long-term conditions like this, aside from mental health. Although this is changing and I imagine it is better than it once was. (Queer, diagnosed in the past 6 months)

I knew little about HIV when I was diagnosed. I thought someone had just told me I had 5 years to live. Now I know it is a manageable long-term condition, you can have babies and you suppress the virus to UD [undetectable] levels. The only problem is the stigma attached to it. Had I been diagnosed with some other illness I would have told my mom and close family members. I would have told my now ex-boyfriend. (Female, diagnosed in the past 6 months)

The contrast between public conceptions of HIV and those within a clinical setting in particular is highlighted by this respondent:

Yes, the illness is [the same as other LTCs], though the stigma around HIV is very different to, say, something like diabetes. It's acceptable to discuss that openly in any environment. With HIV, people's reactions are very different. We are a long way from HIV being viewed as just another long-term chronic illness. (Male, diagnosed 4–5 years ago)

From a biomedical perspective, HIV was most definitely seen as another LTC and respondents welcomed the surety and confidence that this provided – that it was a manageable/treatable condition. However, respondents were also overwhelmingly adamant that it was profoundly different. It was different because it did not elicit sympathy in ways that other LTCs did, rather it resulted in judgement, and bodily experiences of 'contagion/infection' were a very dominant narrative, even in the context of viral suppression as a result of effective ART. The feeling of *being infectious* is, clearly, not linked to actual viral infectiousness, a legacy, it would seem, of HIV stigma.

Interestingly, respondents articulated an ambivalence with the way in which health professionals embraced the normalised approach to HIV – many were of the view that it is reassuring to hear that HIV is 'not different'. The medicalised discourse of 'normalcy' provided by health professionals, in particular, was welcomed:

It has been compared for me as similar to diabetes, which helped me to understand that there's thousands of people coping with the same problems and similar issues. (Male, diagnosed 1–2 years ago)

Others, however, found this approach potentially undermined the impact of the social significance of living with HIV:

I've found that my GP and the NHS in general treat HIV like any other long-term chronic illness, but HIV has so many nuances together with the mental and social elements. I would not, and could not, access generic services because none of it addresses the needs of someone with HIV. (Male, diagnosed 4–5 years ago)

I understand medically that some professionals compare living with HIV as the same as living with diabetes, however, the stigma attached to HIV and the preconceptions people have, I feel, means this is not the case. (Female, diagnosed 4–5 years ago)

Race (2001) suggests that medical technologies, particularly viral load testing, have had the effect of making the epidemic undetectable (p. 172). However, the biomedical imperative to reduce 'HIV health' to this primary clinical marker not only ignores the 'social diagnosis' described above but it also becomes a vehicle through which HIV 'becomes visible as a private responsibility, as a 'chronic manageable illness', as something about which it would be shameful to make too much of a fuss' (Race, 2001: 178).

It remains the case, as Race (2001) suggested, that the absence or presence of clinical markers fundamentally underpins the ways in which HIV is conceptualised, treated and experienced. Respondents' narratives reflect Race's (2001) arguments but simultaneously speak to a desire to foreground very real, hidden (stigmatised), illness experiences that sit at the heart of life with the virus. The desire for viral undetectability thus sits side by side with the need for clinical and social validation of the illness experience which is otherwise obfuscated by the medical discourse. The contemporary context of self-management, or 'private responsibility', to which Race (2001) refers, amplifies this experience.

Discourses of normalisation, articulated, for example, by health practitioners are, thus, both desired and resisted. This respondent suggests, however, that closing the space in which 'to make a fuss', might have the effect of, at best, muting the social impact of his illness or, at worst, actively silencing it:

I feel incredibly blessed and incredibly lucky that it's a manageable condition now, it's not in any way shape or form a death sentence and so I do try and always keep that in mind but, at the same time, it's very difficult to be grateful for something which is a huge burden ... They minimise your experience and they, they kind of think that, you know, you're fine, the drugs are okay, and you'll be great. (Male, diagnosed 3 years ago, Interview 1)

In rendering HIV 'everyday', spaces to articulate the experiences of living with HIV have shrunk. Paradoxically, the possibility of actively articulating an HIV-positive identity in this context may also be reduced, or perhaps seen as not necessary, in a context where HIV is 'normal' or 'everyday'. It is perhaps the case that the more 'chronic' a condition becomes the less 'acute' the need to provide social and clinical validation of the illness – a situation which is compounded by the absence of public education and awareness campaigns (certainly outside of major cities) and the ongoing closure of HIV support organisations due to reduced funding (Dalton, 2016):

It can be minimised by some people ... I think there is a huge amount of self-exerted pressure not to talk about it. (Male, diagnosed 3 years ago, Interview 1)

Discussion

The question which framed this research was: Is living with HIV in the United Kingdom different in a contemporary context, and, if so, how? The results of this research project indicate, perhaps unsurprisingly and in line with other research, that it is both significantly different, yet frustratingly similar – the data suggest that it is characterised by a combination of complexity and confidence (both biomedical and personal) though remains, for many, underpinned by past (but tenacious) legacies of fear, distress and stigmatisation. In the context of treatment, in particular, the results demonstrated positivity, strength and determination which are rooted in clear knowledge, understanding and faith in treatment. Treatment possibilities also provide the scope and space for anonymity and withdrawal – some respondents chose to remain silent and abstracted from the experiences of living with HIV – an option which would not have been available historically. Yet, there are also elements of living with HIV which clearly continue, as Squire (2010) suggests, to strongly 'resist normalisation'. These contradictory experiences echo Persson et al. (2014), whose research with HIV doctors in Australia similarly

revealed an intriguing tension between describing HIV as normal yet special; between wanting to mainstream the disease vs. emphasizing its distinct care needs; between positioning HIV as just another chronic illness vs. highlighting its extraordinary history and continuing stigmatization and marginalization of those affected. (p. 12)

This research underlines the fact that contemporary experiences of living with HIV are highly paradoxical, being both mundane and extraordinary.

It also highlights one of the ironic consequences of normalisation – the muting effect of normalised expectations. The pressure to conform to these expectations reduces the legitimacy of fear, anxiety and distress in the face of a dominant medicalised discourse, which is one of success and ‘normality’. The legacy of biomedical achievement, coupled with the history of political struggle, makes it difficult to articulate dissenting, or at very least different, perspectives. Owen and Catalan (2012), in their work on narratives of ageing with HIV, point to the ways in which their respondents ‘constructed “moral identities” in relation to circulating discourses about successful ageing and living with HIV’ (p. 66). Their participants, in ways which are not dissimilar from the younger people’s perspectives outlined above, ‘sought to position themselves as empowered, independent, people living with HIV’ (Owen and Catalan, 2012: 66). However, this perspective was one which their participants found hard to sustain, as they experienced increased illness and uncertainty. The ‘moral identity’ work of trying ‘to keep it together’, while particular to some aspects of ageing with HIV, is also useful in understanding the tensions of ‘normalcy’, where sometimes it is not possible, or desirable, to simply ‘get on with it’, in ways which might be socially and medically expected (Owen and Catalan, 2012: 66). Furthermore, Owen and Catalan (2012) suggest that one consequence of normalcy is that ‘society now requires the person with HIV to abandon the “sick role”’ (p. 67). Yet, the findings of this research, as with other mainstream chronic conditions, suggest this is not possible or, for some people, desirable. The ‘sick role’, in the context of HIV, is one from which it is not possible to escape, given that the everyday lived experiences of HIV are ones which are both normalised, through effective medication, yet, simultaneously shamed and shaming.

This suggests that the ‘sick role’, in the context of everyday chronicity, is highly complex and without direction or precedent (Bury, 1988). In contemporary society, as Nettleton (2013) suggests, the ‘sick role’

is more diffuse and responsibilities for responding to symptoms and managing illness potentially more onerous. Even in those circumstances where people are not blamed for the onset of a condition, there is an expectation that people should do what they can to get better. A positive personality and creative response to disease is triumphed. (p. 72)

Yet, HIV remains a stigmatised, (now) LTC – which requires a great deal of ongoing ‘illness work’, which cannot always be made transparent due to fear/stigma (Grue, 2016). It is a role which many respondents in this study sought to occupy – tussling with the tensions of normalcy and discourses of empowerment.

To conclude, this study has identified contemporary tensions and challenges among young people recently diagnosed with HIV, a group whose voices have been given little prominence in recent literature. HIV has receded in prominence from the public health agenda with different consequences. Persson et al. (2014) found that ‘although HIV had become far less invested with negative meanings, it had not been reframed by a more informed discourse so much as having “fallen off the radar” of public consciousness’ (p.

12). The more HIV is ‘mainstreamed’ or normalised as an everyday chronic illness, the more biomedical HIV narratives dominate, and the less public and policy priority it receives. Therefore, the tensions and contradictory experiences which are part of the everyday lived experience of HIV become increasingly difficult to voice. Flowers (2010) argues, ‘it is the chronicity of this “everyday” problem [past constraints and future possibilities] that demands some recognition from service providers and policy makers’ (p. 14). Opportunities (both discursive and embodied) and the legitimacy to express doubt, anxiety and fear, while acknowledging the significance of normalcy, are critical to the experience of everyday life with HIV.

The generation of which Sullivan (1998) wrote experienced the extraordinary transition to biomedical normalisation. The generation with which this research has been concerned continues to face the contradictions and tensions that normalcy brings: not least the challenges of finding the space to articulate anxieties in the context of ‘disease triumph’, while occupying a legitimate (yet hidden) sick role, from which there is no escape – one of the contemporary challenges which might have been unimaginable for earlier generations of people living with HIV.

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