



Changing and unfinished narratives of the mental health impact of HIV in the UK

Jose Catalan^a, Damien Ridge^{b,*}, Barbara Hedge^b, Anna Cheshire^b

^a Central North West London NHS Foundation Trust, South Kensington and Chelsea Mental Health Centre, 369 Fulham Road, London, SW10 9NG, UK

^b School of Social Sciences, College of Liberal Arts & Sciences, University of Westminster, 115 New Cavendish Street, London, W1W 6UW, UK

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ABSTRACT

The mental health impacts of HIV have evolved significantly over the last four decades, in parallel with changes in the virus's overall health consequences. This study charts transformation in narratives about mental health problems associated with HIV over the course of the epidemic, as outlined by people with HIV (40%), professional carers (45%) and activists (25%) in the UK. In particular, our study examines evolving mental health impacts and changing service provision during three key periods: The early days of the epidemic; after the introduction of effective antiretroviral therapy (ART) in 1996; and in more recent times as HIV came to be regarded as a chronic manageable condition. Fifty-three participants were recruited: Male (68%), female (32%), White (90%), African/Afro Caribbean (6%) and South Asian (4%). Results indicate that despite important changes in the severity and nature of the mental health impacts of HIV, there were persistent challenges, related to the long-term mental health consequences of HIV among earlier generations of people with HIV. There were additional challenges associated with: ageing with HIV; the development of sexual dysfunction; and the possibility of neurocognitive impairment. The organization of mental health care for people with HIV moved from specialist teams to general practice, presenting challenges of mainstreaming care. The commissioning and delivery of mental health services need to be sensitive to the ever-changing social contexts and the potential for 'left behind' people living with HIV, despite the overall 'naturalisation' of HIV.

1. Introduction

The health impacts of HIV in terms of mortality and morbidity have changed significantly since what came to be known as AIDS was first described over 40 years ago (Centers for Disease Control, 1981). Following evidence of the efficacy of highly active antiretroviral therapy (ART) in 1996 (Williams & De Cock, 1996), reductions in mortality and morbidity of HIV disease significantly improved the prospects of people living with HIV (Murphy et al., 2001). The psychological impact of HIV, recognised from the start of the epidemic (Catalán et al., 1995; Citron et al., 2005), also changed in response to ART, with a decline in acute psychiatric disorders and an increase in the prevalence of mental health problems of the chronic variety, including depression and anxiety (Adams et al., 2016; Catalan et al., 2000).

The life experiences and expectations of successive generations of people with HIV (and those at risk of acquiring HIV) have also played a part in the manifestation of the mental health impact of HIV. Owen and

Catalan (2012), for example, studied a sample of gay men ageing with HIV and identified narratives describing biographical disruption, loss of life objectives, multiple AIDS-related bereavements, and a long history of dealing with HIV-related issues, even in the ART era. More 'progressive' narratives, on the other hand, tended to establish storylines aimed towards life objectives; however, these participants were mainly diagnosed in the ART era and so avoided many HIV-related losses and traumas. Odets (2019) described the HIV experiences of three communities of gay men for whom the contexts of their lives were quite different. The first group included older men who confronted the epidemic before the introduction of ART in 1996 and who experienced grave uncertainties, fears, and lived through ongoing deaths. The second or middle group encountered HIV post-1996 and had less direct experience of the traumas and concerns from the earlier period. The third group of younger men had no exposure to the early epidemic and its traumas, and were more likely to perceive HIV as a treatable and manageable condition.

* Corresponding author.

E-mail addresses: j.catalan@talk21.com (J. Catalan), d.ridge@westminster.ac.uk (D. Ridge), barbarahedge124@btinternet.com (B. Hedge), a.cheshire@westminster.ac.uk (A. Cheshire).

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Those described by Odets (2019) as confronting the epidemic before the introduction of ART saw important changes in political, social, and economic circumstances. In the early period, media-driven negative attitudes and stigma, a conservative political context, and financial constraints worsened the psychological impacts of HIV. As effective treatments became available and social attitudes became more positive, the social context included greater tolerance, even if economic difficulties were continuing. In more recent times, financial austerity and changes to health care provision created new difficulties for people living with HIV (Catalan et al., 2020). The fact that many survived and lived much longer lives than had been originally anticipated is to be celebrated. Nevertheless, the mental health challenges and social difficulties associated with ageing with HIV – in particular, for the generation who lived through the worst period of the epidemic – continue (Meadows et al., 1998; Owen & Catalan, 2012). A recent report from a London clinic dedicated to people ageing with HIV found that mental health disorders were the third most common co-morbidity, with over 15% suffering depression and/or anxiety disorders (Pereira et al., 2022).

Concerns about HIV-associated dementia were common in the early days, however, the prevalence of dementia was lower than anticipated and usually associated with advanced HIV disease (Catalán et al., 1995). Neurocognitive impairment has also been found to be uncommon (Barber et al., 2017), and when present it is often associated with confounding conditions, such as severe depression or substance use (Haddow et al., 2018). There is concern, however, about the possible risk of neurocognitive impairment among people ageing with HIV (Aung et al., 2021). However, people ageing with HIV are known to use a range of strategies to improve their mental health, including shifting focus away from their difficulties and securing external support (Rosenfeld et al., 2018). The intersectional nature of health-related quality of life and stigma among people ageing with HIV (e.g., according to sexuality, ethnicity, age, class), suggests that individualised interventions are likely to have limited impact (Hsieh et al., 2022).

To understand the needs and desires of this population, it is now important to study the way changes to the clinical outcomes of HIV, with an increasing older population with HIV, including the impact of government austerity measures, have affected mental health and access to care. In this UK-based study, we aimed to document mental health challenges as well as the care and support responses developed at different stages of the HIV health crisis, by analysing the voices of key participants in the epidemic. Participants describe first the mental health problems that developed in the pre-ART days (1981–1996) and the interventions available at the time, including information about the delivery of care (person-centred model, community organizations, volunteers, and activists¹). We then detail the ART (1996–2019) mental health landscape, focusing first on the early impact of effective antiretroviral therapy (ART). Finally contemporary health interventions and models of care are explored in this current era, where HIV is constructed as a chronic manageable medical condition.

2. Methods

2.1. Design

The study was qualitative using one-to-one narrative interviews to collect participant stories around involvement in the HIV epidemic. A qualitative approach was chosen as the best method to gain in-depth information about mental health, and one-to-one narratives were elicited to explore detailed personal accounts and follow-up emerging issues. Narratives themselves provide people with overarching means to create and transmit meanings about everyday life (Greenhalgh &

¹ Activists include those who were/are working in groups or organizations (paid or unpaid) to support the rights of people with HIV; they may or may not have HIV themselves.

Hurwitz, 1999), compelling listeners to consider the emotional and moral dimensions of their experiences.

2.2. Participants and recruitment

A total of 53 participants with long-term associations with HIV services, including people living with HIV, were purposely recruited into the study, representing wide-ranging experiences of HIV. Different roles played in the UK HIV epidemic, and the unfolding of diverse health care specialities which catered to those with HIV were included. Inclusion criteria were that participants should be 18 years old and over, be able to attend an interview in London or in a location to which the researchers could travel to (which meant living in the UK mainland), and have had at least 10 years experience with HIV. Exclusion criterion pertained to the presence of significant mental illness at the time of interview. Mean participant age was 58 years old, with a range of 39–75 years. Table 1 provides details of the demographics, role, and HIV status of participants. Note that all those living with HIV were diagnosed pre-ART.

Key voices in the HIV field who offered a range of experiences were initially identified via the professional and research networks of the authors. Later, snowballing sampling was used to locate participants missing from our original list (e.g., those from Black and ethnic minority backgrounds). Our final sample included people with HIV, healthcare professionals, HIV activists and charity workers, politicians, and HIV-related policymakers.

2.3. Procedure

Ethical approval for the study was obtained through the University of Westminster Psychology Ethics Committee (Reference: VRE1516-0494). Full written consent from each participant was obtained prior to interview. Due to the sensitive nature of the topic, a ‘sensitive research protocol’ was adopted (e.g. monitoring the participant for signs of distress, pausing or stopping interviews if needed, use of a narrative interview approach so participant control could guide the topics covered). Provision was in place for post-interview psychological support if

Table 1
Participants’ demographics, roles in the epidemic, and where given, HIV status.

Demographics	N (%)	N (%)	N (%)
Gender	Male 36 (68)	Female 17 (32)	Total 53
Ethnicity	White 35 (97)	African/Afro-Caribbean 2 (12)	South East Asian/Indian 2 (4)
HIV Status	Positive 19 (53)	Negative or not reported 17 (47)	2 (12) 15 (88) 21 (40) 32 (60)
Role ^a	Health Professionals 14 (39)	Activist 9 (25)	Charity Worker 3 (8)
	people with HIV 19 (53)	Other ^b 6 (17)	10 (59) 0 (0) 1 (6) 2 (12) 4 (24) 24 (45) 9 (17) 4 (8) 21 (40) 10 (19)
Mode of transmission ^c	MSM 14 (39)	Heterosexual 1 (3)	People who inject drugs 2 (6)
	Haemophilia 2 (6)	0 (0) 2 (12) 0 (0) 0 (0)	14 (26) 3 (6) 2 (4) 2 (4)

^a Participants may have more than one role.

^b Journalist/Politician/Clergy/Academic.

^c Self-reported as most likely.

necessary. Interviews were conducted between April 2016 and November 2019 by a consultant clinical and health psychologist (BH), a consultant psychiatrist (JC), and a health psychology researcher (AC). Two interviewers (JC & BH) had many years' experience of working in the HIV field, and another (DR) had extensive experience in conducting interviews to elicit personal narratives. A combined narrative and semi-structured approach was used (Anderson & Kirkpatrick, 2016). Participants were encouraged to tell their own stories of working/living with HIV from their initial involvement to the present time, using a 'what happened after that?' approach. Prompts were also used to cover specific topics of relevance e.g. mental health challenges, and treatment options. Interviews aimed to gain a complete picture of living/working with HIV. However, the focus of this article is on mental health impacts (an example topic guide is provided in Supplementary File1). The interviews were recorded and transcribed verbatim by a professional transcription agency that signed a confidentiality agreement. Interviews lasted on average 81 min, ranging from 20 to 196 min. Transcripts were checked for accuracy and returned to the participants for further checking. Identifying names and places were removed from the data.

2.4. Analysis

Data were analysed iteratively and inductively (Bowling, 2014), across the different time periods of the HIV epidemic. The study used reflexive thematic analysis and an experiential orientation to understanding the data, which prioritises the examination of participants' experiences of the topic (Byrne, 2022). To explore changing mental health narratives across the complete dataset, themes emerging from the data pertaining to mental health were explored further. Semantic coding was used here, i.e. a focus on the surface or descriptive meaning of codes. Whilst data from different groups (e.g. persons with HIV, health professionals, activists) highlighted different experiences and areas of concern, there was a broad congruence between groups on pertinent topics across time periods, thus all data were analysed together. JC drafted the first version of the paper which was elaborated, edited and agreed upon by all of the authors to reach a robust understanding of the results. All authors were subsequently involved in editing and finalising the manuscript. NVivo 11 software was used to explore and manage the data throughout.

2.5. Theory

In interpreting our results, we rely not only on narrative approaches to research which evoke different meanings regarding various time periods (Greenhalgh & Hurwitz, 1999), but also on the concept of 'naturalisation' as it pertains to HIV (Squire, 2010). Here, naturalisation saw HIV as increasingly cast as natural and manageable over time, through processes such as medicalisation (e.g. via successful treatments) and normalisation (e.g. via anti-stigma work) (Hedge et al., 2021). This is in contrast to the exceptionalism that previously distinguished HIV in the early stages of the epidemic, where HIV's high fatality rate, incurability and stigmatisation were a feature. Nevertheless, Squire argues that those whose experiences do not align with naturalisation narratives risk being 'left behind'. Naturalisation thus became a 'sensitising concept' that we used throughout our analysis to be inclusive of outlier perspectives.

3. Results

To illustrate the changing nature of mental health challenges, the results are presented over three historical periods, starting with the early days of the HIV epidemic between 1981 and 1996 before effective antiretroviral therapy (ART); followed by the 1996–2010 ART years when effective treatments start to be widely implemented; and then the 2010 to 2019 period when the perception of HIV increasingly developed as a chronic treatable condition.

3.1. EARLY DAYS: 'I was back on the AIDS ward and during the night ... there was screaming'

The first 15 years were considered the most traumatic and disturbing period of the epidemic, with mounting fears about the spread of HIV first within stigmatised minorities, and later radiating out to the rest of the population. Media and public views were frequently intensely negative; and the lack of effective treatment meant infection with HIV was widely perceived as a death sentence. Clearly, for reasons such as homophobia, mental health problems were prevalent in affected populations, even before a diagnosis of HIV was made. Mental health often deteriorated as the person received a diagnosis, became unwell and/or developed AIDS. In response to the burden of mental health problems, specialist psychological and social support treatments were established. While the significance of a positive HIV test was initially unclear, deterioration in health was a common pattern, and many people became rapidly unwell. Major depression, manic episodes, fear of dementia, and suicidal behaviour were prominent concerns. The majority of people with HIV were gay men, but other demographic groups, like injecting drug users, people with haemophilia, women and Black Afro-Caribbean people soon started to emerge. The potential for life-changing impacts of an HIV diagnosis were described by some, while others were more able to accommodate their new diagnosis, as described below:

'So, it was a real shock to me, and I began to feel quite ill, quite stressed, and I got a lump in my belly ... it really was the start of a new chapter for me, because I was suddenly homeless, penniless, loverless, back on an AIDS ward. During the night, the man in the bed next to me died and there was screaming'. [male, living with HIV]

'... we were pretty sure that disease led to death ... and I thought, well, I will just get on with it ... I managed to live day by day, I didn't look too much in the future'. [male, living with HIV]

As people became unwell, admission to HIV wards was often required. These wards became both a refuge and a source of further distress because the experience of illness and death was ubiquitous:

'The wards were places of great contrast ... it was very difficult and very distressing, but at the same time there was an element of laughter, of visitors, of animation'. [male, living with HIV]

Severe psychiatric disorders often developed among those living with HIV. For example, suicides 'tended to happen in clusters ... in the early days' according to a team psychiatrist, although in time, such events reportedly reduced in frequency. The HIV wards sometimes resembled psychiatric units: Psychiatric units were at that time reluctant to admit people with HIV, adding pressure to the care provided on HIV-specific medical wards.

'I was working in an acute psychiatric unit, and we had a patient who had HIV dementia, and we had no facilities to look after him ... he was demented and psychotic, and needed to be in a psychiatric ward, but we didn't have physical facilities in terms of his incontinence and infectious bodily fluids, and it was really awful'. [female, psychiatric nurse]

While the majority of people with HIV were men who had sex with men (MSM), groups where HIV was less prevalent, such as women, could experience additional social isolation and related difficulties:

'For gay men, the local charity was there and provided good support for them in those days, and they had their whole community around them. And the women had nobody, they were so isolated, socially isolated, and dying in the same way, and were single parents as well. None of them had a partner.' [female, community nurse]

The demographic profile of people with HIV continued to evolve, and soon Black Afro-Caribbean people started to present to HIV services, with different mental health issues, such as surviving torture and seeing

very many of their peers die from AIDS-related illnesses. Social isolation and domestic difficulties combined to make the lives of some Black African people with HIV especially crisis prone, as this Black woman living with HIV told us:

‘My relationship was really, really bad, domestic violence ... I had a lot in my mind, but being in this country is tough if you come from a culture like ours where you have a lot of people you can talk to, and then suddenly you don’t have anyone, and people don’t talk about their business.’ [female, living with HIV]

In response to the scale and intensity of mental health difficulties that developed in the early days of HIV, two remarkable developments followed. The first one involved the growth of grassroots HIV community organizations providing support and counselling. The second concerned the provision of integrated NHS care from medical and nursing teams, including mental health specialists attached to the HIV services. Both efforts represented important steps in the development of a model of person-centred care for people with HIV. HIV community organizations grew organically out of the experiences of people with HIV, as described by an activist living with HIV involved in developing what became the *Terence Higgins Trust*, which quickly had to switch its focus from research to care, ‘we realised fairly quickly from autumn of ‘82 onwards, that we needed to do direct services, and particularly about education and mental health.’ Community organizations involved not just people with HIV themselves, but also a range of sympathetic volunteers who continued to expand the support and counselling provided. In parallel with the growth of support and counselling led by HIV community organizations, an integrated model of care involving nurses, doctors, psychologists, psychiatrists, and other professionals, such as health advisors and social workers, developed and soon became established in NHS HIV wards and outpatient clinics.

‘It was the ideal model, the utopia of healthcare, and for some years we all managed to achieve it ... it was a real first name terms, no patronising, no talking over you ... [psychological care] was brilliant ... I started seeing the psychiatrist years and years ago, he was the mainstream of my psychological wellbeing ... every six months he listened, he knew my whole story, and he also became, without overstepping a boundary, a sort of friend in a way.’ [male, living with HIV]

Nevertheless, integrated approaches to mental health had to be developed in stressful and at times hostile environments. An HIV nurse working with injecting drug users with HIV described how her team responded to patient difficulties in the face of the lack of support from other professionals:

‘We developed a service around the patients, not expecting them to fit in with us, and we prescribed their methadone, and that was the carrot, so they came to get their methadone prescription and their [other] medication ... but the psychiatric hospital staff made it very clear they didn’t want anything to do with prescribing methadone ... that methadone prescribing was not a psychiatrist’s job ... we later realised there was a lot of mental ill health amongst our patients, and so a post was created for a consultant psychiatrist, but there was very little interest in the job and only one applicant that was appointed’. [female, nurse]

3.2. THE mixed blessing of antiretroviral therapy: ‘ART made a huge difference ... but what were they going to do with their lives?’

Research first published in 1996 revealed the game-changing effect of combining several antiretrovirals at once for treatment (Williams & DeCock, 1996), eventually significantly improving the mortality and morbidity associated with HIV. The medical improvements – not to mention hope – resulting from the introduction of successful treatments reduced the frequency of severe mental health presentations, such as

manic episodes, severe depression, and dementia. In this phase of the epidemic, the identification of both pre-existing and unresolved mental health difficulties was possible. In addition, the unexpected survival that many people with HIV suddenly had to face was a new mental health challenge. A person with HIV who had lived through the change from likely death to hope commented on this experience in the first quote. In the second quote, discovering there was a future raised new challenges, as one charity worker outlined:

‘I think a lot of people who were very ill before the new treatments came but survived, have been damaged psychologically and physically, and I know that was my case. Over this time, I have had several sessions with the psychology team at the hospital for anxiety and depression. A few years ago I had a florid manic episode ... I’d never got my life back together fully in the ways that most people would expect’. [male, living with HIV]

‘So, for many people we had known for some time, there was definitely that conversation, OK, I haven’t died, so what do I do now? People whose lives were more chaotic, who were and perhaps still are drug users, not a lot had changed, it is just that they are alive ... others who had been working or studying before would now say, I haven’t worked for 10 years and in the meantime, computers have come in ... Most of it was about loss of confidence, not skills’. [female, charity worker]

Opportunities began to present themselves to those with HIV who had given up on life’s options. The possibility of picking up the threads of a pre-HIV life, including the development of emotional and sexual relationships, created new opportunities and concerns, as a clinical psychologist discussed in the first quote below. Resuming sexual relationships was complicated, and a significant proportion of people with HIV experienced sexual dysfunction as reported by a psychiatrist in the second quote:

‘... being well also meant wanting to go back to a social life, to have sex again, and so there was a risk of transmission of HIV to others, something that had not happened when people were unwell and had no interest in sex’. [female, psychologist]

‘Around this time, we started to see people living with HIV wanting help for sexual dysfunction problems, like loss of interest and erectile dysfunction ... It wasn’t just a question of prescribing Viagra or similar drugs, there were psychological and personal issues as well as relationship issues ... all part of the process of how to live with HIV, rather than how to die’. [male, psychiatrist]

As in the early days of HIV, the model of integrated care involving HIV doctors and nurses, mental health workers, and charities continued, although the changes brought about by ART, led to fewer people with HIV needing hospital beds and an increase in outpatient and community work. The nature of the mental health problems seen also started to change, moving away from acute and severe problems, towards adjusting to drug regimens, and addressing social as well as financial difficulties.

Some people with HIV in the community (confined to narratives about gay men in our sample) who were attempting to return to a life away from the direct pressures of HIV, became more involved in recreational drug use, which could result in adverse health consequences, including poor treatment adherence. A psychiatric nurse working with people with HIV and recreational drug use problems described her work and care changes:

‘My work as psychiatric liaison nurse changed over time ... people were taking recreational drugs, specifically a drug called crystal meth became a real problem, and it ended up pretty much being my job, dealing with the fallout of crystal meth use ... it was having a massive impact on their physical and mental health, they weren’t looking after themselves, they were coming in with hepatitis C, some

psychotic ... Drug clinics were developed to deal with the crystal meth problem' [female, nurse & activist]

The wider context of economic, political, and social changes that followed the international financial crash of 2008 had consequences for the provision of care and support given by the HIV charities and the UK health services, as a charity worker and psychiatrist both describe:

'So, when people stopped dying, the number of people living with HIV grew, and that created twin challenges of needing to do more on prevention and growing pressure on services that had become very underfunded because there was a decline in public visibility and engagement with AIDS issues ... and there was exhaustion by that point, we had been dealing with a crisis for 15–20 years'. [male, charity worker & activist]

'By 2007/8 funding started to become limited and prescribing for sexual dysfunction and HIV related fatigue became difficult ... neither the mental health pharmacy nor the HIV pharmacy was willing to prescribe these drugs, and few GPs were agreeable, so it became a bit of a battle'. [male, psychiatrist]

Mental health treatment for people with HIV became more difficult to fund, and NHS management changes contributed to a more segregated provision of services, a far cry from the previous person-centred model of care:

'We have been very lucky in terms of access to psychology, but we lost the liaison psychiatrist ... the psychologists are now part of the mental health team, not the HIV team, and they have become stricter, they will only offer a 12-week intervention and will not deal with alcohol problems'. [male, consultant]

3.3. HIV is a chronic but not always manageable disease: 'anxiety and depression are general labels that cover many different problems ...'

Progress in the development of antiretrovirals with fewer side-effects and simplified regimes, together with the continuing advances in dealing with co-morbidities and risks associated with HIV, meant that people with HIV were now considered as 'living with a chronic manageable disease'. However, not all people with HIV found life as manageable as this discourse suggested. The contrast between the assumptions of 'managing' and the actual lived experience could be striking, due to the significant psychological scars left by HIV and other life circumstances. An older woman living with HIV described her feelings of uncertainty in the first quote below, while a man with haemophilia and experience of chronic illnesses and loss anticipated grief in his narrative (second quote):

'I've just like come out of the HIV bubble, and I'd say I'm scared ... it's like, it's frightening, like you are venturing out into something new and unknown, and that's your future. Because that's something you never contemplated, actually having that future.'. [female, living with HIV]

'I find it hard to feel very much more optimistic about future health, partly because of my arthritic problems have been worse. I'm feeling sort of ... like the skeleton is wearing out ... I should feel more optimistic ... maybe it's my wife's illness, this feeling of mortality is with me for all sort of reasons'. [male, living with HIV]

Many of the generation of people with HIV who lived through the early traumas report continuing to be unsettled, even if less distressed than previously. There were many old and newly unresolved issues reported, including an enduring sadness from the number and manner of deaths, and from personal losses of many friends who did not live long enough to receive ART. A psychiatrist working with people with HIV describes in the first quote some of these issues. In the second quote, a charity worker described 'the greying of HIV' as both a blessing – so

many people with HIV have survived – and a source of new problems:

'Over the years, there has been a change in the kind of problems patients present with, with more cases of anxiety and depression, and fewer acute, urgent cases. Anxiety and depression are general labels that cover many different problems – side-effects of treatment, return of cancer suffered years before, pressure from the DWP [Department of Work and Pensions] for further review of benefits, but mostly baggage of half-resolved problems from before the person developed HIV'. [male, psychiatrist]

'Those older than that had died, those right on the cliff edge had their health often badly damaged, the treatment came just in time, but their immune system had already been badly damaged. And of course, those who are now in their 60s had lost a lot of their social support network, had often cashed in what minimal pension they had ... so now they face an old age of poverty ...'. [male, charity worker & activist]

Additional forgotten issues affecting people with HIV beyond the basic medical and mental health support were also raised, such as problems with benefits and the cost-of-living:

'... social isolation, the threat of losing benefits, to the point that some people stop their drugs so that they (became ill to) get their benefits'. [male, living with HIV]

Efforts to support people with HIV are now a challenge due to limited resources. The earlier model of HIV medical care based on the HIV unit, with integrated care from other specialists, including mental health workers, became disjointed. Doctors and people with HIV also expressed concerns about the ongoing poor links between HIV services and general practice, such as coordinating mental health input and prescribing, and people with HIV unable to access the same GP who understood their situation. This left people with HIV feeling unsupported and 'forgotten', as illustrated by a nurse running groups for older people with HIV in the first quote:

'... existential stuff, coping with death, dying, how will I die, will I die like my friends, or will it be different? Depression, social isolation, there is a feeling that they have been forgotten, that there was a great deal and now there's not very much.'. [female, community nurse]

'I've got a depressed guy ... we'll start citalopram and [he'll] come back and see me in four weeks, can't come and see the psychiatrist for four months, so I say, I cannot really start something I am not going to be monitoring, by the time the letter gets to your GP who is going to be in a bad mood, saying can you have a look at this, he'll say well I haven't got a letter yet because it's lost in the hospital system'. [male, doctor & activist]

4. Discussion

What is novel about this paper is the illumination of narratives of mental health that evolved over different HIV eras in the UK, as told by a range of participants, including activists, people living with HIV, healthcare workers and others. Our participants' narratives illustrate how the psychological impact and mental health problems associated with HIV changed over the decades in parallel with the medical and therapeutic progress that took place during that time. In interpreting our results, we rely not only on a narrative approach to research which evokes different meanings in various time periods (Greenhalgh & Hurwitz, 1999), but also the concept of 'naturalisation' as it pertains to HIV (Squire, 2010). As Squire argues at length, the process of naturalisation creates ambiguities, contradictions as well as power imbalances, establishing a subgroup of those with HIV who are potentially 'left behind'. In turn, it provides us with the potential to understand what could be done better.

The starting point for HIV was severe mental health problems, including severe distress and acute psychiatric disorders against a background of inadequate medical treatments. With successful treatments, difficulties evolved into chronic conditions such as anxiety and depression, which were linked to uncertainty about the future and the need to adjust to an unexpected survival (Adams et al., 2016). In parallel with these evolving psychological difficulties, were supportive responses included the involvement of volunteers and charities, and the development and strengthening of a person-centred model of care (Catalan et al., 2020). There were also ongoing needs to cope with medication side-effects and adherence to complex drug regimens. Interventions to increase treatment adherence and to promote more independent living became part of therapeutic supports.

Following the introduction of ART, people with HIV entered what was regarded as a more natural, 'chronic manageable condition' era. In spite of what may be regarded as positive changes and a reduction in the adverse mental health impact of HIV, participants nevertheless continued to describe difficulties adjusting to living with HIV. In a recent global systematic review, Hoare et al. (2021), reported a high prevalence of common mental health problems like depression and anxiety among people currently living with HIV, that ranged from between 28% and 62%. Furthermore, mental disorders are associated with worse HIV-related outcomes (Mayston et al., 2012), with an excess mortality among people with HIV (Haas et al., 2020). The good news is that there is evidence for the efficacy of interventions for depression and anxiety disorders, as well as the enhancement of coping, among people with HIV (Asrat et al., 2020; Clucas et al., 2011; Harding et al., 2011; Sherr et al., 2011; van Luenen et al., 2018). Peer support in particular is a significant contributor to the well-being of people with HIV, reducing isolation and depression, but there is a risk that reduced visibility of HIV may consequently reduce access to peer support. The provision of mental health care for people living with HIV as well as for those at risk of acquiring HIV is currently seen as fundamental to achieving an end to the epidemic (Collins et al., 2021; Remien et al., 2019).

The introduction of ART made it possible for many with HIV to resume emotional and sexual relationships, but for some this led to the development of sexual difficulties, both for men and women (Asboe et al., 2007; De Vincentis et al., 2021; Schönnesson et al., 2018). Help for sexual difficulties was not always readily available, partly due to the shortage of trained therapists, but also due to the lack of attention to the complex causes of such problems, such as personal and relationship problems, medication side-effects, and the presence of medical co-morbidities. Suicidal ideation and plans were more common in the early period of the epidemic, frequently associated with the poor prognoses for those with HIV and severe psychiatric disorders (Catalan et al., 2011), but were infrequently reported by our participants. It has been suggested that suicidal risk remains high in people with HIV, with a suicide rate many times higher than the global general population (Pelton et al., 2021). There is, however, evidence that treating common psychiatric disorders in HIV treatment centers could lead to significant reductions in suicidal behaviours (Bantjes & Kagee, 2021).

The practical organization of the delivery of mental health care and support for people with HIV has undergone significant change over the years. An important shift in the development of care for people living with HIV involved the move from inpatient HIV services towards those based in specialist HIV outpatient clinics and general practice. Research into the experience of primary care for people with HIV in London has shown that while two in three reported a good experience with their GPs, others felt uncomfortable asking questions about HIV, feared (or had anticipated) stigma, or had concerns about the level of expertise available to deal with their problems (Rai et al., 2019), highlighting difficulties with mainstreaming services. The person-centred care that developed in the early days of the epidemic has therefore had to adapt to social and NHS changes (Catalan et al., 2020). While some of the 'one-stop shop' model of care has survived, broader policy changes affecting the NHS have led to fragmentation of services. Professional

organizations, such as the British HIV Association, British Psychological Society and the Medical Foundation for AIDS & Sexual Health (2011) have continued to champion the need for psychological support for people with HIV. They have set standards for psychological support that emphasises the need for coordination and the creation of pathways of care. Here, peer support is regarded as essential to HIV care, improving coping, mental health and clinical outcomes for people living with HIV (Berg et al., 2021; Peterson et al., 2012).

Consistent with the aims of these organizations, but broadening their remit, *Fast-Track Cities London: Evolving the Care of People living with HIV in London* (2021) contains a detailed analysis of the strategic aims and commitments of London's political, NHS and public health organizations to achieve in the capital by 2030. One of the structural priorities is to achieve the best health and quality of life for people with HIV, including the need for coordination of care, integration of primary and secondary care, and ensuring the right of mental health care for anyone requiring it, especially the most vulnerable. The goals are ambitious, but London has already achieved success in tackling HIV (*Fast Track Cities, 2023*), being one of the first cities to exceed the UN's 90-90-90 targets, i. e. for 90% of people with HIV to know their status, 90% of those diagnosed to receive ART, and of those 90% to sustain viral suppression by 2030. It is important to note that over time, those living with HIV will increasingly comprise people ageing with HIV (Rosenfeld et al., 2018), many subsequently presenting with co-morbidities, such as diabetes, cardiac problems and other conditions, all of which may bring associated psychological problems. However, typically, the focus of HIV and ageing research is on physical co-morbidities. Our study has suggested that mental health challenges and social support needs are equally important to include in discussions on policy and practice.

In terms of study limitations, whilst efforts were made via snowball sampling to recruit a range of views, and our findings are congruent with much literature in the field, recruiting via researcher personal and professional contacts, may have resulted in a relatively narrow range of data collected. With more resources, we could have added additional sources of recruitment (e.g. via advertisements targeted at specific groups), which might have led to less bias in the sample. Groups whose experiences are not included in the study include MSM diagnosed after the introduction of ART, children who have grown up with HIV, transgender people with HIV and migrants with HIV. Migrants to the UK with HIV, for example, face unique challenges including high levels of deprivation and the need to strictly manage information about HIV when it comes to personal networks due to high levels of stigma, including the threat of violence (Chinouya et al., 2017). We also only interviewed a small number of women with HIV, so a full examination of women's issues, such as domestic violence and HIV, sexual and reproductive health rights, mental health issues and navigating the healthcare system particularly around pregnancy and childbirth, are not covered in any depth. Issues within these groups are complex and would benefit from a more specific focus than this study could offer. The focus of the study was very much on the experiences and services in the UK, other countries may evoke different experiences. Whilst these findings have a narrow focus on HIV, they may well be useful for consideration of the long-term mental health impacts of other conditions, such as the Covid pandemic, with many people living with the chronicity of long-COVID. Finally, collaborative or coproduction approaches to research in the field of HIV have a long tradition (Sanstad et al., 1999). Whilst such an approach was beyond the resources of the current project, these ways of working provide valuable insights, support more equal power dynamics, promote community research ownership, as well as drive research impact (Papageorgiou et al., 2022).

4.1. Conclusion

Much has changed in terms of the pattern and severity of mental health problems associated with HIV and how care is approached in the last four decades. Progress has been made in many areas, but as HIV has

become naturalised, clear challenges remain to ensure that people living with HIV are not forgotten and that the psychological impact of HIV is adequately addressed for all. Ageing with HIV can bring mental health difficulties, and suicidal behaviours remain a problem, as does the possibility of neurocognitive impairment. Ongoing structural difficulties and the effective coordination of commissioning and delivering of services in a changing social and political context need constant attention.

CRedit authorship contribution statement

Jose Catalan: Formal analysis, Funding acquisition, Investigation, Writing – original draft, Writing – review & editing. **Damien Ridge:** Conceptualization, Funding acquisition, Investigation, Writing – original draft, Writing – review & editing, Methodology, Supervision. **Barbara Hedge:** Funding acquisition, Investigation, Writing – review & editing. **Anna Cheshire:** Data curation, Formal analysis, Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Damien Ridge is co-investigator on the Roche funded study into carers and Alzheimer's disease: 'Portraits of Care'. All other authors report no conflict of interest.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ssmqr.2023.100386>.

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