‘We can’t be perfect all the time’: Life with HIV before antiretrovirals: A narrative analysis of early published stories by women with HIV in the United Kingdom

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Abstract
Objectives: The experiences of women like me, diagnosed with HIV before the development of effective antiretrovirals, tend to be neglected and overlooked. Research, policy and services can better serve us if our lived experiences are known and understood within a contextual framework. This small study revisited published personal experience stories by women diagnosed with HIV before 1992 in order to examine what the women said and why.

Methods: Due to limited data, a single published collection of 12 stories was chosen, Positively Women: Living with AIDS. Narrative analysis was used to make some overarching sense of identified themes, plots and genres within the women’s accounts. This method allows for a deep contextual reading. I adopted an inductive and reflexive approach using my lived experience to weave in contextual detail and analysis.

Findings: In their search for sense-making, the women often expressed their life with HIV as transformative. Speaking out and peer support helped women construct a more positive identity and develop strategies for survival that were influenced by ideas contextually situated in an emerging public health crisis. However, women also felt defined and confined by their status, and others spoke of a conflict in living up to an emerging HIV subjecthood that was adherent to wellness regimes, self-improvement and positive thinking.

Conclusion: The analysis brings to light some of the contradictions and conflicts within these early HIV narratives. Contextually examining women’s narratives from the perspective of lived experience offers new readings and fresh insights into wider cultural narratives that may resonate with today’s stories of living with HIV.

Keywords
HIV, lived experience, narrative, peer support, treatment, women

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Introduction
We live in the era of successful HIV treatment and a growing number of women diagnosed with HIV when they were younger are reaching older age. Yet, the experiences of women like me who were diagnosed in the United Kingdom (UK) before the treatment breakthrough of 1996 are under-addressed and under-recognized. This could be because effective treatment has partly normalized HIV, and to some extent, silenced talk of it must also be attributed to the invisibility of women in the UK’s HIV response. Key findings in the 2018 report ‘Women and HIV: Invisible No Longer’ suggest that research, policies, and services are not serving women living with HIV. The
report recommends that greater focus is given to women and knowledge gaps are addressed.7 This must include the diversity of different women’s experiences so that treatment, care and support services are responsive to women’s priorities.

Documented accounts by women diagnosed with HIV in the 1980s and 90s provide immediate access to events as experienced 30 years ago. This study offers a contextual reading of a collection of stories from this period, to understand both what the women experienced and how they narrated a stigmatized and silenced condition. Positively Women: Living with AIDS, published in 1992, is a collection of personal experience stories of living with HIV written and spoken by 12 UK-based women from Positively Women, a voluntary support organization based in London.4

There were few women diagnosed with HIV in the UK in the late 1980s and early 1990s, but the pattern was changing. By December 1992, there were 19,065 reports of HIV in the UK, 12.4% of these in women.5 The early HIV epidemic devastated the gay community, which felt both the moral backlash of Margaret Thatcher’s social conservatism and the rollback of public services under her neoliberal project. HIV was attributed to behaviour that fell outside of ‘family values’ – homosexuality, promiscuity, drug use and sex work. The dominant narrative was fear, blame and an inevitable death. Gay activists had to set up voluntary education, support and healthcare services to fill the gap left by Government’s reluctance to fund statutory services. By 1989, there were over 30 national AIDS organizations.6 Although these charities included services for women, they were largely organized around the priorities of gay men. AIDS was not perceived as being a woman’s disease and subsequently a woman-centred response was weak and fragmented.7 Despite the gendered dimension of HIV (how gender inequality affects experiences of HIV and the social and political responses to it), the UK feminist movement failed to engage with the issue.8 It was left to small groups of women living with HIV and their feminist allies to recognize and call out HIV as a women’s health issue.

The first women in the UK to mobilize support for other women with HIV were ex or current drug users. In 1987, they started Positively Women, a London-based support service responding to the lack of women-centred support and information. Positively Women drew loosely on principles from alcohol/drug recovery programmes – peer-led and empowerment through testimony – and feminist consciousness raising – sharing experiences to expose gender inequality, build solidarity and agendas for change, or ‘the personal is political’.9 It was to Positively Women that I was first referred when diagnosed in 1990. I remember sitting in a circle in the front room of their office, high above the bustle of Kings Cross, as we took turns to tell our ‘story’.

Soon after my diagnosis, I spoke out publicly. My story felt sought, validated and legitimized. Telling stories from lived experience within the discourse of censoring and silencing is profound and powerful10 and can be a therapeutic act of self-care that helps re-shape and re-store a sense of self-shaken by diagnosis, illness or stigma.11,12 My speaking out was also part of a political process – an act of my own choosing that broke the silence, challenged stigma and reminded people that women got HIV too. HIV narratives have been central to social change as they work to mediate, resist and shift social realities, and build solidarity and community.13,14 As I repeatedly told my ‘story’ – a co-constructed narrative informed by where, why and with whom I was sharing – I was creating a ‘living with HIV’ self, a moral subject that was empowered and transformed by my experience, similar to the arc of the ‘coming out’ story, whereby narrators proclaim their sexuality.13

Methods

In order to make some overarching sense of the stories, the method of narrative analysis was used – an approach that allows for a deep contextual reading, considering social and cultural contexts and the co-constructed and performative aspects of how we make sense of our lives.15–17 Narratives encourage us to organize thoughts and experiences into a temporal and coherent sequence as the story journeys through a sense-making process to a destination. In doing so, personal narratives may use plotlines and distinct styles, structure and content that belong to specific types of narrative or genres. Since genres are culturally and socially constructed ways of telling a story, they inform how we give meaning to our lives.18 Genres relevant to HIV stories include, but are not limited to, Plummer’s transformative ‘coming out’ genre13 and Frank’s illness genre1 with its different narrative paths of quest (finding meaning), recovery (returning to health) or chaos (no ending).

The analysis used an inductive and reflexive approach to identify narrative patterns, themes and characteristics of types of stories to help answer the question of why the story was told in this way. Having insider knowledge offered unique perspectives and insights with which to address issues relevant to women with HIV. People living with HIV have a long history of setting and reshaping research agendas that translate into needed policy, services and interventions.19

There are very few written accounts of women’s personal experiences of living with HIV before 1996.4,20,21 In order to avoid a comparative analysis by including stories collected by different methods, over different time periods, from women who were affected but not necessarily living with HIV, in other geographical contexts or by editors and researchers with different agendas, one compilation was chosen, Positively Women: Living with AIDS.4 It
is the first collection of women’s personal experience stories of living with HIV from this era published in the UK. The editors, Kate Thomson, a woman living with HIV and working at Positively Women, and feminist ally, Sue O’Sullivan, started to compile the stories in 1989, two years before publication. A second edition in 1996 invited those who were still alive to update their story. The book has two main parts: ‘Our Lives, Our Stories’, followed by an informative section on a range of topics. Analysis focused on the first part. Contributors to the personal stories were women who had been service users, volunteers or employees (often all three) at Positively Women. They could use pseudonyms although a few retained their actual names. Without knowing how the narrators may have self-identified, we can partially deduce their demographics from their stories. It would appear that all are cis-gendered. The majority are white British, one is mixed heritage, two are Black African and one is Irish. Two are in their 20s, the remaining in their 30s. Only one woman identifies as a lesbian. The length of time since diagnosis ranges from eight years to one, with the average being four. Five women were unwell with either a diagnosis of AIDS or episodic illness, three of these women died before the second edition was published. Fifty percent describe a history of drug use. Nine out of the 12 women describe having a professional occupation or university degree or coming from a middle-class family. Women could choose to write or be interviewed. It is not mentioned who chose what. The stories vary in length from only four pages to 44. The three women who had been most heavily involved in running the organization had the longest stories. It is not clear how representative these women were of Positively Women as information on service users is unavailable. Confidentiality fears and language barriers may have deterred some women from participating. The demographic impact of the epidemic was also changing in early 1990s and the editors mention that Positively Women was not yet reflecting the growing number of Black African women diagnosed.

Findings

Some of the stories take a life history approach, starting with early experiences, others focus on the period since diagnosis. According to the book’s introduction, the women were asked to ‘go beyond their HIV experiences’ in order to contextualize and humanize HIV. Most of the contributors construct a narrative of evaluation and sense-making with practical advice and reflections on a wide range of topics. The analysis produced three thematic parts: (1) re-evaluation and redemption post-HIV diagnosis; (2) resistance and conflict to living a life boundaryed by HIV; and (3) living up to ideals of perfection and positivity.

‘Now I actually feel stronger than I was before’

For women diagnosed before the advent of HIV treatment, life had to be abruptly re-evaluated in the light of this shocking information. Despite this unifying event, each woman’s reaction and experience differs, their heterogeneity coming out of multiple negative and positive experiences, different backgrounds, length since diagnosis, health status, family status and so on.

Marianne, 26 years old and diagnosed two years earlier, describes a position of hopelessness and struggle that moves to resolution as she constructs meaning and purpose out of her experience.

I was insecure, and it was only through getting to terms with being HIV positive that I’ve been able to deal with my own fears and my own personality. Now I actually feel stronger than I was before. (p44)

Her story uses the suffering, surviving and surpassing plotline of a ‘coming out’ story, or a quest genre whereby the narrator moves from acceptance to searching for meaning in the experience.13 Within Marianne’s ‘coming out’ genre is a narrative of HIV romance22 that also offers resolution, perhaps allowing Marianne to situate difficult feelings about her past relationship and acquisition of HIV:

He was my biggest love and even if someone had been able to look into my future and tell me I would get infected from him, I probably wouldn’t have done anything differently. . . . Maybe I do believe in some kind of fate, or a pre-determined life. (p40)

Sheila, a co-founder of Positively Women, is 36 years old, diagnosed eight years prior and has AIDS. Sheila starts her story in her teenage years as if searching for early triggers to explain her drug-taking. Four of the six narrators with a history of drug use deploy similar start points. Her story charts a trajectory, a journeying through a metaphorical landscape of hitting ‘rock bottom’ and going ‘down-hill’ that suggests she will bring her story to a destination or conclusion. Sheila’s moment of clarity comes once she takes action and starts the support group and drug rehabilitation, allowing her to reclaim self-esteem, a sense of self and agency, a new HIV subjecthood. She draws her story to a redemptive conclusion:

During the last five years I’ve become so much more accepting about who I am, what I am, and towards my attitudes and feelings . . . I believe I was meant to be doing this work. (p13)

Sheila had previously joined Narcotics Anonymous – modelled on the 12 steps of Alcoholics Anonymous – and then the 12 steps of Positively Women.
Power and informed the context in which some of the women chose to find meaning from their experiences.

‘I can’t imagine life without HIV now’

Positively Women’s editors make clear that the storytelling aims to empower individual women and effect wider change. Collectively, stories of marginalized and silenced conditions can allow for political or social change. But did the women’s storytelling also explain and define the women’s experiences and sense of self? Some of the women express ambivalence and resistance to being defined by HIV when other lived experiences also shape where they place HIV in their lives. ‘But I’m not all virus’, voices Sheila (p12). Marianne writes that HIV is not such a ‘big issue’ in her life (p48). She observes, while volunteering in the support group, that for some women, ‘it’s her whole life which is in a mess’ (p49).

The narrators express multiple adverse events and intersectional experiences; seeking asylum, drug use, the care system, incarceration, homelessness, sexual abuse including rape, and more positive ones such as being mothers. Sheila, who struggles with addiction before and after her diagnosis, describes how HIV gave her a ‘disrupted’ status in that she was not ‘allowed to have other problems’. Here, she describes the counselling programme at drug rehab:

... I was never allowed to have problems without someone saying, ‘Never mind about that. What about the virus? You’re avoiding it, you’re in denial’. Couldn’t they understand that, yes, it was a big problem – but so was my drug using, so were the problems I had around relationships. (pp8,9)

Maya writes of the multiplicity of her experiences, AIDS being only one, although one that demands her constant attention – a ‘tapping reminder’ (p63). She articulates through poetry/prose the conflict of living a life boundaried by HIV, where everything, even one’s resistance to this, is in relation to it.

Kate who worked full-time at Positively Women but has left due to burn out, also speaks of the intrusiveness of HIV beyond a boundary of acceptance:

I can’t imagine life without HIV now. It’s become too much a part of who I am and how I lead my life. Even if I forget, it’s always there, lurking, some place not too far from the surface. (p100)

Her quote speaks to the relationship and tension between activism and lived experience, of becoming defined and inhabited by something larger than a virus – an HIV subjecthood that becomes an identity, a cause, a representation, a set of choices that as we see in the next section must be continually negotiated in order to stay alive.

‘We can’t be perfect all the time’

Positively Women’s editors criticize the notion that if you are a ‘good enough’ person or adhere to holistic therapies then you will ‘get better’[xii]. It jars from the vantage point of today, where surviving HIV is understood in medical terms. But it was exactly how I used to view my health. If only I could ‘do it right’; start yoga, quit alcohol, go to bed early, cut out stress. With my book on natural healing and my mantra, ‘I have eight years, I have eight years’, I thought I could control the outcome of my life. I would also have read the 1990 leaflet by Positively Women and Immunity, Positive Result? Look after yourself. It offers a mix of practical holistic advice and self-help with poorly referenced pseudo-science, including these quotes from Luc Montagnier; ‘It simply isn’t true that the virus is 100 per cent fatal. If you lead a normal life, sleep regularly at night, avoid alcohol, coffee and tobacco, your immune system could resist the disease’. ‘If you suppress psychological support by telling someone they are condemned to die, your words alone will have condemned them’.

Most of the stories describe attempts to adhere to alternative therapies. Maggie writes; ‘I’ve started doing T’ai Chi and I’m thinking this could work, it might really do something for my white blood cells’. But she also adds, ‘...my whole life can’t be a regime’ [p57]. Not only did the women worry about their physical and sexual health (and that of partners or prospective partners) but they also had to control internal thoughts in order to influence and subjugate the world by force of will. Marianne articulates the conflict of over-focusing on health and her resistance to being assigned an inevitable death:

Too much hard work at it [health regime] leads to stress which is the opposite of what you need. ... It’s your mind which determines your life, whatever is in your mind is going to influence what happens. If you decide to die, you may well die. It’s possible to gain energy through being HIV positive too. ... I’ve changed almost 100% in my attitude to life. (p46)

Sheila voices conflict in living up to this ideal. Here, she repeatedly uses the language of strength and health and an opposing binary where vulnerability equates to imperfection:

I believe that letting other women think we are continuously strong and positive is wrong and would be doing them no favours. In reality we are human, we can’t be perfect all the time. The women coming to Positively Women now have to know that those of us who set up the organisation are imperfect and we have contradictions in our own lives. (p12)

All the women in Positively Women express a desire to live with agency and in resistance to the stigma and marginalization they experience. This is narratively presented as a
correct way of living with HIV – taking up alternative therapies, making decisions about clinical treatment, reducing stress, balancing workloads, improving diet, cutting out drugs/alcohol/cigarettes, exercising, negotiating safe sex, planning or avoiding pregnancy. On top of this, they were expected to think positively and present a positive, resilient image to others. The pressure to get things right was bound up with a desire to survive and live with dignity but as Sheila realizes on falling ill, this narrative has limitations.

‘I wasn’t so special and such a crusader for women and AIDS that death could be warded off indefinitely [p17] . . . I’m too tired to live up to the superwoman/heroin role. (p19)

Suzanne, now ill with AIDS, writes, ‘It’s such a big part of your life that you can’t hide it anymore or pretend’ (p144). ‘It’s a strange thing, this positive thinking . . . I don’t want to feel that if I get ill, it’s my fault because I’m not being strong enough or thinking positively enough’ (p145).

**Discussion**

While noting that each woman’s story is singular and unique, collectively their narrative constructions are recognizable forms of sense-making storytelling, for example, the illness and ‘coming out’ genres, and chime with Corrine Squire’s HIV genre analyses. The women commonly used these narrative constructions to find and express resolution and purpose to what often felt inexplicable. However, genres cannot fit all experiences, for example, those that are indescribable or in flux. Suzanne struggles to find meaning as she moves from living with HIV to dying of AIDS, similarly Maya cannot make ‘sense of the senseless’ (p62).

The 12-step recovery programme with its roots in Christian faith and reliance on a ‘Higher Power’, may have contributed to some of the women’s framing of experiences as redemptive. Williamson in her essay on media, meaning and AIDS, attributes ideas of being invisibly chosen for predetermined outcomes to a deep-seated Anglo-Saxon Calvinist theology, whereby redemption from punishment of sin is for those who are chosen. Certainly, Positively Women’s founders were familiar with the 12-step model, and even if religion was absent, these cultural narratives and tropes were available and useful. Squire notes in her work on South African HIV narratives that conversion narratives may still resonate outside of religious context as they offer a way of presenting one’s life as a moral subject in the face of intense stigmatization.

Imposing narrative constructions on stories brought together for the specific purpose of making women’s individual lives visible is in itself a contradiction. Homogenizing the stories in Positively Women can also inadvertently replicate the practice in HIV services of defining women with HIV only by their HIV status. As the findings indicate, insistence on categorizing narratives of people living with HIV as ‘HIV stories’ is in contradiction to our lived experience – part of living with HIV occupies a ‘non-HIV’ space requiring a further narrative genre. The expression of an identity, independent of HIV while also determined by it, characterizes the plurality of many HIV narratives.

We have seen that re-claiming a moral identity in resistance to stigma can encourage stories with positive outcomes and by focusing on specific topics such as diagnosis or even HIV itself, can close down the potential for other stories to emerge. Squire as part of her long-term research with people living with HIV used different topics to decentralize HIV and give space for women to talk about other aspects of their lives. Desirée Ciambrone in her narrative research with women in the United States found that women, particularly those who are marginalized, experience other disruptions in their lives that influence the meaning placed on HIV. Her findings resonate with the experiences of the women in Positively Women.

The AIDS narrative has always been one of metaphor where many categories and narratives intersect – us/them, homo/hetero, guilty/innocent and virus/victim. Susan Sontag’s deconstruction of AIDS metaphors notes that illness as a metaphor for mortality, human fragility and vulnerability has always been there; AIDS just fitted right in Sontag. For HIV-positive women, countering the language of fragility and vulnerability is played out in the roles they feel expected to live up to; to avoid being seen as passive victims they must now be heroic. Further binaries of order/chaos, flawed/perfect speak to the tension of appearing to transcend illness by doing everything right while always faced with the stigmatizing visibility of AIDS and, by logical conclusion, having failed. The dichotomy between the virus and the self and how to control both within this new HIV selfhood created an ongoing and unresolved conflict.

The ‘getting it right’ narrative is not dissimilar to the HIV blame narrative in that responsibility for adversity lies with the individual. When moral identities are constructed in the face of adverse events like HIV, we give the event purpose – ‘I am a better person’. This inadvertently implies that if we do not adopt the ‘correct way’ of living that we are morally flawed, we have failed. I would argue that the ‘getting it right’ narrative resonates with a contemporary performative narrative of women living (well) with HIV – heroic, empowered, positive, resilient, healthy, adherent to medication and undetectable – and that this risks excluding women who do not, and cannot, satisfy these norms. In the context of this article, this may include women with lipodystrophy from early drug regimes, women with disabilities and complex health conditions, and women with long-term untreated poor mental health such as post-traumatic stress disorder (PTSD).
Conclusion

These young women’s early narratives respond contextually to a life-threatening and stigmatizing diagnosis and to Positively Women’s call to action. It is storytelling intended for personal empowerment and wider change. The process of sense-making is revealed through the narrative analysis, but it is emerging contradictions and conflicts that tell us more about these women’s lives. The women worry about the consequences of being defined by HIV and of finding a ‘correct way’ of living with HIV, anxious that getting this wrong will lead to illness and death. This is contextually situated. With no effective treatment available, un-evidenced remedies, denialism and magical thought offered hope. The guiding principles of 12 steps – personal responsibility, self-improvement and self-scrutiny – also influenced women’s moral subjectivities and framing.

These early stories deserve scrutiny. They act as templates, framing and shaping collective narratives,18,31 which reverberate through to contemporary narratives of living with HIV. The findings draw attention to a small but under researched group of women who survived the epidemic and hint at the impact formative experiences may have on well-being today and the need for tailored support.

Contributions and limitations of the study

This study encourages further peer-led qualitative research so that this cohort can benefit from not only telling their stories but from having their experiences inform HIV services. As a peer researcher, my lived experience offers nuanced insights in a process that is both meaningful and transformative. While most of the narrators in this study are no longer alive, some of them are and may have been willing to embark on a more meaningful interpretative process of collaboratively re-visiting the stories.

As an ‘insider’, it was important to practice reflexivity in order to honour the individual stories and not compromise perspective or selectivity, but there is bound to be a potential for bias, after all it is my story too. I am also an unaffiliated researcher/writer with less access to resources. The sample is not representative; they were women who voluntarily consented to having their stories shared, which may have excluded women who were unable to, adding further bias to the sample.

Dedication

I ordered a secondhand copy of Positively Women Living with AIDS and inscribed in red biro on the title page were the words; ‘Nick, I hope you enjoy this with love from Leigh’. I checked in activist circles and yes they recognized the writing. It was Leigh Neal, one of the contributors and long-time activist, sending a copy most probably to Nick Bamforth, author of the 1987, AIDS and the Healer Within. Leigh died in the winter of 2020 so it feels precious and fitting that the book surfaced with the imprint of her hand as if to remind me that yes, we were really there.

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Jane Shepherd: Conceptualization; Formal analysis; Methodology; Writing – original draft.

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