


'The spiral just keeps on going': Cascading health and social issues for women living and aging with HIV

Women's Health
Volume 18: 1–12
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DOI: 10.1177/17455065221074882
journals.sagepub.com/home/whe


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Abstract

Background: There has been limited qualitative inquiry aimed at understanding the gendered and unique experiences of women living with HIV in high-income countries. In Australia, the relatively small number of women living with HIV means they have been largely overlooked in social, clinical, and policy representations of HIV over time.

Objectives: To explore the experiences of women living long-term and aging with HIV, to understand the complex intersections between their health and social trajectories.

Methods: Data were collected as part of Living Positive in Queensland, a longitudinal qualitative study of the experiences of living long-term and aging of people living with HIV in Queensland, Australia. This study analysed data from three annual, semi-structured interviews with the 11 female participants.

Results: Women negotiated gendered roles and identities as they grappled with ongoing and intertwined health and psychosocial challenges over their life course. Development of co-morbidities, experiences of stigma, gendered social roles, financial precarity, and limited social support amplified the challenges of living with HIV and cumulatively impacted women's health and wellbeing as they aged with HIV.

Conclusion: The health and wellbeing of women living with HIV are adversely impacted by intersecting complex health issues, HIV-related stigma, gendered identities, social disadvantage, and aging. Greater attention to the unique needs of women living with HIV is necessary to reduce the prevalence of psychological distress, financial stress, and vulnerability to social isolation which, in turn, lead to poorer health.

Keywords

HIV, lived experience, social context, stigma, women

Date received: 14 October 2021; revised: 17 December 2021; accepted: 4 January 2022

Introduction

Globally, half the adult population of people living with HIV are women.¹ However, in many high-income countries, the epidemic has been concentrated among men who have sex with men (MSM), with women comprising a smaller proportion of people living with HIV, for example, 19% in the United States,² 31% in the United Kingdom,³ and 12% in Australia.⁴

The experiences of women living with HIV are uniquely embedded within both biology and gender. In addition to sex-specific differences in modes of transmission, biological susceptibility, and risk perceptions,^{5–9} women diagnosed

with HIV experience gendered stereotypes, stigma, and unwanted disclosure,^{10–12} they are more likely to receive a late diagnosis (defined as having CD4+ cell count less than 350 cells/ μ L at diagnosis) due to lingering perceptions that

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women are at low risk¹³ and to experience gender-specific barriers to HIV-specific services and support.^{13–16}

Despite clear evidence that women's lived experience of HIV is different to men's, their unique circumstances remain poorly understood.¹⁷ Advances in HIV treatment, management and policy over the past 30 years – particularly the introduction of highly active antiretroviral therapy (HAART), in 1996 in Australia – have re-positioned and redefined HIV, shifting focus from a socially embedded terminal illness to a biomedically managed chronic disease, with a growing cohort of people living with HIV aging.^{18,19} Yet there is limited understanding of the health and social implications of a 'lifetime' with HIV, particularly among women living with HIV.¹⁷ In Australia, the relatively small number of women living with HIV – around 3,495; 12% of people living with HIV in 2020⁴ – means they have been largely overlooked in social, clinical, and policy representations of HIV over time.^{20,21}

In Australia, women living with HIV are geographically dispersed and often isolated, more likely to live in regional or outer suburban areas where there are fewer HIV-specific services,^{22,23} and they face challenges seeking and receiving social support.²⁴ According to *HIV Futures 9*, the latest in a series of national, cross-sectional surveys of people living with HIV in Australia, that included 88 women aged between 24 and 69 years (average 45 years), most had been diagnosed late, 95% were taking ART but only 81% were virally suppressed, and many were experiencing poor mental health.²³ The income of most female participants was well below the Australian average, and more than half had experienced significant financial stress in the past year, with one in three experiencing food insecurity.²³

Qualitative inquiry aimed at better understanding the gendered nature of the HIV epidemic and unique experiences of women living with HIV has been limited in Australia and other high-income countries. A recent review of qualitative research with women living with HIV in Australia, Canada, New Zealand, the United Kingdom, and the United States over two decades highlighted a commonality of experiences across a diverse sample of women living with HIV that have persisted over the last two decades of the epidemic.¹⁷ Much of the research examined in the review focused on the impact of stigma, healthcare experiences, and engagement in care, seeking and receiving social support, and motherhood (including experiences of reproductive decision-making, pregnancy, and mothering/caregiving roles). The review also found that there has been limited attention to the social contexts of women living with HIV: the social, environmental, economic, and gender factors that shape their health and social needs over time.¹⁷ Furthermore, limited qualitative research has explored women's lived experiences of aging with HIV, particularly across changing health and social biographies.¹⁷

The redefinition of HIV as a chronic disease has changed the way HIV is understood and lived,²⁵ engendering a discourse of responsabilization and self-management.²⁶ Much of the focus on self-management has been a-contextual, despite evidence that an individual's capacity for lifelong management of chronic disease is substantially affected by social context.^{27–29} Qualitative studies that have enabled women living with HIV to identify their greatest concerns or stressors have found that aside from the deep impact of HIV-related stigma, for many, it was not their HIV, but poverty or financial stress;^{30,31} lack of information and social support;^{32–34} restrictions on parenting and social participation;^{35,36} intimate partner violence;^{37,38} immigration status and the stress associated with migration;^{39–41} and relocation, housing insecurity or poor living conditions that were issues of most concern.^{42–44}

Manderson and Warren²⁷ describe interactions between illness and the social context of people's lives as a *recursive cascade*. Drawing on research with women living with chronic illness, they illustrate the complex ways social conditions such as poverty, unemployment, and limited social support contribute to an ongoing spiral of poorer health, which subsequently leads to a further spiralling of social outcomes.

In this article, we draw on Manderson and Warren's notion of recursive cascades to examine the contemporary experiences of women living and aging with HIV. Data from the Living Positive in Queensland (LPQ) study (described below) were analysed to explore the cascading intersections of health and social issues across a life course. Living with HIV involves chronicity of gendered physical and social bodies, contextualized within life trajectories and biographies that parallel the changing HIV landscape.^{27,44} This article analysed data from the LPQ study to explore the experiences of women living and aging with HIV in Queensland, Australia, to understand the complex intersections between health and social trajectories.

Methods

The LPQ study is the largest and longest running qualitative longitudinal research study involving people living with HIV in Australia. The study was conceived and designed in partnership with the leading peer and community-based HIV organizations in Queensland (Queensland Positive People (QPP); Anglicare Positive Directions (until it was defunded in 2014); the Queensland AIDS Council (now known as Queensland Council of LGBTI Health (QC) – hereby referred to as our community partners). The study was developed to increase understanding of the lived experiences of people with HIV, particularly in relation to aging, place, social support, and social isolation in regional and rural Queensland. Through extensive service provision, research, and consultation, the community partners identified the need for greater understanding of

the experiences of living with HIV, especially in regional and rural areas, to inform future service development and planning. Queensland, the second-largest state in Australia, comprises a spectrum of urban, regional, rural, and remote locales, enabling exploration of the experiences of people living with HIV living in diverse environments with differential access to services. As a qualitative longitudinal research study, LPQ sought to gain a nuanced understanding of change and continuity over time, situated in socio-cultural context.⁴⁵

Recruitment and participants

The LPQ sample was purposively recruited to capture the experiences of the diversity of people living long term with HIV. Sampling was stratified to reflect the diversity and geographical spread of the population of people living with HIV in Queensland, with purposive recruitment in regional centres, and to ensure representation of different age groups, genders, and people of culturally and linguistically diverse and Aboriginal and Torres Strait Islander backgrounds. Recruitment was facilitated through the research partners' networks and social media accounts, with all participants who responded to the invitation to participate contacted via telephone and/or email. The only inclusion criteria were diagnosis of HIV and age over 35 years; however, no one who registered interest in participating was excluded. Seventy-three people completed the phase-1 interview, with three further phases of data collection carried out between 2014 and 2020. Across phases 1–3, only two participants were lost to follow-up, and four died. The high response rate can be attributed to the ongoing relationship maintained with participants by the research team, which included the compilation of an annual newsletter reporting the study's progress. This article reports the experiences of the 11 female participants (15% of the sample) in the LPQ study across the first three phases of data collection.

Data collection

All 11 female participants completed three in-depth interviews of between 60 and 180 minutes duration. All interviews were conducted by female researchers, predominantly by L.F. and A.M., the LPQ Study lead investigators with extensive experience in qualitative interviewing. Longitudinal data collection via repeated face-to-face interviews allows trust to be built over time.^{46,47} All interviews were conducted in participants' homes or a location chosen by them. In a few cases, interviewees chose to have a family member present during the interview, though in most cases, it was only the participant and one or two interviewers present. At the commencement of the interview, the researchers introduced themselves and the research project, explaining the nature and

purpose of the research and its intended aim of informing service provision and planning.

A semi-structured interview guide was used to enable broad exploration of the experience of living with HIV and to elicit information in participants' own words about a range of issues including experiences of healthcare and social support services; their social networks; and experiences of stigma and discrimination. The interview guide was developed in collaboration with the community partners and piloted with two people living with HIV who worked for the community partners.

Analysis

All interviews were audio recorded and transcribed verbatim and extensive field notes taken. Transcripts were available to participants on request. Interview transcripts were imported into NVivo (version 11) software and inductively coded and analysed by L.H., L.F., and A.M. to identify salient themes and relationships.⁴⁸ A grounded theory approach was used to guide analysis of the data.^{49,50} Emerging themes and categories were constantly compared between the three time points for each individual and across individuals to identify similarities and differences. To ensure reliability of the analysis, the interviews and data analysis were conducted by three investigators (L.H., L.F., and A.M.), and all researchers and community partners cross-checked the results and interpretations with disagreements and differences resolved by discussion. Despite the small sample size, analysis did demonstrate some 'conceptual depth' that provided confidence in our understanding of the themes that emerged.⁵¹ Field notes, taken during/following interviews, were used to guide the development of case studies.

Ethical considerations

The LPQ study was granted ethical clearance by The University of Queensland's *Medical Research Ethics Committee* and *Behavioural and Social Sciences Ethical Review Committee* (approval no. 2011001387). All women provided informed, written consent, and were advised that they could withdraw from the study at any time. To protect the identities of participants, pseudonyms are used in this article and potentially identifying details were removed or altered from the quotes.

Results

Socio-demographic characteristics

Socio-demographic characteristics of the 11 participants at the time of recruitment are presented in Table 1. At time 1, the women were aged between 35 and 64 years and had been living with HIV for 4–26 years (median=13 years). All participants identified as heterosexual/straight. The

Table 1. Socio-demographic characteristics of participants at the time of recruitment ($n = 11$).

Characteristic	Number of participants
Age	
35–44	2
45–54	8
55 and over	1
Years lived with HIV	
<10	4
11–15	4
16+	3
Relationship status	
Single	7
In a relationship	4
Children	
Yes	7
No	4
Country of birth	
Australia	7
Other	4
Primary income source	
Disability support pension or other Centrelink benefit	9
Salary	1
Other	1
Employment status	
Not employed	6
Part-time employment	2
Full-time employment	3
Highest education level	
University degree	3
Trade, diploma or certificate	4
Secondary school	1
Less than secondary school	3
Housing situation	
Public housing	2
Renting	7
Own	2

HIV: human immunodeficiency virus.

majority were single and four were in a relationship. Most were mothers (two grandmothers; five single parents). Most participants lived in regional cities; three were residents of major cities. Four women had migrated to Australia from other countries. The majority lived in rental accommodation or public housing. Three women were employed full-time, two worked part-time, and six were not employed. Most relied on government welfare payments (disability support or carer's pension) as their primary source of income.

Living with HIV: the recursive cascade of health and social determinants

Women negotiated gendered roles and identities as they grappled with ongoing health and psychosocial challenges.

Their biographies were marked by the ebbs and flows of negotiating health and psychosocial issues across their life courses. We begin by presenting Maria's case study, which encapsulates the recursive cascade of health and social issues through her biographical account of living with HIV for over two decades.

Maria

Maria was diagnosed in the pre-HAART era²⁶ when treatment options were limited. She was prescribed early treatments, including the toxic AZT and recalled that '*At one stage I was on 85 pills before breakfast*'. She experienced the advancements of HAART, which changed HIV from a death sentence to a chronic illness, but across her HIV trajectory, she has also experienced major side-effects associated with her many treatment regimes.

Consistent with the mobility of many people living with HIV diagnosed during this era, she left the small rural town where she had been living to travel Australia, using up all her savings to pay for a last trip.

So the first period of being diagnosed was like . . . I finished work up . . . they gave me three years to live. I had quite a lot of savings at that stage because I was a workaholic, had quite a few jobs. I did a quick trip down to [southern city] . . . and then it took me about eight months to travel . . . back

She continued to be highly mobile across her life course, moving to new geographic localities for various reasons: to remove herself from stigma and family not coping with her diagnosis; for new relationships; to escape a violent relationship; for employment; and to access affordable housing and support.

I moved somewhere for my health, I've moved somewhere for my heart, for love reasons – but most of it was easier to run away from things that were happening because of the HIV and the nastiness of the people and small mindedness of the people.

Maria described the decade from her mid-30s to mid-40s as '*hidden years*'. She married an older man, who increasingly used her HIV status to control her. They moved to a small rural town '*set off from the rest of the world*' where Maria was unable to make friends, go shopping, or access local health services. Playing on the stigma of HIV, her husband told her if people found out she would be '*run out of town*'. To access treatment and health services, Maria drove 400 km, covering travel costs with her limited income, and leaving at 4 am to ensure she could be back in time to fulfil her gender roles of wife and homemaker.

Maria subsequently left her husband, resulting in another change of location with limited resources. Socially isolated with no family or friends in the new regional locality, she struggled to find affordable housing and

described an escalating spiral of poor health, limited support, and resources.

The positiveness is so easy to lose when you're already on a down. The spiral just keeps on going. Chuck another handful of cement in there. Unless you have that support . . . The pain, the hurt, the struggle to get off the floor when you're down.

Maria moved in with another positive woman for a short time while she slowly '*got my life together*', eventually moving into her own home, obtaining furniture and a dog. During this time, she found her '*voice*', which gave her a sense of agency and helped her face the stigma and discrimination of the preceding 10 years.

It took me 18 months to even find my voice back again. But having my voice back again is probably the most important thing, [it] was being able to talk to someone. It's not a secret. It's not the worst thing in the world that can happen to you . . . [I'm] grateful for every breath that I take. It's not just HIV that puts you in that state of mind. Struggling makes you see through clearer eyes.

Discovering the limited information about HIV available for women, she made it her mission to raise awareness and became an active peer supporter connecting women living with HIV to health and support services, which she critiqued for almost exclusively focusing on gay men.

Our second interview with Maria took place in her garage, surrounded by packing boxes as she was preparing to move for the third time in 12 months. She had been diagnosed with cancer, experienced stigma when undergoing treatment, and had had significant dental work – a consequence of long-term HIV medications. With limited social networks and support, and after the closure of psychosocial services for people living with HIV, Maria was forced to patch together support from several community organizations to help her navigate cancer treatment and access subsidized home care. Co-payments for the home care drained her limited savings, and she could not afford continuing care – 'food is much more important'. She had to borrow \$2000 to pay the accommodation bond for her new rental. The decline in her health and ongoing financial precarity left Maria feeling like she was 'going backwards'.

A year later, Maria had moved again, this time to focus on supporting other positive women. Her health was 'pretty good', although she had been diagnosed with another chronic condition and was worried about 'What's going to happen next?'. Despite the challenges of her new regional location and a broken phone and car, Maria's focus remained on volunteering and supporting women living with HIV.

You've only got five minutes to be miserable today. Five minutes to put shit on yourself and the rest of the day, no,

that's for other things . . . I mean I've spent bloody days on my hands and knees sick and no, not allowed to cry anymore, get up and do something . . . I spent bloody three years of my life just like ohh, when there was no support. So to think that there is no support [for women] now when I'm a part of it – no, not a chance!

At interview 4, Maria's cancer had metastasized to her liver, and she had half her liver surgically removed. Maria described limited social support – her sister had recently died, and she did not want to burden her family. Ongoing stress and depression were followed by a heart attack. She had little energy but worked in her garden when she could, otherwise enjoying the view from her bed – now located in her lounge. Maria's house lease was running out soon and she feared she would have to move again.

Maria's narrative encapsulates the recursive cascade of health and social issues, including the increasing impacts of physical and mental illnesses, managing relationships and/or families, financial precarity, housing insecurity, and other life circumstances that compounded the challenges of life with HIV. For Maria, her life course was consumed with the ongoing navigation of physical illness alongside HIV-related stigma, precarity, and the demands and constraints of gendered roles, alongside her efforts to enhance the lives of women living with HIV. Her experience exemplifies the complexity of life for women with HIV, particularly the intersections of long-term health effects of HIV with complex social contexts and experiences of aging – key themes explored in the next section.

Long-term health effects of HIV

Maria's description of ongoing, complex co-morbidities was not unique. Many participants were contending with co-morbid conditions that required extensive engagement with, and navigation of, complex healthcare systems. Most experienced at least one co-morbidity but many had multiple conditions including: mental health issues, cancers, heart disease, diabetes, dental issues, premature menopause, osteoporosis, and cognitive and memory issues including HAND (HIV-associated neurocognitive disorders).

Participants described multiple HIV healthcare challenges including changing treatment regimes, polypharmacy, living in geographic locations with limited healthcare options, health practitioners with poor HIV literacy, HIV-related stigma and discrimination, financial barriers, fear of sharing their HIV status or having it revealed by others, and lack of trust in healthcare providers. For many women in the LPQ study, poor health was further exacerbated by their experiences of aging with complex comorbidities and managing the uncertainty of accelerated or accentuated aging.

Aging with HIV and co-morbidities impacted gender roles, self-identity, mobility, and the capacity to engage. Many were knowledgeable about HIV management, but

management of co-morbidities, along with supporting an aging female body was not well understood by clinicians and created challenges for many women. Several participants, like Maria, needed to travel to large cities from their regional homes to ensure continuity of care and communication across their healthcare teams. Many women struggled to find healthcare providers, particularly GPs, to coordinate their often increasingly complex healthcare. For example, Anna described how her general practitioner (GP) was unaware of, and insensitive to, the increasing complexity of her health issues and related social and economic challenges.

I was going through menopause and everything, and [the GP] just couldn't understand it. I was a wreck. I was going through depression, I was going through breaking up with this man, and trying to get a house, and I was going through a disaster, yeah, and he just couldn't deal with it. He'd rather just pass me on to someone else. (Anna)

Mental health issues were commonly reported comorbid conditions experienced by participants. Yet, despite the prevalence of mental health issues, some participants described difficulties accessing appropriate HIV-friendly mental health services, which often resulted in further social isolation.

Complex social contexts

The following section considers how the management of health and illness intersected with the management of gender roles, experiences of stigma and precarity, which led many women, including Maria, to identify clinical management of HIV as 'the least of my worries . . . HIV is probably the simplest part of my life. Every day is a struggle'.

Living with HIV-involved managing and (re)negotiating, multiple and intersecting identities and gendered social roles. In addition to being a woman living with chronic illness, participants negotiated social roles as mother (and/or grandmother), carer, (sexual) partner, and employee. Participants such as Anna described the double burden of coping with HIV and care work, as they juggled caring for dependent children and/or aging parents/relatives, on top of the complexities of managing their HIV and comorbidities.

My CD4 counts and all that are getting better but I'm getting a bit more down. I'm on antidepressant tablets, anxiety tablets, I'm on Valium, I'm on cholesterol. Since the last year my cholesterol's gone high and I think it has something to do with the pills. And I also care for my mum as well as being a student. (Anna)

Being a carer – particularly for women who were single parents to young children – increased physical, emotional,

and financial stresses. Grace's experience highlights this dichotomy. After separating from her violent husband, she was solo parenting small children '90% of the time'. It was physically demanding, tiring, and emotionally stressful, but her children were her focus and concern.

There have been days where all I wanted to do was stay in bed and cry but I can't and I think that if I didn't have the children . . . I wouldn't have been able to take enough anti-Ds to stop me from – if the children weren't here making me get out of bed and get up and make them breakfast, if I didn't have that motivation then I probably wouldn't. But my responsibility is my children and I will not fail them. It's very important that I'm there for them because they're going through this as well (Grace)

Capacity for self-care was reduced as women prioritized the responsibilities embedded in their gender roles. As Zoe explained, regardless of the severity and impact of HIV treatment side-effects and managing multiple comorbidities, the primary concern of women was caring and providing for others:

. . . positive women still have to get on with – they can't just stop and [say] 'Oh, woe is me, the world is ruined'. They still have to – if they've got families or they've got whatever – they still have to keep going. (Zoe)

Focus on family often restricted social participation and networks as the needs of families were prioritized over women's needs.

I just want to deal with my own family and all their dramas. . . I need to conserve my energy for those times. (Madeline)

Intersecting women's navigation of identities and gendered social roles, were ongoing experiences of stigma and discrimination, which continued across their life courses, despite biomedical advances in HIV care. Most participants had experienced discrimination in accessing healthcare: they described incidents of doctors, nurses, and/or health service staff expressing judgement, breaching confidentiality, demonstrating fear of contagion by physically distancing themselves or using two pairs of gloves, or revealing limited knowledge about HIV. Recent experiences of stigma and discrimination by medical practitioners were described by Sophie and Vivian:

The doctor goes, 'How did you catch it?' I said, 'Well, I had unprotected sexual intercourse with a man who was positive'. He goes, 'You know that that's a very rare way to catch it, don't you?' And I went, 'Yeah, okay'. He goes, 'Are you sure that's how you got it?' I went, 'Yes'. So he then wrote down on my forms for the X-ray and a couple of other ultrasounds that I had to get done mainly to do a check up on body parts to make sure that they were all functioning and everything was normal. He'd written over everything in great big bold letters,

‘HIV Positive. HIV Positive. HIV Positive. HIV Positive’ over absolutely all the forms. I was quite horrified at this. (Sophie)

We just went to a family friend who is a GP. I had to get some scripts because I’m going overseas. He said ‘I think you should get a TB shot’. So, he rang the nurse and said ‘oh and extra precaution because she has got HIV’ – of course a nurse wears gloves all the time so what are the extra precautions? But he’s mum and dad’s age so he’s probably out of the loop a bit . . . (Vivian)

Women explained how their healthcare and other life choices were shaped, and constrained, by experiences of discrimination or fear of stigma. Like Maria, some discussed travelling long distances to obtain healthcare and/or medication from providers in other locations. It was common for women to consult multiple healthcare providers to separate their HIV care from their ‘routine’ healthcare and, for those who were mothers, their children’s healthcare.

Many women received support from family, friends, and service providers, but all had encountered negative stereotypes and were confronted by assumptions surrounding their diagnosis.

. . . we’re ostracized and women, a lot of the women, who are HIV positive don’t end up reaching out to anyone . . . it’s still seen as a shameful, horrible, you’re a dirty whore type thing if you’ve got HIV and that’s how the public look at it. (Zoe)

Many had experienced rejection by family members, partners/potential partners, friends, neighbours/communities, and employers, often attributed to poor HIV literacy, ignorance, and fear of contagion.

It was very isolating . . . you felt like there was something very seriously wrong with you, for a start. People were uninformed, uneducated and concerned about – Can I be sitting next to you? Can I be sharing that glass of water with you? (Chloe)

Experiences of discrimination fed women’s anticipation of stigma, and many were not willing to share their status, telling only a small circle of trusted people. This not only limited opportunities for social participation but meant some women had few people they could rely on for help and emotional support. For women with children, keeping their status secret was a mechanism to protect their children from stigma and discrimination, as Grace described:

I need to think about my child and the impact it could have on him if friends or the parents of friends . . . judged me because I was positive, tried to ostracise him because of my positive status. I didn’t think that that would be fair on him and, in turn, all of our children . . . I need to remain anonymous for the sake of the children otherwise I’d be out everywhere. (Grace)

HIV-related stigma intersected with other forms of stigma connected to ethnicity, gender, and disadvantage. Culturally and linguistically diverse participants described intersectional stigma,⁵² where racism further compounded the experiences of HIV-related stigma and discrimination. As a migrant from a country with high rates of HIV and correspondingly high rates of HIV-related stigma, Emma had expected Australians to be ‘educated about AIDS and HIV and sexual health’ but found that was not the case in the small regional communities where she lived:

everybody treats you as if you have freaking some contagious disease or something and it . . . takes you to a really bad or dark place where you think that you’ve done something wrong . . . Because they are uneducated about HIV, they just treat you as if you should be shunned from the community. (Emma)

The cumulative impact of stigma was most prominent among some long-term diagnosed female participants who discussed how ongoing experiences of discrimination had impacted life choices, including limiting relationships, education, and employment.

I’m sure I would have been doing something with my life and knowing my life would have been different and probably a little bit more function. I feel like I’ve made the best of a bad situation and that’s probably all in your head anyway, but stigmas do that to people don’t they. (Chloe)

Participants described relationship challenges that impeded social support. Many had experienced grief and loss within relationships – due to death of partners, intimate partner violence, and stigma/discrimination. Most feared telling (sexual) partners about their HIV and described a reluctance to establish relationships. Women described wanting self-reliance and independence.

Not at all. I never will. I like to be my own person now. I’m too vulnerable and the last person I had took advantage of that. So, I’d like to be me and in control of me. I’m happy with that. (Anna)

I found that disclosing to anybody was very hard. I don’t know what they used to think but, I mean, it didn’t bother me so much. It could get a bit embarrassing. A lot of the times the partner would absolutely freak because they didn’t know what it meant. Trying to let them understand that, you know, I can live in the house with you without being a danger. I think on the whole it’s put a dampener on my sex drive because it’s, I mean, rather than face the rejection because of their ignorance it’s easier just not to put yourself there. (Sophie)

Many had tried, or wanted, to access formal HIV support services but felt uncomfortable with services that were not focused on (and, for some participants, delivered by) women with HIV. Zoe reflected a view expressed by

many participants that in terms of HIV-specific services women were 'an afterthought and we're secondary'.

. . . you still need to be able to talk to people who understand, who know what the issues are, and can give you whatever kind of support, even if it's just talking to you, letting you know where you can go, what you can do, what options are available to you outside the city area. With not having that, a lot of people can feel very lost. (Sophie)

Consequently, participants reported seeking practical support from community services that did not understand HIV, to support them to manage their complex needs. But for many women, particularly those living in rural and regional towns, the combination of stigma, restricted social networks, limited finances, and challenges accessing formal support made them increasingly vulnerable to social isolation.

Nearly all participants reported financial and housing stress, and over their life courses their experiences of precarity worsened or were sustained. Most were reliant on government pensions, and described difficulties meeting basic living expenses along with the costs of their HIV treatment and medication:

I struggle. I can live on [the pension], but I struggle. There is a lot that I do go without. (Sophie)

If I didn't have my little part time job I would be behind. I wouldn't be able to – because electricity's astronomical, food is astronomical. . . . I would be struggling to pay my bills. (Madeline)

Several women reported spending more than a third (and one, more than half) of their income on housing costs, leaving little for food, medication, and utilities. Financial stress directly impacted women's health. Participants attributed mental health effects, particularly depression, as well as missing check-ups or failing to seek healthcare, to 'tight' finances.

Financial precarity meant many women struggled to access affordable housing, with several living long term in public housing. Most participants had been highly mobile, moving to outer suburbs or regional areas out of economic necessity to seek cheaper housing, or to stay with family or friends. This often meant a loss of established social networks. Many expressed concerns about the impact of long-term low income and unemployment on their future financial security, particularly as they aged:

I don't have any finances. I don't have any super[annuation]. . . . I'm not a real good planner for my future. (Madeline)

Living and aging with HIV

Ambivalence and uncertainty have been features of positive peoples' lives across the history of the epidemic associated with changing understandings of HIV.⁵³ Women described uncertainty about aging, expressing ambivalence in the face

of debates surrounding adverse HIV aging discourses and unknown futures. Alongside uncertainties about health and increasing comorbidities, participants described uncertainty about finances, housing, and access to care. Intersections of living with HIV and precarious life courses informed perceptions that life was not predictable. Many were reluctant to set goals or share 'dreams' for the future and were not able to think about 10 or 20 years 'down the track' (Emma). As a result, there was little interest in looking forward, or considering the long-term consequences of HIV and its intersections with aging.

Participants discussed how HIV amplified age-related morbidities with many experiencing signs of aging and declining health over the course of the study. Some became increasingly conscious of, and concerned by, the lack of knowledge about 'how aging and HIV are going to go together' (Madeline) for women.

the fact that I'm getting old doesn't bother me. We all get old. But you've just got to remember that being positive and age together, whatever's going to go wrong is going to go wrong a lot quicker. The possibility of things that are going to happen as I age are there. They're always going to be there. There's always that chance. Being positive just increases the risks and if I do have kidney problems or hip problems or whatever, being positive is going to amplify whatever goes wrong (Sophie)

The development of new or additional co-morbidities, and the sudden worsening of physical health, shook women's self-perceptions and raised concerns about the effects of long-term medication and the intersections of HIV, social life, and aging, as Anna observed:

I don't have any finances. I don't have any super. I have no – I just have this faith that things will turn out okay. I don't know. But I'm scared. I have side effects of medication, So I'd go see the doctor and, you know, I was scared. He said 'Don't keep coming to me for every little rash you have'. I thought, 'For God's sake, I'm scared shit', you know. I've got HIV, I'm aging and there's all these symptoms. I don't know whether I'm going to live. Nobody's told me, you know, [that] I'm going to live forever (Anna)

Many worried about limited resources impacting their futures and faced uncertainty about availability of government pensions and future housing options, including access to long-term care facilities, and barriers to subsidized housing because of their age and HIV status. For older female participants, intersections of living with HIV and precarious life courses informed their perceptions that life was not predictable and needed to be approached 'one day at a time' (Emma).

Discussion

Across this study's participants, co-morbidities, stigma, gendered social roles, precarity, and limited social support restricted women's choices and control, amplifying the

challenges of HIV and cumulatively impacting their health and wellbeing. This qualitative research has enabled a deepening understanding of the experiences of women living with HIV over time and the recursive cascades of compounding social and health problems.

Evolution in the understanding and epidemiology of HIV and advances in HAART have vastly improved survival rates and re-cast HIV as a manageable, chronic disease.⁵⁴ However, increased longevity and a reclassification have not automatically translated to improved quality of life for all people living with HIV. In Australia (and other high-income countries), the focus in HIV policy and funding on obtaining the UNAIDS targets of 90–90–90, and improving the treatment cascade to achieve viral suppression, has eclipsed the importance of considering the contextual and structural factors that impact on health outcomes and wellbeing, particularly for women living with HIV. The biomedicalization of HIV and a focus on the causal relationship between disease and treatment has obscured lived and subjective experiences of ‘feeling well’,⁵⁵ which – as this study’s findings reinforce – may not correlate with a person’s viral load. Many participants described their health as good and their HIV as something they did not ‘dwell on’. But over the course of the study, it became clear that having HIV and requiring lifelong treatment, intersected with other (generally increasing) health issues and social and financial precarity to disrupt women’s everyday lives. Despite their resilience and representations of adjustment and optimism, participants’ narratives revealed the social and psychological challenges for many women living with HIV in a context of continuous management of sharing their status and fear of stigmatization, gendered social roles, and social disadvantage. Participants were unable to manage HIV as ‘just another’ chronic disease⁵⁶ when faced with daily reminders of its significant impacts on their lives including unemployment and financial stress, stigma, and worries about their gender roles.

Our findings reinforce the conclusions of others that it is essential to contextualize women’s illness experiences within the wider ‘framework’ of their lives, especially the impacts of structural determinants and stigma,⁴⁴ in order to illuminate the intertwining economic, health, and social issues that impact women’s illness experiences.²⁷ Paying attention to women’s social contexts highlights the myriad of factors beyond HIV status and treatment that impact health and wellbeing, and how these factors intersect and layer with cumulative effect. HIV infection and the acceleration of aging it causes, mean multimorbidity is common in people living with HIV, with more than half having two or more chronic comorbidities.⁵⁷ Over the period of data collection for this study, it was clear that the development of comorbidities increased the complexity of living with HIV, uncertainty about the future, and women’s vulnerability to increasing financial stress and social isolation.

Our findings reinforce and add to understanding of how experiences of stigma and discrimination shape healthcare

and other life choices for women living with HIV. While the community fear and demonization that characterized the early years of the epidemic have greatly subsided,⁵⁸ this study shows that stigma and stereotypes of women living with HIV have endured, with most participants reporting ongoing experiences of stigma and discrimination. Participants described negative evaluations and questioning by doctors similar to that reported by Lawless et al.⁵⁹ more than two decades ago. Those recently diagnosed were as likely as women who were diagnosed in the early years of the epidemic to have experienced stigma, and several women reported incidents in recent years. These findings mirror the conclusion of a recent review of research with women living with HIV in high-income countries,¹⁷ that despite the biomedical advances and changes in societal views over the past 25 years, women’s experiences of stigma and precarity have endured.

For most participants, financial precarity increased over time, often exacerbated by duration of illness and continuing costs of care and medication. In high-income countries like Australia, most healthy women in midlife are participating in the workforce (with economic and social benefits). For women living with HIV in this study, long-term unemployment and/or low income was common, particularly for those who were diagnosed in the pre-HAART era. These early decisions, made following diagnosis and often within the context of debilitating early illness and treatment side-effects, impacted decisions around healthcare, housing (choice and stability), employment, and future security.

The case study of Maria, who has lived with HIV for more than 30 years, illustrates the changing, and accumulating, impact of intersecting health and social issues. Maria’s experiences exemplify a recursive cascade²⁷ – a trajectory of increasing ill health and social and financial precarity underpinned by both HIV- and gender-related challenges. Over the data collection period Maria described a significant decline in her physical health (multiple comorbidities), financial security and social network and participation. Exacerbated by the unavailability of HIV-focused support services, these intertwined impacts wore Maria down from a ‘bloody fantastic’, healthy and optimistic woman to a socially isolated woman managing multiple comorbidities with depleted financial and social resources just a few years later. As many other participants experienced, limited informal social networks, and the absence of HIV support targeted to, or even inclusive of, women, severely hindered access to economic and practical resources and informational and emotional support.

Like our participants, women living with HIV have consistently identified the need for women-focused, and peer-delivered, services to address some of the unique burdens they experience. In surveys and consultations conducted by our community partners, women living with HIV across Australia have called for strategies such as establishing networks and group workshops for

women, run by women, to enable information-sharing and discussion about common experiences such as stigma, managing comorbidities, caring and parenting, and aging well with HIV. In-person interactions and facilitated sharing of information and experiences can be used to foster feelings of inclusion and enable women to build connections, alleviating or reducing the risk of social isolation and loneliness that our participants described. Tailored services currently delivered by our community partners, include support delivered by women living with HIV working as peer navigators to address social determinant challenges. Expanding these services and developing group-based interventions to improve economic participation and reduce financial precarity should also be considered. Importantly, further qualitative research is needed to determine which models of care and interventions best address the concerns of women living with HIV and reduce the impact of the cascading issues our participants have identified, to support women living with HIV to flourish.

Strengths and limitations

To our knowledge, this is the first qualitative study of Australian women living long-term with HIV that follows their life course over time. Most previous qualitative studies have been cross-sectional, focused on particular experiences for women with HIV. Longitudinal qualitative research provides a 'long view' that enables insights into how and why individuals live as they do.⁴⁷

Although attention was paid to recruit women with diverse characteristics and situations, the study is based on a small sample of cis gender, heterosexual/straight women, and does not encompass the experiences of trans, lesbian, or other women experiencing social marginalization. While the number of participants was small, the method of repeated interviews over time gathered rich data from a group that has traditionally been under-represented in research. The nuanced narratives and themes identified provide insights into experiences of a heterogeneous group of women living with HIV. In addition, all but one of the participants were diagnosed before 2010, pre-dating current treatment guidelines that recommend all HIV-infected individuals commence ART immediately.⁶⁰ Hence the experiences of our participants may not be typical of women diagnosed more recently, whose experiences require further qualitative inquiry.

Conclusion

This study highlights the ways in which, over time, an intertwining of long-term complex health issues, enduring stigma, intersectional identities and social precarity – situated within a changing HIV landscape – influence the health and wellbeing of women living with HIV. Women negotiated gendered roles and identities as they

grappled with ongoing and intertwined health and psychosocial challenges over their life course. Development of co-morbidities, experiences of stigma, gendered social roles, financial precarity, and limited social support amplified the challenges of living with HIV. Greater attention to the unique needs of women living with HIV is essential if we are to deepen understanding of the ways in which these issues intersect and cascade over time.

Acknowledgements

The authors are grateful to the women living with HIV who participated in the LPQ Study and openly shared their experiences. They also acknowledge the continuing support and contribution of Queensland Positive People to this research.

Author contributions

Lisa-Maree Herron: Data curation; Formal analysis; Investigation; Writing – original draft; Writing – review & editing.

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Melania Mugamu: Formal analysis; Writing – review & editing.

Chris Howard: Conceptualization; Formal analysis; Writing – review & editing.

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Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The LPQ study was supported by the Australian Research Council, Linkage Project (2011–2014) (grant no. 110200318).

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Supplemental material

Supplemental material for this article is available online.

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