

Changes in the lived experiences of women with HIV over two decades? A review of qualitative research in high income countries

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Abstract

Women diagnosed with HIV face unique burdens associated with their gender, yet the lived experience of HIV for women remains poorly understood. In particular, there has been little attention to the consequences for women living with HIV (WLHIV) of changing social, epidemiological, biomedical and policy contexts over the past nearly four decades, or to the implications of long-term treatment and ageing for the current generation of HIV-positive women. We conducted a review of qualitative research with WLHIV in selected high-income countries (Australia, Canada, New Zealand, the United Kingdom and the United States of America) to identify the breadth of experiences of HIV for women and the most prevalent subjects and themes, trends over time, and gaps in understanding. The review highlights the relative homogeneity and consistency of experiences of a diverse sample of WLHIV living in high-income countries, particularly the enduring prevalence of HIV-related stigma for women, sociostructural barriers to healthcare and support, and negative encounters with health professionals. It also reveals gaps in current knowledge, particularly the dearth of research exploring HIV-related adjustment and coping over time. The findings support the need for further qualitative, especially longitudinal, research to explore the unique experiences, burdens and needs of WLHIV. Understanding women's experiences, particularly their changing needs and strategies for self-management and coping as they live long-term and age with HIV, is key to the development of support and services that will enable WLHIV to cope and thrive.

Research highlights

- This paper reviews qualitative research with women living with HIV over 2 decades
- Across time and the selected countries experiences were relatively homogeneous
- HIV-related stigma and negative healthcare experiences endured
- Little is known about HIV-related adjustment and coping over time for women
- More attention to barriers to healthcare and self-management for WLHIV is essential

Key words: HIV, women, lived experience, gender, stigma

Introduction

Globally, women 15 years and older represent more than half the population of people living with HIV (PLHIV) (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2018). There are significant regional differences in both new HIV infections among women and the proportion of women living with HIV (WLHIV) in comparison to men, with the highest rates in Africa, the Caribbean, Eastern Europe and Central Asia (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2018). Women and adolescent girls in these regions are disproportionately affected by HIV due to vulnerabilities created by unequal cultural, social and economic status (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2017).

In many high-income countries the HIV epidemic has been more contained and concentrated among men who have sex with men (MSM), with women comprising a smaller proportion of the HIV-positive population: 23% (2014) in the United States of America (US) (Centres for Disease Control & Prevention, 2017a), 23% (2018) in Canada (Public Health Agency of Canada, 2018), 31% (2015) in the United Kingdom (UK) (Kirwan et al., 2016) and 12% (2016) in Australia (The Kirby Institute, 2017). In Australia, the relatively small numbers of women affected –108 newly diagnosed, and 3349 living with HIV, in 2017 – mean women have been largely absent from national discourse and HIV strategies (The Australian Government Department of Health, 2014).

HIV-positive women living in high-income countries experience unique burdens associated with their gender and differences in biological susceptibility, risk perceptions, access to HIV services and treatment, and experiences of stigma and unwanted disclosure (Aziz & Smith, 2012; Ion et al., 2017; Johnson et al., 2015; Scully, 2018; UN Women, 2017). However, the lived experience of women with HIV remains poorly understood.

Reviews of qualitative research involving WLHIV in high-income countries have focused on specific experiences or issues for women: stigma and discrimination (Darlington & Hutson, 2017; Ho & Holloway, 2015; Paudel & Baral, 2015; Sandelowski et al., 2004), the meaning of motherhood (Sandelowski & Barroso, 2003), and psychosocial factors impacting older positive women living and ageing with HIV (Rubtsova et al., 2017). Some reviews focused on women in restricted geographical areas – for example, Darlington and Hutson (2017) examined HIV-related stigma among WLHIV in southern USA – or were limited to short spans of time, for example Rubtsova et al's (2017) review of studies published between 2013 and 2016.

In 1996, Lawless, Kippax and Crawford described the pervasiveness of stigma and discrimination, particularly enacted by health professionals, experienced by WLHIV in Australia. Twenty years on, have the experiences of WLHIV changed? Research does not

appear to have captured the impact of significant changes in the social, epidemiological, biomedical and policy contexts shaping the lives of women with HIV, particularly following the introduction of highly-active antiretroviral therapy (HAART), and the re-casting of HIV as a chronic disease (Green & Smith, 2004). Understandings of the health and the social implications of changing contexts, particularly in relation to women's experiences of long-term HIV treatment and ageing, are also absent from current debate.

In light of these empirical shortfalls, it is timely to consider if, and how, HIV-related experiences have shifted for women over time within the context of biomedical, social and policy changes. This review synthesises and critically compares key findings of qualitative research published over the past two decades, since the introduction of HAART, to identify the breadth of experiences of, and any changes to those experiences for, WLHIV.

Methods

Search strategy

Searches were conducted using the online databases PubMed, APA PsycNet and ProQuest (CINAHL). These databases provide comprehensive coverage of literature including reviews in the health, public health and social science fields.

This review focused on published studies involving WLHIV in high-income countries with shared language and similar demographic profiles including Australia, Canada, New Zealand, the UK and US. Differences in HIV rates among women in these countries, and the overrepresentation of women of particular races/ethnicity in the US and UK, are acknowledged below ("Characteristics of included studies") and in the Results where pertinent.

The aim was to identify qualitative research exploring first-hand experiences of WLHIV. Hence these and related terms were used in database searches to identify the breadth of qualitative research exploring experiences of WLHIV.

The following key terms were used across all databases:

["HIV"] AND ["women" OR "woman" OR "female"] AND
["experience" OR "lived experience" OR "life experience" OR "meaning" OR "narrative"
OR "perceptions" OR "understanding" OR "quality of life" OR "stigma"] AND
["Australia" OR "United Kingdom" OR "UK" OR "United States" OR "US"
OR "America" OR "Canada" OR "New Zealand" OR "NZ"].

Publication date was restricted to 1 January 1996 to 'present' (searches were completed in October 2017). The focus was on studies published in or after 1996 as the year in which

HAART was introduced in Australia, significantly improving treatment and survival, and altering perceptions of life with HIV.

Study selection

Studies were eligible for selection if they met the inclusion criteria (see Table 1).

Table 1. Inclusion criteria

Study population	WLHIV (no limitations on age). Studies including women and men were included if there was explicit differentiation and discussion of results by gender.
Study focus	Self-reported experiences
Methodology	Qualitative studies, employing any data collection methods/approaches (e.g. interviews, focus groups; phenomenological analysis, ethnographic fieldwork)
National context	Australia, Canada, New Zealand, UK, US
Publication type	Peer-reviewed reports of primary research
Language	Published in English
Publication dates	January 1996 to October 2017

In total, 801 records were identified through database and internet searches. Records (title and abstract) were downloaded into EndNote software and assessed for relevance to the aims of this review. After removing duplicates and reviewing titles and abstracts against inclusion criteria (Table 1), 114 articles were retrieved for full-text review. Additional papers identified through hand searches of reference lists (of key articles, as well as reviews and grey literature that were excluded from analysis) were also screened for possible inclusion. Finally, 102 articles were selected for analysis (Figure 1).

Figure 1: Literature review flow diagram [at end of this document]

Characteristics of included studies

Included articles were reviewed to identify country of origin, participant characteristics, methods, and key findings (Table 2). Included articles report predominantly descriptive, original research. While articulated in various terms the objective of most studies was to explore the experiences and perceptions of women with a diagnosis of HIV, either to identify issues faced by WLHIV or to explore specific issues or factors related to women’s experiences, such as engagement in care, pregnancy decision-making or stigma.

Included studies were conducted in the US (n= 62), Canada (n=17), UK (n= 12), Australia (n= 8) and New Zealand (n=2), and one “global” study included participants from these countries. The number of participants ranged from 4 to 489. In many US and UK studies

samples were entirely or largely a specific racial group, predominantly African American women (n=39), or African migrant women living in the UK (n=10). This reflects the disproportionate prevalence of HIV among African American women in the US who represent 59% of WLHIV (Centres for Disease Control & Prevention, 2017b) and among African women living in the UK, who comprise 65% of WLHIV (Kirwan et al., 2016). Some studies focused on older women (i.e., 50 and over), and 14 studies involved WLHIV who were mothers.

Most studies did not report a specific theoretical perspective or framework; where this was reported, the most common was Grounded Theory. The most prevalent method of data collection was in-depth, semi-structured interviews. The most common data analysis method was thematic analysis, followed by interpretative phenomenological analysis and narrative analysis.

Research interest in the lived experiences of WLHIV was relatively stable over the period covered by this review (1996 to 2017) but the number of articles meeting the review inclusion criteria increased over time, peaking in 2015 and 2016 (11 studies in each year). This suggests an increasing interest in the experiences of WLHIV and/or in subjective accounts of living with HIV. Included studies indicated the need for and value in exploring experiences over time, yet this review identified only three longitudinal studies involving WLHIV (Squire, 2003; Stevens & Hildebrandt, 2006; Taylor et al., 2017).

The main findings from each study were extracted (Table 2) and key topics identified (as indicated in bold in the 'Key findings' column). A narrative synthesis of the key themes across the included literature follows.

Results

Several themes, encompassing the most common and/or significant experiences described by WLHIV, were identified: stigma, social isolation and loneliness, experiences and engagement in healthcare, living with HIV (including managing HIV and comorbidities, "living well", coping and self-care strategies), social support, motherhood (including reproductive decision-making, pregnancy and mothering/caregiving roles), and sexuality/ intimate relationships. The following discussion considers these key themes, the commonalities and differences highlighted by the literature to date, and changes over time.

Stigma and its impacts on WLHIV

Stigma is the most pervasive theme in the literature investigating the experiences of WLHIV, and PLHIV more broadly. After diagnosis, stigma and the resulting psychosocial consequences became a focus for women (Carr & Gramling, 2004). Women were aware of

negative stereotypes of women with HIV and assumptions they contracted the virus through sex work and/or illicit drug use (Carr & Gramling, 2004; Lekas et al., 2006; Logie et al., 2011). Lekas and colleagues' (2006) study engaging women diagnosed pre- and post-HAART found these stereotypes persisted over time. The internalisation of stereotypes led women to feel self-blame, self-loathing, shame, guilt, distress and increased fear of discrimination (Lawless et al., 1996b; Lekas et al., 2006).

Studies have identified significant and persisting emotional distress and suffering for WLHIV, largely attributable to the shame, stigma and discrimination that shaped how women engaged in their social and interpersonal worlds and their ability to gain support (Peltzer et al., 2017; Rouleau et al., 2012; Teti et al., 2015). Depression, anxiety and uncertainty were common across settings and samples; depression was nearly universal among participants in many studies over the past two decades (Doyal & Anderson, 2005; Hackl et al., 1997; Himelhoch & Njie-Carr, 2016; Illangasekare et al., 2014; Mphande-Finn & Sommers-Flanagan, 2007; Orza et al., 2015).

Women perceived HIV as a self-inflicted problem, unworthy of sympathy (Sanders, 2008). Many suggested women faced greater stigma and discrimination because of their gender (Bennett, 2007; Ingram & Hutchinson, 2000; Lekas et al., 2006; Logie et al., 2011; Metcalfe et al., 1998). WLHIV felt judged, as "dirty" and "contaminated" (Bennett, 2007), and for failing in social roles as mothers and caregivers (Lekas et al., 2006; Logie et al., 2011). This experience was magnified for WLHIV marginalised due to race, poverty, social class and/or substance use (Lekas et al., 2006; Sangaramoorthy et al., 2017a; Solomon & Wilkins, 2008). These views and experiences have persisted over time with recent studies among African American in the US and African migrant women in the UK and NZ identifying intersectional stigma as a central feature of their lives (Fletcher et al., 2016a; Poindexter, 2013; Sangaramoorthy et al., 2017b). Others highlight the convergence of HIV-related stigma with stigma associated with drug use, mental health, transgender identity or sex work (Logie et al., 2012; Orza et al., 2015).

Different types of stigma (enacted, internalised and anticipated) (Earnshaw & Chaudoir, 2009) and discrimination were experienced across different realms (intra/interpersonal, social/community and organisational/political) (Logie et al., 2011). Included studies found loss of self-worth caused by internalised stigma affected women's ability to cope, their psychological wellbeing, relationships, employment status and opportunities, use of healthcare services, and pregnancy decision-making. Enacted and/or anticipated HIV-related stigma made it difficult for women to cope with their illness (Lekas et al., 2006; Logie et al., 2011), and caused increased shame, anxiety and stress (Treisman et al., 2014; Tufts et al., 2010). Many WLHIV told of experiences of exclusion, rejection and/or mistreatment from

family, friends, healthcare providers, employers and/or members of their church community (Blake et al., 2008; Carr & Gramling, 2004; Rouleau et al., 2012; Siegel et al., 2006). African American women and African women in the UK commonly reported emotional and physical abandonment by a romantic partner and/or family or friends, being denied contact with their children and being evicted from their homes (Doyal & Anderson, 2005; Fletcher et al., 2016a). Concerns about stigma and discrimination also impacted employment, participation and opportunities for WLHIV (Carr & Gramling, 2004; Poindexter, 2013; Solomon & Wilkins, 2008). Some women were fired, encouraged to leave jobs, or had job offers withdrawn after their HIV status was disclosed (Carr & Gramling, 2004; Poindexter, 2013).

Experiences of stigma commonly occurred in medical and healthcare settings, enacted by doctors, nurses and other health professionals (Carr & Gramling, 2004; Greene et al., 2016; Ingram, 1999; Ingram & Hutchinson, 2000; Ion & Elston, 2015; Lawless et al., 1996b; Lingen-Stallard et al., 2016; Logie et al., 2012; Moneyham et al., 1996; Peltzer et al., 2016; Sanders, 2008; Sangaramoorthy et al., 2017b). In several studies, including with pregnant WLHIV (Kirshenbaum et al., 2004; Sanders, 2008; Treisman et al., 2014), most participants experienced marginalising or stigmatising healthcare encounters that demonstrated lack of knowledge about HIV (Ion & Elston, 2015; Kirshenbaum et al., 2004; Lawless et al., 1996b; Sanders, 2008). Stereotyping about who ‘gets’ HIV, breaches of confidentiality, overt reactions of disgust or disdain, excessive use of contact precautions (fear of contagion) and refusal to treat were exhibited by health care professionals (Carr & Gramling, 2004; Ingram & Hutchinson, 2000; Ion & Elston, 2015; Lingen-Stallard et al., 2016; Logie et al., 2012; Moneyham et al., 1996; Sanders, 2008; Treisman et al., 2014). Despite significant advances in HIV and its clinical management over the past 20 years, these experiences were identified in the earliest studies (Ingram, 1999; Lawless et al., 1996b) and contemporary research (Greene et al., 2017; Greene et al., 2016; Ion & Elston, 2015; Lingen-Stallard et al., 2016).

Experiences of stigma created, and continue to create, barriers to health and support services for WLHIV (Anderson & Doyal, 2004; Fletcher et al., 2016a; Lawless et al., 1996b; Logie et al., 2012; Moneyham et al., 2010; Ndirangu & Evans, 2009; Peterson, 2010; Sandelowski et al., 2004). Early studies also found women delayed accessing care or avoided critical healthcare services altogether as a consequence of stigmatising experiences with health care professionals (Goggin et al., 2001; Lawless et al., 1996b; Marcenko & Samost, 1999).

HIV-related stigma impacted pregnancy decision-making and was a concern for women during pregnancy. WLHIV continue to experience stigma related to motherhood during pregnancy, birth and the postpartum period (Greene et al., 2017; Greene et al., 2016; Sanders, 2008), and – even in recent years – faced judgment and questioning of their pregnancy intentions (Greene et al., 2016). Despite significant advances in treatment, Green and

colleagues (2016) found pregnant women's ability to cope with an HIV diagnosis was hampered by stigmatising practices by medical professionals and fear of inadvertent disclosure by healthcare staff. A recent study found women still experienced stigma and felt subjected to surveillance during pregnancy, labour and the postpartum period, which lead them to distance themselves from clinical and social support networks (Greene et al., 2017).

Disclosure

Stigma, particularly anticipated stigma, often manifested as lack of disclosure and self-isolation. For WLHIV, disclosure is a difficult process that does not seem to have become any easier in recent years (Treisman et al., 2014). Deciding if, when, and to whom to disclose required careful analysis of the nature/quality of the relationship, anticipated reactions, levels of trust, and weighing up of potential risks and benefits (Black & Miles, 2002; Ndirangu & Evans, 2009; Peterson, 2010; Sowell et al., 2003; Treisman et al., 2014).

Anticipated stigma, associated with fear of abandonment and/or rejection by family and friends, hostility and even violence, meant women engaged in significant work (e.g. hiding appointments, medication, side effects) to prevent, or strictly control disclosure (Anderson & Doyal, 2004; Beauregard & Solomon, 2005; Blake et al., 2008; Doyal & Anderson, 2005, 2006; Grodensky et al., 2015; Nicolas & Schilder, 1997; Orza et al., 2015; Peterson, 2010; Rouleau et al., 2012). Some women did not disclose to anyone (Sowell et al., 2003), particularly older WLHIV who believed their HIV status was more shameful at their age (Grodensky et al., 2015). Women who did not disclose lived in fear of their status being revealed and the ensuing discrimination, damage to familial relations, and "spoiling" of their identities as 'normal' women and/or mothers (Anderson & Doyal, 2004; McDonald, 2011).

In their narratives many women identified a 'disclosure dilemma', whereby revealing their status was necessary to access support, encouragement and acceptance, but also put them at risk of stigma, discrimination and isolation (Blake et al., 2008; Carr & Gramling, 2004; McDoom et al., 2015; Peterson, 2010; Rouleau et al., 2012). In response, WLHIV commonly practised selective or "protective" disclosure (Peterson, 2010); telling only trusted individuals, which allowed them to gain emotional support (Black & Miles, 2002).

For WLHIV who were mothers, disclosure to their children was one of the most difficult decisions (Ingram & Hutchinson, 2000; Marcenko & Samost, 1999; Schrimshaw & Siegel, 2002). Across the studies participants described feeling consumed by grief, worry and guilt about inflicting psychological pain on their children (Hackl et al., 1997; Ingram & Hutchinson, 1999; Ndlovu et al., 2010). Many chose not to disclose (Ingram & Hutchinson, 1999; Solomon & Wilkins, 2008), lying, being "hypervigilant" and hiding evidence to conceal their status and protect children from stigma and ostracism (Hackl et al., 1997;

Ingram & Hutchinson, 1999; Ndlovu et al., 2010). Reasons for nondisclosure included: believing the children were too young or immature, believing it would be too big an emotional burden, and not wanting their children to fear losing their mother (Schrimshaw & Siegel, 2002). Conversely, reasons for disclosing to children included: wanting to be honest and educate them about HIV, wanting their children to hear it from them, and disclosing before they became very ill (Schrimshaw & Siegel, 2002; Vallerand et al., 2005).

Despite the dominance of findings reporting concealing or restricting disclosure, two recent studies highlighted efforts by some women to “normalise” HIV through full and open disclosure of their status, to educate people and empower other WLHIV (Greene et al., 2017; Robillard et al., 2017). Further research may confirm if increasing openness is a ‘sign of the times’, and identify the characteristics and perceptions of HIV-related stigma for women who fully disclose.

Social isolation and loneliness

Social isolation and loneliness were major themes, related to lack of disclosure, limited support and community for WLHIV, decreased social participation, secrecy and guilt (Blake et al., 2008; Nicolas & Schilder, 1997; Peltzer et al., 2017; Rouleau et al., 2012; Siemon et al., 2013; Solomon & Wilkins, 2008; Stevenson et al., 2017). The time-span of publications indicates little change in WLHIV’s experiences of isolation and loneliness over time.

Participants in several recent studies described a retreat into isolation in response to stigma, discrimination or betrayal, or to protect themselves (Lingen-Stallard et al., 2016; Orza et al., 2015; Peltzer et al., 2016; Peltzer et al., 2017; Rouleau et al., 2012; Solomon & Wilkins, 2008). An earlier study involving 158 WLHIV in New York found the internalisation of stereotypes and corresponding feelings of self-loathing and shame often led to self-exile (Lekas et al., 2006). The lack of desire or energy to engage socially, unhappiness with their physical appearance, mental health issues and feeling marginalised were also associated with isolation (Siemon et al., 2013; Solomon & Wilkins, 2008). Profound loneliness stemming from isolation was common (Peltzer et al., 2017), but even women with supportive partners, families or friends felt isolated (Peltzer et al., 2016).

Women’s isolation or withdrawal reduced opportunities for social engagement and participation. Studies published in the late 1990s highlighted the isolation of many WLHIV and the resultant reliance on primary care providers as their only source of support (Lawless et al., 1996b; Nicolas & Schilder, 1997). Social isolation is an enduring issue for WLHIV: a Canadian study found many WLHIV did not leave their homes, socialise or try new activities (Solomon & Wilkins, 2008). More recently, older WLHIV described social isolation and limited social interactions stemming from the lack of support services and resources

appropriate to their needs (Siemon et al., 2013), along with reluctance to disclose their HIV status (Enriquez et al., 2008; Grodensky et al., 2015; Stevenson et al., 2017). In contrast, facilitators of social participation included a supportive network, a strong sense of self, and their children (Solomon & Wilkins, 2008), as well as spiritual or faith-based connections, volunteer work and instrumental (e.g. financial) support (Siemon et al., 2013).

Seeking and receiving social support

WLHIV identified social support as central to coping with their illness, engaging in care and psychological wellbeing (Ndlovu et al., 2010; Peterson, 2010). Older WLHIV described social support as essential to their wellbeing (Psaros et al., 2015; Stevenson et al., 2017) and survival (Enriquez et al., 2008). Studies with women diagnosed in the 1990s (Metcalf et al., 1998) and more recently (Walsh et al., 2012) identified unmet needs for information, peer and social support immediately following diagnosis.

Key providers of emotional and practical support included family members and friends (Ciambrone, 2002; Peterson, 2010; Siemon et al., 2013). Younger women relied on parents, especially mothers (Ciambrone, 2002); for older WLHIV, adult daughters were primary sources of support (Grodensky et al., 2015). Older African American women identified intimate partners (present or desired) as emotional supports and aids to self-managing (Warren-Jeanpiere et al., 2014). Distance from family and associated supports was extremely damaging to migrant African women in the UK (Doyal & Anderson, 2005). Despite the importance of these supports, studies also identified that family and friends are not always supportive following diagnosis (Ciambrone, 2002; Rouleau et al., 2012), and their negative reactions were devastating for WLHIV (Anderson & Doyal, 2004; Carr & Gramling, 2004; Ndirangu & Evans, 2009; Rouleau et al., 2012). Supportive relationships and communities were particularly important to HIV-positive women living in rural areas (Groft & Robinson Vollman, 2007; Mphande-Finn & Sommers-Flanagan, 2007). Pet dogs also have been identified as sources of unconditional and non-judgmental support (Kabel et al., 2015).

Studies reviewed indicated a diversity of views and experiences of formal support: stigma, the lack of support services, difficulties locating or accessing services, or inappropriately targeted services, were key challenges (Peterson, 2010). One of the earliest included studies highlighted the lack of support services available to WLHIV in Australia (Lawless et al., 1996b), a finding reiterated by one of the most recent studies from the UK, which identified increasing barriers to support, along with amplified loneliness and isolation, due to funding cuts for community organisations (Stevenson et al., 2017). Despite challenges with access, and concerns about confidentiality and anticipated stigma, the potential benefits of accessing support services outweighed the risks (Doyal & Anderson, 2005; Watkins-Hayes et al., 2012)

(Peltzer et al., 2017). Women with HIV continued to want more peer-delivered care and support (Carter et al., 2015b; Metcalfe et al., 1998; O'Brien et al., 2017). Women who had received or provided peer-driven services felt they were supportive, inclusive and accessible (Carter et al., 2015a), and met their needs for community, empathy, empowerment (O'Brien et al., 2017)

Healthcare experiences and engagement in healthcare

Several studies focused on barriers and facilitators of healthcare access and engagement for WLHIV. Significant differences exist between healthcare systems across the countries included in this review, but some experiences reported by WLHIV were common across settings. In particular, many WLHIV described negative healthcare experiences adversely impacting their engagement with services and continuation of treatment. In studies across the 20 year timeframe of the review, women expressed concern and frustration at the perceived lack of knowledge of medical professionals about HIV generally, particularly the impact on women's health (Nicolas & Schilder, 1997; O'Brien et al., 2017) and in the context of ageing (Enriquez et al., 2008). Health professionals were judgmental, lacked understanding of women's concerns and did not consider WLHIV as "whole persons" (Bennett, 2007; O'Brien et al., 2017). Some women felt non-HIV-related health problems were discounted and/or not investigated because providers presumed symptoms were HIV-related (Carr & Gramling, 2004).

In studies focused on experiences of seeking and receiving healthcare, WLHIV identified structural, social and personal barriers. Poverty and lack of stable housing impacted women's health-seeking behaviour and decisions (O'Brien et al., 2017; Solomon & Wilkins, 2008; Walcott et al., 2016). Women faced with limited resources often 'de-prioritised' their health, instead focusing on providing basic needs and taking care of their families (Walcott et al., 2016). WLHIV in the US emphasised structural barriers including: lack of access to care (Sangaramoorthy et al., 2017b), lack of coordinated care (Sangaramoorthy et al., 2017b), distance from services and transportation challenges (Buchberg et al., 2015; Kempf et al., 2010; Moneyham et al., 2010; Walcott et al., 2016), and the high cost of healthcare (Moneyham et al., 2010; Sangaramoorthy et al., 2017b; Stevens & Keigher, 2009; Walcott et al., 2016). Other US studies have drawn attention to health system barriers such as length of appointments and waiting times (Moneyham et al., 2010), along with healthcare providers who were disrespectful and insensitive to women's time and needs (Marcenko & Samost, 1999). HIV services were not considered "female-friendly" (i.e. they were oriented to gay men) or appropriate for women (Bennett, 2007; Carter et al., 2015b; Cummins & Millar, 2004; Logie et al., 2012).

Experiences or fears of HIV-related stigma remain significant barriers to seeking, engaging in or sustaining HIV care (Buchberg et al., 2015; Cummins & Millar, 2004; Ion & Elston, 2015; Kempf et al., 2010; Lawless et al., 1996b; Logie et al., 2012; McDoom et al., 2015; Moneyham et al., 2010; Peltzer et al., 2016). Some women would ‘shop around’ to find services/practitioners they were comfortable with, or not disclose their HIV status and/or drug use (Lawless et al., 1996b). Distancing themselves from spaces, places and individuals associated with HIV was a common strategy used by WLHIV worried about stigma (Greene et al., 2017). For older WLHIV, fear of judgment, being “outed” and stigma were barriers to accessing services at HIV or infectious disease clinics (Cummins & Millar, 2004; McDoom et al., 2015) and to accessing non-HIV specialist healthcare and social support (Stevenson et al., 2017). Other enduring social or personal barriers to access included: caregiving responsibilities (particularly caring for children); lack of social support beyond immediate family members (Buchberg et al., 2015; Gant & Welch, 2005; Marcenko & Samost, 1999); drug use; denial or “submersion” of awareness of the diagnosis; and depression (Moneyham et al., 2010; Stevens & Hildebrandt, 2006).

WLHIV were more likely to remain in the healthcare system if clinicians were trustworthy, supportive, knowledgeable and non-judgmental (Blake et al., 2008; DeMoss et al., 2014; McDoom et al., 2015). Canadian women recommended women-centred care that coordinated and integrated services addressing HIV and women's health needs, as well as addressing structural barriers to access (e.g., violence, poverty, motherhood, stigma and challenges to safe disclosure) (O'Brien et al., 2017). Similarly, Aboriginal women in Australia reported greater adherence and engagement if health services recognised their individual and holistic needs, and provided psychosocial and welfare support alongside medical care (Newman et al., 2007). For African American women, encouragement and support, whether formal (received from healthcare providers, support groups, case managers, social workers or HIV/AIDS community organisations) or informal (especially from family), facilitated engagement in HIV care (McDoom et al., 2015) and treatment adherence (Gant & Welch, 2005).

Life with HIV

Diagnosis

Irrespective of the ‘era’ of diagnosis, shock, devastation, fear, anger or indignation were common responses to diagnosis (Lingen-Stallard et al., 2016; Logie et al., 2011; Metcalfe et al., 1998; Nicolas & Schilder, 1997; Peltzer et al., 2017; Persson, 2013; Sanders, 2008; Teti et al., 2015; Treisman et al., 2014). Many attributed these views to the belief they had not been at risk (Doyal & Anderson, 2005; Lingen-Stallard et al., 2016; Persson, 2013; Stevens & Hildebrandt, 2006; Walsh et al., 2012). For women diagnosed pre-HAART, diagnosis was

traumatic and most experienced emotional distress (Nicolas & Schilder, 1997). Women diagnosed post-2000 were similarly distressed, with some escalating drug and alcohol use and suicidality (Logie et al., 2011; Peltzer et al., 2017; Stevens & Hildebrandt, 2006; Teti et al., 2015).

Transition to acceptance and positive growth

Many WLHIV were able to transition from fear and disbelief at the time of diagnosis to gradual acceptance and integration of HIV into their lives (Lingen-Stallard et al., 2016), although for some, uncertainty remained (Doyal & Anderson, 2005) or intensified as they aged (Psaros et al., 2015). Studies have drawn attention to the resilience and strengths of WLHIV, their resolve to face the future with optimism, and their capacity – despite adversity and complex needs – to experience positive transformation or see HIV as a motivating force to make positive changes in their lives (Dibb & Kamalesh, 2012; Goggin et al., 2001; Psaros et al., 2015; Robillard et al., 2017; Siegel & Schrimshaw, 2000). In these studies, average time since diagnosis for participants ranged from four to 16 years. Evidence suggests acceptance and optimism or “positive growth” improved with time since diagnosis (Lingen-Stallard et al., 2016; Metcalfe et al., 1998; Robillard et al., 2017).

In several studies, high proportions of WLHIV (whose average time since diagnosis was four years or more) reported their illness experience was meaning-giving and had positively changed their lives (Mayers et al., 2005; Mphande-Finn & Sommers-Flanagan, 2007; Siegel & Schrimshaw, 2000). Three-quarters of African American women in a recent study described not just surviving, but thriving: despite physical challenges, mostly related to the side-effects of HAART, stigma and other negative consequences, they were relatively healthy and hence saw HIV as a manageable disease rather than a debilitating “death sentence” (Watkins-Hayes et al., 2012). Many WLHIV described a sense of gratefulness and improved valuing of life, particularly those diagnosed pre-1996 who thought death was imminent at the time of their diagnosis (Beauregard & Solomon, 2005; Psaros et al., 2015; Siegel & Schrimshaw, 2000). For some older WLHIV, religious faith was key to personal growth and confidence in their own strength (Plach et al., 2005); for others, mostly long-term diagnosed, ‘successful living’ with HIV was predicated on acceptance, appreciation and self care (Psaros et al., 2015).

Over time WLHIV found more meaning and value in life, and discovered new goals and opportunities, often related to helping other WLHIV through awareness-raising and peer support (Dibb & Kamalesh, 2012; Doyal & Anderson, 2005; Psaros et al., 2015; Siegel & Schrimshaw, 2000). As a consequence, women were motivated to make health behaviour

changes in a range of areas (Siegel & Schrimshaw, 2000) and those who enacted changes reported feeling greater control over their lives (Dibb & Kamalesh, 2012).

Managing HIV

The included literature reported insights from many WLHIV about managing daily life and coping with the psycho-social impacts of HIV. Dominant concerns included: parenting (Hackl et al., 1997; Marcenko & Samost, 1999; Ndlovu et al., 2010), financial stress (Keigher & Stevens, 2011; Siemon et al., 2013), housing security or quality (Marcenko & Samost, 1999; Ndlovu et al., 2010). US studies highlighted the ways financial insecurity destabilised participants' medical care, treatment adherence, nutrition, housing and their children's lives (Keigher & Stevens, 2011), and impacted social participation and access to programs and services (Siemon et al., 2013). For African migrant women in the UK, economic difficulties, poor living conditions and uncertain immigration status were central, often overshadowing HIV (Doyal & Anderson, 2005; Treisman et al., 2014).

At the physical level, a small number of studies examined how WLHIV manage HIV. Goggin et al.'s (2001) US study identified significant challenges associated with coping with HIV-related physical symptoms and disorders. Similarly, a UK study of predominantly African WLHIV described physical symptoms that limited or adversely affected everyday life, including the capacity to work (Doyal & Anderson, 2005). An early study found nearly all participants reported fatigue, physical illness and negative moods (feeling "depressed" or "stressed out") (van Servellen et al., 1998).

More recent research suggests the burdens of self-managing HIV increased as women's health declined with age and increasing comorbidities (Sangaramoorthy et al., 2017a; Warren-Jeanpiere et al., 2014). Older WLHIV highlighted concerns about the intersection of HIV and ageing (Enriquez et al., 2008; Sangaramoorthy et al., 2017a; Stevenson et al., 2017; Warren-Jeanpiere et al., 2014). In particular, women were frightened and frustrated by the lack of information and uncertainty of ageing and their inability to determine whether changes were symptoms of advancing HIV or 'normal' effects of ageing (Enriquez et al., 2008).

Self-care and coping

WLHIV described the importance and value of self-care and the strategies they adopted to control symptoms and enhance their physical and psychological wellbeing. Key self-care strategies were consistent over time, including health behaviour changes aimed at sustaining or enhancing physical and mental health. For example, one in five WLHIV in Goggin's (2001) New York based study reported taking better care of their physical health, and around one-quarter entered recovery from substance abuse and dependence following diagnosis.

Over time, spirituality, prayer or religious practices have endured as commonly-identified sources of support and strategy to ameliorate psychological distress, suffering and stressors associated with HIV/AIDS (Nicolas & Schilder, 1997; Siegel & Schrimshaw, 2000), particularly for African American women (Peltzer et al., 2017; Shambley-Ebron & Boyle, 2006) and African women living in England (Anderson & Doyal, 2004; Doyal & Anderson, 2005). Older WLHIV identified spirituality as an important coping strategy (Grodensky et al., 2015), and an essential element of self-care (Plach et al., 2005). Recent studies described women's reliance on individual forms of worship (spirituality, prayer, private relationship with God) rather than communal worship due to concerns about judgment and stigmatisation by members of their church community (Grodensky et al., 2015; Himelhoch & Njie-Carr, 2016; Siemon et al., 2013).

For other women, self-care meant taking care of their mind, body and spirit through 'pampering' or participating in religious customs (Tufts et al., 2010). Strategies identified by midlife and older women included caring for their mind and body (particularly eating well, exercising and managing stress, depression, and anxiety), changing or eliminating "toxic" relationships or behaviours (such as substance abuse), and engaging in meaningful activities or doing good for others (Plach et al., 2005; Psaros et al., 2015; Warren-Jeanpiere et al., 2014). A recent study found women whose HIV was "well-managed" were more likely to report supportive relationships, self-awareness and self-efficacy, including active coping and using resources to effect change (Brody et al., 2016).

Motherhood

Reproductive decision-making

WLHIV of childbearing age/capacity were mostly positive about having children, despite stigma (Ingram & Hutchinson, 2000) and non-supportive messages or social exclusion from healthcare providers (Fletcher et al., 2016b; Orza et al., 2015; Sandelowski et al., 2004; Sanders, 2008). Earlier studies also identified vertical transmission and beliefs about efficacy of risk reduction strategies as primary considerations in pregnancy decision-making (Kirshenbaum et al., 2004). WLHIV described a "sociocultural double bind" (Kirshenbaum et al., 2004): their desire for children violated social norms about 'acceptable mothering'. They weighed their personal reasons for seeking or continuing a pregnancy against the negative, even hostile, public opinion and social condemnation of childbearing by WLHIV (Black & Miles, 2002; Ingram & Hutchinson, 2000). Several US studies found HIV-positive mothers perceived a consensus among the general public, family members and healthcare providers that HIV-infected women having children was morally and socially irresponsible (Barnes & Murphy, 2009; Ingram & Hutchinson, 2000; Kirshenbaum et al., 2004; Lekas et al., 2006).

Few identified studies focused on the lived experience of pregnancy for WLHIV, but research that did identified preventing transmission and protecting the child from harm as central (Giles et al., 2009; Goggin et al., 2001; McDonald & Kirkman, 2011). Women who accepted interventions to prevent mother-to-child transmission reported feeling fear and guilt (Giles et al., 2009) or worry for their child and/or themselves (McDonald & Kirkman, 2011).

Experiences of motherhood

A small number of articles explored the mothering experiences of WLHIV (Giles et al., 2009; Ingram & Hutchinson, 1999; Ingram & Hutchinson, 2000; McDonald, 2011) and challenges associated with managing a chronic disease and maintaining caregiving roles (Ciambrone, 2002; Sangaramoorthy et al., 2017a). For some WLHIV (mostly diagnosed pre-HAART or early in the post-HAART era) motherhood involved worry and guilt about the impact of diagnosis on their families (Goggin et al., 2001; van Servellen et al., 1998), anxiety about failing to meet cultural expectations of mothers as moral guardians (Doyal & Anderson, 2006), and a range of existential issues including responsibility and choice, helplessness and loneliness (Mayers et al., 2005). Despite concerns about the impact of their HIV on the family, WLHIV valued motherhood as a mechanism of ‘normality’ (Doyal & Anderson, 2005; Ingram, 1999), socially valued identity, and a way to fulfil social expectations of them as women (Barnes & Murphy, 2009; Doyal & Anderson, 2005; Fletcher et al., 2016b; Ingram & Hutchinson, 2000; Kirshenbaum et al., 2004; Sandelowski & Barroso, 2003; Sanders, 2008). For some, becoming a mother was transformative and an opportunity to “get their lives together” (Sanders, 2008) or to reshape social identities, particularly for women marginalised due to drug and alcohol use and/or criminality (Fletcher et al., 2016b; Sanders, 2008).

Across study settings, populations and years, women identified their children as a source of strength, emotional support and happiness (Ciambrone, 2002; Grodensky et al., 2015; Sangaramoorthy et al., 2017a). Children provided meaning and motivation for social participation for many WLHIV who were also experiencing poverty, depression and/or isolation (Mayers et al., 2005; Solomon & Wilkins, 2008). For women who were mothers or pregnant when diagnosed, their children were a ‘reason to live’ (Doyal & Anderson, 2005; Ingram & Hutchinson, 1999; Ingram & Hutchinson, 2000; Treisman et al., 2014; Wilson, 2007), and the motivation for them to engage with and remain in care or keep themselves healthy (McDoom et al., 2015; Sangaramoorthy et al., 2017a; Siemon et al., 2013; Treisman et al., 2014; Warren-Jeanpiere et al., 2014).

Several articles highlight the importance of HIV-positive mothers establishing and maintaining identities as “good mothers” (Wilson, 2007): they put their children’s interests before their own, including sacrificing personal relationships, and protected their children from stigma (Shambley-Ebron & Boyle, 2006; Wilson, 2007). Women felt they failed to be

good mothers when fatigue, periods of acute illness or the physical demands of HIV hindered their capacity to care for their children (Ingram & Hutchinson, 2000).

Sexuality and intimate relationships

Prior to 1996 research examining the sexuality of WLHIV was limited largely to reproductive decision-making, conception and safe sex (Lawless et al., 1996a). Two decades on, this remains an under-researched topic with only a handful of qualitative studies focusing on sexuality and sexual activity of WLHIV (Gurevich et al., 2007; Lawless et al., 1996a; Psaros et al., 2012; Siegel et al., 2006; Taylor et al., 2017). American, Australian and Canadian WLHIV have depicted HIV as inhibiting and restricting their sexuality and sexual practices (Gurevich et al., 2007; Lawless et al., 1996a; Siegel et al., 2006). Many discussed, and were upset by, reduced sexual pleasure, decreased sexual activity, diminished sense of sexual attractiveness and fear of rejection by sexual partners (Siegel et al., 2006). Reasons WLHIV gave for discontinuing sexual activity included anxiety about HIV transmission, fears of rejection (after disclosure) and emotional hurt, not wanting the hassle of a relationship and body image concerns (Grodensky et al., 2015; Nicolas & Schilder, 1997; Orza et al., 2015; Psaros et al., 2012; Sangaramoorthy et al., 2017b; Siegel et al., 2006; Taylor et al., 2017). HIV-related stigma and fear of disclosure (and consequent pain and suffering) meant some women resigned themselves to leading celibate lives and were discouraged from pursuing romantic relationships (Nicolas & Schilder, 1997; Sangaramoorthy et al., 2017b). Older women felt disclosure was more challenging for them as they perceived men of their generation had more negative beliefs about HIV and WLHIV, hence some chose to remain single (Psaros et al., 2012).

Irrespective of age, many WLHIV desired an intimate relationship (Grodensky et al., 2015; Nicolas & Schilder, 1997; Psaros et al., 2012; Squire, 2003; Taylor et al., 2017). One recent study concluded that for many older women, the challenges of managing HIV and growing older extinguished interest in pursuing intimate relationships (Stevenson et al., 2017). In contrast, other research found most older WLHIV were involved in or desired intimate relationships (Grodensky et al., 2015; Psaros et al., 2012; Taylor et al., 2017; Warren-Jeanpiere et al., 2014).

Discussion and conclusions

Taken as a whole, the literature reviewed highlights the commonality of experiences of a diverse sample of WLHIV living in high-income countries, over the past two decades of the HIV epidemic. The review highlights similarities and distinctions in experience associated

with the diverse demographics of the women represented in the included studies, and considers the reported experiences of WLHIV within a changing HIV landscape.

HIV-related stigma was an enduring focus of research with WLHIV over the last two decades; while studies of experiences of pregnancy and motherhood for WLHIV largely clustered between 2006 and 2011 (Barnes & Murphy, 2009; Giles et al., 2009; McDonald, 2011; McDonald & Kirkman, 2011; Sanders, 2008, 2009; Shambley-Ebron & Boyle, 2006) and, apart from a couple of earlier studies (Enriquez et al., 2008; Gosselink & Myllykangas, 2007; Plach et al., 2005), most research with older WLHIV was published in the past few years (Grodensky et al., 2015; McDoom et al., 2015; Psaros et al., 2015; Sangaramoorthy et al., 2017a; Siemon et al., 2013; Warren-Jeanpiere et al., 2014). A handful of qualitative studies investigating sexuality and sexual activity of WLHIV over the past two decades (Gurevich et al., 2007; Lawless et al., 1996a; Siegel et al., 2006; Taylor et al., 2017) have provided valuable insights into these under-studied issues. Concern about the psychological costs to women of withdrawing from all intimacy (Siegel et al., 2006) and divergent findings in recent studies about women's sustained interest in sexual relationships, suggest more research in this area is needed.

Overall, HIV-related stigma and discrimination were dominant themes; over half the studies described women's experiences or fears of stigma and the consequences in their lives. Findings also highlighted the pervasiveness of gendered HIV-related stigma, with a small number of articles revealing how this was further exacerbated by intersections with race, age, socioeconomic status and/or sexual and substance use risk behaviours (Fletcher et al., 2016a; Lekas et al., 2006; Logie et al., 2011; Orza et al., 2015; Poindexter, 2013; Sangaramoorthy et al., 2017b; Solomon & Wilkins, 2008). Enduring stereotypes and negative public reactions, along with stigmatising attitudes and practices of health professionals, were reported by hundreds of study participants in articles spanning the two decades (Carr & Gramling, 2004; Greene et al., 2016; Ingram, 1999; Ingram & Hutchinson, 2000; Ion & Elston, 2015; Kirshenbaum et al., 2004; Lawless et al., 1996b; Lingen-Stallard et al., 2016; Logie et al., 2012; Moneyham et al., 1996; Peltzer et al., 2016; Sanders, 2008; Sangaramoorthy et al., 2017b; Treisman et al., 2014). Not only has HIV-related stigma endured for WLHIV, but recent studies indicate the ways this is enacted, including in healthcare settings, have changed little over time (Carr & Gramling, 2004; Greene et al., 2016; Ingram, 1999; Ingram & Hutchinson, 2000; Ion & Elston, 2015; Lawless et al., 1996b; Lingen-Stallard et al., 2016; Logie et al., 2012; Moneyham et al., 1996; Peltzer et al., 2016; Sanders, 2008; Sangaramoorthy et al., 2017b; Treisman et al., 2014).

Direct or perceived experiences of stigma meant women struggled with decisions surrounding disclosure and many retreated into social isolation (Lekas et al., 2006; Lingen-Stallard et al.,

2016; Peltzer et al., 2016; Peltzer et al., 2017; Rouleau et al., 2012; Solomon & Wilkins, 2008). Experiences of self-exile and loneliness were not restricted to a particular population of WLHIV and did not appear to have declined over time. In contrast, social support, particularly the emotional and practical support of family and friends (Ciambrone, 2002; Enriquez et al., 2008; Grodensky et al., 2015; Peterson, 2010; Psaros et al., 2015; Siemon et al., 2013; Stevenson et al., 2017; Warren-Jeanpiere et al., 2014), and the value placed on peer support (Carter et al., 2015b; McLeish & Redshaw, 2015; Metcalfe et al., 1998; O'Brien et al., 2017) were central coping mechanisms that helped women address the isolation associated with a diagnosis of HIV.

Temporally, coping and self-care strategies improved over time and within the context of time since diagnosis. Despite some studies identifying significant and persisting emotional distress and suffering for WLHIV (Peltzer et al., 2016; Rouleau et al., 2012; Teti et al., 2015), many women in studies over the past two decades have described making the shift from fear and shock at the time of diagnosis to acceptance, positive adjustment and meaning-finding (Dibb & Kamalesh, 2012; Goggin et al., 2001; Mayers et al., 2005; Mphande-Finn & Sommers-Flanagan, 2007; Psaros et al., 2015; Robillard et al., 2017; Siegel & Schrimshaw, 2000; Watkins-Hayes et al., 2012).

Perhaps one of the most significant and striking findings of the review was the enduring prevalence of negative encounters with health professionals for WLHIV. Despite significant changes in HIV over the past two decades, these experiences have prevailed over time and across countries. Structural barriers to healthcare and support also significantly impacted many women, although this was generally mediated by the country in which the research took place. Nonetheless, while differences in healthcare systems influenced women's access to services and treatment adherence in different countries, WLHIV across study settings described similar barriers in terms of lack of appropriate services for women (Bennett, 2007; Carter et al., 2015b; Cummins & Millar, 2004; Logie et al., 2012), stigmatising encounters or fear of disclosure (Buchberg et al., 2015; Cummins & Millar, 2004; Ion & Elston, 2015; Kempf et al., 2010; Lawless et al., 1996b; Logie et al., 2011, 2012; McDoom et al., 2015; Moneyham et al., 2010; Moneyham et al., 1996; Peltzer et al., 2016) and environmental factors such as poverty (O'Brien et al., 2017; Solomon & Wilkins, 2008; Walcott et al., 2016). There was limited attention to social barriers such as caregiving responsibilities and lack of social support or personal barriers.

In line with a 2003 literature review (Sandelowski & Barroso, 2003), this review found that for many mothers living with HIV, mothering was important to optimising their health and giving them strength and purpose (Ciambrone, 2002; Doyal & Anderson, 2005; Grodensky et al., 2015; Ingram & Hutchinson, 1999; Ingram & Hutchinson, 2000; Mayers et al., 2005;

Sangaramoorthy et al., 2017a; Solomon & Wilkins, 2008; Treisman et al., 2014; Wilson, 2007). Findings also highlighted the dual challenges for mothers living with HIV of being a caregiver and a patient, including their guilt and stress about potential impacts of their illness on their children (Goggin et al., 2001; Hackl et al., 1997; Ingram & Hutchinson, 1999; Ingram & Hutchinson, 2000; Ndlovu et al., 2010; Schrimshaw & Siegel, 2002; van Servellen et al., 1998) and their perceived failure to be “good mothers” (Ingram & Hutchinson, 2000; Shambley-Ebron & Boyle, 2006; Wilson, 2007). These findings highlight a need for further attention to the impact of HIV on women in their caregiving roles – as well as the impact of caregiving responsibilities on the capacity of WLHIV for self-management and self-care.

This review has highlighted some gaps in exploration, and hence understanding, of the lived experience of HIV for women in high-income countries. Studies that provided opportunities for women to identify the greatest burden on their physical and psychological health found that for many it was not managing HIV but interwoven burdens such as financial stress, unemployment, restrictions on parenting and social participation, and other stressors such as housing insecurity and poverty (Hackl et al., 1997; Keigher & Stevens, 2011; Marcenko & Samost, 1999; Ndlovu et al., 2010; Siemon et al., 2013). Otherwise, there has been limited attention to the social contexts of women’s lives: the social, environmental, economic, biological and gender factors influencing their HIV-related experience and outcomes. There was also little exploration of women’s social positions and intersecting identities; how women were forced to renegotiate their roles as mothers, wives and daughters and to preserve their identities as ‘normal’ women following diagnosis (McDonald, 2011; Sangaramoorthy et al., 2017b). The research draws attention to the impact of intersectional stigma on WLHIV and the need for further exploration of the complex web of social marginalisation that continues to shape the lives of WLHIV (Rice et al., 2018).

The small number of studies with older WLHIV has provided some insights into particular challenges and issues for women ageing with HIV in high-income settings. Articles highlighted the increasing burden of self-managing HIV for older WLHIV as their health declined and comorbidities increased (Sangaramoorthy et al., 2017a; Warren-Jeanpiere et al., 2014) and their frustration at the lack of knowledge about the intersection of HIV and ageing (Enriquez et al., 2008; Sangaramoorthy et al., 2017a; Stevenson et al., 2017; Warren-Jeanpiere et al., 2014), but there has been little attention to HIV-related adjustment and coping over time (Psaros et al., 2015). While some studies emphasised increasing optimism and positive adjustment for WLHIV with time since diagnosis (Lingen-Stallard et al., 2016; Metcalfe et al., 1998; Robillard et al., 2017), others noted the adverse effects of uncertainty, frustration and fear related to lack of knowledge and support for older WLHIV (Doyal & Anderson, 2005; Psaros et al., 2015; Stevenson et al., 2017). These findings highlight the

need for further research to learn from mid-life and older WLHIV about strategies for ‘successful ageing’ in the context of HIV and the factors that facilitate or hinder self-management and self-care. Further exploration of the experiences of WLHIV in high-income countries is important, given both the number of WLHIV and the fact that they are surviving longer and getting older (Mahy et al., 2014).

This review highlights the need for further qualitative, especially longitudinal, research to explore the unique experiences, burdens and needs of WLHIV in high-income countries, particularly contextual and sociostructural barriers to healthcare and self-management, factors other than stigma that influence women’s social participation or isolation, and women’s changing needs and strategies for coping and self-care as they live and age with HIV.

Declarations of interest: None

Figure 1: Literature review flow diagram

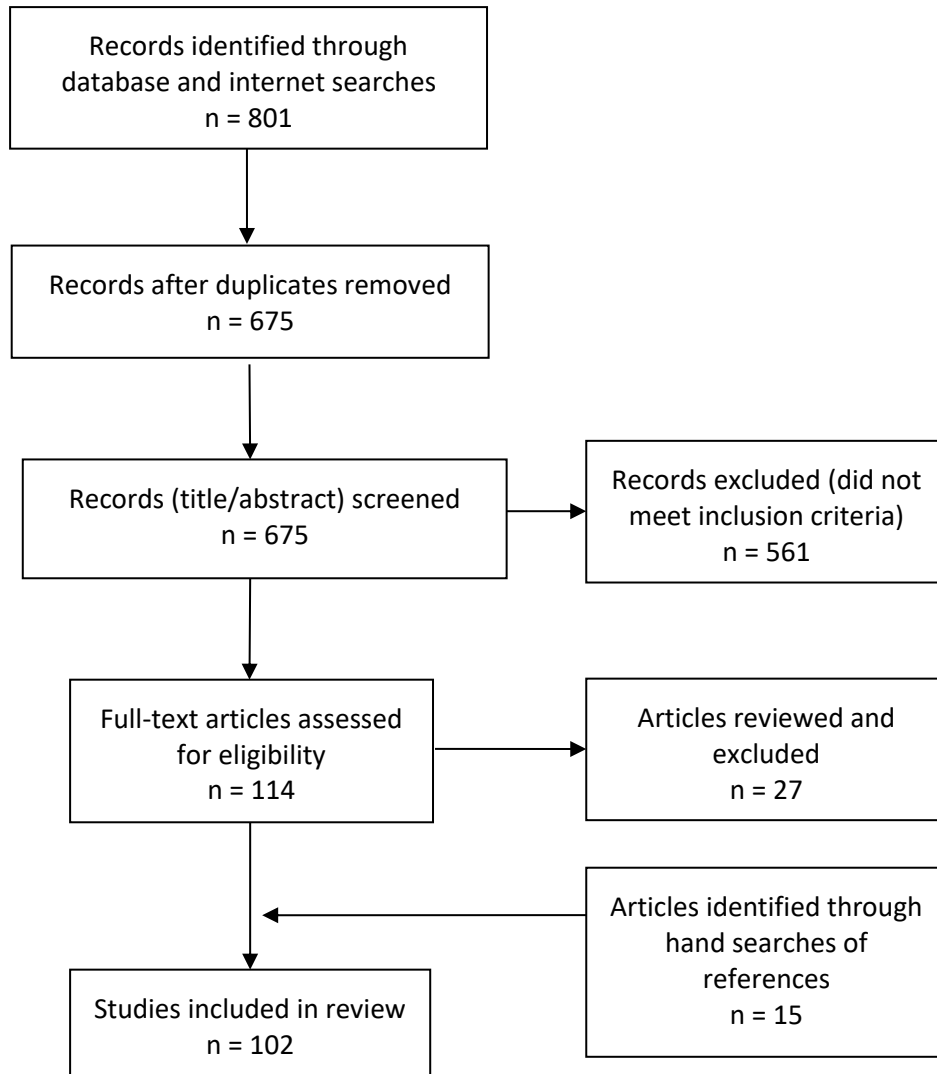


Table 2: Summary of the included literature

Author/s	Year	Country (region*)	Participants: sample size and characteristics*	Data collection method; Data analysis; Methodology and/or theoretical lens*	Main topic/s and key findings
Anderson and Doyal	2004	UK	62 WLHIV from Africa living in London	In-depth semi-structured interviews; narrative approach	Life course, stigma, spirituality: Stigma, both actual and perceived, had a profound impact on women's lives, hence controlling disclosure was important - and this impacted on access to health services and voluntary sector agencies. Resilience was strengthened by religious belief.
Barnes and Murphy	2009	US (3 cities)	80 HIV-positive women of childbearing age, primarily women of colour	Interviews; Grounded theory	Reproductive decision-making, motherhood: Reproductive decisions of women with HIV were based on their judgement of their personal reasons for seeking or continuing a pregnancy against negative, even hostile, public opinion and anticipated condemnation in their social context. Women perceived mothering as a socially valued identity, a reason to live and look to the future, and a chance to regain missed mothering experiences (often related to drug use).
Beauregard and Solomon	2005	Canada	5 WLHA; 40-48 years	In-depth interviews; Phenomenological approach	Living with HIV: Four main themes captured the lived experience of these WLHA: fearing disclosure, experiencing challenges (physical and psychological), having supportive networks, and coping positively (spirituality and opportunity for living and learning).
Bennett	2007	NZ	9 WLHIV	Semi-structured interviews; Thematic analysis, feminist perspective	Living with HIV: Dominant concerns of WLHIV were stigma, the associated problem of whether to conceal or reveal their status, concerns that health professionals were judgemental and lacked understanding of women's concerns, and feeling subordinate because HIV/AIDS services were not appropriate for women.
Black and Miles	2002	US (South-eastern)	48 African American HIV-positive women, primary caretakers of young children	Observation; Content analysis	Disclosure, stigma: Women's disclosure dilemma was characterised by the threat of stigma, feelings of shame, and the concurrent need for support. Determining to whom and when to reveal their HIV diagnosis involved a careful evaluation of the risks and benefits of disclosing.
Blake et al	2008	US (East Texas)	23 HIV-positive women (and 23 HIV-negative)	Focus group interviews; Content analysis	Stigma, experiences of healthcare services: Women with HIV faced rejection and mistreatment from family, friends and healthcare providers. Women living with HIV are more likely to remain in the healthcare system if healthcare professionals are supportive, knowledgeable, and nonjudgmental.
Brody et al	2016	US	20 WLHIV (10 HIV well-managed, 10 HIV not well-managed); mostly African American, low SES	Life turning points and projective story task; Thematic analysis	Coping, self-efficacy: Narratives of women whose HIV was "well-managed" more frequently reflected (a) mutuality (growth-fostering relationships involving reciprocal care and empathy); (b) self-awareness (recognition of personal strengths and weaknesses and multiple factors contributing to life choices and trajectories); and (c) self-efficacy (active coping, self-advocacy, and using resources to effect change, as well as believing that change is possible).

Buchberg et al	2015	US	22 HIV-positive women, postpartum; mean: 28 years, mostly Black/African	Semi-structured, in-depth interviews; Content analysis	Retention in care: Barriers to retention included competing responsibilities for time (especially caring for children), lack of social support outside of immediate family members, limited transportation access and experiences of institutionalised stigma. Facilitators included knowledge about the benefits of adherence and strong relationships with healthcare providers.
Carr and Gramling	2004	US	9 European American WLHIV; 27-52 years	In-depth interviews and observation; Ethnographic	Stigma: At the time of diagnosis, women were already aware of the stigma associated with HIV; they immediately saw themselves differently. Women told of rejection by family members, friends, healthcare providers, employers, and church members. Rejection and stigmatisation affected access to health care, medication adherence, social interaction, and social support.
Carter et al	2015	Canada (BC)	28 WLHA; 18 years and older (65% 31-50 years); 50% Caucasian, 39% Aboriginal ancestry; 25% identified as LGBTQ	Focus groups; Thematic analysis, critical feminist and social determinants of health frameworks and community-based research approach	Healthcare experiences; peer support: As recipients and/or providers these women felt peer-driven services better met their needs in a supportive, inclusive, and accessible manner. Participants described multiple benefits and tensions of taking on peer leadership roles within their care communities. Some women were encouraged to become involved as service providers but were frustrated by HIV-related “discrimination” that curtailed advancement to paid positions.
Carter et al	2015	Canada (BC)	28 WLHA; 18 years and older (65% 31-50 years); 50% Caucasian, 39% Aboriginal ancestry; 25% identified as LGBTQ	Focus groups; Thematic analysis	Access to healthcare, Support: For many women accessing healthcare was a journey through contested places and spaces. Socio-spatial order had significant impact on women's choice to access care in their home community or travel to Vancouver in search of woman-centred HIV care. Some women who had experienced exclusion from HIV services enacted 'geographies of resistance', rejecting available services and relying on peer communities and self-care to manage their health.
Ciambrone	2001	US (North-eastern)	37 WLHIV; 27-60 years; 60% white, 30% black, 10% Latina	In-depth, semi-structured interviews; Biographical disruption as analytic framework	Living with HIV: While a HIV diagnosis was a traumatic event for most of the women, many women did not consider HIV to be the most devastating event in their lives; they reported violence, mother-child separation and drug use to be more disruptive.
Ciambrone	2002	US (North-eastern)	37 WLHIV; 27-60 years; 60% white, 30% black, 10% Latina	In-depth, semi-structured interviews; Biographical disruption as analytic framework	Support, social networks: Nearly all women reported having at least one person, usually a family member (and most often mothers), on whom they could depend for emotional and instrumental support. However about a quarter of participants described negative support (significant others who did not offer assistance, invalidated their illness and/or rejected them because of their serostatus). Mothers often identified their children as great sources of strength, motivation and a sense of normalcy.

Cuca and Rose	2016	US	20 WLHIV; 35-60 years (mean=46)	In-depth interviews and participant observation; Grounded theory	Reproductive decision-making: Many of the women wanted children, but described experiences of overt HIV-related stigma from multiple sources, including healthcare providers. Several were encouraged not to continue their pregnancies and to abort, but others described HIV clinics and providers as an important source of support and gateway to rehab, housing and support groups. Participants' decision making was impacted by their experiences of trauma and instability in their lives.
Cummins and Millar	2004	Australia	33 HIV-positive women, 18 or older	Self-administered survey questionnaire (closed and open-ended questions); Thematic analysis of responses to open-ended questions	Health service use: Obstacles to accessing healthcare for women included services not being female-friendly/being oriented to gay men, perceived discrimination and their heterosexuality (lack of awareness about HIV in heterosexual community).
De Moss et al	2014	US (Deep South)	12 African-American WLHA, predominantly middle-aged	In-depth semi-structured interviews; phenomenological inquiry	Treatment adherence: HAART adherence is a complex issue for WLHIV. Adherence is positively influenced by sentinel events (which led to changes in perspective and motivation), recognition of personal strength, and positive relationships with healthcare providers, especially a sense of trust.
Dibb and Kamallesh	2012	UK	12 African WLHA	Semi-structured interviews; interpretative phenomenological analysis	Positive adjustment, self-care: While all women had experienced negative consequences of HIV, they had all found their diagnosis contributed something positive to their lives. Participants coped by positively interpreting their situation and making behaviour changes. Positive growth since the HIV diagnosis resulted from finding more meaning and value in life, and discovering new goals and opportunities, largely related to helping others with HIV.
Doyal and Anderson	2005	UK	62 WLHIV from Africa living in London	In-depth, semi-structured interviews; Thematic analysis	Stigma, Support: Lived experiences of HIV-positive African women in London were shaped by their sex and gender, status as migrants (far from their economic, cultural and social roots) and their seropositivity and its physical and psychological implications. Almost all women feared stigma if their status was known. About a third of participants reported direct experiences of stigmatisation such as rejection by husbands or partners, eviction from their home and not being allowed contact with children. Most described religious faith as a major source of support.
Doyal and Anderson	2006	UK	62 WLHIV from Africa living in London	In-depth, semi-structured interviews; Thematic analysis	Coping strategies: Participants faced difficult decisions about sexuality, pregnancy and childbearing and felt constrained by their own and social expectations of women as wives and mothers. As migrants, they were far from home; many lived in poverty and inadequate housing and without the support of extended family. The healthcare they were able to access in the UK was a major resource in their survival strategy. Motherhood brought many burdens but also gave WLHIV a reason to live. Women were concerned about restricting disclosure of their status given experiences of hostility both 'at home' and in African communities in the UK. Despite the difficulties, women reported determination and optimism about the future.

Enriquez et al	2008	US (midwest)	18 low-income WLHIV, 41-68 years	Semi-structured interviews; Content analysis	Ageing with HIV: Participants described physical and emotional health concerns. In particular, they wanted more frequent health screenings and were concerned about the inability to differentiate symptoms of advancing HIV from those of "normal" ageing. Women felt isolated and needed social support.
Fletcher et al	2016	US (South Carolina)	42 HIV-positive African American women of childbearing capacity; mean: 38 years	In-depth interviews; Narrative analysis	Pregnancy and motherhood: HIV-infected women's perspectives on conception and pregnancy were heavily influenced by their personal understandings of HIV and the risk of mother-to-child transmission. Most had positive views about pregnancy and motherhood despite non-supportive messages from interpersonal influences, including healthcare providers.
Fletcher et al	2016	US (South)	42 HIV-positive African American women of childbearing capacity; mean: 38 years	In-depth interviews; Narrative analysis, Social Ecological Model	Stigma: HIV-positive African American women living in the South are vulnerable to experiences of multilevel HIV stigma. Stigma complicated women's disclosure decisions and made it difficult for them to feel supported in places (including social and medical settings) that are generally considered safe spaces for non-infected individuals.
Gallagher et al	2013	Canada	16 women with self-identified HIV-associated neurocognitive challenges	In-depth, semi-structured interviews; Thematic analysis, using disability lens	Health impacts, parenting: Participants described impairments (e.g. memory loss, difficulty multi-tasking) and participation restrictions (e.g. parenting, work roles) resulting from their neurocognitive challenges as having a larger impact on their daily lives than activity limitations. The women with children drew strength from parenting, while women without children worried that parenting could compromise their health. Participation in work and volunteering roles was considered integral to managing neurocognitive challenges and overall health.
Gant and Welch	2005	US	98 HIV-positive women; 17-64 years, mostly African American	Focus groups and interviews	Treatment adherence, self-care: From the focus groups, factors identified as weakening medication adherence were medication regimens (number of pills, complexity), feeling symptom-free (no need to take medications) or very ill (feeling that medications contributed to ill health), and side effects. Women reported adherence was increased or sustained by strong relationships with providers, presence of emotional supports, children, and factors that simplified obtaining and taking medicine (e.g. simpler timing, voucher payments). Analysis of interview data found the continuing presence of poverty, substance abuse, and unresolved sexual abuse were barriers to adherence.
Giles et al	2009	Australia (Melbourne)	15 WLHIV who gave birth after being diagnosed; 18-44 years	Semi-structured interviews	Stigma, treatment uptake/adherence (during pregnancy): Women engaged in significant work in decision-making about interventions to prevent mother-to-child transmission including "surveillance and safety work" to minimise stigma and infection, obtaining information, and calculating risk and benefit. Major concerns included potential side effects, toxicity and teratogenicity. Women who accepted interventions reported fear and challenges reconciling guilt.

Goggin et al	2001	US (New York)	55 HIV-positive women; median: 36 years	Semi-structured interviews; Content analysis	Living with HIV, positive change: Despite experiencing moderate levels of distress, the women in this study reported that HIV served as a motivating force for positive change. They enhanced personal relationships and made positive changes such as recovering from substance abuse and increasing self-esteem. The most commonly-described negative experiences included physical symptoms, awareness of a limited lifespan, alienation and stigma.
Gosselink and Myllykangas	2007	US	4 older HIV-positive women, 50-56 years	Photovoice and interviews; Constant comparison	Living with HIV: For older WLHIV inability to remain employed due to illness and loss of income (and related move to rural locations and loss of private transportation) were barriers to leisure (as a resource providing health-enhancing benefits). The meaning of leisure changed following diagnosis; for all participants, the real meaning of leisure had become spirituality.
Greene et al	2016	Canada	64 WLHIV; 21-42 years (mean: 33)	Interviews (in third trimester of pregnancy and again at 3 months postpartum); Content analysis (narrative-informed)	Experiences during pregnancy, motherhood: Women experienced stigmatising practices in their perinatal healthcare. In the absence of overt discrimination, women still feared, worried about or planned for stigmatising practices by medical staff, and feared inadvertent disclosure by medical staff to other staff, patients, family members and friends. Fears were based on their past experiences or knowledge of HIV-related stigma.
Greene et al	2017	Canada	64 WLHIV; 21-42 years (mean: 33)	Interviews (in third trimester of pregnancy and again at 3 months postpartum); Content analysis (narrative-informed)	Stigma during pregnancy, motherhood: Women described the multiple forms of surveillance they experienced during their pregnancy, labour and early postpartum period. Surveillance had negative impacts on many women, due to enacted and anticipatory HIV-related stigma. To navigate anticipated and enacted experiences of stigma and surveillance the women engaged in acts of distancing (from clinical and social support networks), planning (to manage surveillance and prevent disclosure), and/or resisting/normalising (being open about their status and educating others).
Grodensky et al	2015	US (Southeastern)	15 HIV-positive older women (mostly African American); 50-79 years	Semi-structured in-depth interviews; Content analysis	Experiences of older WLHIV: Many women described being socially isolated with limited support, and inhibited social connection due to reluctance to disclose their HIV status. Women felt that because of their age their HIV status would be viewed more shamefully (compared to young WLHIV). The main sources of social support were close family members. Spirituality provided great support for all participants, but fear of stigma and condemnation meant many women limited disclosure and participation at church.
Gurevich et al	2007	Canada (Ontario and Nova Scotia)	20 WLHIV; 25-57 years	Semi-structured interviews; Thematic decomposition	Sexual activity and functioning: Women constructed HIV as inhibiting and restrictive in relation to sexuality. Dominant discourses related to diminished spontaneity; responsibility imperatives and safer sex constraints; and struggles finding a partner and with sexual intimacy. Women's accounts highlighted a discourse of self-regulation, in which their focus on responsibility and protecting others impedes fulfilling (and safe) sexual and emotional relationships.

Hackl et al	1997	US	8 WLHA; 23-47 years (mean: 35.6)	Semi-structured interviews; Thematic analysis	Living with HIV: All participants exhibited evidence of clinical depression. The primary concerns of the women were stigma, childcare concerns and roles (particularly lack of guardian), the paucity of women's support groups, and barriers associated with seeking services. Primary coping strategies were denial, concealment of their status from others, isolation from others and crying.
Himelhoch and Njie-Carr	2016	US	4 African-American WLHIV, diagnosed with depression, mean: 45 years	Semi-structured in-depth interviews; Transcendental phenomenological analysis	Spirituality: The four women shared concerns about feeling judged by others, feeling punished by God and feeling ostracised. After their diagnosis they attended regular, individual worship instead of communal forms due to concerns about judgement and stigmatisation from the church community.
Illangasekare et al	2014	US (Baltimore)	24 HIV-positive, low-income, urban women who experienced IPV and used cocaine or heroin in their lifetime	In-depth interviews; Thematic content analysis and grounded theory	Depression, social support: All women discussed feeling sadness or depression; the majority had been diagnosed with depression and/or other mental illness. Women reported their HIV, intimate partner violence and drug use as individual and synergistic catalysts for depression. Depressive symptoms were both a trigger for and a result of drug use. Women accessed varying sources of social support, relying on informal sources for instrumental support related to IPV and formal sources for support related to HIV, drug use, and depression.
Ingram and Hutchinson	2000	US	20 HIV-positive women (mothers)	In-depth interviews; Grounded theory	Reproductive and mothering experiences: Women's descriptions of their reproductive experiences illustrated a "double bind": they believed having children would fulfil their personal and the social expectation of reproduction as desirable and fulfilling, but were also aware of the social condemnation of childbearing for HIV-positive women. Mothers put the needs of the children and family before their own health. They felt unable to mother effectively because of the physical demands of HIV, particularly fatigue.
Ingram and Hutchinson	1999a	US	18 HIV-positive women (mothers), 18-44 years	In-depth interviews; Grounded theory	Stigma, motherhood: Participants felt different and set apart from others because of their HIV, and engaged in "defensive mothering" in response to fear of being exposed and stigmatised. This involved much mental work, assessing situations and potential consequences if their status was exposed.
Ingram and Hutchinson	1999b	US	18 HIV-positive women (mothers), 18-44 years	In-depth interviews; Grounded theory	Stigma: HIV-positive mothers valued being perceived as normal but acknowledged that normalcy was lost for them because of HIV-related stigma. They tried to pass as normal by managing information and manipulating their environment, including lying and covering up their status.
Ion and Elston	2015	Canada (Ontario)	17 WLHIV, 32-74 years (median: 48), 66% born in Canada, 29% of African origin	Semi-structured interviews; Thematic analysis	Stigma: Women described interactions with healthcare providers that demonstrated lack of HIV knowledge and unethical practices that left them feeling stigmatised and insulted, resulting in their disengagement from healthcare.

Kabel et al	2015	US (midwest)	20 WLHIV (7 shared stories about dogs); 19-61 years (mean: 45)	Focus group; Constructivist grounded theory	Support: Women described their pets (dogs) as spiritual custodians (having awareness of when their owners needed support and warning them when they faced danger), sources of unconditional and nonjudgmental support (in the wake of their stigmatised condition), and providing a sense of purpose.
Keigher and Stevens	2011	US (Wisconsin)	9 HIV-positive women enrolled in financial assistance program	Repeated in-depth interviews; Narrative analysis	Financial stress: Participants faced the double stigma of HIV/AIDS and welfare in their efforts to secure health care, income, and social services. As a consequence of their illness and benefit disruptions (due to welfare reform), the mostly long-term HIV survivors described feeling exhausted, angry, and demoralised. Financial insecurity destabilised their medical care, medication adherence, nutrition, housing and their children's lives.
Kempf et al	2010	US (Rural Alabama)	40 HIV-positive women; 29-69 years (mean: 46), 92% African American	Focus groups; Content analysis	Retention in care: Factors that facilitated adherence to clinic appointments included women's relationships with the provider and perceptions of how they were treated by clinic staff, illness concerns (concern about their own health, duration of HIV disease, comorbidities) and the organisational structure of the facility (e.g. hours and short clinic appointments). The main barriers described by women were transportation and HIV-related stigma (feared disclosure if seen at the clinic).
Kirshenbaum et al	2004	US (four cities)	56 HIV-positive women; 20-55 years (mean: 39.4)	In-depth, structured interviews; Grounded theory	Pregnancy decision-making: Women reported a variety of decision-making experiences and considerations including vertical transmission risk assessment, risk reduction strategies and outcomes of previous births that occurred after HIV diagnosis. Women also weighed up their desire for motherhood, opinions of partners and healthcare providers, religious values and their perceive capacity to parent successfully.
Lawless et al	1996	Australia	24 WLHA, 22-55 years	In-depth interviews; Grounded theory	Sexuality and sexual activity: Most women reported difficulty engaging in sexual practices following diagnosis, as they suffered a form of sexual identity crisis. There was a dearth of non-judgemental information and support around issues of women's sexuality. Messages that HIV positive women receive (focused on 'safe sex') present contradictions, leading to tensions for them and their partners in trying to negotiate sex and condom use.
Lawless et al	1996	Australia	27 WLHA, 22-55 years	In-depth interviews; Grounded theory	Stigma: Experiences of discrimination and negative evaluations by healthcare professionals, and the self-stigmatisation that increases fear of discrimination, reduce women's willingness and ability to access health and support services.
Lekas et al	2006	US (New York)	158 WLHA (from two samples: 79 interviewed pre-HAART and matched sample of 79 interviewed post-HAART); 20-45 years	Interviews; Thematic content analysis	Stigma: Stereotypes of HIV-positive women remained unchanged over time; in both periods and across samples, women believed the stereotypical assumption is that HIV-infected women contracted the virus through unprotected sex and/or drug use. Women felt gender, race and ethnicity played a role in shaping stereotypes - Black and Puerto Rican women were more likely to be stereotyped and blamed whereas White women were often depicted as "innocent" victims. Internalisation of stereotypes was a necessary and sufficient condition for feeling stigmatised and caused feelings of self-loathing, shame and psychological distress, often leading to self-exile.

Lingen-Stallard et al	2016	UK	13 black African WLHA	In-depth semi-structured interviews; Thematic analysis, interpretive phenomenological approach	Diagnosis, stigma, positive growth: Women were shocked by their diagnosis (none expected a positive result) and denial was common. Common reactions were anger, turmoil and self-imposed isolation. All but two participants reported the pervasiveness of stigma from partners, family, health professionals and local communities. Fear of stigmatisation heightened concerns about confidentiality and led to social isolation. Women described acceptance, resilience and transformation over time, whereby they integrated their HIV status into their lives and optimism increased.
Logie et al	2011	Canada (5 cities across Ontario)	104 WLHIV; mean: 38 years; 69% ethnic minority; 23% lesbian/bisexual; 22% transgender	Focus groups (15); Thematic analysis	Stigma: Participants described stigma/discrimination and coping across micro (intra/interpersonal), meso (social/community), and macro (organisational/political) realms. They attributed experiences of stigma and discrimination to: HIV-related stigma, sexism and gender discrimination, racism, homophobia and transphobia, and involvement in sex work. Coping strategies included resilience (micro), social networks and support groups (meso), and challenging stigma (macro).
Logie et al	2012	Canada (Toronto)	23 HIV-positive women: 7 lesbian, bisexual and queer, 16 transgender	Focus groups; Thematic analysis, intersectional theoretical framework	Healthcare use, marginalisation: Women described multiple barriers to accessing appropriate HIV care and support, including pervasive HIV-related stigma, heteronormative assumptions in HIV-positive women's services and discriminatory and incompetent treatment by health professionals. Participants believed healthcare professionals lacked education and knowledge about transgender people and deliberately discriminated against or disrespected them.
Marcenko and Samost	1999	US	40 HIV-positive mothers; 23-54 years (mean: 34); 70% African American	Focus groups; Thematic content analysis	Living with HIV: Stressors for HIV+ mothers were decisions about disclosure (including if and when to tell their children), feelings of guilt and anger and parenting concerns. Resources they drew on to cope included spirituality, inner strength, positive thinking and support from family and friends. Many lacked trust in medical practitioners and in their prescribed medications. Housing was the greatest resource problem for women and their children.
Mayers et al	2005	US (New York)	9 HIV-positive women (8 receiving public assistance and mothers to HIV-infected children), 29-48 years	Interviews; Thematic cross-case content analysis	Living/coping with HIV, positive growth: The mothers in this study struggled with a range of existential issues that included guilt, responsibility and choice; helplessness and control; death anxiety, loneliness and isolation; and meaning and authenticity. Despite the burdens of a stigmatising disease and poverty many described their illness as a growth-producing and meaning-giving experience. In particular, children were a crucial meaning-giving force and protective factor in coping and minimising feelings of isolation.
McDonald and Kirkman	2011	Australia	16 women who gave birth after being diagnosed with HIV; most <40 years old	Semi-structured in-depth interviews; Constant comparison method, informed by narrative mode of thought	Treatment uptake and adherence: Women's decision regarding ART was underpinned by their desire to protect their baby from harm. Those who rejected treatment mostly perceived ART to be harmful to baby. Women who accepted treatment expressed worry for their child and/or themselves.

McDonald	2011	Australia	17 HIV-positive women who had conceived children within a serodiscordant relationship	Semi-structured in-depth interviews; Analysis informed by Goffman's theory of stigma and narrative mode of thought	Sexual activity, pregnancy: Many of the women had constructed a conception story for the benefit of family and friends, to reinforce their identity as responsible and moral - generally that conception resulted from unprotected sex, once, for the purpose of conceiving. However, most revealed their partner did not like condoms and used them sporadically or not at all. Their accounts indicated understanding of viral load and the smaller risk of transmission from woman to man, but some women reported worrying about ensuing stigma from their and their partner's families if the partner did seroconvert.
McDoom et al	2015	US (Boston)	20 Black HIV-positive women over 50 (currently in HIV care); 50-63 years (mean: 56.6)	Semi-structured interviews; Content analysis informed by grounded theory	Engagement in care: Women's fears or experiences of stigma discouraged or even prevented them from seeking care. They were concerned at being judged or "outed" if they accessed services. Feeling connected to and supported by their social environment facilitated engagement in care. Women were fearful of judgement or stigma if they disclosed their HIV status, but realised disclosure was necessary to access support and assistance.
McLeish and Redshaw	2015	UK (London)	47 WLHIV who were peer support volunteers and 42 HIV-positive mothers who received peer support during pregnancy	Semi-structured interviews; Thematic analysis (volunteers and mothers as separate data sets), informed by phenomenological social psychology	Support: A primary purpose of seeking peer support was emotional connection: having an empathetic listener with whom HIV-positive women could share their feelings and problems. Both mothers and volunteers described the importance of shared characteristics or identity. Mothers valued non-judgemental and empathetic support from 'someone like me'. Many volunteers expressed the desire to help other mothers avoid the difficulties they had faced.
Metcalf et al	1998	Canada	8 HIV-positive women	Interviews; unstated	Support, stigma: Most common emotions at diagnosis were shock, anger and fear. Coping improved with time since diagnosis, but most women needed extra support and wanted peer support. Women felt stereotyped and felt they were more stigmatised, faced more discrimination and were less supported than MLHIV.
Misener and Sowell	1998	US (southeastern)	22 HIV-positive women, 20-43 (mean: 31.5), 80% African American	Focus groups; Dimensional analysis	Treatment uptake and adherence: Participants' decisions regarding use of antiretrovirals were influenced by their healthcare providers (trust, confidence in their knowledge and relationship with), beliefs about antiretrovirals (efficacy and risk), side effects, and attitudes of significant others (particularly their mothers and other women with HIV).
Moneyham et al	2010	US (Deep South)	40 HIV-infected African American women	Focus groups; Content analysis	Healthcare use: Major barriers to care were personal issues (drug use, denial, depression); HIV-related stigma (concern that in seeking care they would be identified as having HIV and consequently subjected to discrimination and rejection); cost (co-payments for clinic visits and medications), distance from services and lack of transportation, and health system organisation (length of appointments, time spent waiting).
Moneyham et al	1996	US (southeastern)	19 HIV-positive women, 24-44 (mean: 33)	Focus group interviews; Content analysis	Stigma: Women's perceptions of how others think about and respond to HIV-positive individual were themed as: Distancing (perception that others desired to maintain distance from those with HIV, attributed to fear of contagion); Overgeneralising stereotypes; Social discomfort (e.g. people avoiding talking with them about HIV), and Pity. Participants experienced health care providers avoiding contact with them and refusal to treat.

Mphande-Finn and Sommers-Flanagan	2007	US (Northwest)	7 HIV-positive women, 16-57 years	Interview; Constant comparative approach, grounded theory	Emotional adjustment: Every participant reported experiencing sadness and depression. Emotional and physical abandonment by romantic partner, family or friends was common. Women stressed the importance of a good support system. Many expressed finding meaning in the illness and personal growth.
Ndirangu and Evans	2009	UK (Britain)	8 African immigrant WLH; 30-50 years	Semi-structured interviews; Framework analysis	Living with HIV; stigma: The ability of migrants living with HIV to "live positively" with HIV was shaped by their migration history, legal status, experience of stigma and Christian faith. Fear of HIV-related stigma hindered access to seek support, but for most women health services were a safe social space and highly valued as a source of advice and support.
Ndlovu et al	2010	Canada	6 HIV-positive women; 23-58 years (mean: 41.5)	Narratives + questionnaire; Content analysis	Stressors, coping strategies: Analysis of participants' 'stressor narratives' found the most prevalent concerns were related to children (the implications of disclosure) and housing security or quality. Seeking social support was key to coping with stressors.
Newman et al	2007	Australia (Western Australia)	20 HIV-positive Aboriginal people (16 women); 22-54 years	Semi-structured interviews; unstated	Treatment uptake: For these Australian Aboriginal women the main barriers to treatment uptake were fear of disclosure and discrimination, heavy alcohol consumption and poverty. Pregnancy was an incentive to start ART. Participants reported greater adherence and feeling supported by holistic healthcare that was inclusive of their diverse needs, providing psychosocial and welfare support alongside medical care.
Nicolas and Schilder	1997	Canada (Winnipeg)	5 WLHA; 24-41 years	Unstructured interviews; Interpretive research approach/hermeneutical phenomenology	Living/coping with HIV; stigma: An HIV diagnosis was a traumatic event for participants and most experienced psychological struggle. Women felt healthcare professionals were uninformed of the manifestations and impacts of HIV/AIDS on women's health. Women feared abandonment and/or rejection from family members. They felt socially isolated, secretive and 'very alone with their disease' and had no options for support other than primary care providers. Coping was related to spiritual beliefs.
O'Brien et al	2017	Canada (3 provinces)	77 WLH; most 31-50 years	Focus groups; Thematic content analysis	Healthcare experiences, services: Women were concerned and frustrated at the lack of HIV knowledge of some health professionals, and providers who did not recognise them as "whole persons". Based on their care-seeking experiences, women recommended women-centred HIV care should be coordinated and integrate services addressing both HIV and women's health needs; recognise and respond to structural barriers that limit women's access to care (such as violence, poverty, motherhood, stigma and challenges to safe disclosure); and foster peer support and peer leadership in its design and delivery.
Orza et al	2015	Global	489 women diagnosed with HIV (subset who responded to optional mental health section)	Online survey including open free-text section re mental health; thematic analysis text responses	Health (mental, sexual and reproductive): The majority of women reported depression symptoms and a higher number of mental health issues after diagnosis. Women described how depression, rejection and social exclusion, sleep problems, intersectional stigma, challenges with sexual and intimate relationships, substance use and sexual risk affected their ability to enjoy their right to sexual and reproductive health and to access services.

Peltzer et al	2017	US	22 HIV-infected African American women; 25-73 years (mean: 48)	Interviews; Inductive content analysis	Psychological distress/coping strategies: All participants experienced significant distress and many described pervasive negative emotions and suicidality following diagnosis. Spirituality/religion were common personal strategies to cope with emotional distress. Psychoemotional distress was increased by contextual factors such as poverty or addiction. Experiences of stigma meant many women lived in isolation from family and friends and reported profound loneliness.
Peltzer et al	2016	US (midwest)	11 African-American women infected with HIV; 21-35 years	Interviews; Hermeneutic phenomenology	Stigma: Young women's stories revealed an overarching pattern of "Infected Lives", the idea that HIV had invaded their physical, spiritual, emotional, mental and social worlds. Women felt alone; even those who had supportive partners, families, or friends felt they were facing their disease by themselves. Experiences of betrayal, stigma and discrimination left women humiliated and some retreated into isolation.
Persson	2014	Australia	16 WLH; 23-65 years	Semi-structured interviews; Thematic analysis	Coping: Most of the women acquired HIV through unprotected heterosexual sex. They were shocked and bewildered at diagnosis (few thought they were at risk for HIV), but did not present themselves as "victims" or blame the man who infected them.
Peterson	2010	US (midwest)	45 women with HIV; 19-64 years (mean: 39), 80% African American	Interviews; Grounded theory	Social support: Social support was a key factor in coping with HIV. Women identified challenges seeking support including stigma and a lack of resources. Challenges receiving support included a mismatch of goals, concern about overburdening family members, lack of independence, and lack of readiness to accept support. Women engaged in "protective disclosure" and carefully evaluated potential sources of support to avoid stigma and maintain control of confidentiality of their status.
Plach et al	2005	US (Wisconsin)	9 HIV+ women; 50-56 years (mean: 52)	Semi-structured narrative interviews; Narrative analysis	Self-care: For these women self-care incorporated nurturing physical health (attending to health-promoting activities, dedicating oneself to wellness, and contending with symptoms) and sustaining heart, mind, and soul (drawing on inner strength, changing their thinking, having faith in God).
Poindexter	2013	NZ	4 HIV+ African immigrant women	Semi-structured interviews; Narrative thought and analysis	Stigma and discrimination: The four women reported stigma and discrimination by healthcare providers. They witnessed inappropriate use of universal precautions, experienced violations of confidentiality rights, heard discriminatory comments about Africans or persons with HIV, and were told misinformation about HIV transmission. They felt sad and humiliated as a consequence.
Psaros et al	2012	US (Boston)	19 HIV+ women >50 years old (mean: 56.8); 47% Black/African American, 37% White	Semi-structured interviews; Grounded theory	Sexuality and intimate relationships: Most participants expressed desire to have an intimate partner relationship, but described multiple challenges to pursuing relationships related to stigma, concerns about body image and the disclosure dilemma (characterised by a strong sense of obligation to disclose HIV status and feared reactions to disclosure).

Psaros et al	2015	US (Boston)	19 HIV+ women >50 years old (mean: 56.8); 47% Black/African American, 37% White	Semi-structured interviews; Content analysis using grounded theory approach	Living/ageing with HIV: Participants described a progression from fear and disbelief at the time of diagnosis to acceptance and survivorship. However for some women, health-related uncertainty remained and intensified with age. Identified strategies to 'live well' in the context of HIV included caring for mind and body (particularly managing stress, depression and anxiety), changing or eliminating 'toxic' relationships or behaviours, and engaging in meaningful activities.
Robillard et al	2017	USA (Southern)	23 HIV+ African American women 18+ (mean: 44.5)	Women's written stories + semi-structured interview; Content analysis	Living/coping with HIV: The women's narratives revealed themes of self-actualisation and self-worth, highlighting their strengths and resolve to face the future with optimism. However, some also reflected helplessness and hopelessness exemplified by sorrow, depression, loneliness and fatalism.
Rouleau et al	2012	Canada (Quebec)	7 French-speaking, Quebec-born WLH; 32-64 years (mean: 46)	Semi-structured interviews; Hermeneutic phenomenological analysis	Disclosure and stigma: Disclosure was a matter of personal choice and participants exercised control through non-disclosure or restricted disclosure (to protect against stigma or avoid worrying others). Most felt apprehension and fear of consequences of revealing their status, and conducted a thoughtful analysis of the potential risks and benefits. Every participant had experienced exclusion and social isolation.
Sanders	2008	US (New York)	9 HIV+ women who were pregnant or had become mothers post-diagnosis; 34-53 years (mean: 37.25)	In-depth interviews; Phenomenological analysis (Giorgi's method)	Pregnancy; stigma: All participants had made conscious decisions to have children after learning of their HIV diagnoses, and had struggled with the experience of stigma and feelings of ambivalence about having another child and the potential health risks involved. They perceived motherhood as completion of being a woman and a second chance to make things right (after previous negative experiences of motherhood related to substance use and custody issues). All participants reported experiencing at least one healthcare encounter in which they felt marginalised, vulnerable, and stigmatised.
Sanders	2009	US (New York)	9 HIV+ mothers; 34-53 years (mean: 37.25)	Interviews; Thematic analysis	Pregnancy: Participants had engaged in unprotected sexual relations with intent to become pregnant. They reported instances of delaying disclosure of HIV status to sexual partners and relinquishing responsibility for maintenance of safe sex practices. They had insufficient knowledge of how to reduce partner transmission risk in relation to childbearing, but were knowledgeable about means to minimise transmission to the foetus.
Sangaramoorthy et al	2017	US (Maryland)	35 midlife and older Black women living with HIV; 40-71 years (m:52)	Semi-structured interviews; Modified grounded theory approach	Stigma: Intersectional stigma is a central feature in midlife and older Black women's lives. Participants reported experiences of intersectional stigma at the interpersonal/familial, community, and institutional/structural levels. Women's ability to cope with stigma and manage their condition improved as they aged, but they continued to experience negative responses related to their gender, race, age and HIV.
Sangaramoorthy et al	2017	US (Maryland)	35 midlife and older Black women living with HIV	Semi-structured interviews; Grounded theory	Retention in care, ART adherence: Participants were highly retained in HIV care and ART adherent; they developed a renewed interest in their own health and wellbeing through greater engagement in HIV care and treatment as they aged and lived longer with HIV. The most common barriers to retention in care and ART adherence were structural challenges such as lack of access, no coordination of care (particularly for women with multiple comorbidities), and routine financial hardship.

Schrimshaw and Siegel	2002	US	45 HIV-infected mothers (African American, White and Puerto Rican)	Interviews; Thematic analysis	Disclosure: Most mothers had disclosed their HIV infection to one or more of their children. Reasons for disclosing included wanting to educate their children about HIV, wanting their children to hear it from them, wanting their children to know before they became very ill and wanting to be honest with their children. Reasons for nondisclosure included believing the children were too young or immature, believing it would be too big an emotional burden, not wanting children to experience rejection and not wanting children to fear losing their mother.
Shambley-Ebron and Boyle	2006	US (rural southeast)	10 HIV+ African American mothers with HIV+ children, 21-39 years (mean: 30.4)	Semi-structured in-depth interviews and observation; Critical ethnography	Mothering, self-care: For all mothers, providing for their children was their first priority. "Strong mothering" also involved protecting children against HIV stigma and preparing them for the future. Instead of practicing self-care behaviours prescribed by healthcare providers, such as eating well, exercise and reducing stress, African American mothers relied on culturally specific strategies including spirituality and religious practices, family support and the act of mothering itself to maintain their health and function in their mother role.
Siegel and Schrimshaw	2000	US (New York)	54 African American, Puerto Rican, and non-Hispanic White women WLHA; 20-45 years	Semi-structured interviews; Thematic analysis	Positive growth: While these women acknowledged the negative stresses of living with HIV/AIDS, 83% reported at least one positive change in their lives that they attributed to their illness experience. Domains of potential growth identified included health behaviours, spirituality, interpersonal relationships, view of the self, value of life, and career goals.
Siegel and Schrimshaw	2006	US (New York)	158 WLHA (2 matched samples: one pre-HAART and one after HAART was widely available), 23-45 years (mean: 36.3)	Interviews; Thematic analysis	Sexuality and sexual activity: Participants (both pre- and post-HAART) frequently discussed diminished pleasure in sex, decreased sexual activity, and diminished sense of sexual attractiveness following HIV diagnosis. Reasons reported for discontinuing sexual activity or loss of interest in sex included anxiety about HIV transmission, loss of freedom and spontaneity, fears of emotional hurt, not wanting the hassle of a relationship and feeling insecure about their appeal/attractiveness. Types of sexuality changes and reasons offered for them did not differ between women in the pre-HAART and HAART eras.
Siemon et al	2013	Canada (Southern Ontario and Nova Scotia)	20 WLHIV, 50 or older	Semi-structured interviews; Constructivist grounded theory approach	Social participation: Participants emphasise the importance of emotional support and practical assistance from friends and family members. Social participation also was enabled by spiritual or faith-based connections and volunteer work. Social engagement was limited due to women's isolation or withdrawal which they attributed to lack of desire or energy to engage socially with others, unhappiness with their physical appearance, mental health issues and feeling marginalised, and barriers to employment. Participation was hindered by multifaceted stigma and inadequate instrumental supports.

Solomon and Wilkins	2008	Canada	23 WLHIV; Mean age: 41	Semi-structured interviews; Phenomenological approach	Social participation, positive growth: Barriers to social participation were mostly environmental - poverty, fear of disclosure and stigma (and resulting isolation and depression) and lack of support. Facilitators to social participation included supportive networks, strong sense of self and ability to frame HIV as a transformative experience. For some, their children were motivation to participate and provided meaning.
Sowell et al	2003	US (southern)	322 HIV-infected women (265 codable responses), predominantly African-American, single women of reproductive age, low income	Interviews; Content analysis	Disclosure: The majority of women had disclosed to some ex-partners, close family and friends, and health professionals. However for some, disclosure was a difficult issue, particularly because they were of reproductive age and/or had children. For women who did not disclose fully, criteria for deciding to whom to disclose generally included their relation to the person, the quality of their relationship (accepting versus rejecting) and the perceived ability of the other person to keep the information confidential. Other women based their decision to disclose on feeling close to or trusting someone or sense they were the right person to tell ("emotional disclosure").
Spiers et al	2016	UK (London)	10 HIV-positive, West African women of black heritage	In-depth interviews; Interpretative Phenomenological Analysis	Treatment use: Nine of the 10 participants talked about negative experiences of ART. These included features of the medication (size), not seeing results or symptom improvements and feeling 'trapped' in a 'life sentence' of adherence. Social context (work or family life) impacted adherence, particularly if participants didn't want to disclose their status. Several women described an improvement in their feelings about ART over time.
Squire	2003	UK	34 HIV-positive women, early 20s to 50s	Longitudinal, semi-structured interviews; Content and narrative analyses	Romantic relationships: Many of the women told 'romance' stories, of their search for male partners and the happy or problematic results. One version involved a quest for an ideal heterosexual relationship, with an actual or hoped-for happy ending; in the second version, women discussed problems in romantic relationships (the quest was never over even if they arrived at an apparently happy ending). Women reported storytelling about HIV and romance enabled them to conceptualise and talk about wider relationship issues and reproductive possibilities with other HIV-positive women.
Stevens and Hildebrandt	2006	US (urban and rural Wisconsin)	55 HIV-infected women; 23-54 years (mean: 41); racially-diverse	Series of (10) narrative interviews; Thematic analysis	Coping (at diagnosis and long-term): Women's immediate reactions at diagnosis were devastation, shock and indignation. Long-term responses (lasting for months or, in some cases, years) included depression, submersion of awareness of the diagnosis, escalated drug and alcohol use, shame and suicidality.
Stevens and Keigher	2009	US (urban and rural Wisconsin)	55 HIV-infected women, 23-54 years (mean: 41)	In-depth, "story-eliciting" interviews; Content analysis	Healthcare access: Participants describe difficulties getting the healthcare services and medication due to up-front, out of pocket costs (whether insured or not). Women related limitations imposed by health insurers on the amount, duration and scope of service, provider choice and frequency of utilisation.
Stevenson et al	2017	UK	18 WLHIV over 50; 15 of black African origin	Participatory workshops; Thematic analysis	Ageing with HIV: Specific challenges of ageing identified by WLHIV included loneliness and isolation (current and concern for the future), adequate provision of social care and access to the health system, successfully managing comorbidities and uncertainty. Women described both the necessity and popularity of support services specifically for women.

Taylor et al	2016	US (3 cities)	50 African American and Latina WLH, 50-69 years	Focus groups and in-depth interviews; Thematic analysis guided by integrative biopsychosocial and sexual health models	Sexuality and sexual activity (older WLHIV): Most older WLHIV reported being involved in intimate and sexual relationships, and indicated sexual pleasure remained an important aspect of their lives. Most commented on changing sexual abilities and sexual health needs including physical limitations, increase or decline of desire due to menopause, and discomfort due to physiological changes as they age. A few reported decline in safe sex practices due to perception that the risk of transmission was low due to their gender, viral suppression, partner trust, or because partners were HIV-uninfected despite repeated condom-less sex.
Teti et al	2015	US	30 HIV+ women; mostly African American (83%), low income (83%)	Photovoice, group discussions, interview; thematic and narrative analysis (grounded theory)	Living with HIV; positive growth: Despite the challenges of living with HIV, women experienced positive transformation and growth related to healthfulness, spirituality, self-acceptance and confidence (the realisation that they were strong). Women described health improvements including recovery from substance abuse, improved medication adherence, safer sex and mental health.
Treisman and Shaw	2014	UK	12 African women diagnosed with HIV during pregnancy; 23-41 years (mean: 32)	Semi-structured interviews; Interpretative phenomenological analysis	Coping (during pregnancy): Emotional responses to diagnosis included shock fear, hopelessness and disbelief. But for the majority of participants HIV was part of a wider life tapestry; some were more concerned about other stressors including economic difficulties, poor living conditions and uncertain immigration status. Coping was impacted by experiences of HIV-related stigma and responses of health professionals (some participants reported compassion and empathy, some perceived stigma and breaches of confidentiality). Motherhood was central to these women's lives and children were seen as protective factors and a reason to live.
Tufts et al	2010	US (south-eastern)	21 African American WLHIV; 29-61 years (mean: 43.9)	Focus groups; Content analysis	Self-care; stigma: Over time women learned (from other WLHIV and healthcare providers) to actively care for themselves. Actively managing HIV disease was essential to overall health; women also reported taking care of their mind, body and spirit (through 'pampering' and taking part in religious customs). For some disclosure resulted in a sense of empowerment and decreased stress; for others, it led to stigma from friends and family. Stigma and fear of disclosure caused anxiety and stress and negated the effects of behaviours aimed at stress reduction.
Vallerand et al	2005	US	35 HIV-positive women; 27-56 years (mean: 38.5), 89% African American	Semi-structured interviews; Thematic analysis	Disclosure: For HIV+ mothers, the decision to disclose to their children depended on the child's developmental level and the degree of their illness. Positive aspects of disclosure from the mother-child dyads included open, honest communication, and closer relationships. Common negative themes included fear, uncertainty, forced secrecy for fear of being ostracised due to HIV-related stigma, behavioural changes in the children, and shifting responsibilities between the mother and the child.

Van Servellen	1998	US (Los Angeles)	44 WLHIV (mostly "women of color", lower SES and unemployed)	Semi-structured interviews; Content analysis	Living with HIV: Fatigue was the most frequently reported worst symptom (by 98% of participants). When asked to describe their "worst day" physical illness and having a negative mood (feeling "depressed" or "stressed out") were the most commonly mentioned descriptors. Common descriptors of "best days" were being active (taking children out, going to market, cleaning the house), feeling physically healthy, and having positive mood. The most commonly used strategies to control symptoms were rest/sleep and a healthy diet.
Walcott et al	2016	US (Alabama)	46 WLHIV (89% African American)	Focus groups; Thematic analysis (social-ecological model)	Engagement in care: Women's health-seeking behaviour and decisions were impacted by structural community factors such as poverty, poor employment opportunities, limited access to healthcare resources, stigma, transportation challenges and access to illicit substances. At times women had to prioritise meeting basic needs, such as satisfying hunger and taking care of their families, over engaging in HIV care.
Walsh et al	2012	US	20 women diagnosed with HIV in previous 12 months	In-depth interviews; analysis adapted from meta-ethnographic model and grounded theory	Living with HIV: Many women were surprised by the diagnosis because they did not fit the profile of people at high risk for HIV. They emphasised the importance of social support immediately after diagnosis. Most participants were concerned about the potentially negative impact of HIV on their roles as caregivers to children/grandchildren.
Warren-Jeanpiere et al	2014	US (Washington DC)	23 HIV-positive African American women; 52-65 years (mean: 57)	Focus groups; Constant comparison approach	Ageing with HIV: For most participants, self-management of HIV included adhering to daily medication regimen, eating well, exercising, doing something good for others and self, and engaging in spiritual activities (i.e. prayer, meditation). Women reported that co-morbidities, including diabetes and hypertension, were more difficult to self-manage than HIV. Caregiving responsibilities (even for adult children) motivated women to stay healthy. Some participants stressed the role of an intimate male partner (present or desired) as an emotional support and in helping them self-manage as they grow older.
Watkins-Hayes et al	2012	US	30 African American women living with HIV/AIDS; 18-55 years (mean: 36)	In-depth semi-structured interviews; Grounded theory	Coping, support: Interactions with 'framing institutions' (non-profit and government organisations) shaped how WLHA conceptualise and cope with their diagnosis and illness. Through provision of information and resources they shape women's movement from beliefs they are 'dying from' HIV to acceptance they can 'live with' HIV. Most women described HIV as a chronic but manageable condition rather than a debilitating 'death sentence'.
Wilson	2007	UK	12 WLHIV who were mothers; 26-44 years	In-depth interviews; Grounded theory	Motherhood: Participants emphasised their need to survive and to protect their children. Women described the importance of establishing and maintaining identities as good mothers in the context of a stigmatised condition; the threat posed by the potentially fatal nature of HIV; and their efforts to minimise the impact of their diagnosis on their children.

* In describing the participant sample and data collection and analysis methods generally the terms used by the authors are presented. Characteristics such as age and ethnicity, and geographic region in which the study was conducted, were included where they were clearly reported and pertinent to the study's aim and/or results.

WLHIV = women living with HIV

WLHA = women living with HIV/AIDS

LGBTQ = lesbian, gay, bisexual, transgendered or queer

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