Beyond Hot Flashes: Centering Lived Experience in Menopause and HIV

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Abstract

Women living with HIV often experience menopause earlier and with more severe symptoms, yet these are frequently misattributed to HIV, antiretroviral therapy, or aging. Drawing on lived experience, this commentary describes how lack of recognition can erode trust and compromise care. We present the four P's nursing lens (patterns, physiology, psychosocial, partnership) to complement existing guidelines. This framework emphasizes listening, thorough histories, recognition of overlapping symptoms, attention to comorbidities, addressing stigma, and partnering through shared decision making and culturally relevant resources. Centering lived experience highlights the need for compassionate, holistic care that enhances autonomy, builds trust, and makes menopause care a standard part of HIV practice across the lifespan.

Key words: HIV, lived experience, menopause, nursing practice, perimenopause, women living with HIV

Women's lives are marked by specific transitions: childhood, adolescence, emerging adulthood, adulthood, and later years. Somewhere between adolescence and adulthood, menstruation begins, which is traditionally seen as the entrance into "womanhood" and the start of reproductive aging (Forman et al., 2013; WHO, 2024). For many of us, the acquisition of HIV or learning about one's HIV status comes as another unexpected transition. It is often traumatic and, like menopause, can be physically and emotionally distressing (Cianelli et al., 2022; Durvasula, 2014). Menopause itself is yet another period of shifting perspective in a woman's life, from perimenopause to menopause and eventually postmenopause (WHO, 2024).

I was fully unprepared for perimenopause. For a decade, I had lived well with HIV, but as my body began to change, a new wave of emotionally and physically draining symptoms emerged. I spent years misattributing a confusing mix of ailments to my HIV or use of antiretroviral therapy (ART). The brain fog, fatigue, and joint pain, I blamed on accelerated aging from HIV (Graham et al., 2024). The hair thinning and loss, I blamed on my medication (Okhai et al., 2022). The sudden intensity of my existing anxiety and depression was a mystery. I came up with every reason possible related to HIV or aging for all the symptoms I was having, except menopause. I underreported symptoms for fear of sounding hysterical or like a hypochondriac aging with HIV.

Clinically, some of the symptoms did not make sense in the context of how long I had been living with an undetectable viral load and well-managed HIV, unless and until menopause was considered. My health care providers, both infectious disease specialists and male, dutifully ran tests for HIV and age-related concerns to rule out thyroid, pituitary, and autoimmune issues but never once considered the hormonal shift I was undergoing. Similarly, during a gynecological examination after revealing my HIV diagnosis, the provider simply wished me luck with the pending workup. None of them considered menopause the source of my symptoms any more than I did. It was not about assigning personal blame, but it did highlight a systemic failure rooted in the lack of awareness about menopause and HIV among infectious disease providers, the hands-off approach many general care clinicians take and the lack of parity in information available to women about menopause regardless of sero status (Dragovic et al., 2022; Scofield et al., 2024).

My experience, it turns out, is not unique. Research confirms that women living with HIV may experience menopause earlier, with symptoms that are more burdensome and severe (Graham et al., 2024; Okhai et al., 2022). Quality of life, an important driver of health

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outcomes, can be affected by all of these transitions and life stages (Stanton et al., 2019). Moreover, the quality of support from health care systems before, during, and after menopause and after learning one's HIV status is essential to health outcomes (Cianelli et al., 2022). When women do not feel heard or believed, trust in the health care system is eroded, further compromising engagement in care (Dragovic et al., 2022).

Menarche, the first period, has cultural and social significance that varies by culture (Forman et al., 2013). Some women may be shunned and separated from their community during menses, whereas others are celebrated (Forman et al., 2013). Menopause, in contrast, is too often seen as a loss of vitality, attractiveness, and worth (WHO, 2024). These stigmatizing perceptions overlap with the stigma of HIV (Cianelli et al., 2022; WHO, 2024) and can intensify shame, uncertainty, and fear. Women living with HIV often approach menopause with trepidation, unanswered questions, and very little guidance (Okhai et al., 2022).

Although people tend to associate menopause with aging, the two are not the same. Aging is a natural process marked by the number of years lived or the degree to which our cellular makeup changes through DNA methylation. The body undergoes cellular and hormonal changes that culminate in menopause, the end of reproductive years (Prakoeswa et al., 2025). All people will age, and all people with ovaries will experience menopause (WHO, 2024). HIV complicates aging physiologically through increased health risks and accelerated aging (Gandhi et al., 2025; Prakoeswa et al., 2025). For menopause, this can mean earlier onset and more severe symptoms in the perimenopausal and menopausal stages. It is important to note that the cessation of periods, menopause, does not necessarily mean an end to the transitional symptoms that indicate hormonal change (Okhai et al., 2022).

The uncertainty of differentiating the symptoms of menopause from those of normal aging and HIV is further complicated by the side effects of ART (Okhai et al., 2022; Tariq et al., 2019). Night sweats, fatigue, muscle aches, and cognitive difficulties are not simply hallmarks of HIV, its treatment, or aging. They are also classic signs of menopause (Okhai et al., 2022). Without a thorough history, consideration of hormonal change, and a process of elimination, symptoms are easily misattributed. Too often, women are left in limbo, unsure if what they are experiencing is due to HIV, medication, or menopause (Dragovic et al., 2022). This confusion increases the risk of misdiagnosis and leaves women vulnerable to heightened health risks such as cardiovascular disease and osteoporosis (Matovu et al., 2023).

Even in cases where HIV is well managed, the virus is often the first thing providers suspect when new health issues arise (Dragovic et al., 2022). The lack of research around women-specific issues, and especially around the convergence of HIV and menopause, means women have more questions than answers (Graham et al., 2024). These conversations must extend beyond reproduction into sexual well-being, health, and pleasure (Stanton et al., 2019). Individual health management, regardless of disease, is influenced by accessibility to care, the equitability of that care, health literacy, and autonomy (Cianelli et al., 2022). It is critical that women living with HIV be given the information and tools to understand menopause and perimenopause and how it may manifest in symptoms that are easily confused with other conditions or medications. Clinicians must be trained in and engage in the shared decision-making process and be prepared to refer to specialists when needed (Scofield et al., 2024).

As nurses, advanced practice providers, health care clinicians, and researchers, we are uniquely positioned to help change the paradigm (Dragovic et al., 2022; Scofield et al., 2024). A survey of HIV health care providers in Europe found that 44% lacked confidence in assessing menopausal symptoms, with many believing that menopause should be managed in primary care or gynecology, whereas HIV comorbidities were handled separately (Caixas et al., 2024). This fragmented model perpetuates the very gaps I experienced. Nurses can break this cycle by initiating conversations about menopause as a standard part of care (Scofield et al., 2024), validating women's lived experiences (Cianelli et al., 2022), and using them as a foundation for holistic treatment (Dragovic et al., 2022).

To make this shift, nurses must recognize and act on several priorities. Drawing on both existing guideline reviews, our own nursing perspectives, and clinical experiences, the coauthors developed the four P's nursing lens (patterns, physiology, psychosocial, partnership) as a practice-oriented framework to complement Scofield's (2024) comparative guidelines (Table 1).

- Patterns: Listen and take a thorough history. Carefully listening to the patient and taking an excellent history are foundational to nursing. Attending closely to how women describe their experiences can reveal patterns that distinguish menopause from HIV or ART-related issues. This collaborative approach ensures that care plans reflect both clinical knowledge and lived experience and helps strengthen trust between women and their providers (Cianelli et al., 2022; Dragovic et al., 2022).

Table 1. Framework for Considering Menopause in Women Living With HIV: Integrating Comparative Guidelines and the Four P's

Domain	Comparative Guidelines[a]	4 P's Nursing Lens[b]
Patterns (history and symptom recognition)	Annual assessment of menstrual and menopausal symptoms for women older than 45 years	Take a thorough history, listen carefully, and identify overlapping patterns among menopause, HIV, ART side effects, and aging
Physiology (clinical and biological considerations)	Highlight risks for comorbidities such as cardiovascular disease and osteoporosis; consider hormone replacement therapy when appropriate	Place hormonal transition in context with HIV disease course and long-term ART exposure to avoid misattributing symptoms
Psychosocial (well-being, stigma, sexual health)	Emphasize quality of life, mental health, and sexual well-being beyond reproduction	Validate lived experience, acknowledge stigma, and discuss intimacy, pleasure, and self-image during midlife
Partnership (shared decision-making and resources)	Call for integration across specialties (infectious disease, gynecology, primary care) to reduce fragmented care	Build partnerships through shared decision making, provide culturally relevant resources, and refer to specialists when needed

Note. ART = antiretroviral therapy
[a] Comparative guidelines adapted from Scofield et al., (2024).
[b] The four P's nursing lens was developed by the authors for this commentary.

- Physiology: Recognize overlap and address comorbidity risks. Use differential diagnosis to distinguish between symptoms caused by menopause, HIV, and aging (Okhai et al., 2022; Tariq et al., 2019). Many symptoms overlap across these conditions, making misattribution common (Dragovic et al., 2022). International HIV guidelines recommend annual assessment of menstrual cycle and menopausal symptoms for women older than 45 years (Scofield et al., 2024). Although formal guidelines on screening and managing age-related comorbidities in women with HIV remain limited, organizations such as the American College of Obstetricians and Gynecologists (ACOG, 2016) provide guidance on menopause treatment. US guidelines on opportunistic infections also recommend considering menopause and hormone replacement therapy when appropriate (Panel on Guidelines for the Prevention and Treatment of Opportunistic Infections in Adults and Adolescents With HIV, 2023).
- Psychosocial: Address stigma and support well-being. Stigma related to both HIV and menopause compounds distress and can discourage women from seeking care. Clinicians should acknowledge stigma, validate lived experience, and create space to discuss intimacy, pleasure, and mental health as part of midlife care (Cianelli et al., 2022; Stanton et al., 2019; WHO, 2024).
- Partnership: Partner with women in care. Build partnerships through shared decision making, provide culturally relevant resources, and use patient-centered tools during clinical encounters (Scofield et al., 2024; WHO, 2024). This collaborative approach ensures that care plans reflect both clinical knowledge and lived experience (Dragovic et al., 2022).

This commentary offers lived experience as a guide toward more compassionate, holistic care that enhances autonomy, supports shared decision making, strengthens trust, and promotes the well-being of women across the lifespan, making menopause care a standard of care for women and all people living with HIV.

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Key Considerations

- ❍ Listening carefully and taking a thorough history is essential for distinguishing menopausal symptoms from those related to HIV, ART side effects, or aging.
- ❍ Integrating menopause screening into HIV care promotes early recognition, prevents misdiagnosis, and supports holistic health outcomes.
- ❍ Stigma associated with both HIV and menopause compounds distress and can discourage women from seeking support; clinicians should address this openly and with empathy.
- ❍ Nurses are uniquely positioned to lead in bridging HIV and menopause care through education, advocacy, and shared decision making.
- ❍ Using existing guidelines and culturally appropriate resources provides a roadmap for evidence-informed, patient-centered care.

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