


# The Problematization of Sexuality among Women Living with HIV and a New Feminist Approach for Understanding and Enhancing Women's Sexual Lives

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**Abstract** In the context of HIV, women's sexual rights and sexual autonomy are important but frequently overlooked and violated. Guided by community voices, feminist theories, and qualitative empirical research, we reviewed two decades of global quantitative research on sexuality among women living with HIV. In the 32 studies we found, conducted in 25 countries and composed mostly of cis-gender heterosexual women, sexuality was narrowly constructed as sexual behaviours involving risk (namely, penetration) and physiological dysfunctions relating to HIV illness, with far less attention given to the fullness of sexual lives in context, including more positive and rewarding experiences such as satisfaction and pleasure. Findings suggest that women experience declines in sexual activity, function, satisfaction, and pleasure following HIV diagnosis, at least for some

period. The extent of such declines, however, is varied, with numerous contextual forces shaping women's sexual well-being. Clinical markers of HIV (e.g., viral load, CD4 cell count) poorly predicted sexual outcomes, interrupting widely held assumptions about sexuality for women with HIV. Instead, the effects of HIV-related stigma intersecting with inequities related to trauma, violence, intimate relations, substance use, poverty, aging, and other social and cultural conditions primarily influenced the ways in which women experienced and enacted their sexuality. However, studies framed through a medical lens tended to pathologize outcomes as individual "problems," whereas others driven by a public health agenda remained primarily preoccupied with protecting the public from HIV. In light of these findings, we present a new feminist approach for research, policy, and practice

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toward understanding and enhancing women's sexual lives—one that affirms sexual diversity; engages deeply with society, politics, and history; and is grounded in women's sexual rights.

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“I hate the way it [having HIV] affects sex. It's like being in a room making love with all the lights on. My counselor, doctor and society are judging me about doing it right. It's no longer sex, it's a public health problem.” – A woman living with HIV (VanDevanter et al. 1999, p. 186)

An HIV diagnosis can be a traumatic experience for women around the world (Anderson et al. 2010; Cain et al. 2013; Kaplan et al. 2016; Liamputtong et al. 2011; Stevens and Tighe Doerr 1997; Stevens and Hildebrandt 2006), with profound effects on their sexual lives (Beckerman and Auerbach 2002; Gurevich et al. 2007; Keegan et al. 2005; Maticka-Tyndale et al. 2002; Persson 2005, 2008; Rispel et al. 2011; Welbourn 2013). As feminist scholars theorized when the epidemic began, “it is the sexually transmissible nature of HIV that transforms sexuality into something highly stigmatized and fraught with panic” (Lawless et al. 1996a, p. 17). Originally synonymous with sickness and death (Sontag 1988), those living with HIV were once advised to never have sex again (Kaplan et al. 1985). The accompanying discourses of risk and contamination in society created a major cultural context of fear (Conrad 1989; Herek and Capitanio 1994) that continues to foster widespread harassment and prosecution against women living with HIV (International Community of Women Living with HIV/AIDS 2016). This history plays a prominent role in how sexuality among women in the context of HIV takes shape today.

Presently, however, combination antiretroviral therapy (cART) is enabling women with HIV to live healthier lives, with less comorbidity, longer life expectancy, and zero risk of HIV transmission to sexual partners with sustained viral suppression (Cohen et al. 2011; Montaner 2011; Montaner et al. 2014; Patterson et al. 2015; Prevention Access Campaign 2017; Rodger et al. 2016; Samji et al. 2013; Vernazza and Bernard 2016; Vernazza et al. 2008). Although these outcomes are not equally experienced among women around the world owing to differences in health system infrastructure as well as poverty, violence, and intersectional stigma (Berger 2010; Logie et al. 2011), women are increasingly counselled in clinical practice that they can live a “normal” life with HIV, including a sexual life if desired (Barrington et al. 2017; Mattes 2014; Mazanderani and Paparini 2015). However,

societies have stigmatized and criminalized women with HIV so harshly that, as activist Alice Welbourn (2013) explains, “sexual pleasure becomes something scary for us to think about, let alone realize, as it is couched not in terms of what is our right and how we can be supported in this, but in terms of our evil intent” (p. 154).

Indeed, individuals and institutions still see women with HIV (and so, women often see themselves) primarily as a risk to sexual partners (Bayer 1997; Stevens and Galvao 2007) rather than as sexual beings with their own sexual rights. Women's personal testimonies reveal extreme pressures to always disclose their HIV-status and always practice “safer sex” (defined narrowly as male condoms), every time, with everyone (Gurevich et al. 2007; Lawless et al. 1996a). Those who do not disclose face threats of imprisonment (International Community of Women Living with HIV/AIDS 2016) and demonization in the media (Mykhalovskiy et al. 2016; Persson and Newman 2008). Those who do disclose commonly encounter violence, rejection, and abandonment by partners (Gielen et al. 1997), in addition to fear, prejudice, and moral judgement from society (Herek and Capitanio 1998; Lawless et al. 1996b).

It is not surprising then, that some women living with HIV, prefer to avoid sex altogether or report “lost” or “damaged” sexuality (Closson et al. 2015; Gurevich et al. 2007; Keegan et al. 2005; Lawless et al. 1996a; Nevedal and Sankar 2015; Persson 2005; Siegel et al. 2006; van der Straten et al. 1998; VanDevanter et al. 1999). Many others, however, are reclaiming sexual freedom and fullness through personal and political acts (Abrams 2017; AIDES 2016; Becker 2014; Caballero 2016; Cardinal et al. 2014; Fratti 2017; Iacono 2016; International Community of Women Living with HIV/AIDS 2016; McClelland and Whitbread 2016; Mitchell et al. 2011; Nade'ge 2016; Nicholson et al. 2016; Petretti 2017; Prevention Access Campaign 2017; Sanchez et al. 2017; The Well Project 2017; Whitbread 2017; Whitbread 2016).

To support community efforts in redressing the denial of women's sexual desires (Welbourn 2013), we critically examined two decades of quantitative research on sexuality among women living with HIV around the world (1996 to 2017). In line with international reports that emphasize the importance of women's pleasure to achieving sexual health and rights (Salmander Trust 2014; World Health Organization 2017), we sought to make visible studies that moved beyond safer sex and encompassed broader aspects of sexuality. As an interdisciplinary team conducting empirical research on this topic using quantitative methods (Carter et al., Archives of Sexual Behaviour, unpublished; Kaida et al. 2015), we focused only on quantitative data. We situated our analysis and critique, however, within several literatures (i.e., feminist theoretical, qualitative empirical, non-academic personal stories) and disciplines (i.e., sexuality, gender, HIV). This allowed us to be as comprehensive as possible in our review of available quantitative research

while bringing needed critical perspectives to the field. Our ultimate goal was to advance understandings of women's sexuality in the context of HIV across multiple, often-contradictory knowledge cultures, and, in turn, shape the direction of future research, policy, and practice.

We synthesized the literature using a rigorous scoping review methodology (Arksey and O'Malley 2005), an approach to map broader topics underpinning a research area, unlike the often narrow scope of systematic reviews. Our process is documented in detail in the online supplement to this review. Briefly, it involved five iterative and non-linear stages: (a) engaging key stakeholders including women living with HIV, who partnered in framing the study, elucidating the findings, and making recommendations; (b) identifying and selecting articles for inclusion; (c) reviewing the materials and charting relevant information; (d) comparing the data within and between studies; and (e) synthesizing and reporting the data as a coherent whole. The key terms and search strategy used to select articles are shown in Figs. 1s and 2s of the online supplement, respectively, and details for each study are provided in Table 1s.

What follows is a critical overview of the evidence aimed at supporting a way forward in research so that policymakers, practitioners, and women living with HIV can make effective use of the findings. Because most papers included in our review lacked conceptual analysis (Fahs and McClelland 2016), we first defined key terms and looked toward feminist perspectives on sexuality, gender, and HIV to deepen our analysis. With these guiding frameworks, we then summarized the key patterns and issues underpinning the research area, taking care to uncover the diversities of women's sexual experiences, on the one hand, and the uniformities of positivist quantitative analyses on the other. Finally, we offer recommendations for action at all levels to support and enhance the sexual lives of women living with HIV.

## Conceptual Analysis

### Defining Sexual Health, Sexuality, and Sexual Rights

Sexual health and sexuality has a variety of meanings that have changed over time (Edwards and Coleman 2004; Fortenberry 2013; Impett et al. 2013; Sandfort and Ehrhardt 2004). The World Health Organization (2006, p. 5) has defined sexual health as “a state of physical, emotional, mental and social well-being in relation to sexuality...not merely the absence of disease, dysfunction or infirmity.” It has likewise offered a broad definition of sexuality:

Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and

reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. (World Health Organization 2006, p. 5)

Critically, these and other reports, including those from feminist scholars, have emphasized the centrality of sexual rights to sexual health and sexuality (Fahs 2014; Little 1991; McClelland 2010; Tiefer 2001; World Association for Sexual Health 2014; World Health Organization 2006). Simply put, it is the right to control one's body, desires, and experiences in relation to sexuality. This includes freedom from all forms of sexual harm including coercion, discrimination, violence, and oppressive mandates, as well as freedom to enjoy all modes of sexual expression including pleasure and satisfaction (Fahs 2014; McClelland 2010), regardless of age, race, gender, sexual orientation, nationality, marital status, social and economic situation, health (including HIV) status, and so forth (World Association for Sexual Health 2014).

### Feminist Perspectives on Sexuality, Gender, and HIV

Although perspectives vary widely, most feminist researchers tend to agree that sexuality is diverse and primarily socially constructed—influenced by culture, relational dynamics, economic conditions, and historical, legal, and political factors (Cacchioni 2007; Carpenter 2010; Holland et al. 1990; Holland et al. 1994; Holland et al. 1992; Little 1991; Meadows 1997; Reddy and Dunne 2007; Ryan 2001; Tiefer 2004; Vance and Pollis 1990). What sets feminist approaches apart is their theoretical anchorage in intersectionality (Berger 2010; Bowleg 2008; Bredström 2006; Crenshaw 1989; Dworkin 2005; Hancock 2007; Purdie-Vaughns and Eibach 2008; Shields 2008). This theory encourages critical attention to how women's sexual experiences are tied to interlocking social positions, structural inequities, and historical discourses on sexuality, gender, and HIV.

Research by Lawless et al. (1996a) provides one of the earliest empirical examples of intersectional feminist theorizing on sexuality among women living with HIV, although they do not explicitly use this term. Based on the narrative accounts of 24 heterosexual women with HIV in Australia, researchers illuminated how women's sexual pleasure and safety was undermined by violence, gender norms (e.g., penetrative sex for men's satisfaction; condoms as incompatible with romance), and both subtle and overt messages from care providers that their sexuality was contaminated and a threat to the public. The authors also found differing negotiations for women in casual versus ongoing HIV sero-concordant and sero-discordant relationships.

Gurevich et al. (2007) extended this theorizing in interviews with 20 women living with HIV in Canada, highlighting the ways in which lower social statuses due to gender and HIV intersect with multiple cultural dialogues (e.g., female promiscuity) and imperatives (e.g., disclosure demands; prevention burdens) to constrain women's sexual freedoms. Feminist analyses by Squire (2003) and Persson (2005) further reveal how socio-historical discourses concerning romance conflict with those regarding sexuality (e.g., HIV as dirty; women with HIV as sexually deviant and vessels of disease; women as sexually passive). Their research demonstrated how women and partners internalize dominant cultural messages and then enact them, consciously and unconsciously, within intimate relationships, leading to both interpersonal and self-stigma, which ultimately shape women's feelings, identities, and possible sexual lives with HIV.

Recent critical work has also drawn attention to how these prevailing cultural norms are reinforced by laws (International Community of Women Living with HIV/AIDS 2016; Kaida et al. 2015), the media (Mykhalovskiy et al. 2016; Persson and Newman 2008), and medical and public health practices (Kaida et al. 2015; Mazanderani 2012; Persson 2014) that impact, often negatively, but sometimes positively, how women sexually live with HIV. Collectively, in examining women's sexuality in relation to these multiple social and political forces, feminist scholarship is increasingly illuminating how “the most private aspects of living with the virus can at the same time be the most public” (Mazanderani 2012, p. 393).

### Pathologizing Women's Sexuality

Despite these insights, much of contemporary quantitative research on women's sexuality is plagued by over-medicalization and biological reductionism, which has been critiqued for decades, both by feminist scholars (Angel 2010, 2012, 2013; Bancroft 2002; Cacchioni 2007; Moynihan 2003; Riessman 1983; Spurgas 2013, 2016; Tiefer 1991, 1996, 2003, 2004; Tosh and Carson 2016; Wood et al. 2006) and clinical, psychology, and sexology experts (Balon 2008; Bancroft 2002; Basson et al. 2003; Basson et al. 2004; Brotto 2010; Graham 2010; Payne et al. 2006; Segraves et al. 2007). Most pressingly, these debates have centred on the construction of “female sexual dysfunction” in the Diagnostic and Statistical Manual of Mental Disorders (DSM) (American Psychiatric Association 1980, 1987, 1994, 2000, 2013). Although several revisions were made to the latest edition (Basson 2014; Graham 2016), the medical community at large continues to broadly define these “disorders” in relation to sexual desire, arousal, orgasm, and pain as documented in models of the “human sexual response cycle” (HSRC) (Kaplan 1974; Masters and Johnson 1966). Both frameworks have been criticized for positioning sexual

response as a linear sequence of physical, mechanical events that occur similarly in men and women and for labelling those who deviate from the heteronormative sexual scripts buried therein (i.e., high desire, high arousal, frequent (penetrative) intercourse and orgasm as end-point) as abnormal or unhealthy (Tiefer 2004).

However, researchers have, for some time, argued that sexual experiences cannot and should not be universalized in this way for several reasons (Basson 2000; Brotto 2010; Heiman 2002; Tiefer 2001). Most importantly, not all women want to have penetrative sex and supporting rather than problematizing their decision is vital (Hayfield and Clarke 2012; Tosh and Carson 2016). Further, sexual response cycles are far from universal. Some researchers suggest women's sexual desire is responsive and extremely context-sensitive, with interest in sex sometimes preceding and other times following some form of sexual arousal or excitement (Brotto et al. 2009; Carnevalheira et al. 2010; Goldhammer and McCabe 2011; Graham et al. 2004). Others point out that sexual arousal consists of both physiological (e.g., lubrication) and cognitive (e.g., feeling “turned on”) elements, with non-concordance between the body and the mind being common among women (Graham et al. 2004). In addition, despite the privileging of intercourse (Peterson and Muehlenhard 2007b), most cisgender women do not reliably orgasm through penetration alone, with the frequency and intensity varying greatly depending on clitoral stimulation and genital anatomy (Basson 2000; Pfaus et al. 2016; Wallen and Lloyd 2011). Importantly, however, feminists also caution against essentializing gender differences (Angel 2013; Spurgas 2013, 2016)—that is, treating such differences as if they were biological or natural as opposed to resulting from dissimilar socialization (i.e., norms about “proper” femininity and masculinity) (Holland et al. 1990; Holland et al. 1994). They also emphasize differences between groups of women, likewise owing to divergent social realities (Tiefer 2002).

### From Disease to Diversity

To avoid over-pathologizing what many view as simply rich and expansive individual difference, Barker and Richards (2013) have advocated that “perhaps a move toward the language of diversity rather than dysfunction/problem would be appropriate as it would remove the implication that being non-sexual, non-orgasmic, non-erectile or non-penetratable are necessarily problems.” Some scholars also encourage a shift toward a positive psychology of sexuality (Impett et al. 2013). Recent critical work, for example, has explored concepts of sexual empowerment (Lamb 2010), pleasure (Sanchez et al. 2005), and satisfaction (McClelland 2010, 2011, 2013). A common thread in these studies is analytic attention to broader social issues such as sexism/genderism, heterosexism, racism, classism, sexual stigma, and violence that can limit what



women feel they deserve when it comes to sex and pleasure (Carpenter 2010; McClelland 2010; Tiefer 2004). Such theorizing is especially important for understanding sexuality among women living with HIV whose experiences unfold within particularly unjust environments.

One theory of relevance to our discussion is the dual control model, which proposes widespread individual variability in sexuality due to the interaction between an individual's "sexual excitation system" (SES) and "sexual inhibition system" (SIS) (Bancroft et al. 2009). These systems receive information from the external and internal environment causing the mind and body to react in different ways depending on whether the stimuli are pleasurable or threatening (Bancroft et al. 2009). For instance, a warm and emotionally connected relationship may be exciting for some, whereas fears of HIV transmission may be inhibiting, along with numerous other potential stressors (e.g., discrimination and abuse from partners, threats of criminalization, and feelings of unattractiveness). By emphasizing the importance of context, this model and feminist theories both advance the notion that there is no normative standard for sexuality and that challenges and changes with sexuality and intimacy after an HIV diagnosis—whether related to having sex, desiring sex, arousal, orgasm, satisfaction, or pleasure, among other many facets—are understandable, given the numerous overt and covert oppressions in women's intimate lives.

These concepts and critical approaches have together informed our critical feminist review of the quantitative literature on sexuality among women living with HIV. The theoretical framing used to inform this review enabled a broader conceptualization and contextualization of women's sexuality in the context of HIV. In doing so, we attempted to resist overmedicalizing women's sexuality and over-pathologizing diversity, while thoughtfully acknowledging and responding to the sexual grief and loss described by many women living with HIV (Gurevich et al. 2007; Lawless et al. 1996a; Nevedal and Sankar 2015; van der Straten et al. 1998).

## Critical Review of Past Research

In total, 32 quantitative studies involving 11,552 women living with HIV were included in our review (Agaba et al. 2017; Bernier et al. 2016; Bogart et al. 2006; Bouhnik et al. 2008; Bova and Durante 2003; Castro et al. 2010; Courtenay-Quirk et al. 2009; Craft and Serovich 2007; De Vries et al. 2013; Denis and Sung-Mook 2003; El Fane et al. 2011; Florence et al. 2004; Goggin et al. 1998; Hankins et al. 1997; Inoue et al. 2004; Kaida et al. 2015; Kilmarx et al. 1998; Lambert et al. 2005; Luzi et al. 2009; Negin et al. 2016; Oyedokun et al. 2014; Peltzer 2011; Pinzone et al. 2015; Robinson et al. 2017; Rosenberg et al. 2017; Schrooten et al. 2001; Taylor et al.

2015; Trotta et al. 2008; Valadares et al. 2014; Wessman et al. 2015; Wilson et al. 2010; Zierler et al. 1999).

## Quantitative Conceptualizations of Sexuality

Our review of the 32 studies revealed several biases, omissions, and assumptions that are shaping and ultimately limiting knowledge about women's sexuality in the context of HIV. Although the studies spanned 25 countries in six of seven continents, most were conducted in North America and Europe, with fairly few (25%) in Africa (Agaba et al. 2017; Bernier et al. 2016; El Fane et al. 2011; Oyedokun et al. 2014; Negin et al. 2016; De Vries et al. 2013; Peltzer 2011; Rosenberg et al. 2017), where 70% of all people with HIV live (UNAIDS 2016). Nearly half ( $n=15$ , 47%) of all studies were mixed-gendered cohorts (Bernier et al. 2016; Bogart et al. 2006; Bouhnik et al. 2008; Castro et al. 2010; Courtenay-Quirk et al. 2009; De Vries et al. 2013; El Fane et al. 2011; Inoue et al. 2004; Kilmarx et al. 1998; Negin et al. 2016; Peltzer 2011; Pinzone et al. 2015; Rosenberg et al. 2017; Schrooten et al. 2001; Trotta et al. 2008), highlighting a persistent lack of research focus on women with HIV, unlike the relative plethora of sex studies for men with HIV (Scanavino 2011) and women with cancer (Abbott-Anderson and Kwekkeboom 2012; Emilee et al. 2010) and other chronic illnesses (Basson 2010; Giralaldi and Kristensen 2010). Of these studies, just seven disaggregated their data by gender (Bernier et al. 2016; Bogart et al. 2006; Courtenay-Quirk et al. 2009; El Fane et al. 2011; Kilmarx et al. 1998; Pinzone et al. 2015; Robinson et al. 2017). Further, across the mixed-gendered cohorts, women's bodies, desires, and experiences were largely conceptualized as no different from men's.

Although samples were diverse with respect to age, ethnicity, country, education, and time since HIV diagnosis, studies almost exclusively provided a cis-gendered, heterosexual picture of women's sexuality. Trans and gender diverse women and women identifying as lesbian, gay, bisexual, two-spirited, or queer were either ignored, excluded, or under-represented in quantitative research, severely limiting the full scope of sexualities presented here. In addition, few studies theorized how women's sexuality may differ by membership in other marginalized groups that face multiple sexual stigmas and stereotypes (e.g., younger women, older women, women of colour, women who use substances, or women involved in sex work) (Berger 2010; Logie et al. 2011) (exceptions: Hankins et al. 1997; Negin et al. 2016; Taylor et al. 2015). There was also little cross-cultural theoretical analysis, even in multi-country research (Bernier et al. 2016; Florence et al. 2004; Schrooten et al. 2001; Wessman et al. 2015).

In contrast with international definitions of sexuality (World Association for Sexual Health 2014; World Health Organization 2006), quantitative conceptualizations of this multifaceted construct were severely limited. The vast majority of reviewed studies were oriented toward understanding sexual inactivity ( $n=13$ ,

41%) (Bernier et al. 2016; Bogart et al. 2006; Courtenay-Quirk et al. 2009; Craft and Serovich 2007; Hankins et al. 1997; Kaida et al. 2015; Kilmarx et al. 1998; Negin et al. 2016; Robinson et al. 2017; Rosenberg et al. 2017; Taylor et al. 2015; Wessman et al. 2015; Zierler et al. 1999) and dysfunction ( $n=16$ , 50%) (Agaba et al. 2017; Bouhnik et al. 2008; Bova and Durante 2003; De Vries et al. 2013; Denis and Sung-Mook 2003; El Fane et al. 2011; Florence et al. 2004; Goggin et al. 1998; Lambert et al. 2005; Luzi et al. 2009; Oyedokun et al. 2014; Pinzone et al. 2015; Schrooten et al. 2001; Trotta et al. 2008; Valadares et al. 2014; Wilson et al. 2010). Just three studies (9%), all involving mixed-gendered cohorts (Castro et al. 2010; Inoue et al. 2004; Peltzer 2011), were principally interested in sexual satisfaction (though studied from a deficit perspective, i.e., dissatisfaction); added insights come from the descriptive statistics of three women-only studies (Hankins et al. 1997; Kaida et al. 2015; Lambert et al. 2005). Other affirming aspects of sexual life remained almost entirely overlooked (e.g., feelings of pleasure, love, sexual self-esteem, agency, deservingness) (exceptions: Hankins et al. 1997; Lambert et al. 2005)—evidence that the primary concern of quantitative research is pathologizing the state of sexuality among women with HIV rather than exploring broader, more positive emotional and pleasure-based aspects of women's sexual well-being (Fahs 2014; Impett et al. 2013). In this way (and others), research can reinforce and perpetuate societal stigma.

Of significance, researchers tended to presume sexual activity, function, and satisfaction are universally understood, desired, and experienced between individuals, despite evidence to the contrary (McClelland 2010, 2011, 2013; Peterson and Muehlenhard 2007b; Sanders et al. 2010; Tiefer 2001). In much of the literature, investigators provided no definition of sexual activity at all, leading readers to assume that it meant heterosexual (penile-vaginal) intercourse. When definitions were provided, they were most often restricted to interpersonal sex involving vaginal and anal intercourse (Bogart et al. 2006; Peltzer 2011; Taylor et al. 2015), and, in two cases, oral sex as well (Kaida et al. 2015; Robinson et al. 2017). Two studies also counted caressing and foreplay (Denis and Sung-Mook 2003; Wilson et al. 2010) and just one reported on self-pleasure among women (Hankins et al. 1997). Moreover, notions of consensual and wanted sex (Bay-Cheng and Eliseo-Arras 2008; Peterson and Muehlenhard 2007a) remained missing from existing survey items with one exception (Kaida et al. 2015 operationalized consensual but not wanted sex).

This narrow conceptualization of “sex” is consistent with a frequently implicit objective of reducing HIV risk that underlies sexuality studies in the context of HIV. It also ignores the multiple meanings of being sexual (Fahs and McClelland 2016; Peterson and Muehlenhard 2007b) including the vast array of non-penetrative experiences that women with HIV describe as essential to their overall pleasure and satisfaction (e.g., kissing, touching, mutual masturbation) (Taylor et al. 2016). Furthermore, quantitative discourse on the implications of sexual

abstinence is replete with contradictions, with public health research framing it favourably, as an “[HIV] prevention strategy among several (e.g., condom use)” (Bogart et al. 2006, p. 1078) that can protect the health of populations, and medical health research viewing it negatively, as a “chronic disease” (Zierler et al. 1999, p. 83) that is afflicting individuals living with HIV.

Diversities in sexual function were likewise diminished in the studies reviewed and replaced with a narrow, inflexible set of heteronormative standards. Specifically, women who were not having sex (as defined previously) with high levels of desire, arousal, and orgasm were considered sexually “dysfunctional.” This definition is consistent with the view of the DSM (American Psychiatric Association 2013), which has been rigorously critiqued by feminist scholars (Angel 2012, 2013; Cacchioni 2007; Farrell and Cacchioni 2012; Spurgas 2016; Tiefer 1991, 2004; Tosh and Carson 2016; Wood et al. 2006). Notably, however, the measurement of “dysfunction” has been highly variable. Some investigators relied on clinical diagnosis according to DSM criteria (El Fane et al. 2011; Goggin et al. 1998). Others employed single-item survey questions (Bouhnik et al. 2008; Schrooten et al. 2001; Trotta et al. 2008; Valadares et al. 2014), some of which were exceptionally vague (e.g., “dysfunction in sexual activity”; “sexual difficulties”). Many more used several different non-validated (Bova and Durante 2003; De Vries et al. 2013; Goggin et al. 1998) and validated (Agaba et al. 2017; Craft and Serovich 2007; Denis and Sung-Mook 2003; Florence et al. 2004; Lambert et al. 2005; Luzi et al. 2009; Oyedokun et al. 2014; Pinzone et al. 2015; Wilson et al. 2010) multi-item scales. The most commonly used scale was the Female Sexual Function Index (FSFI) (Agaba et al. 2017; Florence et al. 2004; Luzi et al. 2009; Oyedokun et al. 2014; Pinzone et al. 2015; Wilson et al. 2010), originally adapted from an erectile dysfunction index (Kaplan et al. 1999; Rosen et al. 2000; Rosen et al. 1997). The FSFI quantifies desire, arousal, orgasm, pain, lubrication, and satisfaction in the past 4 weeks, with an overt assumption that sex (or more specifically, penetration) is necessary for sexual well-being. This is evident in the scoring methods: sexually inactive women are automatically assigned the lowest score and, thus, are assumed “dysfunctional” (exceptions: Luzi et al. 2009 and Pinzone et al. 2015 excluded these women from analyses).

Finally, in contrast to the prevailing medical and public health reasoning in the abovementioned literatures, understandings of sexual satisfaction were entirely atheoretical, notwithstanding available theories (Byers et al. 1998; Byers and Macneil 2006; Byers et al. 2004; Lawrance and Byers 1995; McClelland 2010, 2011, 2013). All researchers operationalized sexual satisfaction dichotomously (Castro et al. 2010; Hankins et al. 1997; Inoue et al. 2004; Kaida et al. 2015; Peltzer 2011), using self-reports of the degree to which an individual feels content with their sexual life (e.g., “In general, concerning your sexual life, you would say that you are satisfied or dissatisfied?”). Evaluating results remained difficult, however, owing to several conceptual limitations, including a lack of critical engagement with whether

individuals' appraisals focus more on physical or emotional aspects of sexual satisfaction (McClelland 2013), reflect self or partner fulfillment (McClelland 2011), and are determined within the individual or influenced by social and political conditions (McClelland 2010).

## Sexual Diversities

### *Sexual Activity*

Most studies tended to conclude that the “majority of women” (Hankins et al. 1997, p. 267) living with HIV are sexually active, although one report suggested the exact opposite (Robinson et al. 2017). Both conclusions elide diversity of experiences. Although not enough is understood about sex and sexuality following diagnosis, studies have found that some women continue to be sexually active after learning their HIV status (68–90%) (Bova and Durante 2003; Hankins et al. 1997; Lambert et al. 2005), whereas others stop having sex altogether (42%) (Bernier et al. 2016). Cessation of sexual relations is reported to be higher among women than men (23%) (Bernier et al. 2016). No studies have been conducted among young women living with HIV since birth and navigating sex for the first time, although qualitative research suggests variations in sexual behaviours (Fair and Albright 2012; Greenhalgh et al. 2013, 2016; Mergui and Giami 2014).

For women who are sexually active, one study estimated that 44% of 161 women resumed their sex life within one month of their HIV diagnosis, whereas the rest took on average 4 months (range: 2 months to 8 years) (Hankins et al. 1997). Half of these women reported that the decision to re-initiate sex depended more on desires to please one's partner rather than oneself (Hankins et al. 1997), underscoring the role of gender norms in shaping women's sexuality (Holland et al. 1990; Holland et al. 1994; Holland et al. 1992). Other studies suggest women experience changes in sexual activities after diagnosis and treatment, including a reduction in the frequency of intercourse (Hankins et al. 1997; Kilmarx et al. 1998), oral sex (Zierler et al. 1999), and masturbation (Hankins et al. 1997) as well as number of sexual partners (De Vries et al. 2013; Zierler et al. 1999) and casual sex encounters (Kilmarx et al. 1998). One research team described the drop in number of sexual partners as “encouraging” (De Vries et al. 2013, p. 173), highlighting the often not-so-hidden prejudice against HIV-positive women's rights to express and enjoy their sexuality as they wish.

In terms of recent sexual experience (i.e., past month to past year), studies most often indicate about two-thirds to three-fourths of women engage in intercourse (Bouhnik et al. 2008; 5, Castro et al. 2010; Courtenay-Quirk et al. 2009; 8, Denis and Sung-Mook 2003; El Fane et al. 2011; Goggin et al. 1998; Hankins et al. 1997; Lambert et al. 2005; Luzi et al. 2009; Peltzer 2011; Pinzone et al. 2015; Taylor et al. 2015; 30, Wilson et al. 2010; Zierler et al. 1999), although estimates range

considerably by socio-demographic, economic, and cultural factors, from as low as 14% among 59 Nigerian women aged 50 and over (versus 50% of Nigerian men) (Negin et al. 2016), to 44–49% with 1795 Canadian women reporting high stigma (Kaida et al. 2015; Robinson et al. 2017), to as high as 93% in 43 Italian women engaged in care (Pinzone et al. 2015). Among those who are sexually inactive, past research estimates that 48–74% of these individuals have deliberately chosen to abstain from sex (Bogart et al. 2006; Courtenay-Quirk et al. 2009), at least for some time (range: 2 months to 24 years). The overall prevalence of deliberate abstinence (i.e., among all people with HIV) is 18–23% for women and 11–20% for men (Bogart et al. 2006; Courtenay-Quirk et al. 2009).

When asked about reasons for sexual inactivity (whether intentional or not), many women across studies reported difficulties finding the “right” partner, anxieties about disclosing to partners, fears around the possibility of transmitting HIV, and low interest in sex (Bova and Durante 2003; Courtenay-Quirk et al. 2009; El Fane et al. 2011; Lambert et al. 2005; 20, Zierler et al. 1999). Other reasons included depression, guilt, religious taboos, pregnancy concerns, a dislike of condoms, and pain during intercourse (Bova and Durante 2003; Courtenay-Quirk et al. 2009; El Fane et al. 2011; Lambert et al. 2005; 20, Zierler et al. 1999). All of these factors inform understanding of the numerous internal and external contexts shaping women's sexual activity in the context of HIV.

### *Sexual Function*

Although a “majority of women” with HIV are sexually active, as narrowly defined and described by the prior literature, many studies assessing sexual function report that “female sexual dysfunction is frequent” (Florence et al. 2004, p. 556). According to most research using the FSFI, an estimated 25–34% of women living with HIV have a sexual “disorder” (Florence et al. 2004; Luzi et al. 2009; Pinzone et al. 2015; Wilson et al. 2010), and one study reported that such problems were more than twice as likely in this population ( $n = 1279$ ) than among women without HIV ( $n = 526$ ) (Wilson et al. 2010). A much higher prevalence of sexual difficulties has been reported among Black African women in Nigeria (66–89%, based on a total sample size  $n = 370$ ) (Agaba et al. 2017; Oyedokun et al. 2014), Morocco (69%,  $n = 72$ ) (El Fane et al. 2011), and the United Kingdom (60%,  $n = 82$ ) (Lambert et al. 2005). Although this pattern may be due to differences in social, cultural, and religious norms around sexuality (Agaba et al. 2017; El Fane et al. 2011; Oyedokun et al. 2014), these and other factors (e.g., political, economic) remained under-theorized in research. Moreover, it is unclear whether Western-based psychological instruments (and sexual concepts and normative standards therein) were adapted and validated across cultures. When examining this outcome across genders, two studies suggested sexual “dysfunctions” were more



frequent in men than women (El Fane et al. 2011; Pinzone et al. 2015), although the study populations are arguably not readily comparable because of differences not just in anatomy, but also in socio-sexual development and interaction.

Just one study with 101 women in the United States, composed mainly of sexually active women (90%) with injection drug use (64%) and sex work (55%) histories, described a “good level of sexual functioning” (Bova and Durante 2003, p. 80). This was based on women’s responses to three questions about whether their “health” impacted their interest in, frequency of, or problems with sex. The meaning of “health” (i.e., whether it referred to HIV or other conditions) was unclear, and how this population may differ from others in crucial ways (e.g., sexual agency; power within relationship; sex for female pleasure versus work, survival, or male pleasure) was unaddressed. In fact, there are reports that some women living with HIV were angered by the study’s positive conclusions, which felt disconnected from their own lived realities (Gurevich et al. 2007; Kahn 2000), underscoring the importance of unearthing multiple rather than singular experiences.

In terms of specific domains of sexual functioning, some studies report low desire is common (39–43%, based on a total sample size  $n = 54$ ) (Goggin et al. 1998), with variation between those having (33%,  $n = 57$ ) and not having (45%,  $n = 39$ ) sex (Craft and Serovich 2007), while other studies suggested it is rare (9%,  $n = 116$ ) (Denis and Sung-Mook 2003). Additional concerns such as vaginal dryness and painful intercourse are reportedly infrequent among women with HIV (Denis and Sung-Mook 2003; Florence et al. 2004), whereas difficulties reaching orgasm is prevalent (41–78%) (Denis and Sung-Mook 2003; Hankins et al. 1997), varying not only by HIV-status (Denis and Sung-Mook 2003;  $n = 116$ ) but also other forms of social difference (e.g., race, IDU) (Hankins et al. 1997,  $n = 161$ ). However, given that women with HIV are less likely to receive oral sex than women without HIV (Zierler et al. 1999), combined with past research showing that two-thirds of cis-gender heterosexual women rarely or never orgasm with penetration alone (Basson 2000; Wallen and Lloyd 2011), this finding may have more to do with partners’ inattention to female pleasure in the context of HIV despite zero risk of transmission when virally suppressed (Rodger et al. 2016) and other safer sex methods, rather than a “dysfunction” on women’s part.

Among all studies we identified, just two provided insight into women’s own views on the social, mental, and physical factors underlying reduced sexual functioning (El Fane et al. 2011; Goggin et al. 1998). In response to a question about the cause of low desire, women’s explanations were varied and included fears of rejection, persistent worries about HIV transmission, relationship problems, lack of a partner, and fatigue (Goggin et al. 1998,  $n = 54$ ). In a more recent study in Morocco (El Fane et al. 2011;  $n = 72$ ), women likewise attributed sexual difficulties to fear of infecting a partner and anger toward a partner as well as feeling that their sexuality reminded them of

disease and that their sex life was constrained by the use condoms. These accounts are consistent with women’s reasons for sexual inactivity and reflective of aforesaid theories positing that changing and high-stress contexts can, understandably, alter women’s sexual interest and arousal.

### *Sexual Satisfaction and Other Subjectivities*

Because most quantitative research has focused on physical aspects of sex, much less is known about the impact of HIV on women’s sexual feelings, although several key findings are apparent and complemented by qualitative narratives (Carlsson-Lalloo et al. 2016). One study reported that many women (84%,  $n = 161$ ) experience a “sexual adjustment period” after an HIV diagnosis (median duration: 8.5 months; range: 1 month to 5 years) (Hankins et al. 1997). In some ways, this may be akin to the psychosexual adjustment frequently reported among women with other chronic illnesses such as breast (Emilee et al. 2010) and gynaecological (Abbott-Anderson and Kwekkeboom 2012) cancer. The difference, however, is that HIV is transmitted between people (most often through sex, followed by injection drug use) and rooted in discourses of risk, responsibility, and stigma (Lawless et al. 1996b; Sontag 1988). Consequently, it is not uncommon for women with HIV to report extreme discomfort with their sex life immediately following diagnosis, and a range of negative emotions (e.g., fear of being touched; worries about infecting others; concerns about having to use condoms and sex feeling less “natural”; diminished spontaneity and freedom) (Hankins et al. 1997). Reduced levels of satisfaction, enjoyment, and pleasure with sex have also been reported (Hankins et al. 1997; Lambert et al. 2005; Peltzer 2011).

Yet sexual feelings can be radically different for every woman. Two studies explicitly asked women their beliefs concerning the impact of living with HIV on their sex lives using fixed responses (Bova and Durante 2003; Lambert et al. 2005). In research with mostly Black African women in the United Kingdom ( $n = 82$ ) reporting high rates of sexual abuse (41%), including during war or violent conflict, 24% of women said HIV made it impossible to have sex; 58% felt that being HIV-positive slightly, moderately, or greatly reduced their sexual enjoyment; and 28% felt it made no real difference (Lambert et al. 2005). In contrast, among sexually active women with injection drug use and sex work histories in the US ( $n = 101$ ), few (11%) reported that the quality of their sex life became significantly worse after testing HIV-positive, whereas about half (52%) said it remained the same or improved (Bova and Durante 2003). Both studies underscore the wide variation in women’s sexuality because women inhabit different social environments, including varied experiences of trauma, stigma, medical care, and vulnerability and positions of power (Maxwell 2006).

For some, to have sex and feel pleasure, they have to feel safe. Feeling safe is not just about learning how to live with



HIV; it is also about healing from incredible trauma and providing women with the right environment to do so (e.g., freedom from further violence, discrimination, criminalization, and other wrongs) (International Community of Women Living with HIV/AIDS 2016; Salmander Trust 2014). For others, such as those involved in street drug use and/or sex work, it is possible that some women live in the same social contexts before and after HIV diagnosis, resulting in no appreciable difference in subjective experiences of sex. Some women may even find themselves excluded from understanding what “great sex” is and feeling entitled to it, owing to socio-economic status, gendered expectations and attitudes to sex, and other factors (Kleinplatz et al. 2009; Maxwell 2006; McClelland 2010).

While difficulties feeling excitement and pleasure during sex can occur after diagnosis, other studies suggest sexual satisfaction ratings can improve over time (Hankins et al. 1997; Peltzer 2011), even increasing to higher levels than before diagnosis (Hankins et al. 1997). In fact, about two-thirds (61–67%) of women (and men) with HIV report being satisfied with their sex lives (Bouhnik et al. 2008; Castro et al. 2010; Kaida et al. 2015; Lambert et al. 2005), though rates can vary considerably between countries [i.e., 41% in Japan (Inoue et al. 2004;  $n = 61$ ), 30% in Morocco (El Fane et al. 2011,  $n = 72$ )]. One study also indicates that men and women experience equal levels of sexual satisfaction (Castro et al. 2010;  $n = 521$ ). A limitation of all these findings, however, is a lack of analysis on the ways in which HIV stigma and gender role norms may be biasing self-reports, with women living with HIV reporting feeling satisfied with less owing to lower expectations toward sex and sexuality (McClelland 2010). Further, women (and men) are not monolithic, and assumptions of sameness are challenged when sexual satisfaction is considered among subgroups of individuals with varying levels of social privilege. For example, Hankins et al. (Hankins et al. 1997,  $n = 161$ ) found that more marginalized women report higher sexual dissatisfaction (i.e., 41% of 61 non-IDU White women vs. 58% of 53 non-IDU African/Haitian women vs. 71% of 47 IDU women), consistent with findings outside the HIV field (Fahs and Swank 2011).

Studies of satisfaction also help to subvert another aforementioned assumption—namely, that not having sex is universally unsatisfying. In a study of South African women and men followed for 20 months after initiating cART, sexually active participants were, in fact, less satisfied than their sexually inactive counterparts (Peltzer 2011). Interestingly, researchers attributed these findings to biological effects in the former group (i.e., cART-induced sexual dysfunction) and individual responsibilities in the latter (i.e., acceptance of abstinence to prevent HIV transmission). In another study of Canadian women, the opposite was found; sexual satisfaction was positively correlated with sexual activity (Kaida et al. 2015), consistent with most research claims in the broader sexual health literature (Haavio-Mannila

and Kontula 1997; Henderson et al. 2009; Young et al. 1998). Nevertheless, a sizeable proportion (i.e., 49%) of the 595 sexually inactive women in this study rated their present sex life as reasonably, very, or completely satisfactory (Kaida et al. 2015). As mentioned, for some, this may be related to what women feel they deserve sexually (McClelland 2010). For others, intersecting stigma, institutional racism, and structural violence against women living with HIV (Berger 2010; Logie et al. 2011) may also mean that not having sex is truly very sexually satisfying.

## Determinants of Sexual Activity, Function, and Satisfaction

### Medical Factors

In analyses exploring predictors of sexual outcomes, factors relating to physical health were examined in most studies (i.e.,  $n = 27$  of 32, or 84%) (Agaba et al. 2017; Bernier et al. 2016; Bogart et al. 2006; Bouhnik et al. 2008; Bova and Durante 2003; Castro et al. 2010; Courtenay-Quirk et al. 2009; Denis and Sung-Mook 2003; Florence et al. 2004; Goggin et al. 1998; Hankins et al. 1997; Kaida et al. 2015; Lambert et al. 2005; Luzi et al. 2009; Negin et al. 2016; Oyedokun et al. 2014; Peltzer 2011; Pinzone et al. 2015; Robinson et al. 2017; Rosenberg et al. 2017; Schrooten et al. 2001; Taylor et al. 2015; Trotta et al. 2008; Valadares et al. 2014; Wessman et al. 2015; Wilson et al. 2010; Zierler et al. 1999), consistent with the overarching medical and public health lens framing this field. Although it is widely assumed that cART adversely affects sexual functioning, most studies showing a link have been conducted among men and focused on erectile dysfunction (Collazos 2007; Colson et al. 2002; Lamba et al. 2004; Wang et al. 2013) or non-specific sexual difficulties (Bouhnik et al. 2008; Schrooten et al. 2001; Trotta et al. 2008). Analyses involving women only, however, have consistently demonstrated no association between women’s sexual functioning and use of cART, type of regimen, or other HIV-related clinical markers such as viral load, CD4 cell count, disease stage, adherence, time on treatment, number of previous medication switches, HIV symptoms, or time living with HIV (Florence et al. 2004; Lambert et al. 2005; Luzi et al. 2009; Pinzone et al. 2015) (exception: Wilson et al. 2010, where women with CD4 > 200 cells/ $\mu$ L reported higher functioning). These same factors also play little to no role in explaining differences in women’s sexual satisfaction (Castro et al. 2010; Peltzer 2011) and sexual activity in recent years in settings with high cART uptake (Bova and Durante 2003; Kaida et al. 2015; Wessman et al. 2015) (exception: Hankins et al. 1997 and Zierler et al. 1999, both conducted around the advent of cART and linking higher CD4 counts to sexual activity).

The same conclusion is reported for other physiological factors (e.g., sex hormones, body mass index, diabetes, or medications for seizures, blood pressure, heart disease, or

estrogen replacement) (Goggin et al. 1998; Luzi et al. 2009; Wilson et al. 2010), whereas findings are mixed when it comes to physical health-related quality of life (Bogart et al. 2006; Courtenay-Quirk et al. 2009; Kaida et al. 2015; Negin et al. 2016). Perhaps the most consistent finding lies in the possible influence of menopause on women's sexuality (Luzi et al. 2009; Taylor et al. 2015; Valadares et al. 2014; Wilson et al. 2010). Specifically, researchers estimated that the odds of sexual activity decrease after menopause by 22–25% for 1927 women living with HIV and 18% for 742 women without HIV ( $p = .724$ ; i.e., no significant differences by HIV-status) (Taylor et al. 2015), whereas sexual functioning depends on the domain considered (Luzi et al. 2009; Valadares et al. 2014) but is reportedly lower overall according to measurements with the FSFI ( $\beta = 4.42$ ; referent group: postmenopausal women) (Wilson et al. 2010, total  $n = 1805$ ). It is worth noting that the effect size for menopause and other correlates (i.e., depression, relationship status, age) in this study (Wilson et al. 2010) was double, and in some cases triple, that for HIV-status ( $\beta = 2.53$ ), signifying that being a woman, first and foremost, may matter more to sexual experiences than one's identity as a woman with HIV.

### *Mental Health and Violence*

Although sexuality is most often viewed in physical terms, emotions play an important role. It is important to recognize that women with HIV disproportionately cope with the effects of violence (Brady et al. 2002; Gruskin et al. 2002; Logie et al. 2017a; Whetten et al. 2006), physical and psychological trauma (Machtinger et al. 2012), and depression (Morrison et al. 2002; Rabkin 2008) compared to women without HIV. In fact, it is through sexual violence that a significant proportion of women come to be living with HIV (Logie et al. 2017b), a social status that can, in turn, trigger further violence and poor mental health (Gielen et al. 2000a; Gielen et al. 2000b; Gielen et al. 1997; McDonnell et al. 2003). Prior research has shown that these physical, emotional, and mental states can activate stress responses and affect women's interest in and enjoyment of sex (Hamilton and Meston 2013; Lykins et al. 2006; ter Kuile et al. 2007).

In spite of these realities, less than half of reviewed studies (i.e.,  $n = 15$  of 32, or 47%) considered how acute and chronic stressors may impact HIV-positive women's sexuality, with most focusing on emotional health (Bova and Durante 2003; Courtenay-Quirk et al. 2009; Craft and Serovich 2007; Florence et al. 2004; Goggin et al. 1998; Inoue et al. 2004; Kaida et al. 2015; Lambert et al. 2005; Negin et al. 2016; Oyedokun et al. 2014; Peltzer 2011; Pinzone et al. 2015; Robinson et al. 2017; Wilson et al. 2010) and just four studying violence (Bova and Durante 2003; Courtenay-Quirk et al. 2009; Lambert et al. 2005; Valadares et al. 2014). In particular, depression and anxiety were linked to lower sexual desire (Goggin et al. 1998), activity (Craft and Serovich 2007; Kaida et al. 2015), and

function (Bova and Durante 2003; Florence et al. 2004; Lambert et al. 2005; Wilson et al. 2010). Mixed (gender-aggregated) findings were reported in relation to sexual satisfaction (Inoue et al. 2004; Peltzer 2011). A history of sexual violence was correlated with abstinence after HIV diagnosis among some women (Lambert et al. 2005), whereas sexual abuse during childhood was associated with more reports of pain during intercourse among others (Bova and Durante 2003). Bivariable associations between dyspareunia and physical and emotional violence have also been reported among menopausal women (Valadares et al. 2014), although vulvovaginal atrophy took precedence when choosing variables to include for multiple regression. Clearly, when studies on sexuality are orientated toward medicalized lines of inquiry, the physical and emotional traumas that frequently underlie woman's anxieties and challenges around sex in the context of HIV go unseen and unsupported.

### *Relationship Characteristics*

Not all sex involves another person. However, when it comes to partnered sexual experiences, relational dynamics are central. These were investigated in 56% ( $n = 18$ ) of reviewed studies (Agaba et al. 2017; Bernier et al. 2016; Bogart et al. 2006; Bouhnik et al. 2008; Bova and Durante 2003; Castro et al. 2010; Courtenay-Quirk et al. 2009; Inoue et al. 2004; Kaida et al. 2015; Lambert et al. 2005; Negin et al. 2016; Oyedokun et al. 2014; Peltzer 2011; Robinson et al. 2017; 25, Valadares et al. 2014; Wessman et al. 2015; Wilson et al. 2010). Despite the variety and complexity of intimate relationships (Bowleg et al. 2004; Devries and Free 2011; Longfield 2004; Manlove et al. 2014; Nelson et al. 2011; Sassler 2010; Vasilenko et al. 2015; Wentland and Reissing 2014), quantitative HIV research is dominated by studies assessing women's marital status (Agaba et al. 2017; Bogart et al. 2006; Bouhnik et al. 2008; Bova and Durante 2003; Castro et al. 2010; Courtenay-Quirk et al. 2009; Denis and Sung-Mook 2003; Goggin et al. 1998; Kaida et al. 2015; Kilmarx et al. 1998; Negin et al. 2016; Pinzone et al. 2015; Robinson et al. 2017; Rosenberg et al. 2017; Wessman et al. 2015; Wilson et al. 2010). Described as a "self-evident" association (Bogart et al. 2006, p. 1083), studies have consistently demonstrated a strong correlation between being married/partnered and sexual activity (Bernier et al. 2016; Bogart et al. 2006; Courtenay-Quirk et al. 2009; Kaida et al. 2015; Lambert et al. 2005; Negin et al. 2016; Robinson et al. 2017; Wessman et al. 2015). However, conflicting findings regarding associations with sexual function (Agaba et al. 2017; Wilson et al. 2010) and satisfaction (Castro et al. 2010; Inoue et al. 2004; Peltzer 2011; gender-aggregated) may indicate that the quality, not just existence, of an intimate relationship is important when it comes to women's sexual responses and satisfaction with their sexual life.

Most other studies have focused on partnership dynamics presumed to involve sexual risk (Hankins et al. 1997; Kaida

et al. 2015; Kilmarx et al. 1998; Lambert et al. 2005; Peltzer 2011; Wessman et al. 2015), although they reveal interesting associations with sexual pleasure. According to one study (Hankins et al. 1997), sex is more frequent, orgasms are easier to achieve, and satisfaction is higher among women with a new regular partner since HIV diagnosis compared to those with the same regular partner or casual partners. In two other studies, sexual activity has been associated with knowing a partner's HIV-status (non-significantly) (Wessman et al. 2015), and sexual satisfaction with having an HIV-negative partner (Peltzer 2011). For many, an HIV diagnosis changes relationships, and, in turn, affects sexuality and intimacy (Beckerman and Auerbach 2002; Gurevich et al. 2007; Keegan et al. 2005; Maticka-Tyndale et al. 2002; Persson 2005, 2008; Rispel et al. 2011), although the precise impact depends on various factors including the kind of relationship women had before HIV diagnosis, whether or not they acquired HIV from that partner, and how couples cope with difficult emotions (e.g., anger, distrust, worry, fear) (Nevedal and Sankar 2015; Persson 2005; Siegel and Schrimshaw 2003). People may either deepen feelings or close them off.

### *Social and Political Context*

Sex and relationships unfold within a broader socio-political environment. However, just 11 (34%) studies (Bernier et al. 2016; Bogart et al. 2006; Bouhnik et al. 2008; Bova and Durante 2003; Castro et al. 2010; Courtenay-Quirk et al. 2009; Goggin et al. 1998; Inoue et al. 2004; Kaida et al. 2015; Peltzer 2011; Schrooten et al. 2001), 8 of which were mixed-gendered (Bernier et al. 2016; Bogart et al. 2006; Bouhnik et al. 2008; Castro et al. 2010; Courtenay-Quirk et al. 2009; Inoue et al. 2004; Peltzer 2011; Schrooten et al. 2001), considered how multiple social processes related to HIV might impact women's sexuality (Caballero 2016; Gagnon and Holmes 2011, 2012; Lawless et al. 1996a; Psaros et al. 2012; Siegel et al. 2006; Thomassilli 2010; Welbourn 2013). Sexual inactivity was significantly related to experiences of enacted, anticipated, and internalized stigma (Kaida et al. 2015), as well as feelings of loneliness and needing help with disclosure (Bernier et al. 2016). Conversely, factors associated with having sex included receiving support from a community-based organization (Bernier et al. 2016), obtaining information on the role of an undetectable viral load on decreasing HIV transmission risk from a healthcare provider (Kaida et al. 2015), and having regular discussions about HIV with a partner (Bernier et al. 2016). Regarding sexual function, research has tended to focus on internalized stigmas. In particular, one study found that sexual interest may be reduced for women who associate sex with how they acquired HIV (Goggin et al. 1998), whereas others have suggested anxiety about one's body due to abdominal fat accumulation is a major determinant of lower overall and domain-specific

sexual functioning (Bouhnik et al. 2008; Luzi et al. 2009; Trotta et al. 2008). Lastly, in the literature on sexual dissatisfaction, independent associations have been reported with HIV stigma at interpersonal levels (e.g., discrimination in a relationship) (Castro et al. 2010) and individual levels [e.g., internalized stigma (Peltzer 2011), negative attitudes toward sex because of HIV (Inoue et al. 2004), stronger feelings of responsibility to protect partners' health (Bogart et al. 2006)], although these issues arguably arise from injustices at the structural level (Parker and Aggleton 2003).

These HIV-related social processes also intersect with other matters of everyday life to affect women's behaviours, responses, and feelings around sex. Twenty-four studies in total (75%) examined such factors (e.g., age, ethnicity) (Agaba et al. 2017; Bernier et al. 2016; Bogart et al. 2006; Bouhnik et al. 2008; Bova and Durante 2003; Castro et al. 2010; Courtenay-Quirk et al. 2009; Florence et al. 2004; Goggin et al. 1998; Hankins et al. 1997; Kaida et al. 2015; Luzi et al. 2009; Negin et al. 2016; Oyedokun et al. 2014; Peltzer 2011; Pinzone et al. 2015; Robinson et al. 2017; Rosenberg et al. 2017; Schrooten et al. 2001; Taylor et al. 2015; Trotta et al. 2008; Wessman et al. 2015; Wilson et al. 2010; Zierler et al. 1999), although most conceptualized them as characteristics of persons rather than as identities shaped by the larger social and political world. Most studies examined the influence of age and report reduced sexual activity among older women (Bernier et al. 2016; Bogart et al. 2006; Bova and Durante 2003; Kaida et al. 2015; Robinson et al. 2017; Taylor et al. 2015; Wessman et al. 2015; Zierler et al. 1999), with one study estimating that the odds of sexual activity declines by 62–64% for every 10-year increase in age (Taylor et al. 2015). This drop across ages was higher among women than men in one study (Rosenberg et al. 2017). Varied results, however, were found for function (Florence et al. 2004; Pinzone et al. 2015; Wilson et al. 2010) and satisfaction (Castro et al. 2010; Peltzer 2011), and the relative contribution of social and physical aging-related challenges on sexuality remains unstudied (Narasimhan et al. 2016). Research has also explored the role of substance use (Agaba et al. 2017; Bova and Durante 2003; Florence et al. 2004; Hankins et al. 1997; Zierler et al. 1999). For instance, a Canadian study of 161 women reported that women who were injecting drugs desired sex less often than those who were not (41% vs. 65%) yet were more likely to be sexually active (96% vs. 45%), have sex daily (54% vs. 0–10%), never/rarely have orgasms (78% vs. 41–65%), and be dissatisfied with their sex life (71% vs. 41–58%) (Hankins et al. 1997). Whether this is linked with substance use or factors related to sexual autonomy and power differentials (such poverty, abuse, or sex work) is unknown. Sexual activity, orgasm, and satisfaction were also unequally experienced between White and Black women in this study (Hankins et al. 1997) (also see Robinson et al. 2017), with group differences on a

number of sexuality outcomes also seen by socioeconomic position [e.g., income (Kaida et al. 2015), education (Peltzer 2011), employment status (Castro et al. 2010; Robinson et al. 2017)]. Combined, these findings demonstrate that the context within which sex occurs—both external circumstances (e.g., discrimination from partners, cultural norms regarding ideal sexuality) and women’s internal states (e.g., shame associated with HIV)—is a centrally important, albeit neglected, determinant of sexual experiences among women living with HIV.

## The Way Forward

In summary, findings of quantitative research suggest women experience declines in sexual activity, function, and satisfaction following an HIV diagnosis. What is striking, however, is that studies perpetuate gendered assumptions about women’s sex and sexuality—inclusive of with whom they have sex and what sex looks like. Moreover, despite the huge variation in experiences and the clear influence of context, researchers tended to over-pathologize outcomes, framing sexual issues as “diseases” or “disorders” as if they lie within the person rather than being historically rooted and socially situated. Consequently, recommendations for action are often narrow in scope, with an emphasis on the “management/treatment” (Schrooten et al. 2001, p. 1022) of women’s sexual activity and function in clinical practice or social programs (including especially counselling on condom use and treatment adherence to prevent transmission) (Agaba et al. 2017; Bernier et al. 2016; Bouhnik et al. 2008; Bova and Durante 2003; Courtenay-Quirk et al. 2009; Craft and Serovich 2007; De Vries et al. 2013; Denis and Sung-Mook 2003; El Fane et al. 2011; Florence et al. 2004; Hankins et al. 1997; Inoue et al. 2004; Lambert et al. 2005; Luzi et al. 2009; Negin et al. 2016; Oyedokun et al. 2014; Peltzer 2011; 23, Robinson et al. 2017; Schrooten et al. 2001; Taylor et al. 2015; Trotta et al. 2008; Valadares et al. 2014; 30, Wilson et al. 2010), as opposed to altering the disempowering environments of stigma and stress within which women with HIV are often forced to navigate their sexuality (Castro et al. 2010; Kaida et al. 2015). Such conclusions demonstrate the pervasive influence of the medical disease model, consistent with research findings on women’s sexuality more broadly (Angel 2010, 2012, 2013; Bancroft 2002; Cacchioni 2007; Moynihan 2003; Riessman 1983; Spurgas 2013, 2016; Tiefer 1991, 1996, 2003, 2004; Tosh and Carson 2016; Wood et al. 2006).

In the context of HIV, however, this problematization extends beyond clinical practice to the realm of public health. Although (some of) the reviewed studies are helpful toward legitimizing women’s broader needs around sexuality, it is apparent that much of the literature is pre-occupied with protecting others from HIV acquisition. For instance, in

Bova et al.’s study (2003), the last word on the subject was the following:

the future task for [HIV] prevention and research will be...to pay heed to the sexual lives, well-being, and problems of HIV-positive people *in order better to understand the situations in which unprotected relations occur. On that basis* they can be supported to live as well as have *safe* sexual lives” (p. 82, emphasis added).

In other words, the sexual lives of women living with HIV matter in so far as they are relevant to public health. However, with the exception of one study (Robinson et al. 2017), little effort has even gone into truly assessing HIV risk (e.g., whether women were having penetrative versus non-penetrative sex, intimate with male or female and HIV-positive or HIV-negative partners, virally suppressed, using condoms, and making informed choices with their partners around negotiated safety). It would seem from our review that despite the fact that knowledge around transmission and risk has been accumulating for many years (Cohen et al. 2011; Montaner 2011; Montaner et al. 2014; Prevention Access Campaign 2017; Rodger et al. 2016; Vernazza and Bernard 2016; Vernazza et al. 2008), research more generally has been slow to shift, despite community demands for the truth (Mejia 2017).

Importantly, couching research under “women’s sexual health” when, in fact, it has little to do (read: nothing) with women’s health at all, is not just erroneous, it is unjust. Further, in reducing women’s sexuality to a “public health problem” that must be solved, opportunities to develop rich, contextualized, and compassionate understandings of sex and intimacy in the context of HIV are severely limited. Instead, women become positioned into one of three discrete groups: (a) they are abstinent and presumed unhappy (but also doing their “public health duty”), (b) they are sexually active and potentially have considerable negative effects on the dynamics of the epidemic, or (c) they are sexually “dysfunctional” (read: damaged or abnormal). This leaves very little space for women to have and enjoy a satisfying and pleasurable sexual life of their choosing. It also stifles much needed dialogue on how to empathetically address, structurally and individually, the concerns and suffering of women who do experience sexual problems.

From a feminist lens, four points merit comment to move this field of research forward. First, researchers must recognize that sexuality in the context of HIV is not just a matter of prevention. Women living with HIV are sexual beings with their own needs, desires, and concerns. Achieving sexual health and rights demands considerably increased attention to their own well-being. This necessarily involves studying the positive outcomes (Impett et al. 2013; Jolly et al. 2013) they want to achieve and the enabling factors necessary to do so (Salmander Trust 2014), not simply the negative aspects to avoid. Sexuality must also be



understood beyond physical acts and physiological stages. Sexuality encompasses a vast range of experiences (e.g., pleasure, intimacy, love (including self-love), respectful relationships, agency, bodies and identities) and studying diverse forms of sexual expression will greatly support women's access to full emotional, spiritual, intellectual, relational, social, and physical well-being in relation to sexuality (World Association for Sexual Health 2014; World Health Organization 2006).

Second, whereas sexuality is a personal right, its manifestations are not simply a personal matter. Sexuality is deeply connected to politics. Feminist theory encourages us to see sex and sexuality as social and cultural processes (Tiefer 2004). This is especially important in the context of HIV, where historical and current-day structural inequities (e.g., stigma, violence, the law) shape the way women view and experience themselves as sexual beings. Further, sexual healing and living with HIV is far from uniform; it varies markedly by intersecting social positions such as age, gender, race, and sexual orientation likely owing to broader systems of ageism, sexism/genderism, racism, heterosexism, and homophobia (Berger 2010; Logie et al. 2011). Women are so much more than the virus. Rather than viewing them as one group and intensely investigating their disease (e.g., viral loads and CD4 cell counts), it is essential that researchers recognize that significant diversity exists among women and focus more heavily on the broader social and relational conditions shaping their sexual lives. Greater attention, in particular, to the experiences of gender diverse and lesbian, bisexual, trans, and queer women is needed.

Third, in order to deepen these understandings, we advocate, as other critical quantitative researchers have (Harnois 2013; Sprague 2016), for the adoption of diverse theories, methods, and approaches. Research to date has been largely atheoretical. Conceptual analysis (e.g., defining key terms, tracing historical meanings, developing new ideas) is critical in future studies to bring greater depth to our thinking (Fahs and McClelland 2016). Research has also almost always relied on traditional cross-sectional statistical approaches such as logistic or linear regression. New data designs for understanding multi-dimensionality (Lanza et al. 2013), directionality (Vasilenko et al. 2011), and dyadic interactions (Kashy et al. 2000) will also bring new insights. Intervention research is a particularly barren field, both in terms of improving women's quality of sexual life (Fernet et al. 2017) and relating to larger programmatic and systemic transformation (Salmander Trust 2014; World Health Organization 2017). Regardless of the approach, we encourage researchers to push the boundaries of their discipline(s) by becoming more connected to other fields and more reflexive about their own positioning in the research, and how their training and worldview affects what and how they choose to study (Ryan and Golden 2006;

Shaw 2010). The meaningful involvement of women living with HIV in the research process has been ignored (exception: Kaida et al. 2015) and its rectification in future work is critical (Carter et al. 2014; Orza 2012).

Finally, we strongly emphasize the need to de-medicalize sexuality and de-pathologize sexual diversity among women living with HIV (Angel 2010, 2012, 2013; Bancroft 2002; Cacchioni 2007; Moynihan 2003; Riessman 1983; Spurgas 2013, 2016; Tiefer 1991, 1996, 2003, 2004; Tosh and Carson 2016; Wood et al. 2006). Studies that frame sexual inactivity as inherently worse than sexual activity (or vice versa) are fundamentally biased and overlook the importance of women's agency over their own sexuality. If a woman is choosing to be sexually inactive, especially in a context filled with HIV stigma and discrimination, then that may be a better sexual health outcome than a woman who is sexually active but not by active choice. On the other hand, someone else may desire and enjoy intercourse but feel great disappointment in its absence. And someone might be sexually active and sexually satisfied, but report difficulties with orgasm. Women's sexual experiences are varied, and future research must attend to whether women *themselves* perceive their experiences to be problems. Measuring and theorizing around sexual autonomy and satisfaction is crucial in this regard (McClelland 2010). If a woman is satisfied with her sexual life and it was freely chosen, or even if she reports dissatisfaction and distress, she should not (nor should she ever) be labeled as having a "disease" or "dysfunction," however dissimilar her feelings or behaviours may be from a statistical mean.

In putting together and unpacking these findings using a critical feminist lens, it is clear that evaluations of reduced sexual activity, function, or satisfaction observed among women living with HIV are far less pathological than they are social. To quote an expert:

When a woman has to worry each time about disclosure, discrimination, rejection and the criminalization that comes with HIV, it's but normal that sex is not of interest to her. Stress, depression, and other health issues associated with HIV definitely make me lose my sex drive. (POZ Magazine 2010)

This comment was made by a woman with HIV in response to a research-based blog post (on Wilson et al. 2010) in POZ Magazine (2010). Given the presence of HIV stigma and numerous other medical, psychological, relational, and structural forces at play in women's lives, we argue, as others have (Bancroft et al. 2003; Tiefer 2001), that it is wrong for sexual problems to be chalked up to a dysfunctional sexual response system. This system is, in fact, functioning as expected in an unjust environment. The problem is not women or their sexuality. Rather, challenges around sex for women living with HIV lie in context. And therein lies the solution.

## Implications for Policymakers, Practitioners, and Women Living with HIV

To enhance women's sexual lives and redress social injustice, we advocate, first and foremost, for continued collective action at the political level. Communities affected by HIV are already leading this charge in a number of creative ways including, for example, the PosterVirus project that is reclaiming sexual autonomy by challenging dominant ideologies and legislations that aim to control HIV-positive people's bodies and behaviours (McClelland and Whitbread 2016). Additional mass public education campaigns that tackle stigma while normalizing sex and desire for women with HIV are also needed, like "Fuck Positive Women" (Mitchell et al. 2011), "Love Positive Women" (Whitbread 2017), "#Révélation" (AIDES 2016), and "Undetectable = Untransmittable" (Prevention Access Campaign 2017). Messages that target straight HIV-negative men are critical in this regard, because HIV is still hidden in the heterosexual community (Persson 2005), and weaving it into cultural discourse (as it has been for gay men) will help make safe disclosure, relationships, and intimacy more possible for those who desire it.

De-stigmatizing and normalizing sexualities and relationships with HIV necessitates decriminalizing HIV non-disclosure (International Community of Women Living with HIV/AIDS 2016). Such laws ignore the advancements in cART (Montaner et al. 2014; Patterson et al. 2015; Rodger et al. 2016; Samji et al. 2013) and unduly place the burden of prevention on people who have HIV (Canadian AIDS Society 2011; Global Network of People Living with HIV (GNP+) 2011; International Community of Women Living with HIV/AIDS 2016). They also perpetuate decades-old misconceptions about clinical and survival outcomes of HIV, which continue to govern women's intimate lives (Gurevich et al. 2007; Lawless et al. 1996b; Mazanderani 2012; Persson and Newman 2008).

When it comes to sexual health programming for women with HIV, we must expand discussions of "safer sex" and include broader, more sex-positive considerations. From how women feel about their bodies and identities; to their interests, wants, desires, and boundaries around sex (including no sex); and to the full range of types of sexual contact, practices, attractions, responses, and more. Sex positivity is inclusive of all women and all sexuality types in all their diversity. Empowering women living with HIV to make the sexual choices they want also requires providing them (and their partners, if applicable) with accessible and affirming information and support that is culturally-sensitive, trauma-informed, context-aware, and inclusive of an array of important topics about sexual well-being including autonomy, consent, women's anatomy and pleasure, mutuality in sex, and non-penetrative sexuality.

Creating physical and virtual opportunities for women living with HIV to talk to other women living with HIV about various aspects of sexuality and relationships with HIV should be made

a priority through peer-led advocacy, counselling, support groups, sexuality workshops, and online communities and forums. HIV-positive women have been at the forefront of such efforts for many years (Abrams 2017; AIDES 2016; Becker 2014; Caballero 2016; Cardinal et al. 2014; Fratti 2017; Iacono 2016; International Community of Women Living with HIV/AIDS 2016; McClelland and Whitbread 2016; Mitchell et al. 2011; Nade'ge 2016; Nicholson et al. 2016; Petretti 2017; Prevention Access Campaign 2017; Salamander Trust 2014; Sanchez et al. 2017; The Well Project 2017; Welbourn 2013; Whitbread 2017; Whitbread 2016). *Life and Love with HIV* ([www.lifeandlovewithHIV.ca](http://www.lifeandlovewithHIV.ca)) is a grassroots community-based initiative led by our team to bring these strong voices together and move research evidence and community insights about sexuality and relationships directly into the hands of women living with HIV and those who love and support them.

Healthcare providers such as family doctors, nurses, and counsellors also have a role to play in initiating conversations around sexuality during post-test counselling and annual check-ups, as well as offering shame-free support for challenges that may be distressing to women. Many tools such as the PLISSIT model (Taylor and Davis 2006) are available to guide clinical interactions of this nature. Referrals to sexuality and trauma therapists, where necessary, are crucial, as is funding to support this service. Mindfulness-based therapy is one option with empirical support for women wanting to address self-perceived sexual problems (Brotto 2013; Brotto and Basson 2014; Rosenbaum 2013). However, as Cacchioni and Wolkowitz (2011) and others (Tosh and Carson 2016) have cautioned, sexual therapies can, albeit unwittingly, reproduce normative heterosexuality. Thus, it remains important to embrace sexual diversity and acknowledge the centrality of context (rather than individual deficiencies on women's part) in influencing sexual experiences as part of providing women with multiple options for healing from sexual pain and reclaiming sexual joy.

For women wanting to enrich their sexual well-being, changing context where possible to reduce inhibitions (e.g., managing depression; recognizing and resisting stigma narratives) and activate excitations (e.g., creating sexually arousing contexts; cultivating resilience and self-love) is key [for other insights, see (Kleinplatz et al. 2009)]. Maximizing autonomy, satisfaction, and pleasure for women (not just their partners) should be the goal. Finally, the non-universal, highly contextual nature of sexuality uncovered in our review reinforces our universal message to women living with HIV: *You are normal*.

## Conclusion

Although science has achieved much in terms of advances in HIV treatment, it has yet to undo the three and a half decades worth of stigma against women living with HIV. The present review shows that an HIV diagnosis can have significant

impacts on women's sexuality, manifesting in different ways for different women depending on the contexts within which they live. A satisfying sexual life—inclusive of pleasure and free from discrimination and violence—is a human right. If we are to truly support women with HIV in achieving sexual health and rights, we have an obligation not only to destigmatize and de-criminalize HIV as well as women's bodies and sexuality, but also to affirm women's sexual desires, normalize their experiences of sex and intimacy, and support them in leading a (self-defined) satisfying, pleasurable, and fulfilling sexual life.

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