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The current state of qualitative research on sexual functioning with HIV in developed nations: a thematic synthesis

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ABSTRACT

The life expectancy of HIV-positive and HIV-negative people is approaching parity. Therefore, quality of life concerns, such as sexual functioning, are increasingly important in HIV care and support. This thematic synthesis is the first of its kind to describe the current state of qualitative research on sexual functioning with HIV conducted in developed countries. A systematic search of key databases identified 15 peer-reviewed qualitative studies that met inclusion criteria. The synthesis revealed that qualitative research on the impact of HIV on sexual functioning, including the impact on desire, arousal, orgasm, and satisfaction, is limited. Findings revolved around the following themes: (i) disclosure of HIV status, (ii) changes in the experience of sex, (iii) celibacy: short-term or sustained, and (iv) condom use of HIV-positive people. Future research into sexual functioning with HIV is required, taking account of contemporary understandings of the risk of transmission in the context of undetectable viral load.

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HIV; sexual behaviour; sexual functioning; qualitative research; evidence synthesis

Of the 36.7 million people living with HIV (PLWH) worldwide, the majority acquired the virus via sexual transmission (UNAIDS, 2017). To date, research into sexual behaviour relevant to HIV has focused upon primary prevention strategies to reduce sexual risk behaviour of people without HIV who are at higher risk of acquiring the virus (Herbst et al., 2005; Lyles et al., 2007). A more recent focus of such interventions has been secondary prevention strategies, which target the sexual behaviour of those living with HIV (Crepaz & Marks, 2002; Johnson, Carey, Chaudoir, & Reid, 2006). These strategies are integral to reducing the impact of HIV on society. However, such focus on the risk that people with HIV pose to others has been at the

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expense of research on the overall well-being and sexual functioning of PLWH. This is becoming increasingly important given that the life expectancy of HIV-positive people is approaching parity with HIV-negative people (Nakagawa, May, & Phillips, 2013). Whereas the focus of treatment and support for PLWH was formerly on length of life, quality of life concerns, including support and therapy to promote healthy sexual functioning in the context of HIV, have become increasingly more salient.

To date, research relevant to sexual functioning of PLWH has mostly documented the prevalence, and different forms, of sexual dysfunction. Approximately half of PLWH report sexual difficulties (Collazos, 2007), most commonly arousal disorders, difficulty gaining or maintaining an erection, anorgasmia, and premature or delayed ejaculation (Collazos, Martínez, Mayo, & Ibarra, 2002; Lallemand, Salhi, Linard, Giami, & Rozenbaum, 2002). Numerous factors show associations with sexual dysfunction in PLWH, including: (i) demographic factors, such as being older in age (Moreno-Pérez et al., 2010), menopause (Wilson et al., 2010), being heterosexual (Asboe et al., 2007), and not being in a partnered relationship at diagnosis (Wilson et al., 2010)); (ii) health behaviours, including greater alcohol consumption (Asboe et al., 2007) and condom use (Santi, Brigante, Zona, Guaraldi, & Rochira, 2014); (iii) physical health and treatment-related factors, such as abnormal distribution or degeneration of fat on the body (lipodystrophy) (Moreno-Pérez et al., 2010), HIV-related comorbidities (Santi et al., 2014), protease inhibitor treatment (Moreno-Pérez et al., 2010), duration of HIV treatment (Asboe et al., 2007); and (iv) mental health-related factors including depression (Moreno-Pérez et al., 2010), fear of passing the virus to someone else (Santi et al., 2014), body image concerns (Santi et al., 2014), psychotropic medication (Asboe et al., 2007), and experience of stigma (Santi et al., 2014). However, with the exception of depression, these factors have not been replicated across studies. The result is a disconnected set of diverse factors thought to be contributing to sexual dysfunction reported by PLWH (Asboe et al., 2007; Moreno-Pérez et al., 2010; Wilson et al., 2010). There is a pressing need for an integrated and connected understanding of the factors influencing sexual functioning in order to promote healthy sexual functioning of PLWH.

Focusing on high-income countries, the aims of this thematic synthesis were to document and clarify: (i) the current state of qualitative research on patient perspectives of sexual functioning with HIV and (ii) *how* factors identified in past quantitative research in the field may contribute to sexual dysfunction, including the processes that connect and underlie these factors. Qualitative methods offer this information by exploring the underlying mechanisms which explain how HIV can impact sexual functioning. To our knowledge, this is the first thematic synthesis of qualitative studies documenting patient perspectives of sexual functioning with HIV.

Method

Search strategy

A search of key databases (PsycINFO, Medline, Embase, Scopus, and CINAHL) was conducted to identify peer-reviewed studies published in the English language. The following search terms were used: (i) HIV, (ii) qualitative research, and (iii) sexual

Table 1. Selection criteria.

Types of studies	Peer-reviewed qualitative studies with a focus on sexual behaviour of people living with HIV conducted in developed nations **Excluded**: Studies which reported answers to survey questions in percentages without qualitatively analysing data, conference abstracts, programme evaluations, non-peer-reviewed studies (including book chapters), and studies conducted in developing countries.
Type of participants	Adults (18 years or older) living with HIV who acquired the virus behaviourally **Excluded**: studies in which participants acquired HIV vertically (from mother perinatally), studies in which being HIV + was not the focus of the study (i.e. incidental recruitment of people with HIV), co-infection with Hepatitis C or other viruses
Topics explored	Interest and enjoyment in sex, sexual intimacy, condom use, sexual desire, feelings of sexual attractiveness, and sexual attraction. Studies on risk negotiation, relationships, and disclosure of HIV status were also included if the key focus of these topics was sexual behaviour **Excluded**: studies in which the main aim of the study was not to explore the impact of HIV on sexual behaviour, but aimed to explore alcohol and other drugs, sex work, incarceration, fertility and contraception issues, childhood sexual abuse, intimate partner violence or abuse in the context of HIV

behaviour or sexual function, as well as synonyms of these terms. In addition, search results were limited to those studies which were not focused on screening or prevention of HIV. A comprehensive list of search terms used for each database can be obtained from the corresponding author. The reference lists of identified studies included in the review were further searched for additional relevant studies.

Screening

Study titles were first screened, and those which did not fit selection criteria were excluded. Next, abstracts of studies whose titles appeared to meet criteria were read and further exclusions occurred. Full texts were then reviewed and the inclusion exclusion criteria further applied. For the inclusion and exclusion criteria, see Table 1.

Data extraction and analysis

Data extraction and analysis followed Thomas and Harden (2008) guidelines on conducting thematic synthesis using three stages: "line-by-line coding, development of descriptive themes, and deriving analytic themes." A summary table collated information on the aim, methods, design, sample size and source, response rate, and findings for each study (see Table 2). Author BH coded text manually line-by-line, and then organised the coded text under descriptive themes in consultation with authors IJ and JdW. Further discussion between BH, IJ, and JdW of the communality and nuance between the descriptive themes resulted in four over-arching analytic themes, which were (i) disclosure of HIV status, (ii) changes in the experience of sex, (iii) celibacy: short-term or sustained, and (iv) condom use of HIV-positive people. The descriptive themes were synthesised together to form the content of the analytic themes. For a list of descriptive themes organised under the analytic themes to which they contributed, see Figure 3.

Quality assessment

The quality of the included studies was assessed using the standardised Qualsyst assessment tool criteria for assessing qualitative research (Kmet, Lee, & Cook, 2004).

Table 2. Summary table of 15 qualitative studies reviewed.

Authors Year Country	Quality rating	Design method	Sample Source Response Rate	Findings
Adam & Sears 1994 Ontario, Canada	50%	Design: Individual interview Method: [Qualitative method unclear]	Sample: $n = 60$ Source: support groups, informal word of mouth	Results analysed separately for those not in couple relationship at time of diagnosis, and those who were. Finding 1: testing positive for those in not in couple relationships Sub-finding 1: early quandaries after testing HIV-positive Sub-finding 2: looking for new relationships Sub-finding 3: disclosing seropositivity Finding 2: testing positive in the context of an existing relationship
Cusick & Rhodes 1999 London, UK	70%	Design: individual interview Method: inductive method	Sample: $n = 73$ Source: community advertising, health professionals, direct approach at treatment centre and snowballing	Finding 4: clue interpretation and assumptions Finding 5: expected reactions and sexual safety Finding 7: reactions from targets in sexual relationships Finding 8: discloser experienced processes
Green 1994 Scotland	70%	Design: individual interview Method: [qualitative method unclear]	$N = 66$ Source: unclear	No headings or sub-headings used – findings have been created for ease of understanding. Finding 1: celibacy adopted Finding 2: celibate or impotent for limited period(s) Finding 3: sex life continued but less frequent and less fulfilling Finding 4: little disruption, no change in behaviour Finding 5: trust and commitment important Finding 6:patterns and implications
Harawa, Williams, Ramamurthi & Bingham 2006 California, USA	75%	Design: three 90 minute semi-structured focus group interviews Method: grounded theory	$N = 30$ Source: direct outreach (night-clubs, coffee houses, HIV clinics, on street), word of mouth, fliers posted in community-based organisations	Finding 1: condom use Finding 2: impact of HIV on sexual activity Finding 3: disclosure of HIV status to sexual partners
Keegan, Lambert & Petrak 2005 London, UK	75%	Design: semi-structured interviews Method: interpretative phenomenological analysis	$N = 21$ Source: two London HIV clinics	Finding 1: sex Sub-finding 1: interest in sex Sub-finding 2: sexual enjoyment Sub-finding 3: changing sexual behaviour Finding 2: safer sex Sub-finding 1: safer sex practice

(*continued*)

Table 2. Continued.

Authors Year Country	Quality rating	Design method	Sample Source Response Rate	Findings
				Sub-finding 2: commitment to safer sex and condom use Sub-finding 3: control Sub-finding 4: passive negotiation Finding 3: relationships Sub-finding 1: disclosure, rejection and acceptance Sub-finding 2: concordance Sub-finding 3: relationship strategies Sub-finding 4: what women want
Lawless, Crawford, Kippax & Spongberg 1996 New South Wales, Australia	75%	Design: unstructured interviews Method: grounded theory	$N = 24$ Source: fliers, support groups, AIDS councils, referral from health professional, word of mouth	Finding 1: messages for positive women: "Any sex you get … " Finding 2: impact on relationships: "I think he's very brave actually … " Finding 3: sexual negotiation: if it's not on … Finding 4: casual sex Finding 5: ongoing relationships with sero-discordant partners Finding 6: ongoing relationships with sero-concordant partners
Maticka-Tyndale, Adam & Cohen 2002 Ontario, Canada	80%	Design: individual semi-structured interviews Method: [qualitative method unclear]	$N = 35$ Source: invitations from nurses at HIV Care Program and mail out by AIDS services organisation	Finding 1: couple relationships Sub-finding 1: sexual intimacy Sub-finding 2: condom use: Sub-finding 3: sexual desire Finding 2: singles
Paparini, Doyal & Anderson 2008 London, UK	60%	Design: individual semi-structured interviews Method: thematic analysis using a modified grounded theory approach	$N = 8$ Source: voluntary HIV organisations, e-networks for black MSM and MSM/W, London HIV clinics	(Sexuality included as small topic, but not key focus) Finding: sexuality, sexual practices and HIV Finding: health services and social support
Rhodes & Cusick 2002 London, UK	75%	Design: individual semi-structured interviews Method: unclear, inductive approach	$N = 73$ Source: HIV newsletters, support agency notice boards, health professionals' contacts	Finding 1: stories of agency Sub-finding 1: risk calculus and condom accidents Sub-finding 2: alcohol and drug effects Sub-finding 3: powerlessness and coercion Sub-finding 4: forces of nature Finding 2: stories of acceptability Sub-finding 1: antibody concordance

				Sub-finding 2: commitment and emotion Sub-finding 3: alter responsibility Sub-finding 4: intentional HIV transmission
Rutledge 2007 Washington, U.S.A	80%	Design: individual interview Method: grounded theory	$N = 15$ Source: reapproached participants involved in a previous quantitative study Response rate: unclear	Finding 1: applying the personal disclosure policy to the sex environment Finding 2: timing, staging, and enacting disclosure Finding 3: evaluating reactions and consequences
Sandstrom 1996 Iowa, USA	80%	Design: individual semi-structured interviews Method: grounded theory	$N = 25$ Source: flier, or letter of introduction from physician, case manager, nurse or support group facilitator	Finding 1: diagnosis with HIV: disruptions evoked in sexual self-images Finding 2: challenges encountered in negotiating sexual relationships Sub-finding 1: challenges faced in negotiating new relationships Sub-finding 2: challenges faced in negotiating ongoing relationships Finding 3: advanced illness: declines in sexual attractiveness, desire, and ability Finding 4: reconstructing sex, intimacy, and intimate identities
Siegel, Schrimshaw & Lekas 2006 New York, USA	80%	Design: individual interview at two time points Method: thematic content analysis	$N = 146$ at time one, $N = 138$ at time two Source: fliers in community organisations, advertisement in local newspapers, word of mouth	Finding 1: diminished Pleasure Finding 2: diminished participation in sex Finding 3: diminished sense of sexual attractiveness
Siegel & Schrimshaw 2003 New York, USA	70%	Design: semi-structured individual interviews Method: [qualitative method unclear]	$N = 30$ Source: community-based organisations, support groups, advocacy organisations and drug treatment centres	Finding 1: reasons for celibacy among older women Finding 2: reasons for celibacy among older men
Stevens & Galvao 2007 Wisconsin, USA	95%	Design: 10 repeated interviews conducted with 55 participants over 2 years Method: narrative interviews	$N = 55$ women Source: personal contact and invitation from trusted community members and service providers	Finding 1: sexual activity and use of condoms in the total sample Finding 2: narrative exemplar of sexual risk Finding 3: interpersonal situations in which sexual risk occurred Finding 4: absence of health care providers Finding 5: other women with sero-discordant partners
van Kesteren, Hospers, Kok & van Empelen 2005	75%	Design: individual semi-structured interviews	$N = 30$ Source: HIV consultants at Maastrict University Hospital and	Finding 1: sexual activity Finding 2: impact of HIV-positive diagnosis Finding 3: risks to self: HIV superinfection and STDs

(*continued*)

Table 2. Continued.

Authors Year Country	Quality rating	Design method	Sample Source Response Rate	Findings
Amsterdam, Rotterdam & Maastricht, The Netherlands		Method: [qualitative method unclear]	Outreach workers of the Dutch Gay and Lesbian Association	Finding 4: personal norms: Feeling responsible Finding 5: responsibility and behaviour: the role of contextual influences Sub-finding 1: partner type Sub-finding 2: social norms Sub-finding 3: sex partner characteristics Finding 6: negotiating safety and sexual risk behaviour Finding 7: disclosure

The tool includes a checklist for assessing the quality of the following aspects of each reviewed study: research question, study design, study context, connection with past research or theory, sampling strategy, data collection methods, data analysis, use of verification procedures, reflexivity, and whether the conclusions drawn are supported by the results found (Kmet et al., 2004). This tool was selected due to its thorough and detailed manual which allowed two researchers to independently rate the identified studies in a standardised manner before comparing scores. Where disagreements occurred, the researchers discussed their reasoning for their scores until agreement was reached. Assigned study scores appear under quality rating in Table 2.

Results

Of the 3,321 studies identified through database searches, 3,151 studies were removed on the basis of their title. If study eligibility could not be determined based on the title alone, the abstract was read, which resulted in 170 studies retained. After removing 42 duplicate entries, the full text of 128 studies was assessed for eligibility. Based on these full-text reviews, 116 studies were removed, and 12 studies were retained. The review of reference lists of these studies identified three additional relevant studies, resulting in a final sample of 15 studies for the review. See Figure 1 for details of the study selection process.

Study characteristics

Of the 15 studies included, 13 were conducted in North America or the United Kingdom (Adam & Sears, 1994; Cusick, 1999; Green, 1994; Harawa, Williams, Ramamurthi, & Bingham, 2006; Keegan, Lambert, & Petrak, 2005; Maticka-Tyndale, Adam, & Cohen, 2002; Paparini, Doyal, & Anderson, 2008; Rhodes & Cusick, 2002; Rutledge, 2007; Sandstrom, 1996; Siegel & Schrimshaw, 2003; Siegel, Schrimshaw, & Lekas, 2006; Stevens & Galvao, 2007); the remaining two were conducted in Australia (Lawless, Crawford, Kippax, & Spongberg, 1996) and the Netherlands (Van Kesteren, Hospers, Kok, & van Empelen, 2005). Just over a third of the included studies sampled participants with HIV regardless of their gender or sexual identity (Adam & Sears, 1994; Cusick, 1999; Green, 1994; Maticka-Tyndale et al., 2002; Rhodes & Cusick, 2002; Siegel & Schrimshaw, 2003); one-third of studies involved HIV-positive women (Keegan et al., 2005; Lawless et al., 1996; Siegel et al., 2006; Stevens & Galvao, 2007), and four studies sampled HIV-positive men who have sex with men (Harawa et al., 2006; Rutledge, 2007; Sandstrom, 1996; Van Kesteren et al., 2005). In many of the included studies, it was unclear which qualitative research method had been used (Adam & Sears, 1994; Green, 1994; Maticka-Tyndale et al., 2002; Rhodes & Cusick, 2002; Siegel & Schrimshaw, 2003; Van Kesteren et al., 2005). In studies that identified their qualitative research method ($n = 8$), most used the grounded theory approach (Harawa et al., 2006; Lawless et al., 1996; Paparini et al., 2008; Rutledge, 2007; Sandstrom, 1996). Others used thematic content analysis (Siegel et al., 2006), interpretative phenomenological analysis (Keegan et al., 2005), and narrative analysis (Stevens & Galvao, 2007).

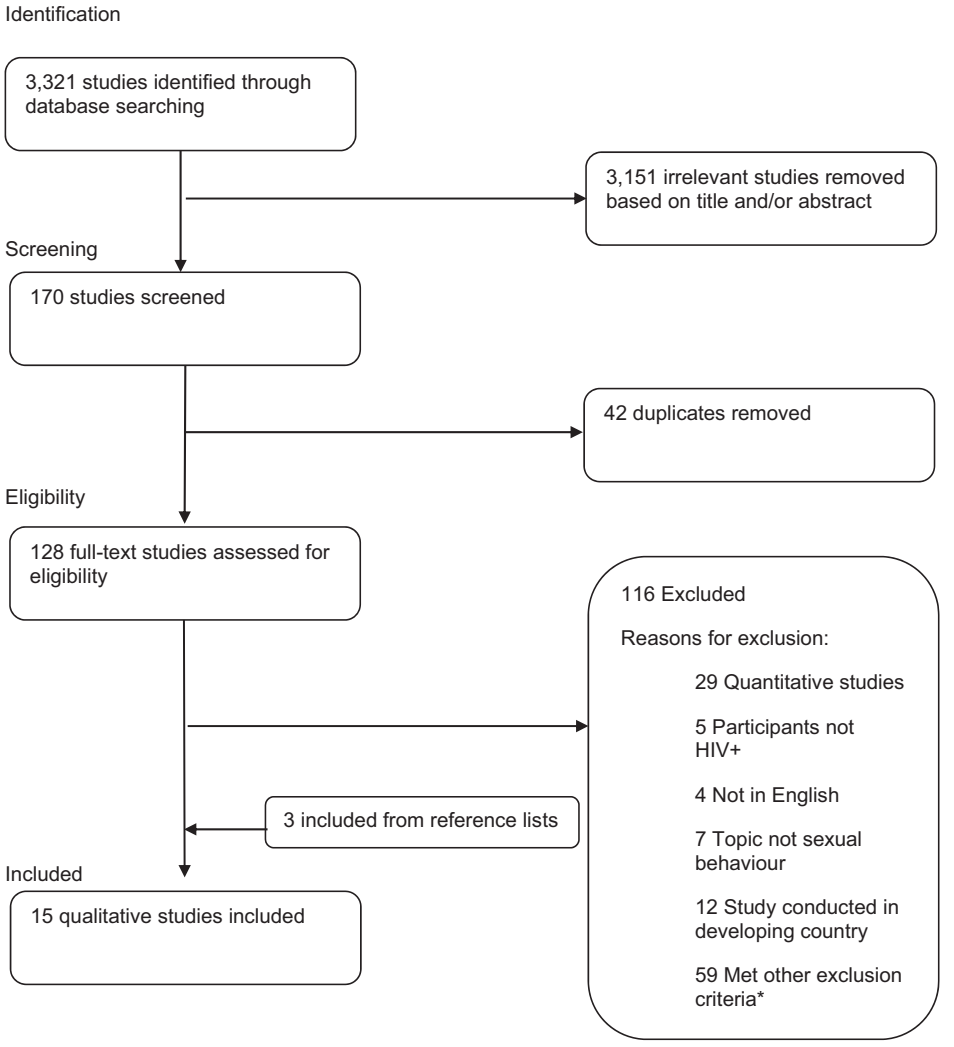

Figure 1. Flow diagram of the study selection process.

Eleven of the 15 included studies were rated 75% or greater on the Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields (Kmet et al., 2004). Five studies received lower ratings (i.e. 50% (Adam & Sears, 1994), 60% (Paparini et al., 2008), and 70% (Cusick, 1999; Green, 1994; Siegel & Schrimshaw, 2003)), mostly due to insufficient sample characteristics such as omitting ethnicity information and place of recruitment. Such studies also tended not to specify the type of qualitative data analysis.

Figure 2 graphs the years of publication of the included studies. From 1981 (i.e. the year the Centers for Disease Control in The United States of America identified HIV) to 1993, no published qualitative studies met the specified inclusion criteria, and four studies were conducted prior to the introduction of combination therapy for the treatment of HIV in 1997. No peer-reviewed qualitative research published since 2008 met the inclusion criteria.

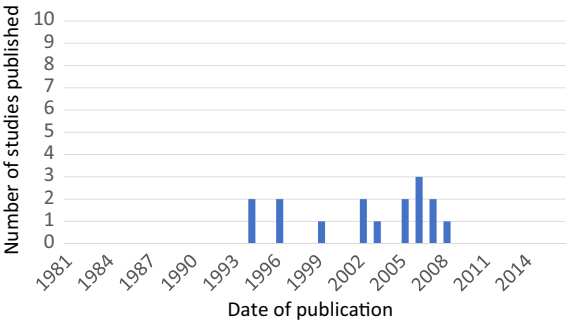

Figure 2. Dates of publication of included studies.

disclosure of HIV status	changes in the experience of sex	celibacy: short-term or sustained	condom use of HIV-positive people
• learning to disclose • chosing to disclose before all sex • taking precautions and waiting to disclose • Fear of rejection	• reacting emotionally to diagnosis • changes in sexual behaviour • fear and anxiety around sex • fear of transmission and sex • changes in relationships	• choosing celibacy • resuming sexual behaviour • fear of transmission and celibacy • ceasing sex for a short period • celibacy for self-protection	• directions from health professionals and condoms • risk related reasons behind condom use • relationship related reasons behind condom use • partner coercion and condom use • socical group related reasons behind condom use • serosorting

Figure 3. Descriptive themes and the analytic themes under which they were synthesised.

Thematic findings from qualitative studies

The included qualitative studies suggest that sexual functioning after HIV diagnosis follows a number of broad pathways. These include: ceasing sexual behaviour with others (Green, 1994), reducing sexual behaviour by withdrawing from others (Paparini et al., 2008), making no change in sexual behaviour and continuing sex life as previous (Green, 1994), or making changes to sexual behaviour in order to reduce risk of transmission to others (Green, 1994; Sandstrom, 1996).

More specific findings from the included studies have been synthesised under the following themes: (1) disclosure of HIV status, (2) changes in the experience of sex, (3) celibacy: short-term or sustained, and (4) condom use of HIV-positive people.

Theme 1: disclosure of HIV status

… it seemed really stupid to me to meet [a sexual partner] and then go into all that [disclosure] right away - to say, "Well, you should know that I have HIV" and all of that. (Sandstrom, 1996)

Across the studies, learning to disclose HIV-positive status was described as a "trial and error" process (Adam & Sears, 1994; Cusick, 1999), with disclosure generally restricted to a trusted few (Paparini et al., 2008) such as close friends, family, and

longer-term sexual partners (Sandstrom, 1996). Most studies described disclosure to sexual partners as a considered process involving clue giving, clue interpretation, imagined rehearsal of disclosure, and imagined prediction of others' reactions (Cusick, 1999; Rutledge, 2007). In this synthesis, we focused on disclosure of HIV-positive status to potential or actual sexual partners, as opposed to disclosure to family or friends.

From the studies that explored disclosure in sexual contexts, two disclosure strategies emerged: (i) disclosing HIV-positive status prior to all sexual intercourse or (ii) taking precautions against transmission and having sex without first disclosing. Not disclosing HIV-positive status prior to sex was a common finding, which was found in studies published between 1994 and 2006, and therefore not specific to any particular time point. This finding was also found in various samples including men who have sex with men (MSM; Sandstrom, 1996), heterosexual women (Lawless et al., 1996), as well as studies that used mixed samples of genders and sexual identities (Cusick, 1999; Maticka-Tyndale et al., 2002). Studies of MSM (Sandstrom, 1996; Van Kesteren et al., 2005), a study of bisexually active men (Harawa et al., 2006) and studies with samples of individuals of mixed gender and sexual orientation (Adam, Husbands, Murray, & Maxwell, 2005; Cusick, 1999) all found that PLWH were likely to use this disclosure strategy with casual sexual partners. Moreover, each of these studies found that if a partner was thought to become a regular or long-term partner, then it was felt that disclosure should happen sooner rather than later (Adam & Sears, 1994; Cusick, 1999; Harawa et al., 2006; Sandstrom, 1996; Van Kesteren et al., 2005). A study with MSM found that the reasons for this strategy were that not disclosing to a regular sexual partner was considered unfair to that partner and also to increase the likelihood of being rejected by that partner if disclosure later occurred (Sandstrom, 1996).

Findings related to disclosing HIV-positive status prior to any sexual intercourse were reported by six of the 15 included studies (Adam & Sears, 1994; Harawa et al., 2006; Maticka-Tyndale et al., 2002; Rutledge, 2007; Sandstrom, 1996; Van Kesteren et al., 2005). Most of these studies sampled MSM (Harawa et al., 2006; Rutledge, 2007; Sandstrom, 1996; Van Kesteren et al., 2005). The experiences of women were represented in only two of these studies (Adam & Sears, 1994; Maticka-Tyndale et al., 2002). The most recently published MSM study found those who disclosed prior to sex often felt a heavy personal responsibility to prevent HIV transmission (Rutledge, 2007). Importantly, in three of the included studies, PLWH who decided to disclose their HIV-positive status prior to all sex and strongly feared rejection tended to avoid disclosure by avoiding sex altogether and becoming celibate (Harawa et al., 2006; Maticka-Tyndale et al., 2002; Van Kesteren et al., 2005).

Theme 2: changes in the experience of sex

> Then he said, "Maybe we should just go to sleep" … well, that's how it ended … we both ended up mad and frustrated. And it was clearly because of HIV. (Sandstrom, 1996)

Three of the included studies found that fear of transmission of HIV altered PLWH's experience of sex, such that sex contained a sense of threat and anxiety (Keegan et al., 2005; Sandstrom, 1996; Siegel et al., 2006). Two of these studies sampled women (Keegan et al., 2005; Siegel et al., 2006) and their findings specifically connected this sense of threat and anxiety during sex to reduced satisfaction with sexual life overall and a range of poor psychosexual outcomes. Specifically, a study with a female sample conducted in the UK reported reduced sexual confidence, difficulty maintaining arousal, difficulties with orgasm, and greater inhibition and aversion of sexual practices which were previously enjoyed (Keegan et al., 2005). A study of women in New York City found reduced feelings of intimacy, and the loss of freedom and spontaneity due to the need to negotiate risk through planning and behavioural changes (Siegel et al., 2006). This anxiety and associated outcomes were attributed to a fear of onward transmission of the virus, and this finding was equally present in a study of MSM published in 1996 (Sandstrom, 1996), as it was in the two studies with women published a decade later (Keegan et al., 2005; Siegel et al., 2006).

Three studies included findings related to reduced libido in the context of HIV (Harawa et al., 2006; Keegan et al., 2005; Maticka-Tyndale et al., 2002). A mixed sample study explored perceived reasons underlying reduced libido, and found that PLWH attributed this to medication or psychological factors (Maticka-Tyndale et al., 2002). A study of women found that a supportive romantic partner could help to overcome such difficulties (Keegan et al., 2005).

Theme 3: celibacy: short-term or sustained

> I don't want to have sex with no one … I don't want to give nothing to nobody. (Siegel & Schrimshaw, 2003)

Celibacy was a very common finding across studies and was synthesised under two subthemes: short-term celibacy and sustained celibacy.

A *short celibacy* period after which sex life was resumed was a common finding (Adam & Sears, 1994; Green, 1994; Maticka-Tyndale et al., 2002; Sandstrom, 1996; Van Kesteren et al., 2005). Fear of HIV transmission was dominant within such findings, and was equally evident in samples of individuals of mixed genders and sexual orientations (Adam & Sears, 1994; Green, 1994; Maticka-Tyndale et al., 2002), as in MSM-only samples (Sandstrom, 1996; Van Kesteren et al., 2005). The latter reported additional reasons for short-term celibacy including feelings of threat to life, altered body image, physical difficulties, and feelings of disgust about sex (Sandstrom, 1996; Van Kesteren et al., 2005).

Sustained celibacy was reported in three of the included studies. Dominant motivations for sustained celibacy reported across studies were fear of transmission of HIV during sex and fear of rejection by sexual partners (Green, 1994; Siegel & Schrimshaw, 2003; Siegel et al., 2006). These findings were reported by both male and female participants (Green, 1994; Siegel & Schrimshaw, 2003). Self-protective motivations for celibacy were also evident, such as feelings of anger and distrust toward a sexual partner to whom acquiring the virus was attributed (Siegel & Schrimshaw, 2003), perceiving sexual relationships as "an unwanted hassle" (Siegel

et al., 2006), or a desire to focus on one's own needs for a while (Siegel & Schrimshaw, 2003). These self-protective findings were found in a study which sampled women only (Siegel et al., 2006), and were attributed to women only in a study which analysed findings for men and women separately (Siegel & Schrimshaw, 2003).

Theme 4: condom use of HIV-positive people

> It's just a piece of rubber. It's just not natural. It's horrible. (Rhodes & Cusick, 2002)

Condom use among HIV-positive people was a dominant topic which was explored in 10 of the included studies, with findings overwhelmingly focused on reasons PLWH reported for not using condoms. As could be expected, a sizeable proportion of such findings directly relate to risk of transmission. In fact, the only finding not about reasons for condom-less sex was a US study of women with HIV, which found that imperatives from health professionals to use condoms were highly distressing and had no impact on condom use (Siegel et al., 2006). With regard to reasons related to risk of transmission, sero-concordance (both partners being HIV-positive) was a common risk-related reason for sex without a condom, which was not specific to studies which sampled any one gender or sexual orientation (Keegan et al., 2005; Lawless et al., 1996; Rhodes & Cusick, 2002). A study of MSM found that not using condoms based on sero-concordance could be problematic if sero-concordance was guessed or assumed rather than discussed. For example, this study found that sometimes a sexual partner's willingness not to use condoms was taken to mean that this partner was HIV-positive without any discussion, and therefore condoms were considered unnecessary in situations in which negotiation of risk may have been required (Rutledge, 2007).

Two studies found that a belief that HIV-negative sexual partners should have shared or had equal responsibility for ensuring condom use influenced decisions to have sex without a condom (Rhodes & Cusick, 2002; Van Kesteren et al., 2005). Other less explored risk-related findings were: the disinhibiting effects of alcohol or other drugs leading to condom-less sex (Cusick, 1999; Harawa et al., 2006; Rhodes & Cusick, 2002), confusion about what constituted safe sex (Keegan et al., 2005), and the potential fallibility of condoms being used to justify not using condoms (Rhodes & Cusick, 2002).

The most dominant and repeated reason for condom-less sex across studies was not directly related to risk of transmission, but instead focused on relationship aspects, namely a desire for greater feelings of intimacy with a sexual partner (Cusick, 1999; Harawa et al., 2006; Keegan et al., 2005; Lawless et al., 1996; Rhodes & Cusick, 2002). A thematically related desire for greater sexual pleasure was a reason given by both men and women in one further study (Rhodes & Cusick, 2002). Such findings were not specific to a particular gender or sexual orientation.

Dynamics within the relationship were also found to influence decisions behind condom use or non-use. Three studies found that the level of commitment and/or length of the sexual relationship influenced condom use, such that condoms were more commonly used with casual sexual partners, but were less common with regular

sexual partners (Green, 1994; Maticka-Tyndale et al., 2002; Van Kesteren et al., 2005). This finding was present in studies across time, gender, and sexual orientation.

In studies with female participants, a common finding related to HIV-negative male sexual partners coercing HIV-positive female partners to have condom-less sex, citing love, denial of risk, god's will, or a desire for greater sexual pleasure (Lawless et al., 1996; Rhodes & Cusick, 2002; Siegel et al., 2006). A related relationship dynamic was found in a study of MSM, such that some HIV-positive men were found to defer to their HIV-negative partner's wish not to use condoms, particularly if such deference to the others' wishes was a pre-existing pattern in the relationship (Rhodes & Cusick, 2002). Broader group-based dynamics were also found to influence condom use. For example, in one study condom-less sex was described and justified as usual behaviour within the individual's social group (Rhodes & Cusick, 2002).

Discussion

This synthesis aimed to take stock of the current state of qualitative research on sexual functioning after HIV diagnosis, and understand the processes and mechanisms which underlie sexual functioning with HIV. Findings coalesced around four themes: disclosure of HIV status, changes in the experience of sex, celibacy, and condom use.

In sexual contexts, PLWH appear to use either a pre-sex disclosure strategy involving disclosure of HIV-positive status prior to any sexual interaction, or a non-disclosure strategy of taking precautions against HIV transmission and not disclosing HIV-positive status to casual or new sexual partners prior to sexual interaction. The evidence synthesis suggests that the pre-sex disclosure strategy is more likely to lead to poor psychosexual outcomes such as avoidance of sex and sustained celibacy, possibly because this strategy evokes greater fear of rejection by sexual partners.

Public health laws promote the pre-sex disclosure strategy (HALC, 2013a, 2013b, 2013c), and HIV-status disclosure is a common outcome measure for evaluating the efficacy of interventions to promote safer sexual practices (Lapinski, Randall, Peterson, Peterson, & Klein, 2009; Serovich, Reed, Grafsky, & Andrist, 2009; Teti et al., 2010; Wolitski, Gómez, Parsons, & Group, 2005). In the period after HIV was first identified, promoting disclosure of HIV status, possibly at the expense of PLWH's sexual quality of life, could have been considered a necessary evil required to prevent new acquisitions of the virus. This was based on the assumption that increasing disclosure by PLWH would reduce risk of HIV transmission. However, the evidence for this argument is mixed, with some studies concluding that greater disclosure does not increase safer sexual behaviour, while others conclude the opposite [see Simoni & Pantalone (2004) for a review]. Indeed, Crepaz and Marks (2003) have argued that rather than disclosure in and of itself, it is sexual communication and negotiation around risk after disclosure of an HIV-positive status that leads to safer sexual behaviours between couples (Crepaz & Marks, 2003). More importantly, scientific understanding of risk of transmission in the context of an undetectable viral load (UDVL) has advanced dramatically. There is now a consensus within the medical community that risk of transmission of HIV with an UDVL is very low if not impossible (Boyd et al., 2016). This is in line with recent findings from the PARTNER

study (Rodger et al., 2016). Considering that in Australia, 90% of PLWH were found to have an UDVL (KirbyInstitute, 2016), it is now both medically and ethically unreasonable for health professionals and therapists to insist that PLWH with UDVL taking reasonable precautions against transmission always use the pre-sex disclosure strategy at the expense of their psychosexual well-being and adjustment to HIV.

Not surprisingly, condom use was the largest theme covered in the synthesised body of qualitative research. The predominant focus of such research has been to understand reasons PLWH gave for not using condoms. These studies were therefore focused almost entirely on sexual risk, and risk-related reasons for condom use. The current synthesis reveals that, while consideration of risk of transmission is a factor, it is greatly overshadowed by relationship factors, such as a desire for intimacy, and group factors, such as peer behaviour, which exert a particularly strong influence on this particular sexual health behaviour. When intervening to promote condom use among PWLH, it is common practice for health professionals and therapists to focus wholly or mostly on sexual risk-related reasons (W. D. Johnson et al., 2008). In order to promote the psychosexual health and well-being of PLWH, it is important for health professionals and therapists to account for the commonly neglected relationship and social influences on sexual behaviour.

The synthesis showed that fear of transmission of HIV was associated with sexual dysfunction and led to a range of poor psychosexual outcomes. Unfortunately, only three studies meeting the inclusion criteria covered this topic. Limited evidence from these studies provide further support for the positive correlation found in the quantitative literature between fear of transmission and sexual dysfunction (Santi et al., 2014). However, further research is required to understand the processes and mechanisms underlying this relationship. It is only with this information that health professionals and therapists can adequately intervene to support good sexual quality of life. By contrast, celibacy has been more thoroughly explored, and fear of transmission of the virus together with fear of rejection by sexual partners emerged as prominent over-arching phenomena that lead to short-term or sustained celibacy.

Regarding limitations, included studies often did not identify which qualitative methods were used and did not adequately characterise their sample, which in turn limited the ability to account for such features in the process of synthesising findings. The generalisability of the current findings is limited by the fact that only studies written in English and based on data collected from samples in high-income countries have been included in the analysis. Due to differences in economic and cultural conditions which inevitably influence HIV experiences, we excluded studies conducted in low- and middle-income countries, and have limited our review to studies conducted in Australia and comparable countries. Further research is required to understand the experience of sexual life of PLWH in other country settings, and a thematic synthesis of qualitative studies would be an appropriate means of grounding this research.

Two large gaps are evident in the current qualitative literature. The first is a paucity of recent research, and the second is the breadth and depth of the covered topics. Regarding the first, it is surprising that no qualitative research fitting the inclusion criteria has been published since 2008. In the past 3 years, the importance of commencing HIV treatment early has been established (Lundgren et al., 2015), and there

has also been significant growth in scientific support and community knowledge of using treatment as prevention, including both UDVL (Rodger et al., 2016) and pre-exposure prophylaxis (Grant et al., 2014; Wright, 2016; Zablotska, 2016). These developments will very likely have a strong impact on the sexual functioning of PLWH, and further qualitative research which accounts for these factors is undoubtedly required if we are to understand the complex psychosocial and relational impact of HIV on sexual functioning of individuals and couples in the current era.

With regard to the coverage of topics, the existing qualitative research has focused disproportionately on sexual risk-related behaviours and outcomes. Specifically, the topics of disclosure of HIV-positive status, condom use, and celibacy have been well covered. There is, however, limited coverage in qualitative research of the mechanisms underlying sexual dysfunction, and there is currently a lack of qualitative research on changes in sexual functioning over time, from pre- to post-diagnosis, and thereafter. Further research which provides an understanding of the process of adaption and maladaptation to HIV over time is required to better understand and promote the sexual well-being of PLWH.

There has been a dramatic shift and advancement in biomedical understanding of HIV treatment and the efficacy of treatment as prevention. Optimism about ending HIV transmission within the next decade is increasing. A similar shift is now required in understanding of how best to support and promote healthy sexual functioning of PLWH who will continue to live increasingly normal lives, long into the future. Qualitative research to understand and promote psychosexual well-being of PLWH in this current era is a critical component of this endeavour.

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