

‘Experience of sexual self-esteem among men living with HIV’

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Abstract

Much of the focus on sexual health for people living with HIV has been on promoting safe sex behaviours. However, also important for sexual health is a positive sexual self-esteem. This article reports on an Interpretative Phenomenological Analysis of interviews with seven men about the impact that having HIV has had on their sense of sexual self. Five overarching themes were identified: the 'destruction' of a sexual self; feeling sexually hazardous; sexual inhibition; reclaiming a sexual self; finding a place through sero-sorting. With HIV now being a chronic illness, interventions are required to support people to lead sexually satisfying lives.

Key words: HIV, sexual self-esteem, sexual health, mental health, wellbeing

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Introduction

Significant advances in the medical treatment of Human Immunodeficiency Virus (HIV) mean that it is no longer a death sentence, but can now be regarded as a chronic, manageable illness (Siegal & Lekas, 2002). However, HIV remains a stigmatising disease potentially 'spoiling' (Goffman, 1963) the identity of persons living with it. This stigma may be layered on previously socially stigmatized identities (Swendeman et al., 2006). For example, Flowers and colleagues (2006) report how the experiences of HIV-positive African migrants living in the UK may be layered with existing issues concerning minority status and immigration. Kamen et al., (2012) demonstrated that HIV positive men who have sex with men experienced more adverse effects from traumatic experiences than men who have sex with women. As a result of such stigma, and the multiple challenges of managing a chronic illness, living with HIV may significantly impact on an individual's mental health and wellbeing (see Sherr et al., 2011 and Catalan et al., 2011 for reviews of HIV and mental health issues).

Whilst research has explored the potentially damaging impact of HIV and stigma on a person's overall sense of identity (e.g. Flowers et al., 2011 and Skinta et al., 2014) and on sexual relationships (e.g. Starks and colleagues study (2014) which investigated the relationship between HIV stigma and the perception of condom use as a barrier to sexual intimacy), the impact on sexual identity and wellbeing is less studied. Research on sexual health matters in relation to HIV has mainly focused on promoting safe sex behaviour and ameliorating problem behaviours, in order to prevent HIV transmission. While important, relatively less attention has been given to

more positive aspects of the sexual health and wellbeing of people living with HIV. Yet this is a key aspect of health-related quality of life (e.g. see Herrmann et al., 2013), sexual health being defined not only as the absence of disease or dysfunction, but entailing social, emotional and mental wellbeing, and pleasurable as well as safe sexual experiences (World Health Organisation, 2006).

In this context, sexual self-esteem (SSE), that is, a person's sense of self as a sexual being, is a useful concept. Mayers and colleagues (2003) define this construct as "the value that one places on oneself as a sexual being, including sexual identity and perceptions of sexual acceptability" (p.207). SSE may include aspects of past and current experiences. It may influence and guide a person's sexual behaviour (Andersen et al., 1994), and be important for sexual satisfaction (Menard & Offman, 2009). SSE may be particularly important in aiding open sexual communication, sharing one's needs, desires and preferences with one's partner (Oattes & Offman, 2007). SSE is also important for sexual assertiveness, defined as an ability to communicate sexual needs and initiate sex (Ménard & Offman, 2009). Aside from the importance of these for sexual satisfaction, they are aspects that are key to negotiating safe sex practices.

HIV is associated with poor self-esteem and feelings of shame and guilt (Cantisano et al., 2013; Manhas, 2014). Yet, surprisingly few studies explore issues of SSE and sexual wellbeing among people living with HIV. Other sexually transmitted infections such as Herpes and the Human Papilloma Virus were found to have a negative impact on individuals' sense of sexual self (Newton & McCabe, 2008).

Issues of sexual wellbeing are a significant concern for people living with HIV. For example, Gurevich and colleagues (2007) found that women living with HIV reported a need to discipline their sexual desires and as a result experienced less sexual spontaneity. In a recent survey (Bourne et al., 2012) of 1777 HIV-positive men who have sex with men, respondents reported poor self image (44%) and loss of libido (44%), as well as fears of rejection from sexual partners (34.7%). Many respondents reported wanting help to achieve a more satisfying sex life.

With these issues in mind, we conducted an exploratory study to examine the SSE experiences among a sample of individuals living with HIV. Our research team represented a convergence of complementary interests: a clinical psychologist with research interests in HIV and mental health (PR), a social psychologist with research interests in sexual minority prejudice (DM) and a health psychologist with research interests in sexual and reproductive health care (RC). We adopted a phenomenological approach, as we wanted to explore SSE from the subjective, lived experience of people living with HIV. The aim was not to identify typical or statistically generalizable areas of concern or sexual problems; rather we wanted to use the concept of SSE to elucidate the impact that HIV has had on their sense of themselves as a sexual being.

Method

Sample

A sample of seven men were recruited through two HIV-support organisations – one in London and one in the East of England. A flyer about the study calling for volunteers was advertised to service users of the two organisations. The flyer did not

specify gender. However, no women volunteered to take part in the study. All men were 18 years and over; their specific ages were not recorded. Five men identified as gay, and two identified as heterosexual. Three of the men were currently in a relationship. At the time of the interview the period since HIV diagnosis ranged from 9 months to 25 years. This unintended wide range offered us the opportunity to explore the experiences of participants at different stages of living with HIV. Table 1 provides a summary of demographic details of the seven participants. Three of the men were recruited in London and four from a city and surrounding villages in the East of England. Participants' specific locations are not identified and pseudonyms are used to ensure anonymity. All participants had disclosed their HIV status to close friends and some (if not all) members of their immediate family. Participants were not asked if they were taking anti-retroviral treatment, although some did report that they were. Ethical approval for the current research was provided by the authors' home institution.

Table 1. Details of the sample

Participant	Currently in relationship	Sexual Orientation	Time since diagnosis
Ken	Yes	Gay	3yrs
Tim	No	Gay	25yrs
Shaun	No	Heterosexual	1yr
Dave	No	Gay	3yrs
James	Yes	Gay	21 yrs
Brian	No	Gay	9m
Chris	Yes	Heterosexual	9m

Data collection

An information sheet detailing the aims and purpose of the study was discussed with all interviewees prior to them giving signed consent to participate. Three participants recruited from the same organisation requested to be interviewed as a group. The remaining four were interviewed individually. All interviews took place in a confidential room at the premises of the two organisations. All interviews lasted approximately one hour. Interviews were conducted by either XX or XX. An interview schedule was used to guide the interviewer. Interviews mainly focused on responses to the following questions:

- How would you describe your sexuality and sexual self?
- How do you feel about yourself as a sexual being?
- What impact, do you think, has living with HIV had on your sex life?
- Have aspects of your sex life changed? If so, what has changed?

As well as asking about difficulties, participants were asked about support and positive changes. These questions were used as a guide, with both interviewers probing the individual narratives of participants. As this was a sensitive topic, with the potential to prompt participants to disclose emotionally difficult experiences, it was thought that any support after the interviews could be provided by the organisations in which the interviews took place. All interviews were audio recorded, and later transcribed verbatim.

Method of analysis

Transcripts were analysed by means of Interpretative Phenomenological Analysis (IPA) (Smith et al. 2009). Operating at a case study level of analysis, IPA allows

researchers to explore what *matters* to a person, and what things *mean* to him or her (Larkin, 2015). Our method of analysis involved a close reading of each transcript and identifying salient themes that captured participants' experiential ideas, views and concerns. An initial analysis of one transcript was done individually by each of the authors, and then discussed as a team. On the basis of this, further analysis was conducted to identify common themes within each case and across the sample, and discussed as a team.

Results

We identified some recurring themes across the sample related to sexual self-esteem. These were: The 'destruction' of a sexual self; feeling sexually hazardous; sexual inhibition; reclaiming a sexual self; finding a place through sero-sorting.

The destruction of a sexual self

All participants spoke of how when diagnosed with HIV, they believed that it meant the end of their sexual life as they knew it. In most cases the initial feeling was that they were never going to have sex again. For the participants diagnosed over 20 years ago, this was linked to the knowledge at the time that HIV would inevitably lead to Acquired Immune Deficiency Syndrome (AIDS), and they thus had a foreshortened lifespan. In light of this, sex did not feature in their imagined (short) futures. As James described in recalling the time after being diagnosed and given an approximate remaining lifespan of 5 years

My feeling was that 'That's it, I'll never have sex again'. There was a real strong sense of, well, that I wasn't expecting to live more than five or six years at that point, that was the prognosis in those days[...] I was told five years was

reasonable. And I just kind of figured 'Ok well that's that then, I'll never have sex again' and I was terrified of the thought that, that I'd pass it on and I just, I just couldn't imagine what that would be like, to do that. So I just thought ok, it is easier just to not have sex anymore

While for James this sense of enforced celibacy was very much linked to having been given a foreshortened life expectancy, it was also linked to feeling sexually hazardous (see below). Medical advances mean that people can expect to live a normal life span, so we might expect that some of this destruction of a sexual sense of self would not be as salient for a person being diagnosed today. However other participants diagnosed more recently spoke of similar reactions. Ken, who had been diagnosed three years previously recalled:

"As far as I was concerned I was never going to have a relationship with anyone again, as I wasn't going to pass things on and I didn't want anyone to know about my status and I just couldn't deal with any kind of sexual activity what so ever or even thinking about it.

Both Ken and James spoke of how sex almost become taboo to them. Ken went on to elaborate that not only could he not imagine having sexual activity with another person, he had stopped engaging in masturbation too. As both James and Ken allude to, some of this enforced celibacy related to a sense of themselves as being toxic. For Brian, who had been diagnosed only 9 months previously, this was something he was significantly struggling to come to terms with. At various points in his interview, he repeated his assertion that he was not going to have a sex life

again. It became a kind of punishing message to himself, as it was so intertwined with feeling dangerous. For example Brian stated:

I don't have sex I just; how could I have sex I've got HIV? I'd be petrified to have sex. I'm dirty.

At other points, Brian went on to say how he denies himself any thought of having sex (“*there is no point in even thinking about sex*”), adding that he is resigning himself to the idea of life “*wanking in front of porn or something like that*”, rather than engaging in any form of sexual relationship. The strength of his feelings is accentuated by his self-condemnation – ‘*I am dirty*’; rather than ‘*I feel dirty*’. Brian was clearly struggling to come to terms with his diagnosis. Chris, also diagnosed 9 months previously, similarly spoke of a definite end to his sexual life. Chris explained how he had an active, adventurous and satisfying heterosexual sex life for many years (Chris was middle-aged), but that this had now come to an end. He explains:

I am still out there but I am not motivated by sex anymore. I am just motivated by talking to people, having a chat, just chilling, having a dance. Whereas before it was a sexual, sexual motivation. It was like, ‘Oh I quite fancy her you know.’ And that, my whole concept, my being has changed. Which is not a bad thing because it was quite bad to have that as a motivator. It was fun, but now I have just found myself and no, it is just friends and I'd love to have sex with this girl or whatever but it's never going to happen.

Chris suggests that there may be an internal conflict and an active denial of sex. The meaning of this for all participants was one of loss. They all spoke about sex as something that they thought they would have to immediately give up. While they tended to speak about this as a new reality they had to accept, their conflict about this was evident. For example, in the quote above, Chris states: *"I'd love to have sex with this girl...but it's never going to happen"*. This seemed to suggest that their thoughts around this was not so much in terms of their *illness*, but rather as an interpersonal issue. As pointed out above this destruction of a sense of sexual self was closely intertwined with feelings of being dirty and dangerous.

Feeling sexually hazardous

All participants spoke about struggling with feeling that their HIV status resulted in them being sexually dangerous. For example, Dave spoke about feeling *"dangerous to other people"*; James spoke about feeling *"toxic"*, and as reported above, Brian repeatedly described himself as *"dirty"*.

Some participants reported this as a general sense of themselves, where they felt like a sort of a social leper. For example, Brian explained:

Who would ever want me? I feel dirty when I have thoughts about - I got my car washed this morning, beautiful Polish guy, he's gorgeous and I was looking at him and I had to look away 'cause I felt dirty. "Don't look at him, don't fancy him, don't look at his butt, don't look at this". I just feel- I panicked you know, I can't, I go like this [humming noises] I just can't do that. If I see a really good looking guy

in the street or, I just look away and think that I can't do that, I can't do it. I can't look because I'm dirty and I'll never be able to have sex again

Brian's case is an extreme example of a real struggle with his diagnosis and its meaning for him. His interview was depressing and lacking hope, although he was receiving support from the organisation that he was recruited from, and he was finding that helpful. However, the other participants who were recently diagnosed and who were clearly coping much better also spoke about this sense of self as sexually dangerous. This arose most when it came to actual sexual interactions, and an ever-present anxiety about infecting their partner. Dave describes his constant worry about what was safe sex and what was not:

I was very worried about whether, you know, cumming in someone's mouth was, how risky that was going to be for them with, with such a high viral load?

James and Tim both described previous relationships with a HIV-negative partners that had ended because of their anxieties about passing on the virus became too much to deal with. Tim recalled how he told his partner "*I can't live like this whereby I may infect you*". James shared a story of a partner many years back who he had felt in love with. He spoke about how he felt that his partner was constantly trying to take risks when they were having sex, as if trying to get infected with HIV himself. He described how he "*just ended up breaking it off because I felt like I was being... it made me feel toxic again*". He went on to add he thought his partner was trying to punish or damage himself and that he "*wasn't prepared to be that weapon*". James use of the word "weapon" and the other participants' descriptions of dangerousness

echoes the enduring metaphors associated with HIV and AIDS as punishment, as crime and as sin (Sontag, 1991).

Two people (James and Dave) spoke about how HIV (and its metaphors) was intermingled with feelings of shame that they already had about themselves. James spoke of how his struggles with shame at the time (25 years ago) were related to his sexuality and masculinity. Similarly, Dave spoke about his pre-existing struggle and poor self-esteem:

What HIV has, has done is that it kind of, sometimes fuels my internal rhetoric about, about you know, about not being good enough you know, and why would anyone want to go out with me?

Although this was not specifically explored further in the interviews, this relates to what Skinta and colleagues (2014) and Cochran and Mays (2009) argue as being a significant factor in HIV-related stigma for MSMs: they argue that HIV stigma is layered with sexual minority stress' (Meyer, 2003), a term that has been used to describe the psychological stress associated with being in a sexual minority group. There were no apparent differences in the accounts of the men who identified as heterosexual and those who identified as gay, other than this layered stigma (Swendeman et al., 2006). For the heterosexual men, feelings of shame and anxiety about being "dirty" were similar.

Sexual inhibition

At the time of the interviews, only Brian and Chris (who had both been diagnosed 9 months previously) reported not having sex since their diagnosis. While for Brian this seemed like his doomed fate, Chris' experience was different. There was more of a sense of possibility:

I still feel sexy, and I get told I am sexy all the time so you think well I must be.

You know, so that's nice, so I don't think that has changed at all. But I, I am not closing, this is going to sound ridiculous like an advert but I am a salesman deep down and I close a deal. The deal is, 'Oh I want to have sex with you.' And I used to close it and now I don't close.

Chris describes having to actively inhibit himself sexually, despite his desire and his sense of still feeling sexually desirable. The other participants, who were having, or had previously had sexual experiences since diagnosis, still experienced other forms of sexual inhibition where they felt that worries about risk and safety during sex spoilt the joy and spontaneity of it. For example, Dave talked about how refusing to have penetrative sex (which he did at one stage) or insisting on the use of a condom would elicit questions from the partner. He went on to describe a typical scenario:

They'll be really interested and there's a long conversation about, you know, and often a lot of their anxieties will come out. But then by that point either it's become, the sit...you know, the situation has just changed and it's become, it's not sort of very, it doesn't feel like it's very sexual anymore

Dave describes how the anxieties (his and that of his partner) inhibit sexual desire, ultimately – *spoiling the moment*. The sexual moment becomes medical and behavioural talk. Similarly, Ken described how HIV had “*almost taken away the joy of having sex or even thinking about having sex*”. He tries to describe what it feels like for him:

You don't get a chance to just feel, look at yourself and sort of feel and on the outside good about yourself, you know. Because this three letter, so called three letter word. Whereas sex might seem an attractive thing and you might of you know, jumped in the shower and made yourself all nice and put some nice clothes on; after you have had so many side effects, you just, that just, it just it kind of like takes it all away, you know [...] you think it's no longer attractive anymore. I just feel that it's almost taken away the, the joy of having sex or even thinking about having sex.

He talks about his struggle between trying to understand whether his feelings about sex and his sense of himself as sexual had more to do with medical side-effects or whether this was also a “*psychological thing*”. Tim similarly spoke of reduced sexual desire as a medical side-effect. However, both at times acknowledged the impact of HIV on their sense of sexual self-esteem. Ken eventually decides that all these things - HIV and all that is associated with it - have ruined sex for him:

I no longer feel attractive myself, I, in terms of sex and even sexual thoughts. I, it all seems to relate to HIV and to me it's like HIV has made it seem ugly, dirty, unattractive. It's like this thing's always there and you no longer feel as if you

want or I feel as if for me the term or the feeling of wanting to have sex is an ugly thing

The representation of dirtiness and toxicity associated with HIV has been repeatedly reported in general research on HIV stigma (e.g. Skinta et al., 2014). As revealed above, the effect of this is very poor sexual self-esteem, where participants feel sexually unattractive, where sexual desire is inhibited and sex itself becomes joyless and full of anxiety.

Reclaiming a sexual self

Tim, James and Dave, who had been living with HIV longer than the other participants, talked about having been able to reclaim or start reclaiming their sexual self-esteem. All described coming to a point of internal dialogue where they acknowledged to themselves that they were sexual and did not want to live a celibate or sexually unsatisfying life. However, this was a period of struggle as it also involved moving from a stage of deciding not to have sex to exploring possibilities but having to disclose their status, and negotiate the anxieties and worries about risk (discussed above). James talked about this eloquently:

having at least a six month period of complete celibacy in which I just couldn't consider sex and it, and that changing and realising I'm not, that I can't cope with just not having sex at all and having no contact to thinking, "Ok, what, what I'll do is I'll have some sexual contact but I'll limit it to only completely risk free things and I won't talk about my HIV status cause nobody is going to do, even do risk free things with me if I tell them first". And so disclosure and

sex, kind of, sexuality were very closely linked. And then as things progressed there was a realisation that “Hmmm actually you know, that’s just, you know, mutual masturbation and it’s not going to do it for me on a long term basis”.

Both James and Dave describe the struggle of trying to reclaim a sexual self, but having to negotiate what feels like a minefield of challenges and difficulties. HIV stigma, whether perceived or actual, was a salient lived experience as both struggled with disclosure and, as Dave put it:

What can I do with whom? And what do I tell them? You know, that was the nub of the issue in terms of sex

For James and Dave, one of the factors that helped them reclaim their sexual self, not only in terms of engaging in sexual activities, but also feeling sexually better about themselves, was the perceived benefits of medication. As Dave described:

I am now on medication, so I have an undetectable viral load and that makes a huge difference to how I perceive myself and how much I am able to enjoy myself without worrying too much

Similarly James, who had been very ill, described a kind of rebirth when he started effective treatment and his health began to improve dramatically. This was the start of a long process of coming to terms with his new life living with HIV and his identity:

I'm more comfortable with myself sexually today than I ever have been. That shift happened in my thirties, and I guess, I don't know, it's been, it was a long process. Some of it relates to disclosure, some of it relates to my feelings about being a gay man

Both felt that improved health through medication was significant, but they also described the support from service-user organisations as immensely important. However, this did not suggest that all was well, as both spoke about finding a sexual life primarily among other people living with HIV. All other participants equally spoke about this as an imagined or lived solution to their sexual lives.

Finding a place through sero-sorting

All participants felt that having sex with someone who was also living with HIV was, or would make things, much easier in terms of disclosure, negotiating sex with or without a condom, and generally enjoying sex relatively free of anxiety and worry. Dave described this in terms of finding his place:

it kind of led me on to meet other kind of men more other HIV positive guys because that was kind of the one group of people where it felt entirely safe in all senses of the word, to be kind of around them and to be able to have sex with them with, without the kind of concerns [...] It gave me a sense of where I fitted in, in the whole maelstrom of things

Even Brian, Chris and Shaun, who had been recently diagnosed and were struggling the most, imagined a possible future with someone who was also living with HIV as

almost the only option. Brian, in possibly the only hopeful thought during his interview spoke about this as a “day-dream” for his future:

it would be lovely to meet somebody whose HIV. I would never, never, I would never have sex with somebody who wasn't HIV positive

For Brian this was the only possibility, as he felt too dirty and dangerous. For Shaun, he saw this not just in terms of a sexual relationship, but a comfort in being able to share his lived experience with someone else:

I would rather go out with someone with HIV, I would, something like that. And then you can look after each other, you can talk to each other and you have someone who knows your situation

Such views not only point to the social isolation from the ‘general’ community that people living with HIV may face, but also to the strategies that people resort to for managing the significant anxieties that the stigma of HIV raises in relation to sex.

Discussion

The good news story of effective HIV treatment and care obscures the reality that, for many, HIV remains a highly stigmatizing illness, which potentially impacts significantly on an individual’s wellbeing. Our findings reveal the adverse effect that HIV has had on the sexual self-esteem of a sample of seven men living with HIV. It is important to note that we did not explore difficulties around self-esteem and mental health prior to diagnosis, and thus we cannot conclude that HIV contributes to poor

self-esteem or mental health. However, these men's accounts suggest that they place great emphasis on the impact that HIV has had on their sense of self. All participants gave similar accounts of the meaning that HIV had for them in terms of their sense of self, their sexual attractiveness, sexual desire, and sexual possibilities. While some recognised the role of medical side-effects on sexual libido, for example, for all participants, there was a sense of loss around their sexual life, with a real struggle (both current and in the past) to reclaim a (new) sexual identity. We have presented the results as if they reflect a timeline of experience. We note however that whilst the participants did speak of their experiences changing over time, there is no identifiable process that all people follow, and indeed some participants remained fixed at a particular point (for example struggling with notions of feeling too dangerous sexually).

We report here on the analysis of the experience of just seven men, and this of course cannot be generalised to a wider population. But our intention was not to investigate statistically generalizable factors affecting sexual self-esteem, but rather to explore what things mean and what matters to individuals. The fact that these men have lived with HIV for long as well as short durations, and come from the large metropolis of London as well as places in the rural East of England, allows us to make some claims as to the importance of considering these issues as relevant for other people living with HIV. There are limitations, however, that need to be acknowledged. We did not recruit any women. This may have been because the two organisations chosen tend to support mostly MSM, and future research should specifically target female participants, perhaps through organisations that support women living with HIV. Recruiting through HIV-support organisations also presents

the potential for bias in our sample, by recruiting participants who are already benefitting from support. However, we note that the participants mostly did not report a 'happy story'.

Our intention was to conduct individual interviews. However, we agreed to respond to the request of three participants to be interviewed jointly. Although the same key questions were asked during this session, individual issues could not be explored in as much detail. However, the session did elicit conversation between participants which facilitated discussion of shared experiences and helped highlight some of the changes over time.

Our study does provide exploratory data in an under-researched and important area. In a large survey study of gay and bisexual men across 38 European countries (Bourne et al., 2013), most reported wanting sex that was emotionally connected, varied and free from harm, and within a committed relationship. When it comes to HIV prevention and care, most of the research and interventions regarding sexual health, revolve around promoting safe sex behaviour. This is important and necessary, but there is a lack of focus on *good* sex, as opposed to just *safe* sex. In conducting and analysing these interviews, we attempted to suspend any judgement around sexual practices; our intention was not to explore safe sex practices, but rather what having HIV means in terms of their sexual life, and what matters to them. It is clear that sex is riddled with many anxieties and fears that negatively affect the ability of these men to feel good about themselves sexually and to find a way to have a satisfactory and enjoyable sex life. James stands out as an exception, but his journey was a long and difficult one. The men in our study spoke about sero-sorting

practices as allowing them the 'space' where they could be freer sexually. This supports findings by Bourne and colleagues (2015) where around half of men living with HIV in their study reported engaged in sero-sorting in order to have sex without a condom, and further reported a sense of freedom in not feeling themselves to be the primary cause of HIV infection. However, it is important to note that the other side of this is the distress associated with feeling sexually excluded from the broader HIV-negative community. Sinkta and colleagues (2014) highlight this when they conclude that the practice of sero-sorting perpetuates the message of stigma and not being acceptable to HIV-negative others. Future research using survey methodology would allow for the recruitment of a larger and more diverse sample, standardization in how data is collected, and the possibility of drawing generalizable conclusions.

Our results echo the findings of Bourne and colleagues (2012), which indicate that interventions are needed to support people living with HIV in having good, satisfying sexual lives, in addition to safe sex. The need for psychological interventions that support people to live positively with HIV is clear. Such interventions should not only address mental health, but need to focus on issues of sexual self-esteem too.

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