Women living with HIV can benefit from peer support as well as the opportunity to voice their own concerns about their diagnosis

Identifying needs of women living with HIV

In this article...

- Identifying the unmet needs of women living with HIV
- Development of a peer support group
- Recommendations for areas to focus on in nursing women

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This article reports on the development of the Between the Sheets project for women living with HIV. It began with an event that provided a forum to address their unmet needs concerning sexual activity and related issues. Development was informed by a focus group of women with HIV, some of whom also presented their personal stories. Attendees’ evaluations have identified further unmet needs and ways HIV services might adapt to better meet the needs of these individuals.

I have worked in the HIV/Aids specialty since 1993, providing specialist nursing care, support and advice across Liverpool. Part of my role is to support patients in their homes, where they are often more relaxed and better able to talk openly. This privileged position has enabled me to identify a number of issues faced by women living with HIV that are currently unaddressed by many services, not just those related to health:

- Many wish to explore and discuss their sexual activity in relation to an HIV diagnosis;
- Many are confused about the relevance of an undetectable viral load to infectivity. (The Swiss Statement (NAM, 2013) states those with undetectable viral loads for six months with no sexually transmitted infections who consistently take antiretroviral medication are sexually non-infectious);
- Difficulties in disclosing their HIV status to new partners are frequently voiced and described as a “tell and kiss, or kiss and tell” scenario;
- There is a reported loss of sensuality, and perceptions of future celibacy;
- Fear of rejection, violence or abuse within sexual relationships are often voiced as serious concerns.

The women’s frustration was both alarming and emotive. Despite safer sex messages from various sources, it was necessary to explore:

- How difficult is it for women living with HIV to negotiate the kind of sex they want?
- How and when does disclosure take place?
- How common is it that abuse or violence within a sexual relationship is a cause or result of HIV?
- How can specialist nurses develop to support women with HIV?

The willingness of the women I support to engage in this highly sensitive area had never been explored. As a result, women who voiced anxieties were encouraged to form a focus group; this helped to gauge whether they would be willing to be involved in, and consider facilitating the delivery of, Between the Sheets, a one-day event aiming to identify and meet unmet needs of women with HIV.

Methods

Three women living with HIV accepted the invitation to form a focus group with myself as project lead; they met regularly and communicated regularly by email. The group’s aim was to gain a greater understanding of the impact of HIV on the women’s sexual activity and to use this

5 key points

1. There is an unmet need for women with HIV to discuss their sexual activity
2. Those with undetectable viral loads for six months and no STIs, taking antiretrovirals, are deemed sexually non-infectious
3. Under the Disability Discrimination Act people with HIV are considered to be disabled
4. Almost half the women experienced violence or abuse because of their HIV status
5. HIV services for women do not adequately address inequality or provide appropriate support

People who are HIV positive can feel marginalised in society
The focus group identified the following objectives:

- To provide a safe, inclusive forum where women can explore issues relating to their sexual activity;
- To impart health messages and factual information via expert presentations and personal stories;
- To provide interactive workshops to address sensuality, empowerment and self-esteem;
- To facilitate networking opportunities to provide peer support;
- To evaluate women’s experiences and establish support provision.

The focus group planned a female-only patient engagement event entitled Between the Sheets for women with HIV living in Liverpool. To ensure it was delivered safely, and to support the focus group, I initiated and led a project group hosted by Liverpool Community Health Trust (LCH). This consisted of internal stakeholders including communications, equality and diversity, information governance, audit, analysis and administration personnel, and was supported by senior management.

A high level of consideration was given to confidentiality and sensitivity during promotion of the event. Details were imparted personally to women living with HIV, and electronically and by post to HIV clinics and the voluntary sector.

Those attending were given the opportunity to complete anonymous pre- and post-event questionnaires. The pre-event questionnaire captured baseline information of attendees’ experiences in relation to sexual activity; the post-event version asked them to identify future support and other requirements they felt were needed. Questionnaires were approved by our information governance department and strongly influenced by the focus group members.

The focus and project groups also liaised with Merseyside’s HIV/Aids voluntary agency, Sahir House, and were able to harness valuable support, such as volunteers to assist with the event, and help for women with transport difficulties. They played a crucial role in imparting health information through exhibition stands.

**The event**

According to research by John Moores University, there were 203 women living with HIV in Liverpool and 323 in Merseyside in 2011 (John Moores University, 2011). A total of 67 attended the event, 85% of whom were aged between 18 and 24.

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**Presentations were delivered by health professionals on:**

- Contraception and HIV – considerations and options;
- Unprotected sex in the antiretroviral therapy era – protection, pleasure and procreation;
- Criminalisation/prosecution.

All the presentations received excellent feedback and included content that was felt to be appropriate.

- Four women with HIV presented their personal stories, disclosing positive and negative experiences of living with HIV and how this affected their sex lives. Two of these women were from the focus group and neither had spoken about their HIV in public before. This gave them a huge sense of pride and ownership of the project.

Workshops were facilitated by qualified therapists including:

- **Speak up – how to confidently communicate your sexual needs;**
- **Your personal pleasure map;**
- The workshop evaluations provided excellent feedback from attendees and facilitators; they delivered messages of empowerment and improved self-esteem.

**Pre-event questionnaire results**

This consisted of questions to establish baseline knowledge on subjects such as stigma and disclosure, and specific details relating to women’s experiences of sex, post-exposure prophylaxis sexual exposure (PEPSE), the effect of HIV on sexual relationships, incidence of violence and abuse as a cause or consequence of HIV, and the influence of viral load on sexual activity. Fifty questionnaires were available, 29 (58%) of which were returned.

Below are examples of some of the questions and responses:

**Are you comfortable about disclosure of your HIV status to sexual partners?**

Almost half (48%) said no. This shows the enormity of the issue of disclosure. A further question showed 65% of women stated a need for support around disclosure.

“I have never had support around this and I have been diagnosed 17 years. I have had to fumble my own way through the pitfalls of disclosure and the consequences, which have sometimes been violent, either verbal or physical.”

Are you aware of where to access help in the event of a condom breaking or not using one at all (for example, PEPSE, morning-after pill, STI screen)?

Forty-eight per cent did not know where to access this help; this clearly indicates the need for ongoing education and support to ensure timely intervention.

**If you have a partner, do you feel your current relationship has been adversely affected by your HIV status?**

All responses showed negative impacts:

- “Hard to talk about.”
- “We argue and he makes me feel small.”
- “Living in denial has taken its toll on present relationship but it’s taken time for me and my partner to accept.”
- “We talk about HIV all the time not our relationship. It shouldn’t all be about HIV. What about just living my life? I can’t live normally.”
- “Wouldn’t have a long-term partner now. Too complicated and they can use the fact you have HIV against you.”
- “Took ages for him to accept me for me and not HIV.”

**What are your thoughts and feelings as a woman if you need help/support/advice regarding your sexual activity?**

Again, responses were mainly negative:

- “I don’t deserve a sex life. I used to love sex.”
- “Very, very, very isolating. Gay men get loads of support and seem more open about sex. Where can I go to talk about HIV and sex as a woman? Nowhere.”
- “I feel lost, who could understand what I need to consider? Embarrassed to talk even to female professionals.”
- “I have never met a woman who has HIV, I would like to ask how they coped telling their partner.”
- “I have never had any support around my sexual activity. I have never been empowered through education to be able to negotiate the sex I want or safe sex.”
- “I feel isolated as a woman with HIV. There is nowhere to talk openly.”

Have you ever experienced violence or abuse in a sexual relationship by either a partner or someone else because of your HIV status?

Forty-five per cent of women said yes to this question.

“Father of my kids constantly throwing it in my face and violence.”
“Emotional violence when you are just left for another woman.”

“Mental – they freaked out thinking you could catch this from kissing, this abused my mental state of health.”

“I never experienced physical abuse but after disclosing to someone they started to talk down to me and treated me like I was contagious.”

“Mental abuse, emotional abuse, financial abuse.”

“I have been spat at, battered and raped because of my HIV status. I have been verbally abused and sexually denied or manipulated by sex either being granted or denied.”

“Intimidating behaviour, bullying, financial abuse, blackmail, threat of criminalisation.”

“Verbal abuse like ‘dirty slag’ and ‘whore’. I don’t deserve that.”

“Name calling, threats of disclosure to others that don’t need to know.”

How has your sexual activity/relationships changed since your HIV diagnosis?

All responses except one illustrated a negative impact:

“It makes it all complicated.”

“At first, thought I could never have sex again.”

“It has become difficult to have a normal relationship.”

“Just don’t bother having sex, I’m just terrified.”

“My relationships have been more short term and often based on poor choices having what was on offer rather than what I truly deserve.”

“Always scared about sex since my diagnosis. Always scared that I will be left behind.”

“I can never have sex without thinking about HIV. It’s always there at the forefront of my mind.”

Post-event questionnaire results

Of the 67 women who attended the event, 43 (64%) returned questionnaires. A small proportion of attendees were female professionals working in the field of HIV; this may account for the unreturned questionnaires.

Attendees were asked which topics they needed support with in the future. The main themes were:

- Confidence in disclosure – how and when to do it;
- Pregnancy;
- Practical information on HIV and sex;
- Information and support around violence towards women;
- African women’s issues and how HIV can affect their ideas of sexuality;
- What sexuality means for a woman;
- Negotiating safer sex;
- Couple issues;
- How to deal with stigma and discrimination;
- How to use a female condom or dental dam;
- Support from black women to get their different perspective;
- Peer support;
- “Funky”, nice, safe things to do with your partner.

Women were then asked how this support should be provided. The main suggestions were:

- Refer to counselling/sex coach;
- Being “buddies” with women who are HIV positive;
- Via other peer-led, safe activities and groups;
- Women-only events;
- More creative workshops/events held in neutral settings to help women explore their sexual activity and empower them in their sex lives;
- A women’s group to explore sex issues.

Discussion

Sixty-nine per cent of attendees did not disclose their sexuality; this might indicate an assumption that all women with HIV are heterosexual and, as such, there is no need to complete the question. However, 23% disclosed they were bisexual; this statistic surprised the focus group and subsequent discussions led to the conclusion that the safe environment and context of the event made disclosure easier. As a result of disclosure, services can be tailored to meet women’s support needs, so this statistic is useful in promoting change within lesbian, gay, bisexual and transgender organisations.

In total, 50% of attendees identified themselves as black, none of whom wanted to speak publicly. However, post-event data showed a need and desire for women from black and minority ethnic groups to “have a voice” and be represented.

Of all attendees, 67% did not consider themselves disabled, 15% did and 18% did not respond to the question. The Disability Discrimination Act 2005 states people with HIV are deemed disabled and protected against unfair treatment at work and in education, housing or accessing services.

The number of women and men with HIV in Liverpool is almost equal (John Moores University, 2011), yet evaluation shows women in particular feel unsupported around sexual activity. The high proportion (45%) of women disclosing HIV as being a cause or consequence of violence or abuse echoed the findings of Hutchinson and Perry’s (2012) study. Despite global interest in this link, little evidence is available in the UK to support it. This presents an area for further research.

The event and feedback showed a clear need for changes to local resources for women living with HIV in relation to sexual activity and addressing unidentifiable and unmet needs. Some service provision was shown to be inadequate in addressing inequality, thereby promoting inclusion and the provision of appropriate support in this area.

The focus group has arranged a follow-up event, inviting women who attended the first one as well as potential funders and other stakeholders. Presentation of the evaluation data is planned, along with discussion on how women with HIV want to progress with the project. Several women who attended the initial event have already offered to present, showing how effective it was in increasing participants’ confidence.

Conclusion

Nurses, particularly those in specialist roles, should be encouraged to pursue service improvement ideas that come directly from patients. Although it may not be feasible to deliver similar projects, they are likely to be in a position to influence, and so bring about required change, in line with local and government proposals.

References

