

# HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

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# HIV NURSING

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## **Aims and Scope**

*HIV Nursing* has been developed as a forum for those at the forefront of caring for people affected by HIV. The journal is supported by a highly respected Editorial Board drawn from a wide range of nursing specialties. This is further strengthened by an Advisory Panel who will be making regular contributions to the journal.

*HIV Nursing* is intended to provide a medium for communication on issues relating to HIV care, which will be run by the care professionals for those involved in the day-to-day matters affecting the lives of patients.

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# Room for improvement – hope on the horizon

Welcome to the summer edition of *HIV Nursing*, which has a focus on women. Stigma features prominently in this issue – we hear about the challenges faced by a blood-borne virus (BBV) service in rural Wales and look at suggested improvements distilled from interviewing HIV support workers. A review of male partner attitudes to HIV testing produced some interesting findings; and there is a remarkable account of two women whose diagnoses led them into the field of human rights and HIV. Finally, our review of the psychological standards for adults concludes with Part 2, outlining applications for nursing practice.

Janice Rees discusses HIV stigma in rural Wales, where her BBV team aims to provide as holistic a service as possible in this small-communities setting. Particular challenges arise for both patients and healthcare workers in this context. The anonymity of a big city is lacking, compounded by services being located some distance from those who need them; at the same time, individuals often have no support from family or friends who are unaware of their status.

Three case studies illustrate perfectly the dilemmas of disclosure. One individual chose to keep her status private and manage without family support, whereas the two who did disclose found their confidence broken and had to move away from the area. Although many PLHIV receive compassion and support from family and community, stigma, repression and discrimination continue to blight the lives of many others – not surprisingly, the conclusion here is that more work is needed to address this ongoing and detrimental issue.

Taking a different perspective on stigma and its associated effects, Paulina Bravo and colleagues gathered and analysed data from interviews with support workers. Four themes emerged: HIV as a life event; disclosure; deciding on medication; and HIV-specific interventions. It was observed that not disclosing to partners is a significant issue that complicates safe sex and brings guilt and shame into the relationship.

This study concludes that the discrepancy identified by participants between the support that is wanted and needed – and what the healthcare system actually provides – can leave individuals excluded and alienated, feeling that they have to cope unsupported with many issues, including stigma. A reshaping of services is proposed at local and national level, with close involvement of PLHIV, so that needs can be addressed as holistically as possible – with confidentiality, anonymity and empowerment as key principles.

Sharon Wilson sought to establish whether the male partners of pregnant women would accept an HIV test if offered in the antenatal period. What few data there are in this area support the benefits of couples counselling and HIV testing. Questionnaires and patient information leaflets were distributed to male partners at anomaly scans over a 6-month period, and some of the results were certainly heartening.

As well as a high proportion of men saying they would undergo testing for the long-term health of the baby or to support their partner having the test, some cited a sense of responsibility for the community and public health, a wish to 'help the hospital and staff'. These findings will inform anticipated service changes and it is hoped that male partner HIV screening, once routine, will allow professional intervention to safeguard the unity and health of families and children. This will be achieved through counselling, safer sex messages and harm reduction information for couples wherever needed.

Alice Welbourn and Silvia Petretti tell us their personal stories. Their initial HIV diagnoses were accompanied by bleakness and despair, which gave way to hope as support and comradeship came from the most unexpected places. With the additional improvements in medical treatment, the outcome was ultimately far happier than they ever could have hoped. They recall the 'Lazarus effect' brought by antiretroviral therapy: 'suddenly we stopped having to go to funerals'.

These two women chose to respond to their HIV status by adopting the highest profile possible and using their experiences to advance human rights. In addition to lobbying for improved HIV education and more appropriate legislation, central to their work is enabling women to empower one another in the context of HIV: 'we should not be passive in our care'. The importance of non-judgmental public health policy is identified, to enable HIV-positive health workers to use their own valuable experiences for the benefit of patients – with accountability provision in this area being particularly relevant given current changes in HIV testing settings.

Our final feature in this issue is the second review of the *Standards for psychological support for adults living with HIV*, this time taking a nursing perspective. You may find it helpful to read this with Part 1 to hand, carried in the previous issue. These standards stress a number of requirements that are clearly close to the hearts of other contributors to this issue, who have proposed them for universal application across HIV care services.

These requirements are: promoting mental and psychological health in a non-judgmental

environment where patients feel safe; facilitating the best referral possible through continuous patient assessment and engagement; and good awareness of all care pathways. The eight standards are presented from a nursing perspective, outlining the areas which the standards do, and do not cover.

This issue's HIV Update looks at where we have got to with injectable hormonal contraceptives and the pros and cons of both male and female condoms. Above all the message seems to be to offer as much choice as possible while supporting women as individuals ... and to remember that, even when data are mixed, sending a few myths on their way is always helpful.

We are very pleased to receive contributions from readers – the author instructions for the journal are on the website, and do remember that there is help at hand if wanted. Alternatively, please let us have your take on what you have read in the journal and, of course, any suggestions as to how we might improve things. Do please get in touch with me or any of the working group via the website – and in the meantime, have a lovely summer.

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# The extra challenges of HIV stigma in a rural community

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## Introduction

From the moment scientists identified HIV and AIDS, social responses of fear, denial, stigma and discrimination have accompanied the epidemic. Discrimination spread rapidly, fuelling anxiety and prejudice against the groups most affected, as well as those living with HIV. Infection with HIV is about social phenomena as much as biological and medical concerns. Across the world, the HIV epidemic has shown itself capable of triggering responses of compassion, solidarity and support, bringing out the best in people, their families and communities. However, the disease is also associated with stigma, repression and discrimination, where individuals affected (or believed to be affected) by HIV have been rejected by their families, loved ones and communities [1].

## Then and now

From the outset, stigma has been a feature of HIV disease and many HIV-positive patients report that their lives are affected by fear of discrimination [2]. Many are petrified that their diagnosis will 'leak out' and they often choose not to reveal it to any family or friends, for fear of recriminations.

All kinds of social groups experience discrimination because they are perceived as 'different', and those who are HIV positive fall into this category [3]. Society sees the HIV virus as being 'different' and associates it with what are perceived as deviant social groups. At the beginning of the epidemic, headlines such as 'gay plague' and 'junkie flu' were common, and the assumption was prevalent that it was *only* gay men, sex workers and drug users who were infected [4]. Although these groups did experience statistically higher HIV incidence in the 1980s, this is certainly not the case today. This early categorisation also led to the term 'high-risk groups', which is now inappropriate.

The blood-borne virus (BBV) nursing service in the area where I work has evolved from the 'pure' HIV/AIDS nurse specialism developed in the early 1990s. The earlier role was funded by ring-fenced monies from what was then the Welsh Office. The current BBV nursing service is based in a very rural part of the United Kingdom, which brings challenges. A lead BBV clinical nurse specialist (CNS) heads the service, covering all three counties along with two other BBV CNSs.

## The work of our service

The CNS roles in our team are multi-faceted and consist of:

- Pre- and post-test counselling for HIV, hepatitis B and C;
- Follow-up care and support of patients diagnosed with a blood-borne virus;
- Nurse-led treatment of patients diagnosed with hepatitis B and C and liaison with the regional treatment centre for patients diagnosed HIV positive;
- Patient education and information-giving;
- Education of healthcare staff in relation to blood-borne viruses;
- Policy development around blood-borne viruses;
- Multidisciplinary and multi-agency working to provide holistic care for people diagnosed with a blood-borne virus.

The treatment centre for HIV patients is 1 to 2 hours' journey away. This means that the BBV clinical nurse specialists provide the only 'link' in the area for patients needing specialised advice and support – especially vital when help from family and friends is not sought for fear of stigma.

The service has been running in one county for 17 years and in the other two counties for just under a year. Many changes in HIV care have taken place during this time – not least of which has been the introduction of highly active antiretroviral therapy (HAART). However, one thing does not seem to have changed very much – HIV stigma. While supporting patients with a range of issues, practitioners in rural areas can themselves experience stigma by association [5]. A senior member of nursing staff who had experienced discrimination states that she had responded by declaring, 'Well, I don't sleep with any of my patients!'

## Stigma in a small community

The case studies below look at three HIV-positive individuals living in a rural area consisting mainly of villages and hamlets, along with four medium-size towns, and show how stigma can affect those living with HIV in such a setting. While Miss A's diagnosis remains known only to her, she lives with a dread of disclosure – corroborated by the experiences of the other two individuals, where confidentiality was not maintained.

Living in a close rural community has many advantages – neighbours 'look out' for each other and there is a very strong sense of community spirit and support. However, this proximity does have drawbacks. A common phrase is 'everyone knows everyone else's business'. Many people still find it hard to believe that HIV has 'reached' the area. An example of this is when a book about HIV was ordered from a local book shop – the counter assistant was shocked that 'HIV had got here', and this lack of understanding contributes to fear and subsequent discrimination [6–8].

## Fear and isolation

These cases illustrate the powerful effects of stigma: both the fear of discrimination and also the consequences suffered by those discriminated against. Miss A is afraid of anyone finding out her diagnosis, because of the consequences for her within the community and the associated stigma her close family network would suffer. Mr B and Mr C have both lost their jobs and their homes due to discrimination and are fearful of returning to the area.

Also highlighted is the isolation experienced by those living with HIV in a rural area. Mr B and Mr C have been forced to move away and lose the physical closeness of supportive family and friends. Miss A, although in contact with close family and friends, dreads disclosing her diagnosis to anyone and so cannot receive the emotional support that her family and friends could provide.

## Conclusion

Nurses working in the field of HIV in close-knit communities face extra challenges, as described. Drug regimens now mean that people living with HIV have a very good physical quality of life. Tackling HIV-related stigma would have a positive effect on their psychological quality of life [10–12]. Despite its negative impact, there have been a limited number of intervention studies aimed at reducing HIV-related stigma [13] and there is a plethora of research data confirming that HIV-related stigma is still prevalent [14]. It is therefore vital that future research around this topic focuses on mechanisms for reducing this discrimination and thus improving the psychological quality of life for people living with HIV.

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## Miss A

Miss A was diagnosed HIV positive in her twenties. At the time she had a young child and lived alone, having had a small number of previous sexual relationships. Her difficulty on diagnosis was that she did not want anyone, including other medical and nursing staff, to be told. From a health-and-safety position this was not a problem – all healthcare staff practise standard precautions. It did, however, highlight the fact that she was afraid of discrimination from the professionals caring for her.

Miss A's other main worry was that, when her parents visited, they might inadvertently be told of her diagnosis. Fear of people finding out about an HIV-positive diagnosis is very common in newly diagnosed patients [1]. She was terrified that not only she would be vilified but, worse still, so would her child. This fear of so-called secondary stigma is common [8,9]. Here was a young woman with the rest of her life ahead of her, who was now isolated with a problem she could not discuss with anyone apart from those very few who knew of her diagnosis. She said at the time that she would never

have a relationship with a man again because she could not face telling anyone she was HIV positive. This feeling is common in women living with HIV. 'Jane', an HIV-positive woman writing in a magazine aimed specifically at HIV-positive women, writes:

'I have carefully avoided relationships because I wouldn't want to infect anybody ... Anyway, it's not easy to find a man and it's even harder when you're HIV positive.' [10]

To this day Miss A has not had a sexual relationship with a man, and has still not told any friends or family members of her diagnosis. She is very afraid that, should she tell a friend, they may tell another friend and before she knows it, her 'secret' will be out. Living in an area where she knows a lot of people and gossip is part of everyday life, she feels she and her child would be ostracised. She is dependent on the support of her family and friends – and if her diagnosis became common knowledge, feels she would have no option but to move away and leave her support networks.

**Mr B**

Mr B was well known in the area. He was diagnosed whilst he was with a long-term partner who did stand by him following diagnosis. His diagnosis was 'leaked' by a friend in whom he had confided. Once rumours started circulating, his long-term partner asked him to leave the house they shared, resulting in him losing his home and his partner, and being forced to move away. He has never returned to the area, even to visit. The question must be asked – had this man been living an 'anonymous' life in a large town or city rather than in a close-knit rural area – would he have faced the same discrimination? Similarly, would the partner have felt the stigma by association?

**Mr C**

Mr C confided in his employer as he had to attend clinic appointments. His employer breached his confidence and told other members of staff, resulting in him being approached out of work and asked if he was HIV positive. He consistently denied being HIV positive, but was still the victim of snide remarks and prejudice. He has also moved out of the area, feeling he is more anonymous in the city where he now lives. He considered taking legal action against his employer but on reflection did not want to face the publicity he felt would inevitably surround the case.

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# 'Not just another chronic illness': the dilemmas of people living with HIV – a support workers' perspective

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## Context

Advances in therapy have resulted in improved life expectancy for people living with HIV (PLHIV). However, there is a need for psychosocial support for PLHIV who now face a long-term illness surrounded by stigma and discrimination. A qualitative research study was conducted to assess the psychosocial needs of PLHIV. Thirteen semi-structured interviews were conducted with support workers, several of whom were themselves PLHIV. Thematic analysis was performed. Coping with the disease and revealing HIV status are the toughest dilemmas for PLHIV. This distinguishes HIV from other long-term diseases and identifies a need for the development of sensitive, empowering and participative interventions. PLHIV face not only a chronic disease but all the social and psychological distress related to it. These needs may have a major influence on the way care is provided and should be considered in the design of supporting interventions.

## Introduction

Living with HIV could constitute an important threat to the psychosocial wellbeing of those who have the disease. The condition of being HIV positive not only affects physical health, but also involves a stressful lifestyle, including issues with personal relationships, sexual life and medical treatment.

A literature review showed that PLHIV face difficult decisions surrounded by stigma and discrimination as a consequence of their HIV-positive status [1]. The review identified that:

- disclosure is a difficult step to take, yet a fundamental and necessary process in terms of accepting the illness and gaining access to services and support;
- adherence to treatment is contingent on a good understanding of the illness and its consequences, on developing a productive relationship with clinical and other services and on being able to secure and maintain a network of social support and effective relationships;
- sexual behaviour is an important concern: high-risk behaviour and spread of HIV are the worries related to sexual practices.

These decisions should be explored and supported by health professionals with the active participation of PLHIV in order to improve the psychosocial implications of this disease [1]. This statement is also supported by the UK's National AIDS Trust, whose recent review of the psychological support needs of PLHIV recommended a systematic assessment of those needs and the design of interventions to support the mental health of PLHIV [2].

This paper reports the psychosocial decision needs of PLHIV and how support workers feel these needs could be addressed. 'Support workers' is understood to mean those who provide direct care and support to PLHIV.

## The study

### Methods

A qualitative study was conducted, using semi-structured in-depth interviews. A phenomenological approach was chosen in order to explore and understand the subjective lived experiences of support workers working directly with PLHIV [3]. Ethical approval was obtained from Cardiff University.

### Participants

Contact was established with the HIV charity organisations in London. Both women and men were required for this study, aged over 18. The inclusion criterion was people working in direct contact with PLHIV, without requirement to disclose their own HIV status.

### Data collection

Interviews with support workers were conducted in the charity where each participant was based or at their home, from September to December 2009. All interviews were audio-taped and transcribed verbatim. Data saturation was reached when no new information was identified and the addition of further participants did not yield new findings.

### Data analysis

A thematic analysis was carried out using a modified version of the steps defined by Colaizzi [4] and assisted by the computer software ATLAS.ti 6. To ensure reliability of coding, two researchers

independently coded interview transcripts, which were then discussed to agree on themes and codes for all remaining interview transcripts.

## Results

### Participants

Thirteen support workers were interviewed. The participants were staff members of five HIV charities/organisations in London:

- five supported black and minority ethnic (BME) PLHIV;
- three supported children living with HIV;
- two supported HIV-positive women;
- two supported positive families living in poverty;
- one supported PLHIV and healthcare professionals.

There were seven male and six female participants (average age 43 years). Although inclusion did not require disclosure of HIV status by participants, five voluntarily disclosed HIV-positive status, one disclosed HIV-negative status and one mentioned the HIV status of his/her children. Interviews lasted 38 minutes on average.

After rigorous analysis, patterns were identified in the interview data and four themes emerged:

- HIV as a life event;
- the tough process of revealing the secret;
- to take or not to take: the HAART dilemma;
- special interventions to support PLHIV (Table 1).

### HIV as a life event

#### *'not just another chronic illness'*

Most of the participants described HIV as a unique illness, where people face the initial psychological shock of being diagnosed. Consequently, interviewees reported that PLHIV seem to give up their plans since they are unable to see any future perspective in their lives, feeling disempowered and without choices.

Although support workers recognised that HIV has latterly been described as a long-term condition, they expressed the need to differentiate HIV from any other chronic disease. This is because of its complexity, with psychological and social problems that are closely linked ('interwoven'). This might be explained by the social impact and stigma attached to HIV. Consequently, any intervention should remain clearly focused on the specific needs of PLHIV.

'... it's not just another chronic illness, it's full with complexities, interwoven problems.'

[male, 37 (PC11)]

#### *the long-term psychological torture*

The level of stigma and discrimination surrounding HIV was described as one of the main issues affect-

**Table 1. Support workers' views of psychosocial issues for people living with HIV**

Themes	Sub-themes	Categories
HIV as a life event	<ul style="list-style-type: none"> <li>• 'not just another illness'</li> <li>• The long-term psychological torture</li> </ul>	Stigma Discrimination Isolation
Revealing the secret	<ul style="list-style-type: none"> <li>• Disclosing: an ongoing dilemma</li> <li>• Living with others in secrecy</li> </ul>	Secrecy Confidentiality Self-protection
To take or not to take: the HAART dilemma	<ul style="list-style-type: none"> <li>• The starting-point conflict</li> <li>• The natural resistance to a lifetime commitment</li> </ul>	Confidentiality Self-protection
Special interventions for PLHIV	<ul style="list-style-type: none"> <li>• The requirements</li> <li>• Barriers and facilitators for developing interventions</li> </ul>	Anonymity Engagement

ing PLHIV. For some participants, interventions to address this negative social reaction could include educating the general population and trying to increase understanding and acceptance of HIV. This could have repercussions for how PLHIV manage their diagnosis and seek help and support.

The lack of community sympathy and comprehension for those who are suffering due to HIV plays a key role in the way PLHIV manage their condition. Participants explained that, although HIV brings psychological distress, PLHIV tend to remain silent and usually decide against sharing this with their social network. As a consequence, many are unable to find relief and support, and cope with the illness on their own.

'It's almost inevitable that you will feel isolated I think, if you don't disclose to anybody.'

[male, 55 (PC12)]

In summary, HIV constitutes not only a physical but also a psychosocial threat to those living with the disease, since it continuously affects individuals' social lives and self-motivation. Consequently, PLHIV face this disease in isolation and apart from their former social networks.

### Revealing the secret

Disclosing HIV status is one of the most crucial and toughest processes for PLHIV. This constant preoccupation can affect their psychological wellbeing, and will influence whether or not HIV-positive people seek emotional and medical support and commit to their treatment.

#### *disclosing: an ongoing dilemma*

Whether or not to disclose is an ongoing conflict for PLHIV. Who to tell, whether telling is safe, and what the consequences might be, are among the

questions that routinely arise every time an HIV-positive person considers sharing this information. In this way, disclosure constitutes an endless process which involves personal experiences and judgment about the harms and benefits of disclosing.

Disclosure was identified by the participants as a process that PLHIV might walk into without any pressure: meaning that they should not be pushed to disclose status, as they struggle with the decision of being honest (and sharing their status with others) and the possibility of being rejected by others as a consequence of disclosure. This process and its potential negative outcomes exemplify the need for social and psychological support – some might struggle to resolve this for over a year, while some might never reach a conclusion.

'Who to disclose to, do you disclose to someone, is it the right thing to do, isn't it? It's a whole lot of social aspects involved, cultural aspects, linguistics aspects.'

[male, 33 (PC06)]

Social rejection could increase the isolation of PLHIV. This social exclusion is avoided by those who decide not to disclose. However, living with this condition in secrecy is a tough task: participants described how PLHIV feel they are living a double life when they decide to hide their status from relatives and friends. On the other hand, when PLHIV decide to disclose, they report relief and a positive outcome if they are supported by others.

[After disclosing] it's so important now you don't have to lie, you're not living double life and you're supported.'

[female, 36 (PC01)]

### *living with others in secrecy*

Given the complexity of disclosing, PLHIV choose very carefully who to share this highly personal information with. Interviewees mentioned that they advise PLHIV to disclose to those they consider trustworthy and with empathetic ability. Furthermore, one participant mentioned the need for being 'resourceful' – in the sense that, when PLHIV have greater understanding of their condition, it is easier to cope with disclosure since they can explain the disease effectively to others, facing myths and general beliefs related to HIV.

Having this stigmatised disease, which involves a complex disclosure process, also makes it difficult to establish and maintain relationship with others. Revealing HIV diagnosis can affect personal relationships. As described by the participants, HIV status breaks relationships by bringing blame: family life can be disrupted, partners can walk away from the HIV-positive person and sexual life can be disturbed. Consequently, disclosure to partners is a complex process that involves more than just stating what your HIV status is.

'I said [HIV] breaks up relationships, it brings blame.'

[female, 43 (PC15)]

To begin an intimate relationship is also problematic. Initially, PLHIV might decide not to disclose but attempt to protect their partner by practising safe sex, typically using condoms. Nevertheless, when a relationship reaches a serious and committed level, the need for disclosure becomes more pressing. The consequences could be either acceptance by the HIV-negative partner – or abandonment, which could stop the PLHIV from disclosing to future partners.

Under British law, HIV horizontal transmission is subject to prosecution if disclosure has not been undertaken. Support workers recognised this as an issue for PLHIV. According to the participants, some PLHIV will avoid any sexual activity in order to evade the disclosure of their status; some PLHIV will follow strict safe sex using condoms without disclosing; and a third group will both practise safe sex and disclose, to avoid any potential criminal prosecution for virus transmission.

'Somebody who is HIV positive and is not taking precautions is really committing a crime.'

[male, 67 (PC14)]

Raising a family is one of the dilemmas PLHIV can face. According to the participants, advances in medicine do not reduce the distress PLHIV experience in relation to the risk of transmission to a new child.

In summary, communicating HIV-positive status appears to be a key process. By disclosing their condition, PLHIV could have access to social, medical, financial and legal support. However, the negative social connotation of this disease puts at risk their social value, condemning them to a lonely and unsafe psychosocial experience.

## To take or not to take: the HAART dilemma

Medical advances, notably the arrival of highly effective antiretroviral therapy (HAART) have improved life expectancy for PLHIV. Although HIV-positive people identified treatment as a matter of survival, the requirements of treatment – such as long-term commitment and strict regimens – are the principal threats to adherence.

### *the starting-point conflict*

Starting treatment is a big task. Some of the participants mentioned the difficulties of initiating the medication – as PLHIV often deny the need for treatment, claiming wellbeing and lack of illness. Moreover, beginning therapy is a confirmation of HIV status.

'One of the biggest problems is taking the step to once start treatment because then there is a reality that you are HIV positive.'

[male, 33 (PC05)]

On the other hand, some PLHIV understand that treatment is also the means to survival and wellbeing. Interviewees explained how HIV-positive people are aware of the need for treatment at some point of their disease, and they accept it because it is the key to improving their health and wellbeing. However, the side effects of medication can make the decision harder, opening a new focus of intervention for PLHIV.

### *the natural resistance to a lifetime commitment*

The natural resistance to commit to lifelong therapy was described by the participants. Additionally, the complexity of treatment meant that PLHIV required expert support. This could result in unpleasant, dependent and disempowering situations for PLHIV.

'People think, oh my God I'm gonna take this medication for the rest of my life, then the other part of it's three or more drugs at one point, it's not just one medicine.'

[female, 43 (PC15)]

In summary, PLHIV struggle with the decision of whether or not to take their medication. Denying their condition and keeping it secret from others negatively affect both initiation of and adherence to treatment; natural resistance to commitment and medication side effects are also issues that affect adherence.

## Special interventions for PLHIV

### *the requirements*

Interventions to support the psychological and social needs of PLHIV were described as unique, with specific requirements and characteristics. Any successful intervention must provide a confidential, anonymous and trustful setting. Strategies focusing on psychosocial needs should consider them as inter-related, linked. Viewing these needs holistically could improve the level of engagement, and support workers noted a need for interventions that involve the whole reality of PLHIV.

'It's not just about talking to them, it's about a holistic approach, it's about how they eat, it's about how they perceive themselves.'

[female, 50 (PC08)]

Participants also described how understanding need properly is central to effective support. One felt interventions should be tailored to each person's needs and preferences. To make this approach workable in practice, culturally-orientated or age-specific support packages would need to be developed, with delivery by staff trained to achieve the best match possible to individuals within this population.

'Creating interventions or getting people to access interventions that are all right for them as individuals is a challenge.'

[male, 33 (PC6)]

### *barriers and facilitators for developing interventions*

The stigma and consequent discrimination associated with HIV define particular characteristics for any intervention that aims to support PLHIV. One is the need to provide the service whilst protecting the identity of the users and retaining anonymity. This was identified by the participants as difficult to achieve.

'But that is the reality in terms of fears that people out there have, will my information be safe? Will it be confidential?'

[female, 41 (PC02)]

Positive experiences of engagement include one-to-one psychosocial support, allowing people to share their experiences in a friendly and open way. Moreover, interventions should evolve and function in tandem with people's needs, with adjustments as necessary over time.

The success of engagement strategies could be exemplified by the empowerment of service users. According to one participant, the aim is to accompany and facilitate PLHIV in the transition from being users to becoming leaders in peer support.

'We don't want them to just stay service users, we want them to make a transition from being a service user to being an empowered person living with HIV.'

[female, 41 (PC02)]

In summary, interventions to tackle the psychosocial needs of PLHIV should recognise their points of interaction and be user centred and holistic, whilst also achieving anonymity and confidentiality.

## Discussion

The findings illustrated the unmet psychosocial needs of PLHIV and how these could be addressed by the development of interventions. PLHIV confront a long-term and stigmatised condition characterised by complex social and psychological issues. As the difficulties are usually beyond their coping mechanisms, it seems essential to communicate and share this piece of sensitive information (their status) in order to access social, medical and financial support. However, the negative consequences of this decision generally lead to a very cautious disclosure process. Any intervention focused on meeting these needs must incorporate, in particular, a user-centred approach, a participatory philosophy and guaranteed privacy and confidential support. Stigma still plays a key role in the experience of those living with and affected by HIV and must be addressed in any potential intervention to help those affected.

Strengths of this research included the diversity of participants. Having support workers involved with

a wide range of PLHIV provided a broad vision of their needs and an understanding of common areas affecting their wellbeing. Additionally, given that the psychosocial decision needs of PLHIV have been little explored [1], these findings offered an account of current needs and some views on how to meet them.

Limitations included the fact that, although the qualitative data provided a detailed understanding of the phenomena, the findings may not represent the vast array of experiences of those living with HIV. Moreover, this was London-based research and therefore any extrapolation of the findings for PLHIV elsewhere in the UK, or overseas, should be undertaken with caution.

Support workers described living with HIV as unlike having any other chronic condition, mainly explained by the negative social reaction towards PLHIV and the consequent isolation experienced among those 'living positively'. It could be argued that any illness represents a threat to one's social value, because it can bring social disparity, stereotyping and consequent stigmatisation. However, a study comparing the impact of stigma, on 130 PLHIV and 76 persons with cancer, showed that PLHIV experienced significantly higher feelings of stigma in all the measured dimensions – including social rejection, social isolation, internalised shame and financial insecurity [5]. Consequently, PLHIV have significantly lower self-esteem than those living with cancer, independent of individuals' characteristics and health status [5,6].

Additionally, PLHIV sometimes face this condition with no perspective for the future, and with a sense of losing control of their lives [6]. Support workers explained this by citing the interwoven complexities surrounding HIV, which form a vicious circle in their minds that drains them of energy. Consistent with this, interviews with 21 Chinese adults living with HIV found that the long-term nature of HIV conferred a certainty of 'imminent death', and also introduced frustrations about lack of control over their health [7]. This 'death sentence' makes them despair of long-term commitments and plans for the future.

Stigma and its consequences have been described as a factor in the psychosocial wellbeing of PLHIV [8]. Interviewees stated that concerns about the negative social reaction that leads to exclusion and stigma are among the main reasons that PLHIV have to avoid disclosure, or undertake it in a very careful and considered way. Similar findings to this study were reported in a study of 521 French PLHIV: 87% declared being very careful about who they disclosed their status to, while 70% were anxious, in particular that people they had disclosed to would disclose to others [8].

The British health system ensures that PLHIV can access free treatment and care. However, this is

more difficult when those living positively do not integrate within a solid and stable social network. Consistent with findings in this study was 2010 research in Northern Thailand of 32 PLHIV, where around 90% of participants cited family encouragement and support as the most important factors, in both starting and adhering to treatment [9] – comparable findings to the 2007 review already cited [6].

According to the support workers, intimate relationships also become a difficult issue for PLHIV. Blame, guilt and shame are some of the feelings that surround their relationships, affecting not only the emotional arena but also their sexuality. Sexual activity can be seen as carrying a risk of illness or death for the other partner and a risk of criminality or imprisonment for the HIV-positive individual. Maintaining safe sexual practice is a challenge on its own, particularly when PLHIV decide to avoid disclosure. This could clearly affect levels of sexual satisfaction: a 2010 study [8] found that 40% of PLHIV were dissatisfied, a situation that is significantly related to fears of stigma and discrimination.

The issues mentioned above are entwined and inseparable. Consequently, any attempt to address those needs should tackle them as an indissoluble whole, incorporating elements of health participation, empowerment and user-centredness.

However, issues such as anonymity and confidentiality should also be kept in mind. Fears about breach of confidentiality are a particular impediment to PLHIV seeking and receiving help. Participants highlighted how alienating this can be: PLHIV are inevitably disclosing their status just by approaching HIV organisations or clinics. A Russian study found similar results, adding that their healthcare system was not meeting those needs appropriately [10]. In the same way, interviews with 45 American HIV-positive women led to the conclusion that stigma is one of the major concerns when seeking support [11].

Participants in this study also described the estranging effect of discrepancies between the services available and what the HIV-positive person needs: problems arising from this could limit the effectiveness of any interventions [11].

Some of the above findings were also recounted by previous studies [1,12–14]. However, this project is the first to take a holistic view of the psychosocial needs of PLHIV, combined with a call to meet those needs with a user-centred approach. As a consequence, the implications of this study at policy level include the need to reconfigure healthcare for PLHIV, with the participation of PLHIV, to best meet their needs in both local and national contexts.

At clinical level this study identifies elements that might improve clinicians' understanding of HIV-specific issues such as disclosure, treatment and

coping with stigma and social exclusion. It is hoped that enhanced understanding will inform fresh approaches to intervention which will also enshrine the key principles of confidentiality, anonymity and empowerment – needs which, it must be said, are already being met by many current services when addressing the psychosocial needs of PLHIV.

As for future research, this study identified the need to learn more about the experiences of PLHIV – and to maintain dialogue with them about how they can best be supported, and by whom.

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# The response of male partners to HIV screening in the antenatal period: a feasibility study

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## Introduction

This paper reviews a feasibility study conducted in 2011 among clients of St Mary's Hospital, investigating whether male partners of pregnant women would accept an HIV test if offered in the antenatal period. The quantitative data focuses on ethnicity while the qualitative content centres on reasons for either accepting or declining a test if offered.

Since the inception of universal antenatal HIV screening, the focus has been solely on the pregnant woman. A growing body of evidence [1–7] now supports the inclusion of male partners in antenatal HIV testing, both to minimise the risk of the baby becoming infected and as an opportunity to pre-empt late diagnosis. (The 2010 estimate for late diagnosis of heterosexual men was 63% with a CD4 cell count below 350 and 14% with AIDS [8].)

The increasing involvement of male partners in maternity – acting as birth partners, supporting the mother, caring for the baby and attending parenthood courses – makes the midwifery service a prime setting to establish connections with male partners as parents [9].

Many women find an HIV diagnosis difficult to discuss with their male partner – citing fear of relationship breakdown, violence, blame and breach of confidentiality by him as a barrier to disclosure. Fear of reprisals often motivates women to mislead health professionals by stating that the partner lives overseas or has left the relationship and cannot be contacted. Offering testing to couples could both facilitate disclosure where there is an HIV diagnosis, and encourage shared responsibility for protecting the unborn baby.

## Key points

- The primary objective was to establish whether or not HIV testing is acceptable to male partners of pregnant women.
- The secondary objective was to determine whether distinct ethnic groups took an identifiable position regarding such testing.
- A quasi-research approach was adopted, in line with the NHS National Research and Ethics System (NRES).
- A confidential semi-structured questionnaire was

used to ask if male partners would accept an HIV test during the antenatal period. They were also asked to give ethnicity and reasons for accepting or declining.

- Completion of the form implied consent. The questionnaire was anonymous and contained no identifiable patient data.
- The questionnaire was accompanied by a patient information leaflet (PIL) on the issues around HIV testing and protection of the unborn baby from HIV.
- The sample group was 300 men attending the 20-week anomaly scan appointment with their partners, randomly selected over a 6-month period.
- Most participants stated that they would accept screening in the antenatal period.
- Data gathered will inform a further project to offer couples counselling and testing for HIV.

## Study background

### 1. Literature search

Prior to the study a review was conducted of relevant published research, via various databases and journals (CINAHL, EBSCO, Medline, BNI, Social Care Online, BMJ, AIDS Care). Key words were progressively introduced (antenatal, prenatal, male, AIDS, HIV; then male partners, couple counselling), and a 10-year time frame was then imposed on the resulting set of articles. An initial trawl of 8696 articles was reduced to 114 using this method.

Most studies were Africa-based, and 30 full articles ultimately had UK relevance – further reduced to 13 by screening questions from the CASP data tool [10], which assesses research for rigour, methods, credibility and relevance.

Study findings indicated low participation rates, mainly due to non-involvement of men in antenatal clinics, which was seen as shameful and a possible source of ridicule by peers [1]. Research findings indicated that hospital staff isolated male partners and treated them badly: antenatal clinics were perceived as a 'women's domain' and not 'male friendly' [2].

The studies indicated male dominance in sexual decision-making [3], limited understanding about HIV and a lack of communication about sexual

health matters between couples. All demonstrated undertones of the fear of HIV stigma – for example, testing without a husband's consent was seen as a mark of disrespect within a marriage that could lead to divorce. Female participants expressed fear that, in this situation, their diagnosis would then become public knowledge.

The literature search supported the benefits of voluntary couples counselling and testing in limiting onward transmission of HIV. It can be argued that maternity services are an appropriate context for such an initiative in the UK, given that midwives work closely with families as well as mother and baby – and further work could be done to apply this successfully in UK settings.

## 2. Ethical considerations

Some (but not all) HIV-positive individuals are within social groups already experiencing discrimination, such as men who have sex with men (MSM) and black Africans [11]. It was anticipated that, although some husbands might have already accessed HIV testing voluntarily, others might be unhappy about taking part in the study. As the project involved 'new enquiry' (that is, nothing similar had been attempted before), ethical approval was first sought and received from the National Research Ethics Committee [12].

## 3. Data collection

Respondents were asked to place their completed questionnaires in a box in the scan department, and these were collected every fortnight between April 2011 and October 2011. A total of 176 questionnaires distributed yielded a return of 70 correctly completed (usable) responses (Table 1). Forms were coded for reference and the content checked – for example, ensuring that the ink, handwriting and details given varied from form to form eliminated any duplicated or fabricated responses. Quantitative and qualitative data from 'yes' and 'no' respondents were entered onto spreadsheets. The qualitative data were coded by theme and grouped by category – and themes then highlighted to identify any common threads across categories. All information was anonymous and stored on a Hospital Trust password-protected computer in line with data protection policy.

**Table 1. Distribution /return of forms**

Distributions	Returns
Questionnaires	176
Patient information leaflets (PIL)	139
Questionnaires without PIL	37
Questionnaires complete	70
Questionnaires incomplete	10
Questionnaires not accounted for / not returned	96

## Quantitative data

The quantitative data concerned ethnic origin and country of birth for both 'yes' and 'no' respondents, as summarised in Tables 2 and 3. The purpose of seeking this data was to add to existing statistics and help inform future planning – given that uptake of antenatal HIV services in Manchester is currently known to be highest (99%) for areas of lower black and minority ethnic (BME) population.

## Qualitative data

### 1. 'Yes' respondents

Despite the relatively small sample size, responses revealed a great deal of useful information about how participants saw their roles as both fathers and partners. The most prevalent incentive for testing among the 'yes' respondents was the health of the unborn baby. Six categories emerged from the data (Table 4):

- The baby
- Peace of mind
- Knowing or checking
- Support for partner
- Public health
- Safety

### 2. 'No' respondents

The small number of replies ( $n=4$ ), yielded little information: three out of four perceived themselves to be at no risk due to having tested negative in the past. One claimed that his unwillingness to test arose from a phobia of needles.

## Discussion

### Approach and uptake

The quantitative and qualitative approaches used for the study were effective methods for gathering information about the participants, especially given the aim to identify ethnic groups taking part and capture the views of as many male partners as possible within the short timeframe. The study is the first of its kind in a UK antenatal setting – although several studies in sub-Saharan Africa have demonstrated that voluntary couples counselling and testing was 'the most effective HIV prevention intervention for cohabiting couples in Africa, said to be the largest group at risk worldwide' [4].

As with studies included in the systematic review [3,5–7], the participation rate was disappointingly low at 70 out of 176 distributed (40%). This was compounded by the low distribution rate of 176 questionnaires from a possible 300 over 6 months (59%), indicating a lack of engagement by scan staff.

**Table 2. 'Yes' respondents: ethnic origin and birth country data**

<b>Ethnic origin</b>		<b>Country of birth</b>	
<i>White</i>		Australia	2
British	44	England / Wales / Northern Ireland / Scotland	41
Irish	1		
Any other White background	1		
<i>Mixed</i>		Germany	1
White and Black Caribbean		Ghana	1
White and Black African			
White and Asian			
Any other mixed background			
<i>Asian or Asian British</i>		India	1
Indian	1	Jamaica	1
Pakistani	5	Nigeria	2
Bangladeshi	1		
Any other Asian background			
<i>Black or Black British</i>		Pakistan	2
Caribbean	2	Middle East	1
African	4		
Any other Black background			
<i>Chinese or other ethnic group</i>		USA	1
Chinese			
Any other			
<i>Not stated</i>	5	<i>Not stated</i>	11
<b>'Yes' respondents to HIV screening total:</b>	<b>64</b>	<b>'Yes' respondents to HIV screening total:</b>	<b>64</b>

**Table 3. 'No' respondents: ethnic origin and birth country data**

<b>Ethnic origin</b>		<b>Country of birth</b>	
<i>White</i>		England / Wales / Northern Ireland / Scotland	3
British	2	India	1
Irish	2		
<i>Asian or Asian British</i>		Ireland	1
Indian	1		
<i>Not stated</i>	1	<i>Not stated</i>	1
<b>'No' respondents to HIV screening total:</b>	<b>6</b>	<b>'No' respondents to HIV screening total:</b>	<b>6</b>

### *Ethnicity and limitations*

The proportion of white British participants has relevance to existing data on local antenatal HIV service uptake, with the highest rate (99%) being from a low BME catchment area. Of the 64 'yes' responses, the vast majority (71.8%) were white British, along with one of white Irish background and one white Australian background. Responses from the Asian or Asian British groups totalled 10.9%, African respondents 6.2% and Caribbean 3.5%. The numbers for the 'no' response category were too small to be representative. A further limitation is absence of ethnicity data for the 96 people who accepted a questionnaire but declined to take part in the study.

Because a non-random process developed during the distribution of questionnaires (staff omitting to hand questionnaires to every couple on arrival), it is

impossible to say if certain groups (ie, white people) were targeted by staff over other groups. During data analysis, it also became evident that scan staff had neglected to give 37 participants the PIL required to fully inform the process. This detracts from the internal validity of the research because, firstly, it is not known if those declining to take part were the ones who did not receive the information; and, secondly, those who did take part may have done so without full information.

### *Significant themes*

The qualitative data is likely to be the most useful in informing and shaping the full implementation of a future couples screening programme. The six main categories showed a very strong focus among participants on the health and safety of their unborn baby and support and solidarity for their partner, even if this caused personal discomfort.

The responses also reflected a need for peace of mind, as though HIV were something lurking in the background causing worry or concern. The notion of wanting 'security and peace' was mentioned repeatedly. Some men indicated that they would relish the opportunity to test, as they had never accessed a health environment that offered such a service.

The most unexpected response was from those who felt that having an HIV test would facilitate patient care. There was an element of public health responsibility in wanting to help reduce the spread of HIV and contribute to research. These notions can be used as positive drivers, to be included in future health promotion material, as well as providing a focus for pre-test discussions with midwives, who will be involved in any future HIV testing programme for male partners.

Although the qualitative responses from the 'no' category were very small (n=4), it is notable that two respondents stated they would decline testing due to previous negative screening. This is an issue that midwives are currently expected to challenge – people change partners and also women coming from abroad or seeking asylum often wrongly assume that they have been HIV tested during health checks.

## Conclusion

This project has highlighted that male partners of pregnant women would want to be included in antenatal HIV testing. The main drivers for this were concern for the baby's health, an opportunity to find out their own status, a public health responsibility and support for their partner.

The qualitative responses from the male partners have provided a great insight into the way fathers care about the health of the baby, and can support pregnant women undertaking HIV screening. Some of their responses will determine the content of resources such as leaflets, flyers and online patient information.

This project has been successful in achieving its primary objective, to demonstrate the acceptability or non-acceptability of HIV testing for male partners of pregnant women. The secondary objective, to demonstrate that any particular ethnic group would more readily accept or decline HIV testing, was not achieved due to the poor distribution and uptake rate and concerns regarding bias during the distribution process.

The information gleaned from this feasibility study will inform service improvement in conjunction with the Manchester Public Health Development Unit: it is anticipated that the antenatal HIV screening programme will be expanded to offer HIV screening for male partners in antenatal clinics. The greatest impact of this development on future clinical practice will be the chance for health professionals to intervene (in the event of an HIV-positive result)

**Table 4. 'Yes' respondents: qualitative data (Total:59\*).**

1. The baby (n=16)	2. Peace of mind (n=8)	3. The baby (n=14)	4. Support partner (n=4)	5. Public health (n=3)	6. Safety (n=3)
Most respondents cited the unborn baby as a reason for accepting HIV testing in the antenatal period. Caring for the baby means awareness of status to ensure the baby's health and reduce risk, for example: 'I would want to have as much information about the baby's health as possible, even if the information was uncomfortable or difficult for me personally because the more information you hold the better decision you can make during the pregnancy.'	This category was a significant theme, for the health of both the baby and the respondent. Peace of mind refers to knowing one's HIV status and being sure that there are not any health risks, for example: 'As I have never had one before and would be willing to comply with a HIV test for peace of mind.'	Antenatal HIV testing offers an opportunity to test for many men who would not seek out screening. Thus there was an overriding feeling that it was 'good' or 'responsible' to check, for example: 'Not that I think I need one, but it's good to check and be sure.'	This category related to the support that male partners felt they wanted to give their partners during pregnancy, for example: 'As my wife was having tests I'd feel like I should do as well.'	This category related to a public health responsibility felt by respondents, a wish to 'help the hospital and staff in curbing the spread of HIV and reducing transmission, for example: 'Happy to participate in this survey and help reduce/eliminate HIV through research and any way possible.'	Respondents perceived that they would be safer, more secure, as would their partner and unborn baby, if they had awareness of their HIV status, for example: 'I was tested a year ago but better safe than sorry.'

\*The remaining 11 respondents offered no information with their answer, or offered information that was not appropriate to grouping by theme.

to promote safer sex messages and harm reduction. Also, it will enable support for couples – to maintain their relationships through counselling and advice and ultimately help prevent another baby from being born with HIV.

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# HIV, health and human rights – for us all

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**W**e were delighted to be asked to contribute to *HIV Nursing* journal. We begin by explaining a little about ourselves – our backgrounds and experiences in relation to our HIV diagnosis. We then describe some of our work together on HIV and human – especially women's – rights.

## Alice's story

I come from a large family of healthcare workers – my Dad, Mum and all but one of my four siblings ... and my husband, who is a retired GP. And I have HIV. All my family are supportive of me and my condition and this has been a huge help to me over the years. It has allowed me to understand not only my own HIV, but also how health professionals are supported – or otherwise – in dealing with and understanding HIV – or anything to do with loss of health, death and dying.

My initial experiences of learning that I have my very own HIV diagnosis were exemplary from the point of view of my healthcare. I was full of excitement, expecting a baby in 1992, with a new partner (who is now my husband). My then GP, a lovely older lady, knew that I had travelled a lot for my work in international community development and suggested that, in addition to the usual prenatal tests, I might have an HIV test. It was Friday 20 June 1992. She phoned me to say there had been a problem and asked me to come in. She explained that all the other tests had come back fine, except for the HIV – which was like a bolt from the blue. I felt fine, I looked fine – but I wasn't.

After telling me this, her first question was, "Can I give you a hug?", which in those days was still a brave offer. She then asked me if I felt able to tell my partner. Fortunately for me, our relationship was rock-solid and I answered, 'Of course'. She then asked me if I wanted to tell him myself or whether I would like her to tell him. I asked her if she could. So we arranged for us both to go back to my home, where I could sit with and hug my older children in what I already imagined were my last hours with them, while she took my partner into another room and told him the grim news.

That evening, after she had gone and the older children were in bed, I explained to my

partner as we talked that, of course, I didn't expect him to hang around – to which he replied, 'Don't be ridiculous, of course I am here for you'. We imagined that, since I was pregnant by him, I must have given him HIV. To our amazement and immense relief a few days later, we discovered that this assumption was wrong and that he was – and remains – HIV-free. We also realised that we were going to have to decide extremely fast whether or not to proceed with my pregnancy. Like my GP, our newly appointed HIV consultant was extremely kind and met us the next morning – a Saturday.

We were in total shock, imagining that I was about to die. My consultant was extraordinarily caring and supportive. He introduced us also to an obstetrician who carefully explained the options with regards to the baby. It was feared that, if I went to term, I would deteriorate and die, leaving my older children motherless and my partner a single dad. It was also feared that the baby, even if he was born, might fail to thrive, causing distress to the whole family. We went off alone to North Wales together for a few days to walk high up in Snowdonia and face the future – or lack of it.

We realised that a medical termination was the only manageable way forward, much as I felt devastated by this. I grieved deeply for this son's death – and for my diagnosis also – for 2 years. I contemplated killing myself, until I met an amazing lady at Positively Women, who described how she had been diagnosed in a prison cell and resolved then and there to get released, sort herself out and make sure this never happened to anyone else. What a wake-up call: what right did I have to go round feeling sorry for myself, when she had been through all that and was there supporting me now?

As well as this woman, my husband and these amazing medical staff, kind hands at my local support group OXAIDS in Oxford (which subsequently became part of the Terrence Higgins Trust Oxford), swept me up and nurtured me, encouraging me to get going again and to think about how I could transform my own experiences into supporting others. We started a self-help women's group there – which is still going

strong 20 years later. Through work contacts, I had the huge opportunity to develop a training package on gender, HIV, communication and relationship skills, known as Stepping Stones, which is also still going strong and has spread to over 100 countries around the world, translated into more than 20 languages [1]. We kept my HIV a closely guarded secret except for a very small circle of friends, family and colleagues, since we were very anxious to keep the older children clear of stigma.

I have been incredibly lucky to be supported in so many ways by different, caring people – and to be able to turn grief into something useful.

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### Silvia's story

I was born and grew up in Rome, Italy. I was a troubled young woman. Through my teens and twenties I suffered from depression, low self-esteem and used drugs to cope with my emotional fragility. It was difficult for others to get through to me, as I was hiding behind a mask of toughness and rebellion. Even though I came from a very liberal family, growing up in a Catholic country meant that in many respects I was compelled to adopt a social and cultural model that still made my role as a woman dependent, and subservient to men.

The 80s were strange years – and, as a young woman in a world still greatly dominated by men, it was difficult to feel truly empowered. We were supposed to be 'liberated' and there was almost an assumption that, if we weren't sexually available, we were 'frigid'. However, if we carried condoms we were sluts ... or just fun-spoilers. As a young woman you just couldn't win! I think that my fragility, drug use and these stifling cultural norms made me very vulnerable to HIV. Even when I was in a risky relationship and aware of HIV, I found it really hard to negotiate condoms – and I had never heard of female condoms or any other prevention methods which could have protected me as a young woman.

When I received my HIV diagnosis just before my 30th birthday, I fell apart. I was unemployed, I didn't have a partner, I was looking after my father who had advanced dementia (my mother had died when I was 20) and as a woman, I was expected to play a central role in his care. What made dealing with my diagnosis incredibly hard was the deep feeling of shame that for months stopped me even speaking to some of my closest friends. I had never felt so scared and lonely in my entire life. It wasn't until 2 years later,

after I had moved to London and started accessing my first support groups at Positively Women (now Positively UK), that I was able to overcome that terrible feeling of shame and isolation. Since then, I have become increasingly involved with the organisation and I work now as Community Development Manager.

Unfortunately, despite incredible medical advances which mean we have an almost normal life expectancy, many women with HIV in 2012 still experience the terrible isolation and secrecy I did over 15 years ago. Because of this, I continue working hard with other women living with HIV, such as Alice, at increasing the voice and visibility we have in our communities. I believe that stigma feeds on silence and that, as women with HIV, we can play a central role in ending it and create a world where our human rights are fully respected. In 2004 we established PozFem UK, a national network of women living with HIV. Through PozFem we have organised training sessions for women with HIV to become advocates, to respond to national policy and to get involved with the media [2]. I believe that being part of a collective voice can give us the power to be visible and challenge stigma.

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### Raising the game

We both realised that working at community level, no matter how inspiring, is just not enough for true change is to take place. There was a need to try to influence policy makers and donors, as well as work with people in communities.

So we both joined the International Community of Women living with HIV and AIDS (then with its international coordinating office in London) [3], started by some amazing pioneering women with HIV in 1992. Through that, we also met more women activists with HIV in London. The two of us met for the first time at an international conference of people living with HIV in Kampala, Uganda in late 2003. We met again in 2004 in Leicester at the National Conference of People Living with HIV ('Changing Tomorrow'), when 50 women with HIV met together and PozFem was born, thanks to the leadership of Silvia together with Fiona Pettitt and Carmen Tarrades.

At this point, with the children now a bit older, Alice began to feel able to be more open about her status; while for Silvia, this time marked the end of a relationship and a decision to go more public with activism. We both decided to stand up and be counted. We started to go public about ourselves, to use our own HIV status as leverage to challenge the many rights abuses experienced by other women with HIV, both in the UK and around the world:

discrimination, death, coerced sterilisation, gender violence, and worse – all as a result of their HIV status.

The contrast between the relative support we received, and the lack of it for millions of women in the UK and around the world, was and is stark. We began to learn the language of human rights, of sexual and reproductive rights, the importance of meaningful involvement of those most affected by an issue – whatever it is – in order to solve it. We became political with a capital P.

### The painful truth

However, for all the amazing progress that has been seen, we still have friends in the UK who are rejected when potential new partners learn of their HIV. We have a colleague right now who has lost count of the number of times health staff have asked her why on earth she is 5 months pregnant. We still know many women in the UK who have experienced abusive behaviour from partners or other family members (or healthcare staff) once it is known that they have HIV, whether the abuse is physical, sexual, emotional – or by financial, even legal means. We still know a lot of women in the UK who dare not tell their work colleagues or even their children that they have HIV, for fear of losing their jobs or their children's love and affection.

In addition, we are globally in contact with many, many women with HIV who have had a wide range of extraordinarily intense experiences of pain, rejection and grief as a consequence of their HIV diagnosis, including coerced sterilisation. The experiences of some are recorded in a series of interviews conducted in 2008 [4].

The many appalling issues that face women living with HIV around the world could and should be rectified through the use of human rights legislation.

Yet few know anything about this or how it applies to women with HIV. Unfortunately, the training of health staff, both in and beyond the UK, is severely lacking in respect of human rights legislation. We should all be taught at school about the Universal Declaration of Human Rights [5].

### Education ...

However, failing that, we suggest that all health workers should have it as a fundamental part of first-year studies, along with the World Health Organization (WHO) Definition of Health [6], the Convention on the Rights of Persons with Disabilities [7], the Convention on the Rights of the Child [8] and the Convention to End Discrimination Against Women [9]. The Programme of Action agreed at the International Conference on Population and Development (1994) [10] is another key document in the land of sexual and reproductive rights for women, as are the Millennium Development Goals [11] and the Vienna Declaration from 2010 [12].

### ... legalisation

The latter promotes the science of harm reduction (clean, safe syringe exchange, methadone substitution, legalisation of drugs) and could help us talk openly and in an unbiased way with young people – for instance, about the pros and cons of drug use – so they could more effectively decide what risks they want to take, or not take, with drugs.

Similarly, legalisation of sex work would help to combat violence against sex workers; legislation to make homosexuality legal would enable fully informed, non-judgmental rights-based public health strategies possible here also. (See, for example, the work of the Global Network of Sex

### A change in the weather: life after ART

The picture nowadays is of course worlds apart from the mid-1990s, when Alice was first diagnosed:

'Antiretroviral therapy (ART) arrived in the mid-1990s and I witnessed the Lazarus effect at our women's group in Oxford: suddenly, we stopped having to go to funerals. I had several bouts of shingles and one of Bell's palsy. However, since March 2000, when I have been on ARVs, my CD4 cell count has soared to 860 and I have an undetectable viral load.'

In Italy, however, the impact of ART took much longer to be seen. In the 1990s Silvia had shingles and struggled in the first few years, especially with bouts of fatigue:

'However, having started ART in 1998, I now have an undetectable viral load and a CD4 cell count of 700. Nowadays I look after myself through yoga every day and feel in control of my health. However, you really need to have a good understanding of your care and play an active role in it. By an oversight I was prescribed an overdose of my medication, taking almost double the dose of one of my medications for almost 10 months, and feeling really ill. This shows how strong ARVs are and how important it is for us to make sure we have the access to information that enables us to sort out such mistakes, and that we should not be passive in our care.'

Thanks to the 'treatment as prevention' advances, we can now safely have unprotected sex if we want to, free of fear of passing our HIV to others. And women with HIV can now have babies, with over 99% certainty that they will be born HIV free, even with normal vaginal delivery. Scientific advances, indeed.

Work Projects [13], IPPF's Charter on Sexual and Reproductive Rights [14], IPPF's guide for young people living with HIV (Healthy, Happy and Hot) [15] and the Global Forum on MSM & HIV [16].)

### ... and information

All these measures would enable everyone involved to discuss and share, fully and frankly, information which is their right – in order to keep themselves and others safe. Instead, much of what is currently discussed in schools, health centres, households and elsewhere is wrapped up in restrictive laws and regulations that turn justice, our health and our rights into the prisoners. Yet most people, including health staff, have never heard of these documents, let alone had the chance to consider the effects of restrictive laws and policy on what can or can't be said or done, to support people to look after themselves. With health staff unaware of these issues, there is not much hope for the general public.

So one thing we have been doing is to develop a human rights component to the SHE programme. The aim of the SHE programme is 'to build *Strong, HIV positive, Empowered women* through peer support sessions facilitated by women living with HIV' [17]. This is a peer-led self-help training programme for women living with HIV. (There is also a parallel programme for clinicians, soon to be released.) The SHE programme consists of a toolkit and a website. The human rights component, available free to download by anyone [18], gives participants the opportunity to learn about and discuss some of the basic issues in the documents listed above, in order to understand that, since the UK is a signatory to these conventions, they are protected by these conventions here in the UK.

We also work with second-year medical students at my local university (Alice), and GPs and social workers in London (Silvia) to support them to read and understand these documents and reflect on how the content relates to their own future medical practice. These conventions apply to us all and, if you are working in a country that has signed them, it seems logical to know what they contain. Yet in our experience, few health or social work staff have even heard of them, let alone read them.

### Fear through ignorance

Furthermore, it worries us hugely that many health staff with HIV themselves do not share their status with their colleagues or managers, for fear of being ostracised or losing their jobs – a chosen vocation, of course, which they love. One nurse we know, who works in mental health, described how her colleagues spoke very disparagingly of an individual in their care who had HIV. She felt so lonely and had to pretend to agree with their criticisms, for fear of arousing suspicion.

Meanwhile, an anaesthetist friend at another hospital has recently realised that some theatre nursing staff chose to take the day off or swap shifts when they learnt that someone with HIV was going to be on the operating list. Small wonder that in this context any health professional with HIV is going to keep their status very quiet. WHO states, 'less than 10% of the HIV among health workers is the result of an exposure at work'. The rest of HIV amongst health workers is contracted in the same way that the rest of the general population contracts HIV – in their own lives outside work.

Sadly, no-one in the UK, as far as we are aware, is keeping general health staff abreast of such facts from WHO; nor of scientific advances about treatment as prevention. So general health staff remain understandably fearful and often intolerant of people with HIV in their care, believing that these people pose a major risk to their own health and seeing their own personal lives as somehow separate from – and therefore perhaps magically protected from – the vulnerabilities to HIV exposure of the population at large. Given the rising incidence of heterosexual HIV transmissions and of HIV amongst women in the UK – and the high numbers of *females* working in the NHS – this lack of training support for health workers seems particularly remiss.

### Support through experience

Moreover, the scientific advances of treatment as prevention surely allow greater scope than ever for HIV-positive healthcare professionals to continue working as they have, with no risk whatsoever to fellow colleagues or people in their care, provided universal precautions are observed. We have heard of examples outside the UK where people with HIV find it inspiring and liberating to learn that the health professional looking after them has HIV also. This is true for anyone with HIV, of course. For women in particular, especially if they are only learning about their HIV for the first time when pregnant (the usual point of diagnosis for women), the possibility of having health staff at hand who can say, 'I've been here too, let's work on this together', would be extraordinarily reassuring [19].

Just as health professionals who have had breast cancer or other major conditions can undoubtedly bring this personal insight to their work in a way that enhances their ability to support others, so it is with HIV. However, because the stigma continues, this enhanced insight is often shrouded in layers of secrecy. What an immense lost opportunity!

### Conclusion

Health and human rights advocate, Professor Sofia Gruskin, who directs the Program on Global Health and Human Rights at the Institute of Global Health, University of Southern California, has written with a

colleague, Laura Ferguson, in the *WHO Bulletin*, about the need to introduce human rights indicators into healthcare settings [20]. We welcome these recommendations: as the UK seeks to roll out HIV testing to GP surgeries and A&E departments, this accountability provision is needed more than ever. Such measures are needed to protect the human rights of us all – including health staff with HIV, so that their particular insights and skills may be especially welcomed, harnessed and appreciated.

We look forward to hearing what readers of *HIV Nursing* think about this – please get in touch and share your thoughts with us.

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# Standards for psychological support for adults living with HIV: a review

## Part 2: nursing perspectives

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### Introduction

The aim of this paper is to review the eight standards from a nursing perspective. It is recommended that you read it in conjunction with Part 1, carried in the previous issue of this journal. The standards emphasise the importance of continually promoting mental health and psychological wellbeing in an environment that is non-judgmental and safe for the patient. For a seamless referral to be made, it is necessary to engage the patient in all aspects of care, continually assess for any psychological difficulties and be aware of the care pathways in place.

These standards, published in November 2011, are the first of their kind in the UK. The document was a joint publication by the British Psychological Society (BPS), the British HIV Association (BHIVA) and the Medical Foundation for AIDS and Sexual Health (MedFASH).

The standards cover psychological support of all kinds for adults diagnosed with HIV, from the point at which they are diagnosed. For the purpose of this paper psychological support is defined as 'any form of support which is aimed at helping people living with HIV to enhance their mental and their cognitive, emotional and behavioural wellbeing' [1].

### The scope of the standards

Psychological support includes, but is not limited to, emotional support and a variety of talking therapies, cognitive rehabilitation and appropriate medication [1]. It is provided at different levels of complexity by a wide range of professional groups, peers and informal providers, in clinical settings and in the community. Providers of this support range from psychologists, nurses based in clinics/the community, doctors in clinics/GP surgeries, counsellors from voluntary organisations such as the Terrence Higgins Trust – as well as people living with HIV (PLHIV) offering support as volunteers. These various levels of support are defined in the Step care model, by which the standards defines and outlines appropriate interventions for PLHIV (see Figure 1, Part 1 of this article in *HIV Nursing* 12.1).

It is important to recognise that, although psychological support is important, it is not a

panacea. Other significant issues include housing, income/benefits, problems with immigration, stigma or side effects of antiretroviral therapy (ART). Therefore it is essential to state that, although the possible impact of such issues on wellbeing is recognised, these standards relate to and address only psychological support [1].

The following significant topics fall outside the scope of the standards:

- Testing and pre-test discussion – except in the context of psychological support following a positive result;
- Guidance or recommendations on specific treatments, eg, medication;
- Psychological support for children – guidelines for the support of children and their families are currently under preparation by the Children's HIV Association (CHIVA);
- Particular service models which should provide the care described – service configurations vary according to local circumstances;
- The specifics of competencies required by those providing psychological support at all levels – clinical competency is and remains the remit of that individual's professional body.

### The standards in practice

There are eight standards, which are listed and then outlined in more detail below.

- 1) The promotion of mental health and psychological wellbeing
- 2) Comprehensive psychological support services
- 3) Engagement of people living with HIV
- 4) Support at the time of diagnosis
- 5) Identifying psychological support needs
- 6) Competence to provide psychological support
- 7) Coordination of psychological support
- 8) Evidence-based practice

#### *Standard 1:*

#### *The promotion of mental health and psychological wellbeing*

People living with HIV (PLHIV) report not being asked questions relating to their psychological wellbeing by some clinicians [2] – despite ample evidence of psychological issues associated with

HIV (anxiety; depression; post-traumatic stress disorder; coping difficulties; suicidal ideation; sexual and neurocognitive problems, see Part 1). Notably, PLHIV frequently report experiencing HIV-related stigma from health and social care professionals, especially those not specialising in HIV [3,4].

These issues have been raised recently at various service user meetings in South London, as part of wider consultation reviewing HIV care and support in South London. Strong concerns have been voiced by specialists over the transfer of routine HIV care to GP practices [5], with only complex cases allocated to HIV-specific clinics. This proposal has led some patients to express a range of fears and worries about attending their own GP with HIV-related health problems, hence the misgivings of those specialists who have been caring for them.

The social issues and challenges specific to PLHIV, including stigma and discrimination [6], cause patients to fear disclosure of HIV-positive status. They also need to deal with the potential for onward transmission and the risk of criminal prosecution for HIV transmission [1]. Therefore, it is vital for both clinic and community nurses to reassure patients that services provided for PLHIV are totally confidential – a fact that nurses should constantly publicise and reinforce, with HIV-specialist nurses in particular offering an example for their non-HIV colleagues. This role is key to effective service provision and is an important component in routine practice given the staff turnover that is now a fact of life.

Finally, for those not wishing to discuss their psychological problems with a clinician, details of online support can be very useful.

### *Standard 2:*

#### *Comprehensive psychological support services*

All PLHIV should be assessed for the level of support appropriate to their needs [1]. The Step care model offers guidance for planning and enabling access to the services required – from information-giving and supportive communication (Step 1/Step 2) to more complex intervention (Step 3/Step 4), such as admission to an acute mental unit, or cognitive screening and assessment.

Some practitioners who identify psychological distress may not know how to deal with emotional issues or where to access advice or support for their patients [7,8]. Wherever you are based, as nurses you are the first point of contact for your patient. Therefore, it is essential that you have a knowledge of services and keep abreast of recent changes, particularly in the current economic climate. There is no implicit expectation in the standards that every health worker is expert in psychological therapy. However, talking and above all listening to the patient is important, as is knowing points of

referral for specialist interventions. All patients should, at the very least, have access to the first level of the Step care model (informal counselling/support and signposting to additional services). As nurses, it is paramount that you can deliver this.

In order to support PLHIV in managing their condition and adhering to ART, access to interventions at all levels should be timely [9–11]. Waiting times and delays may cause further psychological difficulties and associated health problems, including non-adherence. Therefore patients should not experience delays in referral to services at levels 2, 3, and 4, when this is indicated [1] – particularly where there is a risk of suicide. Suicide, attempted suicide and suicidal thoughts are all elevated in PLHIV [12], and prompt referral minimises the risk of death by suicide, as well as other delay-associated risks such as onward transmission [1]. Due to regional variations, some UK HIV clinics have dedicated psychological services, whereas others have to access these services outside the clinic setting.

### *Standard 3:*

#### *Engagement of people living with HIV*

Greater involvement of PLHIV in service planning is promoted by UNAIDS, stating the principle that:

'aims to realize the rights and responsibilities of people living with HIV, including their right to self-determination and participation in decision-making processes that affect their lives' [13].

Statutory guidelines on patient participation in planning and delivering care are also included in both the 2002 National Health Service Act and the British HIV Association's 2007 *Standards for HIV clinical care* [14].

Thus PLHIV should clearly be engaged in the planning, delivery and evaluation of psychological support services, and it is part of the nurse's role to facilitate this standard. Nurses should establish which service(s) the patient wants, from the range available; and also encourage them to provide feedback – by questionnaire or service user forums in clinic – which is essential to inform effective service provision [15–19]. PLHIV have an important role to play in sharing information about HIV and HIV services with those more recently diagnosed – as well as providing peer support, advice and advocacy.

### *Standard 4:*

#### *Support at the time of diagnosis*

At the time of diagnosis, all PLHIV should be offered one-to-one emotional support by the practitioner giving them the test result. If, after the initial post-test discussion, more in-depth counselling or other support is urgently needed, rapid referral to

an appropriate provider should be offered if this is beyond the competence or capacity of the testing provider.

As a nurse either working in a clinic or the community, it is always essential to ensure that newly diagnosed clients have had the opportunity to discuss their positive result. It could be at that time beneficial just to give the patient information leaflets, which may be all the patient can take on board at that point. People can experience very strong feelings of shock or anxiety when given their diagnosis, and it can be difficult for them to process information immediately, especially if the diagnosis is unexpected [20].

Support on diagnosis is particularly important for an inpatient on an acute ward, where the PLHIV is not only coping with the shock of diagnosis but also with a serious illness or possibly a life-threatening condition. Late diagnosis is on the increase [21] so a nurse in this environment must be very focused on giving the patient support and referring to more specialist psychological services where necessary.

#### *Standard 5:*

##### *Identifying psychological support needs*

PLHIV should have access to regular screening to identify if they have psychological support needs.

Although many individuals are able to adjust to living with HIV with little need for psychological support, those who experience difficulties may struggle to find or access further support. Psychological distress and specific mental health difficulties in PLHIV are frequently under-recognised by providers [2] and sometimes under-reported by patients. Therefore, nurses should continually screen patients to determine if further psychological support is needed. Screening usually entails asking a set of questions structured to identify the service to which referral should be made [1]. There is no expectation for a formal psychological assessment at this stage because you will be able to tell from the patient's responses whether they need input from specialist mental health services. You can then make the appropriate onward referral, either for assessment of self-harm risk by a psychiatrist or for additional therapy by a psychologist or counsellor. At this juncture you can also screen for cognitive difficulties. Once the patient is screened and their needs are identified, it is essential to make a prompt referral to the appropriate service(s). Therefore, it is important to have effective care pathways in place because early detection and treatment of psychological difficulties in those with long-term health conditions can improve health outcomes and psychological wellbeing, reducing more frequent and costly interventions [22,23]. Effective screening can identify:

- pre-existing or current psychological difficulties where patients require immediate referral for further assessment;

- patients whose mental health could decline due to acute stress or depression following diagnosis;
- where low-intensity interventions may be effective (levels 1 and 2 of the Step care model);
- requirement for onward referral because of alcohol or substance misuse.

For many patients, nurses are a very significant point of contact who retain a position of trust long term. Working in the field of HIV, you will know how common psychological difficulties are in people living with chronic health conditions [11]; however, to maximise the effectiveness of your role, ongoing screening is vital so that you keep up with the changes in circumstance that will inevitably affect your patients.

#### *Standard 6:*

##### *Competence to provide psychological support*

PLHIV should have their psychological support provided by competent practitioners [1]. As an HIV nurse, you will have had to meet the requirements of the Nursing and Midwifery Council; and will also be aware of the NHIVNA Competencies for this field of care [24]. All services providing psychological support for PLHIV should ensure that their practitioners demonstrate competence on an ongoing basis and should make provision to support the maintenance of competence through training, continuous professional development and supervision [25,26]. These standards recommend that practitioners delivering care and treatment at levels 4 and 5 of the Step care model should provide specialist training to practitioners operating to levels 1 and 2.

#### *Standard 7:*

##### *Coordination of psychological support*

PLHIV should have access to appropriate psychological support services within a managed framework.

Psychological support for PLHIV should be given equal priority with other aspects of their care and fully integrated with HIV diagnosis and treatment. Where HIV service networks or clinical networks are in place, consideration should be given to including psychological support for PLHIV within their scope. Networks can facilitate equity of access and care quality across providers, as well as fostering multidisciplinary working and professional development [1].

As an HIV nurse, you need to engage closely with the pathways linking clinical care with psychological support – and be aware of any changes on the horizon. Pathways should be explicit, agreed and adopted by all HIV clinical care providers [27].

## Standard 8:

### Evidence-based practice

All psychological assessment and interventions for PLHIV should be based on the best available evidence: this eighth standard underpins the other seven. The goal of evidence-based practice is to improve outcomes for the service user, enhance quality of care and provide some standardisation of treatment and other interventions. Using evidence-based interventions also improves cost-effectiveness, by avoiding expenditure where return has been shown to be limited [1].

However, it was recognised when writing the standards that the evidence base is limited. Data from randomised control trials (RCTs), by far the most reliable, is relatively sparse in the context of psychological support interventions in HIV [1]. The standards suggest that existing evidence-based practice guidelines should be used as far as possible to inform practice in psychological support for PLHIV – but not to the exclusion of other meaningful sources such as qualitative and outcome research, given growing recognition of what these design modes can contribute [1]. It is also important to acknowledge the ongoing debate on the broader cultural effectiveness of interventions conducted on white American or British populations. With these provisos firmly in mind, it is recommended that all service users from all communities affected by HIV are involved in evaluating assessment methods and interventions.

## Conclusion

The role of HIV nurses on the patient journey has many facets. They help the patient navigate the healthcare system at a very difficult time and provide day-to-day care and support in a myriad of ways. Also, while nursing the patient in a supportive, stigma-free environment, they act as ambassadors to fellow nurses outside the field about the importance of being non-judgmental.

As nurses, the therapeutic relationship you have with your patients places you in a prime position to identify any psychological problems they may be experiencing. These standards, with the additional guidance of the Step care model, offer nurses a framework for determining what level of care is needed, and when. The hope is that this article has offered some useful guidance on early identification of psychological problems – to facilitate prompt and appropriate onward referral.

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# What women need: options for contraception and prevention of HIV transmission

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## Hormonal contraceptives

**I**njectable hormonal contraceptives are the third most prevalent form of reversible contraception used worldwide [1]. Whilst in the UK only 3% of women of child-bearing age choose this method (the vast majority within the 18- to 20-year age group) [2], some 14 million women in sub-Saharan Africa use a hormonal form of contraceptive. Of these, 60% are using injectable depots [1].

In *HIV Nursing* 11.3 we mentioned the publication in *The Lancet* of the results of a 2-year, seven-country study, which contradicted much previous research and generated significant controversy [3]. The study concluded that women using hormonal contraceptives, particularly injectable forms, were at a significantly greater risk of acquiring HIV. It also found that this type of birth control for women living with HIV doubled the chances of transmission to male partners. The women in the study did not specifically identify the methods in use, but the majority were assumed to be using the progesterone-only depot, medroxyprogesterone acetate (DMPA) (Depo-Provera), as the most commonly offered method in family-planning programmes in the developing world. However, not all research on this subject has found such an association with HIV transmission risk. A 5-year study of over 6000 women from Zimbabwe, Uganda and Thailand found that neither the combined oral contraceptive pill nor Depo-Provera injections were associated with HIV infection [4].

This year the World Health Organization has already held two meetings of public health experts and community representatives from a variety of high-prevalence areas, to seek consensus and make recommendations. This was preceded by an extensive technical review which concluded that, in studies judged to be of sound design, no consistent evidence currently exists of a significant association between oral contraceptive use and HIV acquisition. The reviewers observed that, although the evidence was mixed for specific depots such as Depo-Provera, many higher-quality studies failed to show an association. The panel has concluded that there is currently insufficient evidence to amend current WHO guidelines and there are thus no suggested restrictions on the use of hormonal contraception for HIV-positive women to prevent unintended pregnancy [5].

The benefits of effective hormonal contraception are obvious and unequivocal. Women in sub-Saharan

Africa face the world's highest risk of maternal death [6] and depot hormonal contraception makes a substantial contribution to reducing the risk of death due to unintended pregnancy or complications of childbirth. However, to date, the most effective method to prevent HIV acquisition and transmission has been the male condom [7], the success of which relies on the willingness and ability of men to use it reliably.

## The male condom

Working in sexual health promotion, we are familiar with the complexities of advising patients on negotiating condom use with their sexual partners. The challenges are multiple. Many women do not have relationships of equality with men. Condoms are associated in many contexts with illicit sex or sex outside a long-term relationship, and women can fear accusations of infidelity if they request their partner uses a condom. Asking a partner to use a condom can be particularly difficult in situations where the woman's primary concern is to avoid sexual violence. Even in 'equal' relationships, many men are reluctant to use condoms, reporting that they reduce sexual enjoyment [8] or are difficult to use. Other common reasons given for not using condoms include 'trusting their partner', and a perceived remote risk of HIV infection [9]. In addition, the fact that condoms also act as a contraceptive may be a disincentive for some couples to use them, especially where motherhood is a cultural norm for women.

## The female condom

Another method of contraception with a role to play in HIV prevention, which most of us admit to frequently overlooking, is the female condom (Figure 1). Marketed as the first female-controlled barrier method (as Femidom), this new method arrived in 1993 amid great expectations for reducing HIV transmission. However, nearly 20 years later it is still meeting with resistance. At the 2010 International Aids Conference in Vienna, the Universal Access to Female Condoms (U AFC) Joint Programme ran a series of workshops and promotional events. However, they acknowledged that reluctance to use this method remains widespread and further efforts are needed to improve uptake.

Initially, production cost was a barrier to widespread promotion. However, since 2005 a cheaper, second-generation version has been



Figure 1. The FC2 female condom. [www.supportworldwide.org](http://www.supportworldwide.org)

available and there are many distribution and education programmes in a number of developing countries [10]. Researchers in 2008 identified four major categories for facilitators and barriers to the use of the female condom: mechanical, psychosexual, interpersonal, and situational [11]. Difficulties with insertion and lack of product availability were particularly identified as limiting its 'popularity'. The psychosexual and interpersonal factors included female empowerment, relationship status, partner preferences and partner objections.

So far the female condom has not achieved equivalent status to the male condom but it does expand options for contraception and STI prevention, especially for women. It may provide women with a greater opportunity to engage in safer sex, for example, with men who refuse to use the male condom. Equally, in situations where open dialogue is not possible, some women may be able to use one without the male partner being aware that the device is in place.

### Support and choice for women

As nurses, wherever we practise, what we recognise as paramount is that women need affordable and accessible choices in relation to contraception. They need to feel able to make informed decisions about the right method for them as an individual, allowing them to be empowered to determine their maternal and sexual health. These recent findings also reinforce the need for closer integration of sexual and reproductive health programmes with HIV prevention activities. High HIV-prevalence countries in particular depend on family planning services to help reduce high maternal mortality rates. Ideally, health facilities providing care and treatment for HIV and other

sexually transmitted infections should also offer women reproductive health and family planning services, with a variety of contraceptive choices.

Governments and the pharmaceutical industry need to invest in improved technologies to increase the number of contraceptive options on the market. There is also a clear need for further comparative research to establish the safety and usability of a variety of contraceptive methods including implants, patches and non-hormonal methods such as intra-uterine devices.

Our role requires us to find the best way of communicating this information to our female patients and support them in their decision-making. In the meantime, we must stress the continuing importance of dual protection for couples who wish to avoid unintended pregnancy and prevent HIV transmission. All those working in HIV care clearly need to reinforce this message, whether or not our specific field is 'family planning'. Myths, misconceptions and fears need to be explored and unravelled, with awareness of cultural and gender differences. Furthermore, a positive attitude on our part is essential in facilitating open dialogue and making both male and female condoms increasingly acceptable to people in our care.

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