Sex, Life and the Female Condom: Some Views of HIV Positive Women

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Abstract: This article offers some insights into the experiences of HIV positive women with the female condom, drawing on my own personal experience and responses of 18 members of the International Community of Women Living with HIV/AIDS to an e-mail survey conducted in 2005. Major barriers reported to female condom use were cost and sporadic or very limited access. All respondents talked about needing to negotiate the use of female condoms with their male sex partners. Most felt more in control and more confident during sex when using the female condom than with the male condom or unprotected sex. Concerns about female condoms appear to be common, especially among women who have never used one; those who had used the female condom for long periods of time said good things about it. Women reclaiming our bodies is a central part of the joy and the challenge of promoting the female condom. For HIV positive women and girls, using a condom is more than protection against pregnancy, but a matter of life and death greater than the risks pregnancy can bring. Female condoms could make a critically important contribution to protecting HIV positive women’s sexuality and continued sexual activity, as a fundamental part of our sexual and reproductive rights, if only they were more widely available and affordable. © 2006 Reproductive Health Matters. All rights reserved.

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rather than male condoms, how and where they got hold of it and whether it was easily available near them, what it cost and whether they found the cost expensive or not, whether they knew other positive women who were using it in their country or neighbourhood, and how they first decided to try using it.* Eighteen responded. I analysed their responses by hand, grouping the responses according to similar themes that emerged.

This article provides some small insight into the attitudes and experiences of 18 HIV positive women from different countries in relation to the female condom, and draws on my own experiences of female condom use, as my only contraceptive method over the last 14 years, since I was first diagnosed with HIV in 1992. It describes and discusses the survey findings and other issues related to the female condom, women’s sexuality in general and HIV positive women’s in particular.

Findings

Cost

Almost all the respondents reported that a major barrier to female condom access is cost. This appears to be as true in industrialised countries as in others. In Australia, for instance, the cost of the female condom was reported to be $10 Australian for just one. While it was possible for respondents, in countries where they were still available, to obtain free male condoms, female condoms were rarely if ever available free. Therefore, for many, even the opportunity to try the female condom just was not there.

Availability

Most respondents reported that access to the female condom was at best sporadic and at worst, very limited. Even in the UK, three or four years ago, my local branch of a nationwide pharmacy chain stopped stocking the female condom due to low sales, and only re-introduced it after I complained to the store manager. More recently, that same chain withdrew the female condom nationwide, until a concerted letter-writing campaign, backed up by Reproductive Health Matters and Positive Nation, persuaded them to restock. In Australia too, in Melbourne, there only appear to be two outlets who sell female condoms and most pharmacies there appear to be unaware of its existence.

“Every pharmacist I asked didn’t seem to know what I was talking about, so promotion and marketing have been atrocious.” (ICW member, Australia)

Elsewhere, availability is even more limited. My husband and I regularly buy up the whole stock of our local pharmacy, in fear that it may once more become unavailable; and ICW members who use the female condom elsewhere reported similar actions.

Size

For many of ICW’s members, in Asia particularly but not exclusively, the size and bulkiness of the female condom seemed to be an issue. Members commented that it is too large for them to use and that they would like a smaller one to be made available, with which they would be happier. Size does appear to be a factor limiting its popularity in some countries.

Rustling noise

A number of ICW members commented on the rustling noise of the female condom as something which put them off its use. One likened it to “a wrinkling noise, like a supermarket bag”. Others also commented on this sound, which they said drew unwelcome attention to it. However, elsewhere in the world, I have heard that men have grown to recognise this sound as a sexual turn-on, so maybe this is something that needs to be worked on with men, as well as women.¹ In my own experience – and I have been monitoring this carefully over recent months – once you have the female condom warmed up to body temperature the noise seems to stop – but then again maybe I just stop listening at that stage.

*All ICW members are HIV positive and those who belong to this e-mail list are in a higher socio-economic group, by virtue of education and e-mail access, than many of the group’s compatriots. However, they come from a wide age range and diverse backgrounds and interests (including academics, nurses, charity workers and businesswomen) and many are in touch with and/or coordinate groups of other HIV positive women in their own countries, both in urban and rural locations. ICW members number several thousand globally, but most have no access to a phone or computer, let alone e-mail.
Appearance and taste

Appearance is a major stumbling block for many of ICW’s members and I believe they are not alone in this. One thing I would like to know is whether there is any variation in the colour of the female condom around the world. Are there problems in having different coloured female condoms available, just as there are different coloured male condoms? The colour of the female condom in the UK – a rather insipid, creamy white – is definitely not a great attraction for many. In the words of another member from southern Africa: “the sight of it is a serious turn-off”. The question about the taste of the female condom was also raised:

“I work with young people and they tell me that oral sex is a normal part of their sex lives these days, but that no-one ever uses condoms for that. They laughed at the idea when I suggested it.”

“I would like to practise oral sex with my partner but we worry about the safety side of that and he tells me that the taste of the female condom is not so pleasing to him.”

Again, it would be interesting to know whether it would be possible to develop a range of differently flavoured female condoms, as with the male condom, since transmission of some sexually transmitted infections, and also HIV via semen, is a risk with oral sex.

Lubrication and other physical concerns

One ICW member commented about the lack of lubrication available which, she said, resulted in painful intercourse for her. Whilst the female condom is already well lubricated, I wonder if lubrication could be packaged with female condoms for those women who need extra lubrication, so that pain on intercourse is greatly reduced or avoided. This is done with some male condoms.

Another ICW member expressed concern about the possibility that the strands from her IUD might tear the lining of the female condom, thereby damaging its protective value. The accompanying instructions say nothing about this, but a doctor I know who provides the IUD regularly and a gynaecologist have both assured me that the strands of the IUD are far too soft to tear the lining.

Other ICW members felt concerned that the female condom could only be used in the “missionary position” (woman on her back, man on top) and feared that if people had sex in other positions it might slip out. There was also concern from some that the female condom might be dislodged or slip into the vagina easily if sexual activity was anything more than “a gentle thrust in and out of the penis”. I have never found either of these to be a problem.

Another ICW member, who works as a community educator in Africa, told me of a woman in the community who had tried using a female condom a few days previously and “that the condom cannot now be traced. She came to report this four days later after failing to get it out. I referred her to the provincial hospital.” Luckily, this is highly unusual!

However, these concerns do appear to be quite widespread, especially amongst women who do not use the female condom or who have only heard of it. Those of us who have become accustomed to using them regularly have never encountered problems of it slipping into the vagina or disappearing, provided that the outer ring is correctly placed outside the vagina. But it is precisely these kinds of concerns which can spread widely and gain ground as rumours and make people fearful of attempting to try the female condom in the first place. The mention of these concerns at all would suggest that some specific additional information in the accompanying instruction leaflet, to allay potential users’ doubts and fears would be most useful.

Negotiation skills for using the female condom

All the ICW respondents talked about needing to negotiate the use of female condoms with their male sex partners, whether these were occasional partners, more regular partners, husbands or clients. This is not surprising, given that the vast majority of ICW’s members are women who have contracted HIV through heterosexual sex.

Some women, including a member in Asia who works with a group of HIV positive and negative sex workers, said they had had some good experiences of either hiding the female condom from clients, by inserting it well before sex takes place, or by persuading clients to accept it as part of the deal. However, this was not always possible, and some clients could not be persuaded. This lack of ability to negotiate with partners about use of protection and the fear of violence if negotiations went wrong was a
problem reported also by several members in Africa, many of whom echoed the one who said:

“A lot of issues such as women’s empowerment to take decisions, breaking cultural and tradition barriers, need to be addressed. Its usage requires open communication between the partners, as it requires the female to guide her partner into the vagina (which may be difficult given the cultural and traditional barriers that a man should be the initiator or you will be considered a slut).”

Male or female condoms: which to use?

Most members reported that they felt more in control and therefore more confident during sex when using the female condom than with the male condom or with unprotected sex. One respondent expressed her faith in the male condom to prevent pregnancy and HIV transmission, but was not yet sure about the female condom:

“My partner hated having to stop the foreplay and put on the condom, and I guess I did not help matters as to me the [male] condom is such a safety net, as I don’t want to: 1) fall pregnant right now and 2) infect someone else. But he thought that I was not making using a male condom sexy enough, and I guess in a way it made him feel like we were being too clinical. So one day I inserted the female condom, which was fine, and we had sex. He liked it but I found it strange, noisy and very different to using a male one. I really had to make sure that it did not move out of place. Maybe it is worth a second try!!” (ICW member, Africa)

Another expressed different feelings forcibly:

“I never used it and I don’t want to use it. Why? Because I don’t have total responsibility for preventing HIV. If my partner requires me to be ready for sex, in addition to being loyal and in addition to use the female condom, I don’t think it is fair. It is just like prevention of pregnancy, women are not responsible alone. Nowadays the male condom is the only way of involving men in the prevention of HIV and pregnancies, with direct benefit to them and to the woman. This is why I did not even consider the female condom. If my partner is not ready to use the male condom, then he can go.” (ICW member, Central America)

This was the only ICW respondent to express this view, but there are no doubt other women who feel the same way about this issue. I suspect that many women, whether HIV positive or not, have felt like this at times. I do believe that there is indeed often a fine line between choice and obligation: on the one hand, a sense of empowerment through being the primary actor in the process – as the condom wearer, the pill-taker or injection user – or, on the other hand, a sense of being exploited, of becoming a vehicle for men’s pleasure, of having to be the one to take the responsibility and the action. There is no easy answer to this. Ultimately, which side of this line a woman feels she stands on will be determined by the state of her relationship with her sexual partner.

Positive experiences

ICW members who had used the female condom for longer periods of time said good things about it.

“I like the female condom as I often have issues with negotiating safe sex with my partner. With the female condom I can take control and I feel more confident.” (ICW member, Australasia)

Others reported that they had attended a session on the female condom at the recent Asia AIDS conference in Kobe, and that they had explored the idea together of “promoting female condoms to men, as fun sex toys”.

“My experience has been a good one. Me and my husband can feel more sensation when we use the female condom. My husband is not positive and he feels more comfortable if I use a female condom because it protects him better than using a male condom.” (ICW member, Asia)

This is not technically accurate, since the female condom offers the same amount of protection as the male condom, but what was important here was that her partner felt protected.

“I have been using female condoms since December 2002. Before that time I did not know how to use it and I tried but I did not succeed. One day I asked my boyfriend who is now my husband to try and see, and he took it and placed it into my sex and we had sexual intercourse. It was very wonderful and since that time we are still using female condom. With it we can do any movement. I like it, so does my husband, we are happy and have a positive living: we do not think of being
HIV positive, at any time you can find female condoms in our house. With female condoms our love is strong. Both of us are HIV positive. I do not use the pill. In my country female condoms are not expensive: you can get five at $1.” (ICW member, francophone Africa)

Female condoms: a valuable role for HIV positive women

I myself have had nothing but positive experiences with using the female condom with my husband. Like many ICW members who responded so warmly and generously to my survey, my prime motivation for using this protection has been to be able to continue to have a pleasurable and fulfilling sex life, safe in the knowledge that he and I are also practicing safer sex. When I was diagnosed HIV positive, I was lucky that I already had two children and, although I lost my third child at the time of my HIV diagnosis, I have since 1992 never had to face the challenge of trying to have another child without infecting my husband. So using a female condom has been a way of enjoying sexual pleasure, whilst feeling confident that I won’t infect him and won’t get pregnant. My husband and I have both found the female condom more comfortable to use than the male condom. A leading light of the Danish Family Planning Movement for many years, Hanne Risør, described to me in 1994 a poster she had on the wall of her family practice surgery (Figure 1).

Whenever a new patient entered her consulting room, or someone whom she hadn’t seen for a while, she invited them to point to where on the triangle they felt their particular concerns lay. She believed strongly that sexual well-being forms an integral part of everyone’s lives, that we all ignore its presence at our peril and that, in her experience, without this poster to point at, many patients would find it much harder to discuss openly what concerns had led them to her door. She has found that if individuals have problems with their sex lives, these problems can spill out in all kinds of ways into other aspects of their lives, and vice-versa.

Some of the issues that women often raise that concern them in this regard, and that can have an effect on female condom use, are lack of knowledge of female anatomy and ease with their bodies, anxiety that their own bodies are not “normal”, cultural beliefs about the sanctity of the hymen and penetration, access to a vagina owned by a man, and deep shame if things go wrong.

My husband is also a family practitioner, in a rural part of England, and his own experiences bear this out. He has many rather embarrassed but anxious older male patients beating a path to his surgery door, concerned about erectile dysfunction, both as a cause and a consequence of all kinds of stress in their lives. They go away feeling reassured, as he is able to console them that they are far from being alone in their anxieties and experiences. The fact that they are not exceptional alone seems to be a huge reassurance to many, reflecting perhaps the huge pressure placed on men in all societies to be sexually active throughout their lives, and reified through the huge sales of Viagra.

HIV and the denial of sex

“Wanted sex, good sex and the right to enjoy sex are not something that is covered in many intervention programmes... How do we expect young women to understand the importance of consensual sex and negotiating skills if education is only limited to prevention of pregnancy, STIs, and sex being a no-go area in many societies?” (HIV positive Namibian participant, ICW Young Women’s Dialogue Workshop, 2004)

Why are sex, sexual pleasure and fulfillment and the female condom of particular interest or relevance to HIV positive women? Many people believe that once diagnosed, HIV positive women should stop having sex completely. But...
this view negates the sexuality of all individuals, whether we are HIV positive or not; indeed, there is huge potential value in reducing the stress levels of living with HIV through having safer and pleasurable sex. Moreover, this view denies the reality that most HIV positive women have no choice over whether to stop having sex.

HIV positive women around the world have consistently and repeatedly found that their human rights with regard to sexual pleasure and reproduction have been severely curtailed when others find out about their HIV status. Young expectant mothers, once their HIV status has been discovered, have been traumatised by forced abortions and sterilisations. They have been told that they should stop having sex and remain abstinent for the rest of their lives. They have been told that they should on no account consider having children. This has also been a continuing response of some health professionals towards some of ICW's members in industrialised countries, even though antiretroviral drugs, caesarean sections and other medical support are nowadays widely available to minimise the risk of maternal death or vertical transmission.

Thus, some kind of moral judgment is being meted out here and not just concern about the physical health of the woman and child. Some of ICW's members in Africa and Asia have reported that they have only been able to access antiretroviral therapy if they accept a Depo-Provera injection first. Although there are certainly exceptions, in the main, the sexual and reproductive rights of HIV positive women have consistently and repeatedly been violated and abused – by front-line female health workers especially – who often fear for their own HIV status from their own marriage beds – but feel totally unable to disclose or articulate these fears to their colleagues and managers.

Other young HIV positive women, especially perhaps those who have not dared tell their families about their HIV status for fear of the reaction, have been pressured by partners or in-laws to have sex and produce children when they didn’t want to for fear of passing the virus on to their children at birth or breastfeeding.

Challenges

A major barrier with the female condom is that it involves women inserting something into our own bodies. Most women around the world have very detailed ideas about our reproductive anatomy, based on our own experiences, on preparing animals for food and on what we hear from others, but these ideas are often completely different from the biomedical model found in medical textbooks. This fact was highlighted by Andrea Cornwall in her groundbreaking work using body mapping with a group of women in Zimbabwe in the mid 1980s. In those days – and perhaps still now – even female medical students had no real idea what their own reproductive system looked like – or realised how much variety of shapes and sizes we all come in, irrespective of our sex.

For many women, the very thought of inserting a tampon into their vaginas is anaethema. In many parts of the world, the hymen is still considered as a sacred symbol of virginity, which should not be broken until the marriage night. In many parts of the world, female clitoridectomy is practised, and it is seen as women’s duty for their reproductive organs to be sewn up before puberty and then after each and every childbirth, so that a man’s pleasure can be greatest by keeping the opening to her vagina as small as possible. The fear of what happens “down below” in women’s bodies is possibly universal. I well remember myself not being educated about anything to do with this region of my body. As a teenager, thanks to my older sisters, I knew about and used tampons. But I remember the great shame and embarrassment of having to go to the doctor complaining of a dreadful smell “down there” and thinking that I must have some awful infection. The doctor examined me – yet more horror, having to put my legs up on stirrups – and he withdrew the stringless remains of an old and definitely very smelly tampon. But rather than laughter and reassurance and a kindly explanation from the doctor, I was met by his silent, stony glare, as if I were the dregs of life. I don’t think much has changed for many doctors, who rarely receive the right kind of training to deal with people’s feelings and not just the appearance of our nether ends.

How different was the experience I received at the hands of a female doctor at a women’s health centre in North London in the early 1990s when – oh joy, no stirrups, no fierce spotlight – the internal examination was held with me lying on my side, feeling comfortable and relaxed with
the reassuring words of the doctor explaining what she was doing at every stage, instead of feeling trussed up like a chicken ready to be carved. Many of my women friends have had equally bad experiences with doctors over various gynaecological issues in their own youth, yet rarely do we seem to find any of these experiences reported in the academic or service providers’ literature. Indeed, most of that literature appears not only to be devoid of women’s experiences of services, but convention also dictates that it is written in a form which suggests that the authors are somehow on a separate planet from those for whom services are provided. Why is this? Why do feminist academics and service providers in particular feel the need to present their material as if they are not also themselves women who have reproductive health issues which also need respectful care and treatment? It is as if there is a collective fear that we might lose the respect of our colleagues if we admit that we too are the owners of feelings around, and personal experiences, of such issues. Thus, we as women, academics, service providers, yes, even service users, may privately laugh and shudder at these dreadful memories, when we were far too scared to stand up for ourselves, but these experiences are never then committed to print. What is worse, these experiences are still happening on a daily basis to millions of other women and girls around the world – experiences far worse than my own, which can scar them mentally as well as physically, for life.

These things matter, and so deeply, especially to us as HIV positive women when we feel that the very essence of our being – our right to sexuality – is torn away from us because of the judgments of others, on the basis of our own bodies. Women reclaiming our own bodies

I remember another time, as a young student, reading in wonder and amazement that marvellous, and revelatory book Our Bodies Ourselves, published by the Boston Women’s Health Collective, where in marked contrast to most women’s health writing they described how women came together in groups, each with their own hand mirror, so that they could examine their own “nether regions” for themselves. I was never so brave as to do this with other women, but I certainly got out my own hand mirror for the first time and examined my own body carefully, suddenly realising that it was absolutely right and proper to be aware of a part of me which belonged to me every bit as much as the back of my hands – but which I had never actually looked at before.

Reclaiming our bodies for ourselves then is a central part of both the joy and the challenge of promoting the female condom. Whilst sexology still focuses for the most part, in the words of one close friend, on “getting it up and getting it in” and is still very male-oriented in content, for women it should be about reclaiming our bodies, not just with the aim of achieving penetrative sex, but in recognition that there are many other parts of our bodies as women which we feel sexy about and which deserve our own and our partners’ attention. In this context, the female condom should be promoted as a part of sex and love-making in its fullest form.

Some important but all too rare studies have shown that men also benefit enormously from learning about how women’s bodies function (not to mention their own) and how they can help us to have orgasms. Their own lives have improved in all kinds of ways as they have learnt for themselves that the “getting it up and getting it in” approach to sex is far from the whole story.7

Conclusions

Provided women have a good relationship with a respectful sexual partner, condoms, both male and female, are at present the only known means of enabling HIV positive women simply to claim their rights: to start or to continue with a healthy, positive, mutually respectful, satisfying and fulfilling sex life, as and when they want to, without fear of repeated HIV or other STI infection, or the risk of infecting others. For those who use them consistently and carefully, condoms can also provide all the necessary protection needed from unwanted pregnancy. Moreover, the female condom has the additional advantage that it does not present a problem for people who are allergic to latex, which can be a problem with male condoms, though not for most users. In addition, the female condom, made as it is of polyurethane, is not damaged by...
massage oils, which can bring added pleasure to sex. And as the female condom protects the outer parts of the clitoris and the labia, that it can provide some protection against herpes infection or re-exposure (a reported 80% of HIV positive people also carry the herpes virus), this is surely an added benefit for women.

The issues that emerged from my survey contain no surprises, but so far as I am aware, there has not yet been any other survey of HIV positive women's attitudes to or experiences with using the female condom – or male condoms for that matter. Given the critical importance of exploring all possible methods to reduce HIV transmission around the world, and the scientifically proven track records of the female and male condoms as effective barrier methods, this seems an extraordinary oversight.

For HIV positive women and girls, using a condom isn't “just” a matter of protection against pregnancy, hugely important though that is, but is all the more a matter of life and death than the risks of pregnancy can bring. Those of us who aren’t yet on treatment are especially at risk if repeatedly exposed to herpes sores, other STIs and HIV too. Many HIV positive mothers are acutely aware that staying alive and staying well is critical, not just for our own well-being, but in order to make certain that our children remain well loved and well cared for and don’t become orphans.

Almost all the ICW members with whom I have been in contact for this survey expressed an interest in finding out more about the female condom, if only they could get hold of it more easily, if only they could learn about it more easily and if only they could just gain more experience of it from others also. All these women are extraordinary because they are actively seeking ways of making sense of a world which has fallen apart for them, as it did for me, when I was first diagnosed. They are actively engaged with other women and men in seeking new ways of living which respect and protect themselves and those around them, ways which ensure that others in their communities don’t go through the traumas they have faced, and, quite simply, in wanting to make the world a kinder and more caring place for us all.

If the world gets female condoms right for us – making them low cost or free, widely available, in different sizes, attractive, safe and sexy, there would be an extraordinary global group of active supporters and advocates to promote this product. So as HIV positive women, we hope that the world will take on board the huge relevance of the female condom, not just to the majority of women in the world whom we hope will remain negative, but also to the ever-increasing numbers of women and girls who are already HIV positive and also need its support.

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Résumé

Cet article réfléchit à l'utilisation du préservatif féminin par des femmes séropositives, sur la base de mon expérience personnelle et des réponses de 18 membres de la Communauté internationale des femmes vivant avec le VIH/SIDA à une enquête par courriel de 2005. Le coût des préservatifs féminins et leur approvisionnement sporadique ou très limité étaient les principaux obstacles à leur utilisation. Toutes les personnes interrogées ont indiqué qu'elles devaient négocier l'utilisation de préservatifs féminins avec leurs partenaires. La plupart estimaient qu'elles se prenaient mieux en charge et étaient plus assurées pendant les rapports sexuels avec le préservatif féminin qu'avec le préservatif masculin ou sans protection. Les inquiétudes sur le préservatif féminin étaient communes, particulièrement chez les femmes qui ne l'avaient jamais utilisé ; celles qui l'avaient utilisé pendant longtemps l'appréciaient. Redonner aux femmes la maîtrise de leur corps est au centre des satisfactions et des difficultés que procure la promotion du préservatif féminin. Pour les femmes séropositives, utiliser un préservatif est davantage qu'une protection contre la grossesse, c'est une question de vie ou de mort, bien plus grave que les risques d'une maternité. Si les préservatifs féminins pourraient faire une contribution essentielle à la protection de la sexualité des femmes séropositives et les aider à poursuivre une activité sexuelle, élément fondamental de nos droits génésiques.

Resumen

En este artículo se exponen algunas observaciones sobre las experiencias de las mujeres VIH-positivas con el condón femenino, con base en mi propia experiencia y en las respuestas de 18 integrantes de la Comunidad Internacional de Mujeres que Viven con VIH/SIDA a una encuesta por correo electrónico realizada en 2005. Los obstáculos principales al uso del condón femenino fueron el costo y el acceso esporádico o muy limitado. Todas las encuestadas hablaron sobre la necesidad de negociar el uso del condón femenino con sus parejas sexuales de sexo masculino. La mayoría se sintió más en control y con más confianza durante las relaciones sexuales cuando usaba el condón femenino que con el condón masculino o durante el sexo sin protección. Las inquietudes respecto al condón femenino parecen ser comunes, especialmente entre las mujeres que nunca lo han usado; aquéllas que lo habían usado durante un largo plazo dijeron cosas buenas al respecto. Una parte central de la alegría y el reto de promover el condón femenino es motivar a las mujeres a que reclamen su cuerpo. Para las mujeres y niñas VIH-positivas, usar un condón es más que una simple protección contra el embarazo, es una cuestión de vida o muerte mayor que los riesgos que conlleva el embarazo. Si el condón femenino estuviera disponible más ampliamente y a precios más asequibles, este podría influir en gran medida en la protección de la sexualidad y la actividad sexual de las mujeres VIH-positivas, como un elemento fundamental de nuestros derechos sexuales y reproductivos.