

Chapter 21

**Human Sexuality**

**Overview**

While there has been much attention to the spiritual, psychological, social and physical aspects of care for people living with HIV/AIDS, their sexuality needs, problems, and coping mechanisms are rarely mentioned, discussed, and addressed — particularly in Africa, where culture strongly influences sexuality perspectives. To provide holistic care to HIV/AIDS patients, we need to understand that sexuality influences and is influenced by the biological, psychological, sociological, and spiritual aspects of being. Our patients do not leave their sexuality behind when they seek our services. But sexuality, which is central to their quality of life, remains unattended to by health professionals, intervening professionals, and family carers. Experience with patients of Hospice Africa, in Uganda, has shown that it is often ignored by care providers. Fitzgibbon (2000) noted that while other aspects of total pain are recognised and explored in holistic care, sexuality is shelved. Many health care workers (HCWs) do not consider the patient’s sexual health until the patient brings it up. This is perhaps due to the fact that sexuality is a private issue in most cultures, and even more so in African cultures.

While this chapter is based largely on the literature from the West, there are great differences among the indigenous people of Africa, both in their view of sexuality and the balance of power between men and women in sexual acts. This must be kept in mind at all times when assisting patients with sexual problems.

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The Effects of Gender and Role Perception on Sexuality

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## Essentials of Sexual Counselling

### Definitions

The words sex and sexuality are used—interchangeably and often incorrectly—to define the different aspects of sexual being.

The word sex is commonly used to identify biological male or female status. Sex is also defined as the physical activity in which people touch each other's sexual organs, and which may include sexual intercourse. Human beings express themselves sexually from birth to death.

Sexuality pertains to all those things that relate specifically to being a woman or a man. It is subject to life dynamic change as a function of total personality. It includes body image, self-esteem and how we would like others to see us. It involves more than sexual desires, activity and orientation. It encompasses touching, intimacy, and the physical closeness of others, and can be an expression of warmth and caring, relationships and gender roles.

Sexual orientation refers to whether a person is attracted to a person of the opposite sex (heterosexuality) or the same sex (homosexuality) or both (bisexuality), and whether a person feels that his or her gender role (male or female behaviour) is consistent with his or her biological sex (male or female). This chapter addresses heterosexuality. For more on other sexual orientations see Chapter 23: Special Populations.

### Preparing Health Professionals to Address Patient Sexual Needs

HCWs need support to discuss their difficulties and experiences, positive and negative, to build confidence and competence in the area of sexuality (Kiwanuka, 2002). To provide truly holistic care to HIV/AIDS patients, HCWs must be able to:

- Assess sexuality and sexual functions non-judgmentally in order to help clients
- Encourage clients to discuss their concerns and offer suggestions to assist the return of intimacy and sexual functions
- Show proficiency in four basic skills in order to help clients in the area of sexuality:
  - Knowledge of and comfort with their own sexuality
  - Acceptance of sexuality as an important area of health care intervention, and willingness to allow clients to express their sexuality in their own ways
  - Knowledge of basic sexual problems, including how certain health problems and treatments may affect sexuality and sexual functions and which interventions facilitate sexual expressions and functions
  - Good communication skills and patience

HCWs need to allow their patients the opportunity to express the physical and emotional pain of their sexuality. A debate on sexuality in HIV/AIDS needs to be raised in open forum, through appropriate media. At the same time, good role models among men should be identified and invited to assist in raising awareness among other men. There is need to create openness around sexuality in life-threatening illness (Fitzgibbon, 2000).

Suggested steps for HCWs to address the pain of sexuality include discussing the issue with colleagues, sharing experiences of working with patients having such pain, identifying those colleagues who feel comfortable discussing sexuality, acknowledging cultural aspects in the work setting, agreeing on ways to facilitate communication with a patient or partner regarding issues of sexuality, and arranging a date to review and reflect on any new approach to sexuality.

## The Effects of Gender and Role Perception on Sexuality

Western cultures typically raise children to believe that men and women have equal roles in sexual decision making and relationships. Either partner can choose whether to have sex and the kind of sex they wish to engage in, and are encouraged to think of the comfort of their partner rather than just their own.

### *Women*

In many African cultures, women are seen as subservient to men from birth. Among the Baganda, for example, in Uganda, little girls are expected to kneel to men—including their own older and younger brothers. The girl child is taught to see herself as a secondary person. The male child learns to see his role as one of leadership and physical domination of the female. If a female is not subservient to the male's wishes and needs, the male will physically force her into submission.

In sexual matters, often the woman is not supposed to enjoy the sexual act. Hence female circumcision is still practiced (although it is decreasing) to remove the parts of the female's genitalia that provide sexual pleasure, effectively making her a sexual toy for the man and a receptacle for his children to develop in the womb. This carries into life, where the man often considers a child to be his alone. Even though the child legally belongs to both partners, the man will often take the child from the mother to live with a stepmother or his own family.

When a woman with HIV/AIDS admits to sexual problems, it is almost impossible to get the partner to come for counselling or to meet a health professional. For the woman even to suggest such a thing may incite her husband to beat her or inflict such psychological suffering as withdrawing financial support. This means the health professional in the African context must move warily and be aware that some interventions can make matters worse.

Although more educated women are demanding sexual equality in the public arena, their higher social class and advocacy on their own and their poorer sisters' behalf do not prevent them from being subjected to traditional beliefs about their roles in their home and village.

### *Men*

Many men still feel they must dominate their female partner, both sexually and in their own lives. For this reason, a more educated or successful woman often has a greater chance of marriage difficulties. African men base much of their self-esteem on their sexual prowess. Elderly men who are ill and need care are frequently concerned about not being able to get an erection and satisfy a young partner. They may need counselling to overcome this feeling of having lost their dominance and physical prowess, which leads to depression. The partner often will be more prepared to listen to an explanation of these difficulties. After sharing her own feelings, she may offer to support the man by assuring him that she can be satisfied with non-penetrative sex. But men are rarely prepared to discuss the woman's difficulties.

It is important to keep this cultural climate in mind when referring to Western literature on human sexuality, because much of the advice given comes from different problems and in the context of a different economy. Health professionals in Africa need to be aware of their own and the culture's approach to sexuality.

## Sexual Needs and Problems of Patients

### *Sexual Issues in HIV/AIDS*

Every human being has a sexual identity and sexual needs, although their importance may vary greatly from person to person and according to what else is happening in their lives. These needs and feelings may exist regardless of how old a person is or whether or not she or he has a partner at the time.

To maintain self-esteem and a healthy body image, patients with HIV/AIDS nearing the end of life need not only sexual activity but also touching, intimacy, and the physical closeness of others. They also need the satisfaction of fulfilling gender roles within families, effective communication with their partners, counselling, privacy, pain control, and the ability to make their own decisions.

HCWs are often not familiar with these needs and the consequent problems, or shy away from discussing them with their patients. Yet failure to address patients' sexuality needs may result in the loss of body image, self-esteem and libido, as well as an inability to engage in sexual activity, forced and painful sexual intercourse, breakup of relationships, abandonment, domestic violence and stress-related problems. Intervention should aim at achieving better communication between partners, providing expression of the pain of sexuality, giving adequate information, and offering practical support.

People with HIV/AIDS can have a variety of sexual problems, including body image, problems of self-perception, mismatched feelings, loss of libido, low self-esteem, painful intercourse, exposure to violence and sexual abuse, inability to achieve or sustain erection, exhaustion, and failure to achieve orgasm. Sexual feelings and expression may be inhibited by problems such as difficulty negotiating condom use, fear of re infection or infecting a partner if that person is HIV-negative, and either fear of or great desire for pregnancy.

### *Negotiating Condom Use*

Whether as a means of contraception or as protection from sexually transmitted infections, condoms are strongly associated by men and women with extra-marital sex (Bassett, 1991; Meursing, 1995). Condom use varies greatly according to age, type of relationship, number of surviving children and experiences of pregnancy.

For a woman to introduce condoms into a relationship successfully, the cooperation of her partner is crucial. Such cooperation is often followed by periods of great conflict and frequently involves the help of counselors or palliative care workers. This is because condoms are associated with distrust and with use in casual and commercial sex rather than in a steady and loving relationship.

Culturally, women feel that men control a couple's sexual encounters both in terms of when they have sex and whether they use condoms. Therefore it is extremely difficult for women, more so married women irrespective of level of education, to negotiate for condom use. Women were brought up to be subservient to men, and for this reason they have less control over their own risk of infection and the risk of passing the virus to their babies. It is highly likely that the majority of women in sub-Saharan Africa become infected due to the difficulties in negotiating for safe sex. There is an urgent need to change the common cultural expectations of marriage, which includes women having to have children and obeying the husband.

### ***Body Image***

Feeling good about one's body enhances sexual well-being and promotes sexual activities. But if people have negative attitudes about their bodies, as is the case for many people living with HIV/AIDS, it can interfere with sexual activities. Feelings of worthlessness may make it difficult to be aroused sexually. A person's sexual partner may think that he or she is cheating if there is no interest in sex. It is worse if the person with HIV/AIDS has not shared what is causing the problem. For these reasons, health providers should help patients share their experiences with their partners. However, this can also be a problem if the healthy partner blames the person with HIV/AIDS for bringing the disease into the family, particularly in a discordant couple (one partner is positive, the other negative). Continued counselling and support are needed to help couples open up to each other as they walk through the HIV/AIDS journey.

### ***Self-perception***

People living with HIV/AIDS often experience negative feelings about themselves, affecting their sexuality and sexual activities, particularly if they are experiencing social stigma. Patients may feel unworthy to be seen as a man or woman in the community. A woman who shows the signs of AIDS before her husband may be accused of not being faithful to him, even if it was he who infected her. Society tends to perceive women with AIDS as unfaithful if they are married and indecent if not married, which can affect the women's self-worth and cause depression. Health workers should provide counselling and support to women in this situation and their families, to help them to understand the situation rather than becoming angry. Experiences in Uganda have indicated that when patients are angry for some reason, they may engage in risky behavior, which can transmit HIV to others.

### ***Mismatch of Feelings***

Worries caused by HIV/AIDS may result in a loss of interest in any form of sexuality. While one partner may have a need for sex, the other partner may not be interested at all, causing a mismatch in feelings. Because sexual activity starts in the mind, an individual's worries or pains of any kind can affect his or her sexual activities and decrease the libido. This affects the spouse, who may think the individual is cheating on him or her.

### ***Universal View***

There is a universal view that sex is not a priority during illness. Orthodox medicine rarely acknowledges that most ill people are still sexual and therefore have sexual needs and concerns. But dying persons may need love and affection even more than healthy ones (Amenta, 1986). Close, loving sexual relationships create feelings of fulfillment and meaning in life. A dying person, while too weak or ill to engage in intercourse, may desperately need the comfort of caressing, hugging, and kissing from a loving partner. In some cases, sex might help people feel better. It is important to appreciate how important a sense of sexual well-being may be to the overall healing process. HCWs require a supportive attitude as well as sensitivity, tact, skill, and the discernment to assist patients meet this need (ENB, 1994).

### *Cultural Perspective*

In the African context, the sexual losses associated with HIV/AIDS have deep implications for patients, especially women. Women are culturally expected to provide sex to their partners and produce children. If they can not do these things, their partners regard them as no longer worthwhile. They may be forced to have intercourse even when their condition does not permit it, resulting in painful sex, bleeding after sex, and sometimes additional treatment costs. Penetrative sex can be extremely painful if one has penile, vaginal, or vulva sores or herpes simplex, yet partners who do not have these problems may expect the affected partner to engage in painful sex. One female patient described her experience in which her cries of pain were interpreted by her partner as cries of sexual joy and satisfaction.

In some cultures a man is never denied sex; denying him sex leads to rape and domestic violence. Sexual issues may cause strain to marriage and personal relationships. In some Ugandan cultures, it is even worse. Situations of neglect and abandonment are common for women who cannot offer sex any more to their partners due to advanced disease. Men prefer to find alternative partners rather than being intimate with their sick wives. Domestic violence may result from the woman's inability to have intercourse and loss of reproductive function.

Since sexual matters are regarded as private issues, such problems are not revealed to HCWs and worsened if the HCWs also do not feel able to discuss them. Sexual problems are often not addressed by interventions for persons with HIV/AIDS, yet they are a source of social, psychological, spiritual, and physical pain.

### **Assessment of Sexuality Needs**

To offer holistic care to our patients, we must stop being shy and learn to encourage our patients to talk about their sexual problems. We need to assess our patients' sexual needs, particularly those with HIV/AIDS.

The patient assessment tool should include questions about sexuality that explore the patient's sexual problems in the same way that other physical, psychological, spiritual, and social issues are assessed.

#### **Ask questions like these:**

- How has the illness affected your sexual life?
- How has treatment affected your sexual life?
- How has the sickness interfered with your relationship?
- How does your partner feel about your sickness?
- How is your sexual performance during this time of illness?

These questions will start a conversation about sexual issues with the person. Once he or she has gained trust and realizes that you are comfortable and ready to talk about the topic, the conversation can move into more specific aspects of intimacy. Initiating the conversation helps patients to verbalize their problems and feelings about sexuality and it can be therapeutic. Sexuality must be assessed, advice given, and problems solved routinely, because failure to intervene in this important aspect of holistic care creates great distress for patients and their loved ones.

## Meeting Sexual Needs and Coping with Problems

### *Communication Strategies*

Research suggests that many HCWs receive inadequate training, so they are embarrassed to discuss sexual issues and feel the issues are irrelevant to illness. Nurses, however, are ideally suited to carry out the role as assessor, educator, confidante, and sometimes counsellor (Wilson, 1988).

Times of crisis, such as new diagnosis, recurrence, or treatment setbacks, may not be the most appropriate time to discuss sexual issues. The literature does not suggest the best time for such discussion, though there is agreement that discussion should be a routine part of care at diagnosis, treatment, and follow up (Auchincloss, 1986). The assessment is important to meeting the patient's needs. One useful strategy is to move gently from less sensitive topics to issues that are more sensitive (Corner, 2001).

Sex is about communication. But communication is often lacking in sexual matters in African marriages and couples. While one partner may see the lack of sex as a positive aspect of the relationship, the other may not agree unless they talk to each other (ENB, 1994). Improved communication is a prerequisite for both partners to cope with the challenges ahead.

### *The Health Professional's Comfort with Sexual Issues*

HCWs need to be able to deal with issues of sexuality before they can help their patients. The process of developing awareness of our own feelings about sexual organs, relationships, and roles contributes to understanding and self-comfort. Those who are comfortable with their own sexuality will be more comfortable with another's (Amenta, 1986).

This concept is new to the African context, although the traditional puberty rituals bringing a woman or man to adulthood include educating them about sexual roles and traditions with the belief that the woman must give pleasure to the man and that the man has no reciprocal obligation. These rituals separate girls from boys, so they learn not to discuss sexuality with one another. Sexual development and needs are rarely discussed in the family. HCWs need to reflect on these things, learn to assist others from their own experiences of cultural practices, and be able to evaluate the sexual practices that can bring problems during illness.

### *Assessing Sexuality*

The HCW needs to get two types of information about the patient's sexuality:

- What impact has the illness had on the patient's sexual functioning?
- How has the significant other responded to the illness or sexual change?

These questions can help in assessing the patient's and his or her partner's sexual needs and desires. The important thing to determine is whether or not things are different or worse than in the past.

Health providers need to provide information about potential sexual problems to their patients more frequently. In one study, only 30% of patients were given any information about potential sexual problems—though 40% indicated they would have liked such information (Jenkins, 1988). It is important to acknowledge the sensitivity of the topic and its importance in planning future care (Corner, 2001). It is important for HCWs to inform patients that sexuality is an important and recognized part of their care, and that it is appropriate to talk about or ask about any concerns they may have. Simply asking and listening can be reassuring in itself.

The partner and family are important in facilitating psychosexual adjustment and reducing feelings of isolation and abandonment (Weeks, 1989). Without communication and understanding, even the strongest of relationships can be destroyed (Fisher, 1983). This is true even in Ugandan society, where the authors have seen families fall apart due to lack of communication, openness and understanding. In a study of women's experiences, one woman was quoted as saying, 'I think sexual adaptation depends a lot on the support women get from their husbands. If they can reassure you that whatever happens they'll still love you just as much, or you're just as important, you're just as complete a person as you were before' (Weeks, 1989).

**Goals of intervention should include:**

- Helping individuals feel accepted as sexually worthy, loved and wanted
- Increasing sexual self-esteem by helping individuals maintain their appearance
- Clarifying misinformation and providing information and privacy
- Assuring that people with advanced HIV/AIDS are not denied having their sexual needs met

Mungherera (2002) recommends frank, open and honest communication with the partner, especially if the patient is experiencing painful sex. The patient should be allowed to control the depth of penetration. Acknowledgement and understanding of each other's sexual needs and problems is important, particularly the need for love and care.

All the dimensions of sexuality must be addressed in care plans in order to provide holistic care. Helping and supporting patients to understand and cope with sexual concerns enables HCWs to cross the boundaries of sexual taboos and to view someone with HIV/AIDS as a person with individual desires, needs, attitudes and behaviors (Corner, 2001).

### *Practical Strategies*

While HCWs often provide information, they also must provide practical strategies and psychological insight, which should be integral to any intervention. Practical suggestions include providing lubrication for dry vagina to reduce irritation and pain, or suggesting different positions or styles to be tried during intercourse to help increase the woman's comfort and satisfaction. For men, careful assessment of the cause of erectile dysfunction may help in providing solutions to diminished sexual potency. It should be noted that it is unclear in the literature whether these practical strategies are applicable to all settings, including Uganda, with deep-rooted cultural influences on sexuality.

Men and women enjoy many sexual practices and styles, though some are not socially accepted in certain countries or societies. This does not mean they are not practiced. Homosexuality is not socially accepted in many African cultures, but is known to be practiced among youth, particularly in-school youth. Professionals need to be aware of these practices and talk about them freely without condemning. With the HIV/AIDS epidemic, there is no way one can avoid talking about sex although it is regarded as a taboo by many cultures. To help our clients holistically we need to encourage them to talk openly about their sexual problems.

Some patients in Uganda shared their experience relating to the different sexual practices they enjoy as alternatives to the common penetrative practice (sexual intercourse). Such experiences can help professionals to comfortably discuss sexuality issues with other patients. Similar sexual practices are also listed in *The Hand Book of HIV Medicine* (Wilson, 2002).

Being knowledgeable about the different sexual practices enables professionals to discuss an alternative sex practice if a couple has a problem with their usual sex practices. But we need to be aware of differences in cultural traditions. The most important thing we can do is to encourage spouses/partners to be open with each other about their sexuality problems.

This can lead to mutually satisfying alternative activities. For example, in one of the cases described in the Western literature, a husband to a 26-year-old woman with a life-threatening illness was encouraged to lie on his side facing his wife's back, to hold her and to place his penis between her thighs without attempting vaginal penetration. This position proved comfortable for them both, and enabled the husband to come to orgasm much to the pleasure of his wife. Her satisfaction came from being held closely and bringing her husband sexual fulfillment (Amenta, 1986).

When there is physical pain, Mungherera (2002) recommends that penetrative sex be undertaken only after the patient takes analgesics. Pillows can be put under the buttocks or areas where there is pain. Encourage self-pleasing techniques, such as masturbation, or the use of different positions that lead to less strain, or shorter sessions.

Interventions should aim at reassuring the partner and the patient that they may engage in some physical activity that allows them to express their love and affection. Just lying comfortably close can impart security and a sense of belonging. Patients and their partners need to be reassured that feelings of guilt as well as sexual desires are natural even during life-threatening illness, and that the patient may engage in the amount and kind of sexual activity that she or he desires and feels strong enough to handle. Both partners may need to be encouraged to indulge to the desired degree in physical expressions and affection.

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## Suggested Resources

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