Growing old with AIDS:
Perspectives and behaviours of older people in KwaZulu-Natal, South Africa

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Abstract

Despite the important consequences that HIV/AIDS is likely to have for older people in South Africa, very little empirical work has focused directly on this issue. The overall aim of this study is to provide insights into the perspectives and behaviours of older men and women, both infected and affected by HIV/AIDS, by drawing on focus group discussions with men and women aged 50 and above. Levels of awareness of AIDS are high but older people do not perceive themselves at risk of HIV infection. However, some women reported that they were at risk of HIV infection because of their partner's sexual behaviour. Some older men engage in casual and transactional sex which increases their partner's risk of HIV infection. Most report that they are vulnerable to HIV infection primarily through caregiving activities. The study found that the impact of HIV/AIDS is substantial and is compounded greatly by gender dynamics in the household.

Introduction

AIDS is one of the most serious and urgent global problems facing the world today. The United Nations Secretary General has declared the AIDS epidemic the most formidable development challenge to human life and dignity and the enjoyment of fundamental human rights (Declaration of Commitment on HIV/AIDS, 2001). Despite broad-based efforts directed at halting and reversing the tide of the AIDS pandemic, by the end of 2003 an estimated 20 million people had died of AIDS and 38 million people were living with HIV (UNAIDS, 2004). In South Africa, the region with of the world's highest levels of HIV prevalence, AIDS has reached pandemic proportions. Despite the high level of HIV infection, very little is known about HIV/AIDS among older men and women in South Africa. In many developed countries, a vast amount of research is conducted on HIV/AIDS among the older adult population; however, in less developed countries there seems to have been a marginalization of older people in the epidemic. In South Africa, most of the focus of research has been on men and women of reproductive age without adequate attention to the perspectives and behaviour of people aged 50 and older.

There are a growing number of studies which show that people aged 50 and over are increasingly becoming infected with HIV and AIDS. For example, in Uganda, infection data collected between 1992 and 2002 shows that the number of people over the age of 50 registering for HIV testing and counselling services rose sharply from 3 percent to 30 percent and of these, a fifth have tested HIV positive (HAI, 2004). In many developing countries, older people are also the most affected by the AIDS epidemic. Older people have traditionally been financially taken care of by their adult children; however, as a result of the HIV/AIDS epidemic there is a complete distortion of intergenerational support (HAI, 2004). The more productive members of the family who are in their prime adult years have the highest levels of infection and as a result, are more likely to experience increased morbidity and mortality. Not only do older people face the loss of economic support, particularly the loss of remittances from their sick and dying adult children, but they are also faced with the burden of caring for them (UNAIDS, 2002).

The primary objective of the paper is to provide insights into the perspectives and behaviours of older men and women, both infected and/or affected by HIV/AIDS. For the purposes of this paper, older people refers to persons aged 50 and above. South Africa is of particular interest because it has one of the most rapidly ageing populations in Africa with more than one in eight persons aged 50 and over and nearly 7 percent aged 60 and over (Kinsella and Ferreira, 1997). The degree of population aging has been particularly pronounced in South Africa primarily because of the early onset of fertility transition (Cohen and Menken, 2006). South Africa has been one of the first countries in sub-Saharan Africa to experience an overall fertility decline (Nkau 1998; SADHS 1999). The total fertility rate declined from 6.0 in the mid-1950s to about 4.3 in the 1980s and is now reported to be 2.9 (Caldwell and Caldwell, 1993; Statssa, 2002). By 2030 the proportion of older people in South Africa is projected to increase to 11 percent (U.S. Census Bureau, 2005).

Study Context

The province of KwaZulu-Natal was selected as the site for this site because it has high rates of HIV infection, some of the highest in the country, and the urgency of the problem to older people and policy and program is great. The study was conducted in one urban and one rural district in the province of KwaZulu Natal. The districts in which the study was based have been chosen on the basis of their importance as foci of the HIV epidemic, and the contiguity of suitable urban and rural study sites. Both the rural and urban sites are inhabited primarily by isiZulu speaking people of low socio-economic status. The rural site is situated approximately 80 kms south west of the city of Durban and the urban site approximately 15 kms from the city.

Methodology

The qualitative data for the study comes from focus group discussions (FGDs). In total, eight focus groups discussions were held: four in the rural area and four in the urban area. Each focus group discussion was made up of 6-8 people. All the interviews were conducted in the local language (isiZulu). Areas of research focus include the exploration of the extent to which older men and women feel at risk to HIV infection and their subsequent ability to protect themselves. In addition, the

focus is on their role as providers and caretakers of both their children and their grandchildren. The results of the focus group discussion were used to design the questionnaire for the survey. Since relatively little is known about the subject of the topic focus group discussions were deemed necessary to construct appropriate survey questions. The choice of this method is linked to its ability to generate a greater depth of understanding.

Findings

Awareness of the risk of HIV infection

The focus group discussions revealed that knowledge of HIV/AIDS is fairly widespread with the majority of men and women reporting that they had heard of AIDS. Most respondents are also familiar with the major routes of HIV transmission. Interestingly, however, most identified blood or blood products as the major route of HIV transmission. However, on probing, it became clear that both older men and women are also aware of the risk of HIV infection through sexual intercourse. Multiple sexual partnerships are described as a potential method of transmitting the virus.

> One could get infected by wiping the blood of the sick, or if one has an open cut in their hand – there is the possibility of those blood drops getting into the caregiver through open wounds (Urban Male)

> What we believe is that one contracts this disease after a man has slept with a woman (Rural Male)

Respondents stated that younger people have a heightened risk of HIV infection because they are more likely to have multiple sexual partners. Young people are more likely to be sexually active, have more sexual partners and also, have less control over their sexual desires. In the focus group discussions it became clear that older men and women have sexual relationships with young people which increase their own risk of HIV infection.

> Older people sometimes also have young boyfriends and girlfriends. An old lady who is getting a pension would have a young boyfriend who isn't working (Rural Female)

> This disease is caused by older men falling in love with younger girls. Girls like sugar daddies that will support them with money. These older men give young girls money for sex. Young men can only afford to give their girlfriends R2, but the sugar daddies can even buy uniforms. This causes the older men to get HIV and transmit it to their wives (Rural Male)

An individual may also have a heightened risk of HIV infection because of their partner's sexual behaviour. Some older men and women have sexual relations with partners who are considerably younger than them and sometimes it is in exchange for money or gifts. It is possible that their younger partner has other sexual partners and this increases their own risk of HIV infection. There is also the possibility that they may acquire the virus from their younger partner and transmit it to their stable, long term partner. In the focus group discussions older men agree that they are at risk of HIV infection because of their sexual relationships with younger women.

Some older women felt that they were at risk of HIV infection because of their caregiving activities. Many of the participants in the focus group discussions reported knowing someone who was suffering or died from AIDS and in most cases, it was their child. Often it is the woman who has to take primary responsibility for washing, bathing, feeding, clothing, cooking, and cleaning those who are sick and dying of HIV/AIDS. Many women fear that they may become infected while taking care of their sick relatives.

> Old people have to use their pension to care for these children. They have to pay for school fees, buy clothing, provide food and shelter for these children (Rural Female)

> People who are mostly at risk are grannies who can be infected through their children, when caring for them (Urban Female)

Obstacles to Behavioural Change

There are many obstacles that increase the risk of HIV infection. Condoms are known and are accessible but older men and women report embarrassment at being seen obtaining them. This is largely because condoms are usually associated with illicit sex and infidelity. There are a range of problems associated with introducing condoms in the long-term, sexual relationships. In long-term relationships condoms are seen as unacceptable because there is no risk of pregnancy among older people.

> There are condoms in the shop but older people are afraid of buying these condoms. It is not acceptable for an older person to be seen taking a condom. Older people are afraid of taking condoms and they should be someone who will deliver it household to household (Rural Male)

> Sometimes suggesting condom use can evoke a quarrel between sexual partners. I once quarreled with a woman for suggesting condom use. She was of the opinion that I don't trust her (Urban Male)

> The truth is that you must be able to protect yourself because even if you are young or old, you may get infected. I trust my wife but I always carry a condom because I might sleep around. I always carry condoms but I don't use it with my wife (Urban Male)

However, it was clear in the focus groups that it was more acceptable for men to suggest condom use with their married partners, but it was not acceptable for a married woman to propose condom use with her husband. Older men and women observed that should a woman pursue discussion about condom use she is likely to encounter rage, verbal abuse, abandonment, physical violence and even death. Many women feel that they cannot refuse to have sex with their partner in order to protect themselves against the risk of HIV infection. The threat or use of violence is a major obstacle to negotiating condom use and safer sex. Sometimes women may rely on men for financial support and this further increases their risk of HIV infection. These women are afraid to confront their partners because they fear endangering their relationship, perhaps resulting in the disintegration of their relationship. Some women

therefore suggested using the female condom which also provides protection against the risk of HIV infection.

> He will hit her. He will say that she is cheating on him. If she does not to want to sleep with him that means there is someone else she's sleeping with while he is gone. (Rural Female)

> I heard that there is a female condom; she can use it, because her partner might not want to use a condom (Urban Female)

Some older men and women also feel at risk of HIV infection because of their caregiving activities. During the illness of their children older people often have to bear the costs for treatment and care. Caregiving is often provided by an already financially vulnerable group. Many older men and women are aware of the precautions they need to take to protect themselves but are unable to adopt appropriate measures. Older men and women within urban and rural communities report that they rely on their pension to support not only themselves, but also other members of their household. Many older men and women find themselves forced to go into debt and sometimes they look to neighbours and other community members for financial assistance and other support. They feel that their precarious financial situation often leads them to take unnecessary risks and neglect their own health. Older people not only deal with illnesses associated with ageing but are also now burdened with providing physical care for those that are ill due to HIV, as well as caring for those orphaned due to HIV.

> When my child is sick with HIV I know I have to use gloves when bathing her but I do not have any access to gloves. I also know that we are not supposed to share toothbrushes but we end up doing it because we do not have much (Rural Female)

> When your child is sick you may seek help from community health workers. However, sometimes your child messes herself and there is nobody to give you help either early in the morning, during the day or at night, nobody helps.

> Sometimes you need gloves but you don't get them and have to use your naked hands (Rural Female)

Discussion

As with nearly all studies of sexual behaviour, the value of this study depends on the veracity of reported behaviour. Numerous factors may serve as barriers to accurate reporting of behaviour. It is highly possible that social desirability could have led men and women to report fewer sexual contacts. Catania et al. (1990) point out that privacy, embarrassment and fear of reprisals are some of the reasons that may motivate people to conceal their true sexual behaviour. Moreover, it is possible that some respondents have trouble recalling how often and with how many people they have had sexual relationships (Catania et al. 1990). In addition, AIDS is still a highly stigmatised disease and many individuals may be afraid to disclose their sero-status for fear of violent retribution. Due to the association of HIV/AIDS with 'immoral' and 'high risk' behaviour older people may sometimes be isolated and shunned by their peers when it becomes known that they are caring for an HIV/AIDS patient (Legido-Quigley, 2003).

Knowledge is regarded as an important, if not sufficient, precondition for behavioural change. Although basic knowledge of HIV/AIDS is fairly high, there are some common misconceptions about the transmission of HIV. Such beliefs are likely to serve as a barrier for adopting appropriate prevention strategies and contribute to a greater stigma of people living with HIV/AIDS. A number of studies show that knowledge levels of older people are lower than younger people (LeBlanc, 1993). Older people are often not provided with the information required for them to protect themselves against HIV infection. This is due in part to the neglect of HIV information and prevention campaigns to visibly target the older population (HAI, 2003). Health care workers may also fall into the "trap of age stereotypes" which may delay prevention and diagnosis. Often health care workers fail to ask older patients about their sexual behaviour and do not provide the HIV prevention information they would routinely offer to younger patients (Taylor, 2004; UNAIDS, 2004). It is highly probably that some health care workers may not be fully aware of the risk of HIV

infection among older people, while others may experience social barriers that prevent them from openly discussing sexual health matters (UNAIDS, 2004).

Prevention programmes have not been very successful at creating sufficient awareness of the risk of HIV infection among older men and women. Few respondents felt at risk of HIV infection. Some of the female respondents who were at low risk of HIV infection because of their own sexual behaviour felt that they were at risk of HIV because of their partner's sexual behaviour. They felt that they could not trust their partner to remain faithful to them. Men with multiple sexual partners may not use a condom and may infect their regular partners. In many societies, gender relations are characterized by an unequal balance of power, with women having less access than men to education, training and resources (Sivard, 1995). The economic dependency of women severely constrains their ability to adopt risk reducing strategies and contributes to their increased vulnerability to HIV infection. In stable sexual relationships, women often feel that there is no need for condoms because they trust their partners (Zellner, 2003). However, a number of studies show that a significant and growing proportion of all HIV infections are transmitted through sexual intercourse with a spouse or stable sexual partner, either because of prior infection by one partner or because of infidelity (Lindan et al., 1991; Quigley et al., 1997).

Some studies suggest that men often engage in relationships with women who are considerably younger. The phenomenon of sugar daddies has grown over the years, and this leaves older women more vulnerable to HIV infection from their partners (UNAIDS, 2004; Pendry, 1998; Luke, 2005). Even when women suspect that their partner has had other partners, they may not be in a position to abstain from sex or insist on condom use (Gupta, 2002; Dunkle et al., 2004). In addition, older women often fail to protect themselves from HIV infection through the use of condoms because after menopause they do not have to worry about pregnancy (Taylor, 2004; UNAIDS, 2004). For countries with high levels of violence against women, such as South Africa, the strong risk of HIV transmission during violent or forced sexual encounters is also of grave concern. The abrasions caused by forced vaginal or anal penetration greatly facilitates the entry of the virus (UNAIDS, 2004).

Not only are older people infected with HIV but within Africa they are also the most affected by the virus (Knodel et al., 2002). Not only do older people face the loss of

economic support, particularly the loss of remittances from their sick and dying adult children, but they are also faced with the burden of caring for them (UNAIDS, 2002). This burden may be further exacerbated as older people often end up caring for the children, who are orphaned due to AIDS, without receiving any financial, emotional or physical support (May, 2004). One of the most critical effects is that it robs the family of their only social security system; productive members are removed from the equation when they fall ill and die, leaving children and the elderly to fend for themselves (May, 2004).

Older people often have to shoulder the costs not only of the debts incurred from HIV/AIDS related illness (such as doctors' fees, medicine and food) but also, funeral costs (Steinberg et al., 2002). Caregivers are often forced to undertake additional activities such as preparation of food, bathing, feeding and dressing of the sick (Legido-Quigley, 2003). It is found that such palliative care is provided mainly by older women (Juma et al., 2004). This care is often provided in a context of limited resources; a huge burden of household chores and farm work; and a decrease in wage employment (Legido-Quigley, 2003). The health of the person caring for the sick and dying may also suffer adversely. In Tanzania, older people caring for adult children suffering from HIV/AIDS related illness experienced a decline in body mass index (Ainsworth & Dayton, 2003). As symptoms worsen, older people as caregivers of sick and/or dying children are also likely to take on more clinical roles such as keeping track of medications, giving injections, inserting catheters, and cleaning wounds. This exposes them to the risk of infection through contact with infected blood, through open cuts/sores.

Conclusions

Over the last few years there has been a steady growth in the absolute number of men and women in the older age groups. In many developing countries, the AIDS epidemic is producing fundamental changes in the age structure of the population. A particular concern is the increasing number of young and middle age people who die as a result of AIDS, often leaving behind orphaned children to be reared by grandparents, who themselves will be without support from adult kin in their old age (Ferreira, 2000). In most societies, women, because they tend to live longer than men,

constitute the majority of the older population and in many countries, are the most vulnerable. The experiences of older men and women deserve widespread attention because the AIDS epidemic is impacting significantly on their lives in a variety of ways: physical, emotional, social and financial.

There is a growing recognition of the contribution of older people to the family and society. In many societies, older people and older women in particular often have to care for the sick and dying while at the same time assume primary responsibility for providing food and maintaining other basic household needs. However, there has been little attention directed at women's risk of HIV infection. The greater risk of HIV infection among women is attributable to a complex mix of biological, social and economic factors. Although physiology has a significant bearing on this situation, it is arguably women's lack of control over their bodies and their sexual lives, reinforced by their social and economic inequality, that increases their risk of HIV infection (Albertyn, 2003). It is important therefore to strengthen formal and informal support systems and safety nets for older women and in the process ensure that the necessary conditions are developed to enable them to lead healthy and productive lives in society.

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