Exchange ON HIV AND AIDS, SEXUALITY AND GENDER

Contextual sexuality challenges among people living with HIV: TASO's response

By Betty Kwagala

TASO field officer tests family members of the TASO index client in the Home-based HIV counselling and Testing (HBHCT) strategy. *(Picture courtesy of TASO)*

The severity of the HIV pandemic and the pervasive and dynamic nature of HIV and AIDS have brought sexual health into the centre of both reproductive health and development. Sexuality issues were hitherto regarded as private, hence, substantial discomfort remains on the part of (potential) clients (who are people living with HIV) and providers in addressing sexuality issues in the formal health care setting.

This article is based on a study of sexuality counselling services at The AIDS Support Organisation (TASO) Uganda using qualitative and quantitative research methods. Challenges experienced by clients and providers, as well as the organisation's efforts to respond and adopt to clients' emerging sexuality concerns are discussed.

Some key issues clients raise include stigma, disclosure, the personal and social pressure or expectations regarding marriage and child bearing, intimate partner violence, sexual dissatisfaction for women and sexual activity among pre-adolescent and adolescent children.

Although there have been significant achievements in reducing HIV prevalence in Uganda, many sexual and reproductive health (SRH) indicators remain poor. HIV prevalence was 6.4 per cent in 2005, with a higher prevalence among women (8 per cent) than men (5 per cent).

Only 29 per cent of women and 23 percent of men have ever tested for HIV. HIV infections among married couples are increasing, with 43 per cent of new infections occurring in monogamous marriages. This could be attributed to low male condom use (1.7 per cent within marriage) and multiple partnering especially among men, which stands at 29 per cent.

A high socio-economic status does not necessarily result in positive behavioural change in relation to HIV and AIDS. HIV prevalence, multiple partnering and transactional sex are higher among the wealthy and educated. The prevalence of sex and gender-based violence is high; 70 per cent of women have ever experienced physical violence and 39 per cent sexual violence.

A multi-pronged approach

Effecting behavioural change regarding SRH issues, in this case HIV and AIDS, requires a multi-pronged approach. Counselling is one of TASO's strategies, with its HIV programmes providing counselling that addresses sexuality-related issues. Counselling is provided along with medical care, social and nutritional support, advocacy and counselling training programmes. This article is based on findings of a study of sex and sexuality counselling undertaken at TASO between 2007 and 2008.

TASO counsellor talks to a discordant couple (man is HIV positive and woman is negative) about prevention in their home. *(Picture courtesy of TASO)*

The study was conducted at Jinja and Mulago TASO centres, both located at referral hospitals in urban areas with catchment areas of a radius of more than 75 kilometres. Data collection methods used included: key informant interviews at organisational and national levels (11); in-depth interviews with clients (21); in-depth interviews with counsellors (10); focus group discussions (FGD) with client groups and counsellors (6); session recordings (60); session observations (70); exit interviews (65); interviews with facility managers (2); and workshops (3). Only repeat clients of at least one year were interviewed. Each of the various research techniques engaged different respondents. Ethical clearance was obtained from TASO and the National Council of Science and Technology.

Contextual sexuality issues and response

Contextual factors have significant influence on the well-being and behaviours of people living with HIV. Patriarchal cultural and social norms play a role in influencing sex and sexuality in Uganda. Just like any other members of the community, people living with HIV have personal desires and are expected to relate socially, marry and bear children.

HIV-associated stigma hampers access to medical and counselling services; lives are lost due to failure to access care and some clients seek services in distant places for purposes of anonymity. The fact that few couples embrace couple counselling limits the impact of sexuality counselling of women, given the dominant role of men in sexual relations. Physically-challenged persons usually fear seeking counselling services because they are not expected to be sexually active.

TASO has endeavoured to be inclusive by facilitating access to low income and physically-challenged persons by hiring a specialist in the field and making counsellors aware of disability issues. Clients are only required to contribute Uganda Shillings 500 (about 25 US$ cents) user fee. Home-based counselling helps to reach a diversity of people including men. Call-in and home visits have been established for persons of higher socio-economic status who shy away from services.

Marriage and childbirth are expected of all men and women often irrespective of HIV sero-status. This was particularly a problem for clients that have not disclosed their status. Apart from the intrinsic desire, there is significant social pressure for children. Focus group discussion participants noted the following concerning a hypothetical woman in a discordant relationship who is under pressure to conceive.

"There is a problem; the in-laws may tell Betty that she came to fill up the toilet." This implies eating the man's food without producing children. With ARVs, the need to marry and bear children has increased, necessitating major adaptations in response to new counselling needs.

Clients know what counsellors expect of them; for instance disclosure, marrying a fellow HIV-positive person to avoid infection and for purposes of mutual support, and the possibility of getting an HIV-negative baby.

However, changes in the counselling message (from abstinence or limiting sex activity in marriage and not conceiving) have not been heard or understood by many clients.

Some clients who conceived stayed away from the centres due to fear of displeasing their counsellors. There is need for messages to address this issue.

Sero-status disclosure sometimes causes separation. "I disclosed my status to my wife but she did not want to listen to me. She packed and left me, but I got another one [through clients' networks] and wedded her. However, disclosure helps avoid many other problems," a recently married client said.

Unsatisfying sexual relations was a major concern for women. In many Ugandan cultures, the main function of sex is reproduction. Pleasure tends to be secondary and usually for men's benefit. In the past, sexual dissatisfaction could result in extramarital relationships referred to as "pain killers", or "side-dishes." The contents of sexuality counselling offered do not exhaustively address such issues, since emphasis is placed on disease prevention.

TASO has made efforts to respond to some of these issues. Openness about conception is encouraged to enable clients receive counselling and PMTCT services. Marriage among PLHIV is facilitated through clients' clubs and trusted clients at TASO. This helps control infections and at the same time caters for clients' need for marriage.

Client and community-based ssengas (paternal aunts, whose role is to prepare their nieces for marriage) are to be trained to complement counsellors in addressing issues of sexuality. In addition to individual counselling, couple and home-based counselling and peer group support have also helped complement counsellors' efforts in sexuality counselling.

Session recordings showed some women were battered and sexually abused for insisting on condom use. Negotiating condom use is a challenge for married women, given male dominance in most aspects of a marriage relationship and women's insecurity and socio-economic dependence on men. Additionally, the

A TASO field vehicle in the community.

social value placed on marriage makes women stay in abusive relationships.

TASO encourages couple counselling so that both partners share messages. Although still on small scale, seed monies for income-generating activities also contribute to the economic sustenance of families, including families of women who may have been deserted or denied economic support.

Acceptable sexual relations in Uganda are primarily heterosexual. Other sexual orientations are considered taboo and criminal. Same sex relations are believed to be a result of lack of exposure, experience or opportunity for heterosexual relations.

One of the key concerns is the possibility of not having biological children, since according to most cultures and religions the primary purpose of sex is not just pleasure, but procreation. Clients believe that homosexuality can be reversed through becoming religious. Such persons are expected to get tested for HIV, meet girls or boys and marry.

The following observations were made by participants concerning a hypothetical homosexual person: "I think that John doesn't have God or read the Bible, because he has deviated from the plan of God. The Bible talks of a male and a female," a male client said. "They should get a beautiful girl and set him up…" A female client added: "I agree with that one. They should make different beautiful girls available for him; at least he will get interested in one of them."

Although services are available to all irrespective of sexual orientation, anecdotal reports reveal that persons in homosexual relationships fear accessing services in the public sector and yet they highly risk HIV infection. Counsellors are currently trained about the different sexual orientations.

There are major concerns about reported cases of defilement and sex among pre-adolescent and adolescent children. This is a challenge for clients and health providers. This is partly attributed to laxity concerning sensitisation of children about sexuality issues because parents or guardians feel it is too early and yet in some contexts, sexual activities start earlier than expected.

A major concern is the possibility of HIV transmission or re-infection. According to counsellors, perinatally-infected adolescents consider themselves innocent and therefore disease-free, since HIV is usually associated with sexual activity.

Birungi and others found that over 60 per cent of perinatally-infected children who were dating had not disclosed their sero-status while 34 per cent were sexually active. This necessitated urgent response by TASO which entailed modification of adolescent counselling to address key adolescent sex and sexuality issues. A training manual has been developed as a result.

TASO takes a holistic approach in its generally integrated services, which do not only benefit individual clients but where feasible, family members such as spouses, and children, who are encouraged to seek counselling. Home visits and counselling for clients on ARVs provide opportunities for addressing not only biomedical issues, but also social challenges experienced by clients.

Despite gaps in addressing issues of sexuality, counselling has made a significant contribution to improving clients' health and has potential for addressing most of the clients' sexuality counselling needs. In appreciation, clients made the following statements on counselling: "Counsellors are our ssengas in the era of HIV," said a female client. "The counsellor does not get tired of me. He provides all the information that I need. We share the same counsellor with my husband, which is good," another female client added.

Tailored training of counsellors

The relatively good quality of counselling is attributed to careful selection and thorough tailored training of counsellors, fairly good working conditions, monitoring and close supervision, and participation of clients at all levels of management, which ensures their concerns are attended to.

Flexibility and adaptability is essential if an organisation is to respond to clients' emerging needs. Diversification of approaches to counselling for instance in terms of location, numbers counselled in a session and content is necessary for reaching the unreached and addressing their counselling needs.

It is important to tailor counselling to client needs and to ensure inclusion of marginalised groups such as disabled persons (despite their small numbers). Issues of sexuality should not be isolated from clients' socio-economic situations. An integrated approach is essential for delivery of sexuality counselling (within general counselling and other services), the subject being a sensitive one. However, it is important to ensure sexuality issues are given sufficient attention and where feasible, the necessary depth.

Partnering public and private sector providers offering the required services is necessary, particularly where providers cannot exhaustively address clients' sexuality counselling needs. Broader contextual issues such as the hierarchical gender relations in relation to issues of sexuality, economic dependence of women and HIV-associated stigma require broader interventions involving a diversity of actors.

Sexual health is an integral and indispensable part of living positively with HIV and reproductive health in general. For sustainable results, sexuality counselling should be provided within the framework of general counselling on broader reproductive health issues.

Where feasible, specialists could be trained to offer specialised sexuality counselling in case of special needs. In addition to sexuality counselling offered under HIV-associated programmes, it is necessary to establish counselling services that integrate sexuality counselling in public health facilities and institutions and to use avenues such as help-lines that have potential for reaching men and stigmatised groups.

Lessons learnt

- In addition to individual counselling, couple and home-based counselling and peer group support have helped complement counsellors' efforts in sexuality counselling.
- Flexibility and adaptability is essential if an organisation is to respond to clients' emerging needs.
- It is important to tailor counselling to client needs and to ensure inclusion of marginalised groups such as disabled persons (despite their small numbers).
- Broader contextual issues such as the hierarchical gender relations in relation to issues of sexuality, economic dependence of women and HIV-associated stigma require broader interventions involving a diversity of actors. ■

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