

# Exchange

ON HIV AND AIDS, SEXUALITY AND GENDER



## Client perspectives on the responsiveness of HIV services

By Anke van der Kwaak, Karen 't Hooft, Marjolein Dieleman and Elisabeth Kwagala

"At the health centres, you are asked many questions like: 'Have you given birth, what is your age, whom do you live with, are you in your menses...?' a respondent said. "But in the chemist, you are injected without questions," another said. And yet another respondent said: "In chemists it is business." "You only say what you came for, are told to lie down and injected without questions in the chemists," another respondent said.

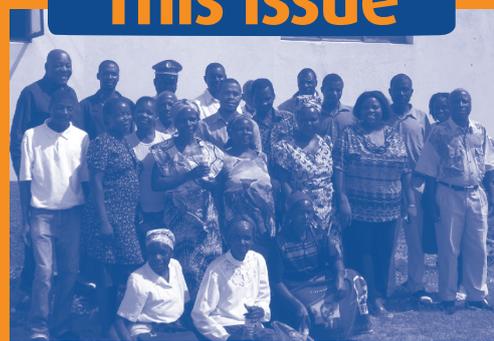
The foregoing are responses at a 2010 focus group discussion involving girls and young women aged 15 to 19 years in Kibera, Kenya<sup>1</sup>. The discussion was part of a widely published, larger study that showed that young people living with HIV prefer receiving healthcare and referral services without being asked too many questions. The study revealed gaps in service quality and in the delivery system from young people's perspective: young people were not sufficiently informed, were embarrassed about being HIV-positive and found their counsellors' approaches and attitudes too patronising.

In order to improve the quality and effectiveness of services, they should respond to the needs of different demographic groups, for example, these young girls'. Clients' needs should therefore be identified and understood first, so that they can be taken into account when designing and implementing healthcare services.

Despite the fact that responsiveness is identified by the World Health Organization (WHO) as a major goal of the health system framework: 'to be aware of and adaptive to the needs of a population', few reports describe and include client perspectives on healthcare services, especially when it comes to HIV and SRH services and the perspectives of (young) people living with HIV and AIDS.

This edition of the *Exchange magazine* is about client perspectives on HIV services. The cases that are presented might leave the reader with more questions than answers: a lot is required to make services more responsive to client needs and this responsiveness is one of the common challenges of health systems. Key questions grappled with include: "How can health and other services be made more responsive to the needs of diverse client groups?", "How can 'needs' be defined, and what are the providers' perspectives on these needs?", "What about referral and collaboration among diverse service providers – public and private?" And, "What factors facilitate or hinder access and uptake of HIV services?"

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## Editorial



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### Integrating sexual and reproductive health needs with HIV and AIDS services

Respondents in a qualitative research conducted with HIV-positive women and men of reproductive age attending HIV and AIDS care and treatment services at a public health clinic in Cape Town, South Africa, praised their HIV and AIDS care and treatment, reflected on how it improved their quality of life and contrasted this with suboptimal care at other public health facilities, including sexual and reproductive health (SRH) services.

Women respondents wanted integrated services, especially for contraception and to reduce stigma. HIV-positive men's lack of experience with SRH services and antipathy towards attending "women's" health services were highlighted. Challenges to involving men in HIV and AIDS care and treatment and SRH services and measures to address this were identified.

Growing evidence from innovative projects demonstrates that linking reproductive health and HIV and AIDS programmes and services can accelerate HIV prevention efforts by increasing knowledge of HIV serostatus, promoting safer behaviours and sexual norms while optimising the connection between services for HIV and AIDS and sexually-transmitted infections (STIs), and integrating HIV and AIDS with maternal health.

These key measures are needed to intensify HIV prevention and improve sexual and reproductive health leading to important public health benefits. Therefore, linking the response to SRH and HIV and AIDS has significant potential for improving SRH and preventing HIV.

Furthermore, providing HIV and AIDS, reproductive health information and services as a comprehensive and integrated package rather than individually creates efficiencies in delivering services; increases opportunities to identify unrealised needs and reaches more people with more services. Most men and women are infected with HIV early in their reproductive lives and integrated services can provide the means to reduce risk of infection and re-infection while also helping to prevent unintended pregnancies among HIV-positive women.

Reproductive health-HIV integration presents important opportunities for national programmes to expand their impact and improve the prospect of achieving HIV prevention, care, and treatment goals. Integration is a feasible means to achieving the prevention of new HIV infections among women and girls, prevention of mother-to-child transmission (PMTCT) of HIV, reducing the number of AIDS orphans, and supporting the reproductive rights and fertility choices of HIV-positive women, sex workers and men who have sex with men.

In this edition of *Exchange magazine*, we present evidence on the scourge of gender-based violence among TASO clients; highlight how one's economic status influences infant feeding options of HIV-positive mothers in western Uganda and discuss factors influencing uptake of HIV services by couples. An analysis of these case studies points to the need for integrating HIV and reproductive health services that could significantly improve SRH and HIV prevention. ■

This article tries to answer some of these questions and discuss important concepts on client centredness.

### Meaningful participation

The need for client or patient involvement in health care has long been recognised: the involvement of people living with HIV and AIDS was first voiced in 1983 in Denver, Colorado, and was formalised in 1994 in Paris. The Paris AIDS Summit for Heads of State reflected that the participation of people living with HIV and AIDS had not been represented in national programmes and policies. The final Paris Declaration, signed by 42 participating countries resulted in "The Principle of Greater Involvement of People Living with HIV and AIDS (GIPA).

Today, several international guidelines and commitments support patient involvement. Examples include the 2001 UNGASS on HIV/AIDS Declaration of Commitment, the 2006 UN High Level Meeting Political Declaration and the Code of Good Practice for NGOs Responding to HIV: Renewing our voice<sup>2</sup>. These efforts have resulted in the greater involvement of people living with HIV being central in policies and national strategies. GIPA was not especially successful and often resulted in tokenism, giving rise to Meaningful Involvement of People living with AIDS (MIPA). However, in order to turn these intended strategies of meaningful participation into practice and to actually involve people living with HIV and AIDS, a lot more needs to be done.

Meaningful participation of people living with

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HIV and AIDS and other health conditions is essential for ensuring that services are appropriate and feasible<sup>3</sup>. Responsiveness of the health system can only be achieved when communities, and specifically the clients, are placed at the heart of the programmes and services. This means that their needs are taken into account and their voices heard in a systematic way.

Elizabeth Pisani, however, has questioned this notion for HIV prevention, sex workers and Asia. She argues that top-down approaches are sometimes more effective, that peer pressure can sometimes be peer competition, and that being HIV-positive does not qualify everyone to be a good counsellor. What we can learn from her bestseller *The wisdom of whores (2008)* is that contextualisation is crucial. That leadership is another important feature. Not all clients will be able to speak out and think what is best for them.

Here it seems that we are dealing with a continuum of meaningful participation, which is highly defined by the setting we are dealing with. On the other hand there are many interventions and services structured along the lines of what programmers and providers think is best for clients without taking diverse backgrounds into account. What Pisani observes for simplistic solutions as bottom-up approaches counts as for the top-down ones. We would like to underline the concept of "effective engagement of people living with HIV" and we are convinced that the active participation of leaders among clients and client networks in identifying their needs helps increase client satisfaction (with services).

### What are the needs of clients?

But clients have different needs based on their backgrounds, their expectations, and the disease they are suffering from.

An interesting overview comes from a modified and validated version of the Cancer Needs Questionnaire (CNQ), the so called Supportive Care Needs Survey (SCN). Although this instrument was validated for Australia, we can learn from its categorisation of patient needs. The five categories are (1) psychological: Needs related to emotions and coping; (2) Health system and information: Needs related to the treatment centre and obtaining information about the disease, diagnosis, treatment, and follow-up; (3) Physical and daily living: Needs related to coping with physical symptoms and side-effects of treatment and performing usual physical tasks and activities; (4) Patient care and support: Needs related to healthcare providers showing sensitivity to physical and emotional needs, privacy, and choice; and (5) Sexuality: Needs related to sexual relationships.

An additional aspect is related specifically to the need for easy access to services and resources, such as transport, childcare, counselling services, information, relaxation classes, and financial assistance<sup>4</sup>.

Psychological, health system and information, and physical and daily living domains ranked highest among clients' perceived needs. Older people and women reported higher levels of unmet need in the psychological and care and support domains. Although research on clients' perspectives on services and clients' needs have been conducted in the areas of TB, HIV and sexual and reproductive health, client needs in these different categories in low and middle income countries are rarely considered when designing services. Major limitations to enhancing potential users' access to services, including diagnosis and/or treatment, are often linked to health services not being patient centred.



Beneficiaries of a community health centre in Harare, Zimbabwe. (Photo courtesy of SAfAIDS).

### Responsive services

In some areas, efforts are underway to improve responsiveness of services and to at least improve understanding of patient needs. For example, presently a patient-centred package is being tested among TB (/HIV) services in Cambodia, Indonesia, Mozambique, Nigeria and Zambia. Here the vision with respect to patient centredness is defined as creating universal access to care and support by addressing the needs, strengthening information and quality care, creating partnerships between providers and patients, creating opportunities for input and participation, and empowering patients in order to facilitate their involvement at all levels in the programme. This emphasises the effective participation of people living with HIV reflected in the central quotation: “Nothing about me without me” (Berwick, adopted by Salzburg group). Here patient-centred care is seen as a key component of the health system and ensures all patients have access to the kind of care that works best for them.

The package includes a tool to measure patients’ views on quality dimensions, to get an insight into the costs one has to pay before even entering a health facility and a literacy tool to raise patients’ awareness. This is an important positive step to improve the responsiveness of services, but is in our view, insufficient. Knowing what clients need does not improve the responsiveness of services if they are not addressed, and when the needs of providers are also not properly understood.

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Healthcare providers are central actors in influencing the policies and procedures of health facilities, as well as being essential in designing and evaluating health systems that take communities into consideration. They are therefore essential in making linkages between clients/patients and the health system<sup>5</sup>.

Moreover, the relationships between providers and clients form the fundamental constituent for the level of engagement and maintenance of clients in their healthcare. In several studies about client perspectives of care, the provider-client relationship dominates client experiences and their satisfaction of the healthcare they receive<sup>6</sup>.

Although there is a strong emphasis on strengthening provider-client relationships in the context of improved responsiveness, this does not seem to come naturally. In an attempt to link the fields of providers and clients, an article was published in *Patient Education and Counselling* in 2010<sup>7</sup>. Positive encounters between providers and clients, the authors argued in the article, are built on mutual trust and respect, and are influenced by space, place and context. But how could the needs and expectations of clients be reconciled with the needs and expectations of providers?



Members of a Namibia community-based distributors group. (Photo courtesy of SAfAIDS).

### Client perspectives

In addition to the health system not being patient-centred, another major challenge relates to the attitudes and behaviours of healthcare providers and their communication to their clients. These attitudes and behaviours are often driven by cultural, social and/or personal characteristics of both the provider and patient<sup>8</sup>. According to a qualitative study carried out in South Africa, empathetic providers and counsellors (often HIV-positive) are crucial for client satisfaction. Respondents of the study identified attitudes and behaviour of individual providers as key in the quality of care. The support received from counsellors even strengthened their determination to deal with their infection. Providers’ ability to communicate in the clients’ own language, and ensuring privacy were commended by clients.

Another gap identified in the health delivery system by the respondents of the South African study, is also a widely recognised one: the integration of SRH and HIV services. In order to achieve the Millennium Development Goals, policies and programmes should focus on the implementation of strategies to integrate HIV and SRH services, especially access to family planning services, (female) condoms and other contraceptives, STI screening and treatment and at least counselling and referral for specific reproductive health issues such as abortion.

The integration of HIV and AIDS and SRH services is crucial for client satisfaction and quality of care, especially for PLHIV<sup>9</sup>. Women respondents in this study unanimously indicated their desire to access both services ‘under one roof’. Besides the fact that separate HIV and SRH services are less cost-effective than when integrated, these HIV-positive women reported encountering many barriers, including stigma, when trying to access contraceptives when these services are offered separately.

The fact that many young people living with HIV and AIDS make poorly informed decisions about sex, builds an even stronger case for the need to integrate services. Evidence of the need for sexual and reproductive health services for young people living with HIV is growing and is still being insufficiently addressed. Young people living with HIV have to deal with – besides onward transmission – issues of disclosure, pregnancy and super infections (infection by a second strain of the virus causing more rapid disease progression or ARV resistance), and have more worries about relationships, sex and having children in the future

than actually about their HIV status<sup>10</sup>.

The young people are more likely to reduce risk behaviour when offered relevant information, skills and services, highlighting their need for integrated services. Furthermore, according to the study by Armstrong<sup>3</sup>, all interviewed HIV healthcare providers identified the need for both SRH information and services, calling for integration of services and referral mechanisms. In the study a change of mindset among providers was emphasised, where providers need to acknowledge teenage sexual activity and the fact that ignoring sexual issues would not prevent teenagers from having sex.

The involvement of men is an identified challenge by female clients involved in the South African study. Both female and male clients felt that the HIV and SRH services should be more adjusted to the different needs of men and their related work commitments (special opening hours of clinics for men), including the number of male staff at the clinics, as cultural aspects might make it difficult for men to visit female providers. It is suggested that different models of care be explored to maximise the involvement of men as both clients of health services and supportive partners, to

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achieve improved women’s and men’s health, decreased gender-based violence and address the needs of HIV-positive men and women.

Constructive men’s engagement – as it is called and implemented by USAID in SRH and HIV prevention, treatment and care – aims at achieving these results by facilitating a more enabling policy and institutional environment for men’s engagement. The engagement of men and boys has not always been a priority for strategies to improve health and gender outcomes. In many countries in sub-Saharan Africa, more than 50 per cent of the people living with HIV and AIDS are women and girls, and gender inequalities increase the risk of HIV infection for them. Besides the identified need for the involvement of men by the female respondents in the Orner research, many other studies show that the engagement of men in HIV prevention and SRH programmes can improve health outcomes and promote gender equality<sup>11</sup>.

**Accountability**

Exclusive emphasis on the perceived needs of clients or patients, making providers responsible for poor quality of services, is simplistic. To improve responsiveness of services, enabling service-users to participate in decision-making processes for health services and policies that affect them is important. Also, engaging service-users in decision making will have a positive effect on their perspectives regarding satisfaction and quality of care.

In this respect, globally the concepts of governance, and in particular political accountability, are mostly used in development and health system debates. According to Brinkerhoff, political accountability can be defined as “measuring performance in relation to civil society’s (patients; populations served) stated needs and demands of health services”<sup>12</sup>. This can take shape in various ways, such as having communities monitor health services and/or health services management, in partnerships with communities. Responsiveness requires actions from both providers and their clients: taking rights or entitlements and responsibilities of both clients and providers into account seems a better option. With such a perspective, clients that are informed and empowered also have the responsibility to share their knowledge with others and try to keep healthy by adhering to their medication regimen.

In the case studies presented in this publication, some examples show the multifaceted nature of provider-client interactions, especially in relation to HIV services. Power relations (gender inclusive), religious and cultural beliefs, and in particular, perceived and enacted stigma characterise these interactions.

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In the last four years, The AIDS Support Organization (TASO) in Uganda and the Royal Tropical Institute (KIT) in Amsterdam embarked on a joint research in which proposals were written and small studies implemented focusing on access and uptake of HIV services by different client groups. ■



Clients and benefactors of a health facility in Manica region of Mozambique. (Photo courtesy of SAfAIDS).

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A group of community-health volunteers in Chitungwiza, Zimbabwe. (Photo courtesy of SAfAIDS).