SAHARA Journal Mission Statement

The journal publishes contributions in English and French from all fields of social aspects of HIV/AIDS (care, support, behaviour change, behavioural surveillance, counselling, impact, mitigation, stigma, discrimination, prevention, treatment, adherence, culture, faith-based approaches, evidence-based intervention, health communication, structural and environmental intervention, financing, policy, media, etc.)

Déclaration de la mission du journal SAHARA

Le journal publie des articles en anglais et en français dans tous les domaines sociaux du VIH/SIDA (soins, traitement et counselling, soutien et prise en charge, changements de comportements, surveillance socio-comportementale, mitigation des impacts, stigmatisation, discrimination, prévention, adhésion au traitement, culture, approche basée sur la foi et la religion, interventions basées sur des succès documentés, communication en matière de santé, interventions structurelles et environnementales, financement, politiques et médias).
The role of HIV/AIDS committees in effective workplace governance of HIV/AIDS in South African small and medium-sized enterprises (SMEs)

Jocelyn R Vass

Abstract
The primary purpose of this study was to assess the role, status and scope of workplace HIV/AIDS committees as a means of effective workplace governance of the HIV/AIDS impact, and their role in extending social protective HIV/AIDS-related rights to employees. In-depth qualitative case studies were conducted in five South African small and medium-sized enterprises (SMEs) that were actively implementing HIV/AIDS policies and programmes. Companies commonly implemented HIV/AIDS policies and programmes through a workplace committee dedicated to HIV/AIDS or a generic committee dealing with issues other than HIV/AIDS. Management, through the human resources department and the occupational health practitioner often drove initial policy formulation, and had virtually sole control of the HIV/AIDS budget. Employee members of committees were mostly volunteers, and were often production or blue collar employees, while there was a notable lack of participation by white-collar employees, line management and trade unions. While the powers of workplace committees were largely consultative, employee committee members often managed in an indirect manner to secure and extend social protective rights on HIV/AIDS to employees, and monitor their effective implementation in practice. In the interim, workplace committees represented one of the best means to facilitate more effective workplace HIV/AIDS governance. However, the increased demands on collective bargaining as a result of an anticipated rises in AIDS-related morbidity and mortality might prove to be beyond the scope of such voluntary committees in the longer term.

Keywords: HIV/AIDS, committees, workplace, governance, small and medium-sized enterprises (SMEs).

Résumé
Le but de cette étude fut d'évaluer le rôle, le statue et le champ de comités de VIH/SIDA dans un milieu de travail comme moyen efficace de gérer l'impact du VIH/SIDA dans des lieux de travail, ainsi que leur rôle à étendre, aux employés, les droits sociaux et protectifs liés au VIH/SIDA. Des études de cas qualitatives et détaillées ont été menées auprès de 5 petites et moyennes entreprises sud-africaines qui exécutaient, de manière active, les politiques et les programmes du VIH/SIDA. Les sociétés communément exécutaient les politiques et les programmes du VIH/SIDA, en milieu de travail, à travers un comité dévoué au VIH/SIDA ou bien un comité générique qui s'occupait d'autres sujets en dehors du VIH/SIDA. La gestion, à travers le département de Ressources Humaines et la personne chargée de santé en milieu de travail, a souvent conduit la formulation initiale d'une politique. De plus, la gestion dominait le budget du VIH/SIDA. La plupart des employés, membres de comités, étaient des volontaires, et souvent ces volontaires étaient des ouvriers et des employés de services. Alors qu'il manquait la participation des cadres et des représentants de syndicats. Etant donné que le pouvoir des comités était largement consultatif, les membres de comités géraient, de manière indirecte, afin d'assurer et d'étendre les droits sociaux et protectifs de VIH/SIDA aux employés, ainsi que de contrôler une mise en œuvre efficace de ces derniers. Entre temps, les comités en milieu de travail représentaient un des meilleurs moyens de faciliter davantage la gestion efficace du VIH/SIDA dans un milieu de travail. Cependant, les exigences croissantes des négociations liées à l'augmentation prévue de la morbidité et la mortalité liées au VIH/SIDA pourraient, à long terme, être au-delà du champ des comités volontaires.

Mots clés: VIH/SIDA, comités, lieu de travail, gestion, petites et moyennes entreprises.

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Introduction
A key factor in the effective governance of HIV/AIDS in the workplace is the collaboration of employers and employees. Thus, guidelines on best practices for effective HIV/AIDS management in the world of work promote the establishment of collaborative mechanisms, including committees at national, regional, company and workplace level (Department of Labour, 2000; International Labour Organisation [ILO], 2004). However, there is very little research available that explores the role, dynamics and challenges of such committees, especially in the workplace. The key research objective of this study was to assess the role, status and scope of workplace committees as a means of effective workplace governance of the HIV/AIDS impact in the participating companies. A secondary objective was to assess the extent to which such committees created new opportunities to extend social protective rights to South African employees to mitigate the scourge of HIV/AIDS more effectively.

In-depth qualitative case studies were conducted in five SMEs in Gauteng province in South Africa, which documented the implementation of HIV/AIDS policies and programmes. Four companies were medium-sized employing 50-500 employees, while the fifth company was small and employed fewer than 50 employees. Most of the companies were in the manufacturing sector, while one was in the services sector. Results for Company D were reported separately as D1 and D2, as these were two different sites belonging to one company.

Background
HIV/AIDS interventions in the South African private sector are largely led by corporates with extensive access to financial resources, and information and knowledge networks. Thus, local studies show consistently that small companies tended to lag behind in the management of the epidemic and access to HIV/AIDS services, while medium-sized companies performed relatively better in this regard (Connelly & Rosen, 2003; Ellis & Terwin, 2004). A study conducted in 2004 showed that while 96% of large corporates and 64% of medium-sized companies had a HIV/AIDS policy, only 17% of small companies had the same. While the existence of a policy does not necessarily reflect effective governance, it does indicate a written commitment to a set of principles and procedures, an essential step in the management of the HIV/AIDS impact. Further, both the International Labour Organisation Code of Practice on HIV/AIDS and the World of Work (ILO, 2004) and the South African Code of Good Practice: Key aspects of HIV/AIDS and employment (Department of Labour, 2000) promote the development of workplace-based HIV/AIDS programmes to facilitate the protection of employee rights and the delivery of HIV/AIDS prevention programmes, care, treatment and support. However, the successful attainment of these objectives requires appropriate institutional and governance capacity within workplaces. This is especially relevant to SMEs, who often suffer resource and capacity constraints in HIV/AIDS management (Connelly & Rosen, 2003). Thus, lessons may be learnt from SMEs that have allocated resources and capacity.

Table 1. Summary of fieldwork activities

<table>
<thead>
<tr>
<th>Company</th>
<th>Key informant interviews</th>
<th>Group interviews</th>
<th>Focus group discussions</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>I (Managing director)</td>
<td>I (HIV/AIDS committee)</td>
<td>2 (14 employees)</td>
</tr>
<tr>
<td></td>
<td>I (OH)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I (Operational director)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I (Trade union)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>B</td>
<td>I (Managing director)</td>
<td>I (HIV/AIDS committee)</td>
<td>2 (17 employees)</td>
</tr>
<tr>
<td></td>
<td>I (OH)</td>
<td>(Trade unions)</td>
<td></td>
</tr>
<tr>
<td>C</td>
<td>I (MD)</td>
<td>I (HIV/AIDS committee)</td>
<td>2 (14 employees)</td>
</tr>
<tr>
<td></td>
<td>I (HR)</td>
<td>(Trade unions)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>I (Training officer)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I (OH)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I (Operational Director)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>D1</td>
<td>I (MD)</td>
<td>Not applicable</td>
<td>1 (12 employees)</td>
</tr>
<tr>
<td></td>
<td>I (HR director)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I (Trade union)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>D2</td>
<td>I (Senior management)</td>
<td>I (Trade union)</td>
<td>1 (13 employees)</td>
</tr>
<tr>
<td>E</td>
<td>I (HR management consultant)</td>
<td>I (2 employees)</td>
<td>Not applicable</td>
</tr>
<tr>
<td></td>
<td>I (HIV/AIDS employee coordinator)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I (Trade union)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The post-apartheid labour legislative framework is largely founded on the principle of consensus-seeking and industrial democracy to resolve differences in a cooperative rather than an adversarial manner. Thus, there exists in the South African labour regulatory framework a range of collaborative mechanisms, often manifested in multilateral committees; some with clear legislative powers, while in others they are left undefined. This paper sought to assess the extent to which this cooperative workplace culture may be observed in the management of HIV/AIDS as well, and the impact on securing HIV/AIDS-related rights and benefits.

Methodology
This study formed part of a larger research project. The research methodology followed was qualitative in nature, and included the development of in-depth case studies of five SMEs, which were recruited using the snowball sampling technique. Thus, referrals from disease management providers were used to recruit an initial list of 15 companies, five of which eventually agreed to participate. These five companies had to:

• Employ less than 500 employees
• Have an existing HIV/AIDS policy and programme
• Allow the research team to interview employees.

The research team conducted semi-structured key informant and group interviews with management and trade union representatives, as well as employee representatives on the workplace HIV/AIDS committees. Where there were no HIV/AIDS committees, those involved in the HIV/AIDS programme were interviewed. The management representatives usually included the managing director (MD), human resources (HR), training or industrial relations (IR) directors, and the occupational health (OH) nurse. In two companies, the operational director was also interviewed.

As part of the larger research project, separate focus groups were conducted with employees from the production and administrative sections of these companies. Focus group discussions were held after the conclusion of interviews with the committees, trade unions and management representatives. The purpose of the focus group discussions was to reflect on employees’ real experiences and their evaluation of the activities of the HIV/AIDS committees, thus hopefully providing a more objective view rather than a one-sided and subjective view from insiders on the HIV/AIDS committees. Where relevant, data generated in these focus groups were included in this article. See Table 1 for details of the fieldwork conducted.

Interviews were conducted once informed verbal consent had been obtained, and generally lasted for an hour. In order to maintain confidentiality and anonymity, names and other identifying details were not recorded. In the focus groups and group interviews, respondents were also asked to maintain confidentiality of the content of the group discussions afterwards as well. The right to withdraw during discussions applied, where respondents felt that confidentiality might be at risk. An additional (and indirect) form of protection for respondents was to conduct separate focus groups for production and administrative employees. Historically, these groups of employees have been more homogeneous (predominantly black and semi-skilled, or white and skilled), and often might have had comparatively different life experiences in the workplace. It was also felt that, given the sensitivity of HIV/AIDS, they might reflect more comfortably among known colleagues. Given the voluntary nature of the focus groups, bias might have crept in, as those with differing opinions might have excluded themselves or were not available due to operational requirements.

The interviews were based on a set of core questions. Probing and follow-up questions were asked depending on the flow and nature of respondents’ inputs. The core exploratory questions were the following:

• What is the nature and role of the HIV/AIDS committees?
• What are their powers and how effective are they in realising HIV/AIDS policy and programmes?
• What rights and benefits have been granted to employees as a result, and what has been the role of the committees in this regard?
• What have been the role of the trade unions in the HIV/AIDS committees and the management of HIV/AIDS?

The research proposal and the research instruments (interview guidelines and consent forms) were submitted to the Human Science Research Council ethics committee for consideration. Full ethical approval was granted subject to changes to the research instruments. All interviews were recorded on tape recorders and in written form, and were transcribed. Thematic content analysis was used to code and analyse the data, based on a number of themes identified in the core questions, sub themes that arose in the process of conducting the fieldwork, and subsequent reflection. Where possible documentary evidence, such as written company HIV/AIDS policy documents, were also collected and used to verify some of the information collected during the interviews. After the conclusion of the larger research study, presentations on the outcomes of the case studies were presented to those participating companies who had made such a request. This provided useful feedback to HIV/AIDS committees on the dynamics and impact of their HIV/AIDS interventions among their employees.
Results
The development and implementation of HIV/AIDS policies and programmes in most of the participating SMEs was driven by a workplace committee, either dedicated to HIV/AIDS, or a “generic” committee dealing with broader employee issues. Thus, three companies had a dedicated HIV/AIDS workplace committee, established with the sole purpose of facilitating the implementation of HIV/AIDS policies and programmes. These non-statutory committees appeared to co-exist with other statutory committees, facilitating sharing of information and feedback on HIV/AIDS activities. On the other hand, in Companies D1 and D2, HIV/AIDS was discussed at site level with the trade union representatives as part of the statutory employment equity (EE) committee as provided for under the Employment Equity Act. This was motivated by a managerial decision to centralise HIV/AIDS policy development and implementation at head office level. It was argued that, “…a committee [dedicated to HIV/AIDS] makes sure that nothing gets done”. In Company E, there was no HIV/AIDS committee, but an employee HIV/AIDS coordinator, elected by the employees, who liaised with the HR consultant and management on HIV/AIDS matters. This practice was largely attributed to the fact that, as a small company, it did not have sufficient resources to sustain an independent structure. The key rationale forwarded by management for a dedicated HIV/AIDS committee was that employee representation would facilitate “…buy-in from the floor”, facilitating a “bottom-up” approach and workforce involvement in the HIV/AIDS programme. It was also recognised that it was a business “best practice” advocated by private sector role models.

Composition of dedicated HIV/AIDS committees
Participation on the committees was voluntary, and members came from the general workforce, senior management, the occupational health practitioner, and trade union shop stewards. There was a predominance of production employees, and relatively poor representation by administrative or non-production employees. Furthermore, this skewed employee representation had racial overtones, as most production employee members were African, whereas administrative employees were predominantly white, or to a lesser extent, coloured. When asked about this phenomenon, employee committee members in Company A and Company B felt that “…they [white or administrative employees] do not believe that it [HIV/AIDS] affects them”. In Company C though, there was a much higher representation of white employees, largely due to the active participation of a trade union representing artisanal employees.

Management representation was largely from the HR, IR or training departments, and the occupational health practitioner. In Company A and Company B, the MD also participated in the committee. However, none of the committees had line management representation. Formal trade union representation was marginal. Thus, in the dedicated HIV/AIDS committees, shop stewards either served in an individual capacity (as in Company A), or were not actively involved. For instance, in Company C, one of the trade unions participated actively (representing artisans), while the other union (representing production employees) was not actively represented. At the two sites in Company D, with a generic EE committee, the shop stewards had either withdrawn or had marginal participation. In this case, it appeared that trade union participation was mostly a consequence of statutory requirements on employment equity, rather than HIV/AIDS per se.

Control of HIV/AIDS budget and expenditure
The case studies suggested that management had virtually sole control over the nature and size of the HIV/AIDS budget. Thus, one of the most glaring weaknesses of the committees was that the employee committee members had very little access to, and knowledge of the HIV/AIDS budgets and expenditure levels. The exception was Company B, where the management and employees had set up a joint fund with equal contributions to pay towards the medical treatment and care of HIV-infected employees. In this case, all committee members and employees had full knowledge of the financial status of the joint fund, and medical expenditure on HIV/AIDS. Interestingly, though, with regard to expenditures related to the treatment of infected employees, most employee committee members (except Company B) regarded such information sharing as a breach of confidentiality, and did not express a wish to have access to such information. As a result none of the members had any idea of the aggregate expenditure on treatment interventions. Finally, none of the trade unions had ever requested information on the HIV/AIDS budget or expenditure trends, with the exception of Company D2. In this case the shop stewards queried the HIV/AIDS budget, but largely in the context of management proposals to cut labour costs in general.

The role of trade unions
None of the trade unions had been involved in the initial development of the HIV/AIDS policy or its implementation. None had negotiated formally on behalf of their respective trade unions, nor presented changes to the proposed HIV/AIDS policy based on union guidelines. Thus, all the policies concluded in these case studies were done outside formal
collective bargaining arrangements and without official support from the trade union offices concerned.

The study found that in two companies, internal labour disputes on non-HIV/AIDS issues had resulted in poor cooperation with regard to HIV/AIDS. In Company C, the inability to resolve a retirement benefit dispute had negatively affected the participation of one of the unions and its membership in the HIV/AIDS program, especially the voluntary counseling and testing (VCT) service. In the case of Company D, the union had withdrawn from the EE committee, in response to disputes on a range of HR issues, thus affecting negatively their participation in HIV/AIDS management as well.

Role of HIV/AIDS committees in policy development

All of the committees operated on a consultative basis, and did not have any formal powers of decision-making. However, the results suggested that these committees influenced the nature and direction of HIV/AIDS policy and programme implementation in a direct and indirect manner. Firstly, influence was directly derived from representation of senior management on the committees, especially those promoting or championing the business importance of HIV/AIDS, in line with HIV/AIDS “best practice” case studies. The exception was Company E, where the management representative felt that “…we [the company] are in the business of production, and not HIV”.

A related finding was that senior management, notably the HR department, generally drove the development of the initial workplace HIV/AIDS policies, often with the assistance of the occupational health practitioner. External consultants also played a prominent role, especially in the absence of an on-site HR department, as is often the case in South African SMEs. The exception was Company A, where the committee had been party to the initial policy development process. Thus, employee committee members and trade union representatives in most cases responded reactively, and tended to “rubber-stamp” the initial HIV/AIDS policy. Overall though, it appeared that high levels of commitment by management representatives were key in the acceptance and implementation of recommendations suggested by the committee.

Employee committee members argued that the apparent absence of a meaningful response to the initial policy was related to a lack of independent institutional support, information and resources. Thus, a lack of access to information sources and technology, such as the Internet and computers, was cited as contributory reasons. In most cases they acknowledged their reliance on, for instance, the occupational health practitioner for information.

Over time however, external sources of information in the communities, such as nongovernmental organisations (NGOs) working on HIV/AIDS, played a role in improving the capacity of some employee committee members.

Secondly, influence was also indirectly derived by the committees. Thus, even though employee committee members were not party to the initial policy development process, they had played a key role post facto in communicating mandatory rights and non-mandatory provisions flowing from such policies to employees, and monitoring their implementation in practice. Thus, the committees facilitated the distribution of information to employees in the form of posters, leaflets and so forth. Another example related to the development of provisions to ensure confidentiality in testing protocols, for VCT or HIV prevalence surveys, and the delivery of AIDS medication.

This does not imply that such communication was necessarily effective, as most of the focus group discussions suggested high levels of distrust, especially with regard to perceptions of potential breaches of confidentiality regarding disclosure of HIV status and test results. In most cases, committees identified such gaps in trust and knowledge among the workforce as areas needing redress. Thus, in the case of Company C, the committee was instrumental in developing procedures whereby AIDS medication was delivered to infected employees without breaching confidentiality. In Company D, some focus group participants felt that, in accessing ART, “… a positive employee would be fighting a losing battle” as confidentiality would have to be breached in the absence of clear and agreed procedures.

In as far as monitoring infected employees’ rights to the continuation of employment was concerned, most committees found this to be complex area, given high levels of employee distrust of so-called job security guarantees. On the one hand, in Company A, in the absence of a company-subsidised anti-retroviral treatment (ART), the committee was involved in procedures to terminate the employment of AIDS-sick employees on the grounds of medical disability. This was not necessarily an optimal solution and flew in the face of a commitment to job security. In Company B, on the other hand, AIDS-sick employees were being relocated to “…lighter jobs” where appropriate, in cooperation with line management, but with due regard to appropriate disclosure of HIV status. While job relocation was not necessarily a problem-free process, joint funding of ART in Company B enabled affected employees to continue in employment. Unlike Company A, retirement on the grounds of medical disability did not necessarily become a primary consideration once AIDS morbidity became evident. Other companies in the study did not have clear procedures as...
to how job security would be ensured. These examples illustrated some of the complexities faced by committees in ensuring that HIV/AIDS related rights were equitably implemented in line with policy provisions.

An important finding was that the committees played a key role in the progressive development of HIV/AIDS policies, from basic prevention programmes (including education and awareness programmes), peer educators, VCT and HIV-prevalence surveys, to more advanced and expensive services such as disease management programmes, including nutritional support, the treatment of opportunistic infections and in some cases the provision of ART. Table 2 provides an overview of the main elements of HIV/AIDS-related interventions, and the extent to which each applied to the companies in the study. While the provision of these interventions was unevenly distributed, it was clear that programme development had been very dynamic.

A striking feature was that this progression of rights and services occurred in the absence of any formal negotiations with the unions involved, nor in response to such union demands. Furthermore, all of these interventions had financial implications – HIV prevalence surveys, VCT and ART being among the most expensive. It might be that this progression was attributable to an appreciation by management of the seriousness of the HIV/AIDS impact. However, the study also suggests that a contributory factor might have been the role of, and feedback from employee representatives on these committees, on the needs and experiences of employees. Thus, examples previously cited, such as protocols on confidentiality for AIDS medication applied here. Other examples of innovative solutions included the Family Day in Company B, where teenagers of employees received information sessions; in Company C the committee was investigating the possibility of “…do it yourself” HIV tests in order to encourage employee participation. In Company B, joint funding of opportunistic infections was the first initiative undertaken by the committee. Many committee members had also trained as peer educators in order to assist employees regarding education and awareness of the company policy and other HIV/AIDS-related issues.

The case studies also suggested that active committees played a fundamental role in ensuring the continuity of HIV/AIDS intervention programmes. In at least three companies, committees expressed concerns about declining employee interest in the programmes. Thus, at Company B the committee was considering conducting a “…needs analysis” in order to “…find a way to people”. At the time, most were exploring viable alternatives to improve employee participation. On the one hand, this might suggest an apparent failure to sustain employee interest in their programmes. On the other hand, and more positively, the concerns expressed by some committees might also reflect a commitment to a continued analysis of obstacles and threats to the HIV/AIDS intervention programme, in order to shift their strategic direction towards greater success. At the time of the research, the committees were entering a period of evaluating programmatic progress and searching for solutions to keep the HIV/AIDS programmes “alive”.

Role of committees in provision of care and treatment

Most of the committees managed to secure limited access to care and treatment of opportunistic infections, nutritional support and anti-retroviral provision through very innovative workplace solutions. These included the introduction of a co-funding model with equal employer-employee contributions and/or arrangements whereby companies paid for ART following the exhaustion of medical benefits. The latter benefit applied to all the participating companies, except Company A.

<table>
<thead>
<tr>
<th>Type of intervention</th>
<th>Company A</th>
<th>Company B</th>
<th>Company C</th>
<th>Company D1</th>
<th>Company D2</th>
<th>Company E</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV/AIDS policy</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Existence of dedicated workplace committee</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No, part of EE committee</td>
<td>No, part of EE committee</td>
<td>No committee, HIV/AIDS employee coordinator</td>
</tr>
<tr>
<td>Peer educators</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Education and awareness</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>On-going VCT</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Prevalence survey</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

Table 2. Summary of company HIV/AIDS-related interventions
Original Article

Table 3. Summary of company HIV/AIDS-related treatment and care

<table>
<thead>
<tr>
<th>Type of intervention</th>
<th>Company A</th>
<th>Company B</th>
<th>Company C</th>
<th>Company D₁</th>
<th>Company D₂</th>
<th>Company E</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical aid provision</td>
<td>Optional; unaffordable</td>
<td>Optional; unaffordable</td>
<td>Optional; unaffordable</td>
<td>98% membership</td>
<td>Compulsory membership</td>
<td>50% membership</td>
</tr>
<tr>
<td>Company pays for ART not covered by medical aid</td>
<td>No, treatment for opportunistic infections</td>
<td>Yes, joint fund for opportunistic infections</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No ART coverage</td>
</tr>
</tbody>
</table>

and Company E. Table 3 provides an overview of the provision of HIV/AIDS-related treatment and care interventions among the participating companies.

As shown in Table 3, medical aid coverage was poor among many production employees, as the premiums were often deemed unaffordable. Further, in the absence of formal collective bargaining to negotiate access to paid ART provision, the alternative arrangements outlined here provided interim yet viable solutions. It is possible that the latter had been facilitated by the fact that at the time of the research, most companies had not had major negative impacts on the labour force and costs through extensive AIDS morbidity and mortality rates. As such, the cost of care and treatment had not been prohibitive, facilitating a form of company subsidisation. Further, management cited the declining market price of ART as a contributory factor. At the time of the study, the rollout of the government care and treatment programme had just commenced, and had not been a primary consideration, as most adopted a “wait and see” attitude or felt that for now they would “…go it alone”. However, there might be a limit to which companies would be prepared to carry the costs, given a significant increase in the AIDS burden. This was likely to test the capacity of the HIV/AIDS committees in deriving further rights and benefits related to care and treatment in the absence of collective bargaining.

Discussion

While this study only included a small number of SMEs, there are a number of lessons to be learnt that are particularly instructive given the relatively poorly resourced context within which most SMEs operate in South Africa. There is no legislative imperative for the establishment of HIV/AIDS committees, as most of the governance provisions of the South African Code of Good Practice on Key aspects of HIV/AIDS and Employment are completely voluntary. Thus, the existence of dedicated HIV/AIDS committees in these companies suggested the adoption of a cooperative culture in the management of HIV/AIDS as well. This applied even to those companies which did not establish dedicated HIV/AIDS committees. However, this cooperative approach was imbued with complexities, and the case studies illustrated some of the challenges that were encountered in practice.

The apparently cooperative context was partly undermined by the finding that the consultative powers of the committees (dedicated or generic), the dominance of HR and OH management representatives, and the capacity and resource constraints of employee and trade union representatives often resulted in the rubber-stamping of initial HIV/AIDS policy development. This confirmed similar research findings elsewhere. One study showed that in most companies the HR department was generally the key to directing company strategy (70%), followed by the HIV/AIDS committee (20%) (DeLoitte & Touche, 2002). This pointed to a massive gap between the importance of the role of the HR department and that of the HIV/AIDS committee. While the cited study primarily included large firms with relatively extensive HR departments, this phenomenon was also likely to apply to SMEs.

In addition, the low level of involvement by trade unions exacerbated this imbalance in authority. One study showed that trade unions (22%) played a more marginal role in drawing up company policy, compared with employees other than trade unions (33%), with directors (44%) and HR/consultants (72%) dominating the process (DeLoitte & Touche, 2002). Other studies confirmed the marginal role of trade unions in managing HIV/AIDS in the workplace (Bowler, 2004; Mapolisa, Schneider & Stevens, 2004). Thus, a lack of substantive impact by trade unions on HIV/AIDS management was probably not peculiar to SMEs, and tended to apply across the board, except perhaps in selected industries such as mining.

However, it raised concerns about the nature of institutional support received by shop stewards from their respective trade union offices. Thus, even though some of the unions represented in this study had very prominent national profiles, this had not translated effectively into HIV/AIDS activism on the shop floor. The lack of union-based training, the apparent absence of union policy guidelines, and the lack of visible involvement by
trade union officials in HIV/AIDS policy development were all manifestations of the disjuncture between the public and shop floor faces of the trade unions in these companies.

In this study, four of the companies belonged to an industry bargaining council and therefore did not engage in plant-level collective bargaining. As a result most of the unions had very little local leverage in negotiating “bread-and-butter” employee issues. One might therefore argue that the relatively weak history of the unions in these SMEs contributed to their inability to be legitimate and credible partners and to participate meaningfully in the management and implementation of HIV/AIDS policies. Finally, the presence of pre-existing collective bargaining disputes among the parties complicated trade union participation in HIV/AIDS management as well, emphasising the need to assess the approach of trade unions in balancing HIV/AIDS and other shop floor issues.

As far as the HIV/AIDS committees were concerned, the study suggested that the merits of the voluntary system of participation needed to be considered carefully. Thus, the volunteer system seemed to be acceptable in these companies, especially given the sensitivity of HIV/AIDS among the workforce, as well as the high level of personal commitment and sensitivity that appeared to be required from committee members. However, uneven coverage of sections of the workforce on the committees seemed to have had unintended consequences. This related particularly to the dominance of production employees relative to the poor representation of white-collar, administrative employees and line management. Furthermore, in most cases the latter sections of the workforce often also displayed low levels of participation in prevention activities. This might perpetuate the stereotype that HIV/AIDS was a predominantly “black” disease and did not affect other (white or skilled) employees. The experience of Company C, where the trade union representing artisans (predominantly white employees) was very active on its committee, however proved the contrary.

Thus, there might be a need to consider alternative mechanisms to establish such committees. While a volunteer system implied that the most committed persons (at a personal level) were likely to come forward, this should be counter-balanced by sufficient coverage of the different sections of the workforce. Improved levels of representation might begin to improve the extent to which prevention messages were adequately and clearly communicated to all sections of the workforce.

The case studies suggested that the one-sided control of the HIV/AIDS budget by management had been unchallenged thus far. However, it appeared that the overall cost of managing HIV/AIDS has not been prohibitive. Significant cost increases in the future, as a result of increased AIDS morbidity and mortality, might require that both employee representatives and the relevant trade unions participated more fully in the budgeting process.

On a more positive note, it appeared that the HIV/AIDS committees, despite their lack of formal power, derived their influence on the development and implementation of HIV/AIDS policies and programmes indirectly. Thus, as shown in this study, rights and benefits might still accrue to employees even if the policy development process had not been inclusive from the start. The committees therefore played a crucial role in facilitating processes and procedures that advocated and communicated the rights enshrined in the Constitution and other labour legislation, especially with regard to the principles of confidentiality, nondiscrimination, and nondisclosure. The main point was that rights enshrined in policy had no utility unless the targeted workforce was aware of them, and their implementation was tracked and monitored. This was important for empowering employees and building trust and confidence in HIV/AIDS prevention programmes. The study showed that distrust among the workforce persisted, but creative solutions to handle potential breaches of confidentiality were crucial for developing and maintaining that trust.

Furthermore, in the process of grappling with the obstacles of implementation in HIV/AIDS programmes, committees had developed innovative, local solutions to extend benefits such as ART, outside the formal collective bargaining process. As such, these case studies suggested that, in these SMEs at least, the HIV/AIDS committees represented a new institutional opportunity to extend employees’ rights and social protection on HIV/AIDS.

The question arises as to whether these findings implied that non-union based HIV/AIDS committees should be the preferred means for building effective institutional governance of HIV/AIDS in the workplace. On the one hand, the rise of these committees reflected the relative weaknesses of the trade unions, the new competencies and attitudes required by the nature of the epidemic, and a shift towards a more cooperative culture within the workplace. On the other hand, however, one of the main contextual factors with regard to the relevance of these committees as an institutional mechanism was that their appropriateness and relevance might only extend as far as the relative impact of the disease.

Thus, in all of these case studies, the impact of HIV/AIDS had been relatively limited. Even those with relatively high HIV prevalence (20% in Company E for instance) had not had major AIDS-related effects in terms of labour costs, labour...
productivity, profitability and other business indicators. The demands placed on the committees thus far were relatively problem-free, not discounting the seriousness of the epidemic. Certainly, the challenges of implementation, such as poor take-up of VCT and fears regarding confidentiality and the failure to adopt protective behaviours among the workforce, were raising the bar regarding the capacity within these committees. For instance, the process of relocating AIDS-sick persons to lighter jobs without compromising confidentiality of HIV status was a critical issue with which some of the committees were having to deal. Thus, more formal negotiation processes might be imminent, as more serious issues such as extending sick leave for the AIDS-sick, job security and relocation to less strenuous jobs became more common and widespread. Given the long-term consequences of the HIV/AIDS epidemic this also implied that all institutions key to industrial democracy, including trade unions, should develop long-term capacity to ensure the long-term sustainability of the management of HIV/AIDS. Thus, stronger and well-supported governance structures might be the key to successful mitigation, especially among SMEs.

Finally, the case studies in this research study were not meant to represent trends within the larger population of SMEs. However, the research did provide more in-depth knowledge on underlying dynamics as well as greater insight into available means for developing and improving governance capacity in the management of HIV/AIDS among SMEs in particular.

Recommendations

The single most effective intervention for meaningful HIV/AIDS governance would be the support and empowerment of employee representatives and shop stewards at the workplace, especially among SMEs. Firstly, where the volunteer system was maintained, representation should be encouraged from all sections of the workforce. Further, the Department of Labour should develop more effective communication and information networks to share information and resources on HIV/AIDS, and monitor the implementation of the code of good practice on HIV/AIDS. The EE inspectorate could play a key role in this regard. Finally, the trade unions needed to address the lack of training and policy information among shop stewards, through centralised collective bargaining agreements or HIV/AIDS policy guidelines, visible support by local officials, and independent training programmes. This would also address the seemingly marginal participation of shop stewards in shaping HIV/AIDS programmes to articulate and meet the specific needs of their members and the broader workforce.

Conclusions

This research study suggests that workplace HIV/AIDS committees could play a key role in improving HIV/AIDS governance capacity in the South African workplace. Furthermore, such committees represent an opportunity for monitoring the implementation of mandatory rights, empowering employees in advocating and communicating such rights, and securing additional rights and benefits related to HIV/AIDS prevention, treatment and care. The study also suggests that in these SMEs the demands on the collective bargaining process had been relatively muted thus far. However, given the anticipated rise in the negative impact of AIDS morbidity and mortality, this might change. In the interim however, an effective and representative stakeholder committee offered one of the best means for effective mitigation of the HIV/AIDS impact, and the extension of employee rights and protection in the workplace.

References


Perceptions of acceptability and utility of microbicides in Ghana, West Africa: A qualitative, exploratory study

Amanda E Tanner

Abstract

Vaginal microbicides, substances that may substantially decrease transmission of sexually transmitted infections (STI) including human immunodeficiency virus (HIV), are currently in clinical trials. They are being presented as woman-initiated prevention methods that have the potential to be used without partners’ knowledge. However, it is recognised that covert use may be challenging, due to the accompanying increase in vaginal lubrication. This study explored factors that may influence acceptability and utilisation of vaginal microbicides in Ghana, a sub-Saharan West African country with relatively low rates of HIV.

Qualitative research methods were employed in Accra, Ghana in 2005. Individual interviews were conducted with 10 staff working in reproductive health settings, and two focus groups were conducted with young women aged 24-28. Three main topics emerged during the interviews and focus groups, including issues related to available contraceptive and prevention methods, perceptions of microbicide interest and acceptability, and cultural influences on microbicide acceptability and use. Participants discussed issues associated with available contraceptive options that may influence microbicide uptake. All respondents suggested that Ghanaian women would have a high level of interest in microbicides, with varying interest in formulas with different contraceptive and disease prevention properties. Cultural factors that may impact on microbicide use, often related to gender and power issues, were also discussed. Thus, as microbicides are being developed, cultural issues and behavioral correlates will need to be assessed to help ensure acceptability and use. In addition, gendered negotiation power and the implications of covert use need to be addressed in microbicide education and social marketing.

Keywords: Microbicides, STI/HIV prevention, reproductive health professionals, Ghana, West Africa, gender.

Résumé

Les microbicides vaginaux, une substance qui pourrait largement réduire les infections sexuellement transmises (IST) et le VIH inclus, font actuellement parti des essais cliniques. On prétend que les microbicides sont une méthode de prévention initiée par les femmes elles-mêmes qu'on peut utiliser sans la connaissance du partenaire sexuel. Cependant, on reconnait que l'utilisation secrète de cette substance peut être un défi difficile à surmonter étant donné la lubrication vaginale exagérée (Global Campaign for Microbicides GCM, 2007). Cette étude examine les facteurs qui peuvent influencer l'admissibilité et l'usage des microbicides vaginaux au Ghana, un pays sous-Saharan de l'Afrique de l'Ouest ayant un taux assez bas de VIH. (UNAIDS, 2005).

Des méthodes de recherche qualitative ont été utilisées à Accra, Ghana pendant le mois de mai jusqu'en juillet 2005. Des entretiens individuels ont été menés auprès de 10 personnes qui travaillent en milieu de santé de la reproduction qui par la suite pourraient devenir de partenaires importants de la promotion des microbicides. En plus de cela, deux groupes de foyer ont été menés auprès des jeunes femmes âgées de 24 à 28 ans. Trois sujets principaux ont émergé pendant les entretiens et les groupes de foyer - les sujets liés aux méthodes de contraception et de prévention disponibles, les perceptions de l'intérêt aux microbicides et leur admissibilité et des influences culturelles sur l'admissibilité et l'usage de microbicides. Toutes les participantes ont suggéré que les femmes ghanéennes seront plus intéressées aux microbicides avec un intérêt varié vis-à-vis les formules ayant des propriétés différentes de contraception et de prévention de maladies. Des facteurs culturels, souvent associés aux sexes et au pouvoir, qui pourraient avoir l'impact sur l'usage des microbicides ont été discutés. Bien qu'il y ait eu un grand intérêt aux microbicides qui font la une, il y a de nombreux facteurs qui pourraient avoir l'impact sur l'usage. De ce fait, pendant que les microbicides sont aménagés, les questions culturelles et les corrélats comportementaux doivent être évalués afin d'assurer l'admissibilité et l'usage. De plus, on doit aborder le pouvoir de négociation entre les sexes et les implications de l'usage secret lors de l'éducation portant sur les microbicides et le marketing social.

Mots clés: Microbicides, prévention de IST/VIH, professionnels de santé de la reproduction, Ghana, Afrique de l'Ouest, les sexes.
Introduction

Globally, human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) affect millions of people. According to estimates from the UNAIDS Report of the Global AIDS Epidemic (2004), 37.2 million adults and 2.2 million children are currently living with HIV. The overwhelming majority of people with HIV, nearly 95% of the global total, live in the developing world (UNAIDS, 2004). This trend is likely to continue in countries where inadequate health care system infrastructures, poverty, and limited resources for prevention and care encourage the spread of the virus (UNAIDS, 2004). On the African continent, the disease has reached epidemic proportions, and sub-Saharan Africa is by far the most devastated area. HIV prevalence varies considerably across the continent - ranging from less than 1% in Egypt and 3.1% in Ghana to 6.7% in Kenya and 21.5% in South Africa (UNAIDS, 2005). Unlike women in other regions in the world, African women are considerably more likely to be infected with HIV than men, as it is estimated that over half of the people living with HIV and AIDS in sub-Saharan Africa are women (Global Campaign for Microbicides, 2004).

The rapid spread of HIV in the female population underscores the necessity for developing new preventive technologies that offer protection from this disease as well as other sexually transmitted infections (STI). This urgency has led to an intense focus on the development of vaginal microbicides. Microbicides are substances that may substantially reduce transmission of STI and pregnancy, although not all microbicides will be contraceptive (Harrison, Rosenberg, & Bowcut, 2003), when applied either in the vagina or rectum. Microbicides can be produced in many forms, including: gels, creams, suppositories, films, or in the form of a sponge or a vaginal ring that slowly releases the active ingredient(s) over time (Bentley et al., 2004; GCM, 2004; Wulf, Frost, & Darroch, 1999). Some of the potential advantages of microbicides are they are a woman-initiated prevention method and may be used without the knowledge of a partner. However, it is recognised that covert use may be challenging, due to the accompanying increase in vaginal lubrication (GCM, 2007). Currently, microbicides are not available, but it is suggested that with sufficient financial investment and commitment, an effective topical microbicide could be available soon (Alliance for Microbicide Development, 2007; GCM, 2004).

Existing research on microbicides suggests that there are particular physical characteristics and socio-cultural issues that may influence utilisation of a vaginal microbicide. The recognition of these broader concerns may be useful in creating a social marketing campaign to increase utilisation of topical microbicides. HIV prevention efforts cannot be successful without integrating the cultural context of the targeted population (Richter, Harris, Coker, & Fraser, 2001; Scott, Gilliam, & Braxton, 2005). For instance, the importance of motherhood for many women has competed with the focus of much HIV prevention. In many African contexts motherhood and the ability to bear children is considered an essential role for women (Lear, 1996). Therefore, the use of barrier methods, including condoms, is an ineffective prevention strategy as it limits women’s ability to reproduce. Attention to this issue may increase the likelihood of use of microbicides, as some formulas in development have the potential to dramatically improve individuals’ ability to be protected from HIV and other STI, while maintaining the ability to become pregnant.

It is suggested that more research is necessary which focuses on the acceptability of microbicides in a cross-cultural context (Mantell et al., 2005; Severy & Newcomer, 2005). Existing studies have identified some potential issues of concern. Thus in some cultures women do not readily accept touching their genitals or inserting products into their vaginas (Hardy et al., 2003). In other cultures, however, the use of vaginal suppositories or spermicidal tablets is common, which may increase use of an insertive topical microbicide (Johnston, 2002). In contrast, cultural preference for ‘dry sex’ may affect how readily a microbial product with lubricating qualities is used (Van de Wijgert et al., 1999). Relationship dynamics, power, and gender roles in broader structural and cultural frameworks may also impact on women’s HIV risk and corresponding prevention method use (Koo et al., 2005).

Creating partnerships with individuals working in the sexual and reproductive health field may help foster a culturally aware environment facilitating microbicide uptake. Currently, sexual and reproductive health professionals play an integral role in providing sexuality-related information and education, in addition to dispensing contraceptive and disease prevention methods (Brieger et al., 2001). Integrating reproductive health professionals into microbicide education and social marketing efforts may significantly increase utilisation. With their help a clearer understanding of the cultural practices and contexts that may facilitate or challenge use may occur, to help increase microbicide use as well as underscore the need for more cross-cultural research.

The continuing rise in HIV infections around the world, in conjunction with the limited woman-initiated contraceptive and disease prevention options, has created an environment primed for the development of new technologies, like vaginal microbicides. As the research and development of these products continue, it is imperative to examine attitudes and perceptions...
of the utility of microbicides in a variety of communities. The purpose of this exploratory study was to examine attitudes and perceptions of the utility of microbicides in the context of urban Ghana, a sub-Saharan West African country. The goal was to gain a better understanding of the unique factors that may influence individuals’ attitudes towards and use of vaginal microbicides from community women as well as reproductive health professionals. Some of the topics that were explored included: existing contraceptive and preventive options and trends of use, issues around using a woman-initiated prevention method, gender norms, and the importance of motherhood. In addition, culturally appropriate ways to gain insight into the issues surrounding microbicide use in Ghana were explored to help inform future research efforts.

Methodology

Participant characteristics

The interview participants (N=10) were half women and half men, working in a variety of reproductive health settings including clinics (N=4), community organisations (N=3) and academic/research venues (N=3). All but one had some type of university or professional degree and all had children. The focus group participants were all significantly younger and had lower levels of educational attainment than the interview participants. The two groups included women aged 18-27 (M=23.5) who did not have any children at the time of the interviews. Tables 1 and 2 summarise the demographic characteristics of the participants.

Data collection

Qualitative methodologies were employed, including individual semi-structured interviews and focus groups strategies. With Ghana's extensive HIV-related educational programme and media campaigns, most people had high levels of familiarity with HIV, and relative comfort in discussing issues surrounding the disease. Interviews were conducted at the workplace of ten individuals employed in the reproductive health field. Additionally, two single gender focus groups with young Ghanaian women were conducted. All interviews were conducted by the author, an American woman, in English. The gender match between the interviewer and the focus group participants was helpful in conducting the focus groups (Frith, 2000). In order to increase the legitimacy of the interviewer, a local professional contact aided the individual interviews by providing a direct introduction. Protocols were approved by Indiana University's Committee for the Protection of Human Subjects.

Table 1. Interview participant characteristics (N = 10)

<table>
<thead>
<tr>
<th>Participant characteristics</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>5</td>
<td>50</td>
</tr>
<tr>
<td>Male</td>
<td>5</td>
<td>50</td>
</tr>
<tr>
<td>Personnel type</td>
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<td></td>
</tr>
<tr>
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</tr>
<tr>
<td>Academic</td>
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<td>30</td>
</tr>
<tr>
<td>Community based</td>
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<td>30</td>
</tr>
<tr>
<td>Education</td>
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<td></td>
</tr>
<tr>
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<td>90</td>
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<tr>
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</tr>
<tr>
<td>Parental status</td>
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<td></td>
</tr>
<tr>
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<td>100</td>
</tr>
<tr>
<td>Do not have child(ren)</td>
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</table>

Table 2. Focus group participant characteristics (N = 9)

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<th>Group 2</th>
</tr>
</thead>
<tbody>
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</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>5</td>
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</tr>
<tr>
<td>Age</td>
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<td>Mean</td>
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<tr>
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<td>University/professional</td>
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</tr>
<tr>
<td>Not university/professional</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Parental status</td>
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<tr>
<td>Have child(ren)</td>
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<td>0</td>
</tr>
<tr>
<td>Do not have child(ren)</td>
<td>5</td>
<td>4</td>
</tr>
</tbody>
</table>
Measures

The interview and focus group interview guides were similar (see Appendix A). Thus, both the reproductive health professionals and the focus group participants were asked questions concerning available contraception, cultural issues, and perceptions about microbicide use. In addition, gender and cultural norms were explored.

APPENDIX A. INTERVIEW AND FOCUS GROUP SCHEDULE

Introduce self and thank respondent.
Discuss the IRB Study Information Sheet.

Introduction: The purpose of this interview is to discuss your perceptions and attitudes about HIV/AIDS and of the utility of a contraceptive option that is currently in development called microbicides, which are substances that have the potential to reduce transmission of sexually transmitted infections (including HIV/AIDS), yet still allow women to get pregnant.

I have some questions that I will use to guide the discussion today to specific topics, but I am really interested in what you have to say and in what you think is important. However, I will occasionally be looking at the guide and writing notes so that I make sure to cover all the topics in the guide. I also have a short survey that I would like you to fill out when I am finished with the interview. With your permission, I will be tape-recording the interview today. Is that ok? (If yes, start recording.) Thanks again for agreeing to share your thoughts with me.

HIV/AIDS

1. The first thing I’d like to ask you about is HIV/AIDS. Ghana has a very comprehensive educational programme (at least in the urban centres), do you think the programme has been effective at increasing people’s knowledge about HIV/AIDS? Why or why not?
2. Do you think the programme has been effective at changing people’s behavior to protect against HIV/AIDS, for example increasing condom use? Why or why not?
3. What do you think people’s perception of risk in acquiring HIV/AIDS is?
   a. Does this vary by group (i.e. age, gender, region, ethnicity)?
   b. Does this vary if people know someone who is HIV positive?

Stigma

4. In the United States, there are challenges that face people who are HIV positive, for example others may believe they are promiscuous, gay, or do drugs. What are some of the notions of stigma surrounding HIV/AIDS in Ghana?
   a. Does this vary by group (i.e. age, gender, region, ethnicity)?
   b. Does this vary if people know someone who is HIV positive?
   c. For those working in an HIV/AIDS related position: Are they any issues that have impacted on your ability to do your job?
5. What are the different methods of contraception that are available in Ghana to prevent sexually transmitted infections and unplanned pregnancy?
   a. Which are the most common? Why do you think that? (some examples: cost, can buy it anywhere, it’s male/female controlled, takes away from the sexual experience, affects intimacy).
6. If you were going to develop an ideal contraceptive, what would be the characteristics of it?
   a. In terms of mode (i.e. barrier, pill, shot)?
   b. In terms of physical traits (i.e. smell, taste, feel)?
   c. In terms of timing of when it would be used/applied (daily vs. for each individual sex act, and applied before or after sex)?
7. The first issue consists of individual factors. How do you think that different people would respond to microbicides?
   a. Would this vary by demographic variables (gender, age, education, religiosity, etc)?
   b. Would this vary by attitudes:
      i. towards contraception?
   2. about perceived HIV/AIDS and other STI risk?
8. The second issue consists of relationship factors. How do you think that couples would respond to microbicides?
   a. Would this vary by length of relationship (short/new vs. long term)?
   b. Would this vary by relationship type (monogamous/not, married, etc)?
   c. Would this vary by level of openness/communication about contraception?
   d. Would this vary by the level of perceived threat of partner violence?
9. The third issue consists of cultural factors. What do you think are cultural factors that would affect how people respond to microbicides? a. In terms of gender relations/roles?
   b. In terms of cultural norms (preference/not preference for dry sex, etc)?
   c. In terms of the possibility of having to touch the genitals to apply?
   d. In terms of the stigma surrounding HIV/AIDS?
10. If you were going to create an ideal microcide, what would be the characteristics of it?
    a. In terms of form (i.e. cream, jelly, film, suppository)?
    b. In terms of physical traits (i.e. smell, taste, feel)?
    c. In terms of timing of when it would be applied (several hours before, right before, the day before or after sex)?
    d. In terms of what it protects against - STIs, pregnancy, both?
        (here I want to get at the cultural importance of motherhood)
    e. In terms of the cost?

Microbicides

There is a new contraceptive option that is currently in development, hoping to be available soon, called a microbicide. It is a substance that can substantially reduce transmission of sexually transmitted infections (STIs) when applied either in the vagina or rectum. Microbicides can be produced in many forms, including gels, creams, suppositories, films, or in the form of a sponge or a vaginal ring that slowly releases the active ingredient over time. There are several issues that I would like to talk to you about regarding the potential use of microbicides.

1. towards contraception?
Data analysis
All interviews, with one exception, were digitally recorded, transcribed verbatim, and managed using Atlas ti 5.0 (Muhr, 2004). The data analysis process included content analysis of the data for emergent themes based on the primary research questions (Weiss, 1994). Thematic analysis focused on specific issues associated with available contraceptive use patterns, the existing challenges associated with these options, and the factors including individual, relational, and cultural that may facilitate or inhibit microbicide use.

Results
Three main topics were discussed during the interviews and focus groups by the participants, namely available contraceptive and prevention methods, microbicide interest and acceptability, and cultural influences on microbicide acceptability and use.

Available contraceptive and prevention methods
Reproductive and sexual health professionals discussed the various contraceptive and disease prevention options currently available and used in urban Ghana. They reported that hormonal methods were more frequently utilised than non-hormonal methods. The most common hormonal methods reported were the oral contraceptive pill and the injection (DepoProvera®), with a nurse reporting that “most women use Depo.” The least utilised non-hormonal options included intrauterine devices, sterilisation, and foaming spermicidal tablets. Several nurses gave explanations for couples not using the spermicidal tablets, including the belief that they did not work well, “they don’t use it because it fails them,” and that sometimes the male partner did not like it because he could feel it. However, one participant believed that the foaming tablets offered security, and acted as a back-up method when used in conjunction with condoms.

The main complaint about available methods was articulated by a woman in the focus groups, “The problem is with all these things, pills, injections, and tablets, they have side effects.” The focus group participants all agreed that some of the available methods have potential complications, and might not be as effective as was claimed, like the injection, “on that one, babies are born plenty.” Focus group participants also reported that men, and often women, did not like to use condoms. One respondent discussed her dislike of condoms, “Sometimes it just hurts, you just get dry and it hurts.” A nurse also suggested that condoms detracted from feeling and reported many patients’ reasoning, “You don’t eat the toffee with the paper on, therefore, why would you have sex with a condom on?” The female condom had similar reactions, several participants indicating that men and women did not like to use the female condom because it was too big and not easy to use. Several participants suggested that since many people did not like condoms, microbicides could be an acceptable alternative.

Microbicide interest and acceptability
All respondents, both women and men, suggested that Ghanaian women would be likely to have a high level of interest in topical microbicides, with varying interest in formulas with different characteristics. Most respondents believed that young women would prefer the formula that had disease prevention properties but would still allow for reproduction. There was a variety of opinion regarding timing of application of the microbicide; for instance when asked when she thought women would prefer to use a microbicide, one nurse reported “before and after [intercourse]” but that “if they don’t want the pregnancy they would use it before the sex.” Another nurse believed that in order to be preventive, “you would have to use it before sex.” A medical assistant, however, thought microbicide use would be most beneficial after sex, in case use of the method was forgotten in “the heat of the moment.” The focus group participants were keen on the covert use potential of microbicides. However, they did not think that surreptitious use would be a possibility, if as with the foaming spermicidal tablets one had to wait a certain amount of time before engaging in intercourse, “Yes, you have to let him know. Because you know it’s the time. So you have to let him know.” In addition, all the male interview participants responded that covert use would be unacceptable and it was necessary for women to tell their partners.

In addition, several of the focus group respondents thought that the potential lubricating property would be appreciated in comparison to using condoms. This was especially true for women who expressed a dislike for condom use. One woman affirmed that people would use microbicides because “using those [condoms] everyday, you are coming to hurt, if you just use condoms. And if your husband wants to go maybe two rounds and you have to change the thing [condom], you’ll be dry.”

Although there was enthusiasm for potential microbical products, some concerns were raised regarding their use. One interview respondent from a national health organisation acknowledged that new products were extremely difficult to market, and suggested that innovative education and marketing programmes would be required with the introduction of a microbicide. In addition, products that require multiple trips to the clinic or refrigeration would be unlikely to be used as frequently as other methods. For instance, nurses commonly reported difficulty in getting women to come back every three months to receive their injection. Finally, the similarity of methods of application of microbicides to available methods,
including foaming spermicidal tablets, may affect microbicide use as, according to a nurse, “Women think they [foaming spermicidal tablets] are deceiving and it often fails them and they don’t like it.”

**Cultural influences on microbicide acceptability and use**

Cultural issues that may impact on the utilisation of microbicides were discussed by the study participants. The cultural factors discussed during the focus groups were often related to gender and power issues. The women reported not feeling like they always had the ability to negotiate contraceptive use, and suggested the ability to use condoms and other contraceptive methods depended on economic and relational issues. One respondent reported “if they [women] see a man for two years then its okay, they’re not going to use their money to buy the condoms.” In addition, a researcher recited an Akan proverb, “If the drum is there, you don’t beat the side, you beat the top,” as the reason why Ghanaian men did not use condoms. She suggested that using a condom for sex was like beating the side of the drum, it just did not feel (or sound) right.

The importance of motherhood was discussed in both focus groups. One woman stated, “In Africa, yes, to grow old is to [have] born a baby. Me, I’m this old and don’t have a baby. If I can’t have a baby, it’s a problem.” The desire for and the inevitability of motherhood for these women led to reservations about using long acting contraceptive methods, for instance oral contraceptive pills and injectables, as there was a belief that they could influence future fertility. One focus group respondent discussed the injection, saying “That one is very risky”, emphasising her belief that it might affect later pregnancies.

In addition to these issues, contraceptive use was also regarded as influenced by societal perceptions of an individual’s status within the community. Condom use reported by a focus group participant, for instance, was complicated by the perception that sex workers were more likely to use condoms:

“Yeah, that one. Those people [commercial sex workers], they don’t get these sicknesses. It’s innocent people who get the sickness. They have their own condoms so they use them. They say ‘I have my condom here’ and the person will just put it on.”

This belief affects other people’s risk of acquiring HIV, as it may dissuade them from using condoms themselves, in order that they would not be viewed as a ‘prostitute’. It could also affect how families respond to an individual’s acknowledgement of their HIV-positive status. While the focus group participants said that some families accepted sick relatives and helped, other families did not, as “AIDS is a shameful sickness, so they’ll say you are bringing shame into the house and they don’t want it.”

**Discussion**

The purpose of this exploratory study was to assess the perceptions of reproductive health professionals and community women regarding the acceptability and use of microbicides in urban Ghana. Within the context of the HIV pandemic, prevention technologies, particularly ones that are female-initiated, are necessary. Most studies have not included individuals working within the reproductive health field who, due to their community connections, are likely to be valuable partners in the dissemination of microbicide products (Brieger et al., 2001). The integration of local reproductive health professionals is a way to identify issues that may facilitate or challenge microbicide use, as well help create and add legitimacy to culturally appropriate education and marketing materials. The results from this study suggest that there is a high level of interest in microbicides; however, use may be moderated by several factors identified in the interviews and focus groups.

**Microbicide interest and acceptability**

There was a high level of reported interest in topical microbicides by the interview and focus group participants. They acknowledged that issues exist that may affect utilisation by Ghanaian women. Evidence supporting the identified issues included that currently available products that are applied similarly to microbicides, such as foaming spermicidal tablets, were not being employed as frequently as hormonal methods. This is an important consideration as reasons why these options are not being employed could have an impact on microbicide uptake. Additionally, reported interest varied by different characteristics including timing, covert use potential, and prevention of STI and pregnancy, or only STI. The final products’ properties would be likely to affect which individuals choose to use the product and for what reasons, for instance whether or not it prevents pregnancy. These characteristics are likely to change as the reproductive goals of women change, for example if they have already had all of the children they desire, a microbicide with contraceptive properties would be more attractive than it was prior to the completion of childbearing.

**Cultural influences on microbicide acceptability and use**

A variety of cultural issues were discussed that may impact microbicide use and acceptability (Koo et al., 2005; Severy & Newcomer, 2005). The saliency of unequal power based on gender in relationships, and women’s economic dependence...
on male partners, greatly influences the utilisation of existing contraceptive and disease prevention methods. The potential of microbicides to be used covertly may allow women to be more agent in protecting themselves and their partners. However, covert use may be challenging for women, due to the accompanying increase in vaginal lubrication with microbicide use (GCM, 2007). This is a complex issue and the promotion of covert use should not put sole responsibility for reducing HIV transmission on women, as it is essential for both partners to be accountable and responsible. In addition, within the context of the importance of motherhood and the beliefs about the long term affects of existing methods on fertility, it will be essential to emphasise that some formulas may still allow women to get pregnant (Harrison et al., 2003). This characteristic may significantly increase the uptake and use of microbicides in comparison to other methods for women with specific reproductive goals.

As microbicides are being developed, behavioural and social correlates, including use of existing products, economic dependency, and the importance of motherhood, will need to be assessed in influencing acceptability and use. In addition, the implications of potential side effects of microbicides and covert use will need to be addressed in education and marketing with both women and men.

**Future microbicide acceptability research**

As an exploratory study there were several limitations to the generalisability of this study, however, the study results are still useful and were similar to those of other studies (Bentley et al., 2004; Koo et al., 2005). Although the sample represented a diverse array of organisations, it was very small and was recruited using snowball sampling techniques. In addition, the participants were from a highly urban area, which also limits the ability to generalise these findings to other areas and communities. Finally, issues associated with conducting highly sensitive sexuality-related research in an international context may have resulted in a higher degree of socially desirable responding (Bancroft, 1997). This highlights the need for in-country partners, for which I am grateful to my associates at the University of Ghana Legon.

The positive results from this small study suggest a need for larger studies further examining the socio-cultural and physical issues that were raised by participants in a variety of contexts. Addressing these issues with individuals working in reproductive health settings is especially important, as they will be likely to provide information and education about microbicides to women. Predicting microbicide use may be difficult, given that most acceptability studies have focused primarily on product attributes and not on interpersonal and contextual factors (Severy, Tolley, Woodson, & Guest, 2005). Therefore, future research efforts should address acceptability in terms of relational and contextual factors, in addition to product characteristics.

Overall, this study provides insight into some of the factors that may influence microbicide acceptability and use in Ghana. The results suggest a relatively high level of interest in microbicides among Ghanaians, and should be used to inform larger scale acceptability research in a variety of cultural and international contexts. Results also underscore the importance of partnering with reproductive health professionals in order to gain a broader understanding of facilitating and challenging factors to microbicide use. These partnerships will also allow for an avenue for microbicide promotion, giving potential users an opportunity to ask questions and get accurate information. In addition, creative social marketing strategies will need to be employed to emphasise the minimal effects on long term fertility, in order to make it a more attractive option for younger women, as well as avoid the issues surrounding the low uptake of the female condom.

**Acknowledgements**

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**References**


Diagnostic social de l'infection à VIH/SIDA et stratégies endogènes de prévention à Gaoua, Burkina Faso

Donmozoun Télesphore Somé

Résumé
En dépit de la sensibilisation et des messages reçus pour la prévention, les femmes restent encore plus que jamais concernées par le VIH/SIDA dans les pays en développement. Comment perçoivent-elles la maladie et les moyens de prévention? Le but de cette étude est d'évaluer le diagnostic social de l'infection à VIH/SIDA et les stratégies endogènes de prévention des femmes de Gaoua.

Une approche qualitative fut adoptée. Quatre focus groups furent réalisés avec des femmes Lobi, Birifor, Dioula, Dagara. La constitution des groupes de discussion (8-12 personnes), les jours, le lieu et la place de la discussion ont été négociés avec les femmes leaders. Un guide d’entretien fut élaboré pour la conduite des discussions. Celles-ci ont été menées dans les langues locales et ont été enregistrées, transcrrites en verbatim et analysées ligne par ligne.

Des dénominations spécifiques du VIH/SIDA faisant chacune référence à un signe/symptôme de la maladie ont été décrites. Les dénominations sont respectivement pour les Lobi, Birifor, Dioula et Dagara _Kpéré ci_ (maigrir et mourir) _gbè yirè_ (pieds en brindilles) _sii dan_ (fin de la vie) _gbè milè_ (pieds minces). Les principaux signes décrits du SIDA sont l’amaigrissement, l’appétit pour la viande, les bons repas, les cheveux frisés, de gros boutons sur le corps, la forte fièvre, la diarrhée, le rougissement des lèvres.

Au regard des signes décrits et pour se protéger efficacement contre la maladie, des stratégies endogènes de prévention de la maladie sont adoptées par les femmes. Les principales sont la “mise en observation” par la consommation d’aliments très pimentés pendant quelques jours pour un mari resté pendant longtemps absent du foyer conjugal, le mariage précoce des jeunes filles.

Le diagnostic social du VIH/SIDA par un groupe spécifique tel que celui des femmes, montre le décalage qui peut exister entre les perceptions de la maladie et les messages de prévention reçus. Ceci pourrait aider à comprendre l’échec de certaines stratégies de prévention et l’intérêt qu’il y a à prendre en compte les perceptions des communautés de la maladie dans l’élaboration des messages de prévention.

**Mots clés:** Diagnostic social du VIH/SIDA, dénominations du VIH/SIDA, femmes, prévention, Burkina Faso.

Abstract
Despite sensitising and prevention messages, women still remain concerned about AIDS in developing countries. How do they perceive the illness and methods of prevention? The objective of this study was to assess the social diagnosis of HIV/AIDS, and endogenous strategies developed by women from Gaoua. A qualitative approach was adopted, involving four focus group discussions with women from the Lobi, Birifor, Dioula and Dagara ethnic groups. An interview guide was developed for the discussions, which were carried out in local languages, tape recorded, transcribed verbatim and analysed in detail. Specific descriptions of HIV/AIDS related to signs/symptoms were given. These were: _Kpéré tchi_ (lose weight and die) _gbè yirè_ (twig feet) _sii dan_ (end of life) _gbè milè_ (thin feet), respectively for Lobi, Birifor, Dioula and Dagara. The major signs of AIDS mentioned were weight loss, appetite for meat, good meals, curly hair, large spots on the body, high fever, diarrhoea, and redness of lips. In relation to these signs, some endogenous strategies were developed by women to protect themselves against the illness, including "observation" and hot spiced meals for a few days for a partner who was absent for a long time, as well as early marriage for young girls. The social diagnosis of HIV/AIDS by a specific group like women demonstrates the gap between perceptions of the illness and prevention messages. This could help to understand that it is important to take account of communities’ perceptions of illness in elaboration of prevention messages.

**Keywords:** Social diagnosis of HIV/AIDS, names for HIV/AIDS, women, prevention, Burkina Faso.
Introduction

Le VIH/SIDA en l'espace de quelques années est devenu le problème de santé publique le plus important, défiant la communauté scientifique et médicale quant à sa prise en charge efficace.

En 2003, il y avait dans le monde, selon l'ONUSIDA et l'OMS, 38 millions de séropositifs et dont les ¾ vivaient en Afrique au sud du Sahara. En 2004, le nombre de personnes infectées a augmenté d'environ 3,5 millions et a avoisiné les 40 millions de personnes. Selon le rapport 2004, la moitié des adultes vivant avec le SIDA dans le monde sont des femmes. Les pays les plus touchés sont malheureusement encore les pays les plus pauvres.

Selon le rapport 2006 de l'ONUSIDA, le nombre d'adultes (15-49 ans) vivant avec le VIH au Burkina Faso était de 140 000 dont 80000 étaient des femmes de 15-49 ans. De plus, le pourcentage de jeunes (15-24) qui avaient des connaissances sur les moyens de transmission était de 23% pour les hommes et 15% pour les femmes. Dans la même tranche d'âge, le pourcentage de jeunes ayant eu un rapport sexuel avant 15 ans était de 4,7% pour les hommes et 7,3% pour les femmes. Toujours dans la même tranche d'âge, 54% des femmes contre 67% des hommes ont reconnu avoir utilisé un condom au cours du dernier rapport sexuel occasionnel.

Face à la propagation rapide de la maladie, les gouvernements et les institutions internationales se sont mobilisés pour parer au plus pressé, c'est-à-dire donner l'information et les moyens de prévention de la maladie. A ce sujet, Dr Peter Piot, directeur exécutif de l'ONUSIDA, a dit "des stratégies sont nécessaires d'urgences pour s'attaquer d'urgence aux inégalités entre les sexes si nous voulons avoir une réelle chance d'inverser le cours de l'épidémie; une action concrète est essentielle pour prévenir la violence à l'égard des femmes et leur assurer comme aux filles l'accès à la propriété et à l'héritage, à l'éducation de base et à des possibilités d'emploi."

La mobilisation contre la maladie a donné naissance à de nombreuses institutions dans le but de canaliser les efforts et les ressources pour une lutte efficace et efficiente contre le SIDA. Au Burkina Faso, le Comité National de Lutte contre le SIDA (CNLS) a vu le jour en 1990 et est devenu par la suite en 2001, le Conseil national de lutte contre le SIDA et les IST (CNLS/IST). Cette structure est placée sous la tutelle de la présidence de la république ; ceci témoigne de l'adéquation entre l'offre et la demande de soins en ce qui concerne des pathologies telles que le paludisme, la tuberculose et les IST/VIH/SIDA financées par la Commission Universitaire au Développement (Belgique) et coordonnée par l'Université Libre de Bruxelles, nous avons été amené à nous intéresser aux représentations et aux moyens efficaces de prévention de ces maladies. Les premiers résultats de cette enquête montrent que les femmes dans leur grande majorité, se montraient impuissantes face à la maladie. Cette impuissance se traduisait par la mauvaise connaissance des moyens efficaces de prévention contre le paludisme et la tuberculose et non-acceptation des moyens de prévention promus pour le VIH/SIDA.

En 2002, dans le cadre d'une étude sur l'adéquation et/ou l'inadéquation entre l'offre et la demande de soins en ce qui concerne des pathologies telles que le paludisme, la tuberculose et les IST/VIH/SIDA financées par la Commission Universitaire au Développement (Belgique) et coordonnée par l'Université Libre de Bruxelles, nous avons été amené à nous intéresser aux représentations et aux moyens efficaces de prévention de ces maladies. Les premiers résultats de cette enquête montraient que les femmes dans leur grande majorité, se montraient impuissantes face à la maladie. Cette impuissance se traduisait par la mauvaise connaissance des moyens efficaces de prévention contre le paludisme et la tuberculose et non-acceptation des moyens de prévention promus pour le VIH/SIDA.

Au cours de cette étude, différentes perceptions des femmes du VIH/SIDA ont été notées : "maladie des jeunes", "maladie envoyée par les blancs pour tuer les africains", "maladie..."
transmise à l’homme après des rapports sexuels avec un chien », « maladie qui attrape les femmes qui aiment l’argent », « le liquide blanc contenu dans le condom transmet le SIDA », « le condom est fait pour les jeunes célibataires », « le SIDA ne concerne que les femmes qui se vendent » ou « ce sont les jeunes filles qui distribuent le SIDA ». Ces perceptions des femmes mariées laissent penser qu’elles ne sont pas concernées par le SIDA vu qu’elles sont en union et ont obligation de fidélité. Seulement, elles reconnaissent que leurs hommes ne sont pas du tout fidèles et entretiennent d’autres relations extra conjugales. De ce point de vue, l’hypothèse que nous formulons est que les femmes en plus des moyens de prévention promus, ont développé des stratégies endogènes de prévention contre le SIDA.

Les stratégies endogènes sont définies dans le cadre de cet article comme toute stratégie propre émanant de la communauté ou des individus et ne faisant pas référence au savoir biomédical.

Le présent article vise à présenter un diagnostic social du VIH/SIDA tel que vécu par les femmes mariées de la ville de Gaoua. Ce diagnostic comprend aussi bien les dénominations locales de la maladie, les signes et symptômes selon les femmes et les moyens de prévention qu’elles ont développés pour une plus grande protection contre la maladie.

**Méthodologie**

**Collecte des données**

La collecte des données s’est déroulée en mars 2003 aux moyens de focus groups réalisés directement dans les quartiers de résidence des femmes. Courant le mois de janvier 2003, pour l’élaboration d’une monographie de la ville de Gaoua, nous avions pris contact avec les responsables des principaux groupes ethniques que l’on retrouve dans la ville.

Pour le recrutement des femmes, nous avions pris contact avec les responsables des principaux groupes ethniques et nos attentes. Les critères de sélection pour les femmes étaient que l’on retrouve dans la ville.

Pour le recrutement des femmes, nous avions pris contact avec les responsables des principaux groupes ethniques et nos attentes. Les critères de sélection pour les femmes étaient les dénominations locales du VIH/SIDA, les signes/symptômes de la maladie, les modes de transmission, les perceptions, les moyens de prévention de la maladie.

A ces femmes leaders, nous avions décrit les objectifs de l’étude et nos attentes. Les critères de sélection pour les femmes étaient qu’elles devaient être mariées, mère d’au moins un enfant, résider dans la ville de Gaoua, avoir déjà assisté à au moins une séance de sensibilisation sur le SIDA et être âgée de plus de 20 ans. Nous avions donné la latitude aux facilitatrices de constituer des groupes de 8 à 10 femmes en fonction des critères définis. Il a fallu plusieurs passages pour la constitution de ces groupes. Les femmes pour diverses raisons n’arrivaient pas à s’accorder sur les jours et les heures du fait qu’elles étaient soit ménagères ou avaient un petit commerce dans le marché de Gaoua. Les obligations des ménagères et la non disponibilité des commerçantes qui passaient leur journée au marché, ne facilitèrent pas les choses. Il n’a pas toujours été possible de réunir en même temps le nombre requis de femmes ; certains rendez-vous furent donc reportés plus d’une fois. Les discussions se sont toujours déroulées chez la femme leader sauf pour les femmes Dagara qui ont préféré se retrouver à notre pied-à-terre.

Au total, 30 femmes ont été rencontrées dont 6 femmes Birifor, 10 femmes Dagara, 8 femmes Lobi et 6 femmes Dioula. Les facilitatrices faisaient parti de ces groupes. Les discussions se sont déroulées dans l’après-midi entre 02 heures et 04 heures sauf pour les femmes Dioula qui s’est tenue la nuit après la prière du soir.

Un guide d’entretien qui servait d’aide mémoire, avait été élaboré pour la circonstance et comportait plusieurs thèmes de discussion. Le chercheur a servi de modérateur et prenait des notes autant que possible. Toutes les discussions avaient une durée d’environ 90 minutes et étaient enregistrées sur cassettes avec l’accord des participantes. Elles se sont menées dans les langues locales, le Dagara et le Dioula. Le Dagara a été utilisé avec le groupe des femmes Dagara et Birifor et le Dioula avec les femmes Lobi et Dioula.

Le contenu des discussions a par la suite été transcrit en verbatim et une analyse thématique a été faite. Les thèmes développés lors des entretiens étaient les dénominations locales du VIH/SIDA, les signes/symptômes de la maladie, les modes de transmission, les perceptions, les moyens de prévention de la maladie.

Les principales difficultés rencontrées ont porté sur la disponibilité des femmes pour les discussions. Aussi, le chercheur étant seul pour l’animation des discussions, la prise de notes n’a pas été systématique. La présence des facilitatrices dans les groupes de discussion, n’a pas toujours permis aux autres femmes de s’exprimer avec aisée. Très souvent des femmes se refugiaient derrière les propos des facilitatrices. Les discussions avec seulement des groupes de femmes mariées n’ont pas permis de comprendre les limites sociales des moyens de prévention préconisés comme le condom, l’abstinence et la fidélité.

**Résultats**

**Dénominations du VIH/SIDA selon les groupes ethniques**

En anthropologie de la maladie, le concept de maladie est difficile à définir si l’on s’en tient au point de vue des anglo-saxons qui la divise en trois réalités (physique, biophysique et socioculturelle) que sont « disease », « illness » et « sickness » (Zempleni A. 1985). Ces trois réalités correspondent chacune à un état de maladie. De même, dans les sociétés africaines, la maladie est appréhendée selon une certaine logique qui fait d’elle une infortune, un malheur. C’est d’ailleurs pourquoi, il est souvent dit que « c’est la maladie qui attrape l’individu ».
De ce fait, les populations expliquent et interprétent les signes de la maladie selon une logique qui leur est propre et qui n’est pas forcément la même que celle des esprits cartesiens.

Toutes les sociétés, quel que soit leur degré d’avancée technologique ou scientifique, ont leur façon d’expliquer la maladie. Pour FASSIN (1992), “toutes les sociétés ont leur façon de classer la maladie et il existe encore des différences entre catégories sociales, entre familles, entre guérisseurs dans une société donnée”. De plus en plus, les points de vue tendent à s’harmoniser et à reconnaître des causes universelles à certaines maladies. Seulement la maladie reste un fait social et lorsqu’elle survient dans un groupe ou une communauté, c’est collectivement que le groupe s’organise pour rechercher son origine, ses causes et le traitement adapté. Mais, depuis l’avènement du VIH/SIDA, cet ordre des choses tend à se bouleverser. Certes, l’origine et les causes de la maladie sont connues, mais l’impuissance se lit sur tous les visages quant à la prise en charge efficace de cette maladie.

Plusieurs discours sont tenus sur la maladie et la mobilisation des politiciens, des financiers, des chercheurs et des communautés, témoignent de la gravité de la maladie.

La dénomination en Lobi n’est pas spécifique aux femmes Lobi mais est une dénomination générique, commune à l’ensemble du groupe Lobi qui n’a pas trouvé une autre dénomination à cette “nouvelle maladie”. La maladie n’a pas de référent culturel du fait qu’elle n’était pas du tout connue il y a quelques années. La dénomination fait référence à un symptôme de la maladie qui est l’amai grissement. L’amai grissement est en effet un des signes, qui se manifeste au stade avancé de la maladie. Il est vrai que des suites d’autres maladies, le malade peut perdre 80% de sa masse corporelle, mais cela ne lui reste plus que les os. La dénomination de la maladie est gbè yirè. gbè yirè signifie in langue Lobiri signifie bras et yirè signifie mince. La récomposition donne bras minces. Ici encore la dénomination est symptomatique mais beaucoup moins morbide que la première. L’amai grissement reste le signe le plus visible de la maladie et est par conséquent utilisé pour nommer la maladie.

L’autre dénomination, moins courante que la première est Yé mina. Yé en langue Lobiri signifie bras et mina signifie mince. La récomposition donne pieds minces. Ici encore la dénomination est symptomatique mais beaucoup moins morbide que la première. L’amai grissement reste le signe le plus visible de la maladie et est par conséquent utilisé pour nommer la maladie.

La dénomination de la maladie est gbè yirè chez les Birifor. Ce groupe culturellement apparenté aux Lobi mais distinct par le parlé, fait aussi référence à un symptôme de la maladie. L’amai grissement est le signe le plus visible et le plus marquant de la maladie. Gbè yirè signifie en Birifor “pieds minces” ou “jambes minces” le malade du Sida à cause de la déperdition de sa masse corporelle, “ne peut plus se tenir sur ses jambes. Il ne lui reste plus que les os” (FG, femmes Birifor). A la différence avec la dénomination Lobiri, c’est que l’amai grissement n’est pas forcément corrélé à la mort. L’amai grissement des jambes dont fait référence cette dénomination est d’un certain point de vue, la réduction, le ralentissement ou l’arrêt de la vie, des activités, des loisirs et des autres plaisirs de la vie.

Pourquoi gbè yirè ? “Lorsque cette maladie t’attrape, tu maigris, tout ton corps finit; les jambes deviennent tellement minces qu’elles ne peuvent plus porter le malade.”(FG, femmes Birifor). Il y a certes d’autres appellations de la maladie mais la plus courante
De même que la dénomination Lobiri, celle-ci ne se dit pas au grand jour. Dans les causeries de cabaret, on appellera autrement la maladie pour ne pas avoir à se justifier aux yeux du malade ou de sa famille. La maladie est si grave et potentiellement mortelle que moralement, il n’est pas permis de dire que quelqu’un en souffre. Dans certaines circonstances, après le décès par exemple, il peut être possible de dire qu’un tel est décédé de telle maladie. Et cela, par le rapprochement des signes qui ont été observés et surtout la diarrhée et l’amaigrissement de la phase terminale.

Les Dagara, proches d’un point de vue linguistique des Birifor, ont une dénomination proche de celle de ces derniers. La dénomination gbè milè est également symptomatique et fait référence à l’amaigrissement des jambes qui est le signe le plus visible. Il est vrai que d’autres maladies peuvent entraîner une déperdition importante de la masse corporelle mais dans le cas du SIDA, cela est très remarquable. Une autre appellation chez les Dagara est gbè viïmè, pour dire que les jambes ont perdu toute leur vigueur, leur solidité et ne sont plus qu’un amas dôs. Selon des femmes Dagara « on ne peut dire que quelqu’un est malade de gbè milè, Même quand tout le monde sait que c’est ça, personne ne le dira. Dans la causerie, on peut dire qu’un tel est fini; il ne lui reste plus que la tête; il est devenu comme un enfant ou bien on évoque une de ses maladies. Comme nous ne sommes pas des agents de santé, nous ne pouvons pas dire avec certitude si c’est le SIDA; ce que nous observons, c’est le changement » (FG femmes Dagara).

La troisième dénomination moins courante mais plus expressive, est fondée sur ce qui est donné à voir et à vivre sur le SIDA. Kpi tjoata signifie en langue Dagara, « mourir les uns après les autres, mourir en chaîne ou en cascade ». Cette dénomination tire sa réalité du fait qu’au cours des quinze dernières années, plusieurs personnes soient décédées les unes après les autres. Les victimes étaient des Burkinabé vivant dans certains pays voisins. Il est même arrivé un temps où l’on ne parlait plus que des funérailles venant de ces pays. Le fait aussi qu’en même une famille, deux ou trois personnes décèdent dans un laps de temps ou un époux et son épouse et peut être les enfants décèdent, a fait parler de décès à la queue leu-leu. Cette situation catastrophique a des répercussions tant sociales, organisationnelles, économiques et symboliques sur ces sociétés du Sud-ouest, très attachées à leurs valeurs socioculturelles (lévirat, excision).

Dans le groupe Dioula, les femmes en plus d’autres appellations, ont adopté l’appellation courante SIDA. « Nous ne connaissons pas cette maladie, elle est une maladie très récente; c’est une maladie très grave qui ne donne aucune chance au malade » (FG femmes Dioula). Le groupe de femmes Dioula ne s’est pas accordé sur une dénomination “standard” de la maladie; chacune y est allée de son appellation en essayant de trouver les expressions qui décrivent le mieux la maladie. Ce qui est remarquable, c’est que la dénomination, fait toujours référence à un symptôme ou mieux, à la fatalité (la maladie étant considérée comme une infortune). On évoquera par exemple “bana djougou” (la mauvaise maladie). Cette dénomination est stigmatisante car “mauvaise maladie” suppose mauvaise fréquentations, mauvais comportements, rendant ainsi le malade responsable de sa maladie.

Les autres dénominations recensées sont dilankan bana, togô fô bali et sii dan.

Dilankan bana signifie « maladie de la couchette ». Sont mis en cause ici, les rapports sexuels. Cette dénomination est très stigmatisante car les personnes infectées et les malades du SIDA sont perçus comme des personnes de petite vertu et de mauvaise moralité. Etre malade du SIDA est systématiquement vu comme lié à des comportements sexuels non responsables, au vagabondage sexuel, à l’infidélité ; les sociétés traditionnelles mettant un point d’honneur à la fidélité.

La peur qu’incarne le SIDA en raison de ses manifestations cliniques, psychologiques, sociales et économiques, fait de lui une maladie redoutable ; la dénomination togô fô bali (dont on ne pourrait dire ou appeler par le nom) traduit la gravité de la maladie.

Sii dan est une autre appellation qui fait référence à la « fin de la vie ». Fin de la vie suppose que l’issue de la maladie est fatale ; le SIDA est perçu comme une maladie incurable dont l’issue n’est que fatale. C’est dire que la perception de la maladie est en rapport avec ce qui est donné d’observer dans la vie de tous les jours. Sii signifie la vie et dan signifie limite, fin. C’est comme si avec l’infection à VIH, le compte à rebours sur la vie se déclenchait.

Modes de transmission de la maladie

Dans nos sociétés, il est connu que c’est « la maladie qui attrape l’homme » et non le contraire. Mais dans le cas du SIDA, cette réalité est quelque peu contredite ; le malade est rendu responsable de sa maladie; Comparé à certaines maladies où l’on dit que « la maladie l’a attrapé », on dira dans le cas du SIDA que « il a attrapé ou a eu la maladie » (Bonnet D. 1986). Cette dernière expression traduit toute une façon de voir les choses.

Pour les femmes Lobi, les modes de transmission de la maladie sont les mêmes que décrivent les campagnes de sensibilisation. Lorsqu’on leur demande les voies par lesquelles une personne peut être contaminée par le SIDA, le premier mode qu’elles citent est la voie sexuelle. Cette voie de contamination est bien
connue des femmes. Seulement, les autres voies qui sont la
voie sanguine et la transmission de la mère à l'enfant ne sont
pas toujours évoquées. Elles disent que « quand quelqu'un
utilise une lame et qu'il se blesse, si tu l'utilises aussi, tu peux
attraper le SIDA » (FG femmes Birifor). La notion d'objets
souillés de sang contaminé n'est pas toujours bien comprise et
est mécaniquement citée par les femmes car faisant partie des
messages qu'elles ont reçu lors des séances de sensibilisation.
« Il ne faut plus raser les têtes de plusieurs personnes pendant les
funérailles avec les mêmes lames ; une personne, une lame » (FG
femmes Lobi). A côté de ce message, les femmes évoquent le
fait de bien connaître leurs proches et ne voient pas le risque à
utiliser les mêmes lames. « Je ne vois pas de problème à utiliser
la même lame que ma mère car je sais que je ne sors pas et qu'elle
aussi ne sort pas » (FG femmes Lobi). Sortir dans ce cas précis
signifie « avoir des relations sexuelles avec d'autres partenaires
que leurs époux ».

Une enquête CAP (N=210) réalisée en 1994-1997 à Kombissiri,
(région centre sud du Burkina Faso), montrait qu'un milieu rural
sélectionné, 100% des hommes et 97% des femmes avaient déjà
entendu parler du SIDA. 95,2% des hommes et 87,1% des femmes
avaient cité les rapports sexuels comme voie de transmission du
VIH/SIDA contre 10,5% des hommes et 5,7 % des femmes
pour le sang contaminé. La transmission de la mère à l'enfant
n'était connue que de moins de 2% des personnes interrogées
(stude transversale ciblant les adultes résidant en milieu rural
(Kombissiri, province du Bazégé). Cet état de connaissances du
VIH/SIDA ne varie pas tellement de celui de notre population
mêmesi nous ne disposons pas de chiffres permettant de faire
une comparaison.

Toujours dans le même sens mais à un niveau plus général,
une autre enquête nationale représentative (N=1631) réalisée
en 1996 dans la population des 15-49 ans montrait que 93,5%
chez les femmes, malgré tout le tapage fait autour du SIDA lors du projet
pilote, ont conservé leurs perceptions propres de la maladie.
Dans la discussion, les femmes disent toujours ce qu'elles ont
retenu des messages diffusés à leur intention lors de séances de
sensibilisation. Mais sont-elles convaincues ? Là est la question.
En les suivant, elles disent des choses qui sont parfois en
contradiction des messages reçus. Aux yeux des spécialistes de la
santé, ces choses pourraient être considérées comme aberrantes,
sans fondement et seraient l'expression que les « populations ne
comprennent jamais rien et qu'il ne faut pas perdre son temps
et son argent pour des gens peu "civilisés" ». Le changement de
comportement escompté dans le cadre de la lutte contre cette
maladie, doit prendre en compte les représentations que les
gens se font de la maladie. C'est tout l'intérêt de l'implication
de l'anthropologie ou de la socio anthropologie dans le champ
medical. Cette implication ouvre de nouvelles perspectives
et comme le dit Tessier (1996) « (...) le SIDA a permis aux
sciences sociales, (...) de vaincre les barrières épistémologiques,
institutionnelles et financières qui empêchaient leur entrée dans le
champ médico-sanitaire». Cette maladie a favorisé une certaine
interdisciplinarité entre sciences sociales et sciences médicales.
L'univers médical n'a pas suffi à venir à bout de la maladie et de
plus en plus la tendance est à l'implication des populations dans
la lutte contre le SIDA en faisant d'elles des actrices et non plus
des bénéficiaires passives. L'intrusion des sciences sociales dans
un domaine qui n'est pas le leur, montre la limite des méthodes
quantitatives à expliciter un phénomène complexe; les données
épidémiologiques n'ont pas suffi à montrer l'ampleur et tous
les drames qui sont autour de la maladie. La stigmatisation

Reconnaissance des signes et des moyens de
prévention de la maladie

Toutes les femmes interrogées avaient déjà assisté à une séance
de sensibilisation sur le SIDA (animation grand public, causerie-
débat, théâtre forum, projection vidéo, etc.) ou au mieux avaient
déjà vu un malade du SIDA. Les signes et les symptômes évoqués
par elles font donc référence à leurs expériences directes ou
indirectes de la maladie. Le plus remarquable, c'est que les
femmes, malgré tout le tapage fait autour du SIDA lors du projet
pilote, ont conservé leurs perceptions propres de la maladie.
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des malades est par exemple difficilement mesurable. Pour comprendre un tel phénomène, les méthodes qualitatives sont plus indiquées pour fournir des réponses et des informations sur la manière dont la science médicale peut entreprendre des actions dans le but de soulager le malade.

Ainsi, pour les femmes Lobi, la maladie se manifeste de la façon suivante : « le malade se plaint de maux multiples; il maigrit beaucoup, devient nerveux, plaintif et méchant. Ses cheveux deviennent roux et cassants, ses lèvres rougissent et il devient friand de viande surtout les parties grasses ». La folie a été évoquée comme signe de la maladie. « Il y a des malades du SIDA qui deviennent fou. Ils ne sont plus contrôlables ; ils font d’importe quoi, ne reconnaissent plus les gens » (FG, femmes Lobi).

Pour les femmes Birifor, ce sont pratiquement les mêmes signes qui reviennent à la différence que le malade a les cheveux frisés qui finissent par tomber. Celui-ci « aime désormais tout ce qui est “bon” comme par exemple la viande. Le corps du malade se couvre de gros boutons et il a de petites plaies dans la bouche et sur le corps » (FG femmes Birifor).

Pour les femmes Dagara, la maladie se manifeste par « les petites maladies qui n'en finissent pas; le malade fait la diarrhée et connaît un amaigrissement important » (FG femmes Dagara). Ce dernier symptôme est le plus important. Les femmes font une relation entre la forte envie de viande, la diarrhée et l’amaigrissement. Ainsi, le malade, à cause des germes qu’il a dans le corps et qui le “dévorent”, lui donnent envie de manger de la viande dans le but de reconstituer ce qu’il perd de sa masse corporelle; malheureusement les morceaux gras (censés faire grossir mais qui ont d’autres inconvénients), provoquent la diarrhée qui entraîne à son tour un amaigrissement. Cette chaîne pourrait bien se prolonger jusqu’à la mort.

Les femmes Dioula parlent de la « fièvre qui apparaît au début de la maladie mais ne baisse pas malgré la prise de médicaments. Cette fièvre conduit à de multiples autres petites maladies qui ne laissent pas de répit au malade. Les maladies s’enchaînent et le malade maigrit, n’a plus l’appétit; ses lèvres rougissent, les cheveux deviennent cassants et tombent » (FG, femmes Dioula).

Les signes principaux de la manifestation possible du SIDA sont connus des femmes; certaines parlent de “prend tout le corps”. Elles évoquent même le fait que “lorsque la bouche du zona se ferme, le malade meurt”. Elles font la différence entre le zona interne et le zona externe. Le plus grave serait l’interne qui se manifeste de la même manière que l’externe mais dans le corps. Cette maladie est appelée “ceinture” et la fermeture de la “bouche” évoquée par les femmes, est la propagation de la maladie sur toute la partie touchée en formant une boucle.

Le stade de SIDA maladie est dépeint comme la glace qui fond jusqu’à disparaître complètement, l’eau s’infiltrant dans le sol ou s’évaporant au soleil. Cette comparaison montre jusqu’à quel point le SIDA est considéré comme une maladie redoutable, ne laissant aucun espoir à qui, à la malchance d’être infecté.

Les moyens de prévention scientifiquement promus sont connus et sont souvent cités par les femmes. En effet, elles font cas du condom, de la fidélité dans le couple et de l’abstinence comme moyens de prévention de l’infection à VIH/SIDA. Seulement la perception du condom comme corps étranger dans le vagin et comme barrière ne permettant plus le dépôt du sperme dans le fond du vagin au cours du rapport sexuel pose problème. Les femmes estiment qu’elles sont fidèles à leurs partenaires. La fidélité comme moyen de prévention est plus accepté par les femmes qui disent que de par la nature du contrat matrimonial, elles n’ont pas le droit d’avoir d’autres partenaires sexuels que leurs époux. Bien que les femmes sachent que leurs hommes ne sont pas toujours fidèles, elles n’envisagent pas l’utilisation du condom. La négociation du port pourrait créer des vagues dans le couple et conduire à leur répudiation par le mari. L’abstinence, au cours des entretiens a été évoquée avec beaucoup de nostalgie comme une valeur qu’elles ont connu et pratiqué mais que leurs filles ne peuvent pas pratiquer. Pour elles, c’est la raison pour laquelle, la maladie ne cesse de se propager. Les moyens de prévention promus, ne correspondent pas toujours au comportement de prévention des femmes. Ce qui a conduit au développement de stratégies propres de prévention. Les stratégies endogènes développées par les femmes sont-elles efficaces ? La question n’a pas été de traiter de l’efficacité mais de montrer comment il était possible de développer des stratégies pour peu que celles connues ne répondent pas aux attentes de ceux ou celles qui sont censés les utiliser. Les principales stratégies endogènes évoquées par les femmes sont-elles efficaces ? 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très pimentées pour voir s’ils ne feront pas la diarrhée. Ceux qui feront la diarrhée seront soupçonnés d’être infectés et pourront être observés pendant plus longtemps. C’est dire que la notion de porteurs asymptomatiques n’est pas du tout connue ou pas bien maîtrisée. C’est ce qui ressort de l’utilisation du préservatif avec un nouveau partenaire. Tous les groupes de femmes pensent qu’il est possible d’utiliser un préservatif au début d’une relation mais au bout de quelques mois, s’il n’y a aucun signe de maladie et que les deux partenaires estiment pouvoir rester fidèle l’un à l’autre, le préservatif est alors abandonné. Ce comportement n’est pas propre à un groupe, à une région donnée mais se remarque partout. La confiance qui naît dans la relation serait à la base de cette “croyance”.

La stratégie du mariage précoce est basée sur le fait que les jeunes filles ne pouvant s’abstenir ou rester fidèle dans une relation, le mieux serait de les donner en mariage très tôt, ce qui leur éviterait de connaître plusieurs partenaires sexuels avant le mariage ; toute femme mariée étant sensée rester fidèle à son mari pour la vie. Le fondement de cette stratégie est la fidélité. Mais les femmes avaient-elles conscience que la fidélité d’un des partenaires seuls ne suffisait pas ou peut-on attribuer cet état de fait à l’ignorance ? Je ne saurai y répondre. Ce qui est sûr, c’est que le moyen de savoir si les deux conjoints sont sains est connu des femmes. Elles évoquent toutes la possibilité de faire des examens dans les centres de santé pour connaître son statut sérologique. « Pour savoir qu’on n’a pas la maladie, on peut aller faire voir son sang à l’hôpital » (FG femmes Lobi) ; À la question de savoir pourquoi les gens ne font pas le test pour connaître leur statut sérologique, les réponses sont très éloquentes. De l’analyse de toutes les réponses, la première raison reste la peur de savoir. « Pourquoi savoir que je n’ai plus de vie ? », « qu’est-ce que je gagnerai de savoir si je suis infectée et de ne pouvoir me soigner, pouvoir guérir un jour, savoir que mes jours sont comptés ? » (FG femmes Daagara). La peur de savoir se justifie du fait qu’il n’y avait pas encore au moment de l’enquête des médicaments accessibles aux populations les plus défavorisées. Ce problème de prise en charge était en son temps une angoisse aussi bien pour les malades, les parents de malades et les soignants. A ce sujet, les femmes disaient que pour la prise en charge de la maladie, les malades ne bénéficiaient que de quelques vitamines et d’antibiotiques. « Quand un malade est hospitalisé, il ne reçoit que l’eau (perfusion) et des vitamines et surtout le cotri (cotrimoxazole). Avec les vitamines, le malade reprend des forces et peut se promener encore quelques jours avant de refaire une autre maladie». (FG, femmes Lobi).

Discussion
Dans la province du Poni à l’instar des autres provinces du Burkina en général, les populations ont leurs représentations de la maladie, de sa prise en charge et des moyens de prévention. La dénomination de la maladie par rapport aux différents groupes ethniques traduit en même temps les perceptions de la maladie des femmes. Le SIDA jusqu’alors perçu comme une maladie redoutable dont l’issue est la mort, surtout qu’au moment de l’énquête, il n’y avait pas encore de possibilités de prise en charge accessible aux populations. Les dénominations utilisées par les femmes sont d’un certain point de vue, l’expression de leurs inquiétudes et de leurs peurs de cette maladie qui a bouleversé les normes en créant ainsi un certain désordre tant social, économique que relationnel (Cros M. 1995). La psychose de la maladie a conduit au développement de certains comportements de prévention dans la population. Cette psychose se traduit à travers les dénominations. La référence à certains signes de la maladie notamment l’amaigrissement extrême du malade en phase terminale est une démonstration que la maladie est mal connue et reste très préoccupante à tout point de vue.

Les voies de contamination de la maladie telles que décrites par les femmes, sont le reflet des messages reçus lors des séances de sensibilisation. Dire que la maladie se transmet par voie sexuelle signifie que les personnes vivant avec le VIH sont celles qui ont connu du désordre en matière de sexualité (infidélité, multi partenariat, vagabondage sexuel, etc.). Il n’est pas fait la relation que la maladie peut se transmettre dans le couple à des personnes d’un certain âge. Seuls les jeunes sont perçus comme les porteurs potentiels et le véhicule de la maladie. Les autres voies de contamination ne sont de ce fait pas bien acceptées au regard des perceptions décrites.

Les moyens de prévention promus sont connus des femmes et elles les citent souvent mécaniquement sans une réelle conviction. Les moyens de prévention décrits et les comportements de prévention sont-ils compatibles ? Le condom ou « sac du pénis » en langue locale est souvent cité avec de la gêne et des femmes trouvent assez ridicule l’utilisation du condom au cours des rapports sexuels. La perception du sperme comme sang nourricier pour la femme, pose problème s’il ne peut plus être déposé au fond du vagin (Bibeau G. 1991). La barrière que constitue le condom ou « sac du pénis » en langue locale est souvent cité avec de la gêne et des femmes trouvent assez ridicule l’utilisation du condom au cours des rapports sexuels. La perception du sperme comme sang nourricier pour la femme, pose problème s’il ne peut plus être déposé au fond du vagin (Bibeau G. 1991). La barrière que constitue le condom ou « sac du pénis » en langue locale est souvent cité avec de la gêne et des femmes trouvent assez ridicule l’utilisation du condom au cours des rapports sexuels. La perception du sperme comme sang nourricier pour la femme, pose problème s’il ne peut plus être déposé au fond du vagin (Bibeau G. 1991).
qui abandonnent précocement le préservatif sans un dépistage préalable avec pour seule raison, le temps passé ensemble sans aucun signe quelconque de maladie de l’un des partenaires. Mettre en observation un partenaire est certes stratégique mais pour combien de temps cela est-il possible ? La femme dispose-t-elle suffisamment de pouvoir pour retenir l’homme pendant longtemps ? Toutes ces questions, loin de remettre en cause les stratégies développées sont, de notre point de vue des messages assez clairs pour tout intervenant dans la prévention du VIH/ SIDA au niveau communautaire. Les aliments qui sont préparés avec une exagération de piments, montrent que la maladie n’est pas bien connue et inquiète beaucoup. Il ressort aussi l’inadaptation des moyens de prévention aux contextes de ceux qui sont sensés les utiliser. Il est clair que même sans SIDA, une forte consommation de piments se traduirait par des maux de ventre et une diarrhée. Seulement, il est admis qu’une personne malade fera continuellement la diarrhée après ce repas tandis qu’une personne non malade ne le ferait pas. Le mariage précoce des jeunes filles ne pose t-il pas un autre problème de santé et de droits de la jeune fille ? Un mariage précoce à un homme déjà infecté ne résout pas le problème de la prévention chez la jeune fille. Seulement la croyance en l’efficacité de cette stratégie pourrait servir à l’amélioration des programmes de prévention axés sur la jeune fille et la femme.

Conclusion
Le diagnostic social du VIH/SIDA et les stratégies endogènes de prévention par un groupe spécifique tel que celui des femmes, montre le décalage qui existe entre les perceptions de la maladie et les messages de prévention reçus. Ceci pourrait aider à comprendre pourquoi certaines stratégies de prévention ont très peu d’impact sur les changements de comportements individuels et collectifs.

Ceci dénote de l’intérêt qu’il y a à prendre en compte les perceptions des communautés de la maladie dans l’élaboration des messages de prévention. L’observation du partenaire et le mariage précoce des jeunes filles sont perçus comme des stratégies efficaces de prévention par les femmes.

Le développement de ces stratégies de prévention autres que celles connues, témoignent de la précipitation dans la conception des messages du début de la maladie qui ne concernaient aucun groupe de façon spécifique ; l’accent avait seulement été mis sur les dangers encourus à savoir que la maladie était incurable et conduisait systématiquement à la mort.

Références

Full text version of SAHARA Available online at www.sahara.org.za
Sexual behaviour and condom use among university students in Madagascar

Onja Holisoa Rahamefy, Michèle Rivard, Madeleine Ravaoarinoro, Lala Ranaivoharisoa, Andriamiliharison Jean Rasamindrakotroka, Richard Morisset

Abstract

Although the number of known HIV-infected students in Madagascar increased significantly between 1989 and 1995, very little is known about student behaviour with regard to AIDS. The study objectives were: to describe Malagasy students’ sexual behaviour and condom use; to document students’ perceptions about condoms; and to study the relationships between students’ socio-demographic characteristics, their perceptions about condoms, and their condom use. The survey used a cross-sectional design and was conducted at the Antananarivo’s university campus sites. Anonymous questionnaires were self-administered to 320 randomly selected students. Descriptive statistics and 95% confidence intervals were calculated. Logistic regressions were performed to identify the predictors of condom use. Participants’ average age was 24 years. Approximately 80% of the participants reported sexual experiences, and the average age at sexual debut was 19 years. Only 5.7% reported consistent condom use. Common reasons for non-use were steady relationships (75.6%), the perception that condoms were useful only during ovulation periods (8.7%), and the decrease of pleasure (6.4%). The predictors of condom use were male gender, and the perception that condoms were useful during ovulation periods. Risky sexual behaviours with regard to AIDS were prevalent in this community. An HIV prevention programme is recommended.

Keywords: Sexual behaviour, condoms, HIV, students, Madagascar.

Résumé

Bien que le nombre connu des étudiants malgaches infectés par le VIH ait largement augmenté entre 1989 et 1995, l'information sur le comportement des étudiants par rapport au SIDA est très limitée. Les objectifs de cette étude furent: 1) décrire le comportement sexuel des étudiants malgaches et l’utilisation du préservatif, 2) documenter les perceptions des étudiants envers les préservatifs, 3) examiner dans quelle mesure l’utilisation du préservatif par les étudiants varie en fonction de leurs caractéristiques sociodémographiques et leurs perceptions envers les préservatifs. Cette étude a été menée dans les sites du campus universitaire d’Antananarivo en utilisant un devis transversal. Un questionnaire anonyme a été auto-administré à 320 étudiants sélectionnés au hasard. Des statistiques descriptives et intervalles de confiance à 95% ont été calculés. La régression logistique a été utilisée pour identifier les déterminants de l’utilisation du préservatif. La moyenne d’âge des participants était de 24 ans. Environ 80% des répondants ont signalé avoir eu des rapports sexuels et l’âge moyen de premiers rapports était de 19 ans. Seulement 5,7% ont rapporté l’utilisation systématique du préservatif. Les raisons de non utilisation furent les suivantes : être dans une relation stable (75,6%), la perception que le préservatif est uniquement utile durant la période d’ovulation (8,7%) et la réduction du plaisir (6,4%). Le genre masculin et l’argument d’ovulation ont été identifiés comme prédicteurs d’utilisation de préservatifs. Les comportements sexuels à risque vis-à-vis du SIDA étaient prédominants dans cette communauté. Un programme de prévention du VIH est recommandé.

Mots clés: Comportement sexuel, condom, VIH, étudiant, Madagascar.

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**Introduction**

Madagascar is a country where trends in the human immunodeficiency virus (HIV) epidemic are frightening. From 2000 through 2003, HIV prevalence increased from 0.15% to 0.95% (Executive Secretariat/National AIDS Control Committee, 2006). Concurrently, a high prevalence of curable sexually transmitted infections (STIs) was recorded. For example, a genital discharge rate of 5.7% was reported in men (Directorate of Demography and Social Statistics, 2000) and the chlamydial infection rate was up by 11% in women (Harijaona, Morisset, Rasamindrakotroka & Ravaoarinaro, 2002). As STIs have been shown to facilitate HIV transmission (Chesson & Pinkerton, 2000), acquired immune deficiency syndrome (AIDS) remains a real threat for the population.

Studies conducted in 1989 and 1995 reported that students represented respectively 0% and 2% of the people living with HIV in Madagascar (National Laboratory of Reference on HIV/AIDS in Madagascar, 2001). On a national level, among the 15 to 24 year-old population, about 17% indicated at least one casual sexual encounter in the year prior to the survey, but only 1.3% reported condom use during their last casual sexual intercourse (Directorate of Demography and Social Statistics, 2000). Given the assumption that the majority of university students are between 17 and 24 years of age, we believed that their community might be vulnerable to HIV infection through sexual risk-taking.

Researchers have reported risky sexual behaviour in African youths. For example, Nigerian university students indicated an average of 3.5 sexual partners at the time they were surveyed (Harding, Anadu, Gray, & Champeau, 1999). Approximately 63% of Togolese university students had more than one sexual partner at the time of the survey, and some 38% reported regular condom use (Sallah et al., 1999). Among Malagasy women, more than one-third had premarital sex, but only 3% reported condom use during their last premarital sexual intercourse (Directorate of Demography and Social Statistics, 1997). None of these results can be transferred directly to the student population because of underlying socio-cultural and environmental diversities. In fact, changes in Malagasy sexual behaviour rates were observed amongst various cultures and regions (Directorate of Demography and Social Statistics, 2000).

Perceptions about condoms have been investigated in order to understand why people practise unprotected sex. The most frequently reported reasons for failure to use condoms were: trust in partners, wanting to have a child, loss of pleasure, and being involved in a monogamous relationship (Eaton, Flisher, & Aaro, 2003; Hawken et al., 2002; Prince & Bernard, 1998). This issue had not been extensively explored among Malagasy youth.

Although studies on links between condom use and socio-demographic characteristics have generated mixed results in different countries (Hawken et al., 2002; Prince & Bernard, 1998), some have revealed an increase in use in younger age groups (Hawken et al., 2002) and in men (Prince & Bernard, 1998; Nuwaha, Faxelid & Höjer, 1999). The socio-demographic determinants of condom use have not been studied in-depth in Madagascar, yet results from a national survey showed higher rates of condom use in the 20 to 24 year age range, and in men (Directorate of Demography and Social Statistics, 2000). Religion is a predominant social marker in Madagascar, but its relationship to sexual behaviour remains ambiguous.

As existing data did not provide public health authorities with an appropriate basis for decisions on the implementation of an HIV programme among Malagasy students, a survey of students' sexual behaviours was carried out on the seven campus sites of the University of Antananarivo, the largest university in Madagascar. Three goals were pursued: to describe male and female students' sexual behaviours and condom use; to document perceptions about condoms among students who do not use them consistently; and to study relationships between students' socio-demographic characteristics, their perceptions about condoms, and their condom use. We firstly hypothesised that reported risky sexual behaviour with regard to STIs/AIDS was prevalent among Antananarivo's university students; and secondly that age, gender and marital status were associated with condom use, but religion not.

**Method**

The study was approved by the Ethics Committee of Madagascar's National Laboratory of Reference on HIV/AIDS. It targeted 4,274 students registered at one of the seven campus sites of the University of Antananarivo: Ambodhipo (site I), Vontovorona (site II), Ankatsos (site III), Ankatsos 2 (site IV), Ambolonkandrina (site V), Ambatomaro (site VI) and 67 Hectares (site VII). The survey was conducted from February through July 2000, using a cross-sectional design. We expected that sexual behaviour prevalence would be between 5% and 95% in this student population. A sample size of 353 was therefore needed to allow for appropriate precision within 2.5% to 5%, considering a confidence level of 95%. The sample size was fixed at N=400 because of anticipated missing values.

Participants were selected using each site's list of registered students. As campus sites had different sizes, we used a stratified sampling scheme according to campus sites. Regardless of
socio-demographic characteristics, site-size equivalent sample fractions of 25.5%, 20.8%, 18.6%, 17.9%, 7.3%, 7.2% and 2.7% were extracted from all sites, which housed 1088 (site I), 890 (site II), 796 (site III), 795 (site IV), 310 (site V), 308 (site VI) and 117 (site VII) students. We expected a better representation of subjects residing in each site by using this procedure.

Data collection used a pre-tested anonymous questionnaire written in French, the university’s teaching language. As recommended by the students during pre-tests, some terms were translated into Malagasy. Most of the relevant items were developed based upon a review of previous research, and the content was validated by three experts. Questions related to the variables of interest are presented in Appendix A. In the course of the analysis process, studied variables were reclassified to fit the local context. Socio-demographic variables included "age", "gender", "marital status" (Single/Married), and "religion" (Christian/non-Christian). Behavioural variables were “Sexual experience” (Yes/No), “Age at first sexual intercourse”, “Sexual orientation” (Heterosexual/Homosexual/Bisexual), “Number of sexual partners in the past 12 months” (None/One/Two or more), “Commercial sex in the past 12 months” (Yes/No), “Vaginal sex in the past 12 months” (Yes/No), “Oral sex in the past 12 months” (Yes/No), “Anal sex in the past 12 months” (Yes/No), “Age at first vaginal sex”, “Age at first oral sex”, “Age at first anal sex”, and “Condom use in the past 12 months”: Never/ Irregularly (sometimes or almost all the time)/Consistently (all the time).

As far as marital status was concerned, the few separated, divorced and widowed students were classified as single, and married students included legally married and cohabiting couples. For each respondent, the age at first sexual intercourse was defined as the one at which either vaginal, oral or anal sex was first experienced. Also, condom use in the past 12 months included using condoms during vaginal, oral and anal sex. Consistent condom use in the past 12 months implied condom use during all vaginal, oral or anal sexual intercourse. In the same way, it was established that a participant had never used a condom in the past 12 months when he or she reported never using one for all the types of sexual practices. The rest of the sexually active participants were considered to be irregular condom users.

In order to document students’ perceptions about condoms, an open-ended question was asked: “why wouldn’t you use a condom during sexual intercourse?” Then variables were extracted from the most common reasons for non-condom use and classified into two categories: mentioned/not mentioned.

The survey was carried out during the annual medical examination visit each student must make to a university health clinic. Two workshops were held for local investigators to ensure uniform data collection. A trained investigator supplied one questionnaire to each selected participant in a private room. After informed oral consent was given, the questionnaire was self-administered by the student. One investigator was present to reply to the participant’s queries. The completed form was immediately put into a large envelope and sealed. In the case of a participant's absence or refusal, the investigators documented the socio-demographic characteristics and reasons for non-participation.

Descriptive statistics and 95% confidence intervals (95%CI) were calculated. A significance level at 0.05 was considered for p-values. Means and percentages were weighted by campus site for socio-demographic characteristics, behavioural and perception variables. In order to compare percentages, the Pearson’s χ² Test, or where necessary, the Fisher Exact Test were used. The Pearson’s χ² Test was not calculated if at least one expected value was less than 1. For the mean comparison between sub-groups, an analysis of variance or, if needed, the appropriate nonparametric test was run. Logistic regressions were performed to evaluate the extent to which students’ socio-demographic characteristics, and some of their perceptions about condoms, were associated with their condom use, the dependent variable. Independent variables, including "age", "gender", "marital status", "religion" and the collected common perception variables. In order to compare percentages, the perceived likelihood ratio test was found to be statistically non-significant, so all the entered product terms were eliminated. Confounding effect was confirmed if the computed odds ratio (OR) changed by at least 10% when removing the factor. The number of sexual partners in the past 12 months was entered as a potential confounder. Some potential effect modifiers were also inserted. When assessing interaction effects, a chunk likelihood ratio test was found to be statistically non-significant, so all the entered product terms were eliminated. Confounding effect was confirmed if the computed odds ratio (OR) changed by at least 10% when removing the factor. The number of sexual partners in the past 12 months was found to be a confounder and was then maintained in the reduced model. Analyses used Epi6 6.04 and SPSS 10.0 software packages.

Results

Participation rates and socio-demographic characteristics

Most of the selected students participated in the survey (320 out of 400 students). Participation rates were respectively 82%, 86%, 76%, 75%, 79%, 79% and of 83% in the sites I to VII. Non-participants did not respond for many reasons: 24 (6%) moved; 16 (4%) lived off-campus; 14 (3.5%) were travelling; 14 (3.5%) had courses or exams; 2 (0.5%) were hospitalised; 1 (0.3%) disliked the research, 1 (0.3%) wanted to preserve his privacy, 3 (0.8%) had administration problems; and 5 (1.3%)
students were not found, in spite of repeated contact attempts by the person responsible for the survey.

Table 1 shows the socio-demographic characteristics of the study participants. Their average age was 24 years (median = 24; range = 18–47). Men represented approximately two thirds of the study population. It was noticed that the average age differed significantly in the sites I to VII: 26, 22, 25, 24, 25, 24 and 27 years respectively (Kruskal-Wallis analysis of variance: \( p < 0.001 \)); as did the proportions of men, which were 65.9%, 80.3%, 50.9%, 53.6%, 73.9%, 59.1% and 40.0% respectively (\( p < 0.01 \)). The majority of students said they were single, and over 90% indicated they were Christians. Of those selected to be surveyed, participants were 2 years younger than non-participants: 24 v. 26 years (\( p < 0.01 \)).

Malagasy students’ sexual behaviour and condom use

Approximately 80% of the participants reported sexual experiences. The indicated age at sexual debut was between 7 and 27 years for men (average = 18.4 years; median = 18 years) while it varied from 14 through 28 years for women (average = 20.2 years; median = 20 years). These distributions were significantly different among men and women (Wilcoxon test: \( p < 0.001 \)). Of all the sexually active participants, one student declared he was bisexual, and the rest said they were heterosexual.

Table 2 presents the sexually active respondents’ sexual behaviour and condom use. During the year prior to the study, 29% of the students had two or more sexual partners, and 7.8% reported having commercial sex. Vaginal intercourse was reported by almost all the participants, while few students declared oral (14.8%) and anal sex practices (3%). While the average age at sexual debut was 19 years for all the sexually active students, it was 19, 21 and 20 years for vaginal, oral and anal sex respectively. Systematic condom use was reported by 5.7% of respondents.

Men were statistically different from women regarding a number of behaviours. While almost one-third of the male students reported two or more sexual partners, only about 1 out of 10 of the female students reported this (\( p < 0.001 \)). Moreover, none of the women reported having commercial sex, while 13% of the men did (\( p < 0.001 \)). Lastly, about half of the women had never used a condom in the past 12 months. This rate was estimated at nearly one-third for the men (\( p = 0.016 \)).

Students’ perceptions about condoms

Table 3 reports students’ common perceptions about condoms. Approximately 94% of the respondents had not used condoms consistently in the past 12 months. Almost all of the latter (215/217) could state at least one reason for not using condoms. The most frequently reported reasons were: sexual intercourse with a steady partner (75.6%); sex during off-ovulation periods (8.7%); and decrease of sexual pleasure (6.4%). Some students mentioned other less common reasons like: trust in the partner (2.8%); feeling uncomfortable when using condoms, including breakages (3.1%); lack of knowledge on how to use a condom (3.8%); unaffordable costs of condoms (1.8%). Infrequently (less than 1% for each variable), students indicated the following reasons: the fear that condoms were contaminated with HIV or other pathogens, the fear that condoms generated side-effects, partner refusal, immediate unavailability of condoms, intention to procreate, safety with a HIV-seronegative partner, spontaneity

| Table 1. Socio-demographic characteristics of the participants and non-participants, University of Antananarivo, Madagascar, 2000 (N=400) |
|---------------------------------------------|---------------------------------------------|----------------|
| Age                                         | Gender                                     | Religion       |
| 18-23 years                                 | Male                                       | Christian      |
| 144 (45.7)                                  | 204 (60.6)                                 | 298 (94.4)     |
| 24-29 years                                 | Female                                     | Non-Christian  |
| 142 (44.3)                                  | 116 (39.4)                                 | 20 (5.6)       |
| ≥30 years                                   | Marital status                             | n.a.           |
| 32 (10.0)                                   | Single                                     | n.a.           |
|                                               | Married                                    | n.a.           |
|                                               | Number (N=320)                             | Non-participants (N=80) |
|                                               | (%)                                        | Number (%)     | \( p \) |
| 21 (29.3)                                   | 21 (29.3)                                 | 21 (29.3)     |
| 43 (54.2)                                   | 43 (54.2)                                 | 43 (54.2)     | 0.016 |
| 12 (16.4)                                   | 12 (16.4)                                 | 12 (16.4)     | 0.483 |
| 47 (55.8)                                   | 47 (55.8)                                 | 47 (55.8)     | 0.016 |
| 32 (44.2)                                   | 32 (44.2)                                 | 32 (44.2)     | 0.085 |
| 60 (84.0)                                   | 60 (84.0)                                 | 60 (84.0)     | -     |
| 16 (16.0)                                   | 16 (16.0)                                 | 16 (16.0)     | -     |
| n.a.                                        | n.a.                                      | n.a.           | -     |
| n.a.: data not available                    | n.a.                                      | n.a.           | -     |
of sexual acts, embarrassment when purchasing condoms, absence of flux, the perception that condoms were unnatural, and inducements to temptation. A statistically significant difference was found when comparing men's perceptions with women's with regard to condoms. Female students were more likely to state that condoms were not useful with a steady partner: 86% v. 69% ($p<0.03$).

Relationships between students’ socio-demographic characteristics, perceptions about condoms, and condom use

Table 4 presents computed odds ratios from multivariate analyses that compared condom use (used condom irregularly) and non-condom use (never used condom) among the studied population. The few students who used a condom on a regular basis were excluded. Most of them found no reason to engage in unprotected sexual intercourse, or did not answer the question related to perceptions about condoms. Results showed that the main predictors of condom use were male gender and the perception that condoms were useful only during women’s ovulation periods ($p<0.01$). Males were twice as likely to report using condoms as females. Students who felt that condoms were useful only during ovulation periods were six times more likely to use them, compared with students who didn’t state such an opinion.

**Discussion**

The findings confirm the first hypothesis that reported risky sexual behaviour with regard to STIs/AIDS was prevalent among Antananarivo University students. Although late sexual debut was recorded, consistent condom use was very low. Results lead one to question whether those students had any sexual health education. Also, the fact that the students were away from their family and free from parental behavioural prohibitions, might have induced them to engage in hazardous sexual intercourse. Consequently, students were vulnerable and there was a risk of HIV infection spread in their community.

The results support the hypothesis that gender is associated with condom use. In Madagascar, rates of using condoms were found to be lower among women than men (Directorate of Demography and Social Statistics, 2000). In the present study, female students were as likely as male students to say that they would not use condoms with a steady partner. A second study...
supported the finding that Malagasy women are unwilling to use condoms with their steady boyfriend (Behets et al., 2005). This suggests that women engaged in unprotected sexual intercourse in steady relationships, and in this way, they were exposed to STIs and HIV infection. This indicates the need to specifically target female students in HIV prevention programmes.

Furthermore, the observed gender and relationship differences with regard to condom use should be taken into consideration when defining condom promotion strategies. Messages tailored to men, women and couples are required.

The last hypothesis that religion is not associated with condom use was verified. This is in agreement with data obtained from research on Malagasy women (Glick, Randriamamonjy & Sahn, 2004). Christian affiliation is predominant in Antananarivo. Results may reflect firstly, the difficulties of integrating sexual education in Christian teachings; and secondly, the gap between Christian identity and individual behaviour with regard to some of its doctrines. For example, condom use was recorded in spite of the Catholic position against condoms. Besides, none of the sexually active students had indicated religion as a reason for non condom use. In the Malagasy social context, Christian churches have shown considerable flexibility. Actually, religious and traditional practices cohabit without competition (Roubaud, 1999). Our data revealed that although the majority of respondents considered themselves Christians, premarital sexual intercourse was quite common. Malagasy students’ sexual behaviour, including condom use, may have been determined by both the existence of sexual health education and the conservation of traditional cultures allowing sexual activities before marriage (Garenne & Zwang, 2004). Data also suggest that instead of religious affiliation or identity, faith-based religiosity could be a measure of interest in the study of relationships between religion and sexual behaviours in Madagascar.

**Table 3. Common reasons for non-condom use among students who do not use them consistently, University of Antananarivo, Madagascar, 2000 (N=215)**

<table>
<thead>
<tr>
<th></th>
<th>Men (N=139)</th>
<th></th>
<th>Women (N=76)</th>
<th></th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>(95%CI)</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>“Condom is useful only during ovulation periods”</td>
<td>10</td>
<td>5.4</td>
<td>(2.9 - 11.5)</td>
<td>10</td>
<td>14.1</td>
</tr>
<tr>
<td>Mentioned</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>“No condom with a steady partner”</td>
<td>96</td>
<td>68.9</td>
<td>(61.4 - 76.7)</td>
<td>63</td>
<td>86.3</td>
</tr>
<tr>
<td>Mentioned</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>“Decrease of sexual pleasure”</td>
<td>13</td>
<td>8.8</td>
<td>(4.5 - 14.2)</td>
<td>4</td>
<td>2.6</td>
</tr>
</tbody>
</table>

n/a: not applicable, 95%CI not calculated

**Table 4. Relationships of students’ socio-demographic characteristics and perceptions about condoms, to their condom use, University of Antananarivo, Madagascar, 2000 (N=209)**

<table>
<thead>
<tr>
<th></th>
<th>OR</th>
<th>(95%CI)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Socio-demographic characteristics</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age†</td>
<td>0.87</td>
<td>(0.54 - 1.38)</td>
<td>0.272</td>
</tr>
<tr>
<td>Gender</td>
<td>2.29</td>
<td>(1.19 - 4.42)</td>
<td>0.007</td>
</tr>
<tr>
<td>Marital status</td>
<td>1.68</td>
<td>(0.78 - 3.61)</td>
<td>0.094</td>
</tr>
<tr>
<td>Religion</td>
<td>1.43</td>
<td>(0.41 - 4.95)</td>
<td>0.188</td>
</tr>
</tbody>
</table>

Common perceptions about condoms

<table>
<thead>
<tr>
<th></th>
<th>OR</th>
<th>(95%CI)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Condom is useful only during ovulation periods”</td>
<td>6.04</td>
<td>(1.53 - 23.83)</td>
<td>0.005</td>
</tr>
<tr>
<td>“No condom with a steady partner”</td>
<td>1.57</td>
<td>(0.69 - 3.55)</td>
<td>0.141</td>
</tr>
<tr>
<td>“Decrease of sexual pleasure”</td>
<td>0.86</td>
<td>(0.25 - 2.88)</td>
<td>0.400</td>
</tr>
</tbody>
</table>

* One-tailed p-value from Wald Test
† Age was classified into 3 categories: 18-23 years / 24-29 years / ≥30 years
However, findings do not support the hypotheses that age and marital status are associated with condom use. The participants’ homogenous educational level, university context, and gender relationships might explain the discrepancy. In fact, two larger studies conducted in Madagascar, in 2000 and 2004, reported significant associations of higher educational attainment with increase in condom use (Directorate of Demography and Social Statistics, 2000; Glick et al., 2004). Since studies were students’ first concern, becoming pregnant before graduating was undesirable for the majority, and the use of condoms to prevent conception interested both single and married students. Men and women in Madagascar have a more egalitarian relationship than couples in many other African countries (Gastineau, 2005). This probably allows for couples’ shared decision to use condoms.

On the one hand, some of the results were not surprising on account of their consistency with available data. For example, the earlier age at sexual debut (Eaton et al., 2003) and the larger number of sexual partners indicated by men than women were consistent with results from other African countries (Hawken et al., 2002). Some reasons for not using condoms among Malagasy students were similar to those mentioned by Kenyans and Nigerians (Anugwom, 1999; Hawken et al., 2002).

On the other hand, some observations differed from other findings. For example, Malagasy students reported a later age at sexual debut (19 years old) compared with South Africans, where more than 50% were already sexually active at the age of 16 (Eaton et al., 2003). At the same time, the median age at sexual debut was 16-17 years among the Malagasy general population (Directorate of Demography and Social Statistics, 2000). Again, the Malagasy students were motivated to postpone their fecund life because of schooling and studies at the university. Furthermore, it is possible that some Malagasy students did not want to engage in premarital sexual activity because of religious convictions. Studies reported the association between religion and sexual initiation (McCree, Wingood, DiClemente, Davies & Harrington, 2003). Lastly, the average age at first intercourse could have been biased because of understatements.

Malagasy students indicated low systematic condom use: 5.7%, which was not much different from the 8% reported condom use among South African students (Eaton et al., 2003). It is a major concern to note that Malagasy students had a low risk perception of contracting AIDS. Only one student stated that he would not use a condom with an HIV seronegative partner (0.5%). Among Nigerian students, 50% would use condoms to prevent STIs/AIDS (Anugwom, 1999). The important difference between Malagasy and Nigerians’ data might be accounted for by the fact that the survey among Nigerians happened during a local HIV campaign. The low risk perception of contracting AIDS in this Malagasy student community needs to be explored by conducting in-depth studies when implementing any HIV programme.

In the present study, condom users were male rather than female. Among Turkish and Nigerian students, condom users were women rather than men (Gokengin et al., 2003; Olley & Rotimi, 2003). Differences in perceived social norms about condoms between the populations might explain the discrepancy. Furthermore, the use of another contraceptive method could have led Malagasy women to abandon the use of condoms. Nevertheless, results indicate that some female students were vulnerable to HIV, particularly, those who never used condoms with a steady partner.

The study was important on two counts. It was the first carried out in this population group and met the local public Health Department’s need to document the risk of HIV spreading in the university student community. Most of the variables were studied in other research projects, and the content validity was checked by experts. Nonetheless, only sexual behaviour in the past 12 months was investigated, and the questions did not include the number of lifetime sexual partners. Thus, the HIV transmission risk might have been underestimated.

The presence of investigators during the questionnaire administration provided the opportunity to get a response to each question, but could have caused information bias. The under-reporting of socially undesirable sexual behaviour, like having a high number of sexual partners, was expected, as well as the overestimation of desirable behaviour like using condoms. As far as the data collection method is concerned, proceeding with an anonymous postal questionnaire might have reduced such information bias. Weaknesses were also found in some interval estimates which could not be calculated, or were too wide. A larger sample would have given more precise point estimates.

Lastly, findings justify the implementation of an HIV prevention programme in this Malagasy student community. The noted gender behavioural differences suggest the adoption of individual focused strategies such as counselling that are tailored to each person’s needs. Although current data are useful for an immediate local HIV intervention, or for further youth sexual health research, they need to be complemented by long-term HIV projects among students.
Acknowledgements
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References


Confidentiality or continuity? Family caregivers’ experiences with care for HIV/AIDS patients in home-based care in Lesotho

Mokhantsö G Makoae, Ken Jubber

Abstract

In the context of poor access to antiretroviral therapies in sub-Saharan Africa, the minimum treatment package intended to treat opportunistic infections common with HIV infection is inadequate but appealing, since it presumes universal coverage of medical care for patients living with HIV and AIDS. The overall objective of this study was to analyse the challenges which family caregivers encountered in home-based care when they tried to access medical treatment for home-based AIDS patients in the context of confidentiality and limited medical care. A qualitative study using in-depth interviews with a sample of 21 family caregivers –16 females and 5 males aged between 23 and 85 years was conducted with the assistance of health personnel in two hospitals in Lesotho. Using the concept of continuity of care, this article discusses the experiences of family caregivers about home care, including their experiences of adherence to confidentiality by health care professionals and non-disclosure of AIDS as the context of illness, the circumstances under which the caregivers initiated caregiving and sought medical care, and how these factors could be stressors in caregiving. There was continuity of care where the caregivers obtained hospital support. However, when confidentiality was adhered to the caregivers were frustrated by lack of information, disrupted treatment, exclusion of their perspectives in medical care, failure to secure hospitalisation, ambiguous goals and non-responsiveness, so that continuity of care was jeopardised. Thus it can be concluded that professional-assisted disclosure benefited the patients because it facilitated continuity of care through the caregivers.

Keywords: Lesotho, HIV/AIDS, confidentiality, caregiving, continuity of care, ethic of care.

Résumé

Dans un contexte africain sous-Saharien où l'accès aux thérapies antirétrovirales est très limité, le paquet minimum de traitement destiné au traitement des infections opportunistes liées à la séropositivité est inadéquat mais attirant puisqu’il suppose une couverture universelle de soins médicaux pour des malades vivant avec le VIH/SIDA. L’objectif global de cette communication est d’analyser les défis auxquels les soignants familiaux font face en soins à domicile lorsqu’ils essaient d’avoir accès au traitement médical pour les malades du SIDA dans un contexte de confidentialité et des soins médicaux limités. Une étude qualitative employant des entretiens détaillés auprès d’un échantillon de 21 soignants familiaux (16 femmes et 5 hommes âgés de 23 à 85 ans) a été menée grâce à l’aide du personnel de santé dans deux hôpitaux au Lesotho. En utilisant le concept de continuité de soins, cette communication met en relief des expériences des soignants sur les soins à domicile. Cette communication examine des expériences des soignants familiaux sur les éléments suivants : l’adhésion par les professionnels de santé et de soins à la confidentialité et à la non-divulgation de séropositivité comme étant le contexte de maladie, les circonstances sous lesquelles les soignants ont initié les soins, les soins médicaux suspects, surtout le diagnostic et le traitement, ainsi que l’hospitalisation et la manière dans laquelle ces facteurs pourraient être à l’origine du stress chez les soignants. On a constaté que la continuité des soins dans le cas où les soignants recevaient du soutien hospitalier – l’information, un traitement gratuit des multiples symptômes et l’hospitalisation de manière prévue et consisante. Cependant, lorsqu’il y avait adhésion à la confidentialité, les soignants étaient frustrés par le manque d’information, un traitement perturbé, l’exclusion de leurs opinions vis-à-vis les soins médicaux, ne pas pouvoir assurer l’hospitalisation des malades et les objectifs ambigus, la non-réceptivité et la continuité a été compromise. En conclusion, on constate que en divulguant sa séropositivité avec l’aide professionnelle a énormément aidé les malades car cela a facilité la continuité de soins assurés par les soignants.

Mots clés : Lesotho, VIH/SIDA, confidentialité, soigner, continuité de soins, l’éthique de soins.

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Introduction
Lesotho has one of the highest HIV infection rates in the world, estimated at 31% among adults aged 15 to 49 years in 2003 (Ministry of Health, 2003), and ranging between 21.9% and 24.7% in 2005 (UNAIDS, 2006). As with most resource-poor countries in sub-Saharan Africa, medical treatment provided for patients with AIDS-related illnesses in the public health sector before 2004 did not include antiretroviral drugs (ARVs) and the approach before this date was “a minimum package of care” intended to treat some of the common opportunistic infections and reduce hospitalisation (Government of Lesotho, 2002). For example, treatment for oesophageal candidiasis and cryptococcal meningitis as well as sexually transmitted infections (STIs) and tuberculosis (TB) was free (Ministry of Health and Social Welfare (MoHSW), 2000). However, due to inadequate and poor access to medical treatment, chronic illness persisted and AIDS-related deaths increased, though the AIDS-related root causes of these deaths were usually not disclosed.

Home-based care was adopted to avert the ever increasing need for hospitalisation, and continuity of care for patients and support for affected families were identified as the pillars of this strategy (Government of Lesotho, 2002; MoHSW & World Health Organisation, 2002). Amidst the high incidence of adult morbidity and death, the policy of confidentiality regarding HIV diagnosis prevailed, leading to a situation whereby ‘chronic illnesses’ became a generic label used in public health documents to gloss over symptomatic AIDS illnesses, especially in the context of home-based care.

The objective of this article is to analyse the caregiving experiences of a sample of 21 family caregivers of patients with HIV/AIDS-related illnesses who were cared for at home and obtained medical treatment at two hospitals in Lesotho. It examines their experiences in obtaining medical care for the patients under the then prevailing confidentiality practices and the limited medical treatment available.

HIV and home-based care
The encouragement of home-based care in the era of HIV/AIDS was intended to reduce the economic and human resource pressure, which health care systems especially hospitals faced. As a result of increased chronic illness due to HIV/AIDS in the hardest-hit and poorly resourced countries, “people who are not normally users of health care: young adults” (Barnett & Whiteside, 2002, p.308) sought hospital admission. Curtailing hospitalisation through informal home care in order to avert frequent and long hospital stays is explicit in AIDS care (Mupedziswa, 1998; Van Dyk, 2001). Although doctors maintain high autonomy in their day-to-day decision-making, their decisions reflect and are influenced by political, economic, social and cultural factors (Johnson 1993; Powell-Cope & Brown, 1992; Schoepf, 1991).

The treatment and management of HIV-related chronic illnesses usually commence with ambulatory patients seeking health care services independently. However, as their health conditions deteriorate, mobility and independent functioning decline. Without comprehensive treatment, which includes the highly active antiretroviral therapies (HAART), acute illnesses are common in poor high HIV prevalence countries. The transition from being HIV seropositive to having AIDS symptoms may be dynamic, and patients with a tenuous link to the health care system may face a crisis when they fall ill. The universally accepted value is that even home-based care patients should have access to medical care when they need it. Access to health care entails timely use of health services to attain the best possible results (Andrulis, 1998). In a study including out-and-in-patient care recipients, Cunningham, Hays, Ettl, Dixon, Liu, Beck and Shapiro (1998) found that patients with symptomatic HIV illnesses generally had poorer access to medical care than patients with other chronic diseases, due usually to the high cost of drugs and reduced incomes as a result of illness.

Confidentiality, stigma and discrimination
Maintaining confidentiality in HIV/AIDS when most of the care is provided by family members is controversial. Confidentiality has mainly been considered from the perspective of protecting people infected and affected by HIV/AIDS from stigmatisation (Corey, Corey & Callanan, 2003; Gwyn, 2002). Negative attitudes such as unwillingness to associate with persons with HIV/AIDS are experienced from “sacred domains – family, medicine, and church” (Poindexter, 2005, p.2). Contrary to the good reasons for maintaining confidentiality, research conducted in Western cultures suggests that informal caregivers for patients living with HIV/AIDS may resent confidentiality if it marginalises them and deprives them of pertinent information about the illness while they assume the bulk of the responsibility for the patient’s wellbeing (Colledge & Maddison, 1992), and are expected to observe universal precautions to prevent HIV infection. Similarly, it is recognised that shared confidentiality has the potential to des-stigmatise HIV/AIDS in resource-poor contexts where families and communities shoulder most of the care responsibility in home-based care (Campbell, n.d.). Ironically, disregarding this principle may have far-reaching consequences for the agencies responsible for the different components of ‘governmentality’ such as surveillance and the compilation of statistics (Johnson,
1993) on the epidemic. Trust in the health care services may be jeopardised (Vedder, 1999) because the integrity of health care professions also depends on maintaining confidentiality, especially where it is promised (Jackson, 2002; Van Dyk, 2004). It is also critical to acknowledge that certain chronic illnesses, especially those which incapacitate the patients, cannot be managed in an exclusive doctor-patient relationship (Haug, 1994) without involving family caregivers. The involvement of family members in assisting relatives with chronic illness includes helping them to access medical treatment (Thomas, Morris & Harman, 2002). It is in this context that the importance of expanding the healing relationship to include family caregivers of elderly patients with dementia (Haug, 1994), and providing both patients and caregivers who manage chronic illnesses with comprehensive information about aspects of the treatment strategies (Rajaram, 1997) are recognised and necessary strategies. Labrecque, Blanchard, Ruckdeschel and Blanchard (1991) found that caregivers of cancer patients considered provision of information a form of social support which alleviated their uncertainty, and that when illness was serious, interaction between the patient, the doctor and the family member was crucial. Poor communication between caregivers and physicians can lead to the former expressing displeasure with physician support (Glaser, Rubin & Dickover, 1990, cited in Haug, 1994). When medical encounters between patients and their doctors are guided by confidentiality, family caregivers are likely not to obtain essential information about the illness if there are barriers to practicing "shared confidentiality".

In most African societies, maintaining confidentiality which excludes family members in the context of care is a peculiar practice which contradicts the fundamental values which provide the basis for social cohesion. Some writers have described HIV-related confidentiality in the African cultural context as controversial (Fombad, 2001; Jackson, 2002). Firstly, home-based care is typically based on familial obligations embedded in the ubuntu philosophy (Okolo, 2002; Ramose, 2002). "Ubuntu is the central concept of social and political organisation in African philosophy … It consists of the principles of sharing and caring for one another" (Ramose, 2002, p.643). It espouses the notion of caring which is inherent in most human relationships and is consistent with the ideas of the theorists of care (Bowden, 1997; Kuhse, 1997); Noddings, 1984; Sevenhuijzen, 2003; Tronto, 1993) who adopt the ethic of care and insist on avoiding the trap of viewing care as inherently burdensome as it is commonly understood. Instead, they emphasise values such as human relationships based on interdependence, trust, openness, acknowledging emotions and dependence, and responsibility to particular others in this social practice. Both the ethic of care and ubuntu are contrary to what Noddings (1984) describes as the Western approach, based mainly on justice principles of reason, abstraction, universalism, rules and rights; and emphasise local contexts and situation specific circumstances when dealing with problems.

Secondly, family members are usually part of the responses to illness (Liddell, Barrett & Bydawell, 2005) and are present in medical encounters between patients and physicians (Andersen, 2004). Furthermore, despite confidentiality, physicians in Africa mostly share information on diagnosis with family members for serious diseases such as cancer, and may rely on the family in disclosing or withholding diagnosis from patients (Harris, Shao & Sugarman, 2003; Holland, Geary, Marchini & Tross, cited in Gotay, 1996). These practices may be seen as ways in which biomedicine has been adapted to the cultural values of communality and sharing or the 'Africanisation of biomedicine' (borrowing from Finkler, 2004 – ‘Mexicanisation of biomedicine’). When HIV/AIDS is involved, the issue of confidentiality becomes particularly problematical, especially in societies where family relationships play a significant role in ensuring that the patients obtain humane care at home (Chimwaza & Watkins, 2004). It is thus important to examine how confidentiality affects continuity of care, as "an essential attribute of a well-functioning health delivery system" (Donaldson, 2001, p.255).

The definitions of continuity in the context of chronic illness emphasise coherence, comprehensiveness and responsiveness of care services, provided on a long-term basis and across different spheres of care, the result of which is improved health outcomes for individual patients (Benjamin, 1989; Haggerty et al., 2003; Mainous & Gill, 1998; Woodward, Abelson, Tedford, & Hutchison, 2004). Haggerty et al. (2003, p.1220) identify two key aspects of continuity as “care of an individual patient and care delivered over time”. They further identify the three types of continuity as informational, management and relational continuity, all of which are crucial in chronic illness. It is the informational aspect which makes Donaldson’s (2001) conceptualisation relevant to this discussion. Donaldson (2001, p.262) adopts the agency theory to understand continuity and defines it as "the degree to which health care activities are structured to increase information available to a clinician and to increase the likelihood of goal alignment between the patient and clinician". Donaldson’s agency model is useful because it emphasises the relevance of information sharing between actors who inherently have asymmetrical access to it – doctor and patient. Although the model identifies the relevance of continuity in chronic illness, it does not accommodate the inevitable loss of agency by the patients as their health dwindles,
and the need for information sharing and goal alignment with the caregivers to ensure undisrupted care overtime.

Research is relatively silent about how the dynamics underlying the HIV/AIDS illness and the care environment, as well as the inevitable loss of independent functioning by patients and confidentiality may be experienced by family caregivers when they try to meet the care needs of home-based patients over time. The question of access to treatments, which exclude ARVs, to alleviate AIDS-related opportunistic diseases is important even today because the adopted approach – ‘scaling-up’ or ‘rolling-out’ of ARVs – does not guarantee immediate access of all the people who need them. However, the focus on ARVs, while unavoidable, might have inadvertently overshadowed the question of access to health care services as currently made available to the majority of PLWHA.

Methodology

Study design

This article presents and analyses some of the findings that emerged from a qualitative study conducted in Lesotho from February to August 2004. The study focused on the caregiving experiences of family members who became involved in home-based care after 2002, when this approach to care for patients with AIDS illnesses was formally adopted and appeared in policy documents in Lesotho (Government of Lesotho, 2002; MOHSW & WHO, 2002). The study participants were identified with the help of the hospital personnel responsible for HIV and AIDS counselling and testing in two hospitals. The hospitals maintained registers of the patients who were in home-based care within their respective health service areas (HSAs) and they provided information on the patients and where they stayed. The counsellors used the information to identify potential interviewees for the study and accompanied the researcher who was responsible for conducting the interviews to make first contact with the caregivers.

Purposive sampling was used to select the caregivers using the following criteria: (a) a current or ex-caregiver who provided care for a family member diagnosed HIV/AIDS positive at any one of the two hospitals, (b) care was provided at home, (c) caregiving was provided after 2002, (d) current caregivers who had experience of what was involved in home-based care, and (e) willingness to be interviewed at length using a tape-recorder. The study adopted a strategy similar to Taraborrelli’s (1993) study on Alzheimer’s carers, in which she discovered the value of interviewing current and ex-carers and realised that each provided different perspectives.

Setting

The study area comprised communities which received health care services from two hospitals both located in the Berea district in Lesotho – the Maluti Seventh-Day Adventist hospital – a church-owned institution – and a government-run district hospital. Maluti Hospital prescribed ARVs on the basis of the patients’ ability to pay for laboratory tests, monitoring and ARVs (Government of Lesotho, 2002b) at the time when government health care policy did not provide for ARVs in public institutions.

Sample

Twenty-one caregivers of patients who had been diagnosed with HIV/AIDS and received medical care which did not include ARVs from the two hospitals were studied. Twelve participants were identified within the Maluti health service area (HSA) and nine from the Berea government HSA by the counsellors, based on the criteria specified above. The caregivers resided in the peri-urban areas of the district administrative town and the rural villages of the district. There were five male and 16 female caregivers aged between 23 and 85 years. The ex-caregivers exited the role because the patients had died and there were instances where the patients died during the fieldwork. The caregiver relationship to the care-recipient included mother, father, grandmother, brother, sister, aunt, uncle, mother-in-law, son and daughter. Only three caregivers were informed by health care professionals about the HIV-positive status of the patients; most suspected the patients had AIDS-related illnesses. Most of the caregivers cared for one family member, but there were some who provided serial or simultaneous care to more than one patient at home. Five caregivers provided care for more than one patient in sequence, while four of the participants provided care for more than one family member simultaneously. They included a father who cared for his two teenage children and spouse; a mother for two daughters; and a grandmother who cared for two grandsons.

Although some participants reported caregiving which extended beyond one year, most caregivers provided care for more than six months but less than twelve months. The duration of caregiving was the time the caregivers spent as carers; it did not necessarily imply the duration of illness as the two tended to vary; in many cases caregiving was ‘delayed’. Also, the caregivers’ perspectives of the duration, as expressed in terms of the period spent in caregiving, differed from their subjective verbalisation of the time spent providing care. Most caregivers tended to preface their responses to the question on duration with ‘it has been for a very long time’ or ‘we come from far with X’ but these ‘lengths’ varied and were framed according to their experiences about caregiving, the intensity of the symptoms and care work,
and the outcomes of their actions. These descriptions were also linked to the metaphors of caregiving as a ‘journey’ and as a ‘battle’. For example, providing care for different patients simultaneously and dealing with complex symptoms were subjectively described as lengthy.

**Ethical considerations**

The research questions and methods of data collection were shared with the administrative officials at the Lesotho AIDS Programme Coordinating Authority (LAPCA) – the statutory body responsible for authorising research on HIV/AIDS in Lesotho; and the health authorities at the two hospitals. The health workers provided input to the approach of the study, by advising that the research should not lead to unintended disclosure of the HIV status of the patients, as they believed the patients had not informed their caregivers. They were informed that the research was for academic purposes, the findings would be published without revealing the caregivers’ identity, and they were free to refuse to participate or withdraw their participation at any point. The study was broadly introduced as intended to obtain their experiences about providing care for relatives at home without specifying the HIV status to the patients.

**Data collection**

The phenomenological method was used to obtain the perspectives of the caregivers about their experiences. The aim of the phenomenological method is: to determine what an experience means for the persons who have had the experience and are able to provide a comprehensive description of it. From the individual descriptions, general or universal meanings are derived, in other words the essences … of the experience (Moustakas, 1994, p.13).

The *epoché*, a requirement in phenomenological research, that researchers suspend or bracket their assumptions concerning the phenomenon being investigated was adopted (Cresswell, 1998; Moustakas, 1994). This allowed for an interviewing approach which did not impose assumptions and existing knowledge about home-based care, such as the close link with AIDS-related illness. All the respondents were interviewed in person in Sesotho by the first author.

The interviews were guided by the interviewer but were allowed to proceed in a conversational and informal manner. Interviews took place at the home where caregiving was on-going, or at the caregivers’ own home if they had exited caregiving. The decision regarding the venue of interviews was left entirely to the caregivers, and in cases where caregiving was on-going they opted to be interviewed in the presence of the patients; sometimes because they hoped to initiate or continue their dialogue with the patients about the illness or did not intend to cause them anxiety about the subject of the interviews. The interviews generated evidence in the form of first-person descriptions of life experiences in caregiving.

**Data analysis**

The procedure followed to analyse the caregivers’ experiences followed the phenomenological method adopted by Worthen and McNeill (2002) and Riemen (1998) in their studies on how individuals experienced supervision and caring interactions, respectively. The ultimate outcome of a phenomenological study according to Polkinghorne (quoted in Cresswell, 1998, p.177) is to: “produce a research report that gives an accurate, clear, and articulate description of an experience. The reader of the report should come away with the feeling that ‘I understand better what it is like for someone to experience that’.”

The following analysis and discussion of the caregivers’ experiences is intended to provide a description of what the interviewees went through in caregiving, and how social, medical and policy factors shaped their experiences.

**Results**

This section presents the caregivers’ experiences with some of the issues which they perceived as necessary elements of effective home-based care: availability of a suitable carer, knowing the patients’ diagnosis, availability of medication at home, and access to the hospitals for outpatient and inpatient care. Although the patients initially sought medical care from the hospitals on an ambulatory basis independently, their noticeable transition to poor health rendered the involvement of the family members necessary. The experiences of the caregivers with the physical changes which marked the illness of their relatives are discussed below.

**Delayed care**

Some caregivers knew only at a late stage about their relatives’ illness; they narrated stories about their ‘delayed care’. They blamed the patients for concealing the illness, and the other kin members who lived close to the patients for being unresponsive to the predicament of such patients:

*When she phoned my neighbour’s house she told me she still couldn’t go to work … she had been to the clinic and they were treating her; may be she would be better… I could sense that she was very weak and as we were talking she choked, coughed, until we terminated the call … She said she could still make porridge for herself but I felt she was not telling the truth … I was so worried (Caregiver 12).*
When I got the message, I could sense the seriousness of her illness even before I saw her... her in-laws didn't inform or request me to help her... there was no adult caring for her. I found that she was being helped by her son, that boy who you saw! ... I was touched when I found her because I could see that she was very ill ... She was already lying down ... I was shocked because I didn't expect that when you are told for the first time (Caregiver 8).

The caregivers' efforts when they assumed the caregiving responsibility included accompanying the patients to the hospital to obtain medical treatment, and negotiating what they perceived as appropriate treatment for the patients on the basis of their experiences at home.

**Diagnosis: the need to know and 'patient-doctor secret'

Part of the caregivers' action was helping the patients to obtain a diagnosis for the life-threatening illnesses which they experienced. The common view was that when illness involved HIV/AIDS-related diseases the doctors and patients managed this with secrecy, making it difficult to obtain information about the HIV diagnosis. However, they believed that at a certain point, it was possible to link the symptoms to HIV/AIDS, though medical confirmation was always necessary. This knowledge was experiential and obtained from public health information in the mass media:

*We hear it is a personal secret with the doctor, what we only see are the symptoms because we have been educated about AIDS symptoms ... people don't agree that they have it or even mention ... There is secrecy around HIV/AIDS and when people have it they will mention all the problems they have to the extent of saying it is a finger or a thigh or just body aches but they never mention that they have this infection* (Caregiver 1).

The caregivers perceived diagnosis as integral to obtaining and being prescribed relevant treatment. They could obtain free and effective treatment if TB was diagnosed. As a result, in some situations the search for a diagnosis did not dissipate. Their experiences when they tried to obtain medical diagnoses were one of the major themes in their narratives:

*When they diagnosed TB I told her, you are now cured. I was saying this because I knew for sure that this hospital is very good at treating TB ... Who am I to question what doctors and nurses who have been trained for years say? ... I just watched because they have this thing that their illness is a secret between themselves and their doctors. I respect it completely but it is painful to us who turn around with someone day and night and you don't know what to do* (Caregiver 2).

Some caregivers would not have a conclusive diagnosis until the patients died, others established clinical diagnosis late when the disease was advanced:

*We could as her caregivers want to know about her status and her doctors to know too so that they can care for her properly knowing what they are doing and why. That's what I am requesting. If there is nothing, then I will know that there is nothing ... What I think is that she can be taken to hospital and be checked, given medication and come back home so that we continue to assist one another -- the doctors and ourselves with caregiving* (Caregiver 8).

But all they did was to give us medicines and I don't know what it was for because even the TB which they suspected I don't think it was there because they did not tell us anything and they said the x-ray was not working. I think they didn't care if she died (Caregiver 9).

Efforts to obtain a credible diagnosis were part of the caregivers' perceived role, in order to help the patients obtain relevant medical care while at home. Some caregivers actually persuaded the doctors to review the earlier medical diagnosis when they continued to experience complex symptoms. HIV tests were also requested, especially when the symptoms caused suspicion or did not respond to prescribed medication, including therapies which were known to work, such as the six-month rifampicin based TB treatment. Three caregivers who requested to have the initial diagnosis reviewed, obtained information about the HIV status of the patients. They reported that following the review the patients' quality of care and outcomes improved. Their experience suggests that obtaining information on the HIV/AIDS status of the person being cared for freed caretakers from the search for a diagnosis, and allowed them to attend to the illness with assistance from the health care providers. The experiences of those who progressed from not knowing to being informed convincingly demonstrated the advantages of the latter situation:

*Every week there would be an episode ... After some time I decided that I should find the root cause of his poor health. I pursued this with the hospital staff and asked them to assist me; I could not understand what was happening. I asked them to do proper examinations and tests so that I could know exactly what I'm dealing with because I was wondering what is wrong with him. They examined him and they found out that he was HIV positive ... Since he started taking the medication which he started in 2002 ... he has stabilised a little, there are no frequent episodes, even though those that have occasionally occurred still frighten us, but at least we now know what we are dealing with* (Caregiver 5).
Disruption of medical treatment
Despite their belief that medication was integral to effective home-based care, some caregivers reported disruptions in the use of medication. This was because some doctors did not respond in a helpful and compassionate manner. A caregiver described her desperate attempts to ensure that the treatment was not disrupted:

I was used to a situation whereby we would go to collect her monthly prescription even before her tablets finished. But this 1½ dose, when I went they were already finished but I came back empty handed. I was forced to go to one family that I knew had a TB patient to ask for TB tablets. I asked for six red tablets … I didn't know what I was doing, I was anxious that she would spend days without medication but I did not know what would happen after these three days. I didn't know where I would go … she spent two days without medication and on the third day I went back to the hospital. But this time they agreed to give me the tablets. You see she had already spent these days without proper medication. I resumed the treatment but there was no use. What remains a puzzle is that this last packet which they gave me, said two tablets a day (Caregiver 2).

Similarly, when the patients had bouts of diarrhoea, the caregivers perceived it as embarrassing to use public transport. They preferred private transport, but this was unaffordable to most affected families. Some caregivers ‘delayed’ consulting hospitals with the hope that the symptoms would improve or helplessly watched “the disease finish” their loved ones, because their perception was that the hospitals would reject them anyway:

When we went so that she could be admitted and have a drip, they refused saying she would have to treat the diarrhoea at home first. What kind of hospital is that? … The nurse wrote a referral letter to the hospital saying that it seemed she did not have blood and water in her body system … he [doctor] read her health record book and it was clear that she had to be hospitalised, so when he suggested that she could be admitted. I had lost hope… She usually spends about 15 days there and comes back. She is usually better and can do a few chores (Caregiver 17).

In some situations, caregiving continued for extended periods without the use of medication, despite the patients experiencing severe symptoms:

There is no medication at all. All the medication got finished because she has now stopped seeing the private doctor who used to come here. Medication is finished because at the moment, she cannot get to the health centre or hospital, she cannot get to the bus stop, we are just watching her (Caregiver 8).

The need for hospitalisation
Severe illness intensified the role of the caregivers and the need for occasional hospitalisation. Some conditions caused anxiety because they disrupted care and interfered with food and medication intake, which they considered as necessary to life:

I wanted her to be hospitalised, this child was very ill. No sensible doctor would let such a patient return home. This girl couldn’t walk. And I told them that she was not even eating well (Caregiver 9).

I was saying she should go to the hospital because her skin has become very dry … I was hoping that if she went to hospital she would get a drip (Caregiver 6).

The caregivers considered hospitalisation when the patients experienced severe pain and life-threatening symptoms such as chest pains, difficult breathing, coughing, diarrhoea, nausea, STIs and vomiting. Under such circumstances, they consulted the hospitals with the expectation that the patients would be admitted. For the caregivers, hospitalisation was associated with positive experiences, because doctors treated problems which would not be treated if the patient remained at home:

They drained the water [from the patient’s lungs]. He spent three to four days at hospital … I found out when I got there visiting him that he was still in pain but feeling better, I felt encouraged (Caregiver 15).

Hospital X brought her life back given the way she was when she was first admitted. I had lost hope… She usually spends about 15 days there and comes back. She is usually better and can do a few chores (Caregiver 17).

Access to in-hospital care
The caregivers were generally aware that it was difficult to secure inpatient care, with non-admission and short stays common. But a few caregivers reported frequent readmission of the patients due to recurring illnesses:

The doctor had said whenever she complained about pain I must just bring her to the hospital … We kept doing this, until she said: mother now I am tired, it has been a long time since you started taking me up and down, just leave me as I am (Caregiver 9).

But many caregivers reported several attempts to obtain hospitalisation without success. Some were discouraged by the common perception that the hospitals were reluctant to admit patients who were highly dependent on nursing care or had diarrhoea. When the patients were not admitted, the caregivers felt rejected and this was experienced painfully, making them doubt the intentions of such doctors:
She was very weak ... they did not admit her, they gave her tablets again and we came back home, very disappointed. I could not understand how these people would not admit this child because she was very ill. I was angry ... It was painful, but I said that doctors know ... I had already heard the nurse and the doctor saying that there was no life in her, so I just thought that everyone was seeing it as a waste of time (Caregiver 12).

Some caregivers convinced reluctant care-recipients that hospitalisation was necessary and when they were turned down they felt powerless, and this situation created difficulties in care relationships:

I convinced her that if she could be admitted and get blood [transfusion] she would be better, it was my song everyday. I was disappointed when she was not admitted and I think she lost hope and that affected her badly ... When the doctor did not suggest hospitalisation I got discouraged, I wished I could say something, thereafter ... she spent most time sleeping (Caregiver 6).

Knowing patients’ HIV status improved access to medical care

Despite the general difficulties, in instances where caregivers identified the care-recipients as 'HIV/AIDS patients' they reported relatively easy access to medical care, which included free treatment of all the symptoms experienced and hospitalisation. However, TB patients with other complications unlinked to the TB diagnosis did not receive free treatment for the myriad symptoms they gradually experienced. This also happened if they developed other illnesses following discharge from the six-month treatment. Separate fees were charged for therapies meant to treat these 'extra' symptoms:

When she first became ill, we went from one place to another seeking help. A lot of money was spent. But at the moment it is better because the hospital is taking care of her, she is now the responsibility of government. When she is hospitalised or attends her check-ups we don't pay anything. She only paid when she had diarrhoea and was hospitalised for one week ... she does not pay for TB treatment and staying in hospital. But if she has other complaints and pains she pays for the medicines (Caregiver 17).

Where the HIV/AIDS status of the patient was shared with the caregivers, the health workers discussed the support available from the hospitals, and encouraged the caregivers to use the services. Knowing that the patients would obtain free treatment because they were diagnosed with HIV or TB was also an advantage, since the caregivers did not consider fees in their decision-making and it contributed to continued contact with the hospitals. The difference in the experiences of the caregivers below illustrates this point:

She became very sick again. I had lost hope completely. Since she does not pay any fees at the hospital, I just make sure that I get money for transport to the hospital and that makes life easy for me. She went to the hospital because at this time she was complaining about the genito-urinary system problems, she could not walk (Caregiver 7).

I had really wanted to take him to hospital at some stage when he started to show things which I had never seen – the diarrhoea worried me because although I tried to give him a hydrant solution I saw that he was losing lots of water. But I could not because I did not have money. The hospital was not telling people that when someone has this infection, the patient could be treated for free. We thought that he would need money to be admitted (Caregiver 16).

Informed caregivers were able to admit their patients whenever their conditions warranted it at no personal cost. They considered it helpful because apart from respite, the symptoms improved subsequently:

He's not on antiretroviral drugs. They treat the complaint that we present every time when we bring him, because he is affected by different illnesses. Sometimes he has acute respiratory problems with fever and he gets tired. And when he is like that we immediately take him to the hospital. Sometimes headache ... every time we notice something that bothers us we don't waste time, we take him to the hospital (Caregiver 5).

Discussion and conclusions

Effective home-based care depends on uninhibited communication about the patients' illness between the various actors involved in the provision of care in the two domains of care – home and hospital. It begins with the illness being brought to the attention of the medical doctors on time, and the doctors' diagnosis, prognosis, and prescription of realistic treatment options and, importantly, communicating these to the patients and their family members. Family members who are responsible for rendering care at home expect the health care system to augment their efforts and provide relevant treatment for the conditions which are brought to medical attention. Doctors assist the family members if they make them aware of the constraints which a particular diagnosis presents to medicine, the health care system and the support available under different circumstances. However, in the context of HIV/AIDS illness this normative approach to care is undermined by both medical and non-medical factors which form part of the care environment in the affected communities. One of the key elements of the HIV/AIDS care environment is confidentiality. As this article shows, how the health care providers manage this factor determines the experiences of the family caregivers when the patients with symptomatic HIV/AIDS are in home-based care.
The policy provision of a minimum package of care for PLWHA, even though it does not include ARVs, is appealing because it is presumed that there is universal coverage for all patients with symptomatic HIV. However, the studied caregivers did not have uniform access to medical care for the changing needs of patients. They had different experiences with access to medical care, despite reporting virtually similar illness patterns which prompted seeking medical care.

Mostly, the caregivers’ experiences varied depending on whether or not the health personnel informed them that HIV/AIDS was the likely cause of their relatives’ illness. Knowing that the patients were ill because of HIV infection was advantageous, and the caregivers who knew tended to express satisfaction with the informational and medical support they obtained from the hospitals’ personnel. They found hospital support predictable and responsive to the emergent needs at home. On the other hand, the caregivers who did not know ‘what they were dealing with’ had chaotic caregiving experiences. For instance, when TB was part of the diagnosis the patients obtained free TB treatment, but problems arose when TB patients experienced ‘extra’ symptoms or relapse, because the caregivers had to consider hospital fees and were charged for the treatment received. This means that the caregivers whose patients had other opportunistic infections besides TB faced severe financial constraints because they were not aware that the patients qualified for free health care services in the hospitals. Doctors would know that with HIV, the infections could recur; including TB which has been found to relapse following completion of treatment (Carter, 2007). However, health professionals’ concern not to contravene confidentiality once the caregivers are part of the patient-providers relationship is a challenge which can jeopardise the provision of treatment if not managed well. The practices followed should benefit the patients and their caregivers equally, by facilitating continued use of health care services and reducing preventable stress among the caregivers. Illness and the related incapacity show that human existence is inherently based on dependency and vulnerability which necessitate care by others (Bowden, 1997; Sevenhuijsen, 2003; Tronto, 1993).

The two points at which disruption in the patients’ provision of care are likely to occur suggest that it is not feasible to provide care within a confidential doctor-patient relationship for PLWHA and not involve family members. Firstly, disruption may occur when the patients become severely ill following periods of independent functioning which included seeking medical treatment on their own. Carricaburu and Pierret (1995, p.66) refer to being HIV-positive as “a situation at the risk of illness” but not being chronically ill yet, because people living with HIV may be asymptomatic. When some of the caregivers initiated caregiving, the patients were on medication but did not have suitable caregiving at home. This suggests that explanations to the effect that one of the main obstacles to home care may be the absence of willing and able caregivers (Williams, 2002) may be inadequate. Diagnosis with a chronic disease provides the opportunity to make such arrangements, and this is one area in which some of the healthcare providers were able to be facilitating when they involved family members. Akintola (2006) indicates that home-based care would benefit from hospitals making proper assessments of the homes before HIV/AIDS patients are discharged. Doctors would know that incapacitation was inevitable and that the patients would eventually depend on caregiving, while long-term hospitalisation would be difficult to secure.

Secondly, care was disrupted when the patients experienced acute illness or their condition deteriorated despite being on treatment or following completion of treatment. The changes entailed severe illness episodes which could be alleviated by occasionally admitting the patients. Again, the caregivers who knew that the patients were ill because of HIV infection reported that the patients obtained the needed medical care, as indicated by availability of medication at home and hospitalisation. These caregivers did not experience disruptions in the patients’ medical care following the HIV/AIDS diagnosis, while some noticed that the symptoms occasionally improved. As some understood the situation, the government was responsible for providing free treatment for HIV/AIDS patients. They also had the perception that the patients were admitted whenever they experienced severe symptoms, thus rendering this service predictable. They could claim the patients’ entitlement to “social care” (Daly & Lewis, 2000), and this seemed to influence how the hospital personnel addressed their needs over time.

Most caregivers who attempted to obtain admission for patients had poignant experiences. This happened for example in cases where caregivers returned with a patient from a hospital visit and, because the obviously sick patient had not been admitted, the community judged the patient to be suffering from AIDS, and stigmatised the carer and the patient. Carers reported frustration, anger, helplessness and disillusionment when the health care providers did not take their perspectives into account. Sometimes the patients were not admitted because of some of the symptoms which caused the caregivers’ anxiety. As Benjamin (1989) argues, access to health care may be improved by recognising that, although HIV/AIDS is a chronic illness, patients occasionally need acute medical care which requires hospitalisation. While most of them were never admitted, it was important that the caregivers who initially encountered similar problems realised that they established rapport with the health
professionals following communication of the HIV status of the patients and review of diagnosis, which in turn led to improved access to medical care including hospitalisation. In some instances, the caregivers did not have medical supplies or were prescribed obscure treatments which did not seem to take the caregivers’ perspectives into account. These experiences suggest that there was a risk that care services would be fragmented once the patients in home care were too ill. The findings also highlighted that there was another side to the relationship between frequency of admission to hospital and continuity. Contrary to Mainous and Gill’s (1998) observation that chances of future hospitalisation tended to be low where there was continuity of care with a doctor, the study suggested that non-attendance at hospital could also be the result of deprivation and poor service delivery which disrupted continuity.

Haggerty et al. (2003) conceptualise continuity of care as the delivery of services in a consistent and prompt manner, designed to meet individual needs over time. Integral to this approach is flexibility in the management of long-term care which is continuously adjusted and responsive to the needs of the patients and their families. These experiences support the findings that continuity existed when care for home-based patients did not involve extraordinary attempts by the caregivers and was responsive (Woodward et al., 2004). We need to consider that it is as crucial to have information flow between spheres of care, and communication among the actors involved in the management of chronic illness (Haug, 1994; Rajaram, 1997), as it is for continuity of care (Donaldson, 2001; Haggerty et al., 2003).

Similarly, Donaldson’s (2001) definition of continuity emphasises the role of information from a doctor in improving “goal alignment” between themselves and the patients. Donaldson’s agency model of continuity identifies acquisition of information about the patients’ needs and its correct use by clinicians in therapy as necessary for providing care that is responsive. This may imply that in situations where caregivers are patients’ ‘intercessors’, the information should be shared with them. Therefore, it is plausible that the caregivers who were informed about the HIV/AIDS status of the patients experienced satisfaction with the services, because the actions taken in the hospitals were in synchrony with their needs and they understood the prognosis. The caregivers who were of the view that their perspectives concerning the patients’ needs were disregarded, viewed the health professionals’ actions negatively, thus suggesting lack of goal alignment in their care situations.

In conclusion, the evidence from the study suggests that continuity of care for AIDS patients who depend mostly on home-based care and family caregivers for their well-being could be a challenge for caregivers in contexts where health care practitioners rigidly adhered to confidentiality, instead of providing counselling and encouraging shared confidentiality. The ways in which medical practice responded to the disease mainly reflect adaptation which was biased towards western medical values, while ignoring the local cultural context and the specific needs of the caregivers. The expression ‘doctor-patient secret’ communicated the discontent of the caregivers, who felt that they had to grapple with complex situations yet with limited information. In this way the medical approach alienated the caregivers, whose expectations to be informed about the nature of the illness were usually not met.

It is recommended that health professionals adopt ways of dealing with HIV/AIDS which empower families to deal with the epidemic competently and without exposing family caregivers to the risk of infection, and that would incorporate the potential caregivers in the doctor-patient relationship. There is an indication that patients benefited when doctors shifted from their conventional role as ‘curers’, and helped the patients and family members to deal HIV/AIDS openly, but there is a need to systematically study how various circumstances, including the age of patients and caregivers and their relationships, influenced the health care professionals’ decision about what was in the best interest of their patients. In the same way that delay in seeking medical care is undesirable, delay in the provision of lay care should be avoided.

Although the findings were based on a small sample, the external validity of these findings emanates from the ‘thick description’ of the care context and detailed quotes of the caregivers. The findings of the study will provide the basis for future research in comparable situations in sub-Saharan Africa. There is a knowledge gap regarding the demand and utilisation of inpatient care services as a resource for home-based care. These findings suggest that while the primary goal of home-based care is reduction of hospitalisation, there is also a risk that reduced utilisation might erroneously be attributed to functioning home-based care programmes, while in actual fact it conceals the unmet needs of the patients and their caregivers, especially in the context of inadequate medical treatment, including poor access to antiretroviral therapies.

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References


Submission of papers

The Journal publishes contributions in English and French from all fields of social aspects of HIV/AIDS (care, support, behaviour change, behavioural surveillance, counselling, impact, mitigation, stigma, discrimination, prevention, treatment, adherence, culture, faith-based approaches, evidence-based intervention, health communication, structural and environmental intervention, financing, policy, media, etc.). While the emphasis is on empirical research (qualitative and quantitative), the Journal also accepts theoretical and methodological papers, and review articles, which should not be longer than 8 000 to 10 000 words, in addition, short communications, letters, commentaries and book reviews. Priority is given to articles, which are relevant to Africa and the developing world and which address social issues related to HIV and AIDS. Special issues may deal with a specific topic, region or country. Submission of papers presented at the biannual International Conferences of HIV/AIDS and STI in Africa and biannual Social Aspects of HIV/AIDS Research Alliance (SAHARA) conferences are especially invited.

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