

AIDS-Related Stigma: Perceptions of Family Caregivers and Health Volunteers in Western Uganda

Walter Kipp, Department of Public Health Sciences, University of Alberta, Edmonton, Faculty of Medicine and Dentistry, 13-103 Clinical Sciences Building, University of Alberta, Edmonton, AB, Canada

Ellen Bajenja, Kabarole Research and Resource Centre, P.O. Box 782, Fort Portal, Uganda. Tel: 256-483-22045, Email: krc@iwayafrica.com

Ednah Karamagi, Kabarole Research and Resource Centre, P.O. Box 782, Fort Portal, Uganda. Tel: 256-483-22045, Email: krc@iwayafrica.com

Denis Tindyebwa, Makerere University, Medical School, P.O. Box 7072, Kampala, Uganda. Tel: 256-77-403178, Email: dtindyebwa@yahoo.com

Correspondence: Walter Kipp, Department of Public Health Sciences, University of Alberta, Edmonton, Faculty of Medicine and Dentistry, 13-103 Clinical Sciences Building, University of Alberta, Edmonton, AB, T6G 2G3, Canada. Tel: 780-492-8643, Fax: 780-492-0364, Email: walter.kipp@ualberta.ca

Abstract

This article reports the findings from a qualitative research study carried out in four areas in western Uganda. Opinions about AIDS-related stigma were elucidated from four focus group discussions with health volunteers of a home-based care program for HIV/AIDS and from 16 in-depth interviews with family caregivers of AIDS patients. While the health volunteers emphasized that AIDS-related stigma is still very strong, the family caregivers said that positive changes have occurred and discrimination against AIDS patients and their family members has eased. The difference in the perception of AIDS-related stigma between health volunteers and family caregivers needs further confirmation through additional studies specifically designed to answer this question. It should also be investigated whether the healthcare system itself contributes to AIDS-related stigma in this environment.

Introduction

Investigating the burden of caregivers for HIV/AIDS patients is especially relevant for sub-Saharan Africa, where the majority of persons with HIV/AIDS live. Here most patients suffering from clinical AIDS remain at home and receive either some care through home-based care programs or no formal healthcare services at all. This situation is reported by many authors, who stress the importance of family caregiving, especially in poor rural settings of sub-Saharan Africa where formal healthcare services such as home-based care are virtually absent (Robson 2000; Ntozi 1997; Chela et al. 1989; Reijer 1999). AIDS patients and their family caregivers in sub-Saharan Africa live in communities where much stigma surrounding HIV infection exists (Kalondo 1996; Anderson 1994).

Stigma often leads to social isolation and loneliness, not only for AIDS patients, but also for their family caregivers and other family members (Casaux and Reboledo 1998). This suggests that the AIDS-related stigma goes beyond the individual AIDS patient in that it affects all members of the household. Powell and others have shown in their North American study that most of the personal suffering by caregivers of AIDS patients was associated with AIDS-related stigma (Powell-Cope and Brown 1992). Information about how AIDS-related stigma adds to the high family-caregiver burden is not easily available from developing countries.

Stigma against persons with a certain medical condition has been widely described. The first examinations of disease-related stigma go back to the work in psychiatric hospitals in the 1950s (Goffman 1961). Goffman also first described "courtesy stigma," a stigma acquired as a result of being related to a person with stigma. Much of the stigma-related research was done in settings where mental disease and/or disabilities played a role (Angermeyer et al 2003). It is mostly within this context that courtesy stigma was described in families having a child with mental retardation (Green 2003). These studies emphasized individual factors of mental patients or disabled children. More recently, other work on stigma has emphasized less the individual factors and more the structural inequalities in the society in which stigma is embedded (Parker and Aggleton 2003).

The complexity of AIDS-related stigma has been described by Castro in Haiti, who pointed out how difficult it is to define (Castro and Farmer 2005). Castro has also emphasized the importance of examining the broader underlying societal factors causing AIDS-related stigma rather than the individual characteristics of AIDS patients and their family members. Reidpath stipulated that stigma associated with HIV/AIDS is not a singular entity, but is layered with other stigmas, such as those associated with the routes of transmission (e.g., sex work, injection of drugs) and personal characteristics such as race, religion, ethnicity and gender (Reidpath and Chan 2005). Songwathana observed from Thailand that limited attention has been paid to how AIDS-related stigma affects the processes and experiences of diagnosis, treatment, prevention and care for AIDS patients (Songwathana and Manderson 2001). As moral issues around sexuality are exposed, when somebody becomes visibly sick with AIDS it is easy to understand why other people react to AIDS in a judgmental way. It has been speculated that other obvious factors possibly contributing to AIDS stigma relate to the features of HIV/AIDS that people generally find very frightening (e.g., fear of contagion, early death in adults and transmission from mother to child). If this is true it would correspond with Reidpath's conceptual framework.

The difficulty of quantitatively measuring AIDS-related stigma in sub-Saharan Africa has been highlighted by Kalichman in South Africa, who stated that AIDS-stigma-related quantitative scales are not available or validated for Africa (Kalichman et al. 2005). This motivated Kalichman and colleagues to test an instrument in South Africa that was derived from a tool validated in developed countries. As AIDS-related stigma is regarded as one of the major barriers to developing effective preventive and care programs (Reidpath and Chan 2005), it is important to examine and follow trends in AIDS stigma. It is also important to determine how AIDS-related stigma evolves, how it changes during a successful HIV/AIDS control program (which has taken place in Uganda and in the study area) and how specific interventions can be developed to mitigate it.

This pilot study on AIDS-related stigma was part of a bigger study that sought to assess family-caregiver issues on a broad scale, measuring them in quantitative and qualitative terms. Our working

definition of AIDS-related stigma included issues surrounding discrimination and ostracism. Similar words exist in the local language Rutooro, and the concept of stigma is well known and understood in the local culture.

In western Uganda, care for rural AIDS patients is almost exclusively provided by family members in the home, since hospital access is very limited and costly. For example, in Kabarole district, one of the districts included in this study, 90% of the population lives in rural and/or remote areas. HIV prevalence is estimated at 14% in the study area, and some 6000–8000 AIDS patients require treatment with antiretroviral drugs (ARVs). The rural study area is typical for sub-Saharan Africa, with a high burden of infectious disease including malaria and tuberculosis. None of the homes visited during this study had running water or electricity, and most were poorly built. None of the care recipients in our study were being treated with ARVs. Health volunteers, who are selected by the communities, are part of the Primary Health Care program in Uganda.

Health volunteers are involved in several district health programs, for example, family planning, HIV/AIDS care, tuberculosis control (direct observed therapy, DOTS) and control of parasitic diseases. The volunteers we interviewed were part of the home-based care program for AIDS patients. The volunteers provided mainly homemaking services such as helping with cooking, buying food and child care, but they also provided basic patient care and HIV counselling for family members (after training in basic counselling skills). They visited a home based on the patient's need, usually 2–3 times per week. The average duration of one visit was around one hour. Volunteers were not paid salaries but received non-cash incentives from the Kabarole District Health Department.

Methodology

This study was designed as a qualitative study, as no validated tools were available to quantitatively measure the level of AIDS-related stigma. Sixteen family caregivers, whose care recipients were clients of the home-based care program, were included in the study. They were purposefully selected from a random sample of 120 caregivers, using a systematic sampling from all active client households of the home-based care program living in four sub-counties in Kabarole and Kamwenge districts. Only family caregivers with care experiences of one year or longer were selected from the list for the year 2003. We started at the beginning of the list, consecutively selecting those who qualified. Family caregivers were contacted by the research team and enrolled in the study if they voluntarily agreed. Of the 16 caregivers recruited, 12 were female and 4 were male.

In addition to the caregiver interviews, we conducted four focus group discussions (FGDs) with 18 health volunteers of the home-based care program for AIDS patients. Health volunteers were purposefully selected from the same four sub-counties where the caregivers were living. They were contacted by the research team after they expressed their willingness to participate. When they agreed to participate, they were enrolled in the study. Of the 18 health volunteers, nine were males and nine were females.

The topics of the in-depth interviews and the FGDs were designed to address issues identified through information from the literature, from local health workers, and from our own experience. For example, caregivers were asked questions about caregiving tasks, housing conditions, financial costs, relationships with the care recipient and other family members, relationships with service providers and issues surrounding AIDS stigma. Health volunteers were asked more general questions about AIDS-related stigma in the community, general attitude of families (public) toward AIDS patients, openness and demand for HIV testing services, and other issues around the care they provide in the homes of their patients. Discussion about AIDS-related stigma was covered in the later part of the interviews/FGDs in order to acquaint the interviewee/group with the interviewer while using less sensitive issues.

All in-depth interviews and FGDs were tape recorded after participants gave consent for recording. Tapes were transcribed word by word in the local language Rutooro. Transcripts in Rutooro were translated into English by an experienced language teacher and reviewed by a second interpreter. Qualitative analytical techniques included content analysis (theming, coding, catego-

rizing, abstracting). Abstracting was done by transforming data from individual instances to create general categories that were derived from the data.

One male and one female interviewer/facilitator with experience in qualitative techniques were trained to properly use the instruments of the study and received refresher training in qualitative interview techniques. Female participants in the in-depth interviews were interviewed by a female interviewer and male participants were interviewed by a male interviewer.

The study was approved by the Health Research Ethics Board (Panel B) at the University of Alberta, the Uganda National Council for Science and Technology, Kampala, and the District Directors for Health Services of the districts involved. Individual consent from all study participants was obtained with a signed consent form after an information letter was read to them. Interviews and FGDs were conducted at locations chosen by the participants in order to protect their confidentiality.

Results

Descriptive statistics for the family caregiver are shown in Table 1:

Table 1. Characteristics of family caregivers (n=16)*

Characteristic	Number of Caregivers
Age (Years)	
Below 40	5
41–50	4
Over 50	7
Sex	
Male	4
Female	12
Marital status	
Married	10
Divorced	1
Widowed	1
Single	4
Duration of caregiving	
Less than 2 years	4
2–5 years	6
More than 5 years	6
Relationship with care recipient	
Parent	3
Sibling	8
Spouse	3
Grand parent	2

*No percentages given due to the small sample.

Health volunteers were between 20 and 30 years of age. All have served as health volunteers for a period of one year or longer.

The following two major themes emerged from the interviews and discussions: 1) AIDS stigma still persists in Uganda, and 2) there is some hope as positive changes have occurred; for example, AIDS-related stigma has declined.

Sub-themes extracted from the transcripts follow.

Families' Fears about HIV/AIDS

Some health volunteers said that family members are worried about their involvement in caring for AIDS patients, not only for fear they will be infected with HIV, but also because of discrimination. Health volunteers also noted that they usually educate families about the prevention and spread of HIV/AIDS to allay any fears clients/caregivers may have. Health volunteers gave the following comments:

"...During home visits we find some patients have no care takers because of stigma, and they are alone. In such a situation the burden of cleaning the patient falls on us. We clean and even feed the patient."

"You have to assure them that this is like any other disease so, they have to be patient and understanding."

"Most of the family members are scared, as I told you, about stigma. The only thing we do is healthy education. We tell them that it is not AIDS; it's just like any other infection. It is just for reassurance that those people are trying to go over it. We explain how the infection is transmitted and how we avoid it."

Most health volunteers reported that stigma is still prevalent among many households and in the community, and this makes disclosure of the HIV/AIDS diagnosis very difficult. They said that stigma affects their work, as they also fear to discuss the diagnosis with the care recipients. To illustrate the problem of stigma, health volunteers reported that many pregnant women did not access services to reduce mother-to-child transmission of HIV because they feared their husbands:

"... There are times when we find a pregnant woman who does not want her husband to know that she is infected. If you tell her to go to the hospital and get drugs so her child can survive, she will not accept, however much you try to counsel her."

While all health volunteers thought that the AIDS-related stigma is still very strong, most family caregivers except two said that AIDS-related stigma has declined. These two family caregivers indicated their doubt as follows:

"... The truth is that a relative might not assist, but a friend or neighbour may be more helpful. Although the patients during the period of extreme weakness usually demand a lot of support and care, relatives will only come in after they have died."

"In fact the father gave assistance in terms of school fees, then after senior six she joined Institute of Commerce. There she got the disease and her father abandoned her, and she had to come to her uncle and I decided to start taking care of her, and when I meet the father he doesn't even greet me. We became enemies. But the problem is attributed by the disease."

Confidentiality of Diagnoses Is Emphasized

Health volunteers strongly emphasized the importance of maintaining confidentiality regarding HIV/AIDS diagnoses in order to make it possible for clients to keep their diagnosis private. The volunteers also said they cannot discuss the care recipients' HIV status with them unless they declare it on their own. In this regard, the volunteers seemed to overemphasize confidentiality issues in comparison with other prevalent infectious diseases, e.g., malaria, tuberculosis and even other STDs, where confidentiality was not seen as an issue. In addition to overemphasizing confidentiality, the volunteers also had an incorrect understanding of confidentiality, as they thought besides not talking to others about one's HIV diagnosis, it would also include not talking to an AIDS patient about his

diagnosis, as shown in the following comment:

“When he comes for counselling, we tell him that since he is sick he should not go for women as he might contact AIDS. He then asks you, you think I have slim (AIDS)? We do not tell him the truth because if he knows he will go ahead spreading it. We tell him that if he goes with other women he will die within a short time. He himself will tell us that he is suffering from slim. Then we tell him not to spread it.”

Risk of Suicide Is a Reality

Results of discussions also indicated that due to stigma, health volunteers reported to be afraid of counselling patients about their HIV positive status for fear that they might commit suicide, as shown in the following comments of volunteers:

“... A patient may come to us for counselling worried and dejected. Although we can see the signs of AIDS we fear that if we tell him that he has HIV/AIDS he might commit suicide or he might say, these people have no AIDS drugs so why should I go back.”

“We cannot directly tell the patients that they have AIDS, so we only advise them on reducing on their sexual contacts because it will weaken them further. We fear that if we mention that they have AIDS they will commit suicide.”

A More Positive Attitude toward AIDS Patients

Responses from family caregivers indicated that in general the attitude toward AIDS patients by relatives and friends has changed from highly stigmatizing to more understanding and sympathetic. A number of family caregivers said that relatives and friends now continue visiting the patient, although they do not provide a lot of support since they are also very poor themselves. In a few situations, caregivers said they are not close to their relatives, but the neighbours show love and care by coming to visit and sometimes pray with the patients and express their concern, as shown in the following comments:

“There is nothing like avoiding her, in fact the friends try to visit her and give her comfort, except the relatives don't mind about her.”

“They have no problem. In the past they would laugh at the patients, but these days at least every family has, even in any way or the other, faced the same problem.”

“Anyway there is no problem with them at all be in the bars or somewhere else. Sometimes friends assist me with money or drinks.”

“They have not changed much and they are not mistreating us in any way, but we visit them and they visit us as well. Even relatives have kept coming to see us.”

Family caregivers associated this change in reaction and attitude with the spread of the epidemic, since almost every family has now been affected by HIV/AIDS, and it is no longer new within their communities.

“Even if most of us have not gone for HIV testing, let us assume that the disease is for everybody because at least every family has been affected, and, currently at least, it is no longer talked about too much, compared to the past, as in 1988 and 1994. Nothing happens because people take it to be very normal compared to the past when people used to fear a lot.”

Overall, most family caregivers said that positive changes toward HIV/AIDS have occurred in this part of Uganda and that AIDS-related stigma is declining. However, there was not a single spontaneous comment from a health volunteer in this regard.

Discussion

Our study tried to elucidate information about AIDS-related stigma in western Uganda from a small group of family caregivers of AIDS patients and health volunteers involved in AIDS care in the home. Almost all participants (both volunteers and family caregivers) were generally very open about HIV/AIDS in the interview and focus group setting. This openness to discuss HIV/AIDS-related issues with others is a precondition for more effective prevention and care programs. Furthermore, more effective prevention and care programs are now available in Uganda in the form of free antiretroviral therapy and related services for AIDS patients, and these may in turn decrease stigma due to HIV/AIDS.

This was a qualitative pilot study with a small sample size and limited categories of participants. A larger, more representative quantitative study should be undertaken, including a greater variety of health professionals, more AIDS patients and their family members, and the general population. Although free antiretroviral therapy was not available during the time of our study, it is now widely available. Therefore it is realistic to assume that the HIV/AIDS stigma has declined on a wider scale since this study was conducted, because of the enormous benefits AIDS patients on antiretroviral therapy and their family members have experienced. The probable decline in stigma needs to be measured in a larger study area with solid methodology, and documented in detail. This would generate important new information on additional benefits of antiretroviral therapy that reach far beyond the health of individual AIDS patients.

It was also important to note that most participants expressed great interest in the discussion and said that they had never been asked about AIDS-related stigma; nor did they recall a similar study being conducted in their community. The open attitude toward AIDS may in itself be a small sign that in the group we interviewed, the stigma is now less of an issue than it once was.

It was interesting to find that most responses saying that AIDS-related stigma has declined came from the family caregivers, while none of the health volunteers expressed this opinion. We would have expected it to be exactly the opposite – that family caregivers would have stronger and more negative feelings than health volunteers about the stigma because they are the ones who directly experience it. We feel that responses of family caregivers, indicating they felt less stigmatization in the community, were very credible. It is not completely clear to us why the difference in responses in these two groups exists. One possible explanation could be a “staff” issue: the health volunteers identified themselves as more a part of the formal healthcare system than as representatives or advocates of their clients and the community. This “staff attitude” of health volunteers is also shown in their responses to some questions, which indicated that the volunteers themselves seem to treat AIDS patients as a “different” group of patients. We have seen circumstances where formally trained healthcare workers, who are usually the volunteers’ role models, have considered AIDS patients a “different” group of patients. Healthcare systems in many countries have treated AIDS patients differently from other patients in many respects, for example, by establishing special AIDS clinics and treatment centers, requiring special counselling skills in staff doing HIV testing, and demanding extensive and lengthy training and certification programs for staff distributing the new ARVs. There is also evidence from the literature that the healthcare system induces AIDS-related stigma (Kelly et al. 1987).

The difference in responses between health volunteers and caregivers raises the question of whether the health volunteers are sensitive to the changes occurring in homes affected by HIV/AIDS (e.g., that family caregivers experience and express a decline in AIDS-related stigma), or whether they represent the more conservative part of the healthcare system that still considers AIDS patients “different” and thus inadvertently may not help to reduce the stigma involved. The question of if and how AIDS patients are stigmatized by healthcare workers and the healthcare system should be

investigated in more detail in developed and developing countries alike. If stigma is mostly a health-care system problem, then it should be addressed by appropriate health system changes. For example, if found to be a staff attitude problem, then additional staff training and enforcement of ethical principles would be required. However, in either case this component of the AIDS-related stigma problem could be effectively and directly dealt with by the healthcare system itself. Introducing measures required to effectively solve these system and staff problems lies within the mandate and control of those who could really make a difference.

Limitations of the Study

1) Participants (especially the caregivers) were self-selected and using home-based-care services. This may have overestimated the reported decline in AIDS-related stigma, as caregivers who are not aware or not using services may be less informed and less enlightened about HIV/AIDS. 2) The small sample does not allow us to draw definite conclusions about trends in AIDS-related stigma. This would require a much larger and more representative study. 3) The discrepancy in responses between health volunteers and family caregivers on AIDS-related stigma could have been, at least in part, due to different data-collection modes, for example, in-depth interviews versus focus group discussions.

Summary

Family caregivers reported that they felt there is now less AIDS-related stigma than in the past; this is important to note, bearing in mind that the opinion comes from a very small, self-selected group. We did not find any published information on trends of AIDS-related stigma in Africa. This is somewhat surprising, as the literature clearly states that AIDS-related stigma is a crucial hindrance to improved HIV/AIDS control. It would be very important to investigate in detail how trends in AIDS-related stigmatization can be best measured and continuously monitored and why changes in the trend occur (Varas-Diaz et al. 2005). This could be done using some of the new tools available since we conducted our study. This knowledge would be crucial to improve the effectiveness of ongoing HIV/AIDS prevention and care programs. Since stigma research in HIV/AIDS has been carried out mostly in developed countries, more knowledge and understanding of this stigma is needed from the cultural context of developing countries in order to be more successful in HIV/AIDS prevention and care.

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