FAMILY SYSTEMS AND HIV/AIDS IN SOUTH AFRICA

J. Iwelunmor,
The Pennsylvania State University

C. O. Airhihenbuwa,
The Pennsylvania State University

T. A. Okoror,
Purdue University

D. C. Brown, and
The Pennsylvania State University

R. Belue
The Pennsylvania State University

Abstract

This study examines the role of family in the care and support of people living with HIV/AIDS (PLWHA) as a way of reducing the burden of stigma in the family. The PEN-3 model provided the cultural framework for this study. Data were drawn from participants' responses in 27 focus groups interviews conducted in South Africa. Participants were asked to discuss experiences of people living with HIV and AIDS in the family. The results highlight the positive and supportive aspects of the family, acknowledge the existential and unique aspects, and discuss the negative experiences shared by participants. This study's findings stress the need to take into account families' experiences with HIV and AIDS in the development of interventions aimed at reducing the burden of the disease on family systems and improving care and support for PLWHA.

INTRODUCTION

HIV and AIDS in sub-Saharan Africa has become a complex collective experience shared by many families and communities across the continent. According to a recent UNAIDS report, sub-Saharan Africa is home to almost 64% (24.5 million) of all people living with HIV. An estimated 2.7 million people in the region became newly infected, while 2.0 million adults and children have died of AIDS [1]. About 15 million children under 17 have lost one or both parents to AIDS, and if trends continue, it is estimated that close to 25 million children will become orphans by the 2010 [2]. HIV and AIDS in sub-Saharan Africa has grown to become an epidemic that affects the family as a functioning system, threatening its supportive capacity, and redefining the manner of coping and adapting to the burden of a disease. Research has shown that living with HIV and AIDS poses tremendous physical and psychological challenges for those who are infected, as well as for their families [3].

Studies have shown that it is the family, rather than the individual, that is affected by HIV and AIDS in profound and tragic ways [4]. The devastation of this disease has prompted

Direct reprint requests to: Juliet Iwelunmor, Ph.D., Department of Biobehavioral Health, The Pennsylvania State University, 315 Health and Human Development East, University Part, PA 16802, jialll@psu.edu.

researchers to re-examine traditional definitions of the family systems and to take into account the diverse social networks affected by this disease [5]. Family systems in sub-Saharan Africa share many similarities with family systems in India. Krishna and colleagues reported that in India, the family represents concentric circles of an individual's social surroundings and hold immense potential for strength and support during times of need and crisis [6]. A fundamental characteristic of African family systems and Indian family systems is the strong emotional ties that bind members together and promote sharing and mutual dependence [6, 7]. These bonds include not only biologic family of origin, but also extended family ties, which may include spouses, children, cousins, aunts, uncles, grandparents, close friends, and neighbors. African family systems tend to live in close proximity, with mutual commitment, acting as a corporate body with a sense of obligation toward members of the system [8, 9].

HIV and AIDS has devastating impact, rendering African family systems in crisis. According to Bor, not only is there potential loss to the family through illness and death, but there is profound economic loss in terms of productivity [10]. In a study conducted by Katapa in rural Tanzania, abject poverty was observed in some caretakers' households, as they had to sell family assets such as radios and cows in order to get money for buying medicine and other essential needs of PLWHA [11]. The epidemic of HIV and AIDS places a particularly heavy burden upon the caring capacity of the family systems so much so that as family systems adapt to HIV and AIDS, the subsequent death from this disease wears down household/family resources [12].

In Africa, studies on the impact of HIV and AIDS on family systems are sparse. While some publications marginally address the issue of HIV and AIDS and families, others simply ignore it. The available literature suggests that the HIV and AIDS epidemic poses a challenge to the family systems in the form of economic hardship by compromising household/family resources and generating new financial demands to cover medical treatment, health care, food, and funeral expenses [13, 14]. It has been reported that HIV is the fastest way for families to move from relative wealth to relative poverty [3]. In a study of 404 HIV and AIDS affected and unaffected households in South Africa, members of HIV and AIDS affected households had incomes and expenditures that were independently (14%–26%) lower than unaffected households [15].

In addition to economic hardship, HIV and AIDS disrupt family systems capacity to care. Family members face feelings and concerns similar to those of the PLWHA—fear, anger, shame, sadness, uncertainty of the illness process, and stigma associated with the disease [16]. Stigma often leads to social isolation and loneliness not only for the PLWHA, but also for the household caregivers [17]. Some families of PLWHA are often the targets of AIDS-related discrimination. In a study conducted in Nigeria by Alubo, Zwandor, Jolayemi, and Omudu, they found that when one member of the family becomes HIV positive, the whole family will be called an "AIDS family" by other villagers [18]. In a sense, the family cohesion that is a source of strength in good times often becomes devastating in bad times. This stigmatization has led many families to hide the truth about the illness or cause of death of family members with HIV and AIDS [19]. Some may shield a sick relative from the community for fear of shame and rejection by friends and neighbors.

So much concern and alarm have been raised about the burden of HIV and AIDS related stigma and the negative impact it has on prevention [20–22]. As the HIV and AIDS epidemic continues to escalate in sub-Saharan Africa, the care of PLWHAs can place a significant burden on family caregivers [23]. Given the paucity of a comprehensive analysis of data on the impact of AIDS on family systems in sub-Saharan Africa, the present study

examines family systems responses to HIV and AIDS in three South Africa Communities: Kyelithsha, Gugulethu, and Mitchell's Plain.

THEORETICAL FRAMEWORK

The PEN-3 model proposed by Airhihenbuwa is used as the organizing framework for this study [24–26]. This model was originally developed as a framework for understanding the health behaviors of persons originating from African countries [25]. This framework serves as a tool for thinking through cultural influences on health behaviors and planning culturally appropriate health education programs. PEN-3 addresses the cultural context of a behavior by applying the domains of cultural identity, relationships and expectations, and cultural empowerment to the development, implementation, and evaluation of health promotion programs.

The first dimension is the relationships and expectations dimension. We examined how perceptions of HIV and AIDS and those who live with the disease are enabled with family resources and nurtured in the family unit. The second dimension of PEN-3 is cultural empowerment. We examined the degree to which the three levels of relationships and expectations are positive and supportive of family members living with HIV and AIDS, existential in terms of maintaining family values, and negative in stigmatizing PLWHA in general and those in family in particular. Existential values refer to those cultural beliefs and practices, and/or behaviors that are indigenous to a group, which has no harmful health consequences. Airhihenbuwa suggests that these beliefs should not be targeted for change, but instead they should be incorporated to strengthen the intervention [26].

The third dimension, cultural identity, of PEN-3 helps to define the appropriate intervention entry point among family members to include a person, extended family, and neighborhood. It should be noted that the Cultural Empowerment and Relationships and Expectations domains are the "assessment" domains, while the Cultural Identity is the "application" domain that helps the public health researchers to assist the community with identifying the point of entry of the intervention.

METHODS

Focus group discussions were conducted among men and women over a one-year period in three different South African communities: Kyelithsha, Gugulethu, and Mitchell's Plain. A purposive sampling approach was used to identify and recruit eligible participants for the focus group interviews. This study is part of an ongoing capacity building HIV and AIDS stigma project in South Africa for Black post-graduate students in the University of Western Cape and the University of Limpopo. The study's content and process were explained to the participants in the regional language, and informed consent was solicited from them individually.

Sample

A total of 27 focus group interviews were conducted with 204 participants: 150 females and 54 males. Both people living with HIV and AIDS and their family members were interviewed to ascertain the impact of HIV and AIDS on family systems in South Africa.

Data Collection

Interviews were conducted by the post-graduate students and they followed an open-ended questions format. The focus group interview guide for this study consisted of six questions/ scenarios for 60–90 minutes. Probes were used during the interview as required.

Data Analysis

Audio-taped recordings from the interviewed sessions were transcribed and loaded into the NVIVO qualitative software package for data management. The software was used to arrange, code, and manage the qualitative data gathered in this study. The text analyzed with NVIVO consisted of the focus group script, moderator probes, and participant responses. Content analysis was employed to identify major themes salient to the context of family systems and the care and support for PLWHA. These themes were arranged according to the elements of the PEN-3 model.

RESULTS AND DISCUSSION

The following three predominant contexts emerged from the analysis of the focus group interviews: family systems as sources of support (evidenced from responses on positive perceptions, positive enablers, and positive nurturers); family systems as unique indigenous entities (existential perceptions, existential enablers, and existential nurturers); and family systems as sources of stress (negative perceptions, negative enablers, and negative nurturers). Consistent with PEN-3, we first present the positive, followed by existential before we present the negative. Each of the three themes is illustrated with quotes from the participants. We organize the quotes into one of the nine possible categories of PEN-3 analysis.

Family Systems as Sources of Support

Studies have shown that coping with HIV infection requires strong social and family support [27]. Strong families remain the first and best line of defense for caring for infected family members who are weakened or dying from HIV and AIDS [5]. Previous research studies have also shown that disclosure of HIV and AIDS status to family members' results in greater social and emotional support for PLWHA [6, 28]. Other studies have found that the support provided by family members make multiple levels of positive impact on both PLWHA and family relationships [29].

In South Africa, Montgomery et al. found that the HIV and AIDS epidemic influences family and household structures [30]. Family support for PLWHA in South African communities was delivered through existing kinship structures, a notion concurrent with previous research on family responses to AIDS [6, 28]. Findings from the focus group sessions centralize family systems as sources of support. Families demonstrated remarkable capacities to adjust to the burden of AIDS by readily providing PLWHA with support during the disclosure process, full homecare support, support for daily activities, monetary support, psychological support, and emotional support. *Positive Perception* underscores many views expressed by participants regarding family support and care for PLWHA. The results of our study indicate that disclosure of one's HIV and AIDS status is an important part of coping with the disease and ensuring family support for PLWHA. One participant reported that it is easy for families to help and support PLWHA when they learn the truth about their status.

> It is easy to support them if a person has told the truth you see. He must come to the family and tell you that there is this and this so that you know that I am going to support there. It becomes easy when they tell the truth nothing hidden as a parent in the family. So that you are able to know that this one has a certain thing such kind of a problem. You will be able as a family to see that OK we can help and support in a certain thing, etc.

This level of support is still based on an expectation of openness and trust among family members. Findings from a study on HIV-related stigma in South Africa found that social support, particularly when it relates to disclosure of one's status, can buffer the stress

associated with living with HIV and AIDS and promote a sense of emotional well-being [29]. One focus group participant shared this sentiment:

> Personally I think in a family setting you need to be strong in order to disclose your status so that you can be eligible to get necessary support from them, i.e., love, appreciation, consistent discipline, because in my case my big brothers called me and they have assured me of their support that I am not alone and to my surprise I never imagine such a respect.

It is important to note that with the disclosure of HIV and AIDS status, family systems adjusted with the crisis of HIV and AIDS by readily providing full home-based care support instead of hospital-based care. The World Health Organization (WHO) defines home-based care as care given to the patient within his or her own home by either formal or informal caregivers. According to WHO, the care aims to maximize patients' quality of life, health, and functioning through appropriate, quality care that is cost effective [31]. Evidence from the focus group sessions suggested that families were the first-line of home-based care support for PLWHA:

> I also want to agree, because HIV positive people do get support and my mother's sister passed away with HIV positive. She was getting a full support in such a way that according to her she should have gone to hospital and die there but they did not allow that at home. They did not want her to die at hospital instead she must stay here at home and get support to be fed and supported in everything.

With home-care support for PLWHA, family members were supportive in PLWHA daily activities. They provided PLWHA with food and warm clothes. They also bathed PLWHA and reminded them to take their medications.

> In my case I had no problem because my family was supportive for example before I knew a lot about my status they used to reprimand me with the way I was using alcohol but now that I know my status and they also know they talk differently now they talk right and nice and even if it's cold they will say do not go outside its cold, go and wear warm clothes, would also remind you to drink your pills, so I would say they are supportive.

One of the characteristics of African family systems is the notion of emotional commitment to deep mutual bond for its members. One participant suggested that even with the advent of HIV and AIDS:

> If your family if you've grown up to be close to each other and things like that, and caring and supporting, I don't see that HIV must take away that bond you know.

Overall, most of our focus group participants suggested that family systems were supportive of PLWHA.

> My family is very supportive. They treat me as normal.

> My life didn't change because the support I got from my family.

> I have a sister who is back at home she get a full support at home.

> I do get a support at home and there is my older cousin who is also who not staying with us in the house, he does get a support also.

> My family is supportive to me because, it has managed to pay me a visit whilst I was in hospital and they also came to fetch me when I was discharged. My aunt also stood on my behalf when I was supposed to get [Igranti] social welfare grant.

As family systems adjust to the care and responsibility of PLWHA, participants highlight the specific roles of *positive enablers* as resources for family systems to cope well with the PLWHA. Some doctors readily provide help to PLWHA and their family members.

> When I went on the treatment for two weeks I was very sick and my doctor came in and the whole weekend I was at trauma and he helped me and so on and he spoke to my husband as well about it and he sent him for testing and I told him we use condoms and he sat with us and spoke to us and I told myself. I got married in 2003 and I was open and he understood and sometimes when I don't feel well he helps me. He's always there to help me even my children and my family.

According to the UNAIDS 2006 report, churches and faith-based organizations, especially in the developing countries, were among the first to deliver treatment, care, and support for people living with HIV and AIDS [1]. In South Africa, one participant reported that a church readily contributed to the AIDS response by asking members to provide support for PLWHA.

> Help for instance at my church there was once an announcement to request people who have AIDS or poor than we do. This was to be done every Sunday that everyone should bring to church whatever she has its either a teen of fish or spaghetti, there is a bin organized for that purpose to throw to even clothes if one has something that you are no more wearing it you also bring it ironed.

In addition to positive perceptions and positive enablers, participants reported forms of *positive nurturers* when they cite examples of how family members were supportive to PLWHA by accompanying them to support groups and clinics. While the highly stigmatized nature of HIV and AIDS can hinder a family's ability to provide care and support for family members living with HIV and AIDS, participants described family systems in South Africa as mutual entities that provide love, hope, and support for PLWHA. These characteristics of family systems are exemplified in the following participant responses:

> Personally my family does support me to an extent that they even go to support group with me to listen and even when I'm using my medication they monitor me even times and they even remind me and take my messages when I'm not around to my friends.

> They love you, when you go to the clinic they accompany you and are not ashamed of you.

> Another thing attending a support group with the family, other people do not have families others find that they go with members of their families and when they go home they are not alone they talk about these and help us there is the role they play in the support group.

> When I found out I was HIV positive my mommy was very supportive by coming with me to find out more about HIV and AIDS and how she can assist me with whatever things I need. When this place was closed we used to have the support group at our place and that also showed that she accepted the fact that I'm HIV positive. She always want to learn more about my sickness.

Family Systems as Unique Indigenous Institutions

HIV and AIDS is a disease that affects the entire family system. Despite the growing burden of this disease on family systems, families in South Africa remain remarkably resilient in determining existential ways to cope with HIV and AIDS. In South Africa, the impact of HIV and AIDS affects societies across all generations, affecting both grandparents and young children. Family systems with certain *existential perceptions* in South Africa remain

the best line of defense for adjusting to the burden of HIV and AIDS. They organize family meetings to understand HIV and AIDS as well as to counsel other family members about its consequences. In these examples, participants cited specific unique indigenous capabilities of family systems in South Africa:

> And if it happened that someone disclosed his HIV status, [we] arrange a family meeting and discuss as to counsel him.

> You … if you are the family that are believers sometimes you counsel your selves. You call a meeting for your own benefit and give advises to each other as these things are preached in our churches every day you understand.

According to participants, family systems provided support and help for PLWHA through sponsoring community funeral scheme.

> We receive support from the family because they pay funeral cover for the community funeral scheme (umasigcwabane). Because in future you are able to get help. They buy you things when they come back from work because when you have this thing there are times you do not want to eat what other are eating.

As South African families adapt to the growing epidemic of HIV and AIDS, acceptable definitions of traditional African family systems are taking into account the diverse social networks affected by the disease. Participants cited forms of *existential enablers* by reporting that HIV and AIDS counselors and health-care workers function as family members because they provide support for PLWHA.

> My counselor, that is now my friend also, it is like she could see me as … for who I am … and with everything I spoke to her about and told her what I was going through, she sort of went through the same, and you have to have somebody to motivate you into something or otherwise you will just sit back also…. I mean, she had supported me in a lot of ways….

> Health employees have treated me well, because I would come and eat the tablets, then when we leave they would give us porridge from there so that when you arrive at home you will first have to eat that porridge and then drink the pills, but you have already eaten the porridge you can eat them on your own.

In coping with the disclosure of HIV and AIDS status, *existential nurturers* were expressed when mothers of PLWHA dealt with the news by adhering to the deeply embedded cultural practice of telling other family members about problems within the family system. Also, in an attempt to ascertain who in the family was most supportive, participants were asked to whom did PLWHA first disclosed their positive test and what was their reaction. Most participants reported that they disclosed first to their mothers:

> I disclosed to my mother. She was worried so that she was the one who disclosed to my uncles, so my uncles when they come to the house they do not want me to leave. Normally when they come to the house I will go to the other room and do my own things because I do not want to be part of adult's conversation but on this day they came and were asking me questions making empty conversation I knew from that, that I had been discussed and they were now here to see how I am.

> I told her (my mom) first. I don't know maybe it was because she's a mother and I know she's always trying to protect and I don't know who else I must tell because I trusted my mom. And I just think she must be the first person to know these things and I was thinking that I'm going to die within that week. I was scared if she can find out when I'm in the coffin. The best thing is I must tell her today. The whole family learnt to know.

Family Systems as Source of Stress

Stress is a common manifestation of the psychological impact of HIV and AIDS on families [9]. Stress is reported to be commonly seen in family members who may react to news of diagnosis with disbelief, shock, and confusion [28]. It was found in other studies conducted in South Africa that disclosing one's HIV status is not always in one's best interest, as it can lead to rejection, abandonment, and other sources of lost social support [32]. In more recent studies, it was found that AIDS patients and their family caregivers live in communities where much stigma surrounding HIV infection exists [33]. Stigma inhibits families from providing adequate support, it reduces the quality of life for PLWHA, and it often leads to social isolation and loneliness, not only for people living with HIV and AIDS, but also for their families [34, 35].

While the results from the focus group interviews suggest that family systems were sources of social support, as well as other institutions like the church, they were also perceived by some participants to be sources of stress. Despite the positive and existential (unique but supportive within the cultural contexts) ways of coping with HIV and AIDS, participants reported that HIV and AIDS negatively impacts family systems capacity to care and support family members living with HIV and AIDS. Participants reported that HIV and AIDS affected families in devastating ways as PLWHA lost family members because of their status. Other aspects of *negative perceptions* were expressed for instance, when families became secretive about HIV and AIDS because of fear, shame, and ridicule.

> Uhm as I said it was something that came very unplanned and to me it feels that it took away so many things, you know, it it had brought a lot of losses with it, because you lose parents, you lose your children, you lose family members and friends, people that is close to you.

> To me as a young person living with HIV, its just still so confusing sometimes, you know. Because you know if you grow up you've got your own dreams with your future thinking. I mean when we grew up we grew up with your parents at home and all that and so you believe that one day I have to be a wife and I have to have children and all those things, you know. And when I actually found out that I'm HIV positive, it was like HIV just took that away, you know.

> Another thing that makes people to be silent or secretive about AIDS is that, in some families people don't like to disclose as to ridicule their families. In some families are rich so then they can't say anything that involve them in HIV/AIDS infection because my family will be disgraced.

The impact of HIV and AIDS on families is compounded by the fact that many families live in communities which are already disadvantaged by poverty, poor infrastructure, and limited access to basic services [36]. Participants also reported a degree of concern related to lack of government grant for living well with HIV and AIDS in the form of *negative enablers*. According to the South African government policy on disability grants for people living with HIV and AIDS, PLWHAs only qualify to receive the grant when they are in stage four of the disease (CD4 counts less than 200). Loss of the grant presented financial difficulties for families, particularly with the loss of family income and the provision of nutritious foods. In addition, some participants reported not knowing about the policy and only discovering they are no longer eligible when they reported at the Social Development office:

> And the one thing that also I want to raise is that fact that Government is giving the grant for HIV positive people and disability people. The rules that they have now that people have to be under 200 before getting the grant. I mean how are we gonna survive when our CD4 count is lower than 200? That is like leaving us without any income like some people at the present moment. Now how are we gonna survive if

we need to eat healthy. How can we eat healthy if we don't have an income if we are not working?

Yes, I'm working here, I do earn a salary but that salary ain't enough and with my CD4 count which is above 200 I'm not qualifying for the grant but I do get sick in the meantime I have to go and see the doctor and if my CD4 count is below 200 then I don't qualify but with the income that I get where I stay, without the grant the money that I'm earning, how can I survive at the end of the day.

If the grant is going to be discontinued, they must give you a notice. In September last year, I was not informed that my grant will be discontinued. When I went to get the grant, Social development said my name had been erased. The Doctor told me that one only get a grant if in stage 4.

Findings reveal *negative nurturers* when family members face complex problems in their adjustments and coping with PLWHA. Family systems experienced ongoing stress as they sought adaptive ways to deal with the news of HIV and AIDS diagnosis. Some participants reported feeling stressed and rejected by family members as a result of their status:

They stress the person, they do not give them time, they do not treat them well, they want to hide the person, they do not wash the person, they hide the person, they gossip, talk about, you can hear the family talking about you to other people sometimes lies and you do not live right you are free.

But it's difficult even the rejection at home, you know if you're a child and your mother is expecting everything from you and you gonna do something at the end of the day and then you. Then you tested HIV positive, your mother will be angry and other ways can be anger, shock so psychological it does work on you, you think about your mother, you think about your children and your anger and, and you think about those things. Is she gonna be able to look after my child if one day I die, you know, so that 's how it is.

One participant reported that constant dispute with a family member was debilitating as family systems provided no support for PLWHA:

A constant dispute with your parents is a debilitating factor for somebody who is HIV positive and that should not be the case, but you find out that they don't support you and it is a problem to a larger a extent that they don't even eat your food you have cooked.

As HIV and AIDS exacerbate ongoing stress and tensions with family systems, participants reported that some family members were fearful and worried about susceptibility to HIV infection through contact with PLWHA. Two participants reported that their fathers threw them out of the house because of perceived susceptibility to HIV infection. One of the PLWHA reported feeling depressed as a result of the actions of their father:

After disclosing in 2004, and then what happened was she got drunk, and after getting drunk she actually sweared me and say "You must leave my house, take our clothes and go, I don't want you here in my house. You've got AIDS and you gonna give us AIDS" and that was two o'clock in the morning and then at seven I got up, packed my clothes and I went to stay with a friend of mine.

And he said "I don't want to see you anymore because you have AIDS and I feel like the ground can open and swallow me because his friends were there." Everyone was there and he was shouting and he started throwing my clothes out. He said because I have AIDS I'm going to infect all of them. And I was crying because I didn't know what to do because everyone, the neighbors was out. He was shouting and saying, "she's got AIDS," and my mother was crying. My sisters were

crying and I didn't want to go out. He pushed me to go out. My mother was very angry and she phoned my sister in P.E. And she was angry and said I must come and live with her. And from that day I suffered from depression because I was thinking because my father threw me out and I thought I was going to die and I didn't have another hope.

CONCLUSION

HIV and AIDS continue to affect entire family systems in South Africa so much so that when a family member is diagnosed with HIV and AIDS, the impact radiates across the entire family system [28]. In Africa, HIV and AIDS has become a complex collective experience shared by many families and communities across the continent. A major concern is that the persistence of HIV is eroding many positive cultural and traditional responses to coping with illness and diseases [25].

The burden of HIV on families notwithstanding, many families continue to support their relatives living with HIV and AIDS in many different ways. Consistent with findings from previous studies [14, 32, 37], participants in this study reported receiving care from family members as well as necessary support, love, appreciation, and hope. Other supportive institutions for PLWHA and family systems were clinics, churches, and support groups in the communities. In all, family systems were described by participants as mutual social networks that provide love, hope, support, and stress for PLWHA.

Although the sample strategy, geographical area, and self-reporting may limit generalizations, this study yields important insights on the impact of HIV and AIDS on family systems in South Africa as described by participants. Overall, findings from our study suggest that family members face complex challenges in their adjustments to having a family member living with HIV and AIDS, as they seek adaptive ways to deal with the news of HIV and AIDS diagnosis. These adjustments can be either positive in supporting PLWHA or negative, as family members become fearful and worried about susceptibility to HIV infection through contact with PLWHA. These findings stress the need to take into account families' experiences with HIV and AIDS in the development of interventions aimed at reducing the burden of HIV and AIDS related stigma in the family and improve care and support for PLWHA.

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