Community-Based Care for People living with HIV and AIDS: Motivations of Voluntary Caregivers in Bulawayo, Zimbabwe

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Abstract

During the past two decades, the public healthcare system in Zimbabwe has increasingly deteriorated to the extent that it is near collapse, as some observers argue. The deterioration of public healthcare coincided with a dramatic increase of people living with HIV and AIDS. It is estimated that currently about 15% of the adult population are HIV-positive. The public healthcare system , overwhelmed by the growing demand for their services, encouraged the formation of groups of voluntary home-based caregivers. Local communities, with the support of national and international organizations, responded and initiated groups of volunteers to serve as a link between the public healthcare system and people living with HIV and AIDS. In recent years, many of these groups have collapsed, due to the lack of funding and other types of support. Our paper is based on systematic observations of voluntary caregivers' groups , interviews with volunteers, and the use of methods common in cognitive anthropology (freelists and pilesorts) in Bulawayo, the second largest city in the country. The paper pays close attention to the motivations of volunteers, an issue often overlooked and not well understood by observers. While macrostructural issues, such as economic and political problems, are obviously threatening the survival of community-based caregiver groups, the motivations of volunteers are additional factors explaining the collapse of such groups. Our research suggests that volunteers tend to regard their care for people living with HIV and AIDS as a kind of "social capital," as defined by Pierre Bourdieu, and exchange their service for prestige in the neighborhood, that can quickly be translated into local influence. Further, the volunteers own experiences with pain and suffering as well as their religious affiliation strengthen their commitment to support neighbors living with HIV and AIDS. Our paper argues that volunteers' motivations can easily be addressed by policy makers as well as national and international organizations, increasing the likelihood that these groups continue to provide care to individuals living with HIV and AIDS.

Full Text (citations and bibliography were removed from the text)

Introduction

This paper is based on research conducted in summer 2001 and the whole of 2003 in Nkulumane, a low-income residential area in Bulawayo, the second largest city in Zimbabwe. We use the term "township" in this paper that refers in southern Africa to low-income residential areas. Follow-up research was done during June and July 2009 at two municipal Bulawayo clinics and in the townships in which they are situated: Magwegwe and Emakhandeni. Within the overarching approach of participant-observation data were systematically collected through various interviewing methods, conducting a survey to a randomly selected sample of a section of Nkulumane, and using freelists and pilesorts with convenience samples of residents in Nkulumane, Emakhandeni, Magwegwe, and faculty and staff at the National University of Science and Technology. The survey data have been analyzed through bivariate analysis using SPSS. The freelist and pilesort data were analyzed using multidimensional scaling, hierarchical clustering, and quadratic assignment procedure with two software programs, Anthropac and UCINET. Interview data were analyzed using Open Code 3.4, a text analysis program, following the "grounded theory" approach. The various analyses inform this paper though we generally do not explicitly refer to them. The original research questions were relatively unrelated to the theme of this paper but the research processes yielded additional data on which this paper is

based. Data were collected by groups of assistants and us with the support and approval of the Department of Health Services at the Bulawayo City Council. Dr. Zanele Zwalima, MD, Director in 2009, was instrumental in obtaining official permission for this study.

During the various research stages, voluntary home-based caregivers spent many days with us walking through the townships to visit homes of individuals living with HIV and AIDS. They organized in-depth individual and group interviews with them, including individuals on antiretroviral therapy – ART – as well as other township residents. The conversations with these voluntary home-based caregivers, their caregiving motivations rooted in religious beliefs and practices, and observations from their caregiving activities and participation in church associations represent the main body of data on which this paper is based.

Home-Based Caregiving in Zimbabwe

In Zimbabwe, where about 15% of adults are estimated to be HIV-positive, home-based care programmes, also called community-based care programmes, play a vital role as an overwhelmed public health system fails to cope with the demands of the HIV epidemic. Across southern Africa, these programmes aim to provide a continuum of care for both patients and families, addressing their material, physical, psychosocial, palliative and spiritual needs. In their ideal form, they consist of formal and informal components. The formal part comprises healthcare professionals who admit patients into the home-based care programmes and, when the need arises, carry out home visits. The informal component is represented by family members who are the principal caregivers for AIDS patients at home. Groups of trained voluntary caregivers link the formal and informal parts of home-based care, mediating between the clinic and the home, while providing basic in-home care for people living with HIV or AIDS.

In the early 1990s, groups were formed in Zimbabwe in response to the call for home-based care programmes and over the years the government has developed policies, standards, and training manuals for home-based care. The growth of such groups has resulted in the discharge of increasing numbers of AIDS patients to be cared for in their homes. Despite substantial efforts, former Minister of Health and Child Welfare David Parirenyatwa admitted that the overall impact of home-based care programmes has not been satisfactory, mainly due to a lack of resources. For patients in Zimbabwe, ‘home care’ often means ‘home neglect.’ Since the early 1990s, the programmes have become increasingly dependent on churches, non-governmental organisations (NGOs) and community resources, with only minimal material and financial support from the government or the international community.

Home-Based Caregiver Groups in Bulawayo

Various home-based-care programmes that were operating in Bulawayo townships sought to address the needs of households with people living with AIDS. The voluntary caregivers had been trained by a municipal community nurse, the Red Cross, or other trainers provided by faith-based organisations and were organized in various groups, which often operated parallel. During the initial years, the Ward AIDS Action Committee (WAAC) was supposed to coordinate and supervise these groups as well as organise the disbursement of government funds to them. However, the WAAC was generally ineffective, inefficient and lacked significant involvement by members. Furthermore, politically motivated individuals dominated the group and used the committee as a venue to strengthen their influence in the

township. Subsequently, the voluntary care groups operated independently and did not pay much attention to the WAAC, which failed to coordinate the efforts of the various voluntary caregiver groups and the healthcare professionals at the local clinic. In 2009 none made a single reference to the organisation during our interviews. Mor recently, voluntary home-based caregiving is being coordinated through the local clinics. Even though different organisations train the volunteers and may keep separate organisational structures for their volunteers, the actual caregiving is now organised at the clinic and according to the areas served by the clinic. Volunteers now meet regularly at the clinic, receive more training from health workers, are given information about patients who are sick, are asked to follow-up on these patients and then give feedback to the clinic personnel. Most of the home visits by caregivers follow a specific pattern: providing some material, spiritual, and psychological support to patients and their families. If clients had not been seen by a doctor for a long time, the caregivers provided them with a voucher that entitled them to a free consultation at the local clinic. If clients could not afford to send their children to school, the volunteers contacted a municipal programme that assists children from low-income households to go to school. If one of the parents had passed away, the children were enrolled in a supplementary feeding programme. Since the roll-out of free treatment programs in urban areas, the number of such extreme cases has been signficiantly reduced and the voluntary caregivers are more involved in supervising the treatment process in homesettings and reporting back to the clinic.

Churches and Home-Based Caregiving

During interviews with township residents, it emerged that churches and voluntary caregivers who are encouraged by their churches to volunteer are greatly appreciated in the community, as the following representative quote from an interviews shows:

> Churches provide psychological healing, give encouragement to the sick not to lose hope and not to die before their time. Within churches there are dedicated home-based caregivers who attend to the sick.'

This perception that churches support and encourage people with AIDS and that churches motivate their members to volunteer caring for those struck by this disease is widespread and matches our observations. The reasons to volunteer are plentiful and range from an expectation to benefit through the access to resources available to volunteers, the hope to gain some sort of employment in the civil or NGO sector, the aspiration to exchange time and energy into social capital (Bourdieu 1986), to a desire to increase visibility in the township that can be translated into political power. However, our observations of and conversations with volunteers suggest that for the majority of them, religious motifs drive their volunteering, which are nurtured by their membership in particular churches and religious organizations. Most volunteers tend to be committed members of their churches as well as actively involved in associations within their churches. This was also recognized by some of the NGOs involved in home-based caregiving. The director of one small, local organization that provides counseling services to people living with HIV and AIDS explicitly mentioned that most people involved in voluntary caregiving are members of various churches, which encourage their members to care for the sick. The focus of our paper is not on individual believers' faith but on religious organizations and networks that shape and determine to some degree the specific form or their beliefs and the resulting practices. To include a discussion on how the beliefs and practices of individuals alter religious organizations and networks would go beyond the scope of this paper.

References to health, illness, and healing are frequent in the services, church gatherings, prayer meetings , and informal conversations among church members. The biblical quotes pertaining to Christ the healer, the curing power of the Holy Spirit, the significance of health, illness, and healing in the biblical texts, and healing miracles in the Scriptures and other traditions are well known to them. During prayers the following references are frequently made:

- "Nkulunkulu, usisilise" – God, heal us
- "Somandla, pholise ubuhlungu bazalwane bethu" – Almighty, soothen the pain of our brethren
- "Jesu, msilisi wethu, beka izandla zakho phezu kwethu" – Jesus, our healer, lay your lands on us
- "Yehla, Moya ongcwele, yelaphe izigulane zethu: - Holy Spirit, come down to heal our sick.

We would go so far as to say that the centrality of such references in collective and individual prayers indicate that health and healing are central to Zimbabwean Christian religiosity and that the vitality of churches depends to a large extent to how they integrate healing into their beliefs and practices.

Church members not only regularly pray for health and healing but also spend a substantial amount of time visiting the sick in their neighborhood in groups (**Slide 2**). This is not a particular mark of Christians but also an important aspect of the general local way of life. Thus, the not only do this as an expression of their faith and to represent a religious group, but also as relatives, neighbors, and colleagues. This is also socially reinforced through beliefs that someone who does not care for a sick individual in his or her social network may be somewhat implicated in the genesis of the disease. The structure of their prayers as Christians is comparable across different religious groups, despite the obvious denominational differences: after entering the home of a diseased person and greeting everyone present, a hymn is sung emphasizing human suffering and God's healing intervention. Then one of the leaders starts to pray that may involve physically touching the sick person, at times shaking the patient, possibly indicating the divine force that can move and heal the sick person. Others may follow to pray and touch the patient. Another hymn is sung and the prayer ends informally chatting with the sick individual and all others present. Even when some material help is offered, the main emphasis is on prayer, on what we could call, spiritual healthcare: assuring the sick person that God can heal him or her.

However, the centrality of healing in religious groups is not unproblematic when addressing HIV/AIDS: (1) because of particular explanations of the epidemic and (2) because of some views on preventing an infection with HIV commonly mentioned in prayers and preachings in various churches.

First, it is common to hear among committed members of Christian groups that the AIDS epidemic is the result of the imminent Apocalypse that was triggered by our immoral behavior. Sheunesu Shumba, a local artist, carved a figure of a preacher announcing that the end of times has arrived (**Slide 3**) and that we all need to convert (1) as individuals and live according to the moral guidelines of the faith if we want to aovid an HIV infection, and (2) as a collective if we want to prevent the annihilation of life as we know it.

The survey data from a randomly selected sample of a section of Nkulumane township, which is representative for townships in Bulawayo, indicates that this message has been readily accepted by many. 43.7% of the 486 respondents (n=213) agreed with the explanation that "The End-of-Days has arrived and AIDS is the proof." 32.2% (n=157) agreed with the statement that "God punishes us for our immorality and other sinful behavior." The interpretation of HIV/AIDS

as divine retribution is also evident in the pilesort data analysis. 482 respondents were asked to group together items that were mentioned during freelistings as associated with HIV and AIDS, that, in their view, somewhat belong together. The multidimensional scaling plot closely relates PFSIN – punishment for sins, with GOD, and LOFAIT – lack of faith (**Slide 4**). This association is even more evident in the hierarchical clustering plot representing the same data, which indicates that God and punishment for sins are very strongly related and somewhat related with lack of faith (**Slide 5**).

The association of HIV/AIDS with transgression of morals and values is frequently expressed by church leaders and preachers during services but also through publishing texts in the mass media. For example, the Catholic priest Fr. Jerome Nyathi published a couple of poems on HIV/AIDS, such as *Ngiyakuthanda Aids*, which literally means "I love you AIDS." I quote some verses from this poem in English:

> I love you, for you say we should keep tradition.
> For you say we should love and respect each other.
> Yes, respecting the well of life.
> I love you AIDS for you humble the proud.
> You straighten the thugs.
> Oh, live with me AIDS!
> Those you take, AIDS, you take them to the Promised Land.
> The land that was built and promised for us.
> You only do what you where sent for.
> I love you AIDS for you don't discriminate.
> Surely you don't choose whether young or old.
> Your only commandment is one, "Control yourselves."

This poem echoes what is being said from many pulpits, during prayer meetings, and in informal conversations: the epidemic was sent, implying sent by God, to remind us of the value of inherited norms, the value of "self control," referring to the need to restrict sexual expressions within marriage. Those who are too too "proud," referring to those who do not accept prescribed rules and norms, will be humbled, through an HIV infection. Those who are "thugs," referring to those who deliberately transgress these rules and norms for their own benefits, will be straightened out, becoming HIV positive. The poem also indicates the tension in many Christian organizations which oscilate between rules and norms for sexual behavior and showing compassion for the sick. Nyathi writes that those who die of AIDS will be taken to the Promised Land, will be saved even though their earthly life is taken. Overall, such messages are highly problematic as they reduce the various modes of HIV infection to a single one: sex, and more specifically sex that transgresses values and norms. In other words, an HIV infection is the fault of the infected and the result of sinful behavior. Subsequently, the stigma of the epidemic is reinforced through the association of HIV/AIDS with immoral individuals, promiscuity, prostitution. Not surprising, AIDS is sometimes also called "umkhuhlane wokuwula," whoring disease.

Another problematic issue arises when religious organizations are involved in disseminating messages aiming at preventing new HIV infections. In southern Africa, the most widely known prevention approach is the so-called ABC model: (A) abstain if you are unmarried, (B) be faithful if you are married, and (C) use a condom if you cannot abstain or be faithful. While religious groups generally readily accept the A and the B, they tend to reject the C. This, however, destroys the model which integrates value-based interventions with other

interventions and gives people the choice to select a prevention method that makes most sense to them at a given time. Some within churches even alter the meaning of this ABC model to match their views on AIDS prevention. We observed a workshop attended by a church youth group. The instructors taught the participants a radically altered ABC: (A) abstain, (B) be faithful to this commitment, and (C) change if this you have difficulties adhering to this commitment. Condoms were totally eliminated in this revised model. As such an approach does not consider the context within which decisions on sexual relationships are taken and disempowers individuals to choose what makes most sense to them at a given moment – to choose either A, B, or C, or something else for what matter, it is highly problematic and potentially exposes individuals to a higher risk of getting infected with HIV.

The question, however, is if such church teaching is really significantly influencing behavior. During our years of research and living in Zimbabwe, I have often been confused by contradictory statements uttered by a single individual about one and the same topic. Knowledge is not absolute abut knowledge-bound. What makes sense in one context is irrelevant in another context. This explains why someone may express support for the churches rejection of the use of condoms when asked in a church-related or other context, but has no problem to positively view the use of condoms in another setting, e.g. at clinics. Most township residents are somewhat affiliated with one of the many churches operating in the area, many of them condemn the use of condoms. However, their views and arguments differ when asked in a different context the same question. My most recent research indicates that the association of abstinence and marital fidelity with HIV prevention is weak compared to safe sex, the use of condoms. The multidimensional plot representing the 25 most commonly mentioned items associated with HIV by 174 respondents show that clearly (**Slide 6**). The hierarchical clustering plot shows it even more clearly that HIV prevention is strongly associated with safe sex, but only weaker associated with abstinence and even less with marital fidelity (**Slide 7**).

When probing individuals' views on such issues, they initially repeated the official mainstream view but had more complex and different views when the abstract doctrine was applied to certain situations. For example, we asked one women about causes and contributing factors driving the epidemic. She mentioned that AIDS is sent by God and punishment for our sins. Later in the conversation, when we discussed illness in her family and neighborhood, she "contradicted" this general explanation of HIV/AIDS. She said that she cannot understand how our loving creator will punish us so severly with sending a terminal disease. Isn't God merciful and forgiving, was her rhetorical question at the end of the interview. Such evidence, let's us cautiously conclude that religious teaching does not have a significant impact on the beliefs about the AIDS epidemic and the sexual behavior of people. But this does not make it less problematic! And there will always be some who strictly follow church teaching that potentially harms them and others.

To sum up: religious organizations provide the bulk of voluntary home-based caregivers. They encourage their members to care for the sick. However, they also contribute to the stigmatization of HIV and AIDS through associating infection with sinful behavior and compromise prevention efforts through demonizing condoms. Fortunately, there is evidence that people, when explicitly asked about HIV and AIDS, that they tend not to follow this particular church teaching.

While some doctrine preached from the pulpit seems, fortunately, not very influential for personal understandings and most likley also sexual behavior – for what we do not have data, the value and potential of religious organizations for HIV/AIDS campaigns and particularly care is

somewhere else: in the various associations within the churches, particularly women's association whose members represent the majority of volunteers. In much of southern Africa, Thursday is the day when church women meet. This day was traditionally the day off for domestic workers. Particularly women dressed in their uniforms that identify them as committed members of their churches can be seen in the townships on their way to homes where someone is sick or in hospitals. It is not uncommon that ministers of religions with groups of women visit hospital wards, surround the beds of their church members, and pray for them accompanied by singing. Health workers tend to accept this as part of the curing process and only intervene if the prayers get too rowdy. In hospitals and homes of sick individuals in the townships, you see the Methodist women in their red and black dresses, the Anglicans in their dark-blue and white dresses, the presbyterians in their black and white dresses, and the Catholics in their beige and brown or light-blue and white dresses, depending on the association to which they belong. The pattern of the dresses is often identical, at least among the more traditional missionary-based churches consisting of a hat, a blouse, and a skirt (**Slide: St. Anne**).

Prayer and preaching are an essential part of the meeting and usually touch issues of importance to them, including the sickness of some of their members and how individuals responded to it. Generally, the different groups representing the association report back to the association about their activities. Where a voluntary homebased caregiver group is established at the local church, the members who are volunteers also report about their activity. Usually practical things are being discussed from how many sick individuals they have visited, describing their caregiving activities, and so on. The women present generally cheer the volunteers for what they are doing and motivating them to continue. The volunteers gain respect among their peers for what they are doing but also the association is gaining respect in the eyes of the local church community because of their involvement. The association gains status within the church through their commitment to voluntary caregiving. This status gives them also a stronger voice within the church community to push their agendas within the local church. To say it with Bourdieu: the volunteers as individuals and the association as a whole gain "social capital" which can be used like any form of capital. Obviously, such an interpretation only captures a few notions of the caregiving dynamics within churches. To gain social capital through caregiving is not the primary goal of why associations' members engage in caregiving. They do so because their faith encourages them to do so, because of cultural expectations to show concern for the sick, because of social pressure within their association to become somewhat involved, because of their personal history, and so on.

Conclusions

While the bulk of the voluntary caregivers are women within such associations, their motivations for caregiving are not yet sufficiently studied (see Mahilall 2006). To understand why they commit themselves to volunteering has become an important issue during the past few years. During the past years volunteers' commitment to caregiving has diminished mainly due to the stigma of HIV/AIDS, lack of funding, and volunteers' 'burnout' (Rödlach 2009). When motivations are better understood, attempts can be made to strengthen these and to counteract the decrease in commitment to volunteering. Based on my research, I would suggest the following.

First, governmental and non-governmental organizations need to directly engage church communities and their leaders in discussions on voluntary caregiving, despite their ambiguous and problematic role in HIV/AIDS work in other areas. Particularly the healthworkers at local

clinics should communicate with pastors and visit church communities, especially the women's association. Though clinic healthworkers are already burdened, they are more likely to engage these groups because they are from a comparable social background and many of them are actively involved in their respective denomination. In addition, they tend not to be so prejudiced against churches and their teachings as international NGOs who generally find it difficult to work with churches. The focus of the communication should be on showing appreciation of what church members are doing with regards to caregiving. Further, discussing the religious messages that nurture caregiving which will result in a literacy of this language among caregivers as well as strengthening positive messages of caregiving. Through such communication, problematic elements can be downplayed and may decrease in importance in preaching over time. All this togther could strengthen the commitment of volunteers in churches to provide care.

Second, health workers need to be better trained to work with volunteers without feeling intimidated by their involvement in healthcare and viewing them as competitors. Observations of the interactions between health workers and voluntary homebased caregivers suggest that there is a tendency of health workers to not to accept the volunteers as an integral part in the provision of healthcare to people living with HIV and AIDS. In the past nurses also did outreach and visited the homes of sick individuals. Due to the shortage of nurses and funds for outreach, this is commonly not done any more. Volunteers fill this void, but particularly nurses feel that this would be their task, which they are unable to do. Volunteers frequently commented that they are not treated as equal partners in healthcare. It is likely that this uneasy working relationhip with the clinic personnel contributes to the large drop-out rates of volunteers. Clarifying the relationship and more fully integrating them into the care continuum could positively impact the caregivers' motivations and their commitment to provide care.

Third, communicative spaces should be established where volunteers are shown appreciation. Though volunteers feel appreciated in their associations and churches, more explicit expressions of gratitude for what they are doing could strengthen their commitment. For example, healthworkers at the clinic, local politicians, and others could regularly organize events to thank the volunteers. I observed that caregivers were organizing a memorial service for those in their groups who passed away in the previous year. No healthworker and no politician was present. None provided them with a culturally appropriate meal for such events, such as cornmeal porridge with choumollier and beef.

To sum up: During the past years, many voluntary caregivers stopped their volunteering. Though the reasons are many, one way of reducing drop-out rates and strengthening the commitment of the volunteers is to better understand their motivations and to design interventions to boost these motivations. As many volunteers are committed members in their churches and religious associations and conceptualize their service in terms of religious beliefs and practices, understanding and supporting these motivations is of utmost importance but is addressed only marginally by governmental and non-governermental organizations involved in the care of people living with HIV and AIDS.