

Double Jeopardy: HIV-Positive Wives Caring for Their HIV-Positive Spouses in Accra

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Abstract

Given improved medical treatment, AIDS seems no longer like a death sentence in many countries. AIDS patients live longer and are expected to be given the necessary care and support. This study explored the experiences of HIV-positive wives caring for their husbands living with AIDS. Using a qualitative method, 15 semi-structured interviews were conducted with women living with HIV/AIDS selected from the Fever Unit at the Korle-Bu Teaching Hospital in the Greater Accra Region of Ghana. The study revealed that although participants demonstrated their willingness to give quality care, care experiences were closely linked to available resources. In other words, care was perceived by all participants as being synonymous with availability of family resources. Insufficient resources (especially in terms of energy and financial resources) hindered the quality of care provided to HIV positive husbands. The challenge of insufficient financial, time, energy and other resources placed a lot of physical, health, economic and emotional burdens on participants and this affected their capacity to engage fully in daily activities. In conclusion, experiences of wives caring for their husband with AIDS influenced care practices in the home. Insufficient resources (especially in terms of energy and financial resources) hindered the quality of care HIV positive wives provided to HIV positive husbands. It resulted in a compromise of adequate and quality care not only to the sick husband but to the children as well. In the light of these findings, it was recommended that there should be sensitization or education on effective Family Resource Management; stigmatization and fear of HIV/AIDS by the Family and Consumer Sciences Outreach Program, HIV/AIDS advocates, Ghana Health, Ghana AIDS Commission and other relevant stakeholders Further research could also be conducted using a larger sample size to gain insight into the challenges of HIV positive wives when caring for their HIV positive husbands.

Keywords: HIV, Wives, Husbands, Care

1 Introduction

Due to advanced antiretroviral treatment, persons with AIDS (PLWHA) live longer than in the past (UNAIDS 2010). Women with HIV/AIDS suffer the most because although they are infected with the virus, they still have to perform their traditional role of caring for the general welfare of the family (Ogden, Esiem & Crown, 2006; Tuyizere, 2007). The family (a basic and economic unit) in Africa plays an important role of providing family care and support therefore they are a valuable resource in times of illness. Although in many African households, people receive care and support from the extended family, Luker (2004) and Radstake, (2000) contend that the amount and kind of support available can be limited by factors such as poverty and the degree to which other kins believe they are obliged to assist a sick person. It has been observed that as a result of stigmatization and fear of being infected by HIV/AIDS, most family members do not give the necessary care and support to meet physical and financial needs of their sick and infected relations. The performance of this role is left mainly to the nuclear or immediate family members to perform. In the case of HIV positive women, these women exhibit the symptoms of HIV yet they still have to care for their HIV positive spouses and the rest of the family.

In terms of care delivery, Barnett and Whiteside (2002) explained that, the home is a very important environment for care and at the same time, a setting in which serious challenges arise. Obviously, these challenges are multifaceted and interrelated and they tend to impact on women's ability to provide quality care (Shaibu, 2006). Women are usually overwhelmed by their primary responsibility to care for loved ones suffering from multiple opportunistic infections in such comprehensive AIDS. The women still perform their duties of showing affection, offering precious time, managing financial resources, preparing meals, caring for children, and taking care of their own personal needs and that of their sick spouses. Studies indicate that AIDS care requires substantial practical support in performing daily activities like: bathing, lifting, washing of clothes, changing bed linen, and toilet visits, administering medications and accompanying to clinics for reviews (Chepngeno-Langat et al., 2009; Savundranagam & Montgomery, 2009). In the case of bedridden PLWHA, care demands increase thus putting excessive pressure on women (Chepngeno-Langat et al., 2009; Savundranagam & Montgomery, 2009). This situation is even worse if the woman or wife is HIV positive.

Another challenge experienced is low income and difficulty to access rented accommodation (Kipp et al., 2007). In certain families, the woman has to take over the bread winning role because her husband is sick with AIDS. Thus the income received by the family is inadequate. Such women's care burdens become complex yet they lack adequate resources and are often insufficiently prepared for this new and complex role of caring for PLWHA in the home (Gilks 2001; UNAIDS, 2010). These women are also confronted with psycho-social trauma in addition to their economic burden (UNAIDS 2008). In addition to practical care demands, these women experience financial shock because opportunistic infections associated with AIDS are expensive (D'Çruz, 2004). A study by Coa et al., (2010), reported that women caring for their chronically ill husbands typically experienced a decrease in physical and emotional function which affects their capacity to engage fully in daily activities. More importantly, since a greater percentage of women who test positive usually have only one partner, they feel betrayed by their spouses unfaithfulness and victimized in the sense that their husbands were often aware of their HIV status but did not take the necessary precaution and as a result they have been infected (Ogden et al., 2006). Studies indicate that inter-partner transmission is common; they are facilitated by the fact that most men do not voluntarily test for AIDS (VAT) until they are plagued by recurring opportunistic infections and are requested by a medical doctor to do the test (Akintola, 2002; Seeley, et al., 1993) Thus, most men infect their partners before they get to know their serostatus.

Other studies demonstrated that chronic ill health of spouses creates immense stress related challenges even among the financially secured families (Kipp et al., 2007; Knowlton, 2003; Mwinituo & Mills, 2006). These women saddled with financial burden induced by AIDS care, coupled with the physical demands of care, tend to experience poor health (Kipp et al., 2007). The onset of the disease in the family therefore triggers a sense of uncertainty as to how the family would meet the additional financial obligations that come with the disease. The debilitating nature of AIDS therefore continues to devastate families and deplete family resources in many homes in Africa (Rakodi & Nkrunzizah, 2007; Azwidihwi & Kyngas, 2009; Mieh et al, 2013).

2 AIDS Care

It was observed by Radstake (2000) in a study that the extended family support for relatives who suffer from AIDS is gradually diminishing because of general economic hardship and stigmatization associated with the disease. A study by Mwinitwo and Mills (2006) confirmed this assertion. They indicated that as a result of stigmatization, caregivers have to deal with embarrassment that comes with the disease, thus they 'hide' AIDS patients from other members of the society. Consequently, AIDS affected nuclear families live in isolation and therefore receive very little support from their relatives or members of the extended family (Mwinitwo and Mills, 2006). The bulk of care burden therefore rests on the shoulders of women (spouses of PLWHA) who have to manage household resources, such as fetching water, engage in other domestic activities and care for their sick husbands (Ardayfio-Schandorf, 1993; Oppong, Oddotei & Oppong, 2006). In Ghana, Anarfi (1995) noted that much of what is known about AIDS in the family particularly caregiving and resource accessibility is largely anecdotal. This study therefore tried to fill this gap in research by exploring the experiences of HIV positive wives caring for their husbands with AIDS.

3. Research Questions:

The research questions that guided the study were:

1. What experiences are associated with AIDS care?
2. How do wives use family resources during care provision for their spouses?

4. Methodology

4.1 Setting, Participants and Procedure

Using qualitative methods, direct observation and 15 in - depth interviews were conducted with HIV positive women who were caring for their HIV positive husbands. These interviews were conducted as part of a four-year research with the purpose of understanding the experiences of caregivers of people living with AIDS. The actual number of people interviewed was based on the principle of saturation (Cobin & Straus, 1990 and Charmaz, 2008). This means, data collection started with the first participant and continued until no fresh category of information emerged from the interviews. Thus, by the time 15 people were interviewed, there was no new information emerging so a point of saturation was reached and the interviews ended. Women who accompanied their husbands to the out-patient clinic of the Fever Unit at the Korle-Bu Teaching Hospital were selected purposively. During a brief eligibility meeting, the women were briefed about the purpose of the study. Informed consent was obtained from those identified as eligible for the study. An eligible participant was: a woman, who tested HIV positive, was a wife of a care recipient; was living together with an HIV positive husband in the same house; and provided continuous care to her HIV positive husband for at least one year. A date and venue for the

interview was arranged with respondents. The participants provided their residential contacts and phone numbers and actual interviews were conducted in their homes. The interviews were recorded with a voice recorder and noted down manually.

4.2 Data Analysis

There are many ways of analyzing qualitative data among which is the use of the Grounded Theory Approach. This approach was used because a social process (HIV positive wives caring for HIV positive husbands) in which there was little information was being studied (Corbin & Strauss, 2008; Charmaz, 2008). Analysis involved concept development, coding of data, summarizing data by reducing it into underlying themes of the research. The transcribed interviews were first hand coded and manually analyzed to draw out themes or main ideas related to the phenomenon under study. The data were further reviewed and combined into broader categories in terms of main variables. The information was then ordered, reduced and classified or coded, displayed, summarized and finally interpreted. During the entire process, ideas, preliminary assumptions and theoretical reflections, referred to as 'memos' were noted. The lived experiences were fully described and verbatim quotes used to illustrate participant's views.

4.3 Ethical Consideration

Ethical clearance (Clearance Certificate Number IRB 0001276) was obtained from the Ethical Committee of the Noguchi Memorial Institute for Medical Research (NMIMR) of the University of Ghana in September, 2009.

5. Results and Discussion

The main result of this study were presented and discussed based on the following themes: dimensions of care; managing resources; care perceived as synonymous with resource availability; care being obligatory; and the 'give' and 'take' of care.

5.1 Demographic characteristics of respondents

Participants' demographic information presented in Table 1 indicates respondents were in the prime of their life. Their ages ranged between 27 and 4 years. Most of them had basic levels of education. These women were sole bread winners of the family. Participants were mainly self-employed and engaged in a variety of small scale businesses that generated meagre profit or income. This income was inadequate in meeting family needs mainly because of the escalating financial expenses associated with HIV care. Those who had children above 10 years said their children sometimes assisted with the sale of their wares.

5.2 Dimensions of care

Opportunistic infections associated with AIDS were varied and debilitating and required that sick persons be supported with intensive care tasks. Care activities participants provided to their sick spouses included: food preparation, bathing, dressing, lifting, accompanying spouse to clinics, changing bed linens and administering medication. Participants' description of care tasks were consistent with those described in other AIDS situations in Ghana and other countries (Radstake, 2000; Anarfi, 2001; Atobrah, 2009; Chepngeno-Langat et al., 2009; Savundranagam & Montgomery, 2009). The participants talked about persistent tiredness due to the combination of care duties. It was further inferred from interviews that as a result of their ailment, respondents were unable to perform household chores like they previously did. Participants reported that they struggled to balance the new demands of care with their personal care and health challenges. The difficulty to balance personal care with physical demands of care was compounded by emotional challenges resulting from their HIV serostatus, how they were infected, the feeling of being victimized and also from not having adequate resources such as money to take care of family expenses. These findings were confirmed in a similar study by Ogden et al., (2006). These are some statements by respondents relating to dimension of care:

"Since the doctor told me that I have the germ in my blood, I've been very worried and I get tired all the time. Although I take my drugs, there are days that I feel like I will die before my husband, I just don't let him know what I am going through." (P2)

"Sometimes, I don't know where to start from, the housework never ends. The disease changes so the care activities also changes." (P5)

"This disease is strange because the condition is changing all the time. I have to change the way I do things depending on how he feels, so, I can't do what I'm used to; everything is different now, even the food." (P15)

"I have to wash spoilt linen all the time but look, water id difficult to come by. I spend the little

money I have to buy water so sometimes the food is not enough. I have to keep the house clean.”
(P6)

In sum, most participants indicated AIDS care was complex and care duties were overwhelming because of their health condition. The participants explained that their children assisted with some household chores but they took full responsibility of direct and primary care for their sick husbands. This compounded their problem because they also had to take care of their health needs. Participants further explained they had difficulty balancing care and personal needs, were worried and mostly emotionally stressed. The prevalence of stress related challenges among caregivers of HIV/AIDS was also realized in other studies (Mwinitwo and Mills, 2006; Knowlton, 2003; Kipp et al, 2007; UNAIDS, 2008). These women experienced a decrease in both their physical and emotional abilities and it affected their capacity to engage fully in daily activities. This situation was also realized by Coa et. al, (2010) in a study.

5.3 Managing Resources

Participants reported that practical care depended on the availability of resources. They indicated that by the time the disease was diagnosed, family resources especially financial resources were completely depleted. Most participants' husbands had no life time savings and investments because most of it was used for medical expenses. Other resources lacking included: time, information, knowledge on care, and inadequate housing facilities (such as room space, lack of ventilation and toilet facilities). These are some statements related to the management of resources.

“Since my husband stopped work, I am the only one who provides for everyone in this house. I sell fruits and we eat some so sometimes the seed money gets finished and I have to borrow from friends and relatives. I want to do my best but I don't have money. If I get, I will do it better.”
(P7)

“Although I'm sad that he brought this disease into this house, I'm happy that I'm strong and able to help him at home so that people will not point fingers at us. Money is difficult to come by, if I get I will be better”
(P4)

“Look at our situation, let me tell you, if you don't have money to buy things to use in the house, people will think that you're not caring for the sick person so, money is the main resources.”
(P10)

“Money is caring as I've told you. The doctors tell us to eat plenty of fruits and vegetables but you know these things are expensive so we eat what we can afford. I use beans and green leaves all the time.”
(P9)

“As you can see, our situation is bad, our children are living with their grandmother. I always borrow from my church members and some give us gifts”
(P1)

“Sometimes I am weak but I try to sell things so we can buy food and medication.” (P12)

“See, this is where we live. We've lived here for 4 years. The room is very hot as you can see. Most of the evenings, I leave the sick person in the room and sleep outside on a mat for some fresh air although the mosquitoes bite me out there. We have a ceiling fan but we can't use it because the landlord has disconnected our source of electricity supply because for some time now we've not paid our bills. If we're able to save some money at the end of the month, we will pay our electricity bill and will be able to relax in our rooms. At the moment we can only think about money for food and drugs.”
(P6)

Running through these statements is the issue or theme of lack of resources. It could further be deduced from these themes that: most participants homes lacked resources especially money; caregivers felt money could solve all problems including health problems; and they could not give what they did not have.

5.4 Care perceived as synonymous with resource availability

All participants equated caring to the availability of household resources, particularly money. Most family resources according to participants were scarce. They explained that the absence of these resources meant

absence of care. It was suggested that care was compromised when resources especially money was not available at home. In effect, most participants explained money was caring; everything used in caring had to be bought so resources needed to be available; and that things or trends were changing thus nothing (no resources) came from outside the home. These quotes reflect some of these views:

“When it comes to spending, I am like a magician. The money I get is small but I spend a lot on food, transportation and drugs but I can’t explain how I get the money. Only God knows.”
(P9)

“How can you care for someone when you don’t have things (resources) to use? Nobody will know you’re caring for the person. They will think that you’re wicked, because without money to buy food or take the person to hospital, something can happen to the person.”
(P3)

“If someone is poor, it is known that there are poor in the society so no one worries about that but, as soon as a disease comes upon the household, everyone watches to see how that family will save the person. When it happens like that, money is considered as life. Do you see why it’s my duty to help my granddaughter to get well? I don’t want the people to point fingers at me.”
(P4)

“This sickness is one that even rich people cannot treat. Caring for someone with such strange sickness is like being a magician who can do strange things to get an answer. With this type of care, I’m always trying different methods to help my husband. The disease costs a lot of money and sets me thinking all the time. If I don’t have money I can’t help him; remember that - it’s gettable, it’s doable.”
(P10)

The current findings confirm the assertions by Barnett and Whiteside (2002) and Shaibu, (2006) that although the home is an environment for care, the setting is affected by challenges that affect the woman’s ability to provide care. The main challenge faced by participants was their lack of resources for their health condition. It was further inferred from these quotes that most participants lacked resources (especially financial resources) and were insufficiently prepared for this new role of caring for an HIV positive husband. This economic burden on HIV positive patient (especially women) was realized in a studies by Kipp et al., (2007) and UNAIDS (2008).

5.5 Care being obligatory - Till death do us part-prolonging life

Caring for PLWA was seen as a societal obligation. The Ghanaian society expects that sick people are supported or cared for by family members. Most caregivers also felt obliged to take care of the sick person because he or she rendered services to the family prior to the sickness thus they could not turn their backs to their husband now that he needed help most. They explained that marriage was for life and that they needed to help each other till death did them part. These findings can be inferred from the following quotes:

“He is my husband; we’ve lived together for many years so now that he is sick, I have to care for him till he gets well. We don’t have money but every day we pray to God to help us. Whatever we have, we agree on what to do-it’s always his food and drugs that we think about.”
(P14)

“When trouble comes, people outside watch to see how you would behave so you can’t change your mind about taking care of him.”
(P8)

This finding confirms findings of Anarfi (1995) in a study of AIDS persons and their caregivers. Participants explained that the amount of care from family members was minimal mainly because of their fear of stigmatization and of being infected with the disease. As a result, this role of caring for the HIV positive patient was most of the time solely left to the partner, who was also suffering from HIV/AIDS. This finding was also realized by Radstoke (2000).

5.6. The “give” and “take” of care

Participants reported that in a marriage relationship, there is sharing and a need for each other – at one point in the relationship, one person gives material things, care and love so in a situation that the person cannot continue to provide, the roles change and the receiver then becomes the provider. Thus the care and affection that the husband gave when he was active was reciprocated in terms of devotional care by the wife. Most participants further explained that now that their husbands were sick, they were willing to care but due to limited resources, fear of the disease getting worse and final death, they felt restricted in providing quality care.

“I do my best to help him. Even when I am sick, I hide my sickness so that he does not see that I am in pain. I do everything for him. You know, this is not a type of sickness that children can handle so I do everything myself. The children only help with sweeping the compound and running errands.” (P9)

“As it is now, I don’t know who will go first [implying death]. Because of this, I have to do whatever I can to make him happy. I am sure that when he gets better, he would also help me when I am down.” (P4)

These statements are an indication that wives felt obliged to readily sacrifice their personal needs in order to support their sick husbands. They suppress their feeling when unwell and continue to render care to their partners who are in a more critical or worse condition. According to Coa et al., (2010), these women experience a decrease in physical capacity when caring for their husbands. To an extent, this finding is related to the previous point where caregivers explained care was obligatory.

6. Summary & Conclusion

The need of women providing care when they themselves are sick was evident in this study. Understandably, wives were supposed to take care of their sick husbands, but the double tragedy of ill-health and AIDS care rendered such women helpless. The practical daily challenges of insufficient money for food, hygiene, toilet facilities and other needs placed an extra emotional burden on the women. Wives also suppressed their health challenges at the expense of care for their loved ones. As a result they experienced a decrease in physical and emotional functions which affected their capacity to engage fully in daily activities.

Participants experienced economic challenges as well. Considering the nature of economic activities that the wives engaged in, the sources of income for the family seemed inadequate. In most Ghanaian low income households, like other African societies, when the breadwinner (the man) is sick and no longer working, the family is likely to be plunged in to deeper poverty. For example, it was realized in Uganda that AIDS contributes to economic and social disruption and tends to accentuate poverty at the household level (Taylor, Seeley & Kajura, 1996; Rakodi and Nkrunziza, 2007). Participants identified their spiritual orientation as a key resource during care. Majority of respondents indicated that their source of ‘strength’ and survival was in terms of their faith in God. The degree of economic challenge explained the connection between the perception of AIDS care and availability of family resources, particularly money. All participants perceived care for a person living with AIDS as synonymous with availability of family resources. This has serious economic implications for caregiving in the context of AIDS, particularly in resource constrained communities.

Drawing from the results, the study concludes that experiences of wives caring for their husband with AIDS influenced care practices in the home. Although participants demonstrated willingness to continue to care for their HIV positive husbands, their minimal understanding of the disease seemed to impact on their emotions and ultimately care given to their spouses. Care experiences were closely linked to available resources (especially money). Insufficient resources (especially in terms of energy and financial resources) hindered the quality of care provided to HIV positive husbands. It resulted in a compromise of provision of adequate and quality care not only to their sick husbands but to their children as well.

7. Recommendation

Participants conveyed a need to balance care work with personal needs. To ensure that these female HIV/AIDS patients effectively balanced care work with their personal needs, it is suggested that the Family and Consumer Sciences Outreach Programs, HIV/AIDS Advocates, Ghana Health Service, Ghana AIDS Commission and other relevant stakeholders provide education on Family Resource Management to identified HIV families. There is the need for the Ghana AIDS Commission to also develop a policy on home care in the National AIDS Framework. Further education also needs to be done to reduce stigmatization and fear of the disease so that affected families could share their challenges in order to receive support from government and non-governmental organizations to supplement the services of family members. Further research could also be conducted using a larger sample size to gain further insight into the challenges of HIV positive wives when caring for their HIV positive husbands.

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Table 1. Demographic Characteristics of Participants

Parents	Age of Wife	Level of Education	No. of Children	Income Earning Activity
P1	40	Basic Education	3	Petty business in cloth
P2	32	Basic Education	2	Orange Vendor
P3	31	Primary school	1	Charcoal Seller
P4	29	Basic Education	1	Second hand Cloth Seller
P5	42	Non-formal	2	Bread Vendor
P6	36	Basic Education	0	Food Vendor
P7	28	Senior Secondary	1	Hairdresser
P8	43	Basic Education	2	Housewife
P9	27	Senior Secondary School	3	Water Vendor
P10	42	Basic Education	3	Dress maker
P11	38	Non-formal	2	Water Vendor
P12	28	Basic Education	1	Fruit Vendor
P13	27	Non-formal	2	Hair dresser
P14	31	Non-formal	1	Petty trader in convenient foods
P15	37	Basic Education	2	Water Vender

(Field Data, 2010)

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