

# THE IMPACT OF CARE GIVING ON AFRICAN ELDERLY WOMEN CARE GIVERS OF THEIR ADULT CHILDREN WITH AIDS RELATED ILLNESS

Thozamile Qubuda, MPhil

## Corresponding Address:

African Centre for HIV/AIDS Management  
Industrial Psychology Building, University of Stellenbosch  
Private Bag X1, Matieland, 7602  
tqubuda@sun.ac.za

## Abstract

**Introduction:** In South Africa, AIDS patients are increasingly cared for at home by women in their traditional role of family caregiver. The number of parents assuming care for their adult children infected with HIV and with AIDS related illness is increasing and this affects parents negatively. The purpose of this phenomenological study was to capture the lived experiences of African elderly women as caregivers in the challenging context of family members who are receiving antiretroviral therapy.

**Objectives:** The objective of this study is to describe the impact of care giving on elderly African women as caregivers of their adult children with AIDS related illness.

**Methods:** The study adopted the qualitative approach using Van Manen's method for hermeneutical phenomenological research to explore the lived experiences of 10 African elderly women who were the primary caregivers for their HIV-positive adult children were investigated. Interviews were audio-taped, transcribed, and subjected to qualitative data analysis. Constant-comparative analysis was done, a process of constantly comparing the data for similarities and differences, guided data analysis, thus capturing all potentially relevant aspects of the data as soon as they were received. Transcription and analysis of the interviews began immediately following the first interview and was preceded by analyzing the transcribed interviews, line by line, highlighting important ideas and themes. Each theme was coded and recoded using Ethnographic computer program.

**Results:** Carers struggled with the physical impact of this disease; there was a clear nexus between the carer's coping capacity and the PLWHA's physical health. As the PLWHA's health declined carers' coping skills were put to the test and new boundaries set. While carers were often 'forced' into silence by the PLWHA, there was a demonstrated desire throughout the research process for these carers to 'debrief' and discuss their past or current care. Of the caregiving, personal care was most difficult and household tasks were most time consuming. Family life, with friends was areas most likely to be affected by caregiving.

**Conclusion:** While it may seem that the carers are coping with care of their children with AIDS, the outer façade is not always an accurate portrayal of the true situation. Health care workers should enquire as to the assistance these carers need from the social and health care services in order to continue to care for their children having AIDS related illness.

**Keywords:** Family; caregiver; person living with HIV/AIDS; experiences, Gugulethu.

## Impact of HIV/AIDS on the caregiver

HIV/AIDS infections impact people on every continent in the world. It has generated phenomenal challenges to health care systems and to the caregivers who provide care to their loved ones with this disease within the home settings (Raveis & Siegel, 1991; Unger, Welz, & Haran, 2002). HIV/AIDS, like any fatal or chronic illness, imposes a stress, which may have long-term effects on family members. Becoming a caregiver is likely to introduce a profound impact on the individual's life and

produce significant changes in his/her lifestyle (Wacharasin & Homchampa, 2008).

In this study, individuals became caregivers because they loved and cared for their ill family members, many of whom were disabled and/or chronically ill. Care giving or helping PLWAs to meet their physical and emotional needs can produce negative and positive impacts for the caregivers. The impact of care giving on the caregivers was discussed with the researcher.

## Methods

Hermeneutic phenomenology is an appropriate method for this research, enabling the phenomena of life's experience to be structurally and systematically analysed, thereby allowing in-depth interpretation of these lived experiences. The aim is to '...construct an animating, evocative description in textual form of human actions, as we have met with them in the life-world' (van Manen, 1990, p. 19). The purpose of this form of research '...is to act as an advocate in progressing human life, by increasing its thoughtfulness and sensitivity to situations' (van Manen, 1990, p. 21).

On examining possible research methods, the main concern was to choose a methodology that would provide a framework within which the research question could be meaningfully addressed. The study adopted a qualitative research approach. Within this approach a phenomenological orientation was accepted since the objectives were to explore subjective meanings and experiences from the respondent's points of view.

## Data collection

Data was collected by structured, in-depth, face-to-face interviews. The purpose of this approach was to elicit the participants' perspectives with as few probes as possible. This specificity assisted in (a) gaining further information, (b) testing preliminary findings, and (c) looking for commonalities and differences in the participants' stories (May, 1998). Interviews lasted from 45-90 minutes. Observational field notes (Lincoln and Guba, 1985; Boyd, 1993) and theoretical memos and diagrams (Strauss and Corbin, 1990) were also used during data collection to ensure a more accurate and thorough recollection of the circumstances surrounding the interview and participants' experience.

## Data analysis

A fear is expressed by phenomenological theorists and researchers that should analysis become too focused on specific steps, quality may be lost. Unlike other methodologies, phenomenology cannot be reduced to a "cookbook set of instructions; it is more an approach, an attitude, an investigation posture with a certain set of goals" (Keen, in Hycner, 1985: 279).

To analyse the rich wealth of data generated by the

in-depth interviews, however, it was necessary that the researcher, being inexperienced in phenomenological analysis, follow a set of guidelines. These guidelines were provided by Hycner (1985) and Giorgi (2005) who felt a need existed to provide guidelines to researchers who did not have enough philosophical background to know what "being true to the phenomenon" meant in relation to concrete research methods (Hycner, 1985: 280).

A practical guideline from Allen (Personal communication, November, 2003) was also helpful. Interviews were audio-taped, transcribed, and subjected to qualitative data analysis. Constant-comparative analysis (Strauss and Corbin, 1990; Cherlin, 1983), a process of constantly comparing the data for similarities and differences, guided data analysis, thus capturing all potentially relevant aspects of the data as soon as they were received. Transcription and analysis of the interviews began immediately following the first interview and was preceded by analyzing the transcribed interviews, line by line, highlighting important ideas and themes. Each theme was coded and recoded using Ethnographic computer program (Siegel, Gluhoski, & Karus, 1997).

## Ethical consideration

A study of people affected and infected with HIV/AIDS needs to be approached with great sensitivity. The stigma of HIV is such that HIV positive interviewees may fear discrimination, rejection or even violence if their HIV status is revealed. Research on HIV explores the most intimate sphere of a person's private, sexual and emotional life. An interview can become a difficult and emotional experience, regardless of how well a person seems to be coping. Morse and Richards (2002: 205) identify the following ethical principles regarding participants' rights:

- The right to be informed of the purpose of the study as well as what is expected during the research process. The amount of participation and time required. What information will be obtained and who will have access to it. Finally what the information will be used for.
- The right to confidentiality and anonymity.
- The right to ask questions of the researcher.
- The right to refuse to answer questions the researcher may ask, without negative

ramifications.

- The right to withdraw from the study at any time without negative ramifications.

## The Impact of Care giving on the Caregivers

### Results and Discussion

#### Negative Impact of Care giving

Providing care to PLWAs had negative consequences to caregivers. For example, their activities could extend over a 24-hour period. Caregivers fulfill the roles that could be described as parent, nurse, and housekeeper. These multiple roles can be demanding and at times come into conflict (Reynolds & Alonzo, 1998; O'Neill, & McKinney, 2003). The negative impacts of caregiving experienced by caregivers in this study included: 1) physical stress, 2) emotional stress, 3) financial burdens, 4) health problems, and 5) life style changes.

#### Physical stress.

The PLWAs required physical care such as hands-on assistance, or around-the-clock supervision. Caregivers who had never cared for their loved ones with HIV/AIDS experienced physical stress. Some caregivers had sleep disturbances that were related to the needs of the PLWAs that also included night-time assistance. Two caregivers explained their experiences.

A 71-year-old female caregiver who cared for her son (30 years old) had this to say.

*"During the time he became very ill, I could not sleep because I monitored his symptoms all day. He had a high fever and night sweats. I had to tepid sponge his body to decrease his body temperature. About every 2 hours I would sponge him and then I would give him the pills. I held his hands all the time. When he moved and needed some help promptly, I felt exhausted but I did it. I understood him. At times I felt as sick as he was I felt just like him, but I continued to care for him." (Case #8)*

Here is another example from a 65 year-old female caregiver who cared for her daughter (27 years old).

*"I took care of her all day and night..., only me. Other family members had to work. They had their own families. I was single, so I took the responsibility to care for my ill younger daughter. I did not sleep well. I was tired all of the time. When she had a high fever and a blurred state of conscious, I could not do much to help her. I felt worried about her. I lost weigh and I lost my appetite. During that time, I didn't want to eat anything because I felt fatigued most of the time. Sometimes, I felt like I didn't have enough energy to take care of her." (case #10)*

In summary, these caregivers' narrations implied that they faced unavoidable tasks in caring for their family members with HIV/AIDS. These tasks can be interpreted as "physical stress or physical burdens," but because of their sense of responsibility, their cultural practices, and their religious beliefs, they continued to provide the care as best they could.

#### Emotional stress.

Half of the caregivers reported that they felt stressed and were anxious when caring for their loved ones with HIV/AIDS. This stress could be heightened by the uncertainty about the PLWAs' health status and prognosis, and the severity of the PLWAs' symptoms. Consider these experiences of the following caregivers.

A 64 year-old female caregiver who cared for his youngest daughter (25 years old):

*"My family faced many problems since I knew that she had become addicted to drugs (injecting drug user). I felt so stressed when I knew that she was also infected with HIV/AIDS. When her symptoms appeared and got worse, I felt more anxious because I was afraid that she would die. I lived with an uncertainty about her life and death." (Case #3)*

Another family member, a 57 year-old female caregiver who cared for her daughter (34 years old):

*"I felt so stressed. Nevertheless, I tried not to be stressed because it is not a good way to be when caring for my daughter. Caring for her was an emotionally intense and physically demanding experience. Um...sometimes, I*

*cried because I thought about her illness that could not be cured.” (Case #7)*

### **Financial burdens**

A family member's illness with HIV/AIDS can adversely affect the economic well-being of caregivers and other family members. In this study, 10 caregivers reported that the course of the HIV/AIDS illness trajectory impacted the economic status of the PLWAs'caregivers badly. They reported a great deal of financial burden and stress. This fact helped to create the extra financial burdens that the family and caregivers had to confront.

A 60 year-old female caregiver who cared for her younger son (22 years old) told her story.

*“The medication and treatment for the disease is expensive. I paid R600.00 per day during the first time he was admitted to the hospital. However, it gradually decreased to R200, 00/day. I did not tell anyone about this expense, not even my husband. I had to withdraw my money from my saving. I used the money for his treatment, food, and transportation. It was not enough, though.” (Case #2)*

Another similar situation follows: A 60 year-old female caregiver and who cared for her son (32 years old) helps to highlight this concern.

*“During his illness, he could not work. So he decided to quit his job. I continued to work for myself. I had to stop working some days when I felt sick. The loss of income made it difficult for us to live. My husband had to sell his property; a golden ring to get the money for living. I felt pity for my son. The money I had was not enough. I had to borrow money from my neighbour. I also had the interest on the money to be concerned about, too. I needed the money to pay for the food and milk for my kids. The rest of the money was used to pay for treatment, and so on....” (Case #4)*

Still, another story about finance: A 60 year-old female caregiver who cared for her 2nd son (26 years old) shared her thoughts about the financial burdens.

*“His family neglected him. His wife ran away*

*after knowing his positive HIV status. He didn't have enough money for care and he was in debt. When he returned home, I was the primary caregiver. I also paid for his daily living expenses and the expenses associated with treatment and care.” (Case #5)*

### **HIV/AIDS related stigma**

Because the stigmatization of persons with HIV/AIDS infection often extends to their caregivers, they, too, have to deal with the prejudice that exists because of the disease, the fear of infection, the loss of friendships, and the forced decision to live with secrets. Fear of social discrimination leads families to carefully consider what they might gain or lose from their disclosure to others about their ill family members' health status. These realities help to motivate the caregivers to keep secrets and protect the family's reputation and the PLWAs from hostilities and community gossip. The caregivers' reported experiences help to highlight their concerns and their struggles. A 67 year-old female caregiver who cared for her son (45 years old) described her predicament.

*“I did not tell anyone about his HIV status. I avoided talking about it. However, my neighbours might have had some ideas about the type of illness that he had but I did not discuss it. They might know from his signs and symptoms. One neighbour said that she would not buy food that I had for sale because she was afraid of the possibility of becoming infected with the HIV/AIDS virus. She made me lose money from selling food.” (Case #1)*

A 64 year-old female caregiver who cared for her youngest daughter (25 years old) added this remark.

*“I did not consult with anyone about my daughter's illness except my family. I called my other daughter who was married and lived far away from my house. She gave me good advice and visited us very often.” (Case #3)*

A 60 year-old female caregiver who cared for her 2nd son (26 years old) also experienced a similar situation.

*“As AIDS was a stigmatizing disease, I concealed his HIV/AIDS infection from other people, so I could not ask for help from anyone.*

*It made me frustrated and miserable.” (Case #5)*

A 57 year-old female caregiver who cared for her daughter (34 years old) made this pronouncement.

*“No one knew her HIV status. Only me I knew this secret. I was afraid that society would reject my children and that rejection would affect my children's education. When my neighbours asked about her illness, I told them that she had a lung infection.” (Case #7)*

Some neighbours were afraid of the disease, and they tried to avoid dealing with family members who had ill relatives. For example, neighbours tried to avoid making contact with the ill members' family; the ill members' family used various avoidance strategies to minimize contact with their neighbours. Moreover, the PLWAs would try to confine themselves to their homes to avoid discrimination and prejudice from the neighbours and others in the community.

### **Positive Impact of Care giving**

#### **Knowledge gained.**

Two caregivers reported that caring for PLWAs helped them learn more about how PLWAs suffered from the disease and the pain that they have to endure. They reported that it was a good experience for them to be aware of the disease and gain a better understanding of what the illness is like. Furthermore, it was beneficial for them to learn more about avoiding the risky sexual behaviours in their own personal lives. They refocused on how to take better care of themselves. Two caregivers explained: “To me, as a caregiver, I gained more knowledge and experience about how to take care of myself. Even though, caregiving was a difficult task and the ill family member needs close attention and care, I learned a lot. I learned how to live with my family member who has HIV/AIDS without any risk of infection. I learned to be more careful and to avoid getting infections.” (Case #7)

*“In the past, I knew little about AIDS because it was not of interest to me. Since my daughter had this disease, it became necessary for me to learn more about it. I searched for information about how to take care of myself, how to protect*

*myself from the risk of infections, and how to take care of my daughter. I noticed that the persons who got the disease were younger persons such as my daughter. She was 27 years old. Then, I thought about myself. I had to use self care and protect myself and learn to stay far away from the disease. It is a frightful disease.” (Case #10)*

### **Discussion**

Assuming the caregiving responsibility for PLWAs affects caregivers both negatively and positively. Regarding the negative impact, the results of this study underline the assumption that the caregivers of PLWAs are physically, mentally, socially, and financially affected by the impact of HIV/AIDS. According to Pakenham and colleagues (1995), psychologists used the term “caregiver burden” to describe the physical, emotional, financial, and social problems associated with caregiving. The physical burden or physical stress of caregiving is documented in the literature and reported as having negative health effects on the caregivers (Aoun, Kristjanson, Currow, & Hudson 2005; Kipp et al., 2007, Prachakul & Grant, 2003; Thomas, 2006). Several researchers have discussed the types of negative outcomes that can occur when caregiving. Examples of some of these negative consequences are elucidated.

Emotional stress in family caregiving is defined as negative feelings or experiences of frustration, anxiety, and difficulties in dealing with the ill persons (Borijan et al., 1993). The caregivers in this study reported emotional distress. Much of the earlier research on the impact of caregiving for PLWAs revealed multiple caregiving problems. The most common problems were emotional distress, relationship difficulties, somatic symptoms, grief, fear of disclosure of the family members' HIV status, and confidentiality concerns (Engler et al., 2006; Holroyd, 2005; Orner, 2006; Shacham, Basta, & Reece, 2008; VanDevanter, Thacker, Bass, & Arnold, 1999).

The loss of family income through the disruption of wage earnings due to the demands for caregiving has been documented in the research literature, particularly in developing countries (Brouwer, Lok, Wolffers, & Sebagalls, 2000; Joseph & Bhatti, 2004; Knodel & Im-em, 2004; Mcgrath et al., 1993;

Oluwagbemiga, 2007; Rajaraman, Russell, & Heymann, 2006; Ssengonzi, 2007). These findings were consistent with previous studies (Irving et al., 1995; Joseph & Bhatti, 2004; Yun et al., 2005).

## Conclusion

These findings lend support to prior research that suggested that caregiving for PLWAs can negatively affect the caregiver's health; however, caregiving can also provide positive experiences that are beneficial for personal growth and development and introspection. This research demonstrated that the stigma associated with HIV/AIDS is a barrier to caregivers' efforts to seek support from family, friends, and health professionals.

Furthermore, the results of this study have substantive implications for the understanding of the impact of caregiving upon family members providing assistance to PLWAs. The importance of the current findings as related to health care practice, social workers and nursing education, health policy, and future directions for research are also included.

## References

- Aoun, S. M., Kristjanson, L. J., Currow, D., & Hudson, P. (2005). Caregiving for the terminally ill: At what cost? *Palliative Medicine*, 19, 551-555.
- Borijan, P., Hatthapanom, W., Keawarj, N., & Rachabut, S. (1993). The study of anxiety and coping in psychiatric patient. Research Report. Khon kaen: Khon Kaen neuro psychiatric hospital.
- Boyd, C. O. (1993). Toward a nursing practice research method. *Advances in Nursing Science* 16(2), 9-25.
- Brouwer, C. N. M., Lok, C. L., Wolfers, I., & Sebagalls, S. (2000). Psychosocial and economic aspects of HIV/AIDS and counseling of caretakers of HIV infected children in Uganda. *AIDS Care*, 12, 535-540.
- Cherlin, A. (1983). Changing family and household: Contemporary lessons from historical research. *Annual Review of Sociology*, 9, 51-66.
- Engler, P., Anderson, B., Herman, D., Bishop, D., Miller, I., Pirraglia, P., et al. (2006). Coping and burden among informal HIV caregivers. *Psychosomatic Medicine*, 68, 985-992.
- Giorgi, A. (2005). The phenomenological movement and research in the human sciences. *Nursing Science Quarterly*, 18(1), 75-82.
- Holroyd, E. (2005). Developing a Cultural model of caregiving obligations for elderly Chinese wives. *Western Journal of Nursing Research*, 4, 437-456.
- Hycner, M. A. (1985). A philosophical method to study nursing phenomena. In M. Leininger (Ed.). *Qualitative research methods in nursing. New readings in cultural anthropology*. Harper Collins Publisher. New York.
- Irving, G., Bor, R., & Catalan, J. (1995). Psychological distress among gay men supporting a lover or partner with AIDS: A pilot study. *AIDS Care*, 7, 605-617.
- Joseph, E. B., & Bhatti, R. S. (2004). Psychosocial problems and coping patterns of HIV seropositive wives of men with HIV/AIDS. *Social Work in Health Care* 39(1/2), 29-47.
- Kipp, W., Tindyebwa, D., Rubaale, T., Karamagi, E., & Bajenja, E. (2007). Family caregivers in rural Uganda: The hidden reality. *Health Care for Women International*, 28, 856-871.
- Knodel, J., & Im-Em, W. (2004). The economic consequences for parents of losing an Adult child to AIDS: Evidence from Thailand. *Social Science & Medicine*, 59, 987-1001.
- Lincoln, Y. S. & Guba, E. G. (1985). *Naturalistic inquiry*. New York: Sage.
- May, J. (1998). *Experience and Perceptions of Poverty in South Africa*. Durban: Glenwood Publishing.
- McGrath, J. W., Ankrah, E. M., Schumann, D. A., Nkumbi, S., & Lubega, M. (1993). AIDS and the urban family: Its impact in Kampala, Uganda. *AIDS Care*, 5, 55-70.
- Morse, J.M., & Richard, L. (2002). *Read me first for a user's guide to qualitative methods*. London: Sage.
- Oluwagbemiga, A. E. (2007). HIV/AIDS and family support systems: A situation analysis of people living with HIV/AIDS in Lagos State. *Journal of Social Aspects of HIV/AIDS*, 4, 668-677.
- O'Neill, J. F., & McKinney, M. (2003). Care for the caregiver. In J. F. O'Neill, P. A. Selwyn, & H. Schietinger (Eds.), *A clinical guide to supportive & palliative care for HIV/AIDS* (pp. 409-429). Rockville, MD: Health Resources and Services Administration.
- Orner, P. (2006). Psychosocial impacts on caregivers of people living with AIDS. *AIDS Care*, 18, 236-240.
- Pakenham, K. I., Dadds, M. R., & Terry, D. J. (1995). Carers' burden and adjustment to HIV. *AIDS Care*, 7, 189-203.
- Prachakul, W., & Grant, J. S. (2003). Informal caregivers of persons with HIV/AIDS: A review and analysis. *JANAC: Journal of the Association of Nurses in AIDS Care*, 14(3), 55-71.
- Rajaraman, D., Russell, S., & Heymann, J. (2006). HIV/AIDS, income loss and economic survival in Botswana. *AIDS Care*, 18, 656-662.
- Raveis, V. H., & Siegel, K. (1991). The impact of care giving on informal and familial care givers. *AIDS Patient Care*, 5(February), 39-43.
- Reynolds, N. R., & Alonzo, A. A. (1998). HIV informal caregiving: Emergent conflict and Growth. *Research in Nursing & Health*, 21, 251-260.

- Siegel, K., Gluhoski, V., & Karus, D. (1997). Coping and mood in HIV-positive women. *Psychological Reports*, 81, 435-442.
- Shacham, E., Basta, T. B., & Reece, M. (2008). Symptoms of psychological distress Among African Americans seeking HIV-related mental health care. *AIDS Patient Care and STDS*, 22, 413-421.
- Ssengonzi, R. (2007). The plight of older persons as caregivers to people infected/affected by HIV/AIDS: Evidence from Uganda. *Journal of Cross-cultural Gerontology*, 22, 339-353.
- Strauss and Corbin (1990). *Basics of qualitative research: techniques and procedures for developing grounded theory*. Cambridge, England: Cambridge University Press.
- Thomas, F. (2006). Stigma, fatigue and social breakdown: Exploring the impacts of HIV/AIDS on patient and care well-being in the Caprivi Region, Namibia. *Social Science & Medicine*, 63, 3174-3178.
- Unger, A., Welz, T., & Haran, D. (2002). The impact of HIV/AIDS on health care staff at a rural South African Hospital, 1995-2000. [Abstract no. MoPeE3762]. International Conference on AIDS, Jul 7-12. Retrieved September 1, 2007, from <http://gateway.nlm.nih.gov/MeetingAbstracts/ma?f=102254184.html>
- Van Devanter, N., Thacker, A. S., Bass, G., & Arnold, M. (1999). Heterosexual couples confronting the challenges of HIV infection. *AIDS Care*, 11, 181-193.
- Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. Thousand Oaks, Canada: The Althouse Press.
- Wacharasin, C., & Homchampa, P. (2008). Uncovering a family caregiving model: Insights from research to benefit HIV-infected patients, their caregivers, and health professionals. *Journal of the Association of Nurses in AIDS Care*, 9, 385-396.
- Yun, Y. H., Rhee, Y. S., Kang, I. O., Lee, J. S., Bang, S. M., Lee, W. S., et al., (2005). Economic burdens and quality of life family caregivers of cancer patients. *Oncology*, 68, 107-114.