

# The experiences of informal care givers in home-based care in the ODI sub-district area in the North West Province

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## Abstract: *Curationis* 31(4): 24-30

The purpose of this study was to explore and describe the experiences of informal caregivers in home-based care in the Odi Sub-District area in the Province of the North West.

A qualitative, exploratory and descriptive study was followed to collect data from the selected population. The study population consisted of informal caregivers who conduct home visitations in the Odi Sub-District area. Participants were purposively selected. Data were collected from the participants by means of focus group interviews, which were guided by the group moderator. The experiences of informal caregivers were shared through the participants' responses to a central research question. Tesch's qualitative method of data analysis was used to analyse the data. The experiences of informal caregivers were related to emotions, social circumstances and support. The participants placed emphasis on emotions of love and caring, fulfilment, frustration, exploitation, anger and helplessness, fear, rejection, shame and denial. Social circumstances regarding finance, antagonism and stigma were also emphasised. The participants raised the issue of the necessity of the support of the family, community and clinic during home-based care. It was recommended that this support group should assist families in dealing with fear, stigma and discrimination. Furthermore, it was recommended that the government should provide the services for developing and empowering informal caregivers in home-based care.

## Introduction

Home-based care is one of the strategies that should be implemented to provide care to the community during home visit. It was introduced in the 1980s and 1990s, as additional health service provision to clients. Home-based care activities are mostly conducted by non-governmental organisations (NGOs) to care for the sick. These organisations are involved in the training of community health workers in assisting families with home-care (Uys, 2002:99).

During home-based visits, opportunities are provided to identify both the barriers and support systems of the families (Stanhope & Lancaster, 2002:276). According to the South African National Department of Health (South Africa, 2001b:5) the implementation of home-based care as the primary healthcare strategy reduces the pressure on hospitals and other resources on a variety of levels of services. With home-based care, patients spend their days in their familiar surroundings, reducing their

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isolation. Considering the above, there is a need to investigate or explore the experiences of informal caregivers in home-based care.

Informal caregivers are therefore trained because they serve as potential partners in the delivery of health services. In return, they gain knowledge of caring and providing a broad range of services, and can achieve a variety of health-related goals with patients (Stanhope & Lancaster, 2002:5-18). Furthermore, the National Department of Health (South Africa, 2001b:9) indicated that home-based care empowers families and other patient caregivers to take care of their health. This could be done through effective education and training, to reduce unnecessary visits and admissions to hospitals. This was also confirmed by the development of a curriculum, the modules of which were based on the multiple roles of home-based caregivers (South Africa, 2002:16). Home-based caregivers were given the chance to suggest different topics on which objectives could be based, in order to promote health and recovery and assist them in the attainment of certain skills.

This study investigated the experiences of informal caregivers during home visits in the Odi Sub-District region in the North West Province, in order to promote the health of the community.

## The background to the study

According to the National Department of Health (South Africa, 2005:5), approximately 4.2 million South Africans are living with HIV and AIDS. It is estimated that the pandemic will infect a further six million South Africans by 2005. It was therefore necessary to educate patients, their families and home-based caregivers. In order to promote and ensure quality healthcare, safety, commitment, cooperation and collaboration should be ensured. Home-based caregivers detected and treated problems, and also assisted skilled and qualified caregivers to render quality care. Mutual trust and rapport amongst patients and family members were established (South Africa, 2004a:5).

According to Zimba and McInerney (2001:84), the escalating increases in the number of HIV and AIDS victims in

Malawi dictated a need for skilled informal caregivers to provide relevant care to the community. They added that new trends in managing HIV and AIDS patients focus on improved outpatient treatment procedures. There is a growing emphasis on community home-based care services, which are less expensive.

Home-based care reduces transport problems, time spent in hospitals, waiting in long lines for treatment and other costs (Department of Health, 2001b:2-3). This was observed when the healthcare providers visited the patients in their homes. Home visits are also conducted to help people to face ill health or death in their familiar surroundings, rather than in a hospital ward (Lundy and Janes, 2001:884-885). The visits conducted permitted better follow-up and provided educational opportunities regarding HIV and AIDS prevention. It was also noticed that regular home visits promoted efficient and effective supervision of families in their homes.

Informal caregivers are exposed to the opportunities where they observe families who experienced the symptoms of the social problem such as poverty. Basic needs, such as hunger and thirst, often remain unmet. In an attempt to remedy this, the Government gives poor families, both in rural and urban areas, relief in the form of food parcels and other incentives. Van Dyk (2001:95) mentioned that informal caregivers should take responsibility for supporting families in need of care, irrespective of their health, religion, culture, norms or values. The identification and implementation of successful prevention strategies for patients, who present with chronic illnesses, will assist policy makers in making progress in the community. In the North West Province it was observed that supplements are provided to the chronically ill, on a monthly basis to cater for the community. These activities are recorded and are kept to control costs, to re-order (depending on client number) and for statistical purposes.

Richter and Peu (2004:31) noted that the number of elderly people and HIV and AIDS victims was increasing and that there was a high rate of malnutrition, HIV and AIDS and TB. This has left families and home-based caregivers to face many challenges. Therefore, the government had to persuade the National Department

of Health to expand centres for training home-based caregivers (South Africa, 2005:6).

The Odi Sub-District was one of the areas in the North West Province that caters for informal caregivers, providing them with information on how to care for various patients. As a result of a shortage of skilled formal healthcare personnel, healthcare has become a scarce commodity. In order to alleviate suffering in communities, informal caregivers should be deployed at grassroots level. Therefore there is a need to investigate the impact and the experiences of informal caregivers during home visits as they are faced with variety of challenges.

## Problem statement

The National Department of Health noted that South Africa has insufficient healthcare resources (South Africa, 2004a: 6). Many people who became ill with HIV and AIDS-related diseases and other chronic conditions were not able to stay in hospitals as a result of shortages of equipment, beds and staff, and an increase in the care demanded by patients.

It has been emphasised that caregivers experienced emotional and physical problems, such as rejection, anger and grievance, physical strain and stress, when providing care to patients confined to their beds (South Africa, 2001b:10).

The following research question guided the researcher to achieve the results *"What are the experiences of informal caregivers in home-based care in the Odi Sub-District in the North West Province"*.

## Significance of the study

The study will assist in the improvement of home-based care services and the relations between informal caregivers and patients during home visits. If services improve, this will reduce hospitals' workload of caring for terminally ill patients. The study will also encourage informal caregivers to provide the best possible care to the community.

## Research question

What are the experiences of informal caregivers in home-based care in the Odi Sub-District in the North West Province?

## Purpose of the study

The purpose of this study is to explore and describe the experiences of informal caregivers in home-based care, in the Odi Sub-District in the North West Province.

## Ethical considerations

The researcher obtained permission to conduct investigation from the North West Province and the institution at which the research was conducted. The Ethical Committee of the University of Pretoria (UP) Faculty of Health Sciences approved the research proposal and participants must signed written consent forms. The researcher provided adequate information, regarding the research, to the participants. They were free to choose or decline participation (Polit & Hungler, 2001:78). Principles of ethics were adhered to.

## Research design and method

A qualitative, exploratory and descriptive design was used. The experiences of informal caregivers were explored and described.

## Population and sampling

The population in this study consisted of informal caregivers who visited patients in their homes in the Odi Sub-District. The inclusion criteria for this population were informal caregivers conducting home visits, residing in the Odi Sub-District area and consenting to participate in this study. The participants also had to understand the culture of the community.

Purposive sampling was utilised in this study. The researcher personally and purposively selected the study population for this study. Bless and Smith (2004:92) noted that a sample is chosen on the basis of what the researcher considers to be a typical unit.

## Data collection and instrument

A focus group interview was conducted to collect data from the participants. In this study, two focus groups were utilised. Each focus group consisted of five participants who were divided into two groups of five each. The groups consisted of both males and females who

are informal caregivers conducting home visits in the Odi Sub-District area. The focus group interviews were conducted in three phases. Phase one involved the preparatory stage, phase two involved the initial focus group interview and phase three involved the post- interview events.

## Data analysis

In the data analysis, the researcher and co-coder analysed the data independently. The data were qualitatively analysed. Burns and Grove (2003:379) define data analysis as a technique used to reduce, organise and give meaning to the data. In this study, the Tesch method of data analysis was used (Tesch, 1992:141).

Audiotapes were listened and re-listened to. Some ideas were noted down as they came to mind. Verbatim transcripts were read and re-read to understand the data properly and to get a sense of the whole. The underlying meaning of the data was sought. Thoughts were written in the margin. A list of topics was made and similar topics were clustered together. Thereafter columns were drawn to identify major topics, unique topics and those that fitted into neither of these categories. The list was used to compare the data. Similar data were identified and categorised as the list was reduced. The topics relating to each other were grouped together and given a title or description. Each category, subcategory and theme was checked. All data belonging to each category, subcategory and theme were assembled in one place and a preliminary analysis was performed. The co-coder and researcher conducted consensus meetings after the data analysis (Coffey & Atkinson, 1996:46; Creswell, 1994:154; Tesch, 1992:141).

Lincoln and Guba (1985:36) trustworthiness strategies were applied. These included credibility, transferability, dependability and confirmability (see table 1).

## Discussion of findings and literature control

During the data analysis, three main categories, namely emotions, social circumstances and support, emerged. Four subcategories emerged from the category emotions, namely informal

caregivers, relatives of patients, community and patients. Three subcategories emerged from the category social circumstances, namely finance, antagonism by family and stigma. The subcategories family, community and clinic emerged from the category support.

## Emotions

The first category that emerged was emotions. The category emotions was further divided into the subcategories informal caregivers, relatives of patients, community and patients.

### • Informal caregivers

The themes love for their jobs and accomplishing caring for their clients, fulfilment for what is expected from them, frustrated by the conditions of work, exploitation by other members of the families, anger and helpless relating to their work emerged from the subcategory informal caregivers. The participants reported that they love their jobs, especially when cooking for and teaching patients in their homes. They felt that they accomplish the goal of caring. Woodward, Abelson, Tedford and Hutchinson (2004:180) stated that home-based caregivers render quality care to patients, based on set goals. When care was provided with both knowledge and compassion, the isolation of the patient is reduced, and their dignity and respect maintained (South Africa, 2001b:4).

Participants also expressed feelings of being exploited during home visits. They felt exploited because the entire burden of care was placed on the shoulders of the informal caregivers. Suspected HIV and AIDS sufferers were harassed, blamed and punished by community members (Herek & Capitanio, 2002:371). Herek and Capitanio (2002:371) noted that informal caregivers witnessed instances of exploitation when HIV patients were turned away from healthcare services employment. These patients were often evicted from their homes by their families and rejected by their friends and colleagues (Herek & Capitanio, 1993:577). Community members also often felt uncomfortable with their children attending school with HIV and AIDS sufferers.

### • Relatives of patients

The following themes emerged from the subcategory relatives of patients, namely

**Table 2.1: Strategies to establish trustworthiness**

Strategy	Criteria	Applicability
Credibility	Member checking	Re-interviews were conducted and the interviews analysed and interpreted.
	Peer examination	The services of an independent co-coder were enlisted. The research process was discussed with experts.
	Persistent observation	The researcher identified characteristics and elements relevant to the problem and monitored the participants' non-verbal cues.
	Triangulation	Multiple methods of data collection were used to increase the reliability of the observations.
	Prolonged engagement	Trust and rapport were established and an in-depth understanding of the culture and language gained by the interviewer. A period of three weeks was spent with the participants in order to do this.
Transferability	Authority of participants	The participants were informal caregivers, who render continuous home visits in the Odi Sub-District area. They were selected due to their acquired skills and knowledge in conducting home visits. The research steps were checked for transferability to other situations by the supervisor.
	Peer debriefing	This assisted the researcher in knowing what steps to take after the interview. The services of the co-coder were enlisted and the research process was discussed with experts
Dependability	Data collection	The findings were well defined, starting with research methods, data gathering, analysis and interpretation. Co-coding and recoding were done and the results compared.
Confirmability	Researcher	The researcher remained neutral throughout the study and carefully guarded against imposing her ideas in order to ensure accuracy, relevance and meaning.

(Barbie & Mouton, 2001:277; Blanche & Durrheim, 1999:430; Lincon & Guba, 1985: 294.)

experience of fear, rejection by the community, shame and denial. The participants mentioned that relatives of infected patients experienced fear, rejection, shame and denial.

It was realised that family members seemed to be afraid of the HIV and AIDS patient. The majority of participants caring for patients in the Odi Sub-District expressed anger over families who rejected their ill family members. Herek and Capitanio (2002:373) argued that HIV infected people were rejected and isolated because of fear of the spread of HIV and AIDS through casual contact. In fearing rejection, they kept their status secret from others, which ultimately

prevents them from receiving societal support.

A study in Botswana revealed that AIDS orphans' rights are abused in different ways. Because their parents have died as a result of HIV and AIDS, they are not allowed to attend schools. As a result of this rejection, stigmatisation and isolation, children dropped out of school and are forced to work as cheap labour (Ndaba-Mbatha & Seloilwe, 2000:218-223).

HIV and AIDS continued to generate fears, misunderstandings, misinformation and discrimination. The exaggerated fears associated with HIV and AIDS

consequently forced infected patients to live with fear, ignorance and discrimination (Arber & Knipe, 2001:1526).

#### • **Community**

The theme stigmatisation caused by HIV and AIDS disease emerged from the subcategory community. AIDS-related stigma refers to the prejudice, discounting and discrimination directed at people perceived to have HIV and AIDS (Unaid, 2000:27).

Denial goes hand in hand with discrimination. Many people will continue to deny that HIV exists in their communities. Unaid (2000:1) stated that

stigma results in rejection, denial and discrediting and consequently leads to discrimination and the violation of human rights, especially those of women and children.

Olenja (1999:189) noted that even sexually transmitted and other related diseases are stigmatised by community members. Stigma also surrounds people with illnesses thought to be infectious, such as leprosy. The majority of patients are denied the privileges of the sick. Olenja (1999:189) also argues that the stigma associated with HIV and AIDS originates in the belief that people with HIV and AIDS are promiscuous, which the community feel relieves them of the obligation to sympathise. People with HIV and AIDS are hated, seen as outcasts and no one wants to be near them.

The stigma that surrounds HIV and AIDS is a problem that is still present in society today. As a result, HIV and AIDS patients may be reluctant to share information pertinent to the assessment, planning, implementation and evaluation of their care (Olenja, 1999:189). Fear of discrimination and stigmatisation may prevent people from seeking treatment for HIV and AIDS, as they face the possibility of being turned away from healthcare facilities, being denied housing and employment, being divorced by their spouses and suffering physical violence and even murder. Stigma affects an individual's experience of illness and the care they ought to receive, and generates the fear of rejection that prevents individuals from disclosing their status (Olenja, 1999:189).

#### • **Patients**

The subcategory patients emerged from the category emotions. The subcategory patient was further divided into themes of shame and denial associated with HIV and AIDS disease. These themes of shame and denial seemed to be closely related to the previous theme of stigmatisation by the community.

Louw; Edward & Orr (2001:5) emphasised that, in many societies, people living with HIV and AIDS are seen as shameful and their disease is associated with behaviours of, for example, homosexuality. HIV and AIDS was seen as the result of irresponsibility. According to Pierret (2000:1593), HIV

positive women in Australia felt ashamed and guilty when they found out their status. They felt they are dirty and a polluted source of infection. This prevented them from revealing their HIV and AIDS status to their partners and families, as they fear rejection. This occurred mostly in people who were symptomatic.

Rassool (2003:235) added that the shame associated with HIV and AIDS discourages individuals from seeking voluntary counselling, testing and treatment, and slows prevention efforts. Stigma directly affected the Government's capacity to respond effectively to the devastation of the HIV and AIDS epidemic. Fears and taboos surrounding HIV and AIDS translated into silence and inaction, despite the consequences for individuals and societies (Rassool, 2003:387). Opportunities for prevention are missed, care and treatment remained inaccessible and the death toll arose.

### **Social circumstances**

The second category that emerged was social circumstances. The subcategories finance, antagonism by family, and stigma emerged from the category social circumstances.

#### • **Finance**

The themes poverty within the community, lack of transport to access health services and lack of facilities to support their daily activities emerged from the subcategory finance. Some participants expressed how poverty impacts patients, families, and the care rendered by informal caregivers, including relatives. Financial problems, such as the loss of income and other financial supports, lead to a lack of food and clothing, and the inability to pay the high cost of medical fees (Unaid, 2000:12). Illness and the inability to pay school fees lead to diminished livelihood opportunities. HIV positive women often feel ashamed of taking care of their children in these circumstances.

Campbell and Foulis (2004:9) stated that poverty refers to the lack of basic needs for survival, such as food and water. Campbell and Foulis (2004:9) further noted that an estimated 22 million people in South Africa could be in danger of starvation. In fact, in this state of abject poverty, even if anti-retroviral drugs were

issued for free, many people living with HIV and AIDS would die of hunger irrespective of the availability of treatment. According to Pierret (2000:1598), the poverty experienced by immigrants, women, and families with HIV positive children places a high care demand on government.

#### • **Antagonism by family**

Two themes emerged from the subcategory antagonism by family, namely poor cooperation and family belief system. The participants reported resistance and an antagonistic attitude by the families toward them as caregivers.

Families of HIV and AIDS patients indicate their antagonism by refusing to cooperate with informal caregivers, by refusing to continue with care in the absence of the caregiver and by keeping secret the patient's HIV positive status. Instead of being caring, loving and patient, participants observed that family members sometimes talk loudly to and are physically aggressive with the patient. Caregivers felt overwhelmed and frustrated, especially when they had to take time off and leave their patients unattended for a few days (Farran *et al.*, 2004:47). Caregivers sometimes provide care to patients without knowing their HIV status. They are only informed after a long period of exposure to the sick, which can be regarded as a violation of human rights (Ndaba-Mbatha & Selolilwe, 2000:222).

#### • **Stigma**

The participants of this study saw family and community stigma as an obstacle in the provision of healthcare. Adebayo *et al.* (2004:54) stated that informal caregivers observe the poverty, stigmatisation and discrimination that people living with HIV and AIDS must endure. Herek and Capitanio (1997:2) mention that the stigma surrounding HIV and AIDS has resulted in HIV positive people being hated and seen as outcasts. Nobody wanted to be near them and many felt it is almost impossible to take care of them. The stigma surrounding HIV and AIDS also resulted in those infected being denied life insurance, which could serve as a guarantee to buy an apartment or a house (Arber & Knipe, 2001:1532). HIV and AIDS also compromised the life of those it infects, resulting in illness, loss of their houses and disempowerment.

## Support

Three subcategories, namely family, community, and the clinic, emerged from the category support.

### • Family

Two themes, namely overburdening of caregivers and neglect of patients, emerged from the subcategory family. The participants of this study emphasised that the patients' families have an impact on the care provided by informal caregivers. Caelli, Downie and Latendre (2002:130) stated that the increase in home-based care as a result of HIV and AIDS placed an enormous burden on informal caregivers. Family members were constantly accosted by the suffering of their terminally ill patient and were faced the challenges of the stigma, fear and uncertainty associated with the disease. This can result in feelings of total helplessness and hopelessness, and total reliance on informal care giving.

HIV and AIDS was often viewed as a death sentence. Caelli *et al.* (2002:130) indicated that family members may begin to prepare for the imminent death of the patient, which can put a lot of pressure on the caregivers. Family members had to seek financial assistance for the costs of the impending death of a family member. Participants experienced a neglect of the patients, whereby wounds were not dressed and maggots had appeared when the home-based caregiver came for a home visit (Gupta, Da Silva & Passons, 2005:242).

### • Community

The theme pity as seen by community members emerged from the subcategory community. Despite cases of rejection, isolation and stigmatisation by the community, pity is evident when community members act as informal caregivers. Gelaw; Genebo; Dejene; Lemma and Eyob (2001:387) noted that the community did feel pity for TB and HIV and AIDS patients. Neighbours would not speak against people afflicted with TB and/or HIV and AIDS. Apart from an avoidance of contact with TB patients and their consequent social isolation, the community agreed that TB could have a strong influence on relationships during engagement and married life.

### • Clinic

The theme good support from local

clinics emerged from the subcategory clinic. The participants spoke of the support they receive from local clinics. One participant expressed a wish for a hospital facility. These were expressed that they cook and prepare lunch boxes and dish them to their clients because of poverty.

Ndaba-Mbatha and Seloilwe (2000:222) stated that the care required by HIV and AIDS patients when they experience diarrhoea and vomiting can become too severe for the informal caregiver to handle. Patients become weak and frail, and the informal caregiver becomes frustrated with his/her patient's deterioration. Hung, Liu and Kuo (2002:97) stated that inadequate support (care) can compromise an individual's ability to maintain a safe and reasonable standard of living. The management of symptoms, such as constant diarrhoea, can overwhelm informal caregivers, especially when they lack facilities and, for example, have to take soiled linen to be washed in the river (McCreary *et al.*, 2004:21).

Rassool (2003:235) indicated that a caring and supportive environment is focused on universal precautions. This reduces the stigma and discrimination surrounding HIV and AIDS. Supportive policies and legal constraints that address stigma should be in place. An effective partnership must be established between the Government, healthcare professionals, informal caregivers, and family members of people infected with HIV and AIDS (Rassool, 2003:235). Those infected and affected by HIV and AIDS should be persuaded to actively participate, so that their opinions can be analysed to ensure the proper formulation of strategies and policies (Rassool, 2003:235).

## Recommendations

The following recommendations are based on the findings of the study:

- The Government should offer informal caregivers relief grants, in order to provide for transport when conducting home visits. The grant should also cover the facilities needed for care giving.
- Anti-retroviral drugs should be made freely available to patients in order to reduce morbidity and mortality rates.

- Informal caregivers and patients' families should undergo training in order to empower them and reduce the overflow of patients in hospitals.

## Recommendations for further research

Because this study was conducted on a small scale in the Odi Sub-District area, the following areas should be further explored, described and quantified:

- The experiences of families with patients who receive anti-retroviral drugs.
- The views of patients who receive food parcels in the area.
- An evaluation of anti-retroviral programmes in the primary healthcare setting.

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