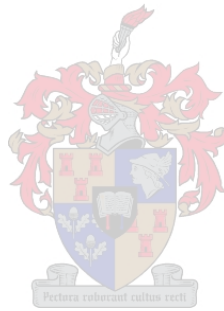


PATIENTS' ROLE EXPECTATIONS OF HOME-BASED CAREGIVERS

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**Assignment presented in partial fulfilment of the requirements for the degree of
Master of Arts (Clinical Psychology and Community Counselling) at
Stellenbosch University.**

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DECLARATION

I, the undersigned, hereby declare that the work contained in this assignment is my own original work, and that I have not previously in its entirety or in part submitted it at any university for a degree.

Signature

21 February 2008

Date

ABSTRACT

This study investigates and describes palliative care patients' expectations of their home-based caregivers. This paper attempts to expand on the findings of a previous study by Armenis (2006b) that reported a need to determine the occupational responsibilities of home-based caregivers within the Stellenbosch Hospice organization. Three palliative care patients were interviewed individually in unstructured interviews whereby expectations were discussed and recorded. Respondents were from the rural town of Klapmuts which is located within the broader Stellenbosch area. Responses were analyzed by means of the phenomenological methodology approach developed by Giorgi (1997). The findings indicate that patients expect physical and psychosocial care which can be divided into six sub-themes: i) hygiene; ii) feeding; iii) physical assistance; iv) communicate care; v) support; vi) need for community. This study revealed in excess of forty caring activities that study participants expect from their home-based caregivers that may be utilized as future focus areas of home-based caregiver training initiatives. Recommendations for future research include the enquiry into the role of patient relatives' and members of the community, as essential components of the unit of care. In addition, further investigation is required to determine the specific psychosocial needs of palliative patients, their relatives, and communities located in the outlying regions of South Africa.

OPSOMMING

Hierdie studie doen ondersoek na en beskryf pasiënte wat palliatief (sorg van pasiënte met ongeneeslike siektes) versorg word se rolverwagtinge van hul gemeenskapsgebaseerde oppassers. Hierdie werkstuk brei uit op 'n voorafgaande studie deur Armenis (2006b) wat 'n behoefte gerapporteer het dat duidelike beroepspesifikasies vir gemeenskapsgebaseerde oppassers wat in diens van die Stellenbosch Hospice is, bepaal behoort te word. Drie ongestruktureerde onderhoude is gevoer met pasiënte wat palliatief versorg word. Pasiënte se verwagtinge is bespreek en op 'n oudioband vasgelê. Deelnemers aan die studie is van die dorp Klapmuts wat binne die Stellenboschdistrik geleë is. Antwoorde is geanaliseer deur die gebruikmaking van die fenomenologiese metode soos deur Giorgi ontwikkel (1997). Die bevindings toon aan dat pasiënte 'n dringende behoefte het aan fisieke en psigo-sosiale sorg. Laasgenoemde kan in ses sub-temas verdeel word: i) higiëne ii) voeding iii) fisiese bystand iv) die kommunikasie van sorg v) ondersteuning vi) behoefte aan gemeenskapsbetrokkendheid. Hierdie studie het meer as veertig aktiwiteite vasgestel wat palliatiewe pasiënte van hul gemeenskapsgebaseerde oppassers verwag. Die vasgestelde aktiwiteite mag bydra tot die bevordering van toekomstige navorsing en die opleiding van gemeenskapsgebaseerde oppassers. Hierdie studie het 'n dringende behoefte vir die opleiding van gemeenskapsgebaseerde oppassers, wat in die Stellenboschdistrik werksaam is geïdentifiseer. Daar is 'n behoefte aan studies wat die rol van gesinslede en die gemeenskap se verantwoordelikhede uiteensit met betrekking tot die uitvoer van palliatiewe sorg. Die behoefte aan navorsing om die spesifieke psigososiale nood van palliatiewe pasiënte, hulle gesinne, en betrokke gemeenskappe wat in die landelike dele van Suid Afrika geleë is, vas te stel.

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INTRODUCTION

Palliative care

The World Health Organization defines palliative care as "active total care of patients whose disease is not responsive to curative treatment" (Harding, Stewart, Marconi, O' Neill & Higginson, 2003, p1). Consequently, palliative care includes the control of symptoms such as pain, and the provision of assistance with regards to psychological, social and spiritual problems (Harding et al., 2003). The term palliative care therefore incorporates a broad range of aspects that are associated with the achievement of the best quality of life for patients and their families. In essence, palliative care extends beyond the concept end-of-life care, as it encompasses physical, emotional, practical, and spiritual aspects of affliction throughout the course of illness (Harding et al., 2003). Terms often used interchangeably with "palliative care" are "Hospice care" and "end-of-life care".

The palliative Hospice programme provides specialized care for patients who do not respond to curative treatment in the latter stages of their disease and to their families and significant others. The patient and family are the primary unit of care with emphasis on symptom and pain control, physical, emotional, spiritual and cultural needs. Palliative Hospice care is provided by an interdisciplinary team consisting of suitably qualified professional members and trained caregivers who work together to co-ordinate a plan of care with the patient and family. For the patient, the goal is the maintenance of the highest possible quality of life, without either shortening life, or artificially lengthening it by the use of life-support systems.

Home-based care in South Africa

Since the World Health Organization (WHO) declaration of Alma Ata in 1978 established the Primary Health Care (PHC) paradigm, home-based health workers have worked in different parts of South Africa, assuming various roles (Friedman, 2002). Non-governmental organizations (NGOs) in particular were early to recognize their value in extending PHC services and have spearheaded much of the home-based health care in and around South Africa (Friedman, 2002).

The concept of home-based care has been formally introduced into the South African rural community through the Hospice organization. J. B. Magno was the founding member of the International Association for Hospice and Palliative Care (IAHPC) which was later introduced to South Africa (IAHPC, 2006). Specifically, the national Hospice Palliative Care Association of South Africa (HPCA) is affiliated to the IAHPC and serves as overall regulating authority for the Hospice movement in South Africa. On provincial level, the Hospice Association of the Western Cape (HAWC) represents the HPCA in the Western Cape. The region chosen for this study is under the auspices of the Stellenbosch Hospice, which is affiliated to the provincial HAWC.

MOTIVATION

This study is based on a two-fold motivation. The first aspect that should be highlighted as motivation for this study incorporates the use of a previous study by Armenis (2006a). This paper follows a previous study undergone as part of a community intervention by the University of Stellenbosch at the Stellenbosch Hospice (Armenis, 2006a). Home-based caregivers were observed within their work environment, with their families, patients, and patients' relatives. The previous study concerned a community intervention that was done using the theoretical conceptualization within the ecosystemic approach. Ecosystemic

thinking presupposes an approach of studying human functioning where the focus is on systems (Meyer, Moore & Viljoen, 2003). A reflection on the researcher's experience during the previous study will draw attention to the recursive patterns between and within the various systems pertaining to the home-based caregivers. Therefore, a brief explanation with the aim of highlighting the impact of the immediate and broader systems that influence the home-based caregivers in the employment of the Stellenbosch Hospice, will be given (Lewis, Lewis, Daniels & D'Andrea, 2003).

The respective study found disparities between the organizational needs described by the home-based caregivers and the Stellenbosch Hospice management team (Armenis, 2006b). Home-based caregivers cited a general lack of representation within senior management as a contributing factor and senior management ascribed the disparity to a lack of cooperation on the part some home-based caregivers who were viewed as instigators in search of improved work conditions (Armenis, 2006b). Specifically, the study found that permanent personnel were represented by a multi-disciplinary management team; and the volunteer home-based caregivers, were directed to a nursing sister and a social worker for support and supervision. In addition, a clear division of labour in a hierarchical structure with the home-based caregivers regarded as assisting personnel and the nurses, doctor, social worker and other permanent personnel wielding more authority within the decision-making mechanism of the multi-disciplinary management team of the Hospice. Consequently, it was discovered that the home-based caregivers experienced numerous psychosocial needs that were not known to the senior management team (Armenis, 2006b).

Regarding the senior Hospice staff as a subsystem, the multidisciplinary team that is responsible for the daily management of the Stellenbosch Hospice was approached and given the opportunity to voice any concerns that were of a psychosocial nature (Armenis,

2006b). A meeting was held with the team whereby it was decided that a folder would be kept with the Hospice administrator where Hospice staff could place any concerns they might have within the folder if they so wished. Furthermore, regular contact was possible by means of electronic mail.

Each nursing sister takes responsibility for a specific geographical area, supervising and mentoring the home-based caregivers who serve that area (Armenis, 2006b). In addition, nursing sisters are responsible for the care and management of patients admitted to the Hospice (Armenis, 2006b). Consequently, a proposal was made by senior staff members that more could be done to improve the quality of care for patients by introducing more creative activity days whereby individuals could participate in fun events that would assist in improving morale and general wellness within the intensive-care patient unit (IPU), situated within the Stellenbosch Hospital (Armenis, 2006b). In addition, senior management proposed that the two masters students involved in the intervention be included in wardround discussions so as to introduce a psychology dimension to the multidisciplinary team (Armenis, 2006b).

Regarding the home-based caregivers as a subsystem, Armenis (2006b) states that after initial consultations were held with the Hospice management team, discussion groups were facilitated with the home-based caregivers in an attempt to assess their psychosocial needs (Armenis, 2006a). The study found an initial reluctance on the part of the home-based caregiver to express concerns with regards to the Hospice environment (Armenis, 2006b). Misgivings on the part of home-based caregivers were ascribed to a lack of representation within the multidisciplinary team, including senior management, and a perception that grievances would disadvantage caregivers in their attempts to foster closer ties with their supervisors. Notwithstanding, the formation of a closed support group for the home-based

caregivers was reported to have increased the level of disclosure within the group (Armenis, 2006a).

The needs assessment found that most of the home-based caregivers reported a conflict of interest between the various roles that they fulfilled in their work and daily lives respectively (Armenis, 2006b). Caregivers reported numerous cases whereby caregivers had been asked to assist patients with tasks that were not part of their job description (Armenis, 2006b). Specifically, the study cited that caregivers were sometimes asked to assist patients after hours without remuneration (Armenis, 2006b). Furthermore, it was found that home-based caregivers experienced their patients as demanding and expressed a need to develop the necessary skills that would assist them in their task of caring for difficult patients (Armenis, 2006b). The study concluded that the clarification of home-based caregiver responsibilities and the introduction of a psychosocial intervention would provide an important measure of relief regarding the expressed role confusion and conflict experienced by caregivers (Armenis, 2006b). As part of the psychosocial intervention, a psychoeducational component (Armenis & Amadhila, 2006) and a support group element (Armenis, 2006a) was introduced to the home-based caregivers.

Despite the delineation of duties within the Stellenbosch Hospice, home-based caregivers reported that they were unable to complete their tasks and some of them stated that their supervisors did not appreciate their position within the community and the degree of responsibility that was placed on them by Hospice management and the community respectively. Specifically, the home-based caregivers reported a conflict of interest between their patient load and their family responsibilities, reporting that they felt ill-equipped to deal with the demands of their nursing supervisors, palliative patients, and their own families. Therefore, the Hospice management and the home-based caregivers experienced

the needs of the organization differently which resulted in tension as both systems vied for access to the limited pool of resources. The needs assessment therefore revealed that the home-based caregivers expressed a need for additional support from the Hospice management and they required a forum in which they could voice their concerns and participate to a greater degree in the decision-making process of the organization (Armenis, 2006b).

From an ecosystemic perspective, the researcher is a subsystem that contributes to the interrelationship between the already abovementioned subsystems that impact on the home-based caregivers. Moreover, the perspective of the researcher may provide much needed insights as to the possible barriers and facilitating factors related to the collaboration between the various subsystems within a Hospice organization (Meyer et al., 2003). Further, the lived experience of the researcher may assist in highlighting possible barriers that could hinder the flow of a rich narrative.

Regarding the researcher's experience of the larger organizational system, the hierarchical structure and management protocol that was in place simplified administration duties and provided the researcher with an established framework that could be used to facilitate the communication between the relevant role players. On the other hand, there were instances whereby the established structure provided by the organization was experienced as inflexible. For example, the researcher was expected to communicate with the organization by means of the Hospice manager and was perceived by the home-based caregivers as having formed an alliance with the senior management. However, attempts by the researcher to communicate with the home-based caregivers necessitated the Hospice management's network which reinforced the view of some home-based caregivers that the researcher had formed an alliance with the Hospice management. Consequently, the

attempt by the Hospice management to foster alliances with the researcher and the resultant hesitation by home-based caregivers to partake within the exploratory process, may suggest the presence of a negative feedback loop within the second-order cybernetics as proposed by Meyer et al. (2003). As a result, the home-based caregivers showed a reluctance to express their concerns to the researcher, promulgating the recursive pattern of interaction between the home-based caregivers and the senior Hospice management.

Furthermore, the senior Hospice management showed a willingness to learn about the confidential issues discussed within the closed support group provided by the researcher and his colleague for the benefit of the home-based caregivers. At first, members of the senior Hospice management challenged the creation of a closed group, citing the need for senior management to have access to all home-based caregiver concerns expressed within the borders of the community intervention. Despite initial resistance to the creation of a closed support group for the home-based caregivers, evidence of a gradual improvement in morale shown by the home-based caregivers increased the level of support for the intervention among the senior Hospice management. In addition, the senior Hospice management perceived the closed support group as a possible mechanism for the improvement of productivity and quality of care within the broader organization. Therefore, the intervention by the researcher as an external subsystem, manifested a positive feedback loop within the second-order cybernetics of the broader system as regards the home-based caregivers and the senior Hospice management team. As a result of the creation of a closed support group for the home-based caregivers, a safe environment was formed for the voicing of grievances by the home-based caregivers. This facilitated the degree of disclosure by the home-based caregivers and improved overall participation within the community intervention. An additional intervention to improve collaboration and

communication within the Hospice organization was introduced through the election of representatives that could represent the interests of the home-based caregivers. Moreover, efforts were made to liaise with the elected representatives during consultations with patients and the Hospice management respectively.

Despite efforts to maintain a neutral stance within the organization, the researcher experienced the hierarchical structure of the organization and the different levels of authority as a factor that divided the home-based caregivers among themselves. The representatives that had been chosen were perceived as having certain advantages over the other home-based caregivers and were soon viewed with some suspicion by a number of their colleagues. Therefore, the home-based caregivers' previous lack of representation and the hierarchical structure within the Stellenbosch Hospice appeared to contribute to the perpetuation of a negative feedback loop whereby the home-based caregivers would withdraw from senior management and one another when individual home-based caregivers perceived a lack of collaboration within the organization.

The researcher was provided with an opportunity to enter the homes of the home-based caregivers that were employed by the Stellenbosch Hospice and lived in the Klapmuts community. The researcher observed that the community in which the home-based caregivers and their patients resided was socioeconomically underdeveloped and observed a tendency among community members to rely on one another for their everyday needs. The researcher observed community members that were in need of assistance; approach the home-based caregivers while they were at home in the presence of family members. As a result, the home-based caregivers' homes appeared to be open to the public, creating a chaotic atmosphere within the small enclosures. The researcher experienced that the home-based caregivers within the Klapmuts community were approached for assistance regarding

matters unrelated to their Hospice caregiver duties. Specifically, caregivers were asked to help with cleaning, cooking, acquisition of food packages, assistance with government subsidies, transport to the provincial hospital, financial assistance, and various other needs. The home-based caregivers appeared reluctant to decline assistance to members of their community. The researcher experienced the persistent calls for assistance as overwhelming and time consuming.

The relative proximity of caregivers to their patients and the long waiting periods, formality, and cost of attending the Klapmuts Community Healthcare Clinic, appeared to make the option of requesting assistance from the home-based caregivers, more attractive to members of the community. The researcher experienced the persistent interruptions and requests for assistance by members of the community as a hindrance to the family and personal well-being of home-based caregivers. Caregivers expressed their distress to the researcher that the senior management of the Stellenbosch Hospice were unable to provide them with the additional support they needed. The perceived lack of agency on the part of the home-based caregiver within the Hospice organization seemed to be experienced as a reluctance to assist members of the community. It was therefore evident that the community placed a disproportionate amount of responsibility on the home-based caregiver.

Subsequently, the need for community and family education with regards to the home-based caregivers' role within the community and Hospice organization were apparent.

The researcher was taken to patient homes within the Klapmuts community and provided with an opportunity to observe the home-based caregivers perform their duties. The homes were small and overcrowded as shared living quarters included patients' extended family. Patients expressed feelings of being a burden, which was enhanced sometimes by having to ask for help. Having to be dependant on others impacted on their

role and those of caregivers, often causing an emotional impact on patients' lives. Nevertheless, the researcher found that patients were pleased to see their respective caregivers and had anticipated their arrival in advance. The arrival of caregivers in their patients' homes often accompanied a celebratory atmosphere as family members could sit back and watch their loved ones receive care. The researcher observed family members examine the caregivers. Caregivers played a significant part in educating family members about their care functions and the researcher experienced the caregivers' presence within the patient household as reassuring.

Numerous difficulties were experienced during the data collection phase of the study. Patients often spoke softly and their speech was muffled by noise from the vicinity. Furthermore, patients did not have dentures which contributed to difficulties in pronunciation and comprehension of speech. Frequent interruptions from members of the household often distracted patients and constricted the flow of a rich narrative. Patients were experienced as being 'at the mercy' of their caregivers which may have contributed to a degree of reluctance on the part of patients to express concerns with regards to the level of care they had received.

The second aspect that should be highlighted as motivation for this study regards the urgent need for research concerning home-based care in the outlying regions of South Africa. Higginson and Bruera (2002) suggest that it is important for new or expanding palliative and end-of-life projects in developing countries to understand both the problems and successes experienced in existing programs around the world. However, the limited amount of available research concerning end-of-life care has emphasized the need for the development of research programs in developing countries. Consequently, the first survey

of HIV/AIDS end-of-life care in sub-Saharan Africa was recently conducted by Harding and associates in 2003 (Harding et al., 2003).

Despite some progress in the formal recognition of CBHWs and their work within the South African community, uncertainty about their precise roles remains (Friedman, 2002). The situation with regards to the issues that confront CBHWs have largely remained the same since the 1980's, however, the HIV/AIDS pandemic, and pervasive levels of poverty within their own communities, have served to increase the demands already placed on them. In addition, the CBHWs have been perceived as a catalyst for community development, with some of the issues included as part of their responsibilities including (Friedman, 2002): i) general safety, ii) nutrition, iii) family planning, iv) HIV/AIDS, and v) sanitation. Consequently, it was envisaged that the CBHW would become an integral part of a more decentralized health service, receiving remuneration and support either by the Government or the local community, in accordance with their training and skills (Friedman, 2002). However, in 1995, a national task force was contracted by the Health Systems Trust to report on the feasibility of greater state support for home-based health programs (Friedman, 2002). The report proposed the implementation of a phased model by the national government, with a recommendation that existing programs be strengthened (Friedman, 2002). Further suggestions included an evaluation procedure to measure the effectiveness of the home-based model prior to a decision, whether to expand or not, with additional recommendations that health personnel in general be re-oriented as to the role of the CBHW (Friedman, 2002).

Notwithstanding the progress in the formal recognition of CBHWs and their work within the community, uncertainty about the precise role of the CBHW remains. Moreover, despite the reaching of a national consensus in standards for the provision of a training

framework for all workers in the category, home-based caregiver, individual Hospice programs remain disjointed with regards to the training protocols they choose to implement with their home-based staff.

The WHO (1997) amended its classification of disability to reflect not only parameters of the life of the person with disability but also their interaction with their community. In the palliative care setting, patients interact with their caregivers regularly and derive meaning from their interactions within the care context (Harding et al., 2003). However, a limited body of research has been done with the aim of highlighting the care-needs of palliative patients within the South African rural context.

RESEARCH GOAL

The overarching purpose of this study was to elicit terminally ill patients' role expectations concerning their respective home-based caregivers. In so doing, it was hoped that a better understanding of the needs and related caregiver roles will be brought to light with the aim of improving the palliative care service provided by the home-based home care program currently in effect throughout the rural and outlying regions of South Africa. There is a need for research with a primary focus on the extended roles of the home-based caregiver within poorer South African communities. Consequently, this study has attempted to address the need for explorative, qualitative data with regards to the palliative requirements of the terminally ill and the corresponding role expectancies of home-based caregivers.

LITERATURE REVIEW

Incidence of Mortality

In a study of adult mortality conducted in a rural South African population, AIDS, with or without tuberculosis, was found to be the largest single cause of adult death (Hosegood, Vanneste & Timaeus, 2004). In addition, AIDS was discovered in all age groups with many

middle-aged, as well as young adults succumbing to the disease (Hosegood et al., 2004). The relative contribution of AIDS to mortality was higher for women than for the male population, with 52% of all female deaths and 44% of male deaths attributable to the disease (Hosegood et al., 2004). In the same study, tuberculosis without evidence of AIDS was found to be an important cause of death, particularly among middle-aged men (Hosegood et al., 2004). Regarding non-communicable diseases, a substantial proportion of mortality was attributed to ages ranging between 45 and 59 years, with 76% and 71% of all deaths found in women and men respectively, aged 60-years or older (Hosegood et al., 2004). In older people, cerebrovascular disease was established as the largest single cause of death, accounting for a 34% mortality rate in women and 17% in men (Hosegood et al., 2004).

Available statistics regarding mortality rates within the Stellenbosch District catchment area have indicated a total of 482 cases recorded as per the period January 2002 to December 2002 (Medical Research Council [MRC], 2002). Of the cases reported in the area, 303 (74.1%) were male and 106 (25.9%) were female (MRC, 2002). In addition, the leading causes of death among males was homicide (39.3%) and among females was undetermined (27.4%), followed by homicide (22.6%), and transport (22.6%) (MRC, 2002). Mortuary figures obtained for statistical purposes however do not contain sufficient data regarding primary cause of death in many cases. Reasons for this fact relate to the stigma often associated with HIV/AIDS as well as the complex nature of the syndrome which results in secondary infection and other complications that are often documented as primary causes of death such as pneumonia and tuberculosis for example.

HIV/AIDS Home-based Care

Efforts to control the human immunodeficiency virus (HIV) pandemic have had limited success. Estimates indicate that between 35.9 and 44.3 million people are living with HIV (UNAIDS, 2004). South Africa continues to have the highest number of people living with HIV in the world, with between 4.5 million and 6.2 million infected individuals at the end of 2003 (UNAIDS/WHO, 2004). Consequently, the need for effective palliative care that is both affordable and accessible to the poorer and outlying communities of South Africa is in great demand as existing hospital infrastructure is often limited or inaccessible (Harding et al., 2003).

Curtis and Patrick (1997) found the following facilitating factors in the discussion of end-of-life care between patients and their physicians:

- Concern about future quality of life
- Desire for autonomy at the end of life
- Physician care about the patient “as a person”
- AIDS expertise of physician

In addition, Curtis and Patrick (1997) propose that most AIDS patients want to discuss end-of-life care with their physicians. However, studies have been cited that report to have found discussions of advance directives to precipitate illness or death and even cause increased levels of psychological pain in terminally ill patients (Curtis & Patrick, 1997). Consequently, the study recommended that health care workers should provide end-of-life patients with ample opportunity to express their concerns regarding the harm that may result from end-of-life care discussions (Drew, Mgombane, Nyaruwa & Foster, 1997).

Spirituality and End-of-Life Care

In the survey conducted by Harding et al. (2003), it was discovered that approximately forty-seven programs, or 98% of the programs in the respective study, reported traditional healers playing a role in local health belief and practice. Notably, 80% of the patients in the surveyed programs reported that they sought the advice of traditional healers, which Harding et al. proposed as the primary reason for delayed clinic presentation and medical intervention. In the programs surveyed, the inclusion of traditional healers was often cited as the key in achieving increased community approval and patient uptake (Harding et al.). Contributing to the effectiveness of the spiritually inclusive nature of the programs was the fact that a vast array of traditional healers was made available for the spiritual needs of patients (Harding et al.). Specifically, priests, Sangomas, Pandits and Mollanas were included in the education programs, with Hindu, Christian and Moslem spiritual care-providers provided as the need arose (Harding et al.).

In a study on tuberculosis patients in a rural South African community, patient beliefs were found to have an impact on the quality of care provided (Edginton, Sekatane & Goldstein, 2002). Consequently, Edginton et al. suggest that holistic patient care requires communication between all care providers in order to accommodate the patients' cultural needs and to avoid conflict between the various care providers. It was suggested that local practices and beliefs concerning tuberculosis (TB) could serve to improve rapport and understanding between patients and health workers (Edginton et al.). Specifically, it was proposed that traditional healers and western health workers should engage with each other to discuss what each can do for the patient (Edginton et al.). The apparent cooperation between the traditional healer and health worker was cited as a factor that may set patients

more at ease with regards to consulting with both healthcare providers, and subsequently facilitate the earlier presentation for medical intervention (Edginton et al.).

Communication and Race

In an American study conducted by Zapka et al. (2006), it was found that African American participants who were under the care of African American physicians were less likely to report pain and/or symptom management than other racial matches. In a Zimbabwean study on the coverage of home-based home care programs, it was discovered that between 2.5% and 23% of the region under study had coverage with regards to home care services (Drew et al., 1997). Furthermore, it was suggested that home care programs should focus on covering larger geographical areas by improving communication between the health care service provider and the broader community (Drew et al.).

Older Adults and End-of-Life Care

Casarett, Teno and Higginson (2006) state that there is an ever increasing need for the evaluation of end-of-life care provided for the elderly. As the average life span in developing countries begins to increase, so too will the demand for palliative and Hospice care services for the aged (Casarett et al.). However, home-based care initiatives offer unique challenges with regards to the evaluation and assessment of care provided to patients within the community.

Palliative and End-of-Life Care as Life Sustaining

Patients who choose palliative care often feel as though they are “giving up,” leading to ambivalent feelings in themselves and members of their families (Sawicki & Graf, 2001). Dudzinski and Shannon (2006) explored the refusal of nursing care by competent patients and argue that end-of-life care can be life sustaining when one considers the following caregiver functions:

- Assisting a patient postoperatively to ambulate helps to protect against deconditioning, deep vein thrombosis, pneumonia and skin breakdown.
- Cleaning patients after urinary or fecal incontinence prevents skin breakdown and reduces the risk of infection.
- Turning patients who are bedridden is a crucial component of maintaining skin integrity to prevent skin breakdown or bedsores.

Consequently, with the basic care withheld or denied, patients can develop life-threatening complications that may not be manageable with antibiotics or other technological advances (Dudzinski & Shannon, 2006).

Palliative care and End-of-Life Decisions

End-of-life decisions are very difficult and may provoke discomfort, anxiety, and fear in patients who face the prospect of premature death. Home-based caregivers and all who play a role in caring for the chronic patient need to develop and refine their communication skills to facilitate discussion (Sawicki & Graf, 2001). One of the challenges most commonly cited in the provision of palliative care is that patients are often reluctant to discuss or plan for the possibility of death (Kramer & Auer, 2005). This may place such patients at a disadvantage regarding the quality of care they receive and the ability to collaborate with caregivers (Curtis, Engelberg, Wenrich & Au, 2005).

Decision-making and patient-caregiver collaboration may become strained during the progressive stages of HIV/AIDS as a result of dementia or delirium and the cognitive decline associated with these two conditions (Coyne, Lyne & Watson, 2002). Coyne et al. propose the introduction of palliative care at the initial diagnosis of HIV to prepare the patient for and assist with collaboration during the later stages of the condition.

METHOD

Research Design

The phenomenological method according to Giorgi (1997) was used to elicit role expectations of home-based caregivers from a predetermined study sample. Patient responses were analyzed by means of the phenomenological methodology approach based on the philosophy and work of Husserl, and further developed by Giorgi. This method was used to ‘bracket’ researchers’ earlier knowledge in order to obtain an insider’s view of the phenomenon spoken about by the respective study participants who have lived these experiences and can explain them (Giorgi). Specifically, bracketing refers to ‘going back to the things themselves’, which is seen as a phenomenological imperative (Randers, Olson & Mattiasson, 2002). Consequently, the phenomenon under study is the everyday world (which in phenomenology is called the life-world) as it shows itself in people’s experiences (Rander et al.).

Participants

There exists to date no research concerning palliative patient expectations of home-based caregivers within the outlying areas of the Western Cape. Therefore, exclusion for participation in the study was based on the following criteria: i) terminally ill status; ii) patient has been assigned a home-based caregiver; iii) English or Afrikaans speaking. Participants for the study were recruited from the Stellenbosch Hospice home-based home care program in Klupmuts. The community from which the sample was drawn was predominantly Coloured and socio-economically disadvantaged. Convenience sampling methods were used to extract a group of three study participants. Two male and one female

patient participated in the study. Two patients were diagnosed with cancer and one was diagnosed with HIV/AIDS.

Procedure

Information regarding the nature and purpose of the study was provided to all participants before consent was obtained. Face to face interviews were performed in an unstructured manner whereby participants were given the opportunity to voice their needs and expectations regarding the care provided by the home-based caregiver. Interviews were recorded with a conventional cassette recorder in a private setting. Each respondent was interviewed for 30 minutes with the entire process lasting approximately 45 minutes per participant.

Data Analysis

The data was analyzed using the Giorgi method of coding, transforming, and synthesizing data (Giorgi, 1997). The phenomenological method implies a rigorous, step-by-step analysis of concrete life descriptions (Merriam et al., 2002). To stay faithful to data and avoid being biased during the analysis the researcher has to set aside any preconceptions or assumptions regarding the phenomenon. This is termed bracketing (Giorgi). The researcher cannot suspend all preconceptions concerning the phenomenon; however, the researcher needs to be aware of his assumptions during the analysis in order to avoid being biased by them (Merriam & Associates, 2002).

The method included the following steps (Randers et al., 2002):

- i. Naive reading in order to grasp a sense of the whole.
- ii. Discrimination of meaning units within the chosen perspective, focusing on the phenomenon under study.

- iii. Every meaning unit was reflected on with free imaginative variation and transformed into a statement expressing its most invariant meaning – a careful transformation of each meaning unit into everyday language in an attempt to shed light on, and better understand the participants' lived experience of the phenomenon.
- iv. When all meaning units had been transformed, the researcher reflected on the variation of meanings that emerged from the analysis of the phenomenon, and subsequent salient meaning units that do not vary between the individual participants' unique meanings were illuminated.

The insights were synthesized and integrated into a descriptive structure containing a succinct list of interrelated constituents (Merriam & Associates, 2002). The general structures emerging from the analysis illuminated the essential meaning of the phenomenon: 'role expectations of the home-based caregiver'.

Ethical Considerations

Participants were asked verbally if they were willing to participate in the research study after which an informed consent procedure was initiated. Proposed shortcomings in the traditional informed consent process include inadequacies of self-disclosure and participant comprehension of that which they have been told (Halpern, Metzger, Berlin & Ubel, 2001). Information regarding the nature and purpose of the study was explained to all study participants. Subsequently, participants were informed that they may discontinue participation in the study at any time they feel the need to do so. In addition, informed consent forms were disseminated to the study sample before commencement of the face-to-face interviews. The informed consent procedure took approximately 10 to 15 minutes to complete. After the prospective participants had been informed, they were asked whether

they formally consent to participate. Acknowledgment of consent was demonstrated by means of a signature that accompanied an indemnity form.

To ensure anonymity, participants were identified by the allocation of numerical codes. Consequently, data was presented under the respective numerical codes of each individual study participant.

RESULTS

The two overarching themes that emerged from an analysis of study participant interviews were the physical care (see Table 1) and psychosocial care (see Table 2) functions expected of a home-based caregiver. Furthermore, respective themes were divided into sub-themes that underscore the relevant expectations promoting physical and psychosocial care within the context of home-based healthcare. In addition, each sub-theme was further subdivided into specific activities that were expected from home-based caregivers.

The theme 'physical care' included the following sub-themes: i) hygiene; ii) feeding; iii) physical assistance. The sub-theme 'hygiene' consisted of the following activities: i) bathing and washing; ii) fresh smell; iii) shave body hair; iv) wash dishes; v) wash clothing and bedding; vi) sweep floors; vii) dust; viii) clean kitchen; ix) take out the rubbish. The sub-theme 'feeding' consisted of the following activities: i) grocery shopping; ii) cooking; iii) provide meals; iv) provide for dietary requirements, v) assistance with food intake. The theme 'physical assistance' included the following activities: i) hair & make-up; ii) dress patient; iii) physical exercise/therapy; iv) wheelchair, chair, bed transfer; v) ambulatory support/pushing wheelchair; vi) take patient outside; vii) take patient for 'walks'; viii) provide patient with opportunities to assist self.

The theme 'psychosocial care' consisted of the following sub-themes: i) communicate care; ii) support; iii) need for community. The sub-theme 'communicate care' included the

following activities: i) patience; ii) punctuality; iii) visit patient on own account/friendship; iv) listen to patient narrative; v) chat with patient; vi) involve patient in decision-making & care activities; vii) remember patient concerns; viii) discipline patient in a firm & friendly manner; ix) encourage patient participation; x) compliment effort.

The sub-theme ‘support’ comprised the following functions: i) supportive counselling; ii) psycho-education; iii) assistance informing significant others; iv) transport assistance; v) financial support; vi) crisis management; v) provide for patients’ dependent others.

The sub-theme ‘need for community’ included the following activities: i) up-to-date knowledge about the community, ii) discuss community goings-on; iii) provide accurate information and guidance regarding the patient to the community (friends & neighbours).

Physical Care Expectations of Home-based Caregivers

Interview responses regarding the physical care functions of a home-based caregiver fell into three sub-themes with each sub-theme further represented by specific activities that were reported as necessary in the satisfaction of the respective physical care functions. The particular sub-themes and activities are given in Table 1. A brief description of each of the sub-themes and their respective activities follows, to better illustrate patient expectations.

Participants expressed a need for assistance regarding their hygiene requirements. Participants reported that home-based caregivers were expected to concern themselves with the personal hygiene of individual patients and the maintenance of a clean household.

- “She must wash me and keep the house smelling fresh”
- “When she comes I would like her to wash the dishes and clean the kitchen”
- “...she can shave my beard and cut my hair when it gets too long”
- “The mattress needs to be turned over and the bedding placed in the sun”

- “The floors should be swept and rubbish taken outside”

Table 1
Summary of Patient Physical Care Expectations Tabulated into Themes and Sub-themes

PHYSICAL CARE EXPECTATIONS	
1. HYGIENE	
i.	Bathe & Wash
ii.	Fresh smell (air room)
iii.	Shave body hair
iv.	Wash dishes
v.	Wash clothing & bedding
vi.	Sweep floors
vii.	Dust
viii.	Clean kitchen
ix.	Take out the rubbish
2. FEEDING	
x.	Grocery shopping
xi.	Cooking
xii.	Provide Meals (contributions/aid)
xiii.	Provide for dietary requirements
xiv.	Food intake (assist with feeding)
3. PHYSICAL ASSISTANCE	
xv.	Hair & Make-up/Physical appearance
xvi.	Dress patient
xvii.	Physical Exercise/Therapy
xviii.	Transfer (wheelchair/bed/chair)
xix.	Ambulatory Support/Pushing wheelchair
xx.	Take patient outside
xxi.	Take patient for ‘walks’
xxii.	Provide patient with an opportunity to assist self

One of the most common expectations to arise from participant interviews was the fulfilment of nutritional needs and assistance with the intake of food.

- “I need somebody to get the food and cook it for me”

- “The cans of food the Hospice gives helps my family”
- “I have difficulty eating and need help preparing food that I can digest”
- “She can help me eat the right things so I don’t get weaker”

Participants cited physical assistance as an important need that home-based caregivers should include as one of their activities.

- “She should help me put on my clothes and shoes”
- “She rubs my body and shows me how to exercise my body in bed”
- “I need her to transfer me from my bed to the chair”
- “She provides support when I sit up in bed and pushes me in the wheelchair”
- “It would be good if she can take me outside so I can see the people”
- “She must let me try to help myself if it is possible”

Psychosocial Care Expectations of Home-based Caregivers

Interview responses regarding the psychosocial care functions of a home-based caregiver fell into three sub-themes with each sub-theme further represented by specific activities that were reported as necessary in the satisfaction of the respective psychosocial care functions. The particular sub-themes and activities are given in Table 2. A brief description of each of the sub-themes and their respective activities follows, to better illustrate patient expectations.

Table 2
Summary of Patients' Psychosocial Care Expectations Tabulated into Themes and Sub-themes

PSYCHOSOCIAL CARE EXPECTATIONS	
1. COMMUNICATE CARE	
i.	Patience
ii.	Punctuality
iii.	Visit on own account (friendship)
iv.	Listen to patient narrative/stories
v.	Chat with patient
vi.	About family issues
vii.	About neighbours
viii.	About the home
ix.	About the environment
x.	Involve patient in decision-making & care activities
xi.	Remember patient concerns
xii.	Discipline (firm & friendly)
xiii.	Encourage Patient Participation
xiv.	Compliment Effort
2. SUPPORT	
xv.	Supportive Counselling
xvi.	Psycho-education
xvii.	Illness & Expectations
xviii.	Medication & Compliance
xix.	Healthy Living (hygiene & nutrition)
xx.	Assistance Informing Significant Others
xxi.	Family Guidance
xxii.	Transport Assistance
xxiii.	Financial Support
xxiv.	Social Welfare (disability grants & related assistance)
xxv.	Crisis Management
xxvi.	Availability
xxvii.	Medical Assistance
xxviii.	Psychosocial Support
xxix.	Provide for the Patient's Dependant Others

Table 2 (*continued*)

PSYCHOSOCIAL CARE EXPECTATIONS	
3. NEED FOR COMMUNITY	
xxx.	Up-to-date Knowledge about the Community
xxxii.	Discuss Community Goings-on <ol style="list-style-type: none"> a. Church b. Safety (police) c. Problems (alcohol/drugs) d. Progress
xxxiii.	Provide accurate information and guidance regarding the patient to friends & Neighbours

Participants expressed a need for their respective home-based caregivers to communicate care. A common activity cited as indicative of a caring attitude involved spending time listening to patient concerns. Other expectations expressed the need for caregivers to be patient and punctual.

- “She must be patient with me when I get upset and visit me regularly”
- “If she is late I feel she does not care about me”
- “I need her to listen to my stories and help me remember my younger days”
- “I enjoy having somebody to talk to about what is going on in the world”
- “I need somebody to talk to about my home and family problems”
- “The neighbours concern me sometimes and I need to talk about that”

Respondents reported that they want to participate in the management of their own healthcare by being consulted before any decisions are made regarding their care. They also cited that caregivers should remember their individual concerns and provide regular

encouragement by acknowledging effort. Further, participants reported that caregivers should be disciplined and professional by telling patients what is inappropriate behaviour.

- “I expect to be asked what I prefer”
- “It is supposed to be like a partnership where I help make the decisions”
- “She must try to help me when I am feeling weak and remember what I say”
- “They need to show you what is right and be professional”
- “I expect her to tell me when I am difficult and finish the job”

Respondents reported an expectation that their respective home-based caregivers provide them with various forms of support. The most frequently cited supportive function of a home-based caregiver was supportive counselling. Another common expectation was that caregivers provide psycho-education regarding various health-related questions.

- “I expect her to guide me when I feel I cannot go on like this...”
- “I need to hear words of encouragement and that it will be okay”
- “She should help me understand what is happening and what I can do”
- “I expect her to explain to me when and why I need to take the tablets”
- “She can tell me how to stay healthy”

Respondents reported that home-based caregivers were better equipped to inform their family members about their medical condition and related needs. They also stated that they expected the home-based caregivers to provide guidance and supportive counselling to their family members.

- “She can explain everything to my family because it is her job”
- “My family can ask questions and she can help them understand”
- “I want her to tell my family the difficult news”

Respondents stated that their caregivers are expected to provide transport and financial assistance. The need for guidance regarding government aid applications and other welfare forms were highlighted by all participants. Moreover, the expectation that home-based caregivers should make themselves available during a medical emergency was cited. Specifically, respondents stated that their caregivers should be willing to provide medical assistance and psychosocial support during a crisis. Participants also reported that caregivers are expected to provide for their dependents' immediate needs following a medical emergency.

- “She must bring the ambulance or help me pay for the taxi if I need to go to the hospital”
- “I need her to fill the disability papers and explain to us how it works”
- “We need her help with the financial assistance the government gives out”
- “Her job will be to come if something happens to me”
- “She will have to come quickly to help me and my family”
- “I want her to help me get to hospital and make sure my wife and children are alright and know what is going to happen”

Participants expressed a need for their respective home-based caregivers to help them maintain their relationship with the community. They explained that they would like to be informed about the community and participate in discussions regarding various topics. Respondents reported that they expect caregivers to give an accurate account of their condition to friends and neighbours.

- “I want her to tell me what is going on outside and talk about the noises I hear”
- “I need somebody to tell me what is happening in this neighbourhood”

- “I expect her to explain to me what they (police) are planning to do about the problems in this street”
- “I want her to let me know what happened in church on Sunday”
- “She must tell my friends and neighbours why I cannot go out as much”
- “I expect her to explain to my friends...how I am doing so they don't worry”

DISCUSSION

Patient opinion, until recently, played a limited role in the assessment of palliative care in Africa (Sepulveda et al., 2003). In the past concerns were determined by healthcare professionals (Armes & Higginson, 1999). However, there is increasing evidence that the contribution of the ‘patient viewpoint’ has augmented the assessment of quality care (Horne & Payne, 2004).

The results of this study illuminated the complex nature of the needs of patients with palliative care requirements. The qualitative approach allowed the interviewees the flexibility to discuss their expectations of their home-based caregivers and enabled the researcher to explore the issues. Many of the issues previously identified as of concern were also highlighted in this study. The three overarching psychosocial needs cited by patients included: i) communicate care, ii) support, iii) need for community. Specifically, the expectations cited by respondents concerned the need for information, community and emotional support.

Patients reported that they expected home-based caregivers to inform them and significant others regarding ‘what to do’ and ‘what to expect’. Furthermore, all respondents stressed the need for emotional support to family members as being of particular concern to their quality of care (Jennings, Ryndes, D’Onofrio & Baily, 2003). Family members are

often the front-line providers of daily care, working in tandem with home-based caregivers. In a study investigating nurse issues within the palliative care context, six of ten obstacles and barriers to the provision of specialist palliative care were found to be perceived by critical care nurses as related to issues with patients and families (Ahmed et al., 2004). In a recent study regarding communication between caregivers, patients and their relatives, over 50% of GPs reported that they experienced difficulties in situations featuring disagreement among relatives and the handling of relatives' hidden agendas (Groot, Vernooij-Dassen, Verhagen, Crul & Grol, 2007). Similarly, Ahmed et al. (2004) found that physicians identified patient and family issues as significant barriers to earlier hospice referral as patient and/or family members tended to show discomfort, anxiety, and fear of death and dying. An additional barrier cited was that of family members being angry and disagreements within their group about treatment options (Ahmed et al.). In the current study, despite the initial sense of relief and gratitude shown by family members towards home-based caregivers, family members seemed critical at times of the care their family members were being subjected to. Similarly, Ahmed et al. reported that in many instances, family members perceived palliative care as giving up on the patient, which was reported to have precipitated feelings of ambiguity and anger towards caregivers. Consequently, the need for educational and emotional support of family members may serve to improve the caring relationship and level of cooperation between home-based caregivers and family members.

To perform their caregiver roles well and alleviate some of the demands placed on home-based caregivers, they require ongoing support, training and information. Roscoe and Schonwetter (2006) posit that barriers to palliative care such as a lack of awareness of options available to patients may be overcome to a large extent through improved

collaboration between family members and home-based care providers. Family members that provide palliative care for a relative desire information on how to provide practical care, how to ease the patients' discomfort, and require knowledge about what they could expect in terms of both the patient's and their own emotional responses to the illness (Aoun, Kristjanson, Currow & Hudson, 2005). The provision of information is therefore recognized as a central form of support for the patient and their family.

All patients interviewed in this study reported a need for additional information about their health and requested that they be encouraged to participate in the provision of their physical needs as much as possible. This finding illustrates the importance of patient education in the provision of palliative care and has been incorporated into legislation within various states in the United States of America; legislation that in some cases perceives patient education as the legal responsibility of healthcare providers (Haley, 2007). By identifying deficits in the knowledge of patients, insight into training needs can be obtained that may be used to supplement in-service educational programs for home-based caregivers. Curtis et al. (2005) posit that informing patients may improve the quality of care provided and the degree to which patients are able to assist their caregivers in decision-making and the sharing of responsibility.

Respondents' reported that they expected their home-based caregivers to assist them in maintaining ties with the surrounding community. In a study that investigated the palliative care training curriculum, the societal context in which palliative care occurs and societal attitudes towards palliative care and dying were reported as required training objectives (Kortes-Miller, Habjan, Kelley & Fortier, 2007). The researcher observed that the members of the Klapmuts community, where the home-based caregivers and their patients resided, tended to rely heavily on one another for emotional and material support. As a result,

patient care may include the community to the benefit of home-based caregivers, patients, and relatives, as the community may contribute significantly to the quality of care provided.

Limitations and Recommendations

The diminutive sample size of this study limits the degree to which these research findings may be generalized to the greater population under study. Moreover, despite the unstructured nature and lack of methodological control found in quantitative research designs, the utilization of qualitative research methods are useful when there is a lack of theory or an existing theory fails to explain a phenomenon (Merriam & Associates, 2002). Furthermore, the inductive nature of qualitative investigation aims to accumulate data on the phenomenon under study, building towards theory from intuitive understandings gleaned from being in the field (Merriam & Associates).

Participants indicated that they were more comfortable being able to change from one language to the other if they wished; this encouraged the flow of a rich narrative. Catania (1999) found that in addition to language issues, respondents encounter problems when investigators examine concepts that are beyond their everyday observations. Therefore, provision was made for both English and Afrikaans speaking participants. Despite this, South Africa's eleven official languages and eclectic cultural mix (Wissing, 2002) made issues of comprehension and informed consent difficult to implement. In an attempt to overcome this barrier to informed consent, commonly used terms were used to explain the possible risks and benefits of participation in the study, however, the extent to which the relevant concepts were grasped remained undetermined.

Catania, Gibson, Chitwood and Coates (1990) found that face-to-face interviews were more likely to make respondents believe that the interviewer can identify with them, connect answers with personal identifiers, and see and hear them during the interview.

Interviews were conducted in a private setting so that respondents were made to feel comfortable, thereby increasing opportunities for self-disclosure (Catania, 1999). Previous research has recommended that health care workers provide end-of-life patients with ample opportunity to express their concerns regarding the harm that may result from end-of-life care discussions (Drew et al., 1997). However, despite measures taken to improve participant disclosure, the degree to which the study cohort relied on its caregivers may have limited the extent to which respondents were willing to express their dissatisfaction with their respective care providers.

For these reasons and given the nature of qualitative methods, the findings cannot be generalized to a larger population. Nevertheless, they do offer tentative insights on the perceived role of home-based caregivers by patients in need of palliative care. The role expectations identified require further systematic assessment before they can be used with confidence in enhancing the quality of the home-based care experience for patients and caregivers alike.

CONCLUSION

This study established the diverse responsibilities associated with home-based care. In particular, despite the more basic hygiene and nutritional needs reported, the provision of psychosocial support and the maintenance of a caring relationship were prevalent.

Caregivers were expected to involve respondents in their management decisions and encourage ongoing active participation. Randers et al. (2002) found that the wish to be confirmed constitutes the basis of human life and human growth and concluded that it was of great importance to the patient's self-experience, self-evaluation and existence. The need for training and ongoing support of family members was cited by patients as being of great

importance and may contribute to the improvement of care and clarification of roles within the palliative care team responsible for the well-being of patients.

Recommendations for future research include the investigation of patient relatives' roles as an essential component of the unit of care. Moreover, the education and support of patients and their significant others within the societal context should be considered with regards to the training of home-based caregivers.

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