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Program of University Diploma in Nursing, 180 ECTS credit points

INFORMAL CAREGIVERS OF HIV/AIDS-INFECTED FAMILY MEMBERS

– a qualitative study of experiences of hospice staff in a rural area, South Africa

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School of Health Science/
University of Pretoria,
Faculty of Health Sciences**

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ABSTRACT

As the number of individuals and households affected by HIV/AIDS multiplies in South Africa, the impact of the epidemic both widens and deepens. As a complement to the formal system of health care, an informal health care has emerged. These informal caregivers, often elderly parents, constitute a national health resource, but they are also a vulnerable population and the care that they provide is unlikely to be costfree. The aim of this study was to illuminate the situation of elderly people in a rural area, South Africa, as informal caregivers of HIV/AIDS-infected family members. The method used was qualitative and data was collected through a focus group interview with staff at a HIV/AIDS hospice. Adaptation and analysis was accomplished as a systematic coding by thematic content analysis. The analysis emerged in two themes; A struggle handling a situation of mixed feelings, difficulties and cultural believes, and A situation constituted by constant needs. The result shows that cultural believes and traditions have great impact in the elderly informal caregivers' lives. Their situation is constituted of mixed feelings, lack of knowledge, physical, practical, financial and psychological difficulties. Hereby a huge need of information, education, help and support was found.

Keywords: HIV, AIDS, elderly, informal care giving, South Africa, cultural care

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Sektionen för Hälsa/
Pretoria Universitet,
Fakulteten för Hälsa**

Sjuksköterskeprogrammet, 120 poäng.

INFORMELLA VÅRDGIVARE I HIV/AIDS-DRABBADE FAMILJER – en kvalitativ studie av hospispersonals erfarenheter från ett fattigt område i Sydafrika

Examensarbete 10 poäng

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SAMMANFATTNING

I takt med att antalet individer och hushåll berörda av HIV/AIDS ökar i Sydafrika, blir påverkan av epidemin både större och mer komplicerad. Vid sidan av landets formella hälsosystem har, som ett resultat av epidemin, ett informellt hälsosystem uppkommit. De informella vårdgivarna, som ofta är äldre föräldrar, utgör en nationell hälsoresurs, men de är också en mycket sårbar population och deras situation påverkar flera aspekter av deras liv. Syftet med studien var att belysa situationen för äldre informella vårdgivare till HIV/AIDS-infekterade familjemedlemmar i ett fattigt område i Sydafrika. Metoden var kvalitativ och data samlades in genom en fokusgruppsintervju med personal från ett HIV/AIDS hospis. Bearbetning och analys genomfördes som en temabildande innehållsanalys. Två teman framkom ur analysen; En kamp för att klara av en situation av blandade känslor, svårigheter och kulturella traditioner och En situation bestående av ständigt behov av hjälp. Resultatet visar att kulturella traditioner har mycket stor påverkan i de äldre informella vårdgivarna situation. Deras situation utgörs av blandade känslor, bristande kunskaper, fysiska, praktiska, ekonomiska och emotionella svårigheter. Resultatet påvisar därför även ett mycket stort behov av information, utbildning, hjälp och stöd.

Nyckelord: HIV, AIDS, äldre, informella vårdgivare, Sydafrika, kulturbaserad omvårdnad

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INTRODUCTION

Many countries in the developing world are confronting two issues that were largely unanticipated until quite recently; the ageing of the population and the onset of the HIV/AIDS epidemic (VanLandingham, Knodel, Im-Em & Saengtienchai, 2000).

In 2001/2002, there were about 40 million people living with HIV or AIDS, according to the World Health Organization (WHO), and the United Nations AIDS Programme (UNAIDS). Since the first clinical evidence was reported in 1981, AIDS has resulted in more than 20 million deaths. HIV/AIDS marks a severe development crisis in sub-Saharan Africa, which is by far the worst affected region in the world. South Africa is one of the most affected countries where one-in-nine or five million people are living with HIV/AIDS (UNAIDS, 2002b).

As well as being an enormous health problem, HIV/AIDS also has a devastating impact socially and economically. In communities already impoverished, the epidemic makes poverty even worse by striking mainly the middle aged generation. Nevertheless, HIV/AIDS also has a huge, but largely unreported, impact on elderly people. In developing countries, social and economic safety nets are often absent. Traditionally adult children have supported their parents in old age. Because of the epidemic, the roles have been reversed. Increasing numbers of elderly are not only losing the support that they might expect to receive from their adult children, but are also now required to care for and support their children and grandchildren. Since it is traditionally the role of the women to care for the sick in the family, women are particularly affected (HelpAge International, 2002).

Research points to a wide range of problems experienced by elderly informal caregivers. Problems such as exhaustion, financial difficulties, grief and emotional problems, lack of knowledge and resources for dealing with adult children with HIV/AIDS, conflicts with grandchildren, social stigma, discrimination and rejection, and exclusion from information and support services (HelpAge International, 2002).

Knowledge about how the HIV/AIDS epidemic indirectly affects elderly informal caregivers is needed in order to hopefully work more supportively with those affected in the future. Also, since most research has taken place in the United States and other developed areas, it is important to survey the situation in rural areas.

In 2002, a cooperation agreement was signed between Blekinge Institute of Technology, Sweden, and the University of Pretoria, South Africa. One of the main benefits of the agreement included a student exchange programme with scholarships from Linneus-Palme. A programme like this made this research possible to conduct.

THEORETICAL BACKGROUND

Theoretical framework

Madeleine Leininger is the founder of cultural nursing and a pioneer of transcultural nursing care theory. She developed her theory from the discipline of anthropology and conceptualized it to be relevant to nursing and health care (Marriner, 1986).

Leininger (2002) developed the transcultural nursing theory based on the belief that care is dependant upon culture, and culture cannot survive without care. Human caring is a universal phenomenon, but the expressions, and patterns of caring vary among cultures. She points out that culture is critical and essential to understand people and nursing, and that nursing and care is a cultural humanistic and scientific discipline and profession with the central purpose to serve human beings worldwide. The theory of culture care focuses on generating knowledge related to the care of people who value their cultural heritage and way of life.

Transcultural nursing theory is defined by Leininger (in Marriner, 1986, p. 148) as “*a set of interrelated cross-cultural nursing concepts and hypotheses which take into account individual and group caring behaviors, values, and beliefs based upon their cultural needs, in order to provide effective and satisfying nursing care to people*”. Her theory is directed toward people in caring situations to get *their* viewpoints, beliefs, knowledge, and practices as bases for professional actions and decisions regarding care (Marriner, 1986).

The HIV/AIDS virus

Human Immunodeficiency Virus (HIV), attacks the body’s immune system and eventually destroys the lymphocytes and the monocytes, which makes it hard to resist infections (HelpAge International, 2002). HIV is a slow acting virus. Except for a generally mild illness a few weeks after initial infection, most HIV-infected people have no symptoms for the first five years or so. They look healthy and feel well most of the time, although they can transmit the virus immediately. Once people are infected with HIV, they are infected for life (World Health Organization, 1994).

Acquired Immune Deficiency Syndrome (AIDS), is not a single disease itself, but the end stage of the HIV-infection. A person is said to have AIDS when the immune system has become weak and cannot prevent illnesses such as cancer, pneumonia and tuberculosis (HelpAge International, 2002). AIDS-infected people can be helped with medicines, but there is yet no cure and most people die within one to three years after diagnosis (World Health Organization, 1994).

The prevalence of HIV/AIDS in South Africa

The estimated situation in South Africa, with a population of 43.6 million, is that five million people are infected with HIV or AIDS. This makes South Africa one of the most affected countries in the world. HIV/AIDS is today the leading cause of death in South Africa and the deaths did increase rapidly from 12 000 in 1995 to 190 000 in 2000 (Medical Research Council of South Africa, 2000).

Younger people are most severely affected by the disease. It is estimated that 40 to 50 percent of South Africa’s workforce could die from AIDS over the next 10 years and that by this year, 2005, there are expected to be around 800 000 orphans. The reduction in the workforce, the increased human and financial resources required to provide care for people living with HIV/AIDS, and the needs of orphans will highly affect the social and economic development in the country (Benatar, 2004).

Although the number of elderly who will suffer from HIV/AIDS themselves is not trivial, a far greater number of them will be affected by the epidemic indirectly through their relationships with younger adults who are HIV/AIDS victims (VanLandingham et al., 2000).

Health policy in South Africa

Human health, patterns of disease, and life expectancy are totally affected by the economic, social, and political situation. In the apartheid era, intense criticism was focused on wide disparities in health and access to health care in South Africa. The changeover to a democracy has been widely admired as a paradigm shift in human relationships. The challenge of limiting the racial disparities in health care is a difficult task for the government. The high rate of HIV/AIDS-infection makes the challenge even more complex. Nevertheless, the new government has made many achievements that have improved health among the nation's approximately 44 million people. These include for example construction of hundreds of new clinics that provide primary health care and desegregated medical services. Unfortunately, these achievements have been ruined by several shortcomings. Because of lack of personnel and finances, poor administration, and expanding demands, many new clinics and the primary health care systems are not yet completely functional (Benatar, 2004).

Extensive new legislation regarding national health has been set up to meet the goals about expanded access to health care within a district-based system of primary health care, nationalization of health laboratory services, greater regulation of health care professionals, and health promotion (Benatar, 2004).

South Africans with health insurance keep access to much that modern medicine can offer. Those without health insurance though, approximately 80% of the population, is dependent on public health services. There is an ongoing tension in South Africa between promoting or allowing private health care, on one hand, and developing a more equitable system of public health care, on the other. There are also tensions within the public health sector. At the same time as resources are being redistributed towards a system based on primary health care that is within reach of all, and common ground is being sought between Western medicine and African traditional healing practices, attempts are being made to form public-private cooperation (Benatar, 2004).

A cornerstone of the South African government's HIV/AIDS policy is to develop home based care. But the ability of affected South African households to care for sick family members is not good as many do not have knowledge to do so, and often deteriorate with time, as the family members become sick, lose employment, use households' resources and die. Financial and logistical planning of social support and health services for households affected by HIV/AIDS clearly needs to be based on valid epidemiological and economic information (Bachmann & Booysen, 2003).

Cultural influence

Leininger (2002) describes that it is necessary to understand the attitudes of different culture groups according to illness and care and how members of such groups react to the causation of illness, treatment and care.

The majority of the people in developing areas have access to traditional health care, and as many as 80% of the people in Africa rely on traditional medicine for many of their health care needs. As a result of this, traditional healers may be one of the main sources of care for people living with HIV/AIDS in these areas (UNAIDS, 2002a). Traditional healers are accessible, culturally appropriate, acceptable and usually affordable for these people (Leininger, 2002).

A traditional healer is described as “*a practitioner who bases his/her healing practice on an ancient system of culture, custom and believes that has been passed down from generation to generation from time immemorial*” (Peu, 2000, p. 20).

Each culture must be accorded the respect and dignity it deserves. Both Western health care and African Traditional health care have a part to play in South Africa, and only by combining the best of both traditions, health care will be able to offer the care that the country expects from them (Peu, 2000).

Informal care giving

Informal care giving is often defined as a person helping a close person with personal or instrumental activities of daily living. There is more to care giving than these tasks, however, and the knowledge about those other parts is sparse (Ekwall, 2004).

As the number of individuals and households affected by HIV/AIDS multiplies, the impact of the epidemic both widens and deepens. Around the world, the HIV/AIDS epidemic has affected tens of millions of peoples' lives. One single AIDS-related illness or death can devastate an entire family and their household through the loss of family income, the strain caused by expensive medical and funeral costs, or the stigma sometimes attached to families affected by HIV/AIDS (Danziger, 1994).

As a complement to the formal system of health care, an informal health care has emerged in response to HIV/AIDS. Informal caregivers, such as parents, often play an instrumental role in the provision of care to family members with HIV or AIDS. The informal caregivers provide complex assistance and health care, typically without professional training and this often affects numerous aspects of their lives. These informal caregivers constitute a national health recourse, but they are also a vulnerable population and the services they provide are unlikely to be cost-free (LeBlanc & Andrew, 1997).

Previous reports

Little research has been conducted about the impact HIV/AIDS has on the elderly in Africa as caregivers of infected family members. The health needs of the elderly, their role in care, and the response of health systems to their current situation have been largely neglected (World Health Organization, 2002). The limited literature on HIV/AIDS and elderly people relates mainly to the situation of affected people in the United States and in other developed countries (Knodel, VanLandingham, Saengtienchai & Im-Em, 2001).

LeBlanc & Andrew (1997) presents a study concerning the potentially adverse impact of care giving on the physical health of informal AIDS caregivers in the United States. Their findings points out that many of these caregivers go about the everyday tasks of care provision while suffering from substantial sickness, discomfort, and pain of their own.

To understand the full range of societal response to the epidemic and how it is conditioned by the combination of culture, the political system, and levels of social and economic development, perspectives from other settings are necessary. Some consequences for the elderly caregivers are likely to be even more profound in developing countries or areas where the HIV and AIDS prevalence is often much higher than, for example, in the United States. In

these developing areas the dependence on intergenerational arrangements for care giving and support is also often more extensive (Knodel et al., 2001).

VanLandingham et al. (2000) points out two levels of HIV/AIDS impacts that the elderly population in developing countries or areas suffer from. *The macro-level impacts* contain dependency ratios and economic disruption. *The micro-level impacts* contain ways in which older people are affected at the individual and family levels.

Research in Africa and Asia shows that caring for sick family members puts elderly people under huge pressure. They must sustain an income, nurse the sick, and care for the young, at a high cost to their own livelihood, health, and wellbeing. They are carrying out these added responsibilities with deteriorating health, low income, limited information and little or no support. Often their sick family member has spent all the family's money on treatment so that they have nothing left to support their grandchildren (HelpAge International, 2002).

As shown, research points out that the situation for these informal caregivers may be affected by several factors; both personal factors and those arising from care giving. Focus is often on the negative consequences, but it is also very important to know that doing something helpful for someone else or being able to keep a sick family member out of an institution and the family together may also contribute to positive feelings from care giving. Both negative and positive aspects are equally important to acknowledge when discussing informal care and designing supportive interventions (Ekwall, 2004).

AIM

The aim of this study was to illuminate the situation for elderly people in a rural area, South Africa, who are informal caregivers of HIV/AIDS-infected family members.

METHODS

Research design

The nature of this study is descriptive and qualitative as it encourages the participants to reflect on their experiences and generates a lively picture of their reality (Holloway & Wheeler, 1996).

Population and sampling

Due to ethical problems with interviewing the elderly informal caregivers themselves, participants in the study included staff from an independent hospice that serves 78 villages in the North West Province, Pretoria, South Africa. Their work is based on a medically directed nurse coordinated programme of care responding to the physical, emotional, social and spiritual needs of patients, families and significant others infected or affected by HIV/AIDS.

The participants included four volunteers from the hospice, all of them female aged between 34 and 41. Their work experience at the hospice varied between five and nine years. All the participants were involved with a variety of informal caregivers, many of these elderly, of HIV/AIDS-infected family members. The participants were recruited in collaboration with the University of Pretoria, Faculty of Health Sciences.

Data collection

A focus group interview was chosen as a method to identify the issues that elderly informal caregivers, according to the hospice staff, may experience.

A focus group interview is a qualitative research technique to obtain data about the experiences of a defined group of participants. The group is focused in the sense that it involves the group considering a given issue or topic (Kitzinger, 1995). Recommendations for the exact requirements for group size vary in the literature (Morgan, 1993., Sim, 1998). Kitzinger (1995) suggests that the ideal group size should be in the range of four to eight as this allows everyone to participate whilst still obtaining a range of responses.

One open-ended question was guiding the focus group through the discussion; *“Please tell us about your experiences of the situation for the elderly people that are informal caregivers of HIV/AIDS-infected family members!”* The purpose of this question was to establish a free flowing discussion between the participants. The meeting lasted approximately one hour and was recorded on tape. One of the authors was the lead moderator of the focus group, whereas the other made field notes and observed the group to discover any influences and interactions between the participants. The language used was English, although this was not the participants’ first language. Because of the language difficulties, and to avoid misunderstandings, an interpreter was present, and could assist in translation if problems arose.

Ethical considerations

The study was approved by the Ethics Research Committee, Faculty of Health Sciences, University of Pretoria.

The participants were informed about the aim of the study and about their anonymity (Appendix 1). A consent form from the Ethics Research Committee, Faculty of Health Sciences, University of Pretoria was filled in and signed by the participants and the authors before the interview (Appendix 2). The participants were interviewed on a voluntary basis and they were free to terminate the discussion at any point. Their identity and all the material collected was handled confidentially. Afterwards, all confidential material i.e. tapes and papers from the interview and transcription was destroyed. After analyzing the data, the participants got a chance to validate it, to let them know and agree with what had been done with the experiences they had expressed in the interview.

Nevertheless, using the focus group method can never guarantee that each participant is maintaining the confidentiality of other participants (Smith, 1995).

Analysis

To analyze the focus group data, a systematic coding by thematic content analysis research method was used. This type of analysis uses important concepts of the research procedure and the content analysis was carried through in the following way according to Graneheim & Lundman (2004):

The tape-recorded interview was listened to several times and compared with the field notes that were made during the interview. This was to get a sense of the whole interview and to get

the first ideas of what the participants were expressing. The interview was then transcribed to a written text, and compared with the tape recording. The written text of the interview constituted the unit of analysis. Even this was read several times before it was divided into meaning units. The meaning units are parts of the text, i.e. a sentence, part of a sentence or several sentences that are related to the research question. After reading through the meaning units, these were condensed, which means they were made as concise as possible without losing their central meaning. The condensed meaning units were also read through and then categorized according to similarities and differences. Each similar meaning unit was labeled with a code. The various codes were then compared and sorted into categories. This constituted the manifest content. The latent content, the underlying meaning of the categories, was formulated into themes. The categories and the themes were tried in different ways and discussed between the authors and the tutor before they were finally stated. (Example of the content analysis is shown in Table1).

Table 1. Exampel of the Content Analysis.

Meaning Unit	Condensed Meaning Unit	Code	Category	Theme
Sometimes they say it's....., ehhhh....., witchcraft who gave them the illness...	Sometimes the elderly believe witchcraft gave the sick the illness	Cultural beliefs	Cultural beliefs and traditions	A struggle handling a situation of mixed feelings, difficulties and cultural beliefs
...and these grannies they just walk around without knowing what is going on with the one who is sick...	The elderly don't know what is going on with the sick	Lack of knowledge	A need of information and education	A situation constituted by constant needs

RESULT

The content analysis of the interview emerged in eight categories and two themes. The first theme, *A struggle handling a situation of mixed feelings, difficulties and cultural beliefs* contains six categories, and the second theme, *A situation constituted of constant needs*, contains two categories (Table 2). The themes that emerged seemed to be connected in the way that the first theme was the central theme in describing the situation for the elderly informal caregivers. The second theme emerged as a response to the first theme.

Table 2. Summarize of Categories and Themes.

Categories	Themes
Cultural believes and traditions A feeling of fear, rejection, shame, isolation and being used or a feeling of doing something good to someone you love Relating to something unknown or something known Own physical health problems Practical difficulties Financial issues	A struggle handling a situation of mixed feelings, difficulties and cultural believes
A need of information and education A need of help and support	A situation constituted by constant needs

A struggle handling a situation of mixed feelings, difficulties and cultural beliefs

The first theme illuminates the struggle the elderly informal caregivers face in handling their situation.

One of the most common concerns that the informants expressed in the situation for elderly informal caregivers was related to *cultural believes and traditions*. It is very clear that cultural believes and traditions make a great impact in these elderly people's lives, and strongly affecting how they are dealing with their situation. They rely on traditional healing and witchcraft rather than modern western medicine, which often make their situation very complicated.

"...when the traditional healers doesn't see the illness, they like to say: This people is ok and there is no problem...", "...so the grannies will concentrate on the bewitched problem..."

The informants were discussing the respect they need to have for the elderly peoples culture and traditions, and how this is affecting their meetings and the way they are helping these informal caregivers with their situation.

“...and then we can't say: No, don't go to them and we are the best that can help you..., we just focus on what happens exactly that time...”

The informants also described several feelings and reactions of the situation that they meet in their every day work with elderly informal caregivers. The elderly informal caregivers' situation causes *fear, rejection, shame and isolation*. A fear for social stigma, for getting infected themselves, and for the fact that their family member is going to die, was described. The informants emphasized that they often experience the elderly as very *alone and isolated in their situation* of providing care to the sick family member. The relatives are not there to help and support them and sometimes they don't even want to be informed about the situation. The informants also expressed feelings of rejection and shame with the informal caregivers. The elderly often rejects and hides the family member who is infected by HIV/AIDS, especially when the sick person is educated, as then the situation causes extreme feelings of shame. Due to this, they sometimes even isolate the sick by locking them in and neither want to see them or feed them.

*“...we had a case were the family locked the sick person in the pigs house...”,
“...because, they are..., I think they are afraid of the stigma...”*

The informants also described the feeling of being used as a caregiver. Many of the elderly informal caregivers that they meet didn't have any contact with their children until they got sick. To just be needed in this situation when providing care is something that many of them don't accept.

“...most of them say: No, she was not staying with us and she was not giving us anything, now she is very sick and she comes to us for help...”

On the other hand, the informants mentioned a love and thereby positive aspects of helping and caring for a sick family member. They pointed out that when the elderly love the one they are caring for, they provide the care in a much better way. It feels better to do something good for someone they love.

“... they have love to their children by caring enough for them...”

The informants emphasized differences concerning whether the elderly informal caregivers are *relating to something unknown or to something known*. Since HIV and AIDS are quite new diseases, most of the elderly informal caregivers have huge difficulties in understanding the situation they are in. They can see that something is wrong with the sick family member, but they don't know what is wrong and why, and they don't know what to do.

“...and these grannies they just walk around without knowing what is going on with the one who is sick...”

One of the results of relating to this unknown situation is that the elderly informal caregivers don't know how to protect themselves against the disease when caring for the sick family member. The informants pointed out that especially when they love the one they are caring

for, they are even more unlikely to protect themselves. They love the family member so much that they don't want to use, for example, medical gloves when they are providing the care. The informants described the elderly informal caregivers as a vulnerable group, when they don't know how to protect themselves.

"...they are infected because they are very rough in handling the wounds of these clients..."

On the other hand, the informants highlighted that some of the elderly are actually quite well informed about HIV and AIDS. For these informal caregivers with knowledge about the diseases, it is much easier to deal with the situation and to seek expertise help.

"...so if they can see..., then they come to us and call us..."

Since elderly people often deal with their *own physical health problems*, the informants expressed that the care giving gets very hard for them to handle.

"...we have a granny who looks after her grandchild..., she is also suffering from diabetic...", *"...so it is very difficult for them to look after themselves and the sick also..."*

The informants pointed out several *practical difficulties* that the elderly informal caregivers have to deal with. Many of them can't read or write, which, for example, makes test results impossible for them to understand. Also, because of practical difficulties, many of them don't have id-documents which are necessary to get the financial support from the government that they are entitled to. Another thing that was emphasized in the interview was lack of equipment, i.e. washing materials, that are needed to provide good care.

"...sometimes there is no water..., they need to go and search for the water before they start helping the sick..."

Another issue that the informants highlighted in the situation of providing care is the lack of money. It is impossible for the elderly to care properly for the sick family member when there is no money and not even their own basic needs are satisfied.

"...you can't just say: Buy this medicines when they don't have meals to eat..."

A situation constituted of constant needs

The second theme illuminates the situation for the elderly informal caregivers in terms of constant needs to handle their situations more effectively.

A huge need of knowledge, even described as "the biggest need for the caregivers", was emphasized by the informants. Lack of information, advising and counseling were points that the informants came back to several times during the interview. According to the informants, *information about HIV/AIDS* would solve many of the problems that they experience for the elderly informal caregivers. The informants discussed that there probably would be a totally different situation for the elderly informal caregivers if they had more knowledge about the diseases they have been forced to deal with.

“...knowledge..., give them the information and then they will be safe living...”

To educate and teach about how to care for a HIV/AIDS-infected person is another huge need expressed by the informants, since the elderly are not usually educated in caring. Workshops about HIV/AIDS were suggested as a good way of educating the elderly.

“...if they can be provided this information they will be able to look after the sick..., how to wash the patient..., and also with the position..., and the treatment also..., how to drink the treatment...”

Poverty was lifted up as an enormous difficulty for the elderly when providing proper care to the infected family members. Money is essential for getting medication, food, equipment etc. As a response to this, *financial support* was expressed by the informants as a constant need for elderly informal caregivers.

“...if they have money they will be able to take the sick to the hospital, to the clinic and those places...”

The informants also expressed problems for the elderly informal caregivers in coping with the situation they are in. They pointed out a need of *psychological support* for them when talking about what is happening in their homes and helping them cope with their situation.

“...if she is sick and her younger daughter is sick..., how is she going to cope? ...”

Practical difficulties were another of the issues emphasized that were reported in the first theme (A struggle handling a situation of mixed feelings, difficulties and cultural beliefs). Therefore also a need of *practical support* was to be found in the analyzing of the interview. The elderly informal caregivers need practical support, both during the time of caring for the sick family member, and after the sick person is dead.

“...we need to sit with those old ladies to tell them..., what does this result saying? ...”

The final need that emerged from the interview was the need of *spiritual support*. The informants expressed a need of spiritual nursing to the elderly.

“...then we are doing a prayer..., when we are talking about HIV/AIDS...”

DISCUSSION

Method discussion

Due to the sensitivity of the topic, the Ethics Research Committee, Faculty of Health Sciences, University of Pretoria did not give this study approval to interview elderly informal caregivers of HIV/AIDS-infected family members. The participants involved though, were very aware of the elderly informal caregivers' situation, and could describe this in detail. They probably even provided more information than the informal caregivers would have done because of the shame of talking about HIV/AIDS and admitting that these diseases are in the family. This means, though, that the elderly informal caregivers described in this study have some support from the volunteers at the HIV/AIDS hospice. Therefore, the results can only get a hint of what the situation is like for those with no support at all.

To make the results as trustworthy as possible, every research study must be open to critique and evaluation. Traditionally, this has been done using the concepts *reliability* and *validity*. Reliability is described as the degree of consistency and validity as the degree of measuring what is intended to measure (Long & Johnson, 2000). Discussions about whether using these concepts or not in qualitative research studies are being made. Graneheim & Lundman (2004) instead suggests the concepts *credibility*, *dependability* and *transferability* when describing and measuring the trustworthiness of qualitative studies.

Credibility refers to how well data and analysis address the intended focus (Graneheim & Lundman, 2004). One way to support the credibility of this study was through member validation. The participants were, after analyzing the data, shown the results for the purpose of verification. This verification was firstly to make sure that the participants were understood correctly, but also had to do with the ethical considerations concerning letting them take part in what had been made from their described experiences.

Dependability refers to the degree of which data changes over time, and changes made in the researchers decisions during the analysis (Graneheim & Lundman, 2004). Since the data was collected at one time only, and all the participants got exactly the same pre information, and were asked exactly the same question, dependability was supported.

The aim of the qualitative research is rather to get deeper understanding and knowledge of the particular phenomena, than to produce generalizations (Leininger in Morse, 1994). Transferability, Graneheim & Lundman (2004) refers to whether the results can be transferred to other settings or groups. The attempt of this study was to provide as exact descriptive information and data of the research procedure as possible. This is a way to ensure that the process and that overall the results are trustworthy. This way others can also review and evaluate whether the results can be applied to alternative situations and groups.

All types of data collection have limitations, and focus group interviews are no exception. Kreuger (1994) points out some of the limitations with focus groups. For example, the researcher has less control compared to individual interviews since the focus group interview allows the participants to influence and interact with each other. It might also be a problem since groups vary considerably.

The focus group interviewed was quite small with four participants, which did have both positive and negative aspects. The smaller group made it more comfortable for the participants and was also easier to recruit. According to Carey (in Morse, 1994) the smaller group also makes greater opportunity for each participant to talk. On the other hand, the bigger focus group would have had more total experiences.

Kreuger (1994) points out the problem with using already existing groups as a focus group. People in work groups may have formal or informal ways of relating to each other that can influence their responses. None of the participants though, became more of a leader than the others in the focus group discussion. All of them were active sharing their experiences and all of them paid attention to the one talking.

Result discussion

The aim of this study was to illuminate the situation for elderly people in a rural area, South Africa, who are informal caregivers of HIV/AIDS-infected family members, as narrated by

hospice staff. The two central themes that emerged from the analysis were; *A struggle handling a situation of mixed feelings, difficulties and cultural beliefs*, and *A situation constituted of constant needs*.

Previous research about how the HIV/AIDS epidemic affects elderly people in developing areas are limited. Although, the ones conducted (Danziger, 1994., HelpAge International, 2002., HelpAge International, 2004b., Knodel et al., 2001) point out various aspects of impacts to these peoples situations and lives. This is also what was found in this study.

The result shows that cultural beliefs and traditions have an unexpectedly high impact in the elderly informal caregivers' situations and lives. The elderly informal caregivers rely on African Traditional health care rather than modern Western health care, and naturally their situation differs upon whether they believe the one they are caring for is bewitched or whether they realize that the sick family member is infected with a virus. This is in line with Leininger (2002) who stress that it is necessary to understand culture, beliefs, and traditions according to illness and caring to provide effective, satisfying and culturally congruent care. This also confirms that a cultural nursing theory is of great importance.

To be forced into a new and difficult situation of providing care for a HIV/AIDS-infected family member contributes several different feelings and reactions. In this study experience of a fear of stigma was found among the elderly. So were also feelings of rejection, shame and isolation. Previous research on elderly informal caregivers in Tanzania shows in a similar way that stigma and discrimination are two big negative consequences for the families affected by HIV/AIDS (HelpAge International, 2004b). Stigma and discrimination make it difficult for the affected families to talk openly about the issues they face and to seek appropriate support (HelpAge International, 2004a). It is shown in this study that doing something good to a beloved family member also can contribute positive feelings within the informal caregiver. This is also what Ekwall (2004) points out in her study of informal care giving of elderly people in Sweden.

The elderly informal caregivers have difficulties in relating to HIV/AIDS since it usually is an unknown phenomenon for them. When they don't know what the situation is about it naturally gets harder for them to handle it. The fact that many of them will think their family member is bewitched rather than have an HIV- or AIDS infection will affect their situation in several ways. Because of this, it is shown in this study, as in previous (HelpAge international, 2004b), that the elderly are unlikely to protect themselves when they are providing care to the HIV/AIDS-infected family member. Due to this lack of knowledge, the elderly informal caregivers are a vulnerable group that sometimes even get infected with the virus themselves.

The result shows that the elderly informal caregivers are most likely to be suffering from their own physical health problems, wich were also found in the study of LeBlanc & Andrews (1997). Providing care for a sick family member is very tiring for the elderly informal caregivers and affects their own physical health. Such as other findings shows (HelpAge International, 2004b), this makes their situation hard to handle, especially since they are often providing the care all alone with no support from relatives or others.

Another aspect of the difficulties faced in the situation of elderly informal caregivers of HIV/AIDS-infected family members, which were found in this study, was practical difficulties. The fact that many of the elderly are not able to read or write for example, makes their practical situation difficult. It has also been found in previous research that written

information is not an effective way of reaching elderly; they rather rely on oral communication and information (HelpAge International, 2004b). Not being able to understand or be involved with information, test results etc. makes their situation even harder to handle.

Financial issues were in this study described as a great problem for the elderly providing care to HIV/AIDS-infected family members in rural areas. A study in Cambodia of the impact of HIV/AIDS on older people also points out that limited financial and material resources constitutes huge difficulties for elderly trying to provide both themselves and the sick person with food, money, and appropriate health care (HelpAge International, 2003). The problem for the elderly informal caregivers in this study seemed to be the fact of being poor and providing care for someone at the same time, rather than that the care giving itself costs money. Lack of money makes it harder to seek expertise help, even if the elderly have the knowledge. As a combination of poverty and cultural believes, the traditional healers are most often consulted since they are often more affordable.

The lack of knowledge has a great impact on the elderly informal caregivers' situation. The elderly often don't understand what is wrong with the HIV/AIDS-infected family members, and therefore don't know how to take care of them. The unknown situation creates fear, and when they don't know or understand it is much more difficult for them to cope with the situation in a constructive way. Information about HIV and AIDS, and education about how to provide care for a HIV/AIDS-infected person was therefore found as a constant need. If the elderly people were well informed, they could easily influence the younger generations on how to protect themselves and avoid risks (HelpAge International, 2004a). Since it was also found that the cultural believes and traditions play such an important role, it is necessary to consider this when giving the informal caregivers the information and the education. The informants in this study suggested workshops as a good way to give the elderly information and education. A study by Mabunda (2004) shows that support groups are a very effective way to inform and educate people about HIV/AIDS.

Conclusion

As shown, the situation for the elderly informal caregivers is constituted by several shortcomings and difficulties. They struggle to handle their situation that are affected by cultural aspects, different feelings and reactions, physical health problems, practical difficulties and limited financial and material resources. It is clear that the elderly informal caregivers not only have a huge need of information and education about the diseases, but also have a constant need of help and support. Elderly people's efforts and difficulties in caring for a HIV/AIDS-infected family member are rarely acknowledged which leaves them feeling unsupported and unrecognized (HelpAge International, 2004a).

Further research and knowledge about how the HIV/AIDS epidemic affects elderly informal caregivers in rural areas is needed in order to work more supportively in the future. It is shown in this study that financial, practical, psychological and spiritual help and support is needed for those affected to help them handling their situation.

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APPENDIX 1

Participant information leaflet

INFORMAL CAREGIVERS OF HIV/AIDS-INFECTED FAMILY MEMBERS

– a qualitative study of experiences of hospice staff in a rural area, South Africa

You are invited to volunteer as a participant in this study. This information leaflet is to help you to decide whether you would like to participate or not. Before you agree to take part in this study, you should fully understand what is involved. If you have any questions, which are not fully explained in this leaflet, do not hesitate to ask the researchers. You should not agree to take part unless you are completely happy about what is expected of you.

The aim of this study is to illuminate the experiences of hospice staff regarding the elderly people as informal caregivers of HIV/AIDS-infected family members. Understanding the situation for elderly informal caregivers will help us as nurses to support them in this important and complex task.

You are requested to participate in a focus group interview of approximately one hour. To be able to analyse the interview, it will be recorded on tape. The tape and the transcription will be kept in a safe place and will be destroyed after analysis of the data.

The following question will form the structure of the interview:

“Please tell us about your experiences of the situation for the elderly people that are informal caregivers of HIV/AIDS-infected family members!”

Your participation in this study is entirely voluntary and you can refuse to participate or stop at any time without stating any reason. Your withdrawal will not be held against you. Please do not use any names by which you or any other person or institution can be identified. All information obtained during the course of the interview is strictly confidential. Data that may be reported in scientific journals will not include any information that identifies you as a participant in this study.

This study protocol was submitted to the Research Ethics Committee, University of Pretoria, Faculty of Health Sciences.

APPENDIX 2

Informed Consent

I hereby confirm that the researchers, Charlotte Andersson and Jenny Svensson, have informed me about the nature and conduct of the study. I have also received, read and understood the above written information (Participant Information Leaflet) regarding the study. I am aware that the results of the study, including personal details, will be anonymously processed into the study report. I may, at any stage, without prejudice, withdraw my consent and participation in the study.

Participant's name _____

Participant's signature _____ Date _____

Witness's name _____

Witness's signature _____ Date _____

The researchers, Charlotte Andersson and Jenny Svensson, herewith confirm that the above participant has been informed fully about the nature, conduct and risks of the above study.

Charlotte Andersson Jenny Svensson

Date _____ Date _____