

**The role of Hospice T.L.C.
caregivers in child and family
care in the Kokstad area**

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*“Some want to live within the sound of church
or chapel bell; I want to run a rescue shop
within a yard of hell.”*

Charles Haddon Spurgeon

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A word of gratitude to:

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T.L.C HOME SERVICES



MISSION STATEMENT

T.L.C. Home Services, a non profit organization, is committed to serving the community of Kokstad and surrounding area by providing specialised palliative care for terminally ill patients and their families. Care is given in the patient's own home backed up by our local health facilities. We are committed to the training and development of our staff/ volunteers, other health carers and the community.

NPO no: 052-644-NPO

PREFACE

This manuscript is submitted in article format as described in Rule A.13.4.5 of the North-West University's Yearbook (2008).

The articles are written according to the editorial requirements of Social Work/ Maatskaplike Werk (Addendum 4).

OPSOMMING

TITEL

DIE ROL VAN HOSPICE TLC VERSORGERS IN DIE VERSORGING VAN KINDERS EN FAMILIELEDE IN DIE KOKSTAD-OMGEWING

OPSOMMING

Weens die toenemende aantal mense wat deur MIV of VIGS geïnfekteer of geaffekteer is, het die behoefte aan tuisversorging skerp toegeneem. Gegaard hiermee het die psigososiale behoeftes van gesinne weens MIV-infeksie toegeneem wat lei tot die behoefte aan meer uitgebreide dienslewering deur toepaslike diensverskaffers. Deur die rol wat Hospice T.L.C.-versorgers ten opsigte van die voorsiening in hierdie behoeftes speel, te ondersoek kan aanbevelings gedoen word vir dienslewering aan gesinne wat met MIV en VIGS geïnfekteer en daardeur geaffekteer is. Die hoof fokusareas vir dienslewering aan hierdie gesinne is geïdentifiseer.

SLEUTELTERME

- Hospice T.L.C.
- Versorgers
- Kinders
- Familie
- Versorging

ABSTRACT

TITLE

THE ROLE OF HOSPICE TLC CAREGIVERS IN CHILD AND FAMILY CARE IN THE KOKSTAD AREA

ABSTRACT

Due to the increasing number of people being infected with or affected by HIV or AIDS, the need for home-based care services has increased. The psycho-social needs of families have also increased due to HIV infection resulting in a need for more extensive service rendering by relevant service providers. By exploring the role of Hospice T.L.C. caregivers in meeting these needs, recommendations could be made for service rendering to families infected with or affected by HIV or AIDS. Main focus areas for service rendering to these families were identified,

KEY TERMS

- Hospice T.L.C.
- Caregivers
- Child
- Family
- Care

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SECTION A

GENERAL INFORMATION

1. CONTEXTUALISATION AND PROBLEM STATEMENT

Worldwide the HIV and AIDS pandemic is impacting on communities. Smit (2007:1) stated that according to the Joint United Nations programme on HIV or AIDS it is possible that by the end of the 20th Century 19 million people could have died from AIDS. The effect hereof on children is devastating. It is possible that the orphan population could exceed 13 million. Of the 34 million HIV-positive people, 70% live in sub-Saharan Africa. These predictions could be wrong, but the prospect of having 44 million children under 15 orphaned by 2010 is shocking (Smit, 2007:1).

This study focuses on the Kokstad community in southern Kwazulu-Natal, South Africa. This community consists of a population of 34 000 registered voters and the census of 2001 counted a total of 56 537 people in the Greater Kokstad area (STATSSA, 2008). Hospice T.L.C. is the name of the local hospice rendering services in this area. Hospice caregivers are trained volunteers who primarily attend to the needs of terminally ill patients and their families. It allows them an opportunity to address the needs of the families, including children. Although hospice care was established to provide palliative (non-curative) services for the dying and their families, the HIV and AIDS pandemic poses new challenges to hospice care such as dealing with the needs of orphans and vulnerable children (OVC) (Buckingham & Meister, 2001:461).

According to Hospice T.L.C.'s mission statement, this Non-Profit Organisation's (NPO) goal is to service the community of Kokstad by providing specialised palliative care for terminally ill patients and their families. Care is given to the patients in their own homes backed by the local health facilities. Hospice T.L.C. is committed to training and development of their staff and volunteers in order to render a professional service to the community (T.L.C. Home Services, Mission Statement, 2003). Hospice T.L.C. provides home-based care within the community and in the process have close contact with the family members affected by HIV or AIDS.

The needs of families infected with or affected by HIV or AIDS are numerous. A number of bio-psychosocial needs that should be addressed are formulated by Danielson, Hamel-Bissel and Winstead-Fry (1993:72) to include aspects related to health, family vulnerability and symptom experience, the sick role appraisal, medical contact, illness career and family adjustment to the impact of HIV infection on the family, recovery, rehabilitation and chronic adaptation.

Van Dyk (2001: 332-333) refers to the following needs of families infected with or affected by HIV and AIDS: medical and nursing needs; basic needs for food and shelter; activities

of daily living; social needs; financial needs; spiritual needs; hospital, hospice and palliative care needs as well as the needs of the primary caregiver in the family. One of the most fundamental needs of a family dealing with a terminal illness is hope. "To offer hope and relief of anxiety, it is necessary to understand what the illness means to the patient and family" (Danielson et al., 1993:172). The illness poses several reasons for experiencing loss such as loss of income or health. The importance of dealing with loss is emphasized by Richter and Rama (2006:13). Families should be supported to deal with their grief (Costa, Hall & Stewart, 2007). The following examples of losses are commonly experienced by families infected with or affected by HIV or AIDS:

- Loss of health and vitality
- Loss of economic security
- Loss of parents or primary caregivers
- Loss of social support
- Loss of hope for the future

In dealing with loss, grief and bereavement, Butler, Lewis and Sunderland (1963:111-112) mention the importance of reminiscence and succession planning in terminal care. Memory work could be important in attending to the bio-psychosocial needs of families infected with or affected by HIV or AIDS in dealing with their losses (Denis, 2005:7; Herbst & De la Porte, 2006:46). The most important aspect in dealing with loss is that people should have the necessary support when services are planned. The *Circles of Support* model of Smart (2003:43) can be of great value in service delivery to families infected with or affected by HIV or AIDS. This model includes the following three circles of support:

1. Help from family, neighbours and friends;
2. Help from the immediate community;
3. Help from resources in the broader society such as Hospice and Child Welfare South Africa (CWFSA).

The Circles of support can be illustrated as follows:

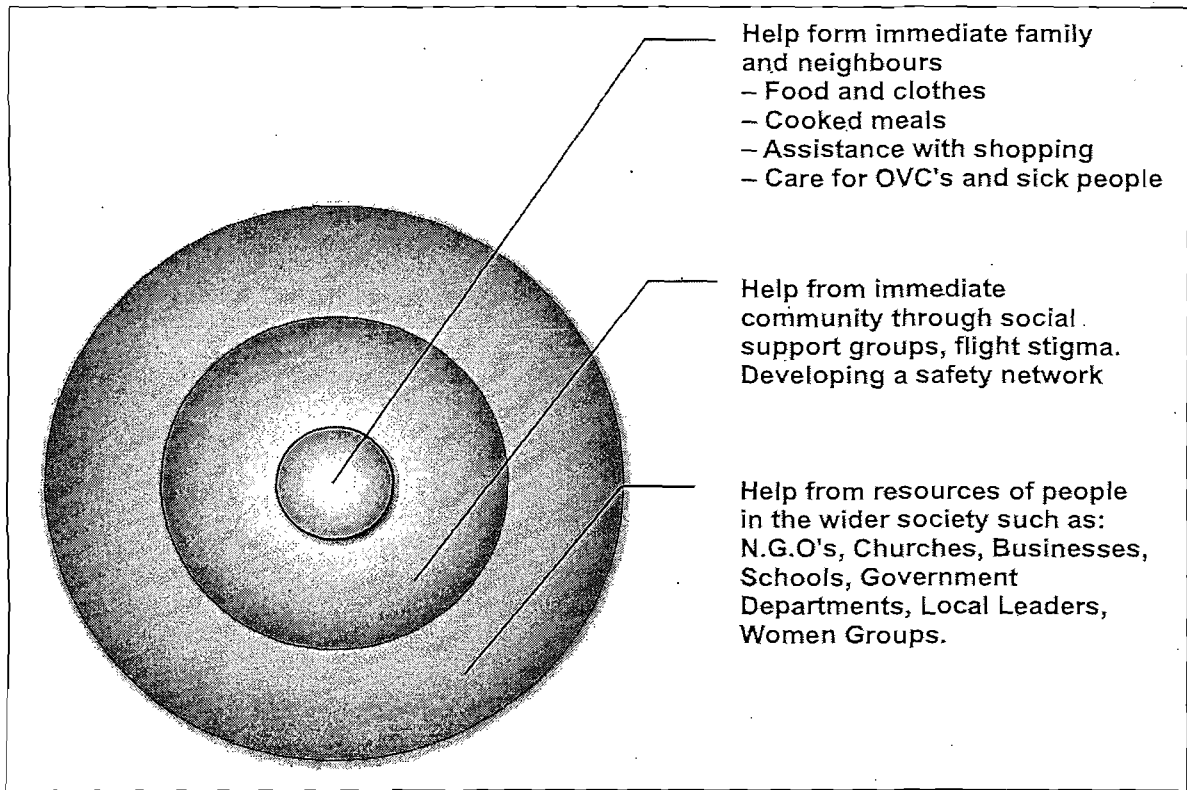


FIGURE 1: Circles of support

It is particularly in circles 2 and 3 where hospice caregivers can play an important role in the care of families infected and affected by HIV or AIDS. Van Dyk (2001: 330) refers to the community of caregivers which consists of the following persons:

- The individual infected with HIV and AIDS
- The family affected
- The programme coordinator (professional nurse or social worker)
- Other members of the multi-disciplinary team
- Trained volunteers (hospice caregivers)
- Complementary services
- Community support

In this study the role of trained volunteers, specifically hospice caregivers, will be further explored. These caregivers play a key role in the "...mobilization of the family's social support network to help relieve strain and stress". Other useful community resources such as clinics, NPO's and schools are identified by Danielson et al. (1993:173). In assisting affected families it is important for the caregivers to understand the psycho-social needs of the families.

This would include trauma, depression, anger and other factors that could be linked to the impact of HIV or AIDS on a family (Iverson, 2007:9). It is clear that a Hospice T.L.C. caregiver can play a vital role within the community. The following research questions were posed to explore their role:

- What is the role Hospice T.L.C. caregivers play in the lives of families infected with or affected by HIV or AIDS?
- Do Hospice T.L.C. caregivers manage to identify the bio-psychosocial needs of families infected or affected by HIV or AIDS?
- What should the focus areas be for service delivery by Hospice T.L.C. and other relevant service providers?

2. AIM AND OBJECTIVES

2.1 General aim

To do a critical investigation regarding the role T.L.C. Hospice caregivers play in the lives of families infected with or affected by HIV or AIDS.

2.2 Objectives

- To investigate the role Hospice T.L.C. caregivers play in the lives of families infected with or affected by HIV or AIDS.
- To identify the bio-psychosocial needs of infected families infected with or affected by HIV or AIDS.
- To explore the level of services to families infected with or affected by HIV or AIDS by addressing the **main focus areas** for service rendering to these families.

3. CENTRAL THEORETICAL ARGUMENT

Hospice T.L.C. caregivers play an important role in the lives of families infected with or affected by HIV or AIDS and make a contribution towards child and family care services in the Kokstad area.

4. METHOD OF INVESTIGATION

4.1 Analysis of literature

There is an extensive amount of literature available on the impact of HIV or AIDS on families. Books, articles, research reports, programs by government departments and NPO's, as well as applicable journals were utilised. Many of the literature sources were obtained from the Ferdinand Postma Library, North-West University, Potchefstroom Campus. Ebsco Host, Web Feat, the Internet and Psyclit database were used.

The policies of hospice and Child Welfare South Africa (CWSA) were included in the literature study dealing with ethics such as confidentiality, patient's rights and the protection of minor children. Ethical aspects in the social sciences and human service professions were studied as outlined by Strydom (2005a:56-69). The main focus areas for service rendering to families infected with or affected by HIV or AIDS show similarities with the Circles of support model (Smart, 2003:43) with emphasis on the helping relationship (Egan, 1994: 5).

Literature on the impact of hospice caregivers on families affected by or infected with HIV or AIDS is limited. An extensive programme titled "The National Programme for HIV and AIDS, a child focused strategy" (Halkett, 2005) is compiled specifically with the aim of training volunteers for the "Asibavikele" program run by (CWSA). The role of hospice caregivers overlaps with that of the Asibavikele child minders, providing valuable literature in meeting the needs of families affected by or infected with HIV or AIDS. Asibavikele aims to train volunteers to meet the needs of orphans and vulnerable children (OVC) infected with or affected by HIV or AIDS within their communities (Halkett, 2005:37).

The literature studied for each article will be discussed briefly:

4.1.1 Article 1

The literature review deals with the impact of HIV or AIDS on individuals, families and communities with reference to relevant statistics as given by Avert (2005), STATSSA (2008) and Van Wyk and Lemmer, (2007). The diagnosis of HIV or AIDS is a traumatic stressor (Kagee, 2008:247). In dealing with the traumatic effect of this diagnosis, the role of the T.L.C. Hospice caregivers is explored by looking at the Hospice philosophy of care, palliative care, talks and roles of hospice caregivers in terms of HIV or AIDS and meeting the needs of families they deal with.

Policy documents from the Department of Social Development (2003) and Pretoria Sungardens Hospice (2006), as well as the ethical nursing code (Pera & Van Tonder,

2005) were utilized as guidelines for service rendering. The home-based caregivers' scope of practice (South Coast Hospice, 2003) provides an outline of the caregivers' duties and training and is supported by Groenewald (2005:134). The support of the broader community is dealt with by Calman (1984:124-127) Mboyi, Carrara, Makaye, Fröhlich & Karim, (2005:10-17) and Groenewald (2005:134). Buckingham and Meister (2001) shed light on the new challenges hospice care is facing with the HIV and AIDS pandemic. This is confirmed by Emanuel, Von Gunten and Ferris (1999:14), as well as Jerant, Rabman, Nesbitt and Meyers (2004).

4.1.2 Article 2

An *assessment tool* (Halkett, 2005:126-131) was used during home visits. It is helpful in identifying an affected family's bio-psychosocial needs. In meeting these needs, the *Circles of support* model of Smart (2003:43) was implemented. The South Coast Hospice (2003) gives an outline of how the three categories of patients may impact on the needs of the affected families. Gennrich (2004:170-174) gives insight into the psychosocial and spiritual needs associated with the progression of HIV-infection. The value of regular home visits is described by Danielson et al. (1993:66); Pera and Van Tonder (2005:6) and Smit (2007:1-10). The aim is to refer the affected families to the relevant community resources in order to meet their needs (Ebersöhn & Eloff, 2002:78; Potterton, Stewart & Cooper, 2007:213; Smart, 2003:43). Needs are described by means of Maslow's model (Herbst & De la Porte, 2006:4; Meyer, Moore & Viljoen, 2002:334-335).

4.1.3 Article 3

The main focus areas for service rendering to families infected with or affected by HIV or AIDS were identified by making use of the *assessment tool* (Halkett, 2005:126-131). The model of *Circles of support* (Smart, 2003:43-44) was utilized as guideline for planning intervention for families infected with or affected by HIV and AIDS. In order to render holistic, multi-disciplinary services, all stakeholders need to take part in the helping process (Pivnick & Villegas, 2000:103; Shisana & Louw, 2006:453-455; Wood, Chase & Aggleton, 2006:1932-1933). Memory work and support groups (Herbst & De la Porte, 2006:47) do not receive the necessary attention at present and should be addressed in future.

4.2 Empirical investigation

4.2.1 The Design

This qualitative study was of both an explorative and descriptive nature (Alston & Bowles, 2003: 34-35; De Vaus, 2001: 1-3; Greeff, 2005: 286) and strived to explore the views of the respondents regarding the role of hospice caregivers and the needs of families infected with or affected by HIV or AIDS (Fouché & De Vos, 2005a:92, 93). Data was collected by asking empirical questions during focus group discussions and interviews. By asking these questions, the researcher aimed to determine the role of Hospice T.L.C. caregivers in meeting the needs of families infected with or affected by HIV or AIDS in order to improve service delivery to them. This study further strived to discover important questions, processes and especially relationships and not to test them. In this study the relationship of the caregivers with their patients and affected families were explored and described (Fouché & De Vos, 2005c:116; Mouton, 2005:55).

4.2.2 Participants

More than one group of participants were involved in this study. For clarity, each group of participants will be discussed according to the article in which their data is reported on.

4.2.2.1 Article 1

The total population (Strydom, 2005b:193) of nine caregivers working for T.L.C. Hospice were included as participants for this part of the study. These participants took part in five focus group discussions (Greeff, 2005:286) of approximately one hour per session. The aim of these sessions was to investigate how the caregivers perceive their own roles in meeting the bio-psychosocial needs of the infected with or affected families they deal with.

4.2.2.2 Article 2

Participants for this part of the study were selected by means of purposive sampling. The population consisted of all 100 families that receive services from Hospice T.L.C. With the help of the Hospice T.L.C. caregivers, a 10% purposive sample was drawn from the population to participate in this part of the study (Strydom, 2005b:202). The inclusion criteria were that the family had to be registered with Hospice T.L.C. and they had to be willing to participate voluntarily. A total of 10 families participated by means of an interview.

4.2.2.3 Article 3

The participants consisted of two groups, namely the total population of nine Hospice T.L.C. caregivers and five participants from service providers. For the latter group, panel sampling (Strydom, 2005b:201) was used to identify five representatives of relevant service providers in the Kokstad community to be interviewed. The relevance of service providers was determined by selecting only service providers to whom Hospice T.L.C. refers families in need of their services.

4.2.3 Measuring Instruments

The following measuring instruments were used during the research process:

Article 1

Data was collected by asking empirical questions during five focus group sessions (Greeff, 2005: 106; Mouton, 2005:53, 54). The questions asked during the focus group sessions were described in detail in Article 1.

Article 2

An interview schedule was developed and tested during the final focus group session before being used on the participants. The *assessment tool* (Halkett, 2005:130-131) was used to identify central themes regarding bio-psychosocial needs.

Article 3

The *assessment tool* (Halkett, 2005:130-131) was used to direct the focus group sessions with the Hospice T.L.C. caregivers to identify main focus areas for service rendering. This assessment tool will be described in more detail in Article 2 of this dissertation. An interview schedule was developed to direct questions to five participants of service rendering organisations (see page 32).

4.2.4 Procedures

The following procedures were followed during the research process:

- All the potential role-players were informed about the planned study.
- An extensive literature study was done.
- A field worker was identified and trained to assist the researcher with interviews and the focus group sessions.

- Hospice T.L.C. was visited, the planned project was explained to the caregivers and potential respondents were identified to participate in the focus group discussions.
- Families infected with or affected by HIV or AIDS, to participate by means of interviews, were identified through a process of purposive sampling.
- Questions were compiled that would direct the focus group sessions (see page 29).
- An interview schedule was compiled for completion with the families infected with or affected by HIV or AIDS (see Addendum 5).
- The information gathered was recorded in a written form in order to shed light on the role Hospice T.L.C. caregivers play in meeting the bio-psychosocial needs of families infected or affected by HIV or AIDS and to improve service rendering to them.
- Data was analysed by means of thematic analysis.

4.2.5 Ethical Aspects

The ethical aspects, as described by Mouton (2005:238-245) and Strydom (2005a:56-70), were taken into account during the research process. Informed consent of the participants, avoidance of any form of harm in a physical or emotional manner of the participant, right to privacy, confidentiality and anonymity was taken into account during the research process. Strydom (2005a:63) mentions the fact that "...researchers are ethically obliged to ensure that they are competent and adequately skilled to undertake the proposed investigation." It was the researcher's aim to act professionally at all times and to deal with the participants in a respectful way across cultural boundaries, especially where minor children were concerned. The participants were informed regarding the outcome of the research, and publication of the findings thereof will be discussed with them as well.

- Ethical permission was obtained from the Ethics Committee of the North-West University (Potchefstroom Campus). The study was approved and the ethical number: NWU-0060-08-A1 was allocated to the study (see Addendum 3).
- Written consent was obtained from Hospice T.L.C. and CWFSA - Kokstad to conduct the research process (see Addenda 1 and 2).
- The ethical codes of these two NPO's were adhered to during the research process.

- Relevant NPO's rendering services to the families referred to them by Hospice T.L.C. were contacted and informed about the study. Their ethical codes were also respected during the research process.

4.2.6 Data Analysis

In the interpretation and analysis of qualitative data, the process of thematic analysis, as described by De Vos (2005:334-339) was utilized. The data collected during the focus groups and interviews were evaluated and processed. Delpont & Fouché (2005:352) remarks that qualitative data is often interesting to the reader, but often difficult for the researcher to process and generalize to other situations. The researcher had to bear this in mind while analysing the data. Central themes were identified from the data by following Tesch's approach of qualitative data analysis (Poggenpoel, 1998:343-344; Tesch, 1990:77).

5. CHOICE AND STRUCTURE OF THE RESEARCH REPORT

The research report will be published in article format under the following titles:

- Article 1: The role of Hospice caregivers fulfil in caring for families infected with or affected by HIV or AIDS
- Article 2: The bio-psychosocial needs of families infected with or affected by HIV or AIDS
- Article 3: Focus areas for bio-psychosocial services to families infected with or affected by HIV or AIDS

Possible journals for publication:

- Maatskaplike Werk / Social Work.
- Health SA Gesondheid.
- Journal of Social Aspects of HIV/AIDS.

Although the researcher is of the intention to submit manuscripts to different journals for possible publication, for purposes of this dissertation all articles are structured according to the guidelines of Maatskaplike Werk / Social Work. The rationale for this decision was that it would provide uniformity with regard to structure, citation of references and general technical care (see Addendum 4 for the guidelines for authors).

6. LIMITATIONS OF THE RESEARCH

- A relatively small sample was taken; therefore the results cannot be generalized.
- Time constraint was another limitation, since the researcher would have preferred to do follow-up visits to the participants and personally inform them of the outcome of this study. Only one home visit was made to the participants taking part in the interviews reported on in Article 2. Feedback on the outcome of the study was, however, given to participants by the Hospice T.L.C. caregivers.
- Language caused some challenges, but thanks to the assistance of the hospice T.L.C caregivers who acted as interpreters, it was overcome.
- The presence of the Hospice T.L.C. caregivers had both a positive and negative influence on this study. The caregivers ensured easy access to participants and trust was more easily established by their presence during home visits, but the participants were reluctant to express any negative aspects in their relationship with the caregivers.

7. TERMINOLOGY

- A child: A person under the age of 18 years (Giese, 2009:11).
- Caregivers: In this case caregivers will be hospice caregivers rendering palliative care based on the needs and circumstances of each patient individually (Lauden, 1999:4).
- CD4-count: This is a marker doctors use to determine how weak or strong a patient's immune system is (Giese, 2009:7).
- Child-headed Household: The parent or primary caregiver of the household is terminally ill or has died due to any cause including AIDS. No adult family member is available to provide care for the children in the household. A child has assumed the role of primary caregiver in respect of a child or children in the household in terms of providing food, clothing and psycho-social support (Halkett, 2005:4).
- Child Welfare South Africa (CWSA): CWSA is a unified body composed of structures and member organisations with a common objective to promote protect and enhance the safety, well being and healthy development of children within the context of the family and community (Halkett, 2005:4).
- Child Welfare South Africa Member Organisation: CWSA members shall mean members in terms of the provisions of the CWSA Constitution and who shall be non-

profit organisations with a common objective to protect and promote the development interests, safety and well-being of children within the context of family and community and to safeguard the rights of children (Halkett, 2005:4).

- Families affected with or affected by HIV or AIDS: Due to HIV or AIDS the diagnosis with HIV-infection has an effect on the family and is therefore affected by the infection (Halkett, 2005:4).
- Family: Individuals who either by agreement or contract choose to live together intimately and function as a unit in the social and economic system. The family is the primary social unit that ideally provides care, nurturing and socialisation to its members. It seeks to provide children with physical, economic, emotional, social, cultural and spiritual security (Halkett, 2005:4).
- Home-based care: Care of the patient by a trained volunteer according to a care plan at home with assistance of a trained nurse, including bereavement care for the affected family (South Coast Hospice, 2003).
- Hospice: An international NPO rendering palliative care to terminally ill patients and their families either in their homes or Hospice's own in-patient wards (Lauden, 1999:3).
- Informed consent: This is a process by which a client, parent, guardian of child older than 12 years agrees verbally or in writing to take part in a procedure after having received information on it, understanding that the procedure is in their best interest (Giese, 2009:8).
- Non-profit organisation (NPO): An organisation that renders services with no intention to gain profit from their service rendering (Halkett, 2005:5).
- Orphan: A child under the age of 18 years who has lost one or both parents due to death from AIDS or from any other cause (Halkett, 2005:5).
- Orphans and vulnerable children (OVC): It refers to children who are made vulnerable by HIV or AIDS. It would include children in child-headed households, children at risk of being orphaned and children whose caregivers or parents are sick or terminally ill (Halkett, 2005:5).
- Service provider: It will include the organisations aiming at meeting the needs of families infected with or affected by HIV or AIDS (Giese, 2009:7-18).
- Volunteer: A volunteer is a person who gives of his or her time, ideas, ideals, resources, knowledge and skills without monetary compensation; a person with a

community spirit who gives freely of their time and talents in an area of their individual choice (Halkett, 2005:5).

- Vulnerable children: Children in child-headed households. Children at risk of being orphaned because their parents or caregivers are sick or terminally ill. Orphans in the care of grandparents, extended family, or other community care givers. Infected children who are members of these families (Halkett, 2005:5).
- Youth: Persons between ages 18 and 35 years (Halkett, 2005:5).

8. ACRONYMS

- CSS: Christian Social Services
- CWSA: Child Welfare South Africa
- NPO: Non-profit organisation
- OVC: Orphans and vulnerable children
- TLC: Tender loving care

(Halkett, 2005:4-5)

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SECTION B : ARTICLE 1

**THE ROLE HOSPICE CAREGIVERS FULFIL
IN CARING FOR FAMILIES INFECTED
WITH OR AFFECTED BY
HIV AND AIDS**

N. BESTER • A.G. HERBST

1. ABSTRACT

In Kokstad, Kwazulu-Natal Hospice caregivers have been rendering services to families infected with and affected by HIV and AIDS. The role of these caregivers was explored by means of a qualitative study making use of focus groups. The focus of this article is the role that Hospice caregivers fulfil in meeting the needs of these families. Through their training and knowledge they obtain access to families infected with and affected by HIV and AIDS. From the study, certain recommendations could be made that could improve future service rendering, and assist the caregivers in meeting the needs of their patients more effectively.

Keywords: HIV and AIDS, hospice, caregivers, palliative care, caregiving, families infected and affected..

2. INTRODUCTION

Hospice T.L.C. is the name of a Non-Profit Organization (NPO) rendering services in the Kokstad area situated in the southern region of Kwazulu-Natal, South Africa. Hospice T.L.C. has been in operation since June 2006 and their main focus is to render holistic palliative and frail care to all patients in their area of operation. In this article the focus will be on the role Hospice T.L.C. caregivers can play in meeting the bio-psychosocial needs of families infected or affected by HIV and AIDS in the Kokstad area. Through their contact with frail and terminally ill patients the caregivers have access to their families, affording them an opportunity to identify and meet some of the bio-psychosocial needs of the families.

This article reports on the results of a qualitative study exploring caregivers' perceptions of their roles in dealing with HIV- infected or affected families in the Kokstad area. Data was obtained by means of a series of focus group sessions with caregivers and the analysis thereof following Creswell's analytical spiral and Tesch's approach.

3. RESEARCH METHODOLOGY

The goal of this qualitative study is to do a critical investigation regarding the role Hospice T.L.C. caregivers fulfil in the lives of families infected with or affected by HIV and AIDS in the Kokstad area and how service rendering to these families could be improved. The nature of this study is both descriptive and explanatory (Fouché & De Vos, 2005c:106) by focusing on the descriptions and explanations of the roles of caregivers in the lives of people infected with or affected by HIV and AIDS.

Data was collected by asking empirical questions (Mouton, 2005:53,54) during five focus group sessions (Greeff, 2005:286) and by means of a literature review (Fouché & Delport, 2005:76). Ethical aspects such as permission from Hospice T.L.C. and Child Welfare South Africa, confidentiality and voluntary participation were considered during this study (Strydom, 2000:64).

The total population of nine caregivers employed by Hospice T.L.C. participated in the focus group sessions. The researcher made use of an interpreter who assisted with the recording of data and with the translation to minimize the effect of misunderstanding due to language barriers. The caregivers are all Xhosa first-language speakers.

In the interpretation and analysis of the obtained data, Tesch's analytical process was used (Tesch, 1990:77). The research was further informed by an extensive literature study dealing with the three questions discussed during the focus group sessions against the background of Circles of Support (Smart, 2003:43) where community involvement and the utilization of community resources form an integral part of the helping relationship (Egan, 1994).

4. LITERATURE REVIEW

The impact of HIV and AIDS on individuals, families and communities

Worldwide, HIV and AIDS are impacting on communities, and Kokstad is no exception. According to Smit (2007:1), 19 million people could have died globally by the end of the 20th century due to HIV and AIDS. The impact on families due to this is devastating. The orphan population could exceed 13 million by 2010. Seemingly 70% of the 34 million people infected with or affected by HIV and AIDS are living in sub-Saharan Africa and a projection of 44 million orphans under the age of 15 is shocking.

South Africa is one of the worst affected countries in the world and the KwaZulu-Natal province has one of the highest infection growth rates recorded at antenatal clinics rising from 19,9% in 1996 to 36,5% in 2005 (Avert, 2005; Van Wyk & Lemmer, 2007:241). This is also true of the Kokstad community which consists of 34 000 registered voters. The census of 2001 counted 56 537 people in the greater Kokstad area (STATSSA, 2008). A person diagnosed with HIV or AIDS, as well as the family, need special care and support. The diagnosis of HIV or AIDS is described by Kagee (2008:247) as a *traumatic stressor*. Trauma can be described as "... any circumstance that affects the body or psyche negatively" (Strydom & Herbst, 2008:171). A diagnosis of HIV or AIDS can be categorized as such circumstances. Such a situation can lead to withdrawal, a sense of helplessness, depression, fear or tension (Strydom & Herbst, 2008:171). The hospice

caregivers are trained in meeting the physical as well as psycho-social needs of families infected with and affected by HIV or AIDS in providing palliative care.

5. THE HOSPICE PHILOSOPHY OF CARE

Hospice care was established to provide palliative service for the dying and their families. Hospice is based on a philosophy of comprehensive care and not a facility that focuses solely on end-of-life care. End-of-life care can be defined as palliative care which is the active, comprehensive and interdisciplinary care of patients with an advanced, progressive and incurable disease. The World Health Organisation (WHO) defines palliative care as "an approach that improves the quality of life of patients and their families facing problems associated with life threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems – physical, psychosocial and spiritual" (Pretoria Sungardens Hospice, 2006:5).

Originally "to palliate" meant to cover with a cloak and the meaning of this term in health care, where it is referred to as "palliative care, would mean to alleviate the symptoms of a disease without curing it (Corr, Nabe & Corr, 1999:196, 199). Most Hospices make use of the T.L.C. model as described by Jerant, Rabman, Nesbitt and Meyers (2004:56). This model is based on the letters T-L-C and is summarized in Table 1.

TABLE 1.1 : TLC model of Palliative Care

LETTER	MODEL ELEMENT	ELABORATION
T	Timely Team oriented	Proactive rather than reactive approach to avoid prolonged unnecessary suffering. Nurses, social workers, trained laypersons, and others involved.
L	Longitudinal	Balance of palliative and curative measures evolves with time.
C	Collaborative Comprehensive	Patients, family members and providers share decisions. All empirically supported domains of palliative care are addressed.

This model is based on holistic principles focusing on the patient as an individual within a family system and part of the broader community.

The general perception of medical care is to prevent death or to cure. Within palliative care the focus is on maintaining or slowing down the process of losing one's quality of life (Jerant et al, 2004:55). In the helping or caring relationship the aim of the caregivers will be to come alongside the patients and their families and offer the necessary support in dealing with the stressful situation caused by the sickness. The relationship itself is central to helping and it requires a certain amount of skills to be developed in the caregiver such as empathy, good listening skills, a warm, caring attitude and ability to identify and address needs. The ultimate goal of the helping relationship will be to help the patients to manage their lives better in order to have maximum quality of life as long as possible (Egan, 1994:47-48). Seen against this background it is important to refer to the continuum of palliative care, as illustrated in Figure 1.

This continuum can be applied to HIV and AIDS and includes the following :

- Counselling before and after voluntary HIV-testing (Category 1 patients). Supporting people with HIV or AIDS who are not sick and their families (Category 1 patients and their affected families).
- Providing home-based care to people who are ill (Category 2 and 3 patients).
- Bereavement counselling and follow-up visits for affected families of dying patients, as well as support after the death of a patient (South Coast Hospice, 2003).

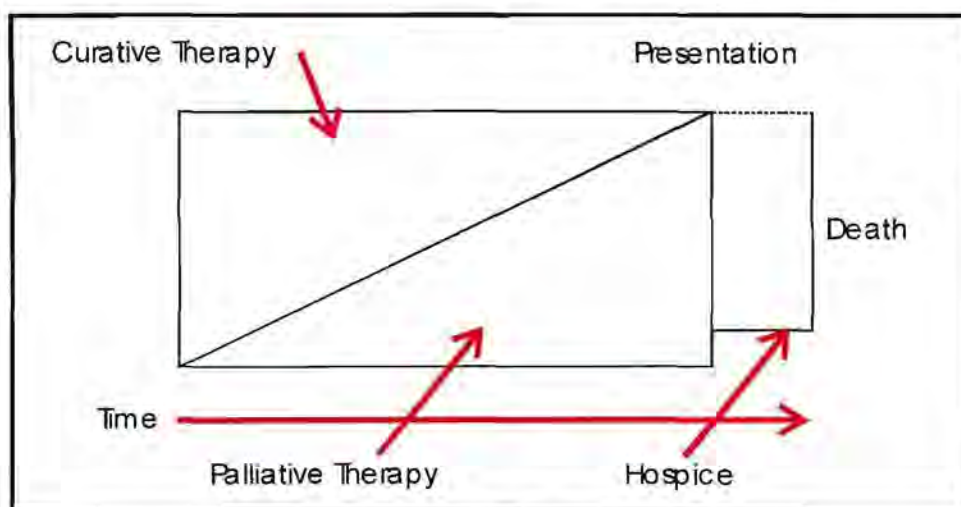


FIGURE 1.1 : The Palliative Care Continuum

Above is the continuum of care as described by Emanuel, Von Gunten and Ferris (1999:14). With the advancement of a terminal illness, the amount of curative therapy will

decrease and palliative therapy will increase. In the last stage of the illness, hospice care will be very important (Jerant et al, 2004:55).

In rendering palliative care on this continuum, the following objectives serve as a guideline for hospice care at the Hospice T.L.C. in Kokstad.

- To provide holistic care to all patients referred to Hospice T.L.C. within its area of jurisdiction.
- To offer a support system to patients and their families during a patient's illness and into the bereavement period.
- To provide effective pain control.
- To enhance quality of life for patients and their families and to positively influence the course of a patient's illness.
- To provide trained caregivers to patients requiring full-time care.
- To provide ongoing training to caregivers so that they can be effective and efficient in administering care within the home-based care system.
- To apply the Multidisciplinary Team approaches in addressing the needs of patients and their families.
- To regularly update palliative nurses on the AIDS programs and treatments so that they can inform patients and refer appropriately.
- To assess the impact and effect of chronic illnesses (T.B, Cancer, Pneumonia Malaria, PCP) to the target region and assist if possible.
- To provide the elderly with frail care services and a step-down facility from hospital back to the home and to assist those who are ill in their places of residence and ensure the necessary care.
- To refer patients to the social workers for the appropriate grants.
- To find placement for orphaned children through the assistance of Child Welfare S.A. – Kokstad.
- To arrange for professional counselling for patients and their families.
- To promote AIDS awareness in its area of jurisdiction.
- To provide food parcels to families in need.

- To communicate with other organizations so as to complement one another and unite efforts.
- To offer training to other organizations.

(Calman, 1984:124; Hospice T.L.C., 2006).

The HIV and AIDS pandemic is posing new challenges to hospice care (Buckingham & Meister, 2001:461). The tasks and roles of Hospice caregivers regarding HIV and AIDS need further exploration and discussion.

6. THE TASKS AND ROLES OF HOSPICE CAREGIVERS IN TERMS OF HIV AND AIDS

6.1 The home-based caregiver's scope of practice

Caregivers at the Hospice T.L.C. in Kokstad are practising as home-based caregivers. According to policy documents of the South Coast Hospice (2003), all actions and procedures of home-based caregivers are planned by a professional nurse and carried out under the supervision of a professional nurse. The scope of practice includes the following:

- Care of the patient according to a care plan.
- Promotion of health and maintenance of the hygiene of a patient or family and community.
- Promotion and maintenance of the physical comfort of a patient, comfort, rest, sleep, exercise and reassurance of the family.
- Prevention of physical deformities and other complications in a patient.
- Assessing patients in a critical condition, e.g. temperature, pulse and respiration and report.
- Promotion and maintenance of body functions.
- Promotion and monitoring of nutrition for the patient and family.
- Promotion of communication with the patient and the family.
- Assist the professional nurse during nursing procedures.
- Care of a dying patient and recently deceased patient.
- Bereavement care for family/carers.

- Referring patients to clinic/hospital or community organizations.
- Networking with other members of the care team.

(South Coast Hospice, 2003).

From the afore-mentioned it is clear that Hospice caregivers have the potential of playing a vital role in meeting the needs of families infected with or affected by HIV and AIDS.

6.2 The training of Hospice caregivers

All Hospice caregivers are properly trained with regard to their scope of practice, the essentials of care and palliative care and their specific roles in this regard. Caregivers at Hospice T.L.C. undergo a 59-day basic training course in home-based care. This is followed up by a course on paediatric palliative care stretching across a period of two weeks. The focus is on the comfort of the patient and the support of the family. The following three important precepts of palliative caring form part of the training:

- Utilizing interdisciplinary resources' strengths;
- Acknowledging and addressing the concerns of the caregivers;
- Building supportive mechanisms and systems.

(Groenewald, 2005:134).

6.3 The roles of the caregiver

The roles of the caregiver fit in very well in ensuring that the patient is comfortable and the family receives the necessary support by utilizing the objectives of Hospice care described earlier in this article. A number of specific roles can be fulfilled by the hospice caregiver in fulfilling the needs of the patient and the family. These roles include those of teacher, coordinator, mediator, communicator and collaborator (Danielson, Hamel-Bissell & Winstead-Fry, 1993:171). Each of these roles will be discussed briefly, namely those of teacher, coordinator, mediator, communicator and collaborator.

The services provided by Hospice T.L.C. caregivers adhere to the ethical code for nursing in general where the aim is to focus on the well-being of patients; it is a commitment which shows respect for persons. Care shows that patients matter as individuals (Pera & Van Tonder, 2005:5). In dealing with the patient it is important to remember that the needs, as well as the rights and choices of the mentally competent patient should be respected in the first place, and not those of the family (Pretoria Sungardens Hospice, 2006:22).

6.4 The tasks of hospice caregivers

The hospice caregiver has several tasks with regard to people infected with or affected by HIV and AIDS. Their first task is to encourage voluntary testing and counselling at local clinics and to provide general health education. Support of infected people is advocated, not only by their family, but also by the broader community (Mboyi, Carrara, Makaye, Frohlich & Karim, 2005:10-17).

Hospice caregivers act as a valuable link between the medical staff actually communicating the diagnosis and the patient him-/herself and the family. In breaking bad news to the patient, in this case the diagnosis with HIV or AIDS, special skills will be required of the communicator. How the patient responds to the news, becomes a very crucial part of the interview. This interview comprises two phases: the sharing of the diagnosis with the patient, and dealing with his/her reaction to the news (Pretoria Sungardens Hospice, 2006:14).

The hospice caregivers assist in informing the family of the diagnosis, answering questions and giving more information, communicating information and test results in a language understandable to the patient and the family (Pretoria Sungardens Hospice, 2006:20).

The hospice caregiver has a valuable role to fulfil when it comes to education and awareness regarding HIV and AIDS.

Once the diagnosis is shared and the initial shock is over, a plan of action needs to be formulated. A family meeting can be useful and should aim at:

- Assessing the family system and dynamics;
- Sharing their understanding of the diagnosis, prognosis and management goals;
- Establishing an atmosphere of trust where feelings could be vented freely;
- Planning advance care;
- Reconciling relationships, where needed; and
- Establishing a sense of control.

(Calman, 1984:124-127).

After having been diagnosed with HIV or AIDS, people need help in coping with the psychosocial distress caused by the diagnosis.

Factors they consider stressful are social stigma, living with their diagnosis and condition as well as starting treatment (Kagee, 2008:249). Hospice caregivers act as a buffer between the patient and the community. Social stigma is still a huge problem within communities and ostracism is a real threat (Buckingham & Meister, 2001:463). Both the patient and the family need ongoing support from the community they belong to. The Department of Social Development (2003:13) emphasizes the importance of introducing patients and families to resources in the community.

Smit (2007:9) points out that family functions are affected by HIV and AIDS, which places an extra burden on family members. These burdens could be alleviated by making use of the model of *Circles of Support* (Smart, 2003:46). The first circle would imply help from immediate family; the second circle would be help from the community, e.g. neighbours, and the third circle would include people in the broader society, e.g. church groups, local AIDS support groups, N.G.Os, e.g. the local Hospice or C.W.F.S.A, businesses and leaders. The "Integrated Service Delivery Model" makes provision for the development of strengths of the individuals, groups and communities by building their capacity for growth and development. This is called the Development Paradigm. The main aim with this approach is to enable communities to meet their own needs (Department of Social Development, 2003:11).

Hospice caregivers play a vital role in identifying the needs of patients and in enabling them to make use of relevant resources within the community to meet their needs (Smart, 2003:42). People living with HIV and AIDS, their families and their neighbours need more support than health care only (Groenewald, 2005:127).

The Circles of Support, as referred to by Smart (2003:43), are important when caring for families infected with or affected by HIV or AIDS. Three circles of support are mentioned:

1. Help from family, neighbours and friends;
2. Help from the community;
3. Resources in the broader society, such as Hospice and Child Welfare – South Africa.

Hospice caregivers resort under "Resources in the broader society."

7. RESULTS

7.1 Focus group information

All 9 permanently employed hospice caregivers participated in five focus group sessions. These discussions were based on carefully formulated questions as described by Greeff (2005:308). A Xhosa interpreter assisted during the sessions to record communication. The duration of each session was approximately one hour.

The focus group discussions were based on the following questions:

- What basic information did the caregivers need to have before the onset of the research project?
- What are the caregivers' personal opinions regarding their role in the lives of families infected with and affected by HIV and AIDS?
- How do the caregivers see the needs of the families infected with or affected by HIV and AIDS?
- What was the outcome of the focus group sessions?

TABLE 1.2 : Focus Group Sessions

FOCUS GROUP SESSION 1	GOAL: TO COMMUNICATE BASIC INFORMATION REGARDING THE RESEARCH PROJECT TO FOCUS GROUP MEMBERS
OBJECTIVES	<ul style="list-style-type: none"> • To make contact with caregivers. • To explain the goals of the research project. • To obtain written informed consent from the participants.
COURSE OF THE FOCUS GROUP SESSION	<ul style="list-style-type: none"> • This session was a contact /contract session. • The researcher introduced herself and her assistant. • The goals of the research project were stated. • Informed consent was obtained in writing. • The number and duration of focus group sessions were discussed. • Ethical aspects were clarified.
THEMES EMERGING	<ul style="list-style-type: none"> • Positive attitude towards the research project from the caregivers. • Appreciation from the caregivers for an opportunity to vent their own feelings regarding their work.
EXAMPLES OF RESPONSES	<ul style="list-style-type: none"> • "I occasionally feel despondent as a caregiver due to the fact that there is only so much that I can do. The need is so huge. I appreciate you taking the time to listen to us."
CORRELATION WITH LITERATURE	<ul style="list-style-type: none"> • Guidelines for conducting focus group sessions, as described by Greeff, (2005:300-311) were utilised successfully.
GOALS OF FOCUS GROUP SESSION	<ul style="list-style-type: none"> • To allow free discussion, facilitated by the interpreter, regarding the role of a caregiver. • To define the specific roles of caregivers with regard to people infected with or affected by HIV or AIDS.
COURSE OF THE FOCUS GROUP SESSIONS	<ul style="list-style-type: none"> • Discussion on the caregivers' views of their own roles in meeting the needs of their patients, together with their affected families. • This session was a lively discussion viewing the work done by the caregivers.

FOCUS GROUP SESSION 2	"WHAT ARE THE CAREGIVERS' PERSONAL OPINIONS REGARDING THEIR ROLE IN THE LIVES OF FAMILIES INFECTED WITH AND AFFECTED BY HIV AND AIDS?"
THEMES EMERGING	<ul style="list-style-type: none"> • Support is important for patient and family within their community. • It takes time to build the caring relationship, but it pays off in the long run. • Caregivers need support and guidance for themselves to prevent compassion fatigue. • Caregivers act as a link between the patient and the resources in the community. • Caregivers fulfil different roles in meeting the needs of their patients and their affected families.
EXAMPLES OF RESPONSES	<ul style="list-style-type: none"> • "We are always with sick people, even in our own families and communities. We become very tired of the sickness." • "We want to help sick people who need support. We want to advise and educate them to have hope again." • "We would like to act as someone objective and supportive who will not judge them for our patients and their families." • "There is still a lot of stigma in our communities, especially from the churches." • "Our patients need love and understanding. Sometimes they are neglected by their own family." • "The people are hungry. We help with food parcels, cooking and veggie gardens."
CORRELATION WITH LITERATURE	<ul style="list-style-type: none"> • The caregivers' scope of practice (South Coast Hospice, 2003) gives good guidelines for the service they render. • They are fulfilling the roles of teacher, coordinator, mediator, communicator and collaborator successfully (Danielson et al. 1993:171). • Caring is the cornerstone of their service rendering (Pera & Van Tonder, 2005:6).

FOCUS GROUP SESSION 3	“HOW DO THE CAREGIVERS SEE THE NEEDS OF THE FAMILIES INFECTED WITH OR AFFECTED BY HIV AND AIDS?”
GOAL	<ul style="list-style-type: none"> To determine how the caregivers see the needs of their patients together with those of their affected families.
COURSE OF THE FOCUS GROUP SESSION	<ul style="list-style-type: none"> An open discussion was held during which the caregivers shared their views on the needs of their patients and their affected families as they interpret it.
THEMES EMERGING	<ul style="list-style-type: none"> Their training as hospice caregivers enables them to identify the needs of their patients and their affected families. The needs of the patients vary in accordance with the stages of their illness. They distinguished three categories of patients; one, being still able to function fairly normally and three, being terminally ill. They act as a link between the patients' and affected families' needs and relevant resources in the community. The support they give to their patients and their affected families is vitally important. Currently they do not have the time to do memory work or run support groups.
EXAMPLES OF RESPONSES	<ul style="list-style-type: none"> “The patients and their families don't have identity documents, therefore cannot get the grants, so they are hungry.” “The families need information on HIV/Aids to understand it better and not stigmatise the patients.” “There is a need for support and for opportunities to disclose.” “The patients need to have hope.”
CORRELATION WITH LITERATURE	<ul style="list-style-type: none"> Their training enables the caregivers to be competent in addressing the needs of their patients and their affected families. Through this knowledge they are enabled to draw up a proper care plan which is evaluated from time to time (Slabbert, 2003:23-24).

FOCUS GROUP SESSION 4	"HOW DO THE OBJECTIVES OF HOSPICE T.L.C. AS STATED IN THEIR CONSTITUTION, AND ACTUAL SERVICE RENDERING, COMPARE WITH EACH OTHER?"
GOAL	<ul style="list-style-type: none"> To determine how the caregivers see their service rendering outlined by the objectives of Hospice T.L.C. as stated in their constitution.
COURSE OF THE FOCUS GROUP SESSION	<ul style="list-style-type: none"> Each caregiver received a copy of the above-mentioned objectives. The group discussed the objectives individually to determine to what measure they were reaching these objectives.
OBJECTIVE 1	<ul style="list-style-type: none"> Follow a holistic approach in meeting the needs of patients and their families.
EXAMPLES OF RESPONSES	<ul style="list-style-type: none"> "Yes, we do follow a holistic approach by addressing emotional, physical and social needs. We treat the person as a whole human being. When it comes to spiritual needs, we prefer to refer their patients to priests, pastors and ministers of the churches they belong to."
OBJECTIVE 2	<ul style="list-style-type: none"> To offer support to patients and their families during bereavement.
EXAMPLES OF RESPONSES	<ul style="list-style-type: none"> "We do give a lot of support, even pay one visit after a patient died to do bereavement counselling. The number of visits will depend on the family's needs and the type of relationship they had before the patient passed away".
OBJECTIVE 3	<ul style="list-style-type: none"> To provide effective pain control.
EXAMPLES OF RESPONSES	<ul style="list-style-type: none"> "As caregivers we are not allowed to give any tablets for pain management, only registered nurses may administer it. It includes Morphine, Panado and Ipbrufen".
OBJECTIVE 4	<ul style="list-style-type: none"> To provide trained caregivers to patients requiring ongoing care.
EXAMPLE OF RESPONSES	<ul style="list-style-type: none"> "We are all trained and still receive training on a weekly basis. We would like more training on trauma counselling and cancer management".

OBJECTIVE 5	<ul style="list-style-type: none"> To provide food parcels to needy families.
EXAMPLE OF RESPONSES	<ul style="list-style-type: none"> "The food parcels are very important and sometimes it is the only food in the home. The children are so glad to see us, for they know we come to help them".
THEMES EMERGING	<ul style="list-style-type: none"> A holistic approach is followed in meeting the physical and psychosocial needs of the patients and their affected families. Support is given by means of visits, depending on individual needs. They also provide bereavement support. Pain management is addressed in a professional manner. Ongoing training for the caregivers is a need, as well as support and debriefing opportunities through supervision. Awareness campaigns regarding relevant issues e.g. cancer as an opportunistic infection, should be addressed. Material needs are prevalent e.g. the need for food parcels, clothing, and help in obtaining relevant documentation with a view to obtain access to grants. There is a need to communicate effectively with other service rendering organizations e.g. Child Welfare SA – Kokstad and Khanyeselani. They have been involved in the training of staff attached to other organizations, e.g. Lusikisiki Hospice.
CORRELATION WITH LITERATURE	<ul style="list-style-type: none"> The objectives, as stated in the constitution of Hospice T.L.C. (2006), were used as guidelines for the 4th focus group discussion. According to the participants' feedback and discussion, it was clear that these objectives were followed with regard to service delivery.
GOALS	<ul style="list-style-type: none"> To give feedback to the caregivers regarding the outcome of the previous four focus group sessions. To lay the ground for the next phase of the research project. (It was not a termination session).

FOCUS GROUP SESSION 5	"WHAT WAS THE OUTCOME OF THE FOCUS GROUP SESSIONS?"
COURSE OF THE FOCUS GROUP SESSION	<ul style="list-style-type: none"> The themes as it emerged during the group sessions were discussed with the caregivers. This seems to have the effect that it enlightened them regarding the value of their service rendering. The researcher praised them for their caring, supportive attitude towards their patients and their affected families. This acted as a motivator to continue their services. They appreciated the time the researcher spent with them and was keen to form part of further research. Being able to speak Xhosa allowed for freer communication.
THEMES EMERGING	<ul style="list-style-type: none"> A good working relationship was established between the researcher and the caregivers, paving the way for further research. To them, receiving the feedback shed more light for them on the value of the service they render. The feedback seems to motivate them for further service rendering. Making use of an assistant who is fluent in Xhosa allowed for the caregivers to communicate freely.
CORRELATION WITH LITERATURE	<ul style="list-style-type: none"> Being aware of cultural differences and communication challenges where English is not the respondents' first language, should be taken into account (De Vito, 2001:69, 139). With the aid of an assistant who is fluent in Xhosa, this was addressed. At the end of this session the facilitator summarized the main viewpoints, verified and expressed her gratitude for the respondents' participation (Greeff, 2005:311).

7.2 Discussion of the results

Considering the Home-based caregiver's Scope of Practice, as compiled by South Coast Hospice (2003), the caregivers have good guidelines with regard to meeting the needs of their patients and their affected families.

The researcher noticed 5 roles the caregivers fulfil while rendering services within their communities, namely those of teacher, coordinator, mediator, communicator and collaborator (Danielson et al, 1993:171). They work under the supervision of two registered nurses who help them draw up care plans for each individual patient along with his/her family. They perform their duties against the background of general hospice and

nursing ethics. Caring is regarded as the cornerstone of all nursing that is centered on the well-being of the patient. It is a commitment which entails respect for all persons:

“Caring means patients matter as persons” (Pera & Van Tonder, 2005:6). Competencies of caring are manifested as follows :

- Having knowledge of the situation impacting the patient in all its diversity and knowing how to address it;
- Implementing a care plan based on the knowledge obtained by good training;
- Evaluating the care plan/actions (Slabbert, 2003:23-24).

In caring for the patients, three categories are distinguished in patient care, namely :

Category 1 patients

These patients are not sick; they may be working, attending a support group or receiving ARV support. They could be receiving contact with a trained member of the care team at least once a month. This contact could be on a one-on-one basis or as part of a support group.

Category 2 patients

These patients would need some medical/nursing care in addition to psycho-social care. Weekly visits from a caregiver would be needed as well as medical attention by an appropriate professional once a month.

Category 3 patients

At this stage the patient is home or bed-bound, needing significant clinical care. Caregivers need to pay at least two visits per week, of which one must include a professional nurse. These visits are on a one-on-one basis (South Coast Hospice, 2003). The objectives set by Hospice T.L.C. together with the Home-based Caregiver's Scope of practice, as compiled by South Coast Hospice, serve as very clear goals in service rendering by the T.L.C. caregivers. During the 4th focus group session the service rendering was evaluated in terms of these goals. The caregivers were in agreement that they are reaching their goals in meeting the needs of their patients, as well as those of the affected family members.

Caring involves stepping out of one's own personal frame of reference into that of the others. “To care is to act not by a fixed rule, but by affection and regard” (Slabbert, 2003:24). Caring would be the main attribute of the T.L.C. caregivers, and in building the

caring relationship it would be expected that they would show certain characteristics such as warmth, respect, consideration and maintenance of confidentiality, knowledge and the ability to listen.

The patient must experience sincerity in the caregiver's attitude in building a helping relationship. Through this relationship the patient and affected family are enabled to explore the impact the sickness has on them, clarify feelings and gain insight into the distressing situation caused by the sickness (Johnson, 2000:214).

Through their training the caregivers are able to identify the impact of the diagnosis of a terminal disease such as HIV and AIDS on their patients and their affected families. Kagee (2008) defined the diagnosis of HIV and AIDS as a traumatic stressor. This could result in emotions of anger and depression as a result of the experience of trauma due to the diagnosis. Common symptoms of depression would be :-

- Sadness
- Feeling of hopelessness or pessimism
- Feelings of guilt, worthlessness or helplessness
- Loss of interest in things the person previously enjoyed
- Concentration problems
- Sleep disturbances: Sleep too much or too little
- Loss of appetite or eating too much
- Weight loss
- Fatigue
- Restlessness, irritability, agitation
- Physical symptoms, e.g. headaches, digestive problems
- Low self-esteem
- Suicidal thoughts or attempts (Iverson, 2007:11)

Chronic illness challenges the ability of the individual patient, as well as the affected family. Under such circumstances the family's ability to communicate effectively, to do problem-solving and to display their internal strengths and durability of the family unit comes under strain. The illness acts as the stressor and the affected family needs social support. Community resources and supports include all individuals and institutions that the family could use to cope with the stressor situation (Danielson et al., 1993:46-47).

The Hospice T.L.C. caregiver is part of the social support system. In the caring relationship, issues such as maintaining the dignity and self-respect of a patient are often more important to the patient than symptom management such as pain relief. For the caregiver it is a challenge to be sensitive to the patient's needs to such an extent that there would be a balance between remaining life as well as possible managing and preparing for approaching death. In dealing with grief, which can start before death with a diagnosis, it is important to understand that grief responses are characterized by individual differences (Costa, Hall & Stewart, 2007:29).

In dealing with their patients and their affected families, the T.L.C. caregivers manage to meet these individual differences towards dealing with trauma and grief. The outcome of the 5 focus group sessions will be discussed in terms of these roles as outlined by Danielson et al. (1993:171).

- **Teacher**

An affected family's need for information regarding the condition, prognosis, progress and comfort of their ill loved one should not be underestimated. They wish to be informed at an understandable level. The information should be given in a trusting, helping relationship with a warm, caring attitude and with respect. Honesty and acceptance is very important (Danielson et al, 1993:170). By broadening the patient's affected family's and community's base of information, they become empowered (Delport, Roux & Rankin, 2008:318). From the focus group sessions it became clear that the T.L.C. caregivers are fulfilling the role of teachers and educators, they act as a link between professional medical staff and manage to communicate knowledge in clear, understandable terms with empathy. Cultural differences need to be taken into account. Different cultures view self-disclosure differently (De Vito, 2001:69, 123, 139). The Hospice T.L.C. caregivers are mostly Xhosa first-language speakers who are familiar with the Xhosa culture. The majority of patients are Xhosa. There is one white English-speaking caregiver and two white English-speaking professional nurses who act as supervisors. By means of their training they have the knowledge to educate the people regarding issues such as voluntary testing, grants, material assistance, documentation and resources within the community. Stigmatization regarding HIV and AIDS is still a reality. Misconceptions still exist, and by fulfilling the role of an educator, this should change in due time (Halkett, 2005:61). Families need information to plan realistically, especially where children are concerned. Should a mother be terminally ill, it is important for all parties involved to be part of the planning of future orphan care. With regular visits to the affected households,

they have an opportunity to give guidance regarding good nutrition and living a healthy lifestyle, e.g. prevention of HIV infection.

Poverty is the biggest problem; therefore the caregivers supply the affected families with at least one food parcel per week. By doing this they build a positive relationship with the families. It is especially the children who look forward to their visits. They assist with the preparation of meals and teach the older children how to cook and to make gardens. Due to the sickness of the primary caregiver, traditions and skills, e.g. cooking, crafts and gardening fail to be taught to the youngsters (Villarreal, 2002:1, 2).

Children often experience compromised parenting and need to witness debilitating illness (Wood, Chase & Aggleton, 2006:1924). The caregiver, who has built up a good relationship with the family, would be able to come alongside the children to support them, answer their questions, teach them skills and help them build their resilience. This is very important, especially for vulnerable children. Resilience could be defined as "the human capacity to face, overcome and be strengthened or even be transformed by the adversities of life".

This is a key concept in the way households deal with being affected by HIV/AIDS. Although all children pay a price in living with or losing a parent due to being infected with HIV/AIDS, it should not necessarily cause developmental or psychological harm to the children affected (Germann, 2005:42).

Due to the presence of a Hospice T.L.C. caregiver in the lives of Orphans and Vulnerable Children (O.V.C) and their families, the resilience of these affected families can be built which would enable them to cope better with the challenges they are face with. They educate them regarding the availability of grants, e.g. disability, foster care, care dependence, old age pension and child support grants in order to meet their material needs (Halkett, 2005:227).

One of the biggest obstacles in obtaining the grants is the unavailability of the relevant documents. The caregivers assist them by referring them to social workers (Halkett, 2005:223).

As a teacher, the T.L.C. caregiver could involve the terminally ill patient together with his/her affected family members in memory work. Some orphans experience distress by not having any momentous or tangible reminders of their lives with their parents. This results in an extreme sense of loss (Wood, Chase & Aggleton, 2006:1925).

By deliberately setting up a safe space for the telling of a life story, parents and children can be engaged in using memory work as a communication tool (Germann, 2005:45). In

practice the caregivers do not have time to do this and the help of volunteers could be called upon to assist with this valuable project of memory work. They do encourage their patients to have memory boxes and get their wills and documentation in order. They also encourage members of the community to go for voluntary S.T.D., T.B. and HIV and AIDS testing, as well as to stick to their ARV-programs. They encourage their patients to go to the clinics on a regular basis for CD-4 count blood tests.

- **Coordinator**

To strengthen communication lines within families, to decrease anxiety and to improve problem solving, efforts need to be coordinated. Hospice T.L.C. caregivers play a vital role as coordinators. By building a relationship marked by trust, support and coordination of services, the affected family's increased stress levels and sense of disorder could be minimized.

With the T.L.C. caregivers' involvement over the last two years, it is evident that the needs of terminally ill patients and their families are efficiently addressed. By rendering support on an ongoing basis, the patient and affected family's sense of bewilderment due to the trauma of the diagnosis is decreased. The caregivers form a valuable link between other resources and members of the multidisciplinary team (Jerant et al, 2004:56).

- **Mediator**

As a mediator, the Hospice T.L.C. caregiver plays an important role. The HIV and AIDS patient might initially only confide in the caregiver, lacking courage to disclose to their family, neighbours or the community (Wood et al, 2006:1924).

The mediator helps by facilitating anticipatory mourning, by assisting family members to maintain a sense of mastery, integrity, cohesiveness, identity and open communication lines (Danielson et al, 2007:171).

- **Communicator**

As communicators, the Hospice T.L.C. caregivers play a vital role. Through research it was found that teenagers prefer to be told the truth regarding the sickness of their parents. In the African culture children are simply told that a person who died "went away". Death is considered an inappropriate topic for discussion with children. Through contact with the affected families they are able to communicate their needs to the appropriate individuals and resources within the community.

Due to stigmatization, AIDS-related death is often considered to be a “bad death”. People tend to link it in their minds to shameful, unacceptable sex, as well as to moral dangers and political transition of modern life.

Within the African context children display a tendency to show signs of internalizing grief by falling into a state of depression, withdrawal and failure to thrive. The opposite also happens when children start with acting-out type behavior by being angry, rebellious and disruptive (Wood et al., 2006:1924-1925).

Through their training, Hospice T.L.C. caregivers are equipped to deal with these cultural issues in which certain topics such as death are “taboo”, as well as to encourage family members to have open communication lines. They are able to identify possible warning signs of children being neglected, abused or made vulnerable due to the impact of the sickness.

The Hospice T.L.C. caregivers have a great sense of loyalty and commitment to the patients and families they deal with. They fulfil the role of collaborator by “working together” (Oxford Student’s Dictionary, 2001:126) with their patients and families. According to them, it takes an average of 16-18 months to build a strong relationship of trust with them. All of the caregivers have experienced loss in their own lives, which enables them to show empathy to the people they deal with. They have persevered over the last 2 years and are presently experiencing a great sense of fulfilment and job satisfaction. They are working as volunteers for an N.P.O. and their main aim is not to work for monetary reward, but to help people in their own communities who are in need. The patients and their families confide in them regarding their fears, doubts and worries. The children bond with them and are glad to see them. They support the primary caregivers. Often a granny is not only caring for the patient, but also for the rest of the family.

To offer realistic hope and relief of anxiety, caregivers need to understand what the sickness means to the family. Ongoing training is necessary in order to increase their knowledge of the needs of the infected and affected people they deal with. They should encourage the family to mobilize their social support network to help relieve strain and stress (Danielson et al., 1993:172-173). The caregivers themselves need support to prevent burnout and compassion fatigue. They have experienced the loss of one T.L.C. caregiver during 2007 due to HIV and AIDS, which was very traumatic.

The researcher pointed out to them during the focus group sessions that they cannot bear all the responsibilities of support themselves. They need to refer the patients with their

affected families to relevant individuals and resources within the community, as mentioned by Danielson et al, (1993:66).

Living with hope is a more positive attitude than constantly thinking of dying of HIV and AIDS. This is the attitude the Hospice T.L.C. caregivers are installing in the people they deal with.

To live with hope :

- Most people infected with HIV are well and could live a good life some years after being infected.
- During this period adults and children with HIV can live active productive lives.
- They need support, advice and counselling to be able to look forward to several years of normal life.
- The surrounding community should be a source of love, care and support.
- Communities need to be encouraged to realize their potential (Halkett, 2005:81).

- **Discussion**

Due to the diagnosis with HIV, people need help in coping with the psychological distress. To live with the condition, receive treatment and deal with the social stigma they need support (Kagee, 2008:249). HIV and AIDS are regarded as stressors. The affected family needs to adapt to the new situation in which they also need support (Danielson et al, 1993:66).

The role of the caregivers working for Hospice T.L.C. would be to give the needed support. This happens through the caregivers gaining entrance to the affected families by taking care of the infected patient (Smit, 2007:2). Through palliative care the needs of the patient are addressed (Corr et al, 1999:186). With the *Circles of Support* (Smart, 2003:43) in mind, the caregivers enable the infected patients together with their affected families to make use of resources within the community to address their needs and to increase community support for families infected with or affected by HIV and AIDS.

8. CONCLUSIONS

1. Through their training, the T.L.C. Hospice caregivers are equipped to render support and care to patients and families infected with or affected by HIV and AIDS. It also gives an appreciation for the research process resulting in good cooperation between the researcher and the caregivers.

2. They act as a valuable "link" between professional medical staff and the patients, together with their families. They are able to communicate information at an understandable level. They are also aware of the cultural context in which the patients and families are functioning, enabling them to "come alongside" the patients and their affected families in a meaningful, supportive manner.
3. As teachers/educators they can help to clarify misconceptions regarding HIV and AIDS, and can help to minimize stigmatization.
4. In addressing material needs, they provide regular food parcels, assist with families obtaining relevant grants and educate families with regard to good nutrition and living healthy lifestyles.
5. They manage to link up needy families with relevant resources within the community and educate them regarding the availability of resources.
6. They motivate the patients to adhere to the ARV treatment program.
7. They assist with planned orphan care by helping the patients to get all the relevant documentation in order and referring them to the appropriate facilities in the community.
8. Memory work does not receive the necessary attention due to their very busy working schedules. Volunteers could be co-opted to assist with doing memory books and boxes.
9. No support groups are in operation. This should receive attention in future. It could also be run by volunteers.
10. Caring for the carers, needs special attention to assist them with debriefing and bereavement counselling. They could easily suffer from burnout or compassion fatigue.
11. The caregivers have been in the field for approximately 2 years. They experience a deep sense of loyalty and commitment towards the patients and families they deal with.
12. As volunteers they do not work for big monetary rewards. They receive a stipend as it is available. Care needs to be taken that good incentives are in place to keep them motivated to remain in the service of T.L.C. Hospice, Kokstad, e.g. to improve their qualifications, or a function in appreciation of their jobs well done.
13. In motivating people for voluntary testing, it is associated with fewer stigmas to be tested for T.B.

14. The caregivers experience that churches are still very judgmental towards people infected with HIV and AIDS.
15. After persevering in their jobs for 2 years as caregivers, they are now experiencing job satisfaction and fulfilment.

9. RECOMMENDATIONS

- Through their training the caregivers have an appreciation for the research project and were thus cooperative. Further training on a regular basis is recommended within the community for them to be able to meet the needs of the families they deal with.
- Material needs are the most prominent and it is recommended that regular food parcels be made available for distribution among needy families.
- As educators, they should continue to help minimise misconceptions and stigma within the community and encourage adherence to the ARV program.
- Children at risk of being orphaned should be referred to relevant resources and be part of planned orphan care.
- Volunteers could be trained to assist with memory work and support groups.
- Special attention and support should be given to the caregivers to prevent burnout or compassion fatigue.
- From the afore-mentioned research, it is clear that the Hospice T.L.C. caregivers fulfil a vital role in meeting the psychosocial needs of families infected with or affected by HIV and AIDS in the Kokstad area and they should be assisted by relevant resources. Therefore it is recommended that the following aspects receive attention through further research :
 - The identification of the bio-psychosocial needs of these infected or affected families;
 - The improvement of service rendering to these families by utilizing their circles of support.

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ARTICLE 2

**THE BIO-PSYCHOSOCIAL NEEDS OF
FAMILIES INFECTED AND AFFECTED BY
HIV AND AIDS**

N. BESTER • A.G. HERBST

1. ABSTRACT AND KEYWORDS

Literature indicates that people are widely affected by the presence of HIV or AIDS in their lives. The effects are of a physical, psychological, as well as a social nature. This has several implications for the affected families. In this study the bio-psychosocial needs, as identified by families themselves, receive attention. This qualitative study was conducted with the help of caregivers of Hospice T.L.C. operating in the Kokstad area, Kwazulu-Natal and involved home visits to affected families where an interview schedule guided the process of data collection. Material needs, as well as a need for emotional support were the most prevalent. The relationship between the caregivers and affected families are very positive, allowing an open door for further service rendering.

Keywords

Bio-psychosocial needs, HIV or AIDS, caregivers, caregiving, families infected or affected by HIV and AIDS, social grants, palliative care.

2. INTRODUCTION

In dealing with families infected or affected by HIV or AIDS a holistic approach should be followed (South Coast Hospice, 2003). The physical needs should be addressed by support and intervention programmes, as well as the psychological and social needs. By doing this, the quality of life of people infected or affected by HIV or AIDS should be improved (Du Toit & Van der Merwe, 2006:56). This article aims to shed light on the role Hospice T.L.C. caregivers in the Kokstad area play in meeting the needs of the patients they deal with, together with that of their affected families. The results show that the respondents see their material needs as the most prominent. They do value the emotional support given by the caregivers as vital for their emotional well-being. The possibility exists for people diagnosed with HIV or AIDS, to experience several psychiatric conditions due to trauma (Kagee, 2008:246). The objective of this qualitative study was to investigate the bio-psychosocial needs of the HIV or AIDS patients as well as their affected families.

3. RESEARCH METHODOLOGY

3.1 Background of the study

The overarching goal of this qualitative study is to do a critical investigation regarding the role Hospice T.L.C. caregivers fulfill in the lives of families infected with or affected by HIV

and AIDS in the Kokstad area. The study consists of two phases: phase 1 focuses on an-depth literature analysis and a needs assessment, while phase 2 structures the focus areas for service rendering by Hospice T.L.C.'s caregiver. This article focuses on the bio-psychosocial needs of families infected or affected by HIV or AIDS and to explore how service rendering to affected families could be improved. Throughout this study data was collected by asking empirical questions (Mouton, 2005:53,54) during focus group sessions (Greeff, 2005:286) and structured interviews. The results of the focus group sessions were reported on in article 1, while this article will focus on the results from the interviews with families infected or affected by HIV or AIDS (Greeff, 2005:286; Mouton, 2005:53,54).

3.2 Research design

The study was both explorative and descriptive in nature and strived to explore the views of the respondents regarding their own needs (Fouché & De Vos, 2005a:92, 93).

3.3 Participants

The population consisted of all 100 families that receive services from Hospice T.L.C. With the help of the Hospice T.L.C. caregivers a 10% purposive sampling was drawn from the population to participate in this part of the study (Strydom, 2005b:202). The inclusion criteria were that the family had to be registered with Hospice T.L.C. and they had to be willing to participate voluntarily. A total of 10 families participated by means of an interview.

3.4 Research instruments

An interview schedule was developed and tested during the final focus group session with the Hospice T.L.C. caregivers (See article 1). They could tell the researcher whether it would be clear and understandable to the respondents.

Only slight changes had to be made (Strydom, 2005b:209) and this schedule could be used to guide the interviews during home visits to the respondents. Home visits are a very important means in identifying the bio-psychosocial needs in families infected with or affected by HIV or AIDS. In identifying the families' needs, an *assessment tool*, developed by Halkett (2005:126-131), was of great value. These outlines acted as guidelines during the interviews held with the respondents in order to identify the central themes of bio-psychosocial needs which forms the main focus areas for further service rendering. During the focus group sessions an interpreter was used.

TABLE 2.1 : An assessment tool for identifying a family's needs

THE FAMILY'S NEEDS	WHAT WE LOOK FOR
<p>Food</p> <p>Clothing</p> <p>Home Environment</p> <p>Hygiene & Infection control</p> <p>Health care & treatment</p>	<ul style="list-style-type: none"> • Does the family have food every day and how many meals? • Is the food nutritious and balanced? • Do they have a change of clothing for protection from the weather? • Do they have school uniforms and shoes? • Shelter against the weather. • Protection against hazards, pests and intruders. • Personal and safe sleeping space and privacy for older children. • Access to water/sanitation/fuel for boiling water and warmth. • A clean environment and spare bedding. • Are there positive personal hygiene practices? • And universal precautions where there is risk of infection • Are the children immunized and have a Road to Health Card? • Is the family aware of and able to respond to indications of illness? • Do they have knowledge of basic first aid? • Is there a reliable caregiver to give medicines, dietary supplements, home remedies?
<p>Protection</p>	<ul style="list-style-type: none"> • Do their circumstances protect the children from abuse, neglect, exploitation? • Are they protected against discrimination and stigmatization? • Is there a caring, constant reliable adult presence to whom the child could disclose abuse and who can get help? • Have arrangements been made for care before the parent/s dies? • Is there a Will that says who the child's guardian will be and states the child's inheritance? • Is there healthy discipline including the settle of rules and limits for socially and culturally acceptable behaviour?

Affection	<ul style="list-style-type: none"> • Is there a caring, constant and reliable adult presence who offers security and continuity and with whom the family members can communicate openly? • An adult caregiver with a positive communication style and who takes time to listen and communicates at the child's level for OVC's.
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3.5. Data analysis and interpretation

Tesch's analytical process was used (Tesch, 1990:77) to analyze the data. This method of data analysis enables the researcher to do a thematic analysis of data with the aim of identifying priorities and to do further planning. The population of the study was small therefore the data could be manually analyzed and interpreted (Herbst & Strydom, 2008:273-289). Basic back-ground information regarding language, sex, age, educational level and relationship of the respondent to the HIV infected person was recorded. The participants' views from their own life experiences were acknowledged and used as a means of data collection (Tesch, 1990:78).

3.6 Ethical aspects

Written consent was obtained from Hospice T.L.C. and Child Welfare SA – Kokstad, to conduct the study (See Addendum 1 and 2). The Ethical Committee of the North-West University (Potchefstroom Campus) also approved this study and allocated the following ethical number to this study: NWU-0060-08-A1 (See Addendum 3). Ethical aspects as outlined by the nursing, as well as social work professions were kept in mind and respected throughout the study (Pera & Van Tonder, 2005:1-10).

The following ethical issues were taken in consideration throughout this study: written, informed consent, voluntary participation, confidentiality and feedback to participants on the results of the study. The best interest of the families infected with or affected by HIV or AIDS were respected and protected during interviews and their information was used anonymously (Strydom, 2005a:64, 67).

4. THE BIO-PSYCHOSOCIAL NEEDS OF PEOPLE INFECTED OR AFFECTED BY HIV OR AIDS

The bio-psychosocial needs of people infected or affected by HIV or AIDS are widely described in the literature. In this study, emphasis was placed on identifying the needs of

families infected and affected by HIV or AIDS in the Kokstad area, Kwazulu-Natal, with specific reference to the input of hospice caregivers in meeting these needs.

In meeting these needs, resources within the community have to be utilized. Smart (2003:43) describes these resources as *Circles of support*. In rendering palliative care, it is important to remember that it is vital to work as a team to achieve optimal relief of suffering and to facilitate enhancement of life for the person living with a terminal, time-limiting illness. Another way of describing palliative care is "to cover with a cloak" (Emanuel, Von Gunten & Ferris, 1999:11). Enhancement of quality of life and regarding dying as a natural part of living is in line with hospice policy (Pretoria Sungardens Hospice, 2006).

A diagnosis with HIV or AIDS is distressing, and dealing with a life threatening disease can act as a stressor. This will impact on the functioning of an individual within the family and society. Stigma, ostracism from friends, family and society could result in further emotional and psychological challenges. This situation will certainly provoke stress in almost everyone (Kagee, 2008:246-247).

In looking at people's basic needs, Maslow's model (Meyer, Moore & Viljoen, 2002:334-335) was taken into account. People have a basic need to live with hope (Corr, Nabe & Corr, 1999:175). The role of the caregivers is to give hope to their patients and their affected families by an attempt to meet their needs. People's basic needs are survival needs or physiological needs or physiological needs. It includes hunger, thirst, a need for oxygen, sleep, activity, sexual gratification and sensory stimulation. These primary needs are followed by safety needs.

Once these physical needs are satisfied a person would be able to identify his or her need to belong and to be loved. This will be followed by a need for self-esteem which could be divided into 2 categories according to Maslow:

- A set of needs based on a person's achievements like strength and independence;
- A set of needs based on the esteem of others like social acceptance and standing, honour dignity and appreciation.

Once these basic needs are satisfied on a regular basis, a need for self-actualization and a motivation for growth come to realization (Meyer et al., 2002:336-341). The hierarchy of basic human needs are summarized in figure 1.1.



FIGURE 2.1 : The hierarchy of human needs

In the helping relationship between caregivers and their patients and families, they often do not understand the emotional and physical impact of a life-changing diagnosis on them. Counselling should therefore focus on the following two aspects:

- Helping families to gain insight regarding the nature of their problems;
- Rendering support to their physical and emotional needs (Smart, 2003:67).

Dealing with the needs of people infected by HIV or AIDS, requires a multi-disciplinary team approach. There are many facts to this situation; therefore the needs should be approached in a holistic manner (Marshall, 2005:69-71). To work holistically refers to dealing with a person as a whole, therefore, all the facets of a person's life needs to receive attention by making use of a multi-disciplinary team approach in meeting their needs (Department of Social Development, 2006:6-9). Co-operation between hospice caregivers, nurses and social workers are particularly important. Very often home visits are the entry point of service rendering to infected or affected families.

5. HOME VISITS AS A MEANS OF SUPPORT TO FAMILIES INFECTED OR AFFECTED BY HIV AND AIDS

Home visits are a valuable means in identifying and meeting the needs of these families. Halkett (2005:126-131) points out that home visits not only assist in identifying the needs of families, but can also bring families in contact with relevant community resources. Hospice T.L.C. fulfils a paramount role in doing regular home visits. Home visits aim to assess initial needs in order to give direction to future service rendering. According to Gennrich (2004:93) home visits may include the following four stages:

- A stabilization stage – families receive emergency provisions in terms of basic needs such as food, clothing and bedding.
- An initial rebuilding phase – weekly visits to assist with needs such as schooling, access to grants and help with a vegetable garden.
- An advanced rebuilding phase where help is given with arising needs.
- A maintenance phase – monthly visits as required (Gennrich, 2004:93).

Usually home visits by Hospice T.L.C. caregivers consist of three phases: the introductory visit, the assessment visit and ongoing visits. The aims and objectives of each of these phases will be briefly discussed.

5.1 Introductory visit

This visit forms the basis of the caring relationship. During this visit the caregivers introduce themselves and become a familiar, helping resource within the community. A friendly, caring attitude is very important. By asking simple questions, essential information can be obtained. A carer has to be careful not to overwhelm the person with too many questions or information. The caregiver should leave information regarding her/his contact details. Immediate needs should be assessed in terms of emergency provisions. Professional work ethics should be followed at all times.

5.2 Assessment visit

The purpose of this visit would be a thorough assessment of the situation and needs of a referred or identified household. It is important to establish whether the family is known to a social worker or other caregivers. If the answer is positive, their details should be obtained and the case followed up with the relevant people. By doing this, duplication of services could be prevented. For purposes of this study, the assessment visit was used to assess the bio-psychosocial needs of the respondents.

5.3 Ongoing visits

These visits would be part of the maintenance phase ensuring that the family is coping with the challenges that they are facing.

- Monitoring of the family's situation could take place.
- Planned orphan care could be done.
- Children's schooling and progress could be monitored.

- Family members' emotional needs could be met, as well as physical needs like food parcels; clothing and blankets could be provided where needed.
- Access to health facilities and medicine.

The fact that the caregivers are from the local community, allows them to have a better understanding of the people they deal with, as well as their needs. They become a much appreciated "presence" in the community. They often step in as "surrogate" parents caring for children, even before the parents die by preparing meals and supporting the children. They also provide support for the caregivers and form support groups, for example sewing groups (Halkett, 2005:125).

5.4 The value of home visits

The value of home visits lies in the building of hope and security through the caring relationship. The value of regular visits to the families infected and affected by HIV and AIDS should not be underestimated (Smit, 2007:2-4). It seems that home visits have particular meaning for children and older persons in families as a means of meeting their affection needs.

5.4.1 The value of home visits for children

According to the researcher, home visits have the following benefits for the children in families infected or affected by HIV and AIDS:

- A relationship with someone who cares;
- Access to resources to sustain life (food parcels, clothing, blankets);
- Access to emergency help in times of trouble;
- Access to a caring person they could talk to and count on to help them when needed for instance to mend clothes;
- A good role model who gives them hope for the future (Smit, 2007:1-10).

5.4.2 The value of home visits for older family members

Very often older family members become the primary caregivers in families infected or affected by HIV and AIDS. This situation can be very stressful for older persons and home visits may offer them the following opportunities:

- It provides support and recognition for the role they play in the affected family.
- Someone who cares enough with whom they can discuss their concerns.
- Planning for the futures of the children they care for, especially elderly caregivers have a need to talk about planned orphan care.
- A care plan could be formulated with the input of all parties concerned, preventing children left in child headed families or without proper care (Halkett, 2005:126).
- People might need help, but they still have a right to keep their dignity. In order to really meet their needs, a proper assessment should be done (Pera & Van Tonder, 2005:6).

In identifying the families' needs an *assessment tool* was of great value. These outlines acted as guidelines during the interviews held with the respondents.

6. CHANGING NEEDS DUE TO PROGRESSION OF THE DISEASE

The *assessment tool* that was utilized in the needs assessment (see table 1) emphasized that the needs of the patients and their affected families will greatly depend on how patients are categorized according to the progression of disease (South Coast Hospice, 2003). Three categories of patients can be identified, namely:

6.1 Category 1 patients

These patients are not sick, might be working, attending support groups or receiving ARV support. They could be receiving contact with a trained member of the care team at least once per month. This contact could be on a one-to-one basis or as part of a support group.

6.2 Category 2 patients

These patients would need some medical/nursing care in addition to psychosocial care. Weekly visits from a caregiver would be needed, as well as medical attention by an appropriate health professional once a month.

6.3 Category 3 patients

At this stage the patient is home or bed bound, needing significant clinical care. Caregivers need to pay at least two visits per week of which one must include a professional nurse. These visits are on a one-to-one basis (South Coast Hospice, 2003).

From the afore-mentioned it is clear that the bio-psychosocial needs of families infected and affected by HIV or AIDS are directly influenced by the progression of the disease. According to Gennrich (2004:170-174) HIV or AIDS progress in four stages:

- The acute stage (Glandular fever-like illnesses).
- The asymptomatic carrier stage (The person shows no symptoms).
- Early symptoms of HIV disease (Tiredness, night sweats, fever, shingles, diarrhea, oral thrush and neurological changes are common symptoms).
- AIDS (Smaller symptoms of HIV disease become serious and persistent. Weight loss, exhaustion, chronic opportunistic infections as Karposi's sarcoma, tuberculosis and pneumonia are present).

The abovementioned would be the physical progression of the disease. On the emotional level there are similar or parallel emotional progressions. These processes were described by Gennrich (2004:170-174) and are summarized in Table 2.

TABLE 2.2 : Psychosocial and spiritual needs associated with the progression of the disease (HIV or AIDS)

PROGRESSION OF DISEASE	EMOTIONAL EXPERIENCE	HUMAN NEED	FOCUS OF COUNSELING	SPIRITUAL FOCUS
1. Diagnostic stage	Denial, fear, anxiety	Security	Empathy	God's compassion (Trust)
2. Symptomatic stage (Health impairment)	Isolation, loneliness, mourning	Connection	Communication & relationships	Belonging to a healing community, acceptance
	Guilt (internal & external) remorse, anger	Forgiveness	Restitution	Reconciliation (with self, others and God)
3. Stage of full blown AIDS (severe health impairment)	Self-rejection, depression, hopelessness, worthlessness	Dignity	Hope and meaning	A hopeful and meaningful life
4. The terminal stage	Wasting away, uncertainty, fear	Peace and acceptance	Letting go	Peace
5. The bereavement stage	Sadness and longing, anger, depression	Grieving the loss	Acceptance of loss, continuing with life	Comforting

These feelings could appear in different stages of the disease therefore the spiritual needs, therapeutic interventions, as well as human needs could also appear in other stages. The carer should remember that experiencing many losses are part of the disease and that the patient, together with the affected family is going through a time of mourning. Some of the losses could be: physical strength and abilities, finances, job, home, friends, trust in God, dreams and hopes for a good future.

The caregiver should have special skills in supporting the people infected and affected by HIV or AIDS. Helpful skills would be empathy, problem solving skills and an ability to render spiritual support, in order to give hope for positive living with HIV or AIDS (Danielson, Hamel-Bissell & Winstead-Fry, 1993:170-173). Living with hope is a far more positive attitude than constantly thinking of dying. This is the attitude that the caregivers would like to install in the people they deal with. They do this by referring them to relevant

resources within the community to meet their bio-psychosocial needs as mentioned by Danielson et al. (1993:66).

7. RESULTS

The results obtained from this part of the study will be presented according to the questions included in the interview schedule.

7.1 Biographical information of participants

To protect participants' confidentiality, biographical information focused only on language, educational level and gender. The biographic information of respondents is summarized in Table 3.

TABLE 2.3 : Biographic information of participants

INFORMATION REQUIRED	NUMBER OF PARTICIPANTS
LANGUAGE	
Afrikaans	1
English	1
Xhosa	8
N=	10
EDUCATION LEVEL	
No schooling	1
Primary level schooling	4
Grade 8-11	4
Grade 12	1
N=	10
GENDER	
Male	2
Female	8
N=	10
AGE	
0-18 years	1
19-29 years	1
30-39 years	3
40-49 years	1
50-59 years	2
60 years and older	2
N=	10

RELATIONSHIP TO THE PATIENT	
Parent	1
Sibling	1
Grandparent	2
Patient self	4
Cousin	1
Child	1
N=	10

The majority of participants were black, Xhosa first language, female patients between the ages of 30-39 years of age with a basic level of education.

7.2 Most prominent needs of participants

The researcher completed the interview schedule on behalf of the participants to ensure uniformity in the way it was completed. The questions asked covered the three areas of needs according to the *assessment tool* (Halkett, 2005:130, 131) namely material, protection and affection needs. The findings will be presented according to each category of needs.

7.2.1 Material needs

Introduction

This section of the interview focused on aspects like good nutrition, adequate clothing, a sufficient home, a safe environment, hygiene and infection control, health care and treatment when needed (Halkett, 2005:130).

Questions asked

- "What would you consider to be the biggest needs of your family?"
- "In which way do the T.L.C. caregivers help you most?"
- "What more can they do to help you?"
- "Where do they fail to help you?"
- "With what do you battle most?"

Some verbatim responses regarding the material needs of the respondents

- “Food is the biggest need for our family. I am the patient and I am not working, I do not yet qualify for a disability grant because my CD-4 count is too high. Thanks for the clothing, blankets and food parcels. We can't survive without it.”
- “Food is the biggest need. I only receive the child support grant, I try to plant veggies, but it is too difficult. We look forward to the weekly food parcels.”
- “Food is the biggest need of our family, my disability grant will be stopped soon because my CD-4 count went up due to the ARV-treatment. Thanks for the regular food parcels and clothing.”
- “The child that is HIV-positive is not schooling, therefore she cannot get a foster care grant. We need the grant for her. The food parcels and clothing help a lot.”
- “Food is a big need for our family, the patient's children does not receive a child support grant. We battle to feed everybody.”

Main themes identified

Food is the biggest need for all the respondents as well as adequate clothing and blankets for protection against the elements, especially for the children when it is cold. They battle to plant enough vegetables to sustain themselves due to drought, lack of strength to work and many mouths to feed. Nine out of the ten respondents live in one-roomed homes. The caregivers supply weekly food parcels to the affected families they deal with. They assist the affected families to obtain the necessary documentation in order to access grants. Financial resources are depleted due to multiple losses of economically productive adults. Funerals, medical expenses and OVC's drain the families' finances. Elderly grandmothers, who are HIV+ themselves, battle to feed orphans on their meager pensions. The caregivers usually refer these respondents to other health care professionals. One respondent was reluctant to continue with her ARV-treatment out of fear that her disability grant could be cancelled. It was her only source of income.

7.2.2 Protection needs

Introduction

These needs would consist of shelter against the elements, privacy, a clean environment, basic services such as water, electricity, sanitation, proper health care and a reliable caregiver. Adequate nutritious food is needed to protect the body against infections.

Protection against abuse, discrimination, stigmatization, exploitation in the form of an accessible caregiver should be available (Halkett, 2005:130, 131).

Questions asked

- “What would you consider to be the biggest needs of your family?”
- “In which way do the T.L.C. caregivers help you most?”
- “What more can they do to help you?”
- “Where did they fail to help you?”
- With what do you battle most?”

Some verbatim responses regarding the protection needs of the respondents

- “My husband is my sick son’s stepfather and he does not like him. When he is drunk we are scared of him and has called the police in the past.”
- “The house is overcrowded and we would like to extend the house to accommodate all the children. The plumbing is a problem. We lack money to fix it but understand that it is not the caregiver’s problem.”
- “We need nutritious food; we eat mainly mealie meal and rice. The children need fruit, veggies and meat. The food parcels helps a lot.”
- “We are trying to plant veggies but the soil is too hard and dry. Thank you so much for the blankets and the clothing.”
- “The patient is in denial regarding her HIV-status. We need someone to care for her because if she gets sicker due to the fact that she does not want to take treatment, who will take care of her? She is very stubborn.”

Main themes identified

The majority of respondents stay in one-roomed houses. It is small, lacking privacy, but it meets the basic needs of the families that occupy it. One house was overcrowded. Basic services such as water, electricity, security, garbage removal and sanitation are rendered by local authorities. Regular food parcels is very important to supply nutritious feeding to the affected families to protect them against malnutrition and infections. Hygiene seems to be good. Regular visits of the Hospice T.L.C. caregivers encourage the affected families to make use of health care services such as mobile clinics for immunizations and

medical services. Each family had a responsible caregiver. Blankets and clothing are welcomed in all the households. The Hospice T.L.C. caregivers helps to educate the families infected or affected by HIV or AIDS regarding the impact of the disease on families to minimise stigma, discrimination and exploitation. To have a caregiver available to them helps to keep communication lines open with a knowledgeable person and to ventilate fears.

7.2.3 Affection needs

Introduction

This indicates a constant caring environment which offers security and continuity of care when needed. Open communication lines are necessary through which persons in need of help could express their needs (Halkett, 2005:126-131).

Questions asked

- “What would you consider to be the biggest needs of your family?”
- “In which area do the T.L.C. caregivers help you most?”
- “What more can they do to help you?”
- “Where do they fail to help you?”
- “With what do you battle most?”

Some verbatim responses regarding the affection needs of the respondents

- “Thank you so much for visiting us, the children get very excited when they see you coming, they know that there will be something nice for them.”
- “I am old and tired of trying to care for all these children. Thanks for the visits, it makes me feel better.”
- “Our caregiver took good care of my deceased mother, I am very grateful for all her help.”
- “I like it when the caregiver visits. I can talk to her about my problems and she listens.”
- “My mother is very stubborn and does not want to take her treatment. The caregiver talks to her to convince her to take the treatment. It helps me to know that the caregiver is there if my mother would get sicker.”

- “The caregivers do their best to help us. We know they love us. We feel nice if they come to visit, they are patient with us.”

Main themes identified

All the respondents needed the ongoing visits and support of the Hospice T.L.C. caregivers on a regular basis. It creates hope. They felt that the caregivers helped in many ways by being present in the community and educating the community regarding HIV or AIDS. This helps to minimise the stigma linked to the condition. They act as a link between resources and the affected family in meeting their needs. This creates a constant caring environment for them. It provides a constant caring person with whom they could freely communicate their needs such as planned orphan care. It also provides continuity of care by regular home visits. The respondents did not feel that the Hospice T.L.C. caregivers failed them in any way. There was clearly a strong bond between them and the affected families, which allowed the researcher good access to the respondents. Stigma is still a problem therefore support of any kind is welcomed. One respondent needed ongoing motivation to continue with ARV-treatment and one respondent was still in denial regarding her status. The caregiver rendered constant support such as getting a child in school. The grandmothers appreciate the emotional support they receive in the challenging task in taking care of their grandchildren. No attention has been given to memory work, due to the fact that the Hospice T.L.C. caregivers do not have time to engage in it.

They themselves also need support and an opportunity to ventilate their own experiences of loss. None of the respondents felt themselves comfortable to approach churches for help and assistance due to the existence of stigma attached to HIV or AIDS.

8. CORRELATION WITH THE ASSESSMENT TOOL OF HALKETT

In applying the *assessment tool* certain questions will be asked addressing the material, protection and affection needs of the families infected or affected by HIV or AIDS.

What we look for regarding the material needs of the families that they deal with

- Does the family have nutritious, balanced food for every day? How many meals per day?

- Do the members of the family have an adequate change of clean clothes for protection from the elements?
- Does the home environment provide shelter against the elements, protection against hazards, pests and intruders? How is the privacy situation, access to water, sanitation and a clean environment?
- Does the family have positive hygiene practices which are in line with general precautions for risk of infection?
- Does the family have access to basic health care?

The role that the Hospice T.L.C. caregivers play in meeting the material needs of families infected or affected by HIV or AIDS

In the light of the *assessment tool*, it is clear to see that the Hospice T.L.C. caregivers play a vital role in addressing the material needs of the families they deal with. Through home visits on a regular basis, they supply a visible presence of care in their community. They assist with physical care for the sick, supply food parcels, blankets, clothing and monitor the living conditions of the families they deal with, should there be problems with hygiene, sanitation and infection control. They act as educators in this regard and refer the families to relevant resources in the community to meet their needs. They also monitor the presence of a reliable caregiver in the household that could take care of the family.

What we look for regarding the protection needs of the families that they deal with

- Do the home circumstances protect all members of the family against abuse, neglect, exploitation, discrimination and stigmatization?
- Is there a constant, caring adult available to whom family members could communicate their needs?
- Is planned orphan care in place should a parent become too sick to take care of their dependents or even die?
- Is the family structure making allowance for a healthy structure of rules and discipline in which children will feel safe and learn culturally acceptable behaviour?
- Is there proper care for the sick and bereavement counseling available to such an extent that children or the very elderly are not left to take care of themselves, together with caring for the sick?

- Are basic, nutritious meals available for all members of the family to meet their basic needs and protect the body against malnutrition and infection?
- Does the family home provide basic protection against the elements?
- Do all family members have adequate clothing, blankets, access to clean water, sanitation, security and privacy?
- How is basic hygiene and health care, do they make use of the resources available?

The role that the Hospice T.L.C. caregivers play in meeting the protection needs of families infected or affected by HIV or AIDS

The Hospice T.L.C. caregivers manage to be on the lookout for any signs of abuse, neglect, exploitation and discrimination against the members of the families they deal with. With their visible presence visiting homes on regular basis misconduct will be identified easier. They play the role of educators which helps to de-stigmatize HIV or AIDS infection. The Hospice T.L.C. caregivers themselves act as a constant, caring adult with whom family members could communicate their needs.

The Hospice T.L.C. caregivers also verify the presence of a responsible adult in every household who could address the needs of the family members. This includes providing a healthy structure of rules and discipline in which children will feel safe and learn culturally accepted behaviour. Planned orphan care takes place with the help of Hospice T.L.C. caregivers. They refer the families to the relevant resources within the community such as Child Welfare for assistance with foster care.

Through the regular home visits of Hospice T.L.C. caregivers, care is taken that proper care for the sick and bereavement counselling is in place. Through weekly food parcels to families infected or affected by HIV or AIDS, nutritious well-balanced, basic meals are ensured to all members of the families. All the families they are dealing with at present have adequate shelter against the elements, access to basic services supplied by local authorities such as clean water, sanitation and security. Donations are given for clothing and blankets on a regular basis by Hospice T.L.C. The one-roomed houses do not provide much privacy, but the caregivers can do nothing about it. As educators the Hospice T.L.C. teach the families they deal with about hygiene, health care, gardening and good nutrition. They also educate them regarding the relevant resources within the community such as the municipal clinic that could meet their needs. It is clear that the Hospice T.L.C. caregivers play a vital role in meeting the protection needs of families infected or affected by HIV or AIDS.

What we look for regarding the affection needs of the families they deal with

- Is there a constant, reliable, caring adult available who offers affection, security, open communication and continuity to all the members of the family?
- Is an adult caregiver available with a positive communication style who can effectively communicate with OVC's?
- Is there an opportunity for family members to have their own identity, have memories, deal with loss and bereavement, ventilate emotions and experience unconditional love and acceptance?
- Do patients and OVC's have the opportunity to be part of decision making impacting their lives?
- Does families infected or affected by HIV or AIDS get treated with the necessary respect, dignity and confidentiality?
- In dealing with OVC's, do they still have time to enjoy just being children, does opportunities exist where they can talk about death, freely seek information, discuss ethics and morals?
- Are children encouraged to go to school, receive help with homework and receive a good education?
- In caring for the sick, is there a caring presence and pain relief, acknowledgement of death, opportunities provided to receive closure when a dear one dies and bereavement counseling?
- With regards to emotional support, is it available when a family experiences difficulties, if a caregiver does not cope with the challenge, does it get referred to the relevant resources within the community?

The role that the Hospice T.L.C. caregivers play in meeting the affection needs of families infected or affected by HIV or AIDS

The Hospice T.L.C. caregivers are constant, reliable, caring adults who visits the families infected or affected by HIV or AIDS allocated to them on a regular basis. By doing this they render support to all the family members in need of care, as well as supply an opportunity for open communication, ventilation, bereavement counseling and support. They verify that there is a responsible, caring adult present in every household to take care of the needs of all the family members. It is important that this caregiver within the family will have the ability to have open communication lines with affected family members

where they feel secure to speak about issues pressing heavy on their hearts, especially OVC's. The Hospice T.L.C. caregivers have an educator's role to play in developing a positive communication style amongst family members infected or affected by HIV or AIDS. The Hospice T.L.C. caregivers lead by their example in the way they deal with their patients in treating them with dignity, respect, non-discrimination, confidentiality and encouragement. This has a positive impact on the family and community in destigmatizing the situation surrounding HIV and AIDS. It is clear that the relationship of trust that the Hospice T.L.C. have with their patients and affected families, is very valuable to them. They value their ongoing support, encouragement and opportunities to ventilate regarding problems highly.

The Hospice T.L.C. caregivers' role in planned orphan care is very valuable. They help the affected families to have future plans in place for OVC's while their parents often are still alive, allowing the parent and children to be part of the planning process for future care. In doing this the caregivers assist family members in obtaining the relevant documentation to be able to apply for available grants. With regards to people's sense of identity, documents such as identity documents and birth certificates are very important, not only for the sake of accessing grants, but people without identity documents feel like "nobodies". OVC's are encouraged to get a good education, attend school regularly and do their homework. The Hospice T.L.C. caregivers monitor this schooling process of OVC's in the families they deal with. The OVC's have a positive relationship with the Hospice T.L.C. caregivers due to their regular contact through home visits, as well as the delivery of regular food parcels to their homes. The caregivers represents a caring, reliable adult to the OVC's who are prepared to listen to their needs and supply information to them where needed. They will often be the person who will talk to OVC's about the death of a loved one and who will do bereavement counseling with them.

In the Xhosa culture, children are often overlooked when it comes to issues regarding death and dying. In an affected household with children, the needs of the children are often overlooked in favour of the sick person. Presently the Hospice T.L.C. caregivers do give attention to the children, but not enough. Memory work also does not receive adequate attention. It is recommended that trained child minders be appointed to deal with the specific needs of OVC's in a more focused way. Memory work should also be addressed and can be done by the child minders or volunteers from the community after they have received training on this matter. At present the Hospice T.L.C. caregivers do not have time to do this. Hospice T.L.C. caregivers plays a vital role in referring the emotional needs of families infected by HIV or AIDS to relevant sources such as social workers, clergy or psychologists. All the respondents, especially the elderly grandmothers

agreed that they value the love, support and assistance of the Hospice T.L.C. caregivers very much. This relationship creates a constant caring environment for the families infected or affected by HIV or AIDS. The Hospice T.L.C. caregivers themselves need constant support and opportunities to debrief and ventilate their own losses to prevent burnout. None of the participants were comfortable to directly approach clergy for support, due to their fear of stigmatization. They were comfortable with the Hospice T.L.C. caregivers approaching representatives of churches on their behalf.

9. DISCUSSION OF THE RESULTS

Ten participants were used out of a total population of seventy families. This enabled the researcher to get a representative response and made allowance, should any participants not be available. Culture and language barriers were successfully overcome by visiting the participants together with the caregivers. The majority of participants were black Xhosa first language speakers.

The company of the caregivers helped the researcher to obtain access and trust with the participants (De Vito, 2001:57). The participants were assured that their views and opinions were important and an opportunity was given to them to ventilate freely (Corr, Nabe & Corr, 1999:185). There were no communication problems. One participant was Afrikaans and one English speaking. They were both coloureds. The majority of participants were females, confirming literature stating that more females than males are infected by HIV and AIDS. Losing mothers as primary caregivers has an enormous effect on children (Ebersöhn & Eloff, 2002:77,78). The level of education was low, ranging from illiterate to matric. When it came to the relationship to the patients, the majority of the participants were the patients; the other participants were grandmothers of HIV+ children, who seemingly obtained the virus via mother to child transfer. All the participants, as well as the caregivers stated that as a community they become tired of the multiple losses, which place tremendous financial pressure on the remaining family members. This confirms the literature study showing that in most cases the economically productive adults have died, leaving elderly grandparents to cover medical and funeral expenses, as well as raise orphans on meager pensions (Germann, 2005:78).

The biggest need seem to be materialistic, basic survival needs like food, clothing, blankets and accommodation. With regard to Maslow's theory, as well as Halkett's *assessment tool* (Halkett, 2005:130,131) for meeting a family's needs, it is important to meet these needs for survival, before needs for self-actualisation can be met (Meyer et al., 2003:341). At the stage where people have a need for self-actualisation, they start

plowing back into their communities. By doing this they become an asset to their communities. It is hoped that this will happen to the patients and their affected families who has been benefiting from the services rendered to them by the caregivers of Hospice T.L.C. The ideal is that the community will become equipped to meet the needs of community members themselves (Meyer et al., 2003:341, 342). This should also help to reduce stigma and a fear of disclosure of HIV-status (Buckingham & Meister, 2001:463). The initial shock of the diagnosis and living with a life-threatening disease should be minimised due to openness regarding HIV or AIDS (Kagee, 2008:249)

With the *Circles of Support* (Smart, 2003:43) in mind, the caregivers can enable the infected patients, with their affected families to make use of available resources in their community to meet their needs. By doing this, community support would increase, building a stronger community. Obtaining the needed documentation in order to access grants is a big need. This is a way to alleviate poverty and ensure identity of individuals. It is therefore very important to get these grants in place. Examples of grants would be :

- Foster care grants
- Disability grant
- Child support grant
- Care dependency grant
- Old age pension

(Smart, 2003:23)

In obtaining access to these grants the services of social workers employed by **non-profit organisations** (N.P.O's) or government organizations (Department of Social Development, 2006:12). The primary caregivers of young children who are HIV positive are often grandmothers who are receiving an old age pension or close to the age where they would qualify for a pension. Often they are unaware of the facts concerning help available in the form of social grants. They experience high levels of stress just to make ends meet, therefore the caregivers form a valuable link to educate them in this area and link them up to relevant resources (Potterton, Stewart & Cooper, 2007:213). The grandmothers step in as carers due to the fact that it is often the mothers of child-bearing and -rearing age that become HIV-positive and die (Ebersöhn & Eloff, 2002:78). It is clear that Hospice T.L.C. caregivers play a valuable role in meeting the needs of the families they deal with on a material, protection and affection level (Halkett, 2005:130, 131).

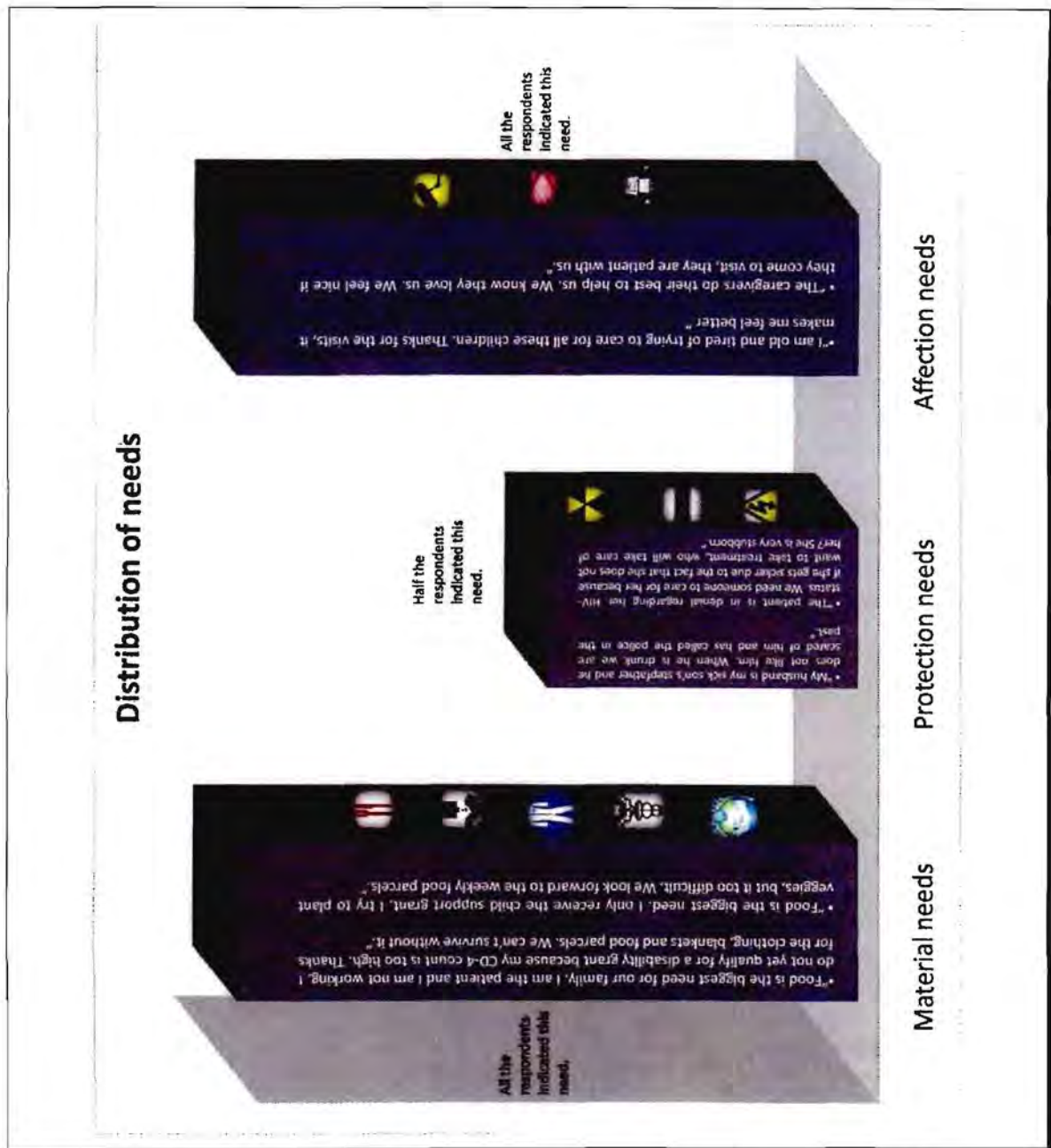


FIGURE 2.2 : Distribution of needs

The distribution of needs as identified by 10 respondents during the interview schedule in terms of importance to them is illustrated in Figure 2 (Puttergill, 2000:234-252). Initially it seemed as if materialistic needs were the most prominent, but as the interview schedule progressed their affection needs became equally prominent with only half of the respondents identifying protection needs as a concern. The reason for this could be that all of them had adequate accommodation, caregivers available and access to health care.

10. CONCLUSIONS

1. The training of the Hospice T.L.C. caregivers equips them to identify the needs of the patients they deal with, as well as that of their affected families. According to the specific needs, services can be rendered.
2. Home visits on a regular basis making use of the *assessment tool* as described by Halkett (2005:130,131) would assist in the identification of needs experienced by families infected or affected by HIV or AIDS.
3. After identifying these needs, they can bring them into contact with the relevant resources within the community to address their needs.
4. Once the most basic needs like food, clothing and shelter are met, the other needs for support, acceptance and self actualisation become more eminent.
5. While rendering support, which all the families appreciate very much, attention can be given to planned orphan care where needed.
6. The older caregivers value the emotional support they receive from the caregivers very much. They often feel overburdened by all the responsibilities they have to deal with.
7. Food parcels, clothing, blankets and medication that the families receive from the caregivers give them hope. It is this hope that has helped to build strong, open, caring relationships between the caregivers, patients and the affected families.
8. Memory work, as well as support groups do not receive the necessary attention. The caregivers have very busy schedules. Volunteers could be co-opted to assist with memory books and boxes, as well as support groups (Herbst & De la Porte, 2006:42-46).
9. In meeting the needs of other people, the caregivers also have a need for support, ventilation and supervision in order to prevent burnout. The researcher experienced the appreciation of the caregivers in doing home visits with them and taking an interest in what they were doing. It strengthened them and they came to her at the Society for help with their own personal problems.
10. The caregivers do not feel themselves equip to deal with spiritual matters and choose to refer the matters to clergy. The patients, with their families still experience a lot of stigma from the side of churches and church people. This confirms the literature view regarding stigma within the communities due to the view of church leaders. This shows a lack of trust communities has in general in terms of support

or for disclosure of their HIV-status (Mboyi, Carrara, Makaye, Frohlich & Karim, 2005:26). Education in this area is required.

11. Liaising with the local Home Affairs Department motivating them to make mobile clinics available in the locations would enable patients to apply for the necessary documents like I.D. documents and birth certificates. In many cases the lack of this documentation hinders the application for social grants such as foster care grants and child support grants.
12. The education level of the population is low in general. A need for education on all levels is very clear.
13. Language and culture could be a barrier.
14. In the study literature it was confirmed that females are more affected than males. The death of a mother has an enormous effect on a child (Ebersöhn & Eloff, 2002:77,78).

11. RECOMMENDATIONS

1. Hospice T.L.C. caregivers should receive ongoing training to enable them to be aware of available resources within the community. This will enable them to a greater extent to link their patients and their affected families up with relevant resources within the community.
2. Correct identification of bio-psychosocial needs is very important in order to meet these needs. Holistic service rendering by means of a multi-disciplinary team approach is needed to address material, protection and affection needs of families infected or affected by HIV or AIDS.
3. Making use of the *assessment tool* during home visits, needs assessment can be done effectively.
4. Material needs are the most prominent needs; therefore it is recommended that regular food parcels should be made available for distribution amongst needy families. The help of the broader community is needed in the form of donations and transport. The community needs to take ownership of these needy families.
5. Open communication regarding HIV or AIDS should take place to educate the community. Especially church leaders, school principals and other prominent members of the local community should be involved in this process. A true change of heart towards people less fortunate within the community should take place.

6. Children at risk should be referred to relevant resources to be part of a planned orphan care program and the foster parents could be assisted by relevant grants to help them financially.
7. Volunteers could be trained to help with memory work and support groups.
8. Volunteers could relief the burden resting on the shoulders of the caregivers. Special attention and support needs to be given to the caregivers to prevent burnout or compassion fatigue.
9. It is clear that Hospice T.L.C. caregivers fulfill a vital role in meeting the bio-psychosocial needs of families infected of affected by HIV or AIDS in the Kokstad area. They could be assisted by relevant resources within the community in order to meet these needs.
10. It is therefore recommended that the following aspects receive attention through further research:

The improvement of service rendering to families infected of affected by HIV and AIDS by means of utilizing their circles of support.

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ARTICLE 3

**FOCUS AREAS FOR BIO-PSYCHOSOCIAL
SERVICES TO FAMILIES INFECTED WITH
OR AFFECTED BY HIV AND AIDS**

N. BESTER • A.G. HERBST

1. ABSTRACT AND KEYWORDS

Hospice T.L.C. is a non-profit organization (NPO) operating since 2006. They are rendering holistic, palliative and frail care services to all patients in the Kokstad area, southern KwaZulu-Natal. This qualitative study was aimed at exploring the extent of involvement of welfare organisations in meeting the bio-psychosocial needs of families infected with and affected by HIV or AIDS. This article deals with the stakeholders rendering services to these families and possible ways in which service rendering could be improved. Data was obtained during a focus group session with the caregivers and their supervisor. Interviews were conducted with members of the relevant resources that could meet the bio-psychosocial needs of families infected with or affected by HIV and AIDS.

Keywords

Orphans and vulnerable children (OVC), (NPO's), hospice caregivers, bio-psychosocial needs, government departments, families infected with and affected by HIV or AIDS.

2. INTRODUCTION

Hospice T.L.C. has been rendering palliative care services in the Kokstad area, to patients and families infected with or affected by HIV or AIDS, as well as all patients with terminal conditions. In rendering palliative care to their patients in an holistic way, they gain access to the affected families. By their training they are enabled to identify the bio-psychosocial needs of these affected families. In an attempt to meet the needs of the families, they refer them to relevant community resources. This article aims to explore the meeting of the identified bio-psychosocial needs by the resources in the local community based on the model of *Circles of Support* as described by Smart (2003:44). In another section of this study, the bio-psychosocial needs of these families had been identified, and the capacity and ability of Hospice T.L.C. caregivers to provide for these needs have to be further investigated.

This article reports on the results of a focus group session and interviews with service providers with the aim of exploring the focus areas for bio-psychosocial services to families infected with or affected by HIV or AIDS.

3. RESEARCH METHODOLOGY

The research methodology applicable to this article is summarized in Table 1.

TABLE 3.1 : Summary of the research methodology

PARTICIPANTS AND SAMPLING	ALL CAREGIVERS OF HOSPICE TLC (TOTAL POPULATION)	SERVICE PROVIDERS IN THE KOKSTAD AREA(PANEL SAMPLING)
NUMBER OF PARTICIPANTS	9	<ul style="list-style-type: none"> • Christian Social • Services (CSS) • Department of Social Development • Child Welfare SA – Kokstad • Khanyeselani • Home of Comfort
METHOD OF DATE COLLECTION	Focus group session	Interview schedule
QUESTIONS POSED TO PARTICIPANTS	<ul style="list-style-type: none"> • How many families are cared for? • What are the families' biggest needs? • In which areas did the caregivers fail the families? • In which area could the caregivers assist the families more? • In which area did the families battle most? • Which relevant service providers were the needy families referred to? 	<ul style="list-style-type: none"> • How many cases have been referred to your organization by Hospice TLC? • What is the main focus area of service delivery in your organization? • What other services have been rendered by your • Organization in order to meet the bio-psychosocial needs of the families infected with or affected by HIV or AIDS?

Aim and objective

The aim of this part of the study was to explore the level of services to families infected with or affected by HIV or AIDS by addressing the **main focus areas** for service rendering to these families.

Research design

The goal of this part of the study was to do a critical investigation regarding the focus areas that need to be addressed to meet the psycho-social needs of families infected with or affected by HIV or AIDS. A qualitative design was used to explore the views of the Hospice T.L.C. caregivers regarding referrals of their patients and affected families' identified bio-psychosocial needs to relevant resources in the community (Fouché & De Vos, 2005a:92, 93). This study was of both a descriptive and an exploratory in nature with the aim of gaining insight into the focus areas for service rendering to families infected with or affected by HIV or AIDS (Fouché & De Vos, 2005b:106).

Participants

The participants consisted of two groups, namely nine Hospice T.L.C. caregivers and five participants from service providers. Data was collected by means of empirical questions (Mouton, 2005:53, 54) posed to the population of nine Hospice T.L.C. caregivers during one focus group session. The aim of this focus group session was to gain insight into how the Hospice T.L.C. caregivers view the bio-psychosocial needs (Article 2) of the families infected with or affected by HIV or AIDS as portrayed during the interview schedule and to which service rendering organization they would refer them to. The researcher obtained a list of representatives of service rendering organisations to which Hospice T.L.C. refers their patients and affected families to on a regular basis in order to meet their needs.

A fixed panel of persons were selected from the population who are involved in a specific issue, therefore panel sampling was used (Strydom, 2005b:201).

Five participants were interviewed of service rendering organisations to which Hospice T.L.C. refers families in need of their assistance were interviewed. The goal of these interviews was to explore service rendering to families infected with or affected by HIV or AIDS.

Research instruments/method of data collection

During the one focus group session with the total population of nine Hospice T.L.C. caregivers, the aim was to give feedback to them regarding the interview schedule (Article 2) and to explore the focus areas of potential service rendering to families infected with or affected by HIV or AIDS (Potterton, Stewart & Cooper, 2007:213). During the first focus group session it was agreed upon to give feedback to the participants regarding the outcome of the study. No interpreter was needed due to the establishment of open communication lines between the researcher and the Hospice T.L.C. caregivers. The

previously formulated questions were used to stimulate conversation during the focus group session (Greeff, 2005:286). It covered the 3 areas of need as outlined by the *assessment tool*; namely materialistic, protective and affection needs (Halkett, 2005:130, 131). The questions asked were:

- How many families are cared for?
- What were the families' biggest needs?
- In which area did the caregivers failed the families?
- In which area could the caregivers assist the families more?
- In which area did the families battle most?
- Which relevant service providers were the needy families referred to?

The Hospice T.L.C. caregivers were linking up needs with relevant service rendering organisations within the community to meet the needs of the families infected with or affected by HIV or AIDS. In order to address focus areas for further service rendering, with the *Circles of Support* in mind, psychosocial needs could be met within the community. By exploring the focus areas for service rendering during the focus group session, T.L.C. caregivers were encouraged to link the identified psychosocial needs of families infected with or affected by HIV or AIDS up with the relevant Circle of Support through which the specific need could be addressed. Smart (2003:43) mentions community involvement and the utilisation of community resources as an integral part of the helping process (Smart, 2003:43). It was coordinated with a list of regular service providers to which Hospice T.L.C. refer families infected with or affected by HIV or AIDS.

Five representatives from these organisations were interviewed to explore the focus areas of service rendering to referred families. The interview schedule (Greeff, 2005:286), used to collect data from the representatives of the five service providers, consisted of the following questions:

- How many cases have been referred to your organization by Hospice T.L.C.?
- What is the main focus area of service rendering?
- What other services have been rendered by your organization in order to meet the psychosocial needs of families infected with or affected by HIV or AIDS?
- In which areas could the caregivers assist the families more?

Ethical aspects

Written consent was obtained from Hospice T.L.C. and Child Welfare SA, Kokstad, to conduct the study. Ethical aspects as outlined by the nursing and social work professions were kept in mind and respected throughout the study. Confidentiality, avoidance of harm, voluntary participation, feedback on results and informed consent to participation were considered throughout the research process (Strydom, 2005a:56-70). The Ethical Committee of the North-West University (Potchefstroom Campus) also approved this study and allocated the following ethical number to this study: NWU-0060-08-A1.

Data analysis and interpretation

In the interpretation and analysis of the data obtained during the focus group session and interviews with community resource representatives. Tesch's method aims at identifying central themes from the collected data. The researcher was further informed by an extensive literature study dealing with the questions asked during the focus group session against the background of *Circles of Support*. The *assessment tool* (Halkett, 2005:130, 131) was used in formulating the questions for the focus group session and the interviews with representatives of service rendering organisations. Smart (2003:43) mentions community involvement and the utilization of community resources as an integral part of the helping process.

4. MAIN FOCUS AREAS FOR SERVICE DELIVERY

Poverty is a risk for physical, emotional and behavioural distress. A lack of food is a major stressor, followed by homelessness, unemployment and no medical care, which add to a situation of risk that could lead to behavioural problems (Andrews, Skinner & Zuma, 2006:274). Families infected with HIV or AIDS could be at risk of developing a situation as mentioned above. According to Halkett (2005:130-131) the focus areas for service delivery to families infected with or affected by HIV or AIDS should address the three main areas in which needs are identified. These areas include the following:

- Material needs;
- Protection needs; and
- Affection needs.

4.1 Material Needs

Material needs would include the need for food, protection, clothing, shelter, education and health care. In short, it would include all physical needs. The socio-economic impact on households affected by HIV or AIDS is extensive due to an inability of infected patients to work, drainage of finances due to medical and funeral expenses and as households become desperate, assets would be sold. One example was of a family who sold the child's school shoes in order to pay school fees. The increased level of poverty is linked to the fact that economically productive men and women are infected with HIV and die because of that. The burden on the family becomes very heavy. Studies have shown that traumatic, challenging experiences have the potential to serve as a vehicle for growth. (Tarakeshwar, Hansen, Kochman, Fox & Sikkema, 2006:449-457). This should motivate the community to look at means for such growth.

Poverty is the biggest stressor that families infected with or affected by HIV or AIDS have to deal with. Due to the multi-generational impact of HIV or AIDS on family life, it is often the economically productive sector of the population that is either sick or deceased, leaving the elderly grandmothers to take care of orphans and vulnerable children OVC. The meagre income of an old age pension is often the only source of household income for feeding many mouths. The added responsibilities of having to care for OVC could place the ageing grandmothers' health at risk (Potterton et al., 2007:210-212). Guardianship by means of foster care is seen as the best option to take care of OVC.

Access to foster care grants is a means of poverty alleviation and could ensure good, ongoing care for OVC. This system is unfortunately open to abuse, therefore proper supervision services should be rendered by social workers of Governmental and Non-Profit Organizations (NPO's). The greater the offered assistance by means of foster care grants then greater the chances would be for potential foster parents to take care of OVC (Freeman & Nkomo, 2006:503).

Economical empowerment is needed to reduce the negative impact of HIV or AIDS on families (Oluwagbemiga, 2007:668). Planned orphan care is very important to prevent children from being in a position where they are left uncared for. This could lead to child-headed families where children become vulnerable to misuse and abuse. Older siblings could feel pressurized to meet the needs of younger siblings forcing them to generate family income. They could fall prey to malpractices such as drug and child trafficking as well as prostitution. Members of the community dealing with OVC should be educated regarding the effect of HIV or AIDS on families. An awareness of the available services in the community such as foster care and grants could assist in meeting the needs of OVC

(Mason & Linsk, 2002:541-569). Reduced access to social services for families infected with HIV or AIDS put them at risk of being less healthy, undernourished and not receiving adequate education, which could have a negative impact on their development. Services that need to be rendered include health, education and social development services which would include grants. Should sufficient support not be rendered, three core areas of dependence have been identified by Andrews et al. (2006:269-276).

- material problems, including money, food, clothing, shelter, health care and education.
- emotional problems, including experiencing lack of care, love, support and space to grieve.
- social problems, including a lack of a supportive peer group, good role models to follow, guidance in difficult situations and the risks of the environment.

4.2 Protection Needs

Protection needs would include all the needs involving protecting and individually, physically, emotionally and spiritually. Traditionally the community formed a safety net for an individual's protection needs. Due to the multi-generational character of HIV or AIDS, this safety net is challenged. When a child tests positive for HIV it almost always means that at least the mother is positive as well. The father might be HIV positive too. This makes HIV or AIDS very different to other chronic childhood diseases.

Families affected by HIV or AIDS are also more likely to be poor and often do not have access to services and support that they do require due to stigmatisation of HIV or AIDS. They might lack access to health care. Families affected by HIV or AIDS experience multiple losses which add to the psychosocial burden and emotional distress the family experiences. Children who are HIV positive require better, more nutritious feeding and care necessitated on account of their illness.

Caring for an HIV positive individual is a time consuming and tiresome activity. This responsibility often rests on the shoulders of the grandmothers who need to take care of their own children, as well as grandchildren, on the meagre income of a pension. Older women are able to bring deep wisdom and emotional support to sick and bereaved family members. This is causing them to be increasingly called upon to nurse their own dying children, often without the required information on HIV and on how to protect themselves, which could put their own health at risk (Gennrich, 2007:13). HIV positive mothers tend to "silence" their own needs in order to put their children's needs first. This could result in neglecting their own health which could eventually lead to their death. Mothers of HIV

positive children have a tendency to experience chronic sorrow for the rest of the child's life. They express the need for ongoing support at a "one-stop" clinic where health and psychosocial needs could be met. Support groups are also a definite need, which could be valuable in dealing with parental stress (Potterton et al., 2007:210-214). The traditional family structures are becoming saturated within the communities. The kinship systems (grandmothers and aunts) are becoming increasingly overburdened by too many OVC to care for. Poor communities struggle to informally care for and support all the OVC without outside help (Ebersöhn & Eloff, 2006:457-467). Protection by means of a well-planned community effort could minimize the negative impact that HIV or AIDS has on families.

4.3 Affection Needs

Affection needs would include needs for love, emotional support, sense of belonging and unconditional acceptance within the community. Families infected with or affected by HIV or AIDS need additional psychosocial support and possibly formal counselling in order to successfully deal with their increased stress levels (Potterton et al., 2007:210-214). With the increase of adult mortality between the ages of 30 and 50 years, the grannies also needed to deal with their own sense of loss. They are losing their own children who were supposed to take care of them in their old age. These households are mostly headed by females trying to take care of their remaining grandchildren on their meagre old age pensions (Gennrich, 2007:13). The extended family was seen as the "social sponge" which unfortunately does not have the infinite capacity to soak up orphans.

The traditional safety net of the extended family becomes overwhelmed by the number of orphans who need to be taken care of as well as multiple losses. This results in child-headed families and young people forced to take on the role of primary caregivers for younger siblings. This situation could make young people more vulnerable to HIV-infection. Due to the fact that they feel the burden of taking care of their siblings, especially girls could turn to prostitution to generate income for their families. Child labour becomes a factor which also impacts on the children's chances of receiving a good education. In a poverty stricken household, education is often the first area to suffer in family life, especially regarding girls. Multiple losses have a severe impact on the family's psychosocial well-being causing a loss of future hope in many cases. Good role models are often absent. This results in long-term negative developmental consequences for the affected children who crave love, security and support. This is why community involvement becomes paramount to assist these families to receive adequate support in order to help children to develop into positive members of their communities (Germann, 2003b:82,84). Children affected by HIV or AIDS are left disconnected, un-rooted and

often stigmatized. To feel rooted and to experience a sense of belonging is often the least recognized, but the most important human need. (Herbst & De la Porte, 2006:46). Unlike any other terminal, life threatening disease, HIV or AIDS impacts on all the involved generations such as children, parents and grandparents, as well as the entire community. In Figure 3.1 the multi-generational impact of HIV or AIDS on families infected with or affected by it is illustrated. The community as a whole needs to be involved in meeting the material, protection and affection needs of resources on all three these levels. This can be done by utilizing the three Circles of support.

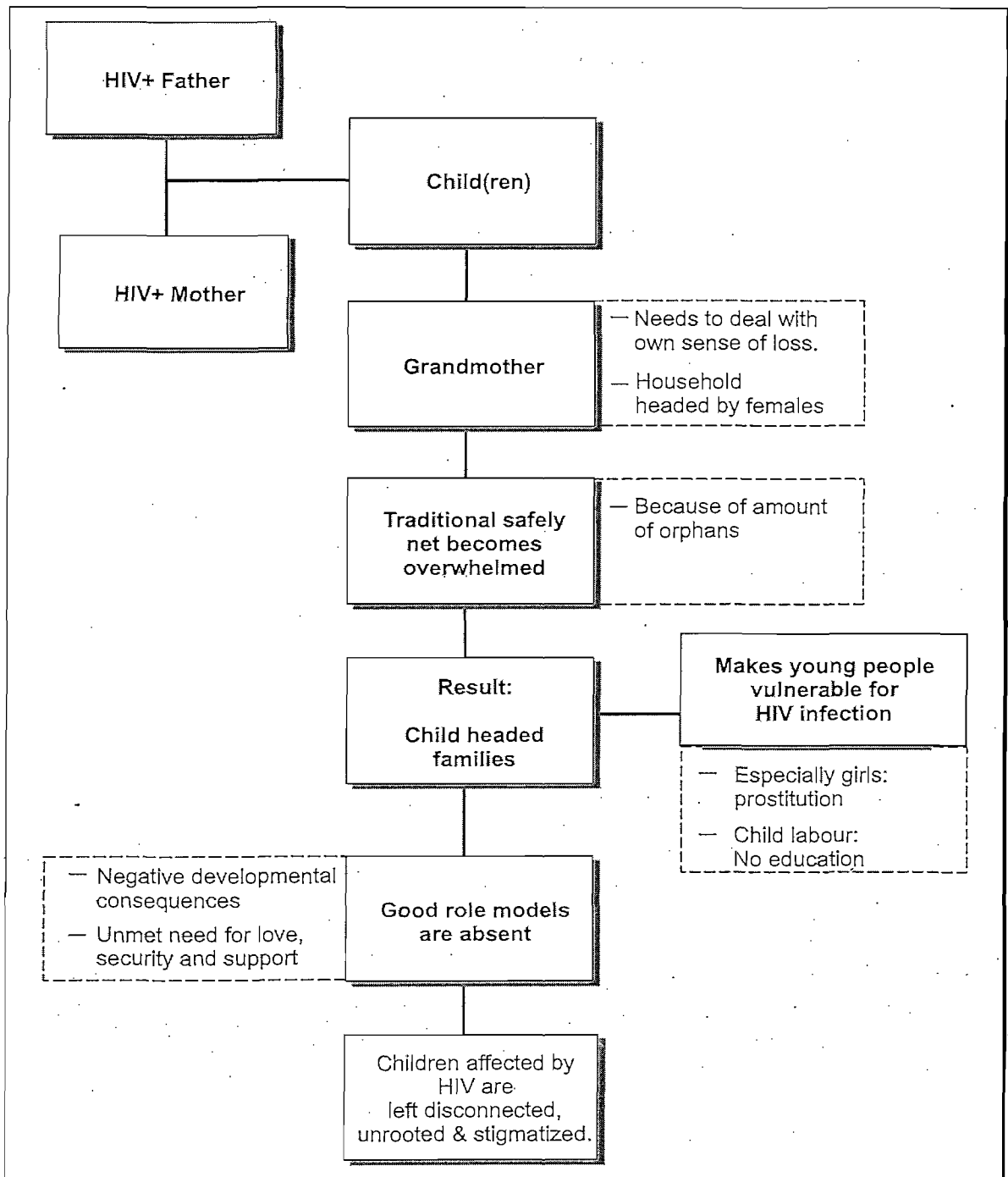


FIGURE 3.1 : The multi-generational impact of HIV or AIDS on families infected with or affected by it

5. COMMUNITY INTERVENTIONS NEEDED

With limited resources, families battle to absorb the OVC in need of care. Interventions from the community's side need to focus on the following:

- improving the social conditions, health, development, education and quality of life of OVC;
- supporting families and households, especially elderly caregivers in coping with the increased burden of infected, affected and vulnerable children;
- strengthening community-based support systems as an indirect means of helping vulnerable children;
- strengthening HIV and AIDS awareness through education of the community; and
- advocating and formulating policy that could benefit OVC;

Shishana and Louw (2006:453-455) did a review of the OVC research intervention project. The findings of this review are summarized in Table 3.2. Existing strategies applied by the SA Government are linked to these findings.

TABLE 3.2 : Review of the OVC research intervention project

SUMMARY ARISING FROM REVIEW DONE AS PART OF THE OVC RESEARCH INTERVENTION PROJECT	SOUTH AFRICAN GOVERNMENT STRATEGY
<ol style="list-style-type: none"> 1. Family coping capacity has been depleted, hence the need to support families. 2. Programmes aiming to provide support for psychosocial development of children should complement those focusing on material support. 3. Effective support of families and communities in responding to OVC is essential. 	<p>Strategy 1, which strengthens and supports the Capacity of families to protect and care for OVC.</p> <p>Strategy 2, which focuses on ensuring that mechanisms are in place to provide psycho-social support to OVC and their families.</p> <p>Strategy 3, which mobilizes and strengthens community-based responses for the care, support and protection of OVC.</p>
SUMMARY ARISING FROM REVIEW DONE AS PART OF THE OVC RESEARCH INTERVENTION PROJECT	SOUTH AFRICAN GOVERNMENT STRATEGY
<ol style="list-style-type: none"> 4. The importance of a human rights frame-work for OVC work needs to be emphasized. 5. Multisectoral collaborations between national and local government, NGO's and community structures appear to provide the most effective services. 	<p>Strategy 4, which ensures access of OVC to essential services; focuses on ensuring that service and service delivery mechanisms are based on the child rights approach; developing and strengthening programmes that make essential services accessible to OVC and supporting resource mobilization for the implementation of programmes that make essential services accessible to OVC.</p> <p>Strategy 5, which engages civil society organisations and the business community to play an active role in supporting the plight of OVC.</p>

(Shisana & Louw, 2006:453-455).

In view of the aforementioned aspects, it is clear that a holistic, multi-disciplinary approach needs to be followed in service rendering to families infected with or affected by HIV or AIDS.

Affected households experience severe financial constraints due to lack of income as well as medical and funeral costs. Educationally children suffer. HIV or AIDS impacts families at a psychosocial level and a need for support from the community is vitally important. Families infected with or affected by HIV or AIDS tend to become more depressed, socially isolated and aggressive. Schools could play a supportive role in meeting the needs of these families by creating a warm, caring attitude of support for their learners and their families. Community gardens could be established on school premises. One of the effects of HIV or AIDS on the community is a gradual erosion of knowledge, for instance gardening skills, occurring when parents are no longer available to teach their children (Villareal, 2002:1.2). These skills could be taught at school by skilled adults from the community who could act as positive role models. Research has shown that teachers are generally helpful and understanding (Ebersöhn et al., 2006:463-465). They are helpful resources in identifying:

- affected families;
- the health status of families;
- emotional and developmental problems of children;
- ways to support children affected by or infected with HIV or AIDS;
- means to help the child who has missed out on schoolwork to catch up;
- ways to follow policy for learners and educators regarding HIV and AIDS;
- ways to show children love, respect and support (Smit, 2007:1-8);
- counsellors or social workers to provide support for affected families, for instance to apply for grants such as child support, foster care or care dependency grants or to liaise with schools (Booyesen, 2004:49-50).

The challenge in meeting the needs of families infected with and affected by HIV or AIDS would be to create a framework of support by channelling resources in the community to support these families through the three circles of support. The *Circles of Support* model described by Smart (2003:43-44) identifies three levels of support for individuals. These circles include the following:

The **first circle** implies help from family, neighbours and friends assisting with:

- Food and clothing;
- Caring for the sick;
- Cooking of meals;
- Shopping;
- Helping with gardening;
- Helping with caring for children;
- Telling stories to children;
- Taking a child to a doctor, clinic or hospital when needed;
- Caring for HIV positive patients;
- Making sure that nobody exploits or misuses orphans and vulnerable children (OVC);
- Assisting in identifying people who are foster children in need of care.

The **second circle** of support implies help from the community, particularly the forming of a Circle of Support Group. The aim of this group would be for neighbours to start with a group helping one another. It could eventually become a network of people within the community helping each other to help OVC, sick people and minimizing stigma and discrimination against people living with HIV or AIDS.

The **third circle** includes resources in the wider society such as:

- church and youth groups who can help in caring for the sick and the children, and in fighting stigma;
- local AIDS support groups who can give emotional support, care for the sick and fight stigma;
- local NPOs such as Hospice and Child Welfare SA (CWFSA) who could help with planned orphan care, prevent abuse and support foster parents;
- local businesses could sponsor food, blankets and clothes;
- and local leaders could assist the community in fighting discrimination.

The circles of support are illustrated in figure 3. 2.

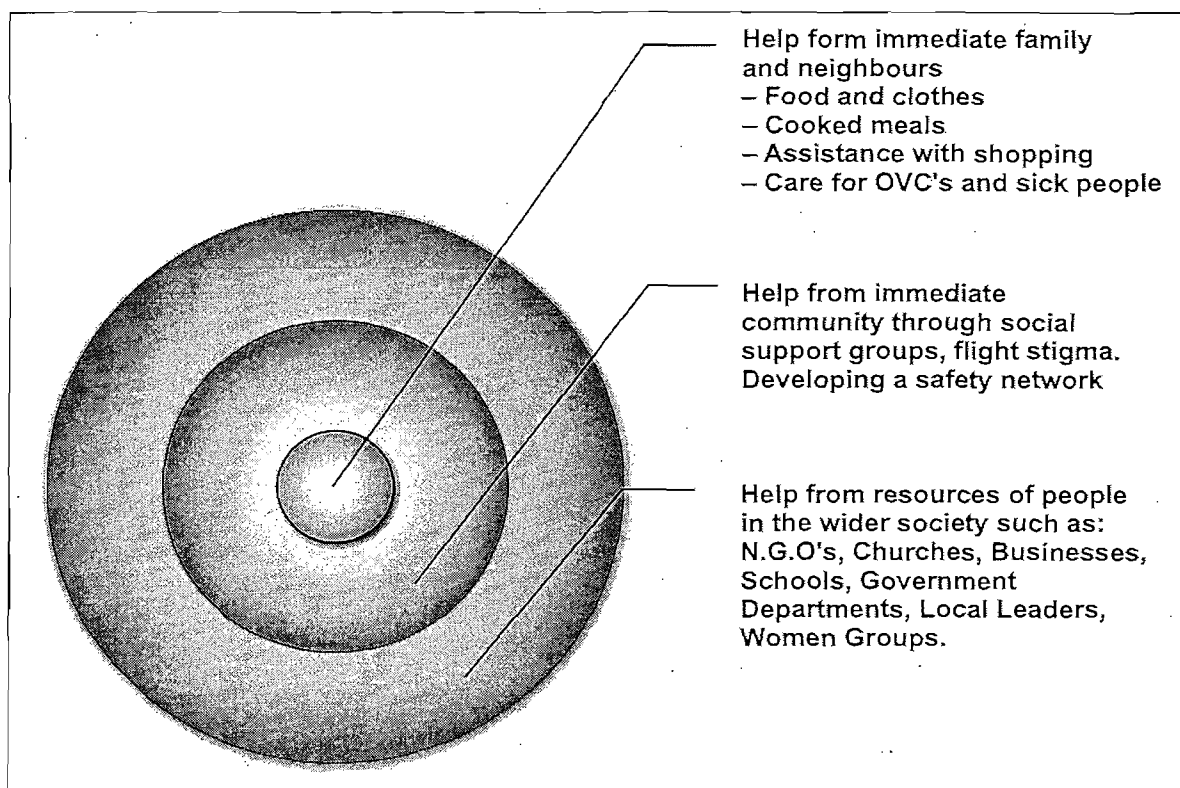


FIGURE 3.2 : Circles of support (Smart, 2003:43)

The *Circles of Support* model shows close links with the “asset-based” approach in meeting the needs of families infected with and affected by HIV or AIDS described by Ebersöhn and Eloff (2006:459-465). This could also be called “*capacity building*” strengthening the key adults who could have an impact in the lives of families infected with or affected by HIV or AIDS (Wood, Chase & Aggleton, 2006:1932-1933). This model or approach emphasizes the importance of community-based intervention, the proper co-ordination of services and co-operation between the different role players and service providers.

6. EXISTING AND POTENTIAL SERVICE PROVIDERS

In the service agreement between Hospice T.L.C. and the Department of Social Development, it is agreed that:

- OVC would be identified; and
- referred to specialized services; or NGO's
- voluntary counselling would be recommended;

- home-based care and visits would be done; and
- food parcels would be provided.

(The KwaZulu-Natal Provincial Government in its Department of Social Development & T.L.C. Home Services, 2008:8,9).

This tie in with the idea of a holistic approach in service rendering to families infected with and affected by HIV or AIDS. Families' need a "holding environment" in which needs could be met at all levels (Pivnick & Villegas, 2000:103). It is therefore important that government departments, NGOs, schools, churches and volunteers join efforts to meet the needs of families infected with and affected by HIV or AIDS. Some churches such as the Catholic Church has established good programmes administering ARV's through clinics and hospitals. Supportive services have been rendered, but unfortunately churches at large have not joined the struggle against HIV and AIDS. Through their involvement, stigma could be minimized and education regarding HIV and AIDS could be done on a much broader scale. People infected with and affected by HIV or AIDS have a need to be treated with dignity, respect and love. The church has an important role to fulfill in this respect (Gennrich, 2007:37). Volunteers could be drawn from churches in order to assist with memory work and support groups (Herbst & De la Porte, 2006:47).

A framework needs to be put in place so that identifies, monitors and supports OVC, as well as the rest of the families affected by HIV or AIDS. The different stakeholders should be in contact with one another in order to identify gaps in the safety net system meant to address the needs of families infected with and affected by HIV or AIDS (Pivnick & Villegas:103).

Smart mentions "essential elements" in service rendering consisting of:

- Food
- Clothing
- Home environment, protection
- Education
- Affection
- Identity
- Participation in future plans
- Understanding, information and communication

- Counselling and supportive systems
 - Recreation / leisure
 - Freedom of expression
- (Smart, 2003:60-63).

It is clear from the literature that more effective services can be rendered through joint efforts of the various service providers to families infected with or affected by HIV or AIDS after a proper needs assessment against the background of the three circles of support (Smart, 2003:43).

7. RESULTS

7.1 Focus group information

All 9 permanently employed Hospice T.L.C. caregivers took part in one focus group session. The aim of this focus group session was to explore the number of families cared for, meeting the needs of these families, identifying the main focus areas for further service rendering and service delivery by other relevant service providers. Feedback on the outcome of the research conducted was given as discussed in Articles 1 and 2.

The focus group session was based on the following questions:

- How many families are cared for?
- What were the families' biggest needs?
- In which areas did the families battle most?
- In which areas could the caregivers assist the families more?
- Which relevant service providers were the needy families referred to?
- In which areas could the families use more assistance by means of referrals to other service providers?

TABLE 3.3 : Review of the OVC research intervention project

FOCUS GROUP SESSION WITH HOSPICE T.L.C. CAREGIVERS	GOALS
	<ul style="list-style-type: none"> • To explore the number of families cared for by Hospice T.L.C. caregivers. • Exploring means to meet the needs of these families. • Identifying the main focus areas for further service delivery. • Identifying the relevant service providers for further service delivery. • Feedback on the outcome of the research conducted was given.
OBJECTIVES	<ul style="list-style-type: none"> • To obtain basic information regarding the families that the Hospice T.L.C. caregivers care for. • To explore what the families' biggest needs were. • To explore in which areas the families battled most. • To explore the areas in which the Hospice T.L.C. caregivers could assist the families more. These last 3 objectives would give an indication of the main focus areas for further service delivery. • To identify the referral of needy families to relevant service providers within the community.
QUESTIONS ASKED DURING THE FOCUS GROUP SESSIONS	<ul style="list-style-type: none"> • How many families are cared for? • What were the families' biggest needs? • In which areas did the families battle most? • In which area could the caregivers assist the families more? • Which relevant service providers were the needy families referred to?

FOCUS GROUP SESSION WITH HOSPICE T.L.C. CAREGIVERS	GOALS
<p>QUESTIONS ASKED AND RESPONSES DURING THE COURSE OF THE FOCUS GROUP SESSION</p>	<p>HOW MANY FAMILIES ARE CARED FOR?</p> <ul style="list-style-type: none"> • 340 patients receive care. • 70 families receive care. • 66 food parcels are delivered on a weekly basis. This information was verified with Hospice T.L.C. statistics.
<p>THEMES EMERGING</p>	<p>70 families receive care out of an average of 340 patients. The majority of these 70 families need regular, weekly food parcels in order to survive. An average of 66 food parcels are delivered weekly indicating a high level of material need.</p>
<p>EXAMPLES OF RESPONSES</p>	<p>"The children are hungry and happy to see us coming with the food parcels".</p> <p>"The grannies battle to feed all these children".</p>
<p>CORRELATION WITH LITERATURE</p>	<p>Poverty is the biggest stressor families infected with or affected by HIV or AIDS have to deal with. The meagre income of an old age pension is often the only source of household income for feeding many mouths (Potterton et al., 2007: 210-212).</p>
<p>QUESTIONS ASKED AND COURSE OF THE FOCUS GROUP SESSION</p>	<p>WHAT ARE THE FAMILIES' BIGGEST NEEDS?</p> <ul style="list-style-type: none"> • Material needs in the form of money to buy food, access to grants, growing vegetables and the food parcels were discussed, • Protection needs in the form of access to good health care such as ARV-treatment, nourishing, well-balanced food, warm protective clothing and blankets were discussed. • Affection needs in the form of ongoing regular support by means of home visits was very important to the affected families. Especially the grandmothers and children count on the security of the availability of the Hospice T.L.C. caregivers in time of need.
<p>THEMES EMERGING</p>	<p>The different material, protection and affection needs as defined by the <i>assessment tool</i> were discussed. The material and affection needs were evaluated at the same level, with protection needs less eminent.</p>

FOCUS GROUP SESSION WITH HOSPICE T.L.C. CAREGIVERS	GOALS
EXAMPLES OF RESPONSES	<p>"Enough food for everybody is always a problem".</p> <p>"We are so worried about the children when it is cold that they will be warmly dressed".</p> <p>"The grannies and children are counting on our visits. They are so happy to see us".</p>
CORRELATION WITH LITERATURE	<p>According to Halkett (2005:130-131) the focus areas for service delivery to families infected with or affected by HIV or AIDS should address the three main areas in which needs are identified.</p> <p>These areas include the following:</p> <p style="padding-left: 40px;">Material needs;</p> <p style="padding-left: 40px;">Protection needs; and</p> <p style="padding-left: 40px;">Affection needs.</p>
QUESTION ASKED AND COURSE OF THE FOCUS GROUP SESSION	<p>IN WHICH AREAS DID THE FAMILIES BATTLE MOST?</p> <p>Material and affection needs were the most pressing, half of the participants regarded protection needs as an area of concern.</p>
THEMES EMERGING	<p>Material needs in the form of basic survival needs, as well as the need for support and acceptance of the families infected with or affected by HIV or AIDS were regarded by the participants as equally important. Protection needs were not that much of a pressing need according to the participants. Protection needs were met in most cases in the families they deal with.</p>
EXAMPLES OF RESPONSES	<p>"It is a constant battle for survival for these families".</p> <p>"They all have houses, clothes and blankets".</p> <p>They want to be loved in spite of the sickness".</p>
QUESTION ASKED AND COURSE OF THE FOCUS GROUP SESSION	<p>IN WHICH AREAS COULD THE CAREGIVERS ASSIST THE FAMILIES MORE?</p> <p>In cases where the Hospice T.L.C. caregivers could not successfully address the needs of the families they deal with, they were referred to relevant service providers within the local community. The participants listed the names of these service providers for the researcher.</p>

FOCUS GROUP SESSION WITH HOSPICE T.L.C. CAREGIVERS	GOALS
THEMES EMERGING	For social work services most cases were referred to Christian Social Services (CSS); they just recently started referring cases to the Department of Social Development; and some cases have been referred to Child Welfare SA – Kokstad. Of the referred cases, all have received attention from social workers.
EXAMPLES OF RESPONSES	<p>"Ms W of CSS helps us most". At that stage she walked in and they gave her a hearty applause.</p> <p>"Child Welfare also helps us, if we ask them, but the social workers are forever changing".</p> <p>"We only started asking the Department for help now recently".</p>
CORRELATION WITH LITERATURE	<p>During the period of 2008/2009 the Hospice T.L.C. statistics show the following number of referrals:</p> <p>Department of Social Development : 8 (Government) (Dept of Soc Dev)</p> <p>Child Welfare SA – Kokstad : 5 (NPO) (CWSA – Kokstad)</p> <p>Christian Social Services : 46 (NPO) (CSS)</p> <p>TOTAL 59</p>
QUESTION ASKED AND COURSE OF THE FOCUS GROUP SESSION	<p>WHICH RELEVANT SERVICE PROVIDERS WERE THE NEEDY FAMILIES REFERRED TO?</p> <ul style="list-style-type: none"> Cases in need of assistance from social workers in order to access grants are referred to: <ul style="list-style-type: none"> Depart of Soc Dev CWSA – Kokstad CSS 30 families need food parcels on a weekly basis to survive, 10 patients were elderly people and 43 were OVC who need support.

FOCUS GROUP SESSION WITH HOSPICE T.L.C. CAREGIVERS	GOALS
	<ul style="list-style-type: none"> • Foster care placements for OVC are done by these service providers. • OVC in need of care are placed at Home of Comfort Children's Home, Kokstad through the above-mentioned service providers where needed. • Khanyeselani is a NPO that also assists the needy families such as assisting clients in applying for birth certificates and identity documents in order to apply for grants.
THEMES EMERGING	<ul style="list-style-type: none"> • In addressing material needs of needy families, proper foster care placements need to be done by welfare organizations in order to access foster care grants. Referrals to the relevant service providers is therefore are of paramount importance. • Identification documents are necessary to obtain grants. Hence It is important that clients receive assistance in getting their documents in place. Having identity documents gives them a sense of self-worth and belonging. This will also address affection needs by enhancing their "rootedness".
	<ul style="list-style-type: none"> • Planned orphan care is very important in order to prevent OVC left without proper care. Welfare organizations play a very important role in this process. This will address protection needs by minimizing the risk of OVC being left without proper adult care. • All referred cases have been successfully followed up by the relevant service providers.
EXAMPLES OF RESPONSES	<ul style="list-style-type: none"> • "Some grannies don't know that they can get foster care grants for the children". • "Some children do not even have birth certificates". • "We are so glad that the social workers help all our people".

FOCUS GROUP SESSION WITH HOSPICE T.L.C. CAREGIVERS	GOALS
CORRELATION WITH LITERATURE	<ul style="list-style-type: none"> • The greater the offered assistance by means of foster care grants then greater the chances would be for potential foster parents to take care of OVC (Freeman & Nkomo, 2006:503). • An awareness of the available services in the community such as foster care and grants could assist meeting the needs of OVC (Mason & Linsk, 2002:541-569).
QUESTION ASKED AND COURSE OF THE FOCUS GROUP SESSION	<p>IN WHICH AREAS COULD THE FAMILIES USE MORE ASSISTANCE?</p> <ul style="list-style-type: none"> • Other service providers were listed that could assist families with their needs such as: • Department of Home Affairs provides identity documents, birth and death certificates needed for access to grants. • Department of Health provides all health related assistance including Anti-retroviral treatment (ARV's). They would refer cases to Hospice T.L.C • Department of Education provides schooling to OVC. • Khanyesilani is an NPO providing child care support with trained child minders who would also identify families infected with and affected by HIV or AIDS and refer to Hospice T.L.C. • Churches should provide spiritual support and volunteers to help families infected with or affected by HIV or AIDS in meeting their needs. Due to stigma this is not really happening. • The community is starting to form a safety net to help itself by connecting the needs of families infected with and affected by HIV or AIDS with relevant resources in the community. • Referrals should be followed up by Hospice T.L.C. caregivers to see if they receive the necessary attention in meeting the needs of the families they deal with.

FOCUS GROUP SESSION WITH HOSPICE T.L.C. CAREGIVERS	GOALS
	<ul style="list-style-type: none"> • Education regarding HIV and AIDS is a growing need in order to create a better understanding of the impact of the disease on a community. Knowledge could help to minimize stigma connected to it. • Material donations in the form of food, clothes and blankets would be welcomed. Skills training are also a need. • All support to needy families is welcomed. This helps to relieve the burden resting on the shoulders of primary caregivers of OVC and ill patients. • The Hospice T.L.C. caregivers could easily suffer from burnout or compassion fatigue. By sharing the workload in meeting the needs of the families they deal with, with other service providers, their own load gets lifted. • A multi-sectoral forum should be in place to address issues related to HIV or AIDS and the impact of it on the community. <p>The researcher available herself of this opportunity to summarize the outcome of the study for the caregivers and gave feedback on it by means of two Figures, namely Figure 1 and 2, as well as the assessment tool.</p>
THEMES EMERGING	<p>The caregivers were led to understand the Three Circles of Support and the multi-generational impact of HIV or AIDS on the community by means of Figures 1 and 2. They grasped that the task in taking care of the material, protection and affection needs of the families infected with or affected by HIV or AIDS is a holistic multi-disciplinary team effort. A proper needs assessment should be done in order to address the needs effectively.</p>

FOCUS GROUP SESSION WITH HOSPICE T.L.C. CAREGIVERS	GOALS
CORRELATION WITH LITERATURE	<p>In order to have well-directed service rendering, the main focus areas for service rendering should be identified by using guidelines such as mentioned in the assessment tool (Halkett, 2005:130,131). In dividing these needs in three categories it should be easy to define the focus areas for service delivery. In addressing the needs, the Three Circles of Support (Smart, 2003:60-63) should be applied. In doing this the community will build an "asset-based" approach (Ebersöhn & Eloff, 2006:459-465) in the community addressing the needs of families infected with or affected by HIV or AIDS in a holistic, multi-disciplinary team approach trying to prevent gaps in the safety net system (Pivnick & Villegas, 2001:103).</p>

7.2 Interviews with representatives of 5 relevant service providers rendering social work services to families infected with or affected by HIV or AIDS

GOAL	To explore the nature of service rendering by the five service providers in the Kokstad area through panel sampling.												
OBJECTIVES	To explore how many of the cases referred to these service providers effectively addressed the needs of these families infected with or affected by HIV or AIDS.												
QUESTIONS ASKED AND COURSE OF THE INTER-VIEW SCHEDULE	<p>HOW MANY CASES HAVE BEEN REFERRED TO YOUR ORGANISATION BY HOSPICE T.L.C?</p> <table border="0"> <tbody> <tr> <td>CSS</td> <td>46</td> </tr> <tr> <td>Dept of Soc Dev</td> <td>8</td> </tr> <tr> <td>CWSA – Kokstad</td> <td>5</td> </tr> <tr> <td>Khanyeselani</td> <td>2</td> </tr> <tr> <td>Home of Comfort</td> <td>1</td> </tr> <tr> <td>TOTAL</td> <td>62</td> </tr> </tbody> </table>	CSS	46	Dept of Soc Dev	8	CWSA – Kokstad	5	Khanyeselani	2	Home of Comfort	1	TOTAL	62
CSS	46												
Dept of Soc Dev	8												
CWSA – Kokstad	5												
Khanyeselani	2												
Home of Comfort	1												
TOTAL	62												

	<p>WHAT IS THE MAIN FOCUS OF SERVICE DELIVERY IN YOUR ORGANISATION?</p> <p>CSS</p> <p>Child and family care services including foster care services in Kokstad and adjacent areas.</p>
	<p>DEPT OF SOC DEV</p> <p>Child and family care services including foster care services in Kokstad and adjacent areas.</p>
	<p>CWSA – KOKSTAD (NPO)</p> <p>All services are aimed at preserving the family as cornerstone of our community including bereavement counselling for OVC prevention of all forms of abuse of children, domestic violence, marital conflict, substance abuse and uncontrollable behaviour of children.</p> <p>KHANYESELANI (NPO)</p> <p>They supply support services to families infected with HIV or AIDS by means of having trained child minders addressing the needs of OVC. They run a soup kitchen and crèche on their premises.</p> <p>HOME OF COMFORT (NPO)</p> <p>This is a registered Children’s home accommodating OVC in the Kokstad community. They render preventive services to OVC who could otherwise become abused or neglected.</p>
	<p>WHAT OTHER SERVICES HAVE BEEN RENDERED BY YOUR ORGANISATION IN ORDER TO MEET THE BIO-PSYCHOSOCIAL NEEDES OF FAMILIES INFECTED WITH HIV OR AIDS?</p> <ul style="list-style-type: none"> • CSS (NPO) Emotional support services as part of bereavement counselling and assistance with access to child support grants was given. • DEPT OF SOC DEV (Government) They run preventative programmes concerning HIV or AIDS infection at various schools. They visit pre-schools and do education regarding well-balanced, nutritious food.

<p>THEMES EMERGING</p>	<p>SOCIAL WORK</p> <ul style="list-style-type: none"> • CSS Social work services are rendered with the aim of meeting material, protection and affection needs mainly by doing foster care placements, rendering supervision services and assist with access to relevant grants for families infected with or affected by HIV or AIDS. • DEPT OF SOC DEV Social work services including foster care placement are rendered as well as preventive programmes are run at schools regarding HIV or AIDS infection and good nutrition. Assistance is rendered with access to relevant grants for needy families.
	<ul style="list-style-type: none"> • CWSA – KOKSTAD Social work services are rendered regarding the preserving of the family as basic unit of our community. These services include foster placements, bereavement counselling, abuse of all forms and dealing with uncontrollable children. • KHANYESELANI Support services are rendered to families infected with or affected by HIV or AIDS, but no statutory services are rendered. • HOME OF COMFORT OVC in need of care are legally placed by social workers at this Children's Home in Kokstad. This acts as a preventive measure for child abuse and neglect.
<p>EXAMPLES OF RESPONSES</p>	<p>"We are glad that we can help in preventing child-headed families or that children in need of care become street children".</p> <p>"We hope that by joining our efforts we could minimize the trauma that children go through in losing their parents".</p> <p>"Home of Comfort must be a home to all these traumatized children".</p> <p>"The young people must learn that they play with fire if they have irresponsible behaviour".</p> <p>"We do so many foster placements!".</p>

CORRELATION WITH LITERATURE	By identifying the main focus areas of need, it can be successfully linked to relevant resources within the community by means of the Circles of Support (Smart, 2003:60-63). This should eventually form a strong network of support within the community, strengthening its ability to deal with the needs of families infected with or affected by HIV or AIDS (Pivnick & Villegas, 2000:103). By means of a holistic, multi-disciplinary team effort, the community will build an "asset-based" approach in meeting the needs of these families (Ebersöhn & Eloff, 2006:459-465).
	<p>OTHER SERVICE PROVIDERS MENTIONED DURING THE FOCUS GROUP SESSION AND INTERVIEW SCHEDULE</p> <ul style="list-style-type: none"> • Department of Home Affairs provides identity documents, birth and death certificates needed for access to grants. • Department of Health provides all health-related assistance including Anti-retroviral treatment (ARV's). They would refer cases to Hospice T.L.C. • Department of Education provides schooling to OVC. • Churches should provide spiritual support and volunteers to help families infected with and affected by HIV or AIDS in meeting their needs. Due to stigma this is not really happening.

8. CONCLUSIONS

- Education regarding HIV and AIDS is a growing need in order to create a better understanding of the impact of the disease on a community. Knowledge could help to minimize stigma connected to it.
- Churches should become more involved in meeting the needs of families infected with and affected by HIV or AIDS. They could do this by making volunteers available that could assist with support visits, groups and memory work.
- Material donations in the form of food, clothes and blankets would be welcomed. Skills training is also a need.
- All support to needy families is welcomed. This helps to relieve the burden resting on the shoulders of primary caregivers of OVC and ill patients.
- The Hospice T.L.C. caregivers could easily suffer from burnout or compassion fatigue. By sharing the workload in meeting the needs of the families they deal with, with other service providers, their own load gets lifted.

- A multi-sectorial forum should be in place to address issues related to HIV or AIDS and the impact of it on the community.
- In order to have well-directed service rendering to families infected with or affected by HIV or AIDS, the main focus areas for service rendering need to be identified.
- A proper needs assessment using guidelines such as the assessment tool (Halkett, 2005:130, 131) should be done for every family in need of help during home visits paid by Hospice T.L.C. caregivers.
- The needs arising from this assessment could be divided into 3 groups, namely: material, protection and affection needs.
- By dividing the needs into these 3 categories, the main focus areas for service delivery should be easily identified.
- The three circles of support (Smart, 2003:60-63) should be applied in addressing the needs families infected with or affected by HIV or AIDS encounter.
- All Three Circles of Support should be utilized in addressing the focus areas of service rendering addressing material, protection and affection needs.
- By utilizing the Three Circles of Support in meeting the families' identified needs, the community will build an "asset-based" approach in meeting the needs of families infected with and affected by HIV or AIDS (Ebersöhn & Eloff, 2006:459-465).
- Identifying the main focus areas of need, linking it up with resources within the community by means of the Circles of Support (Smart, 2003:60-63) the community's ability to deal with needs should be strengthened.
- Through ongoing training Hospice T.L.C. caregivers should be able to identify the main focus areas for service rendering by making use of the three circles of support to address the needs of families infected with or affected by HIV or AIDS.
- Through ongoing service rendering to families infected with and affected by HIV or AIDS, Hospice T.L.C. caregivers will enable these families to reach out to one another by making use of the first and second circle of support. Firstly, immediate family and neighbours will assist each other. Eventually a strong network of support will be formed that could minimize the negative impact of HIV or AIDS on the entire community.
- In order to create a "holding environment" for families infected with or affected by HIV or AIDS, a holistic, multi-disciplinary approach should be followed in order to

meet needs at all levels (Pivnick & Villegas, 2000:103). This will include the services mentioned in the third circle of support (Smart, 2003:44).

- Gaps within the safety net system should be identified (Pivnick & Villegas, 2003:103) in order to address needs at all levels. Gaps in the system could be failure to have planned orphan care; inability for foster parents to access grants due to the lack of proper documentation; or non-adherence to ARVs.
- Volunteers could be utilized to a greater extent in order to get programmes such as memory work and support groups in place, food parcels and skills training.
- The multi-generational impact of HIV or AIDS should be taken into account in dealing with the infected with and affected families. The main focus of care is often on the infected patient, neglecting the needs of the affected family members. Due to a lack of emotional support the vicious cycle of infection often continues.
- Preventative programmes need to be in place in order to break the vicious cycle of HIV or AIDS infection resulting in a multi-generational impact on the entire community. A multi-sectoral forum would be valuable in addressing this gigantic task. The forum should consist of representatives of a multi-disciplinary team.

9. RECOMMENDATIONS

It is therefore recommended that :

- The Hospice T.L.C. caregivers receive training in doing needs assessment with the *assessment tool* (Halkett, 2005:130, 131) in mind.
- The *Three Circles of Support* (Smart 2003:43) should be included in this training to enable them to refer the identified need to the appropriate resource within the community. T.L.C. caregivers should confirm that the needed services are rendered.
- A proper needs assessment will help the Hospice T.L.C. caregivers to identify the main focus areas for service rendering. The T.L.C. caregivers should be well-educated on the different resources available within the community. Professional conduct by all service rendering stakeholders is a requirement.
- A holistic, multi-disciplinary approach should be followed in order to strengthen the entire community in meeting the needs of families infected with and affected by HIV or AIDS. A multi-sectoral forum should approach issues such as preventive programmes to break the negative impact of families at a multi-generational level.
- Good communication channels should exist between all service providers.

- Gaps in the safety net system should be identified and addressed especially with regards to orphan care, access to grants, documentation and non-adherence to ARVs.
- Volunteers should be trained and utilized to a greater extent to give proper attention to issues such as support groups and memory work.
- A service centre where some of the services rendered could be available such as a soup kitchen, support groups, ARV-counselling; a drop-off centre for the aged and a crèche will be an asset in the community.
- A one-stop clinic facility should be established which could serve as a visible presence of some of the services available. Such services should include support groups, a soup kitchen, ARV-counselling, voluntary testing, a drop-off centre for the aged and a crèche, as well as social work services.
- All stakeholders rendering services to families infected with or affected by HIV or AIDS should take hands in forming a safety net addressing the main focus areas where service delivery is needed. By doing this the community will be strengthened and enabled to help itself.

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SECTION C :

**JOINT SUMMARY, FINDINGS,
CONCLUSIONS AND RECOMMENDATIONS**

1. INTRODUCTION

In this section the focus will be on the main findings, conclusions and recommendations in terms of the study. The central theoretical argument, as outlined in **Section A (4)**, will be proven.

2. JOINT SUMMARY, FINDINGS AND CONCLUSIONS

The most important summaries, findings and conclusions pertaining to this study as described by focusing on the methodology, as well as Articles 1, 2 and 3 as stated in **Section B**.

3. RESEARCH METHODOLOGY

The overarching aim of this study was:

To do a critical investigation regarding the **role** Hospice T.L.C. caregivers play in the lives of families infected with or affected by HIV or AIDS.

This aim contained the following objectives:

- To investigate the **role** Hospice T.L.C. caregivers play in the lives of families infected with or affected by HIV or AIDS.
- To identify the **bio-psychosocial needs** of these families and
- To explore the level of services to families infected with or affected by HIV or AIDS by addressing the **main focus areas** for services rendering to these families.
- In order to reach these goals a literature, as well as an empirical study were done.

4. LITERATURE STUDY

Literature on the impact of hospice caregivers on families infected with or affected by HIV or AIDS is limited. This study therefore contributed by making available literature on this topic.

A great deal has been written on the impact of HIV or AIDS on families, as well as on their bio-psychosocial needs. Sources used were books, journals, articles, programs by government departments and NPO's. Many of the literature sources were obtained from the Ferdinand Postma Library using Ebsco Host, Web Feat and Psychlit databases.

5. EMPIRICAL INVESTIGATION

It was a qualitative study in which both the exploratory and descriptive research designs were utilized. Data was collected by means of focus group sessions and personal interviews. Five focus group sessions were conducted with Hospice T.L.C. caregivers. By making use of purposive sampling, affected families were selected to be interviewed. Panel sampling was used to select participants from the existing service providers. The main focus areas for service rendering to families infected with or affected by HIV or AIDS were explored.

The data collected offered a good overview of the role Hospice T.L.C. caregivers play in the lives of people infected with or affected by HIV or AIDS, as well as their bio-psychosocial needs. The identified needs enabled the researcher to formulate the main focus areas for service delivery to families infected with or affected by HIV or AIDS.

6. MAIN CONCLUSIONS FROM THE LITERATURE STUDY AND EMPIRICAL STUDY

The researcher came to the following main conclusions:

6.1 Article 1

- Through their training, the Hospice T.L.C. caregivers are equipped to render support and care to patients and their families infected with or affected by HIV or AIDS. Their knowledge of palliative care allows them entrance to these families; therefore they can act as a valuable "link" between the affected families and relevant resources within the community such as professional medical staff, social workers and other relevant service providers. A diagnosis with HIV or AIDS acts as a stressor and needs to be addressed (Kagee, 2008:246).
- The Hospice T.L.C. caregivers can communicate at an appropriate level with their patients and affected families in a way they can understand. This is due to their knowledge of the cultural context in which their patients and affected families are functioning (De Vito, 2001:57).
- A strong, loyal relationship exists between the Hospice T.L.C. caregivers and the families they deal with. They have earned the trust and respect of the local community (Emanuel & Von Gunten, 1999:11). Regular home visits are a valuable tool in building this relationship (Smit, 2007:1-10).

- In fulfilling the roles of teachers and educators they can help to clarify misconceptions regarding HIV and AIDS and help to minimize stigmatization within the local community (Mboyi et al., 2005:26).

6.2 Article 2

- Hospice T.L.C. caregivers are a “visible presence in the community and bio-psychosocial needs can easily be assessed by means of the *assessment tool* (Halkett, 2005:130-131). Hospice T.L.C. caregivers should be trained to do this to a greater extent. They are already actively involved in identifying the bio-psychosocial needs of families infected with or affected by HIV or AIDS. Material, protection and affection needs are distinguished.
- In order to effectively meet the bio-psychosocial needs of the families they deal with, the Hospice T.L.C. caregivers need to have a good knowledge of the relevant resources within the community. These needs could be effectively met by making use of the *Circles of support* (Smart, 2003:43). By doing this, the community will build an “asset-based” approach, meeting the needs of families infected with or affected by HIV or AIDS (Ebersöhn & Eloff, 2006:459-465).

6.3 Article 3

- In order to create a “holding environment” for these families a holistic, multi-disciplinary team approach needs to be followed to meet their needs at all levels. Care needs to be taken that “gaps” within the safety-net do not exist. This could happen in the case of orphan care, non-adherence to ARV-treatment, or foster parents not having access to foster care grants (Pivnick & Villegas, 2000:103).
- Eventually the ideal will be that affected families will reach out to each other in order to render support to one another. By doing this a stronger community will be built, minimizing the negative impact of HIV or AIDS on the entire community.
- The multi-generational impact of HIV or AIDS is often overlooked. The main focus is often on the patient, neglecting the affected family members. Due to this state of emotional neglect, OVC often experience being unrooted, which could easily result in irresponsible relationships, causing HIV-infection and the vicious cycle continues (Germann, 2003:78).
- Preventative programs need to be in place to break this cycle; therefore a multi-sectoral forum should be formed to address this huge task. This forum should consist of members from a multi-disciplinary team involving teachers, clergy, social

workers, health professionals and leaders from the community, including youth leaders. They should also aim to educate the community in order to minimize stigma.

- Volunteers from the community should be incorporated in services to families infected with or affected by HIV or AIDS. They could assist with memory work, support groups, transport, home visits and material donations. This could relieve the burden resting on the shoulders of Hospice T.L.C. caregivers.

6.4 Joint conclusions

- Caring for the T.L.C. caregivers is important to prevent burnout and compassion fatigue. It is important that they grasp the idea of the *Circles of support* (Smart, 2003:43) in order to understand that the total responsibility of meeting the bio-psychosocial needs of the families they deal with do not rest on their shoulders. They should utilize resources within the community. They need the opportunity to vent their feelings and debrief and experience support in their task of caring for families infected with or affected by HIV or AIDS.
- The overall conclusion would be that it is clear from the study that Hospice T.L.C. caregivers play an important role in identifying and taking care of the bio-psychosocial needs of families infected with or affected by HIV or AIDS. They also fulfil a vital role in identifying the main focus areas for services to them and bring them in contact with relevant resources within the community that could meet their needs. Hospice T.L.C. is a valuable resource within the community of Kokstad.

6.5 Testing of the central theoretical argument

Hospice T.L.C. caregivers play an important role in the lives of families infected with or affected by HIV or AIDS and make a contribution towards child and family care in the Kokstad area.

Through a critical investigation the role Hospice T.L.C. caregivers play in the lives of families infected with and affected by HIV or AIDS was explored. The bio-psychosocial needs of these families were identified in order to identify the main focus areas for service rendering.

It is clear that the role of Hospice T.L.C. is vitally important in identifying the needs of these families in order to address it through a holistic multi-disciplinary team effort. Through the results and conclusions of the research study the central theoretical argument was proved to be true.

7. RECOMMENDATIONS ARE MADE AT LOCAL, PROVINCIAL AND NATIONAL LEVELS

It is therefore recommended that:

7.1 Local level

- The Hospice T.L.C. caregivers receive ongoing training to enable them to do proper needs assessments for the families they deal with. They should become familiar with the contents of the assessment tool (Halkett, 2005:130,131) and the Circles of support (Smart, 2003:43) to be able to effectively address the bio-psychosocial needs of the families.
- Community leaders from schools, churches, government departments, NPOs and the health sector should co-operate in a forum. They could assist with preventive services and education of the community in order to prevent HIV-infection and de-stigmatisation.
- A visible service centre where some of the services rendered could be made available such as a soup kitchen, support groups, voluntary counselling and testing and social work services addressing the needs of OVC.
- Volunteers should be trained to assist with tasks such as support groups, memory work and material donations such as fundraising and food donations.

7.2 Local and Provincial Levels

- A forum consisting of members of a multi-disciplinary team able to address the bio-psychosocial needs of families infected with or affected by HIV or AIDS should be established to render holistic services.

7.3 On National, Provincial and Local Levels

- Communities should take ownership of the impact of HIV or AIDS on families infected with or affected by it and create a "safety net" for these families.
- Stakeholders rendering services to families infected with HIV or AIDS should have open communication channels between them. By joining hands in identifying the main focus areas for service delivery, the community will be strengthened and enabled to help itself.

8. FINAL CONCLUSION

In taking care of the needs of OVC within the community, partners need to be identified. Since the establishment of Hospice T.L.C., referrals of OVC to CWSA, Kokstad, had taken place. The researcher is employed by CWSA, Kokstad, and due to the great potential of partnering with Hospice T.L.C in meeting the needs of families infected with or affected by HIV or AIDS, the idea for this study took shape. The aim was to explore the role the Hospice T.L.C caregivers play in meeting the bio-psychosocial needs of families infected with or affected by HIV or AIDS. By doing this, the main focus areas for services could also be explored.

Due to the small sample used in this study, the results cannot be generalised to the whole of South Africa; therefore further research is needed. The aim is to strengthen the community by building a "safety net" through which the bio-psychosocial needs of the affected families could be effectively met and gaps in the system identified to prevent OVC falling through the cracks ending up in child-headed families or on the streets. HIV and AIDS have a devastating effect on communities, and capacity building within the community is very important. The efficiency of this "safety net" needs further exploration; therefore further research in this area is needed.

SECTION D :

ADDENDA

ADDENDUM 1

T.L.C. Home Services

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HOSPICE

25 Julie 2008

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Dr Herbst

TOESTEMMING VIR NAVORSING MET DIE OOG OP DIE INDIENING VAN N MA-VERHANDELING

Hiermee verleen ons toestemming dat Mev. Nerina Bester navorsing mag doen ten opsigte van die rol wat TLC HOSPICE vrywilligers doen binne die gemeenskap van Kokstad. Ons organisasie verlang dat dië basiese etiese riglyne wat deur ons gevolg word gedurende die studie gerespekteer word.

Die uwe

A handwritten signature in black ink, appearing to read "Teresa Olivier".

Teresa Olivier
Direkteur



**CHILD WELFARE
SOUTH AFRICA**

KOKSTAD
NPO Reg. No. 002/116

23 Julie 2008

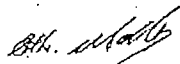
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Dr Herbst

TOESTEMMING VIR NAVORSING MET DIE OOG OP DIE INDIENING VAN 'N MA-YERHANDELING

Hiermee verleen ons toestemming dat Mev Nerina Bester navorsing mag doen ten opsigte van die rol wat TLC Hospice vrywilligers doen binne die gemeenskap van Kokstad. Ons organisasie verlang dat die basiese etiese riglyne wat deur ons gevolg word gedurende die studie gerespekteer word.

Die uwe


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ADDENDUM 3 : NWU ETHICS



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2009-10-31

ETHICS APPROVAL OF PROJECT

The North-West University Ethics Committee (NWU-EC) hereby approves your project as indicated below. This implies that the NWU-EC grants its permission that, provided the special conditions specified below are met and pending any other authorisation that may be necessary, the project may be initiated, using the ethics number below.

Project title PSYCHOSOCIAL AND VALUE-BASED HIV AND AIDS PREVENTION AND INTERVENTION PROGRAMMES	
Ethics number:	N W U - 0 0 0 6 0 - 0 8 - A 1
Approval date: 1 September 2008	Expiry date: 30 August 2013

Special conditions of the approval (if any): None

General conditions:

While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, please note the following:

- The project leader (principle investigator) must report in the prescribed format to the NWU-EC:
 - annually (or as otherwise requested) on the progress of the project,
 - without any delay in case of any adverse event (or any matter that interrupts sound ethical principles) during the course of the project.
- The approval applies strictly to the protocol as stipulated in the application form. Would any changes to the protocol be deemed necessary during the course of the project, the project leader must apply for approval of these changes at the NWU-EC. Would there be deviated from the project protocol without the necessary approval of such changes, the ethics approval is immediately and automatically forfeited.
- The date of approval indicates the first date that the project may be started. Would the project have to continue after the expiry date, a new application must be made to the NWU-EC and new approval received before or on the expiry date.
- In the interest of ethical responsibility the NWU-EC retains the right to:
 - request access to any information or data at any time during the course or after completion of the project;
 - withdraw or postpone approval if:
 - any unethical principles or practices of the project are revealed or suspected,
 - it becomes apparent that any relevant information was withheld from the NWU-EC or that information has been false or misrepresented,
 - the required annual report and reporting of adverse events was not done timely and accurately,
 - new institutional rules, national legislation or international conventions deem it necessary.

The Ethics Committee would like to remain at your service as scientist and researcher, and wishes you well with your project. Please do not hesitate to contact the Ethics Committee for any further enquiries or requests for assistance.

Yours sincerely

Prof MMJ Lowes
(chair NWU Ethics Committee)

Prof HH Vorster
(Chairman: NWU Ethics Committee: Author)

ADDENDUM 4 :

EDITORIAL POLICY/REDAKSIONELE BELEID

The Journal publishes articles, book reviews and commentary on articles already published from any field of social work. Contributions may be written in English or Afrikaans. All articles should include an abstract in English of not more than 100 words. All contributions will be critically reviewed by at least two referees on whose advice contributions will be accepted or rejected by the editorial committee. All refereeing is strictly confidential. Manuscripts may be returned to the authors if extensive revision is required or if the style or presentation does not conform to the Journal practice. Articles of fewer than 2,000 words or more than 10,000 words are normally not considered for publication. Two copies of the manuscript as well as a diskette with the text, preferably in MS Windows should be submitted. Manuscripts should be typed in 12 pt Times Roman double-spaced on one side of A4 paper only. If possible the manuscript should be sent electronically to hsu@sun.ac.za. Use the Harvard system for references. Short references in the text: When word-for-word quotations, facts or arguments from other sources are cited, the surname(s) of the author(s), year of publication and page number(s) must appear in parenthesis in the text, e.g. "... (Berger, 1967:12). More details about sources referred to in the text should appear at the end of the manuscript under the caption "References". The sources must be arranged alphabetically according to the surnames of the authors. Note the use of capitals and punctuation marks in the following examples.

Die Tydskrif publiseer artikels, boekbesprekings en kommentaar op reeds gepubliseerde artikels uit enige gebied van die maatskaplike werk. Bydraes mag in Afrikaans of Engels geskryf word. Alle artikels moet vergesel wees van 'n Engelse opsomming van nie meer as 100 woorde nie. Alle bydraes sal krities deur ten minste twee keurders beoordeel word. Beoordeling is streng, vertroulik. Manuskripte sal na die outeurs teruggestuur word indien ingrypende hersiening vereis word of indien die styl nie ooreenstem met die tydskrif se standaard nie. Artikels van minder as 2,000 woorde of meer as 10,000 woorde sal normaalweg nie oorweeg word vir publikasie. 'n Disket met die teks, verkieslik in MS Windows, moet twee kopieë van die manuskrip vergesel. Manuskripte moet in 12 pt "Times Roman" dubbelspasiëring slegs op een kant van 'n A4 bladsy getik word. Indien enigsins moontlik moet die manuskrip ook per e-pos versend word aan hsu@sun.ac.za. Verwysings moet volgens die Harvard-stelsel geskied. Verwysings in die teks: Wanneer woordelike sitate, feite of argumente uit ander bronne gesitueer word, moet die van(ne) van die outeur(s), jaar van publikasie, en bladsynommers tussen hakies in die teks verskyn, bv. "... (Berger, 1967:12). Meer besonderhede omtrent bronne moet alfabeties volgens die vanne van die outeurs aan die einde van die manuskrip onder die opskrif "Bibliografie" verskyn. Let op die gebruik van hoofletters en leestekens by die volgende voorbeelde.

TWO AUTHORS/TWEE OUTEURS: SHEAFOR, B.W. & JENKINS, L.E. 1982. *Quality field instruction in social work*. Program Development and Maintenance. New York: Longman.

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ADDENDUM 5

Aim: To evaluate the quality of service rendering by the T.L.C. Hospice

Questionnaire regarding the needs of families:

1. Name of respondent (optional)

2. Age: _____ Language: _____
3. Highest level of education

4. Relationship to patient treated by caregiver of T.L.C. Hospice

5. What would you consider to be the biggest need of your family?

6. In which way do the T.L.C. caregivers help you the most?

7. What more could they do to help you?

8. Where do they fail to help you?

9. With what do you battle the most?

Thank you for your cooperation.

Mrs. N. Bester
Social Worker
Child Welfare SA, Kokstad

SECTION E :

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