

**Patients' experience of and attitudes towards care in a lay caregiver run
institution—Tumelong Hospice, Winterveldt**

By

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ABSTRACT

TITLE: Patients' experiences of and attitudes towards care in a lay caregiver run institution – Tumelong Hospice, Winterveldt

Introduction

As the South African AIDS epidemic grows alarmingly, different approaches are being tried to develop effective and appropriate palliative care for terminally ill people in situations of poverty. Home based care is often not adequate for various reasons. The Tumelong Hospice in Winterveldt, North West Province, South Africa, is a residential care backup for a home based care program. It is unique in that it is run by a staff of lay caregivers trained in basic palliative care with the support of one professional nurse and a visiting doctor.

Justification for Study

The hospice has experienced criticism from some professionals who feel that lay caregivers are not able to run a residential hospice service. Past experience in Winterveldt has shown that lay caregivers can deliver good care with appropriate training and backup support. A literature review revealed that little research has been done in palliative care in Africa. The aim of the study was to determine patients' experience of care in the Tumelong Hospice, and whether the standard of care is acceptable to the people who utilise the service.

Methodology

A qualitative study with a small quantitative component was undertaken using semi-structured interviews of patients in the hospice. This was done by a social worker who was not associated with the service. Interviews were conducted in Tswana or Zulu, the main languages spoken in the area. 22 patients were interviewed over a period of five weeks. Patients were selected for interview by simple random sampling. Clear inclusion and exclusion criteria were employed. The interview attempted to assess patient satisfaction in the areas of basic nursing care, symptom control, emotional/spiritual support, understanding and explanation of illness, adequate addressing of concerns around family/social issues, and patients' attitudes towards members of the hospice team. A Likert satisfaction rating scale was employed and patients were also asked to describe one good experience and one bad experience in each area of care. Responses were classified into general themes and summarised. The findings were presented to a hospice patient not included in the study, and the interviewing social worker, to assess the credibility of the findings.

Findings

Patients rated their satisfaction with nursing and medical care as very high. Attitudes towards the lay caregivers and the visiting doctor were very positive. Patients related many positive experiences of care. Patient satisfaction with emotional/spiritual support and assistance with family/social problems was equivocal. Most patients were unaware of the hospice social worker or visiting religious workers' roles. Several patients expressed unhappiness at inadequate explanation regarding their illness.

Conclusions

It was concluded that lay caregivers can provide care that is satisfactory to terminally ill patients in residential hospices in resource poor areas. The study highlighted the need for improvement in the areas of emotional/spiritual and family/social care of the patient. The study identified some aspects of African patients' experiences of AIDS. An in-depth exploration of these experiences could provide professional and lay carers with valuable information.

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CHAPTER 1

INTRODUCTION

1. Brief Background

As the South African AIDS epidemic grows alarmingly, different approaches are being tried to develop effective and appropriate palliative care for terminally ill people in situations of poverty. Many authorities believe that home based care is the solution (United Nations Programme on HIV / AIDS 2000). In practice however, many people do not receive adequate care at home. Existing home based care programmes find it difficult to ensure that patients are visited regularly because of increasing numbers of patients, and coverage is often limited to certain areas (Jackson and Kerkhoven 1995:663-673). Home care may sometimes mean home neglect, especially if no fit carer is available at home, if patients live alone, or are homeless. Even supportive families may be unable to cope with distressing symptoms, and need respite care. In response to this, the Tumelong Hospice in Winterveldt, North West Province, was opened in 1999, as a residential care backup for the Winterveldt home based care programme.

Winterveldt is a sprawling informal peri-urban settlement of +-213 000 people (1997 estimate, Mvula Trust), situated 45 kilometres northwest of Pretoria. Formerly part of the homeland of Bophuthatswana, Winterveldt now falls within North West Province, but technically spans the municipal boundary of Greater Pretoria (Tshwane Metropolitan Council). A participatory needs survey conducted in 1997 by local non-governmental organisations (NGOs) and The African Medical Research Foundation (AMREF) (AMREF 1997) revealed the typical characteristics of a very poor

community. The unemployment rate was estimated at 40 – 50 %; for 34 % of households the main income source was a pension or disability grant received by a family member. The education level was low: 18 % of adults had no formal schooling, while 30 % had an educational level between grade 1 and grade 6 (six years or less of formal schooling). Water supply consists of public standpipes at 100 m intervals, obtained by a pre-paid card system. Most houses do not have electricity; paraffin or coal stoves are the main cooking and heating sources. The ethnic background of Winterveldt residents is very varied – nine of South Africa's official languages have substantial representation. Almost 100 % of residents are classified as Black African (a very small number classify themselves as Coloured). The predominant languages spoken are xiTsonga (24 % of households), sePedi (20%) and seTswana (12%).

The health facilities in Winterveldt consist of three public service (government-run) health clinics (one of which is a 24 hour community health centre) and four NGO (church run) There is an extensive home based care network for terminally ill people run by the NGO's (currently visiting 255 patients; 41 patients have died since January 2002) (personal communication with Ms. Christinah Khoza-Winterveldt home based care programme, August 2002). The HIV prevalence for the area is estimated at 24 % according to the most recent national HIV prevalence survey statistics (assessed by anonymous ante-natal screening) [remove number here] (National Department of Health, Directorate: Health Systems Research, Research Coordination & Epidemiology 2001). Local NGO's, however, have found a prevalence of 29 % at three voluntary counselling and testing centres (personal communication with Ms. M. Mahlangu, Winterveldt Prevention of Mother to Child Transmission Programme, August 2002).

The Tumelong Hospice in Winterveldt, was opened in response to the growing number of terminally ill people being seen at local clinics. A home based care programme, under the auspices of Tumelong Mission (affiliated to the Pretoria Diocese of the Anglican Church) had been in existence for 3 years. The supervisors of the home care programme were finding that increasing numbers of patients were dying without adequate care at home – in some cases single men migrant workers, some single women being cared for by their children, or in many cases patients with families who for various reasons felt they were unable to care for their relative at home.

It was decided to staff the hospice with lay health workers trained in hospice care. This was decided for two reasons: (1) community health workers had already been running a home based care programme very well and this would enable more capacity building within the community; and (2) given a very limited budget, the organisation would not be able to afford salaries for professional nurses.

The present staffing of the hospice is as follows:

- 32-bed in-patient facility (2 general wards, one with 14 beds for women and the other with 9 beds for men, one single room and 8 cots for children).
- 22 lay caregivers (all trained in basic palliative care) supervised by 2 senior caregivers; 5 caregivers on duty during the day and 3 at night
- 1 social worker (family support and assistance with welfare issues)
- 1 cleaner and 1 gardener/maintenance person
- 1 professional nurse (responsible for training and supervision), 1 visiting doctor (the author) (sees all new patients within two to three days of admission, sees all patients once a week, and is on call for any problems)

- visiting clergy

The care offered by the hospice includes basic nursing care, symptom control using the same medications available in community level hospitals (excluding intravenous or intramuscular therapies), emotional and spiritual support of patients and their families, and includes ongoing support of orphans. Because lay health workers run the hospice and the doctor works voluntarily, operating costs are much lower than facilities that employ professional nurses. Currently (2002), the running costs are R59 per bed per day. Since its inception, the hospice has cared for 663 patients to date. On average there are 20 inpatients in the hospice, with nine admissions, six deaths and three discharges per week. Patients who have been admitted for respite care or control of distressing symptoms are discharged after two weeks. This is done only if their general condition has improved sufficiently for them to remain out of bed for a few hours per day, if they wish to go home and if they have a willing caregiver at home. 90% of patients have AIDS; the remaining 10% almost all have cancers (a very small number suffer from other terminal medical conditions e.g., cardiomyopathy). With the exception of one patient over the last three years, all the patients are black Africans.

2. The importance and relevance of this research

Hospices are traditionally run by nurses and doctors, usually in first world environments (Hospice Association of South Africa 1996). In South Africa, in resource poor environments, palliative care is usually confined to home based care or hospitals. Hospices have been viewed as expensive and elitist as they are usually situated in wealthy previously 'white areas' (Hospice Association of South Africa membership list (Hospice Association of South Africa 1996). In Zimbabwe (Jackson and Kerkhoven 1995:663-673), residential hospices have been rejected by some

organisations because the running costs are felt to be unsustainable, and fears that only a few would benefit at the expense of home based care programmes. The Tumelong Hospice has experienced criticism from some professionals (personal communication) who feel that lay caregivers are not able to give adequate care to terminally ill patients. The Tumelong experience to date has been that lay caregivers can deliver good care with appropriate training and backup support.

A review of the literature since 1985 revealed two areas of interest relevant to this study: (1) the role of residential hospice care in the African context; and (2) assessment of patient satisfaction in a hospice setting.

There is a dearth of information concerning residential hospice care in Africa. There are several relevant studies assessing patient satisfaction in a hospice setting in developed countries; these will be discussed further in the literature review.

3. Aim of the Study

The aim of the study was to determine patients' experience of care in the Tumelong Hospice, and whether the standard of care is acceptable to the people who make use of the service.

4. Objectives

4.1 To understand patients' experiences of being cared for in the Tumelong Hospice, with particular reference to:

- nursing care/care of basic physical needs
- symptom control
- emotional and spiritual support
- understanding of diagnosis and information about the illness

- adequate addressing of patients' concerns around family and social issues

4.2 To understand patients' attitudes towards and experiences of the staff who care for them, specifically:

- the lay care givers
- the visiting medical doctor
- visiting clergy
- hospice social worker
- auxiliary and domestic staff

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CHAPTER 2

LITERATURE REVIEW

1. Role of hospice in Africa

As the AIDS epidemic grows in South Africa, home based care has been promoted as the mainstay of care for terminally ill people (United Nations Programme on HIV / AIDS 2000); however, it has its limits. In the experience of Winterveldt, many people with AIDS live alone, especially migrant workers (usually young men from rural areas). Even patients who live with family members or other full time caregivers often do not receive adequate care (Jackson and Kerkhoven 1995:663-673). This may be because of burnout on the part of the primary caregiver because of other demands on the family (work, school, etc.) or because the symptoms of the patient have become too distressing for the caregiver to cope with, especially in the terminal stages of illness (Van Dyk 2001:327-334). Volunteer caregivers who support the family often cannot visit frequently enough to significantly relieve the burden (Jackson and Kerkhoven 1995:663-673). It is therefore necessary that palliative care provided by residential hospices and related institutions be acknowledged as an important part of a comprehensive AIDS care network (Jackson and Kerkhoven 1995:663-673). In a developing world context like South Africa, the traditional Western concept of a hospice has to be modified to reduce the risk of hospice being an elitist, expensive and unsustainable institution. A survey of the literature since 1985 revealed only two references to hospice care in Africa (Jackson and Kerkhoven 1995:663-673 ; Merriman 1993:23-24). Jackson and Kerkhoven (1995:663-673) describe the Mashambanzou respite centre and hospice ward in

Zimbabwe. The centre successfully runs a residential unit, which is well utilised. Good symptom control and emotional and spiritual support are provided. Problems experienced include a high demand on the service resulting in destitute patients (who cannot pay) being turned away. The running costs of the centre were acknowledged to be high and possibly unsustainable (although not explicitly stated, the centre seems to charge fees). This would make it inaccessible to people without medical aid or other form of medical insurance.

Merriman (1993:23-24) describes the experience of Hospice Africa in Kampala, Uganda, which focuses on home based care. Even well known palliative care centres like Mildmay International, also in Kampala, offer out-patient care and day care for children, but no residential hospice care (personal communication on a visit-September 2001).

Both articles seem to view existing hospice care as essentially nurse run, with the use of lay people as auxiliary staff. South Africa has to date followed the international trend of utilising professional nurses to provide hospice care (emphasised by the guidelines of the Hospice Association of South Africa) (Hospice Association of South Africa 1996), although the professional nurse is supported by enrolled (two-year programme) nurses and lay care givers.

Jackson and Kerkhoven (1995:663-673) have suggested an alternative to the traditional hospice residential facility. This is the community care centre, which would be a low technology facility based within a village or township. The community centre would be developed and controlled by home based care services themselves, would need to utilise volunteer labour to avoid the costs of professional staffing, and should have strict admission criteria. Centres should not aim to replicate hospital facilities, but provide basic palliative care and good nutrition in a supportive

environment. Centres could widen their scope of practice to include non-HIV related services. Such centres are still in the planning stage in Zimbabwe (and the deterioration of the Zimbabwean economy in 2002 makes them a remote possibility). All of these principles have been implemented in the Tumelong Hospice, however. The Tumelong Hospice therefore seems to be unique in having a hospice (or community care centre) essentially run by trained lay caregivers, with the backup of a professional nurse and a doctor.

2. Assessment of patient satisfaction in a hospice setting

All the studies assessing patient satisfaction in hospices from 1984 to the present took place in developed world settings. (Studies that were accessible through the South African University library system were read. Abstracts of several other studies not directly accessible were read using the Pub Med Internet search tool.) Measurement of patient satisfaction is done by patient questionnaire or interview (Merriman, 1993:23-24, Van Dyk 2001:327-334, Webb 1997:39-46). Patient-completed questionnaires assume universal literacy and a common language in the patient population. In a patient population like that of Winterveldt, the rate of illiteracy approaches 50% (African Medical Research Foundation 1997). Winterveldt residents belong to two main language groups, but five other groups are significantly represented. Patient questionnaires therefore would not be appropriate for this population.

The use of face-to-face interviews using a standardised questionnaire is also frequently employed to ascertain patient satisfaction (Hohl 1994:52-54, McDonald 1998:S123-S135). This has the advantage of 100% participation (assuming informed patient consent) and the opportunity to clarify any unclear responses.

Various instruments have been employed in an attempt to objectively measure patient satisfaction and experience of care. In a large hospital-based study in Ohio, United States of America, Webb (1997:39-46) utilised the Risser Patient Satisfaction Scale, which contains three subsections:

- technical – professional (measures technical activities and care)
- trusting relationship (measures aspects of communication and interaction)
- education relationship (the nurse’s ability to communicate information to patients about their care)

The instrument contains a 5 point Likert scale, ranging from “strongly disagree” to “strongly agree”.

The results showed a statistically significant difference in patient satisfaction among patients with a non-HIV related medical problem compared to patients with an HIV/AIDS related illness. The study also showed clear differences in the attitudes of nurses caring for these two groups.

McDonald (1998:S123-S135) utilised a similar instrument, but encouraged the patient to make further comments in addition to the scale. The study showed differences in preference for models of palliative care between different groups of patients in St. Thomas’ Hospital in London. Homosexual white male patients had a clear preference for dedicated HIV/AIDS care facilities, while heterosexual patients of Afro-Caribbean descent preferred hospital care because of the perceived stigma of AIDS care facilities. Patients were not universally satisfied with the care they received.

Ng & von Gunten (1998:307-316), in a study amongst hospice patients and family members in Chicago, United States of America, used a simplified Likert scale, asking patients to describe their feelings as positive, OK or negative. He further added open

ended questions on why they chose hospice care, the biggest difference between hospice and hospital care and their impressions of the best and the worst aspect of hospice care. The study showed a strongly favourable impression of hospice care. Patients showed most satisfaction with the nursing care received. 50% of patients found no faults at all with hospice care, while 21% cited communication errors and 17% room/logistical problems as negative aspects of their experience.

Assessment of patients' symptomatology is a common aspect of patient satisfaction surveys (Webb 1997:39-46, McDonald 1998:S123-S135) In the above study, Ng & von Gunten (1998:307-316) utilised a survey instrument that asked the patient to describe their main complaint in their own words, followed by a list of symptoms to which they were asked to respond. This highlighted symptoms, which may not always be raised if patients are asked generally about their symptomatology.

Several authors have raised the concern that some population sub-groups seem to be less critical of their care than others (McDonald 1998:S123-S135, Ng 1998:307-316, Webb 1997:39-46). A common theme seems to be that people of Afro-Caribbean, African-American or Hispanic decent were less critical of their care than Caucasians. Reasons given for this were possible lower education (and therefore less awareness of their options) and marginalisation by society (resulting in "not wanting to rock the boat" type sentiments). This finding was of significance to the study, as all the patients come from situations of dire poverty, deprivation and poor education.

Exclusion criteria are an important issue when considering interviews with dying patients. Several authors have mentioned this (Ng & von Gunten 1998:307-316, Webb 1997:39-46). Patients judged by nursing staff as suffering from clouded consciousness (dementia, delirium or stages of coma) are obviously excluded from being interviewed. In addition, patients with severe pain (or other severe symptoms)

at the time of interview are also usually excluded. This introduces potential bias in that patients with poorly controlled symptoms (and therefore presumed dissatisfaction with care) are excluded.

A systematic literature review of patient and carer satisfaction with palliative care by Wilkinson, Salisbury, Bosanquet et al. (a team of palliative care/health policy researchers in the United Kingdom) was performed in 1999 (1999:197-216). The review covered 83 papers relating to specialised models of palliative care assessing consumer satisfaction, opinion and preference between 1979 and 1999 in the international literature. Research findings from North America did not reveal any reliable or consistent trends, due mainly to methodological flaws in the research. In the United Kingdom, consumers were found to be more satisfied with all models of palliative care (whether residential hospice-based or home-based), than with palliative care provided by general hospitals. Although research findings consistently indicated that patients appreciated the caring environment in hospices, a criticism was that research was based on small-scale local studies, which focused on a single hospice. It was stated by the reviewers that there is a need for high quality, comprehensive research to clearly document consumer preferences.

It is evident from the literature review that local studies need to be done to determine the types of hospice care that should be offered in South Africa, particularly in rural areas. This study is useful as it offers information about Tumelong Hospice as a possible alternative approach to palliative medicine.

CHAPTER 3

METHODOLOGY

1. Introduction

1.1 Aim of the Study

The aim of the study is to determine patients' experience of care in the Tumelong Hospice, and whether the standard of care is acceptable to the people who make use of the service.

1.2 Objectives

1.2.1 To understand patients' experiences of being cared for in the Tumelong Hospice, with particular reference to:

- nursing care/care of basic physical needs
- symptom control
- emotional and spiritual support
- understanding of diagnosis and information about the illness
- adequate addressing of patients' concerns around family and social issues

1.2.2 To understand patients' attitudes towards and experiences of the staff who care for them, specifically:

- the lay care givers
- the visiting medical doctor
- visiting clergy

- hospice social worker
- auxiliary and domestic staff

1.3 Choice of Research Design

A qualitative research design (with a small quantitative element) was chosen as the most appropriate way to develop an understanding of people's experiences and attitudes. This allows the research question[s] to be broad, and allows for participants to respond in depth. Semi-structured patient interviews in the hospice were chosen as the method for collection of data. A Likert scale was used to assist the patients in rating their experiences.

1.4 The Research Process

1.4.1 Problem statement

Tumelong hospice has been providing residential care to patients since 1999. No formal evaluation of patient satisfaction has been performed to date. Some problems with patient care have been encountered in the past, which were resolved by the senior hospice caregivers as they arose. The findings of this study will provide a baseline measurement of patient satisfaction, against which future changes and developments in patient care will be measured.

1.4.2 Selection of interviewer

It was felt appropriate that patient interviews should be performed by an interviewer with no links to the hospice (this obviously excluded the author, as the visiting doctor). It was anticipated that this would allow patients to express their feelings candidly during the interview. The hospice staff requested the assistance of a respected social worker in the Winterveldt area. A locally educated black South

African, who works for an organisation known as People Against Abuse, she specialises in counselling sexually and physically abused women and children. It was felt that her expertise would be valuable, given the sensitive nature of interviewing terminally ill people. She was also able to interview most patients in their home language (either Tswana or Zulu), which facilitated ease of expression.

1.5 Sampling selection

The study population consisted of all patients in the hospice (see inclusion and exclusion criteria). The interviewer was able to commit to interviewing patients for approximately four hours per week (Wednesday mornings). It was estimated that each interview would take about 45 minutes (on average interviews actually lasted 35-40 minutes), and that she would be able to complete four interviews in a morning. The sample size was projected to be about 25 patients due to limited numbers of patients meeting all criteria as well as time constraints (22 patients who met all criteria were interviewed). The interviews extended over a period of five weeks.

The criticism of small sample size mentioned in the literature review (Wilkinson 1999:197-216) is applicable to this study. It reflects the difficulties involved in finding large numbers of terminally ill people who meet the criteria for interview. Despite this shortcoming, the study is an audit of the care offered and therefore provides valuable feedback to staff.

1.6 Choice of Participants

1.6.1. Inclusion criteria

All inpatients over 18 years of age in the hospice were eligible for inclusion. Patients to be interviewed on a particular day were chosen by simple random sampling after the names of those who needed to be excluded (see below) were removed from the

pool of names. After the study was explained to patients, they were asked to give written permission to be interviewed (see Appendix 2). No patient refused to be interviewed.

1.6.2 Exclusion criteria

The following were excluded from the study:

- Any patient who refused to be interviewed or who felt too ill to be interviewed at that time. Should their condition have improved by the following week, they could be approached again. To try to avoid the potential bias of excluding patients with poorly controlled symptoms, we allowed the patient to decide whether their symptoms prevented them from being interviewed. If so, the patient was approached again at a later stage. If still not able to be interviewed, the patient was excluded from the study.
- All patients whose mental state prevented them from being able to participate in an interview (coma, semi-coma or mental confusion). Hospice staff assessed patients with regard to orientation for time, place and person and ability to respond to ordinary requests and questions observed during daily activities.
- All patients who had been in the hospice for less than 24 hours (considered to be too short a time to form an opinion). These patients would be eligible for interview in the following week.

On average, two patients per day were excluded from the study. In addition, five interviews were later terminated by the interviewer after assessment when it became clear that patients were confused or too ill to continue (four patients) or had been in the hospice for less than 24 hours (one patient).

1.7 Gaining access to the study population

1.7.1 Introduction of the study to hospice staff

The proposed study was introduced to all staff members of the hospice at the weekly management meeting. Staff members had previously expressed interest in some form of evaluation of the care they offer. The study was seen as an appropriate way of achieving this objective.

It was emphasised to all staff that although the objective would be to assess patient satisfaction, any negative findings would not jeopardise hospice staff members in any way. Staff members would not be referred to by name in interviews; this was to allay any fears of the study being a “witch hunt” to identify poorly performing staff members. Also, as patients’ names would not be recorded on interview schedules, any complaints or criticisms mentioned by patients would be anonymous.

2. Ethical considerations

The ethics of interviewing terminally ill people about their care is a difficult issue. However, this could possibly be justified by the intention of the study to help improve patient care in future.

2.1 Informed patient consent and confidentiality

All patients agreeing to be interviewed were asked to give written consent. The purpose of the study and all relevant information relating to the interview process were clearly explained in the patient’s home language. It was emphasised that anyone not wishing to be interviewed would not be prejudiced, or his/her care jeopardised in any way. It was also emphasised that their identity would remain completely anonymous and that confidentiality would be guaranteed by the interviewer.

2.2 Risks to subjects

No physical risk to the subjects was perceived. However, talking about emotionally sensitive issues is obviously difficult for many terminally ill people. As a trained social worker, the interviewer used her insight into whether an interviewee was becoming too distressed and was prepared to halt the interview if this was necessary (this was not necessary, however). Confidentiality was maintained and patients' names were not recorded on any documentation. Completed interview schedules were kept in a secure place by the interviewer and later discussed with the researcher.

2.3 Anticipated benefits to subjects

No direct benefits were envisioned for the subjects, although it may have been helpful for some patients to express their feelings and concerns to an outside interviewer.

2.4 Anticipated gain in knowledge

The insights gained in this study will help the hospice to gauge the level of patient satisfaction. In a broader context, this study may be of use in assessing whether lay caregivers can effectively run a residential palliative care program.

2.5 Use of transcribing equipment

No recording equipment was used in the study. Patients' responses were recorded on the interview form (see Appendix 1).

3. Collection of Data

3.1 Qualitative research interview

An interview schedule in English was developed by the author and the interviewer (see Appendix II). It was translated by the interviewer into Tswana and Zulu, the two most widely spoken languages in the hospice catchment area. Translation accuracy

was checked by going through each question individually and avoiding difficult terms. Each question was clarified with several practical examples. (For example, emotional and spiritual support was rendered as, “if you are very worried or thinking about things a lot, is there someone who you can talk to? If you want someone to pray with you, or read the scriptures to you is there someone who can do this?”)

The interview schedule was a slightly modified form of the Risser Patient Satisfaction Scale utilised by Webb (1997:39-46), which contains three subsections:

- -technical – professional (measures technical activities and care)
- -trusting relationship (measures aspects of communication and interaction)
- -education relationship (the nurse’s ability to communicate information to patients about their care)

The instrument contains a 5-point Likert scale (the quantitative component of the study), ranging from “strongly disagree” to “strongly agree”. The questions covered the following aspects:

- nursing care/care of basic physical needs
- symptom control
- emotional and spiritual support
- understanding their diagnosis and the course of their disease
- adequate addressing of concerns around family and social issues

patients’ attitudes towards various categories of staff (caregiver, doctor, chaplain, social worker, kitchen staff, etc.)

Patients were asked to rate their satisfaction using the Likert Satisfaction Scale (1 = very unhappy; 5 = very happy). As previously mentioned, several studies have shown that patients from economically disadvantaged backgrounds tend to be less critical of their care than middle-class patients (McDonald 1998:S123-S135, Ng 1998:307-316, Webb 1997:39-46). These findings are of relevance to this study as all the patients come from situations of dire poverty, deprivation and poor education. As an attempt to compensate for this, patients were also asked for a brief description of their best and worst experience in each of the areas covered in the interview.

As most patients were illiterate, the interviewer read the questions from the pre-printed form. Patients' responses were written in the spaces provided in the interview schedule. The written responses were read back to the interviewees to check for accuracy of transcription.

No patient required translation into another language (although hospice staff were available if this was needed). Patients were interviewed in a quiet room attached to the hospice office. If patients were unable to walk or sit in a wheelchair, they were interviewed in their beds with curtains pulled around the bed to ensure privacy.

3.2 Piloting the study

The interview schedule was piloted prior to the first interview. The names of all patients in the hospice (excluding those admitted in the previous twenty four hours) were put into a container, and four selected, under the supervision of the researcher. Their mental state was then assessed by the senior caregiver on duty. All were judged as fully able to answer questions. The purpose of the interviews was then explained to the patients by the senior caregiver. (Patients were told that a social worker would like to speak to them for half an hour about their experiences in the hospice.

Confidentiality and anonymity were stressed.) All agreed to be interviewed, and were asked to sign the consent form. Each patient was then taken individually by a caregiver to the interviewing room and introduced to the interviewer. The caregiver left them alone, and returned when called by the interviewer at the end of the interview. After four interviews had been completed, the responses recorded on the interview schedule were carefully reviewed by the researcher and the interviewer for possible ambiguities or misunderstandings. None were found. No problems were encountered with the sampling procedure other than the hospice staff being a little unsure about exclusion criteria. The criteria were reviewed with staff and the method of assessing mental state repeated until staff felt confident.

4. Data analysis

The patient satisfaction scores obtained using the Likert rating scale were presented graphically. Although yielding limited information (see discussion, *Limitations of study*), they gave a broad overview of patients' general feelings and attitudes towards their care and caregivers.

The data obtained in response to the semi-structured questions requesting patients to relate positive and negative experiences was analysed using the approach described by Marshall and Rossman (1989) cited by Poggenpoel (1998:334-357) as a guide.

The four stages of data analysis were as follows:

4.1 Generating categories, themes and patterns

As ten general categories had already been identified in the interview schedule, these were used as the basic outline. All the statements made by patients concerning a particular category (for example, Question One: 'Experience of nursing care') were written down in the interviewee's own words. Units of information were identified by

breaking sentences or ideas up into the smallest component of information. For example, Interview Two: Good experience: *“One day I was not full and I asked for more and I was given without any complaints. The treatment that we are receiving is much better than the one at the hospital.”* Two units were derived from this: *“One day I was not full and I asked for more and I was given without any complaints”* – this was sub-categorised under ‘Appreciation of assistance with activities of daily living.’ *“The treatment that we are receiving is much better than the one at hospital”* – this was sub-categorised under ‘Experience of hospice care was better than previous hospital/home care experience.’

4.2 Validating emerging themes

New units were compared to the other units in a category, to ascertain whether the new unit exhibited the properties of the category. For example, in Interview 15 *“When I was admitted here, I could not talk, so I was helped with so much patience”*- this had no connection with ‘Appreciation of assistance with activities of daily living,’ or ‘Experience of hospice care was better than previous hospital/home care.’

This unit was therefore allocated to a new category: ‘Attentiveness and patience were valued qualities.’ Thematic analysis such as this was used for all data, making inductive decisions about what each phrase meant and into which category it fitted best.

4.3 Searching for alternative explanations

Fewer new sub-categories were created as more and more data was processed. Some sub-categories became saturated and well defined. For example, ‘Appreciation of assistance with activities of daily living’ had three sub-categories in total: assistance with washing; assistance with going to the toilet; and assistance with feeding. As

patterns emerged in the data, assumptions were challenged. Other plausible explanations were sought for a particular phrase, linkages with other data were examined, and the most likely explanation selected. For example, in interview No.2, in response to the request to describe a positive experience related to medical care, the patient related the following incident: *"When I came here my bowels were loose and I had to be put in napkins. I felt that my dignity was being lowered and what would my children say when they saw me in napkins. I undressed myself and asked for a bedpan to be put next to my bed, so that I could help myself."* Although this would seem to be a negative experience, the patient reported it as positive. The statement was broken down into two units: *"I felt that my dignity was being lowered and what would my children say, etc."* was recorded as a negative experience under 'Loss of dignity,' while *"I undressed myself and asked for a bedpan to be put next to my bed so I could help myself"* was recorded as a positive experience under 'Patient autonomy respected.'

4.4 Report on the findings

A draft report was written after all data had been analysed. The themes were presented to the social worker who had conducted the interviews. She reviewed the rough notes outlining basic units and categories and concurred with the findings.

4.5 Validation

The findings were also presented to a patient in the hospice, Mr. P.K., who had been admitted a week after the data had been collected. He had previously been in the hospice for respite care several months before. He was selected because he was articulate and had been free to express himself concerning problems that he experienced with care.

He made several comments that gave insight into the study (for example, suggesting that the reason some patients may not be free to share about emotional and spiritual issues might be because of previous negative experiences at home or in hospital). He felt that the findings were a true reflection of his experiences in the hospice (see Appendix 3).

5. Scientific rigour of the study

Because qualitative research differs from quantitative research both in its methods and objectives, assessing the worth of a qualitative study requires using different criteria (Poggenpoel 1998:334-357).

Terms like reliability and validity are not very useful in assessing qualitative research. Guba's model of assessing trustworthiness in research was used in looking at the scientific rigour of the study.

5.1 Truth value

This assesses the level of confidence in the findings obtained from the subjects in the study. As the experiences of human beings are varied, the term 'credibility' is used here, as opposed to 'validity'. Truth value or credibility was assessed by testing the findings on Mr. P.K. (as he had shared the same experiences as the patients in the study).

The findings were also presented to the interviewing social worker, who had not been involved in the data analysis. This strategy is also known as 'triangulation' (Brink 1993:14-18).

5.2 Applicability

This refers to the extent that the findings can be applied to other contexts and settings (Poggenpoel 1998:334-357). Two aspects of applicability are of relevance in qualitative research:

5.2.1 Generalisability

This assesses how possible it is to generalise the findings to other populations (for example, other hospices in general). As the Tumelong Hospice serves a very specific community in a unique way, the generalisability is low.

5.2.2 Transferability

This relates to whether the findings fit into similar contexts outside the study situation. This study may be transferable to such situations as the previously described community centres in Zimbabwe, or to hospices serving poor communities in South Africa.

Lincoln and Guba (Poggenpoel 1998:334-357) also use the term “confirmability,” which combines the truth value and the applicability of a study.

5.3 Consistency/dependability

This considers whether the findings would be consistent if the study were replicated with the same subjects. (The concepts of repeatability and reliability are more of value in quantitative research, as people’s experiences are complex.) There may be ‘multiple realities’(Poggenpoel 1998:334-357); this concept makes credibility more difficult to assess.

During the preparation for the interviews, the interviewer was reminded of the differences between interviewing skills and counselling skills (specifically the

importance of accurate summarising and recording of information). Given her sensitivity and language skills, there are no indications that another appropriately qualified interviewer would have recorded different findings.

The method of recording all statements made by patients in response to each question avoided the bias of some information being accorded greater value by the interviewer. An attempt to minimise subjectivity in the data analysis was made by using the technique of bracketing assumptions (i.e. putting aside pre-existing beliefs concerning patients' experiences). This was difficult, especially during analysis of the negative comments concerning the infrequency of doctor's visits. The temptation to include an explanation in the findings of the study was resisted (but was mentioned in the discussion).

5.4 Neutrality/confirmability

This assesses the freedom from bias of the research procedure. In qualitative research, the aim is for the researcher to get as close to the subjects as possible—different to the 'objectivity' and distance of quantitative research. Lincoln and Guba (1981) cited by Poggenpoel (1998:334-357) suggest that rather than looking at the neutrality of the researcher, the neutrality of the data should be considered. They suggest that confirmability is the best criterion to assess neutrality. This is done by establishing truth value and applicability, which was attempted (as previously mentioned) by presenting the draft of the data analysis to a patient (Mr. P.K.) and the interviewer for their comments (see Appendix 3).

CHAPTER 4

FINDINGS

Section A of the interview schedule covered basic patient profile information portrayed below. Section B consisted of five questions, which dealt with the patient's overall experience of care. Section C consisted of five questions dealing with the patient's attitude towards staff. Each question consisted of two parts; part one consisted of the patient's level of satisfaction measured according to the Likert Satisfaction scale graded from 1 (very unhappy) to 5 (very happy). The findings are portrayed in graphic form and are presented after a summary of the responses given. Part two of each question described patients' positive and negative experiences of care in their own words. As previously described, the data has been analysed and presented in themes and sub-themes.

Section A. Patient Profile

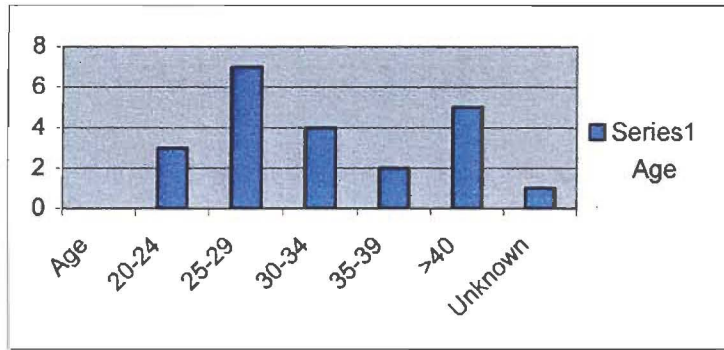
Twenty-two patients were interviewed over the five-week course of the study. The demographic profile was as follows:

1. Gender

Males	11
Females	11

2. Age:

<20	0
20-24	3
25-29	7
30-34	4
35-39	2
>40	5
Unknown	1



3. Diagnoses (according to patients' medical records)

TB	3
AIDS	14
Unknown	2
TB and AIDS	2
Pneumonia and AIDS	1

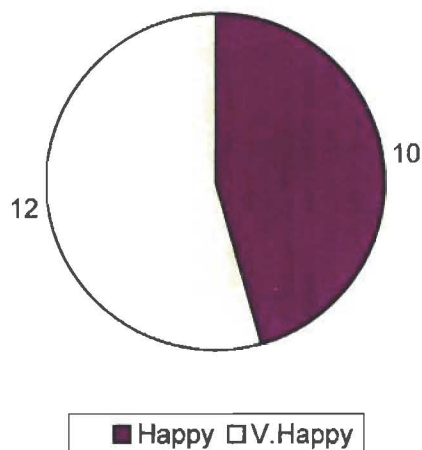
Section B. Patient's Experience of Care

A Likert Scale with five graded options was used for the rating of patient satisfaction. These varied from 1 (very unhappy) to 5 (very happy).

1. Patient's Experience of Nursing Care (Q1 of the Interview Schedule)

All patients felt happy or very happy with the care they received (see Fig. 1). Ten patients described themselves as happy and 12 as very happy with the nursing care.

Fig 1 Satisfaction with nursing care



Analysis of the positive and negative experiences related during the interview yielded the following themes:

1.1 Positive Experiences

Four main themes were identified concerning patients' experiences of nursing care. These were: appreciation of assistance with activities of daily living; hospice care experienced as better than previous hospital or home care; the value of attentiveness and patience observed in caregivers; and assistance with special needs.

1.1.1 Appreciation of assistance with activities of daily living

All patients related examples of assistance, which they appreciated. Three examples of the assistance which was most appreciated are described. Assistance with washing and bathing was the most common example given (9 patients). A typical response was "*They gladly assist me with washing.*" One patient was especially appreciative of the privacy afforded by being last to be bathed, as she was older than the other patients and felt uncomfortable sharing the bathroom with them.

Assistance with going to the toilet was described by six patients. Three patients noted specifically that there was always someone there to help; one noted that even late at night assistance was available.

Four patients mentioned help with feeding as an example of assistance. Apart from the practical assistance, two patients appreciated that they were able to change their minds about what they requested, or ask for more food (i.e., their autonomy was respected)

1.1.2 Hospice care was considered better than previous hospital/home care experiences.

Three patients noted that the care at the hospice was better than that which they had received at home. An example from one interviewee was, "*I cannot walk, so most of*

the time, I'm helped. Even at home, they cannot take care of you this way." For one patient however, the care was comparable to care received at home. Furthermore, two patients felt that the hospice care was better than at hospitals. *"The treatment we are receiving is much better than the one at hospital."*

1.1.3 Attentiveness and patience were valued qualities.

The patience of the caregivers was commented on by two patients. *"When I was admitted here, I could not talk, so I was helped with so much patience."* Rapid response to requests for help was mentioned. *"When I want help with going to the toilet, I will easily get help without any delays."*

1.1.4 Assistance with special needs

Two patients noted that they were helped when they needed special assistance. For example, one patient stated, *"As you can see that I am very weak and I cannot do most of the things on my own, I'm helped with everything I need."* Three patients mentioned overall attention and care in Question 2 (experience of care for physical problems), although this relates more to nursing care than physical care.

1.2 Negative Experiences

Only two patients related negative experiences. Both were experiences of humiliation and a loss of dignity, which compounded the already distressing symptoms that they were experiencing.

1.2.1 Loss of dignity

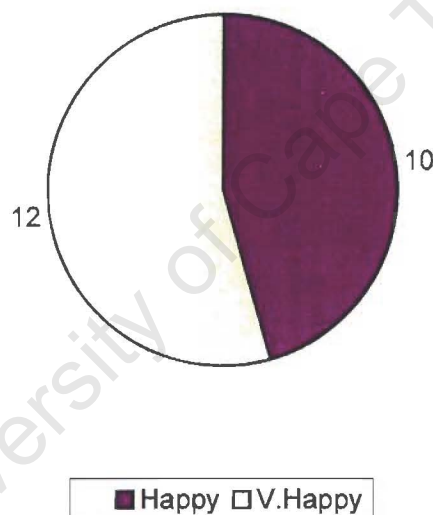
The negative experiences both related to the use of disposable incontinence napkins. A 38-year-old male patient stated, *"It's not something that is done by the caregivers, but I'm just not used to putting on the napkin. It's so uncomfortable and humiliating."* For a female patient, her sense of dignity was eroded by the smell of the soiled napkin. *"Sometimes I feel that my dignity is being put down when I soil*

myself. I hate these napkins and sometimes they take too long to come and change them and the smell is not nice.”

2. Patient’s Experience of Care of Physical Problems/Symptom Control (Q2 of Interview Schedule)

The responses to this question indicated that all patients were either happy or very happy (see Fig. 2). Ten patients described themselves as happy and 12 patients as very happy.

Fig 2 Satisfaction with care of physical problems/symptom control



2.1 Positive Experiences

Adequate control of pain was the symptom described most frequently by patients, although other symptoms like management of diarrhoea and vomiting, pruritis and mouth ulcers were also mentioned.

2.1.1 Prompt attention to reported pain.

Eight patients related experiences in which they had been in pain, requested help, and were helped immediately. This help usually related to prompt dispensing of

analgesics. For example: *“When I have pain, I always get medication on time.”* Only one patient specifically noted that analgesics were being given by the clock: *“I get pain pills always even without asking for them.”* (This should be the standard method of analgesia administration and will be discussed in chapter 5). One patient mentioned massage of painful muscles as being helpful.

2.1.2 Adequate management of diarrhoea and vomiting

Satisfactory management of vomiting was considered to be important in patient care. One patient noted, *“I stopped eating because I was vomiting. The caregivers talked to the doctor and changed my food and medicine.”* Two patients commented that bedclothes were changed promptly when they had vomited in bed. Three patients noted that after having diarrhoea, they also received prompt assistance in being cleaned and having bedclothes changed. Although this aspect appears to relate more to nursing care, it was seen as an important part of symptom management by the patients.

Other symptoms that were mentioned by patients as being important and adequately controlled included the control of pruritis related to chicken pox and treatment of mouth ulcers.

2.1.3 Assistance with walking/mobility

One patient ascribed his improvement in mobility to the treatment he received in the hospice. *“I was unable to walk when I came here, but now due to the love, care, and patience I received here, I am able to walk.”* Three patients mentioned that they appreciated the assistance they received with being wheeled in wheelchairs to watch television in the lounge. (This also relates more to care than to symptom control).

2.1.4 The importance of touch

A comment from one patient (a 25-year-old woman) related to the issue of stigma:

“Here they are treating my mouth sores so well and they are not even afraid to touch me.”

2.1.5 Patient autonomy respected by caregivers

The indignity of incontinence napkins was mentioned again by a 45-year-old woman:

“When I came here, my bowels were loose and I had to be put in napkins. I felt that my dignity was being lowered and what would my children say when they saw me in napkins? I undressed myself and asked for a bedpan to be put next to my bed so that I can help myself.” The patient regarded this as a positive experience, perhaps because she was able to take control of a difficult situation.

2.2 Negative Experiences

2.2.1 Constant/recurrent pain

Pain was part of a number of patients’ daily experiences. *“My feet are always aching,”* commented one patient. But the prompt response of caregivers was appreciated: *“I usually have terrible stomach pains, so each time I ask for help, I get it without delay...”* Another patient explained, *“You can call at any time of the night when you are in pain and they will help you.”*

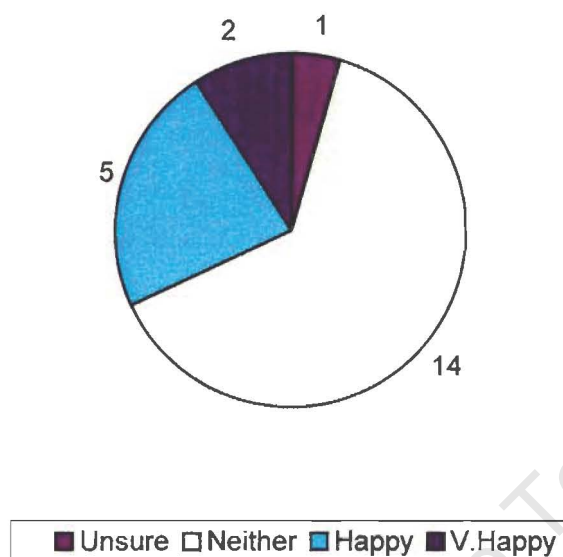
2.2.2 Loss of dignity

As mentioned above, the indignity of incontinence napkins was mentioned by one patient in this category, although it relates to nursing care.

3. Patient’s Experience of Emotional and Spiritual Support (Q3 of the Interview Schedule)

The majority of patients expressed themselves as neither happy nor unhappy (see Fig. 3). One patient was not sure; 14 were neither happy nor unhappy; 4 were happy; and 2 were very happy.

Fig 3 Satisfaction with emotional/spiritual support



The following themes were identified from the experiences described by patients:

3.1 Positive Experiences

All patients who described a positive experience used terms relating to comfort and support.

3.1.1 Comfort/support

Eight patients described experiences of comfort or support, usually in conversation with caregivers. One patient said, *"I worry a lot about my illness, so always I talk with the caregivers, who are always ready to listen and offer support."* Another said, *"Talking to caregivers is very comforting—they make you feel you are not alone in your troubles."* One patient mentioned that he usually spoke to other patients if he needed support.

3.2 Negative Experiences

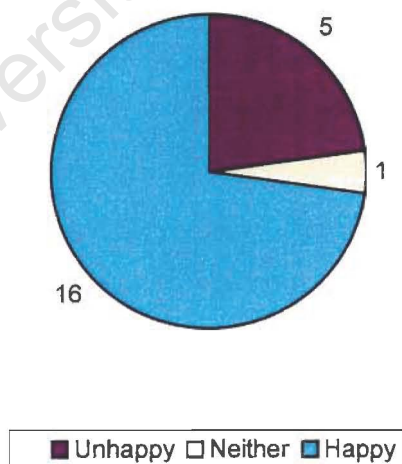
3.2.1 Busyness of the caregivers

Only one patient explicitly described a negative experience, related to perceived busyness of the caregivers. *“The caregivers are too busy and I do not want to disturb them. Most of the time we sit with them and watch TV and discuss TV stories.”* Eight patients volunteered that they preferred not to talk to someone else about personal issues and concerns. A typical response was: *“I feel that I do not feel like talking about my problems. It’s not yet time. Mostly we talk about social issues, not personal problems.”*

4. Satisfaction with Explanation about Sickness/Information Given by Staff (Q4 of Interview Schedule)

Most patients expressed themselves as happy with the explanation they had received from caregivers concerning their illness. Five patients however, described themselves as unhappy (see Fig 4).

Fig 4 Satisfaction with explanation about sickness/information given



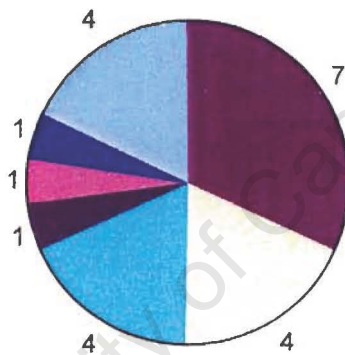
This question differed from the others as, rather than being asked to relate an experience, patients were specifically asked if they knew what was wrong with them.

The responses were as follows:

TB	7 patients
AIDS	4 patients
HIV	4 patients
HIV/AIDS	1 patient
Problems with the brain affecting my legs	1 patient
Chest problems and bedsores	1 patient
No idea	4 patients

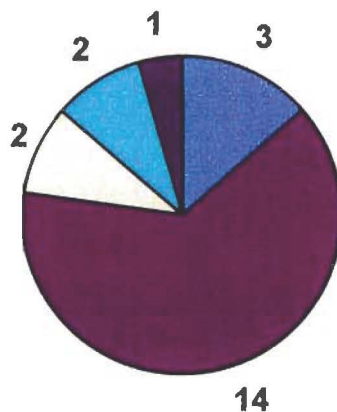
These answers contrast with the diagnoses noted on patients' files. Compared to the 17 patients who, according to diagnosis had an AIDS related illness, only 9 patients reported an AIDS-related diagnosis (see Patient Profile).

Diagnosis according to patient



■ Patients' Perceived Diagnosis ■ TB □ AIDS ■ HIV ■ HIV/AIDS ■ Brain problem ■ Chest problem/bedsores ■ No idea

Diagnoses (according to patients' medical records)



■ TB ■ AIDS □ Unknown ■ TB+AIDS ■ Pneumonia+AIDS

Analysis of the answers showed that all the patients who described themselves as happy with the explanation they had received knew what their diagnosis was. Of the five patients who described themselves as unhappy with the explanation received, four had no idea what was wrong with them. One patient stated, *“No one has ever told me what is wrong with me. I have been to so many places and no one has bothered to tell me my sickness.”*

5. Experience of Assistance with Family and Social Problems (Q5 of Interview Schedule)

The responses to this question showed a large majority of patients (19) selected “neither happy nor unhappy.” Only 3 patients felt happy with their experience (see Fig. 5).

5.1 Positive Experiences

Only two patients mentioned examples of assistance with family or social problems from caregivers.

5.1.1 Practical assistance

One patient felt happy about his experience because the hospice staff had made arrangements with his family for someone to look after him at home, allowing him to be discharged for a short time. Another patient appreciated being given a food parcel to take home whenever he went to visit his family for weekends.

5.1.2 Advice

One patient mentioned that he had been anxious about his property being left unattended. The caregiver had given helpful advice to find someone to look after his things.

5.1.3 Support from visiting family members

Five patients mentioned that they preferred to talk to visiting family members about family/social problems.

5.2 Negative Experiences

Two patients expressed negative feelings about the care they had received. One patient noted that she did not know whom to talk to. *"I have no parents. They have passed away a long time ago. I worry about where I will go when I leave this place. But often I do not talk to anyone, as I do not know who to talk to, as I've only been here for two months."* Another noted, *"I don't talk although I worry about my child—people would just listen and do nothing."* Six patients commented in similar terms that they preferred not to discuss family/social problems with other people. A typical response was *"I hardly talk about personal problems—I keep them to myself."* The reasons for this were not explored in the interview schedule (possible explanations are discussed in Chapter 5).

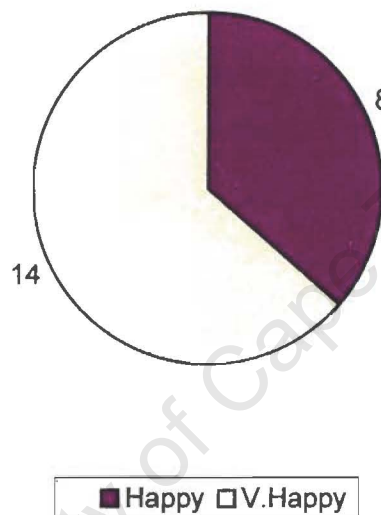
Section C. Attitudes towards Staff in the Hospice

Section C attempted to explain patients' attitudes towards staff members involved in delivering care. In the first part of each question, patients were asked to rate their general feelings towards a category of staff, using the Likert Scale as before. In the second part, rather than describing an experience of care, they were asked to describe one positive and one negative attribute of the staff members. Concrete examples were sought in an attempt to better understand patients' attitudes. There seems to be general satisfaction with the lay caregivers, the doctor, and the auxiliary staff. Attitudes are less positive towards the social worker and the religious workers, with the majority of patients not knowing who these people are.

1. Attitudes towards Lay Caregivers (Q6 of Interview Schedule)

Patients were asked how they felt about the lay caregivers. 8 patients rated themselves as happy in their attitude towards the lay caregivers and 14 patients as very happy.

Fig 6 Attitude towards caregivers



1.1 Positive Attributes

Positive attributes described related to perceptions of a caring attitude of the caregivers; helpfulness, patience and gentleness were all mentioned.

1.1.1 Helpfulness

Six patients mentioned helpfulness as a positive attribute of lay caregivers, for example, *"They are nice people—always there to help us."*

1.1.2 Patience

Eleven patients noted that caregivers are patient or have time for them. An example of this was in Interview no. 3: *"They are patient and understanding. They are so*

different from the staff of the hospitals I have been to. They have all the time in the world to help us.”

1.1.3 Love/Gentleness/Warmth

These attributes were mentioned by 9 patients. One patient commented *“They are very good people. They treat us with love and respect. They have even helped me to accept my illness because of the way they treat us.”* One patient was clearly touched by the welcome she received. *“The first time I came to the hospice, my family and I were warmly welcomed. I will always remember the love and patience shown.”*

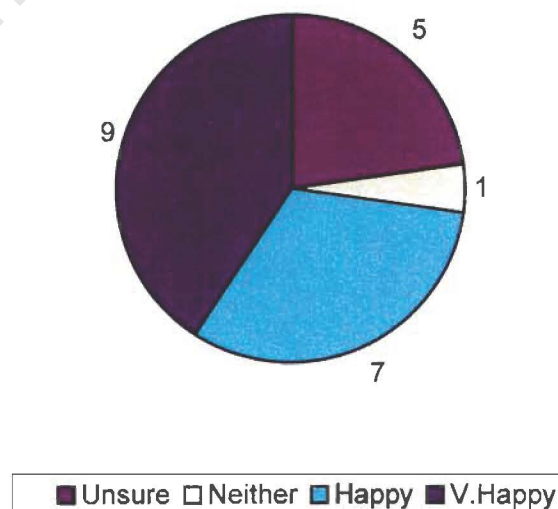
1.2 Negative Attributes

There were no negative experiences or attitudes recorded.

2. Attitude towards the Visiting Doctor (Q7 of Interview Schedule)

Satisfaction with the visiting doctor was generally high, although 5 patients felt they couldn't comment because they had not met the doctor yet. Seven patients rated their experiences as good and 9 patients as very good (see Fig. 7).

Fig 7 Attitude towards doctor



Analysis of patients' statements regarding the doctor yielded the following main themes:

2.1 Positive Attributes

Patients commented on aspects of the doctor / patient relationship such as listening skills, language and communication issues, and careful attention to medical problems.

2.1.1 Listening skills/patience/time spent with patients

Six patients were appreciative of various aspects of the above attributes. Statements like *"He always has time for us, he is always ready to listen"* occurred several times.

2.1.2 Language/communication issues

Five patients mentioned being able to speak to the doctor in their own language. They felt this made it easier to express themselves and increased mutual understanding. For example, *"It's always nice to talk to him in seTswana, as you do not have to struggle to express yourself in a foreign language. It makes talking to him so easy."*

2.1.3 Respect/care/helpfulness/comfort

Two patients mentioned that they felt the doctor treated them with respect. *"He treats us so well. He does not look down on us because he is white. I have never seen a doctor who treats people so well."* Three patients mentioned helpfulness and care as part of their experience, for example, *"He is always ready to help."* One patient noted *"He is always there to comfort us."* Friendliness was also noted as an attribute.

2.1.4 Satisfaction with management of medical problems

Three patients expressed satisfaction with the medical management they had experienced. Aspects mentioned included changing of medication, controlling symptoms, and taking note of complaints, for example, *"One day I felt sick and my whole body was painful. The doctor was willing to change my medication."*

2.1.5 Assistance with problems at home

One patient noted, “You can tell him about problems at home and he will help.”

2.2 Negative Attribute

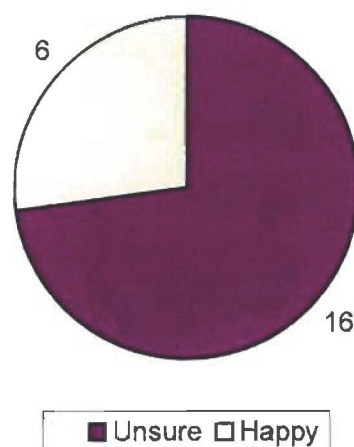
A negative attribute mentioned by several patients was that the visiting doctor seemed to lack time. Patients expressed feelings of disappointment and frustration.

Six patients related negative attitudes, all related either to not yet having seen the doctor (patients who had been in the hospice for less than three days) or to having seen the doctor only once. For example, “I have not seen the doctor since being here. Maybe it’s because I’ve not been here long.” Another patient said, “The only thing is we don’t see him often. He only comes sometimes.” All five of these patients accounted for the relatively high number of “neither happy nor unhappy” responses recorded using the Likert Scale.

3. Attitude towards Visiting Religious Workers/Ministers (Q8 of Interview Schedule)

A large number of patients (16) felt they could not comment on their attitude towards the religious workers because they had never met them. Those who had met them were all happy (6 patients).

Fig 8 Attitude towards visiting religious workers/ministers



3.1 Positive Attributes

Support and encouragement, the feeling of being loved, accepted and listened to were valued by patients. The six patients who were able to comment mentioned three general areas:

3.1.1 Support and encouragement

All 6 patients mentioned this as an important aspect. *“I asked her to pray for me and also to read the Bible—I felt warm inside. Her prayers made me feel strong.”*

3.1.2 Love

Two patients mentioned that they feel loved by the visiting Catholic nun. One patient stated: *“She loves us very much. She brings us flowers and teaches us to sing and pray.”*

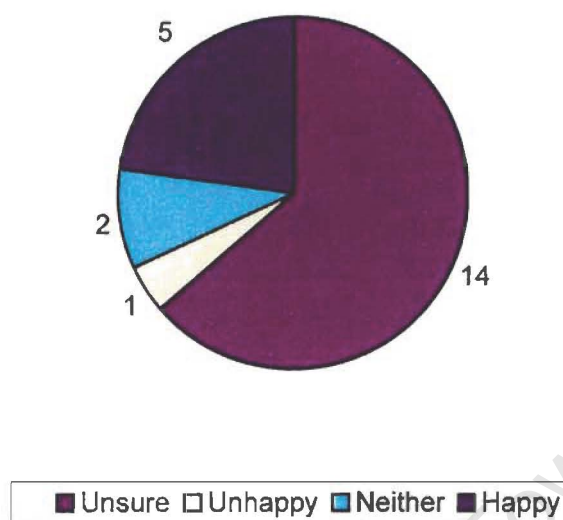
3.1.3 Listening

One patient mentioned that she valued being listened to. *“She is always ready to listen with a smile.”*

4. Attitude towards the Social Worker (Q9 of Interview Schedule)

Patients' responses to this question were similar to the rating of the visiting religious workers. Most patients (14) had never met her and so could not comment. Those who had met her were generally happy (5), although one patient (4,5 percent) was unhappy and 2 were neither happy nor unhappy.

Fig 9 Attitude towards social worker



4.1 Positive Attributes

The patients who felt they could comment described two closely related areas: helpfulness and patience/kindness.

4.1.1 Helpfulness

Four patients mentioned different ways in which they had experienced the social worker's helpfulness in administrative issues. *"She was just fine in helping with my pension grant forms."*

4.1.2 Patience/kindness

Three patients mentioned that they had experienced her as patient or kind. *"She was so approachable. She was the one who came to collect me at home to bring me to the hospice."*

4.2 Negative Attributes

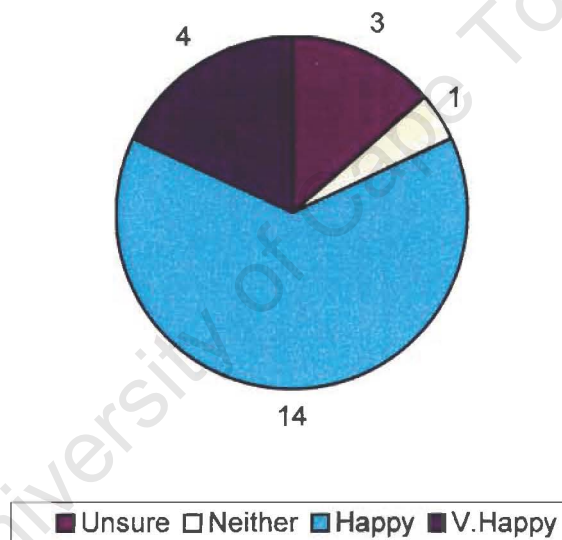
Two patients mentioned negative attributes, both related to the perception of the social worker nor having enough time to spend with them. Frustration and

disappointment seemed to be expressed by the following statement, *“I wanted to talk to her about some personal problems; it seemed as if she was in a hurry and did not have time to talk. She said she would get back to me, but she never did.”*

5. Attitude towards Auxiliary Staff (Q10 in Interview Schedule)

Patients’ attitudes towards auxiliary staff (the two cook / cleaners and the gardener) were positive overall. Four were very happy; 14 were happy; one was neither happy nor unhappy; and 3 did not know (because they had not yet met the auxiliary staff).

Fig 10 Attitude towards domestic staff



5.1 Positive Attributes

Valued attributes were helpfulness, kindness (one cook in particular was mentioned by several patients) and efficiency.

5.1.1 Helpfulness

Ten patients gave examples of ways in which the auxiliary staff had been helpful. For example, *“The gardener is always willing to help—we send him to buy stuff at the shop and he won’t complain.”*

5.1.2 Kindness

Eight patients gave examples of kindness that they had experienced. For example,

“They are always treating us well. The cook that works during the week tells us not to be afraid to ask for some more food and the one who works on Saturdays always asks us one by one if we are okay with the food that is being prepared.”

5.1.3 Efficient service

Three patients commented on the fact that the hospice is always clean and that they enjoy the food.

5.2 Negative Attributes

One patient reported that she had experienced rudeness from one of the cook/cleaners.

She described her experience as follows: *“One day I had a phone call and as I was passing through, one of the ladies who is cleaning was very rude to me and made a rude comment.”*

6. Summary of Findings

Patient satisfaction with the lay caregivers, the doctor, and the auxiliary staff was in general reported as happy or very happy. Patients noted many caring attributes displayed by these staff members. Frustration and disappointment at the infrequency of doctor's visits were expressed by some. The majority of patients were unable to comment on their attitudes toward the social worker and visiting religious worker because they had never met them. Experiences of emotional/spiritual care and assistance with family/social problems were positive where patients felt able to comment, but frustration and disappointment were also expressed in several interviews. The majority describing themselves as neither happy nor unhappy with their care in these areas reflected the undecided feelings of patients.

7. Conclusion

The lay caregivers of Tumelong hospice are capable of delivering care that is satisfactory to their patients. The areas of emotional/spiritual support and family/social care need improvement.

University of Cape Town

CHAPTER 5

DISCUSSION OF FINDINGS

In broad terms, the study showed a high level of patient satisfaction with the nursing care and the lay caregivers in the Tumelong hospice. There was also a high level of satisfaction with the care of physical problems and symptom control and a generally positive attitude towards the visiting doctor. The patients' satisfaction with explanation and information about their illness was also generally high. However, the fact that four of the study's twenty-two patients stated that they had no idea what was wrong with them was of concern to the author, who as the visiting doctor shares the responsibility of relating this information to patients (see later discussion: *Explanation and information about illness*).

Attitudes toward the social worker and visiting religious worker were less positive, with most patients stating that they had never even met them. Reported levels of satisfaction with the emotional/spiritual care and assistance with family/social problems reflected this, with most patients indicating neutral feelings about their care in this area.

1. Nursing care and lay caregivers

The high levels of satisfaction expressed confirm that care given by non-professionals is acceptable to patients in the Tumelong hospice. This finding is summarized by the comment, "The help that we are getting is very good. I cannot recall anything that did not please me." This finding however may be related to the previously mentioned concern raised by several researchers (Hohl 1994:52-54, Merriman 1993:23-24, Webb 1997:39-46) that patients from marginalized communities tend to be less critical of their care. Hohl (1994:52-54) noted that health care providers and researchers have

stressed that patient-rated satisfaction scales generally yield high scores and may not represent useful feedback. Given the dissatisfaction expressed by many patients regarding their emotional/spiritual care and management of family/social problems, it would seem that the patients interviewed were able to express criticism freely. Their expressed satisfaction therefore appears to be credible. This, however, does not apply to patients who had not met certain caregivers (social worker and visiting religious workers). The effect of vulnerability should also be considered, as patients may be less likely to express dissatisfaction with the caregivers upon whom they are most dependent.

A few patients reported overall positive experiences of hospice care compared to home care through statements such as "*Even at home, they cannot take care of you this way,*" and, "*The treatment we are receiving is much better than the one at home.*" Several patients' reported positive experiences were clearly informed by their previous negative experiences in hospital or at home. As mentioned in Chapter Three, home based care often fails patients for reasons such as caregiver fatigue, lack of a continuous caregiver, or flaws in the system meant to support home care (Jackson and Kerkhoven 1995:663-673). This does not invalidate their praise of hospice care, but rather highlights the shortcomings of other components of the health system. Other studies have mentioned patient dissatisfaction with hospital based palliative care; Hohl (1994:52-54) notes that hospice nurses tend to be more empathetic than hospital nurses. Ng and von Gunten 1998:307-316) concluded that hospice care in general was perceived by their patients to be better than hospital care. Webb, Bower and Gill (1997:39-46) noted that hospitalised AIDS patients were less satisfied with their nursing care than were patients with other medical diagnoses.

An area of concern highlighted by the study is the use of disposable incontinence napkins. Patients described them as being "*uncomfortable and humiliating,*" with one adding, "*I feel that my dignity is being put down...*" This perceived loss of dignity adds insult to injury for patients already struggling with the stigma of AIDS. This concern will be discussed with all members of the hospice team and clear guidelines for napkin use will be drawn up. Even if patients are incontinent and bedridden, their explicit consent will be sought in the future before they are used. No conclusion can be drawn from this study as to whether the level of care offered in the Tumelong hospice complies with the standards laid down by the Hospice Association of South Africa (Hospice Association of South Africa 1996). However, a recent visit by a HASA delegation produced very positive feedback on their impressions (personal communication with Ms. Barbara Campbell-Ker of the Houghton Hospice). This still needs to be quantified, and a formal assessment by an objective assessor is planned. Hohl (1994:52-54) has suggested that patient satisfaction is an important prerequisite for delivering quality care. This is especially important in a hospice situation, as the usual ways of objectively measuring quality of care (patient outcome criteria like recovery, short duration of stay, etc.) are less suitable for palliative care than for other fields of medicine.

The overall impression gained is a 'vote of confidence' in the lay caregivers. Important qualities in caregivers, such as helpfulness, patience, warmth and compassion, were clearly identified by patients. This feedback is useful for staff appraisal and development.

2. Medical care/symptom control

Patients reported a high level of satisfaction with the management of physical problems and symptom control. The aspects indicated by patients as important and well-managed include pain control, management of diarrhoea and vomiting, mouth ulcers, pruritus and issues related to mobility. However, a number of patients reported the presence of recurrent pain, and this indicates the need for improvement in the area of pain control. It also appears that not all patients in the study received analgesia 'by the clock'—one of the basic principles of analgesic use in palliative care (Twycross 1997:24-25). The administration of analgesia and management of pain in the hospice will be reviewed at a general staff hospice meeting in the near future.

The attitude towards the visiting doctor was generally positive. Issues around communication were highlighted and the study found that the patients' responses to his communication were favourable. Cross-cultural communication was an important aspect mentioned by patients. The positive comments regarding the importance of doctors speaking the home language of patients is confirmed by Jack, Penny and Nazar (2001:375-380), who draw attention to the barriers that language can present to satisfactory palliative care.

Patients identified several attributes of the doctor, which they considered important—good listening skills, patience, respect, helpfulness, involvement in family issues and attention to symptom control. McWhinney (1989:118-124) outlines the patient-centred clinical method, which has become a central principle in the discipline of family medicine. According to this teaching, the physician attaches equal importance to following the traditional medical agenda and understanding the meaning the illness has for the patient. This involves understanding the patient's expectations, fears and

feelings. The author has found these principles to be personally useful in the practice of palliative medicine.

The importance of touch mentioned by one patient emphasizes the need for patients to feel accepted by others. *"Here they are treating my mouth sores so well, and they are not even afraid to touch me."* The stigma related to AIDS is still widespread in the communities surrounding the hospice. (Personal communication with Ms. Christina Khoza, Winterveldt home based care programme, August, 2002). Touch has been emphasized during caregivers' training as a practical way of removing this stigma. The dissatisfaction raised by patients who had not yet been seen by the doctor is a cause for concern. Since the doctor only visits the hospice twice per week, some patients may have been in the hospice for two to three days before being seen. In the case of an urgent problem, caregivers can call for assistance at any time, but the majority of patients are put on a standard regime for the management of AIDS related conditions until being seen by the doctor. Attempts are being made to get another doctor involved in the hospice to improve coverage. However, this is very difficult, as it would have to be on a voluntary basis due to lack of funds.

3. Emotional and spiritual support

The findings suggest that emotional and spiritual support for patients is unsatisfactory. Many patients said that they preferred not to talk about personal issues. This is of concern, as sharing of emotional and spiritual problems is fundamental to coping with terminal illness, and AIDS in particular (Jackson and Kerkhoven 1995:663-673). The reasons for the lack of willingness to share problems are not clear, but may relate to the busyness of the caregivers and the infrequency of the visits by the religious workers. *"The caregivers are too busy and I do not want to disturb them..."* The large number of patients who had never met a religious worker could be explained by

the fact that the Catholic nun who usually visits the hospice had handed over to a young theological student for a few weeks. Because this student also worked as a caregiver, it is possible that patients did not identify her as a religious worker. As this coincided with the period of the study, it may have affected the accuracy of the assessment.

4. Family/social issues

It would appear from the study findings that these issues are not always addressed. Six patients commented that they preferred not to discuss family/social problems with others. Cultural beliefs could play a role in this, as many people believe that the discussion of taboo subjects such as death, illness and suffering may be a self-fulfilling prophecy (personal communication with Ms. Christina Khoza). Another possible factor is natural reticence. Furthermore, patients who might otherwise be more willing to discuss their concerns may refrain due to a lack of trust or faith in the caregivers. *"I don't talk, although I worry about my child—people would just listen and do nothing."*

The fact that fourteen patients said they had never met the social worker is also cause for concern. It is clear that the current system is inadequate. Presently, caregivers seek the social worker's assistance only when *they* consider it necessary.

Consequently, some patients' needs may be neglected. The hospice staff needs to consider ways of improving this. An option which could be considered is to inform all patients and families on admission about the social worker, and to ask her to introduce herself to all new patients two to three days of admission.

5. Explanation and information about illness

The general impression is that patients were satisfied with the information they had been given. It is clear however, that not all patients received an adequate explanation of their illness, as four were unfamiliar with their diagnosis. The differences between diagnosis as reported by patients and as recorded in the hospice notes also confirm a need for improved communication. Although 17 patients were diagnosed with AIDS related illnesses according to the notes, only nine reported their illness as being HIV or AIDS related. Furthermore, seven patients thought they had TB, while only three were diagnosed as having TB in the notes. This discrepancy is not a surprising finding however, as disclosure of diagnosis is well-known to be difficult for many patients (Jackson and Kerkhoven 1995:663-673) and has been experienced by many of the staff members working in the Tumelong home based care programme (personal communication with Ms. Christina Khoza, (August 2002).

6. Limitations of the study

6.1 Shortcomings of the interview schedule

6.1.1 Interpretation of Likert Scale

Using a Likert Scale to assess patient satisfaction proved to be problematic in several ways. Especially with regard to attitudes towards the social worker and the religious workers, it was difficult to know whether a response such as 'I don't know the person' indicated dissatisfaction, neutrality, or did not belong on the Likert Scale at all. The patients' attitudes had to be deduced from the positive and negative experiences that were described, and this may have resulted in incorrect assumptions.

6.1.2 Use of a scale with patients from a non-literate culture

Rating scales for investigating the experience and needs of patients from non-literate cultures is considered to be inappropriate by McDonald, Free, Ross et al. (1998:S123-S135). The use of focus groups and a narrative method may be a more appropriate method, as it allows expression unhindered by the documentation process.

6.1.3 Restrictiveness of semi-structured interview

Although the use of a semi-structured interview had several advantages (easier analysis of data under headings; easier recording of data than free ranging tape recorded interviews, which would need many hours of transcribing), it may have resulted in some experiences and feelings related to the findings being omitted. For example, patients sometimes openly express distress at the death of fellow patients in the hospice. However, since this distress was not specifically addressed by the questionnaire, it was not noted in any of the patients' responses.

Some patients being cared for at home have resisted admission (personal communication with Ms. Christina Khoza, August 2002) to the hospice because it is perceived as a sign that death is imminent (even though many patients admitted for respite care are discharged again). The interview did not address feelings about hospice as an institution, nor did it explore any issues or feelings about death and dying (although this is not directly related to satisfaction with patient care).

6.2 Sample size

The small sample size of the study is a result of time constraints. The social worker who performed the interviews was only able to spend one half day per week at the hospice. As the study also had to be limited to five weeks due to various logistical factors, only 22 patients were interviewed. Although qualitative research does not require large samples, a general principle is that the data should continue to be

collected until the researcher determines that no new information is being obtained, i.e. saturation has been reached and the theory is well-integrated (Brink 1993:14-18). A clear saturation point was not reached in this study. The previously mentioned systematic literature review by Wilkinson, Salisbury, Bosanquet et al. (1999:197-216) lists small sample size as a criticism of almost all studies of patient satisfaction in hospices.

7. Implications for Tumelong Hospice

The findings of the study will be presented to all hospice staff for discussion. The affirmation received in areas relating to nursing care and medical care will undoubtedly be an encouragement to all staff. The areas needing improvement—social/family support and spiritual/emotional support—will need to be discussed by the social worker, the visiting religious workers, the caregivers and the doctor.

Practical measures previously discussed will be implemented (clear policy on use of napkins; introduction of social worker and religious workers upon admission; increased attention to spiritual/emotional support by lay caregivers; and ongoing attempts to recruit another doctor). Careful noting of patients' awareness of diagnosis upon admission to the hospice will be facilitated by requesting the admitting caregiver to specifically document each patient's understanding of his/her illness. Patients expressing unawareness of their diagnosis will receive extra care.

8. Recommendations

8.1 Reproducing the Tumelong Hospice model in other areas

The findings of this study show that lay caregivers can provide satisfactory care to terminally ill patients in resource-poor areas. This should serve as an encouragement to organizations in similar areas who are considering opening a back-up support

system to home based care programmes, but cannot afford the salaries of professional nurses. Careful selection of the caregiver team and ongoing training are very important. The support of volunteer professional staff is important and may not always be available in other communities. The dispensing and administration of medication by non-professional staff is controversial. However, the Tumelong hospice only makes use of medications that patients receive from state hospitals for home based care. No intravenous or intramuscular medication is prescribed. For example, morphine is only given in liquid oral form of low concentration. Thus the potential for incorrect or inappropriate use of medication is minimized.

8.2 Further exploration of African patients' experiences of terminal illness, especially due to AIDS

The literature review revealed very little documentation of patients' experiences of AIDS in Africa. The interviews touched on several aspects such as loss of dignity, stigma and interaction with caregivers. Many of the comments were moving and offered a glimpse into the experiences of people living and dying with AIDS. An in-depth study would offer valuable insight into this subject. Further research into the personal experiences of living with HIV/AIDS and the care required for terminally ill patients would inform health professionals and lay caregivers of patients' felt needs and concerns.

9. Conclusion

Patients at Tumelong hospice are satisfied with the nursing and medical care they received. For some patients the experience was profound: *"I was unable to walk when I came here, but now due to the love, care, and patience I received here, I am able to walk."* The average of twelve patients who are discharged from the hospice each month bears testimony to the fact that in many cases hospice care restores the

health of patients and is not only concerned with the process of dying. The areas of emotional/spiritual support and family/social care need to be improved so that comments such as, *“Talking to caregivers is very comforting—they make you feel you are not alone in your troubles”* will become true for all patients.

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APPENDIX 1

INTERVIEW SCHEDULE

Section A (Demographic details)

1. Gender
2. Age (from patient's bed letter)
3. Diagnosis (from patient's bed letter)

Section B (Patient's experience of care)

1. How do you feel about the nursing care here? (For example, assistance with washing, going to the toilet, food / feeding, changing the bedclothes).
Are you:
(1) Very unhappy (2) Unhappy (3) Neither happy nor unhappy (4) Happy
(5) Very happy
Could you tell me one good experience you have?
Could you tell me one bad experience you have had?
2. How do you feel about the care of your physical problems caused by your sickness? (For example things like pain, vomiting, diarrhoea, sores on the body, chest or breathing problems, weakness, loss of appetite etc).
Are you:
(1) Very unhappy (2) Unhappy (3) Neither happy nor unhappy (4) Happy
(5) Very happy
Could you tell me one good experience you have had?
Could you tell me one bad experience you have had?
3. How do you feel about the emotional and spiritual support you receive? (For example, if you are very worried or thinking about things a lot, is there someone you can talk to. If you want someone to pray with you or read the scriptures to you, is there someone who can do this?)
Are you:
(1) Very unhappy (2) Unhappy (3) Neither happy nor unhappy (4) Happy
(5) Very happy
Could you tell me one good experience you have had?
Could you tell me one bad experience you have had?
4. How do you feel about the explanation you have received about your sickness and the information the staff have given you?
Are you:
(1) Very unhappy (2) Unhappy (3) Neither happy nor unhappy (4) Happy
(5) Very happy
Could you tell me what is wrong with you?

5. How do you feel about the way the staff have helped you with problems at home, work, or any other problem area? (For example, worries about children, your partner, other family members, work or salary issues, lack of money at home etc).

Are you:

- (1) Very unhappy (2) Unhappy (3) Neither happy nor unhappy (4) Happy
(5) Very happy

Could you tell me one good experience you have had?

Could you tell me one bad experience you have had?

Section C (Attitude towards staff in the hospice)

1. How do you feel about the caregivers that look after you?

Are you:

- (1) Very unhappy (2) Unhappy (3) Neither happy nor unhappy (4) happy
(5) Very happy

Could you tell me one good experience you have had?

Could you tell me one bad experience you have had?

2. How do you feel about the visiting medical doctor?

Are you:

- (1) Very unhappy (2) Unhappy (3) Neither happy nor unhappy (4) Happy
(5) Very happy

Could you tell me one good experience you have had?

Could you tell me one bad experience you have had?

3. How do you feel about the visiting Catholic sister or other ministers?

Are you:

- (1) Very unhappy (2) Unhappy (3) Neither happy nor unhappy (4) Happy
(5) Very happy

Could you tell me one good experience you have had?

Could you tell me one bad experience you have had?

4. How do you feel about the hospice social worker?

Are you:

- (1) Very unhappy (2) Unhappy (3) Neither happy nor unhappy (4) Happy
(5) Very happy

Could you tell me one good experience you have had?

Could you tell me one bad experience you have?

5. How do you feel about the domestic staff (the cook, the gardener and maintenance people)?

Are you:

- (1) Very unhappy (2) Unhappy (3) Neither happy nor unhappy (4) Happy
(5) Very happy

Could you tell me one good experience you have had?

Could you tell me one bad experience you have had?

APPENDIX 2

CONSENT FORM

I, _____ (name and surname), agree to be interviewed in the Tumelong Hospice by Thabang Mogabe. She will write down my answers. The interview will be anonymous (my name will not be written down). I may end the interview at any time if I wish to. Whether I agree to be interviewed or not will not affect the care I receive at the Hospice.

Signature _____ Date _____

Witness _____

University of Cape Town

APPENDIX 3
COMMENTS BY MR. P.K. ON DATA ANALYSIS

Question 1 (Nursing Care):

Agrees with what the patients say. The hospice has improved a lot since last year. There are no problems now with response to ringing of bells.

The care in the hospice is definitely better than at home. The hospital is very bad—there is no care there.

Patience and attentiveness of the caregivers is noticeable. P.K. has watched the caregivers dealing with mentally confused patients—they are gentle.

Use of napkins—doesn't seem to be a problem, as they only put them on very weak, bedridden patients. He has never used one.

Question 2 (Medical Care):

Feels much better after being here for 2 weeks.

Caregivers seem to give medicine regularly. Pain control seems adequate to him. Has not heard anyone crying or groaning in pain.

Question 3 (Emotional Support):

Thinks the reason why patients seem reluctant to talk about their personal problems and feelings is because HIV positive patients are often suspicious/fearful of sharing with others. J and C (2 caregivers) are especially good at supporting patients.

Question 4 (Satisfaction with information about illness):

Thinks the patients who don't know what is wrong with them is because many patients have not had an HIV test. Also many patients refuse testing or are in denial about the results.

Question 5 (Assistance with Social/Family Problems):

Patients need to be introduced to social worker. Her role needs to be better explained.

Question 6 (Attitude Towards Caregivers):

Caregivers are very good—agrees fully.

Question 7 (Attitude Towards Doctor):

Frustration about doctor not coming frequently enough. Suggests patients be told that the doctor comes on Tuesdays and Fridays only—takes away expectations of seeing a doctor daily.

Question 8 (Attitude Towards Visiting Religious Workers):

Has noticed that they seem to spend more time with very ill people near death. Likes church services in the hospice.

Question 9 (Attitude Towards Social Worker):

Thinks she should be introduced to patients upon admission.

Question 10 (Attitude Towards Domestic Staff):

Breakfast is served late—sometimes at 11:00—because of bathing, cleaning, etc. Thinks it should be served earlier.

QUESTIONNAIRE

Appendix 4

Section A (Demographic details)

- 1. Gender F
- 2. Age (from patient's bedletter) 31 yrs
- 3. Diagnosis (from the patient's bedletter) RETRO

SECTION B (Patient's experience of care)

1. HOW DO YOU FEEL ABOUT THE NURSING CARE HERE?

Very happy

Good experience: "Sometimes I become so sick that I cannot even wash myself. People are always willing to help. me."

Bad experience:

The interviewee did not have any comment.

2. HOW DO YOU FEEL ABOUT THE CARE OF YOUR PHYSICAL PROBLEMS CAUSED BY YOUR SICKNESS?

Very happy

Good experience: "Sometimes, I feel pain in my body and usually when I ask for help, I usually get it without any delays or rude comments."

Bad experience:

"There is no problem as far as I'm concerned"

3. HOW DO YOU FEEL ABOUT THE EMOTIONAL AND SPIRITUAL SUPPORT YOU RECEIVE?

Neither happy nor unhappy - "I keep things to myself most of the time."

Good experience:

The interviewee did not have anything to say.

Bad experience:

The interviewee did not have anything to say.

4. HOW DO YOU FEEL ABOUT THE EXPLANATION YOU HAVE RECEIVED ABOUT YOUR SICKNESS AND THE INFORMATION THE STAFF HAVE GIVEN YOU?

"They say that I have AIDS" - happy, because I have information about my illness.

5. HOW DO YOU FEEL ABOUT THE WAY THE STAFF HAVE HELPED YOU WITH PROBLEMS AT HOME, WORK OR ANY OTHER PROBLEM AREA?

Neither happy nor unhappy - "like I said, I usually don't like to talk."

Good experience:

The interviewee did not have anything to say.

Bad experience:

The interviewee did not have anything to say.

SECTION C
(ATTITUDE TOWARDS STAFF IN THE HOSPICE)

1. HOW DO YOU FEEL ABOUT THE CAREGIVERS THAT LOOK AFTER YOU?

Very happy

Good experience: "The care-givers are very warm people, always making an effort to spend time with us."

Bad experience:

The interviewee did not have anything to say.

2. HOW DO YOU FEEL ABOUT THE VISITING MEDICAL DOCTOR?

Happy

Good experience: "He had so much patience and also showed understanding of us as patients."

Bad experience:

"I've only once seen him twice and in all instances I was satisfied."

3. HOW DO YOU FEEL ABOUT THE VISITING CATHOLIC SISTER OR OTHER MINISTERS?

Neither happy nor unhappy. "I haven't seen them."

Good experience:

The interviewee did not have any comment.

Bad experience:

The interviewee did not have any comment.

4. HOW DO YOU FEEL ABOUT THE HOSPICE SOCIAL WORKER?

Happy

Good experience: "She was so approachable. She is the one who came to collect me at work to bring me at the Hospice"

Bad experience: "I don't think I can answer that because I have only seen her once."

5. HOW DO YOU FEEL ABOUT THE DOMESTIC STAFF?

Very Happy

Good experience: "They are very happy. I like the fact that they do not force you to eat things you do not want to."

Bad experience: "The interviewees did not have any comment."

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Appendix 5 Dr. Carpenter

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Research Ethics Committee
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20 May 2002

REC REF: 118/2002

Dr E Gwyther
Public Health

Dear Dr Gwyther

**PATIENTS' EXPERIENCE OF AND ATTITUDES TOWARDS CARE IN A LAY
CAREGIVER RUN INSTITUTION-TUMELONG HOSPICE, WINTERVELDT**

Thank you, for submitting your study to the Research Ethics Committee for review.

It is a pleasure to inform you that the Committee has formally approved your study.

Please quote the above Rec reference number in all correspondence.

Yours/sincerely

Signed by candidate

PROF. CR SWANEPOEL
CHAIRPERSON

copy sent to M... 13/6

FAX TO: S. Carpenter
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