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Chapter 1.

Introduction

1.1 Case Studies

On entering the room one is immediately aware of an atmosphere of fear and tension. An elderly woman lies in the bed, her body an emaciated shell. She looks deathly pale. Her breathing laboured. Despite tranquillising medication, her eyes are wide open; hardly blinking. The family are anxious, uncomfortable and wondering why she can't "let go". She has been like this for days... not eating... talking very little. She has seen all her family and they are all with her. All have said their goodbyes, settled all outstanding business and yet she is still here - suffering.

In another room, on another bed lies another elderly woman. She too, is pale and emaciated. Her eyes are closed, her breathing irregular and sighing. Her daughter is sitting at her side, holding her hand; her presence is soothing and calm. There is an atmosphere of peace and acceptance.

1.2 Palliative Care and Spirituality

Palliative care is the total active care of a patient with a life-threatening illness. It encompasses medical, psychosocial and spiritual care.¹ Good palliative care is not only effective control of physical symptoms or dealing only with psychosocial problems. Palliative care practitioners should also help their patients with spiritual distress. However the term spirituality is often misunderstood. Spirituality means a lot more than just religious affiliation, and often these two terms are used interchangeably. While spirituality may be expressed through religious practices, essentially it is who we are. Spirituality is an intangible part of us that cannot be grasped, and is very difficult to understand. We are all spiritual beings including those who profess to have no spiritual connection, if this is interpreted as religious connection and a belief in God.

The spiritual part of us looks for meaning in life. For each of us, that meaning is different. It is a yearning for something that is transcendent. The feelings elicited by this yearning are often difficult to explain, and spiritual distress may present as a feeling of dis-ease which is difficult to describe and is often misdiagnosed as depression. Puchalski says that “it is crucial to attend to the spiritual dimension of suffering, and it’s distinct from emotional suffering”.² She cites a case of a terminally ill woman diagnosed with depression who is not responding to treatment. On doing a spiritual enquiry, she discovered that the woman had lost her sense of purpose in life and was mostly concerned that her two year old would not remember her. Once these issues had been addressed adequately, the depression lifted with no further medication. There may be people who are healthy emotionally, yet there is a sense, that cannot be fully described, that “something is missing”, which is distressing. In healthy people not facing death, this feeling often leads to addictive or compulsive behaviours in their search to satisfy this “need”.

How many people who seem to “have it all” are still unhappy, still wanting more? It can be argued that, many of the societal ills these days are signs of spiritual distress. From the case cited by Puchalski, it can be seen that spirituality also encompasses relationships. This takes the form of the relationship that many have with God, or a higher being, or with the universe. Relationships with family and friends become very important. Many terminally ill patients wish to heal relationships before they die. Likewise the relationship with self is important and can lead to a lot of guilt and suffering and self recrimination. This suffering also needs to be addressed.

1.3 Suffering may be Spiritual

In the two cases studies described above, both patients had no physical pain. Their physical symptoms were controlled. Both patients were aware of how close to death they were. Both patients had made preparation for death in finalising and tying up all their “affairs”. Both were not alone, but surrounded

by loving family. Yet in the first room, there is the almost palpable pain of the first patient and in the second, the sense of calm and acceptance. The difference in these two cases is the spiritual preparation and spiritual care received by these patients.

Suffering is different to pain³. Physical pain can be affected by our emotional or physical state, and may not cause suffering *per se*. Consider an emotionally healthy woman in labour. She experiences immensely painful contractions, yet may not be suffering as she is supported through the pain. She also understands the meaning of the pain, being the birth of a beautiful, much anticipated baby. Imagine a woman in labour, giving birth to a baby known to have died *in utero*. Her pain is not just physical; it is total – physical, emotional and spiritual suffering. A patient who is terminally ill and is in pain is also suffering and the suffering will affect the experience of pain. When the physical pain is alleviated with medication, the patient may still be suffering; unless emotional pain, or depression, is addressed, together with the spiritual aspects. A patient in pain who has all these needs addressed may need less pain medication or sedation to control his symptoms. Doyle and Woodruff describe suffering as the distress associated with events that threaten the intactness, or wholeness, of the person. They describe multidisciplinary palliative care,⁴ as the appropriate response to suffering for patients with life-threatening illness, as illustrated in Table 1 below.

Table 1. Multiple Dimensions of Suffering and the Multidisciplinary Approach. (Doyle and Woodruff)

Suffering	Care
Pain	Treatment of pain
+ other physical symptoms	& other physical symptoms
+ psychological problems	& psychological problems
+ social difficulties	& social difficulties
+ cultural issues	& cultural issues
+ spiritual concerns	& spiritual concerns
= Total suffering	= Multidisciplinary Palliative Care

Spiritual or existential pain needs to be addressed as much as physical pain. In terms of palliative care, to omit spiritual care would be unethical. A doctor needs to be able to include a short spiritual assessment in the consultation and refer the patient to a spiritual counsellor as necessary. Such a referral is as important as any referral to other specialists, and failure to do so appropriately could be considered as negligent.⁵ A short, simple spiritual assessment tool, to be used as part of the patient history, would enable doctors to address this very important aspect of patient care.

To illustrate the importance of spiritual care in a situation of great suffering, we return to the patient described in the first paragraph of this introduction. The first patient, who was in such distress, was seen by the inpatient doctor. Her pain was so immense, that the spiritual distress was attended to, as a natural first priority, simply by sitting down and acknowledging the patient's emotional and spiritual suffering. After a simple spiritual enquiry, the doctor addressed the spiritual issues with a referral to an appropriate spiritual counsellor. The doctor was willing to be present to the patient in her pain,

sitting with her for a while as she slowly relaxed and fell asleep. No other intervention was required. She died peacefully later that day.

1.4 Doctors and Spiritual Care

Through both personal and professional experience, I have become increasingly aware of the need for spiritual care as an integral part of the care offered to patients. Unfortunately, the health profession generally falls short of addressing this need adequately probably because spiritual care is not seen as part of the doctor's role. I remember a lecturer at medical school once asking the class whether we felt medicine was a science, a trade or an art. The question was left unaddressed throughout our training. People talk about "the art of healing". This is the spiritual aspect of medicine. Many experienced doctors intuitively practise an "accompaniment" of patients through their suffering without recognising or naming this accompaniment as spiritual care.

Puchalski has stated that doctors enter the medical profession in answer to a call to serve humankind. Before the time of antibiotics and modern medicine, doctors had much less to offer in terms of medical cure but offered care through their presence and comforted the patients and their family in their time of suffering. With the advances in the technological aspects of medicine, the capacity for compassion and non medical care seems to have diminished.⁶ Possibly, in hospice care, with the medical options for physical cure exhausted it becomes easier to concentrate on spiritual aspects of care. In the face of seeming hopelessness, one still offers care looking for other sources of hope and healing.

There is an, often unrecognised, personal spiritual need on the part of the doctors to help others in alleviating suffering. We interpret this need in a physical sense of healing because of our physical being in a very physical world. Yet it is a response to a deeper spiritual need which we cannot fully grasp or explain so try to fulfil through a clinical approach. How many medical students start out with a passion for healing and end up disillusioned interns wondering why they chose to do medicine? They advise other aspiring doctors to reconsider their decision to enter the medical profession, often

saying with hindsight that they would choose another profession. It is no coincidence that many doctors enjoy creative activities or the outdoors in their spare time. These are spiritual practices. Many doctors are unaware of their spirituality, while they respond intuitively to another's pain. They just need guidance in recognising it and embracing the spiritual gift they have to heal others.

The importance of the spiritual dimension of care is being recognised and discussed in medical literature.⁷ Aspects of spirituality and pastoral, holistic care are increasingly being included in medical *curricula* in the USA⁶. Unfortunately, our current medical training does not recognise spirituality as a part of healing. Hence, this special, sensitive dimension in doctors is hidden under the burden of all the training and other responsibilities which accumulate with time. This dilemma is not restricted to the health profession. Doctors and priests respond to similar calls of healing, in different dimensions of total human care. Pastoral students feel called to fulfil a role in the priesthood, then become burdened by all the other non-spiritual responsibilities and lose touch with that initial spiritual desire to help others.

The training of medical students, of necessity, concentrates on the physical processes and treatment of human suffering. However, it neglects the spiritual dimension of healing, which should be incorporated into medical *curricula*. In the healing encounter, or consultation, there are various dimensions present. In addition to the physical presentation of illness, there is the spiritual healing capacity of the doctor, the spiritual inner healer of the patient, and the environment of the consultation, all of which contribute to the healing process.⁸ These dimensions may be unrecognised but are all important aspects of every patient-doctor interaction. With a simple, purely physical problem, such as a fractured limb or ear infection, physical treatment will cure the physical problem of the patient. However, in more complex presentations, especially where the patient may be struggling with the meaning of the illness, more than a simple physical remedy is required. The relationship between the patient and doctor becomes more important and will affect the healing that the

patient experiences. Spiritual care is about the relationship and availability⁷, of the doctor to the patient.

Doctors who only tend to the patient's physical needs may feel unfulfilled in their work and continue searching for that fulfilment in other, sometimes self destructive ways. They become disillusioned by their work and calling and are at risk of burn out. Doctors, who find meaning in their work, will find it satisfying. Many hospice doctors, seen to be doing gruelling work, do not burn out because of the relationships they establish with their patients. They also derive satisfaction from the sense of contributing to the patient's wholeness in alleviating total suffering. This is the call they responded to when they embarked on a medical career. Hospice doctors have a lot more support, through hospice care for the caregiver programmes. They are thus; more easily able to maintain a balance between the care they give others and the care they need themselves within the multidisciplinary environment.

1.5 Spiritual Care in Hospices

Hospices, where palliative care is practiced, were traditionally established as faith based establishments, from a spiritually motivated desire to alleviate suffering. Somehow the spiritual aspect of care became less important as we focussed more on physical and psychosocial interventions - and became very good at it. However, this need for more focus on spiritual care is being increasingly recognised within the hospice movement.⁹ It is not always easy to implement. Hospice staff acknowledges the need and enthusiastically support any suggestions to improve spiritual care, however the reality is that it is still not addressed adequately⁹. Spiritual care is talked about, but still tends to focus on the religious aspects of care. A spiritual assessment is included in the patient's history, but is often inadequate in terms of assessing true spiritual suffering. During a medical consultation, the recognition of true spiritual suffering requires some experience and intuition on the part of the doctor.

While in hospices, doctors are more aware of the spiritual dimension of care and may or may not address this aspect. Most doctors, in general, fail to enquire about their patient's spiritual needs. Many feel unqualified to discuss spirituality at any level and feel unprepared to answer any questions, which could arise from such a discussion. Others question the ethics of a spiritual enquiry, reflecting the societal norms and taboos. Spiritual care should be offered but never imposed. The doctor should be available to listen to and be present with the patient through illness and suffering; in addition to giving purely physical care. This does not mean that health professionals should assume any responsibility for giving any spiritual care that is beyond their capability. By being present and open to any spiritual suffering of the patient the doctor can identify an area of need and refer to the relevant pastoral or spiritual counsellor as required; as would happen with any medical condition that the doctor felt uncomfortable treating.

1.6 A Spiritual Assessment Tool as a means of Initiating Spiritual Care.

Doctors should be comfortable with providing a safe space for patients to discuss spiritual matters, without feeling pressured to have the answers. A spiritual assessment tool would help doctors to open up the discussion comfortably, and give patient's permission to talk about their needs. Spiritual care may merely be the means of establishing a good relationship with a patient such that the patient feels valued and understood as more than just a disease, and feels safe to discuss anything that is causing suffering. Such a view challenges the traditional perspective of the doctor's role, and may bring us back to the original intention of the healing profession.

This study was undertaken to evaluate a spiritual assessment tool, which could be used by doctors to include a spiritual enquiry in their consultation. The palliative care setting was chosen as the context for the study because of its heightened awareness of spirituality in care. Terminally ill patients usually become more aware of spirituality, and grow spiritually, as they progressively lose their physical and social functioning¹⁰. Their need to grapple with their

mortality and find closure and heal relationships because of their limited time all speeds up their individual spiritual growth journey; a path which we all travel at a varying pace and level of awareness. Savarimuthu Arockiam states, “The final act of dying is a maturing of self-realisation which embodies the results of what the individual has made of himself or herself during this life.”¹¹

1.7 Research Methods in the study of Spiritual Care

As spirituality is very personal and each experience is as unique as each individual, studies of these experiences are very difficult to quantify. Qualitative research is ideally suited to studying the lived experiences of people and exploring their thoughts and opinions.¹² Using interviews with patients and caregivers allows for the collection of information rich data. The data is carefully analysed by identifying emerging themes. Themes presenting a consistent thread of information can be used to support or challenge the hypothesis. This study focused on the narratives and experiences of people, so the sample could be purposively selected.

Methods of data collection and the type of information required vary according to the phenomenon being studied. With qualitative research, data cannot be collected impersonally or mechanistically. Variables affecting the type of data yielded are numerous, some examples being the personality, beliefs and conversational styles of the participants. The cultural values and lived experiences of the patients will influence the type of responses to questions. The interviewers may unconsciously bring their own views into the process, in the way the patient’s responses are recorded. In palliative care, the possible discomfort with the topic of death and spiritual issues and associated societal taboos will also affect the quality and accuracy of data collected. While society shies away from spiritual issues, my experience of working with patients facing death at hospice is that they are relieved that somebody wants to talk about these issues. These variables need to be considered when designing a study and analysing the data.

1.8 Ethics of Research in Vulnerable Populations

Conducting research with vulnerable people always raises ethical issues. In a society that tends to avoid topics of death and/or spirituality, it is easier to avoid such research justifying that it will be too painful for the patients; or that researchers are exploiting the patient's vulnerability to achieve their goals. In all research, it is important to consider ethical issues and to decide whether the study is useful and beneficial to the population being studied. In addition, it is imperative to conduct such research as impeccably as is possible to avoid unnecessary harm to the participants.

In palliative care research, some patient reactions, such as crying which could be seen as a result of harm caused by the research, can actually be cathartic and healing. The researcher, in this situation, should be asking: "Is the pain caused by the research or by the patient's very real experience?" It is important that the researcher and the assistants are experienced in the field of research and are able to recognise the difference between these possibilities and be able to respond appropriately.¹³

In terms of patient consent, which is a condition of any ethics approval, it is not only important to obtain written informed consent. It is also important to ensure that patients are aware that consent may be withdrawn at any time. This is difficult while conducting a study with sensitive issues which may provoke a seemingly negative response. The researcher has to be able to differentiate between a normal response by the patient to his pain, which can be dealt with therapeutically, and a response elicited by harm caused by the research directly, which should then be stopped in the interests of the patient's well being. This should also be explained to the patient before and during the data collection.

It is important to choose research assistants carefully. They need to be experienced in the area of research and receive any further training required so that they can be fully aware of what to expect and when to continue or stop the process. A relationship of mutual respect and trust between researcher and participants is essential. Confidentiality of both patients and research

assistants must be assured throughout the study. Research with vulnerable people can be conducted effectively and ethically if the ethics and patients needs for respect and good quality care are always considered before the researcher's needs for results.

1.9 Summary

Spiritual care is being increasingly recognised as an important aspect of patient care. Within the context of palliative care it is vital to address the spiritual dimension of suffering. A doctor's decision to enter the healing profession may be in response to an unrecognised spiritual need to help people. Although doctors may feel unprepared to enquire about spiritual suffering, being available to the patient in their pain is a form of spiritual care. The use of a spiritual assessment tool will help doctors feel more confident in the spiritual dimension of care. Spiritual issues and distress will inevitably be raised in any consultation and doctors should be able to recognise such clues as requests for spiritual help and refer the patient to a specialist spiritual counsellor as necessary without feeling uncomfortable or intimidated.

Chapter 2

Literature Review

The literature review starts with descriptions of religion and spirituality. Then the inclusion of spiritual care in palliative care is reviewed, followed by the patient's perception of the need for spiritual care. The need for a spiritual assessment in South African patients and a review of some of the spiritual assessment tools available is presented. The chapter concludes with the rationale for the study.

2.1 Spirituality and Religion

2.1.1 Spirituality

How does one define spirituality? It is difficult to define succinctly spirituality. Whilst many may equate spirituality with religious practice as is sometimes reflected in modern literature, they are not one and the same. It is often assumed that religious people are spiritual. Interestingly M Scott Peck, a psychiatrist with a special interest in spirituality, suggests that some religious people may not be spiritual, but rather secular¹⁴. So spirituality may be expressed through religious practices and beliefs but purely religious practice may not reflect an individual's spiritual being. Some spiritual people may not have any religious affiliation at all, yet they recognise and nurture their own spirituality through various non-religious means. J. LeBron McBride explains how spirituality may be divided into two dimensions; intrinsic and extrinsic¹⁵. Intrinsic spirituality describes one's inner beliefs or faith. Extrinsic spirituality is the expression of the intrinsic spirituality which may include practices associated with formal religions or may be quite secular.

S. G. Post describes spirituality in terms of the ultimate meaning and purpose in life. For some patients this involves a belief in a higher being which may be

a source of hope and reassurance. For others, it encompasses human relationships and values⁵. R.L. Hatch lists a number of underlying principles of spirituality other than belief in a higher power, such as: purpose in life; appreciation for the mystery of life; ability to forgive, others and oneself; ability to apologise; ability to find meaning in suffering and gratitude for life experiences with a spiritual belief evolution¹⁶. To expand on this, some express their spirituality through their pursuit of success, material wealth, public esteem, the “ultimate experience”; all of which are often very illusory goals in terms of true spiritual happiness. It can be seen that there are many descriptions of spirituality, because of the difficulty to describe something that is so personal.

2.1.2 Religion

The term, religion, is also difficult to define clearly. Benedict,¹⁷ says that it is easier to describe it in terms of the functions that religion fulfils: explaining the origins of the universe; understanding the purpose of life on earth; a means of understanding evil and suffering; providing hope for life after death; an authoritative ethical/moral code; providing a community to bind people together and a means by which an individual can experience the transcendent.

Benedict goes on to say that the actual practice of religion can vary in form from strict adherence to rules and rituals to a more liberal, free expression of faith. Common to all religion is the focus on the mystery of death and life after death. Each religion guides its devotees as to how to live a life that ensures a good life after death. It would be important for the doctor to be aware of a patient's beliefs and how they may affect decisions regarding their health care. For doctors dealing with terminally ill patients it is also important to be aware of any special needs around the time of death and immediately after. However, a spiritual assessment goes beyond just finding out what a patient's religious requirements may be.

2.2 Spiritual Needs and Palliative Care

2.2.1 Palliative Care as Holistic Care

The WHO definition of palliative care recognises the spiritual need of the patient, and that addressing this need should be part of the total care plan. It should be given the same priority as the patient's physical and psychosocial care because suffering includes a spiritual dimension. S.G. Post refers to a number of papers reporting the importance of spirituality and religion in the coping strategies of patients, thereby highlighting the importance of spiritual care⁵. J. McBride reports that there is an association between a patient's intrinsic spirituality and their health and experience of pain¹⁵. Pain is readily recognised as having a physical and psychological component. Spiritual pain will add to a patient's total perception of pain. C. Puchalski⁶ writes that "Dying patients who do not have their spiritual concerns addressed often suffer deeply." This suffering will make their lives and their death unnecessarily difficult for them and for their families. Addressing the patient's spiritual needs, may, in fact, reduce their experience of pain, anxiety, and depression helping them find value in their lives and feeling themselves to be valued and loved.

Separate studies by Ehman and Hatch have indicated that the majority of patients would like their doctors to enquire about or discuss spiritual issues with them. However, very few doctors cover these important issues during their contact with their patients¹⁶. The patient's spiritual beliefs will influence their decision-making concerning their health care. Not only will their spiritual beliefs affect their health care decisions, but spirituality will also affect their means of coping with their situation, D.J. Ita suggests that dealing with any spiritual issues will minimise death anxiety and help the patient to cope better through social support.¹⁰ Doctors need to be aware of these beliefs when prescribing treatment to avoid giving offence or doing any harm to the patient.

2.2.2 The Importance of Spiritual Care to Patients

According to recent American polls 90-92% of adults believe in God and about 85% believing that religion was important in their lives¹⁸. These figures do not reflect the level of intrinsic spirituality of the population. However, many people will show accelerated spiritual growth, reviewing the meaning of their

lives, when faced with any life threatening event.¹⁰ Such a personal review may raise important spiritual issues. J.W Ehman, in a study of 177 patients in a pulmonary outpatient practice, reported that 51% of the patients interviewed described themselves as religious and 70% believed in life after death. Forty five percent said that their spiritual or religious beliefs would affect their medical decisions if faced with serious illness. Ninety four percent of this group felt that doctors should enquire about a patient's spiritual beliefs¹⁹. Two thirds of all of the respondents, felt that a spiritual enquiry would be appropriate, including forty five percent 45% of those who denied having any spiritual or religious beliefs.

An Australian study by H.G. Peach in 2003 revealed that Australians were generally less religious than Americans²⁰. Seventy five percent reported a religious affiliation in their 2001 census. Peach stated further that there were very few studies determining Australian spirituality and its impact on their health needs, and concluded that it was not necessary to do a spiritual assessment as part of the consultation. However, H.G. Koenig, comments that a spiritual enquiry is important in the total medical care of the patient²¹. He cites a few Australian studies which support the importance of spiritual beliefs in coping with illness. He points out that, while doctors are not spiritual counsellors, a spiritual enquiry amounts to good medical practice. If the patient chooses not to discuss spiritual issues, his wishes are to be respected. While ongoing research into dealing with spiritual issues with patients is necessary, one cannot ignore the existing spiritual needs of patients.

According to the results of the South African census 2001²², a little over 80% of South Africa's population have some religious affiliation. Fifteen percent were reported as having no religion. This does not indicate the level of spirituality, or give any insight into the need for spiritual care amongst patients, however it has been difficult to find any studies in South Africa assessing the level of spirituality or depth of religion in our population. Furthermore the spirituality and its affect on patient's views on their healthcare is a vitally under researched area in South Africa. Given the results of studies

conducted elsewhere in the world it is probably safe to assume that there would be a need for spiritual care to be integrated into a model of total care for patients in South Africa.

2.3 The Need for a Spiritual Assessment Tool in South Africa

Although there is little research into the spiritual needs of patients in South Africa, one study done by K. Peltzer amongst patients with HIV/AIDS concludes that a spiritual enquiry, as part of the patient history would be very important²³. Various presenters at the Palliative Care conference in Cape Town in 2005 emphasised the growing awareness of a need for spiritual care to be offered to patients.²⁴ A spiritual assessment tool would be helpful in introducing spiritual care into the patient care plan.

Spiritual care may be offered to every patient at every consultation by the doctor being present and open to the patients needs. Showing the patient respect and empathy in their suffering is indeed an aspect of spiritual care, however there may be specific issues that the patient needs to address and would appreciate the doctor's explicit permission to speak about them. Patients may not raise these issues because of the traditional view of the doctor's role in the patient's life. By asking the questions in a spiritual assessment the doctor opens up the opportunity and the patient can lead any further conversation from that point.

2.3.1 Different Spiritual Assessment Tools

Various spiritual assessment tools have been developed, each with its own usefulness, all covering spirituality in similar ways. In the process of looking for a suitable tool to be used in our multicultural society in South Africa, several spiritual assessment tools were reviewed.

Dr C. Puchalski has designed a spiritual assessment tool – FICA, for use by doctors²⁵. She reports that it is brief and should require approximately two minutes to complete. She suggests that it is done as part of the patient's

social history. Any issues that arise from the spiritual assessment can be discussed during the consultation or the patient may be referred to a specialist spiritual counsellor. J.L. Hallenbeck comments in a discussion of psychosocial and spiritual care that although the mnemonic has “a certain artificiality”, it can be useful when initiating a discussion of spiritual issues²⁶.

R.L. Hatch developed an assessment tool called the Spiritual involvement and Beliefs Scale (SIBS)²⁷. This is designed as a self-administered questionnaire. The questionnaire covers all aspects of spirituality and may provide useful information for care-givers. It can be given to patients to fill in while waiting to see the doctor. The patients would have to be literate or, if illiterate, have someone fill in the answers for them. It may be an impersonal approach to spirituality with the patient. The doctor would then have to go through the answers with the patient which could be lengthy. There may not be an opportunity for the spontaneous conversation that the FICA would initiate. This tool is probably more appropriate for research in spirituality.

Another assessment tool called SPIRIT²⁸ is based on the work of T.A. Maugans. It covers issues such as: **S**piritual belief system, **P**ersonal spirituality, **I**ntegration in spiritual community, **R**itualised practices, **I**mplications for medical care and **T**erminal events planning. The categories of questions are similar to those of FICA but SPIRIT is more comprehensive and would take longer to complete.

The HOPE spiritual assessment tool was published by G. Anandarajah and E. Hight in 2001²⁹. The categories are similar to the FICA and SPIRIT tools namely: sources of **H**ope meaning, strength, **O**rganised religion, **P**ersonal spiritual practices and **E**ffects on medical care and end of life issues. They give examples of questions to be asked in each category.

Each of these assessment tools covers common themes of spirituality or religion, importance to the patient and influence on their decisions, involvement in a community and how their needs can be addressed by the

healthcare worker. The FICA assessment tool seems to be short and easy to use. The questions cater for a broad spectrum of patients who may consider themselves spiritual, religious or neither. A further advantage of FICA is that it is non intrusive and non threatening. Dr Puchalski reports that it can be used cross-culturally and may have to be reworded, if necessary, but should retain its spiritual content²⁵. The FICA spiritual assessment tool was chosen because of its flexibility and brevity. These qualities would possibly make it attractive to busy doctors working in our multi-cultural society.

2.4 Rationale for the study

Spiritual care is perceived by some carers to be a very real need amongst palliative care patients in South Africa. This need is not being addressed adequately, causing unnecessary suffering to patients. This means that we are failing in our mission as palliative carers if we do not address the spiritual aspect as much as the other aspects of care. Most staff feel unqualified to offer spiritual care because of the traditional view of its association with religion. However spiritual care is not religious counselling. The use of a spiritual assessment tool would help doctors to grow in confidence when dealing with spirituality as part of their patient care. This study assesses the need for spiritual care and evaluates the efficacy and appropriateness of the FICA spiritual assessment tool in providing such care to terminally ill patients in the South African context.

Chapter 3

Aim and Objectives

3.1 Aim

To assess the need for spiritual care in a multicultural population of patients with life threatening illnesses in South Africa and to evaluate the usefulness of a spiritual assessment tool in introducing spiritual care into the consultation.

3.2 Objectives

- To assess whether the inclusion of spiritual care as a routine part of the consultation with a terminally ill patient is required.
- To introduce FICA as a spiritual assessment tool to assist doctors with spiritual aspects of patient care.
- To evaluate the usefulness of FICA as a means of initiating effective spiritual care.
- To assist doctors to become aware of their own spirituality and how their beliefs may affect the patient/doctor relationship.

Chapter 4

Research Design and Methodology

4.1 Study Design

This is a multi-centre cross-sectional qualitative study, based on purposive sampling. The data was collected using a qualitative methodology and analysed thematically.

4.2 Study sites

The study was conducted at four sites, namely Houghton Hospice, Johannesburg; Soweto Hospice, Johannesburg; Chatsworth Hospice, Durban and Tintswalo Hospital, Bushbuckridge, Mpumalanga.

4.2.1 Houghton Hospice

Houghton hospice is situated in the affluent suburbs of Johannesburg. It serves the Greater Johannesburg area. Patients are treated within the home-care program or as inpatients in the inpatient unit. The patients are representative of all race groups but tend to be more predominantly white. They generally speak English, either as first language or understand it well. The patients fall into a range of income levels and levels of education.

4.2.2 Soweto Hospice

Soweto hospice is located in the traditionally black township adjacent to Johannesburg where people were relocated during forced removals of the apartheid era. While most residents speak one of the major indigenous languages at home, English is often understood. Patients are seen in the home care program or as inpatients in the very modest inpatient unit.

4.2.3 Chatsworth Hospice

Chatsworth hospice is in the Greater Durban area. It serves a largely urban Indian population, although there are also patients from the other population groups. The patients are usually literate and fall into the lower to middle

income groups. They usually understand English, often being their first language.

4.2.4 Tintswalo Hospital

Tintswalo hospital is in a deep rural area near Acornhoek in Mpumalanga province. The community struggles with high levels of unemployment. English is usually poorly understood, if spoken at all in this predominantly black population. The most commonly spoken language is Sepedi. The interviews were conducted in English with the nurse translating for the doctor.

4.3 Participants

The participants in the study were all existing members of the multidisciplinary team at each institution and patients of the institution. They were all experienced in offering holistic care to the patients. They were keen to learn more about spiritual care, seeing a need amongst their own patients.

4.3.1 Houghton Hospice

The patients were interviewed by the home care doctor as part of the outpatient consultation. The interviews were all conducted in English.

4.3.2 Soweto Hospice

The patients in this sample were interviewed by the social workers and were selected from the outpatient and inpatient groups. The social workers translated the questions from English into the patient's home language as required and recorded the responses in English.

4.3.3 Chatsworth Hospice

The patients were all in the inpatient unit and interviewed by the ward sister. The interviews were all conducted in English.

4.3.4 Tintswalo Hospital

The sample of six patients, all with incurable illnesses were taken from the medical ward. They were interviewed by the English speaking ward doctor

with the help of a sister as an interpreter. The responses were recorded by the doctor in English.

4.4 Sampling/selection criteria

The purposive sampling of an information rich group of people means that the data saturation point is reached fairly quickly¹². Smaller samples are required to collect enough information to answer the research question. In this study, samples needed to, as far as is possible, reflect the diversity of South African society. The Houghton and Soweto Hospices were selected because of their convenient location for the research. The Tintswalo hospital was selected to represent the rural population through a common contact of the doctor in the medical ward there. The Chatsworth hospice was selected as representative of the Indian cultural group of people in South Africa. The selection criteria for the patients within each site were:

Inclusion criteria:

- Patients had to have an incurable illness and know of their diagnosis and prognosis.
- Patients had to be older than eighteen years
- Patients had to be strong enough to complete the FICA assessment and to be interviewed at some time afterwards

Exclusion criteria:

- Patients who were too frail to take part in this study
- Patients who did not have the mental capacity to take part in the study

At the convenience of the research assistants, patients were invited to take part in the research project. Religious or spiritual preferences and home language were not considered for inclusion or exclusion.

4.5 Data collection

Data collection took place over a period of four months.

4.5.1 Data collection tools

The data collection tools for the study included; the FICA spiritual assessment tool; the interview guideline for patient interviews and the interview guideline for the caregiver interviews.

4.5.1.1 The FICA Spiritual Assessment Tool

The FICA spiritual assessment tool was developed and copyrighted by Dr Christina Puchalski in 2006, specifically to assist doctors to take an adequate spiritual history, as part of the documentation of the patient history. The mnemonic represents four topics to be covered when doing a spiritual history, namely: Faith, Importance, Community and Address. Each topic has a few questions which can be asked depending on the relationship between the doctor and patient and the responses to prior questions. Dr Puchalski has been training physicians and multi-disciplinary teams in the use of FICA, through workshops and role plays. Participants have found that it is simple to use and say that it does not take a lot of time to do a simple spiritual history. Anecdotal evidence quoted by Dr Puchalski indicates that the tool is useful cross-culturally because of the general principles and open-ended questions.²⁵ Dr Puchalski is currently validating this tool. The tool was not translated. Usually, doctors who do not speak a local language will have a nurse to assist them with translation during the consultation. This is the usual practice at hospitals and hospices in South Africa. Caregivers who do speak the patient's language have trained in English and are therefore competent to use an English format of the assessment, translating into the patient's language of choice.

4.5.1.2 The Guideline for the Patient Interviews

Having completed the spiritual assessment using FICA, a set of 9 questions serves as a guideline to the research assistants to ascertain the patient's feelings about the usefulness of FICA. The interview was semi-structured based on the nine questions to guide the conversation. The questions were therefore not translated or piloted before the study.

4.5.1.3 The Guideline for the Caregiver Interviews

A set of questions were drawn up as a guideline for the caregiver interviews which were conducted by the author. The caregivers were all comfortable speaking English and were familiar with the concepts to be discussed so no translation was necessary.

4.5.2 Data collection methods

Data collection commenced with a workshop in Johannesburg to train the research assistants. They returned to their sites to do the patient spiritual assessments and interviews assessing the usefulness of FICA. The author then interviewed each research assistant individually.

4.5.2.1 Training of Research Assistants

A workshop was conducted prior to collecting the data. It was an opportunity to train the assistants in the use of the FICA tool, to discuss the rationale for the study and to give them space to reflect on their own spirituality. The workshop was a training session and an opportunity to pilot the interview guidelines.

The workshop included a presentation on spirituality, an interactive discussion on spirituality and spiritual care and the ethical questions raised. Story boards were used to display the information gathered. Three large posters with three headings were put up on the wall. The participants wrote their thoughts and comments on coloured pieces of paper and then pasted them onto the posters under the appropriate headings. The posted comments were then discussed and the research assistants shared anecdotal stories of patients and personal experiences. There was then time for guided reflection on their own spiritual beliefs.

The FICA spiritual assessment tool was introduced and the group divided into pairs to do role plays as patient and caregivers, reversing roles to give all a chance to use the FICA tool. They were encouraged to use their own experience or beliefs in the role-play, helping them to examine their own

spirituality further. The outcomes of the role plays and any ambiguities or concerns were discussed. These were written down on a board to be added to the data collected from the proceedings of the workshop.

At the end of the workshop, the research assistants were each given a package with all the paperwork required for the study: introductory letters, consent forms, the FICA assessment and interview guidelines.

4.5.2.2 Patient Interviews

❖ Spiritual Assessment using FICA

At each site patients were invited to participate in the study. Once the patient gave informed consent, a spiritual history was conducted using the FICA tool. (Appendix 1) The patient's responses were written down in English, either as given by the patients or as a translation from their responses in their mother tongue. Many of these histories took place after the first consultation, meaning that a relationship had already begun to develop between caregiver and patient. All the questions on the assessment were asked rather than selecting only one or two from each category. The patient assessments and interviews were not recorded on tape as it was felt that this would be too intimidating and transcription and translation from the local languages would be difficult and time consuming given the scope of the study.

❖ Evaluation of the ease of use of FICA

The patients were interviewed by a staff member after the FICA spiritual assessment was completed. The interviewer conducted a semi-structured interview with the help of the interview guideline provided. (Appendix 2) This guide helped the interviewer ask appropriate questions about the patient's experience of the FICA assessment, their comfort with the assessment, the appropriateness of the questions and the usefulness of the assessment in providing more holistic care. While the questions were in English and all the caregivers were fluent in English, the interviews were conducted in the patient's first language and translated as required. Because the interview was not structured and the questions were only a guideline, strict translations of

the questions were not provided. At one facility the interview was done with the help of an interpreter, as is the usual practice at that facility. At the other three facilities, the interview was done in the patients' first language with the interviewer translating the questions as required. The answers were written down, either verbatim or as translated into English.

Once the sample of patients had been completed, the information was put together into a sealed envelope and collected from each assistant personally.

4.5.2.3 Caregiver Interviews

After the information in the individual packages was read, each caregiver was interviewed individually, using a semi-structured interview to assess the value of the FICA tool to both the patient and the caregiver. (Appendix 3) The guideline was prepared to establish the ease of use of the tool by the caregivers in terms of time, simplicity, the caregiver's level of comfort and their opinion of its value in better understanding their patients' suffering. Any further opinions regarding spiritual care were also discussed. These interviews provided an opportunity for debriefing of the research assistant. The author also asked questions about the records of the patient interviews, clarifying any ambiguities and checking the validity of any possible assumptions arising out of the initial analysis of the data. These interviews were recorded on a cassette recorder and transcribed as soon as possible after the interview took place.

4.6 Data Analysis

The data analysis was completed following the steps suggested by M Terre Blanche, namely: familiarisation and immersion, inducing themes, coding, elaboration and interpretation, and checking.³⁰

The written data was converted into word documents and the answers to the patient interview questions were tabulated. While transcribing the caregiver interviews, common threads of thought and information were already emerging. During the process of immersion in the data, the documents and interview transcripts were read repeatedly to build a mental picture and map

of the information. As the data became more familiar, common ideas and processes started to consolidate into themes.

Different colour fonts were used to code the data. The transcripts and interview documents were checked again for relevant information and the data reduced to key sentences phrases and words which were printed. These copies were pasted onto a wall and commonly recurring phrases and words were extracted and written onto large posters. These were then grouped into common themes first by underlining in colour and then rewritten in those colours onto new posters.

The themes that emerged from the caregiver interviews were then compared to the themes that emerged from the patient interview and the workshop for research assistants and all pasted together side by side. Analysis continued with further checking for common themes that had emerged separately from the different sources. Themes were reviewed and revised after comparison of data from the 3 activities – workshop, patient interview and caregiver interview. A process of repeated comparison and review, refining the analysis, resulted in the emergence of the final themes and sub-themes. These were then checked against the supporting data and quotes to ensure that they were congruent.

4.7 Ethical considerations

It was very important that the study was conducted ethically and that the patients' needs were always considered to be a priority. All the research assistants were experienced in palliative care. They were members of palliative care teams who would be taking care of the patients recruited for the study on an ongoing basis, thereby establishing and maintaining a relationship with the patients after completing the interviews. They were spiritually aware and interested in offering spiritual care. Each site and each research assistant consented to participate in the research project.

4.7.1 Research ethics for research assistants

At the workshop for the research assistants, the ethics of spiritual care in general was discussed in detail. Once the role plays had been completed, there were many questions and further discussion regarding the study in particular, and how to protect patients rights and meet their needs for sensitive quality care. They also were confident that should a need arise as a result of the FICA assessment or interviews that they had access to suitably qualified counsellors to deal with any spiritual or other needs.

4.7.2 Participant information and consent.

The caregivers had all met the patients previously and a relationship had been initiated prior to the assessment. The patients were given an introductory letter and consent form in the language of their choice.

(Appendices 9 – 13) The study was explained to them in the same language and they were informed that if they refused to participate it would in no way affect the care given to them and that they were free to withdraw consent at any time. Some patients chose not to participate usually because of time constraints. Once a patient gave their consent, the caregiver completed the FICA spiritual assessment with them. No patients withdrew from the study during the assessment or interview process.

Chapter 5

Results

The results of this study will be presented in three sections:

- The FICA spiritual assessment tool and its acceptability to patients and caregivers.
- The need for spiritual care and the positive outcomes of offering this care
- The need for caregivers to have ongoing spiritual care themselves.

As an introduction to the data presented, the demographic information of the patients who participated from the four sites, namely Houghton hospice, Soweto hospice, Chatsworth hospice and Tintswalo hospital, is summarised in Table 5.1.

Table 5.1 Demographic Details of Patients at the Four sites

Site		Houghton	Soweto	Chatsworth	Tintswalo	Total
Age	20 -29	-	-	-	1	1
	30 - 39	-	5	-	2	7
	40 - 49	-	1	2	-	3
	50 - 59	1	-	-	1	2
	60 -69	1	-	3	1	5
	70 - 79	1	-	-	1	2
	Total	3	6	5	6	20
Gender	Male	2	3	2	3	10
	Female	1	3	3	3	10
	Total	3	6	5	6	20
Ethnicity	Black	-	6	-	6	12
	Asian	-	-	4	-	4
	White	3	-	1	-	4
	Total	3	6	5	6	20
Religious (self-report)	Yes	2	5	4	5	16
	No	1	1	1	1	4
	Total	3	6	5	6	20
Highest level of education achieved	None	-	-	-	1	1
	Primary	-	-	2	2	4
	Secondary	2	6	1	2	11
	Tertiary	1	-	2	1	4
	Total	3	6	5	6	20
Employed	Yes/retired	3	5	3	4	15
	No	-	1	2	2	5
	Total	3	6	5	6	20

5.1 The FICA Spiritual Assessment Tool

The data on the usefulness of the FICA spiritual assessment tool is presented in three parts:

- the patients' responses to the FICA assessment and examples of the information about the patients gained from using this tool
- usefulness of the tool from the patients' perspective
- the caregivers experience of using the tool.

5.1.1 Patient's Responses to the FICA Assessment

The mnemonic, FICA, represents four categories of assessment, namely; Faith, Importance, Community and address. The analysis of the patients' responses within the framework of these categories, revealed three themes which form a strong foundation for patients' coping with their illness, namely:

- Beliefs/Faith
- Prayer/Rituals
- Relationship
 - Love
 - Respect

Relationship can be further broken down into the sub-themes of love and respect. The following quotes from the patients' responses reveal the background from which the themes were derived.

5.1.1.1 F – Faith, Belief, Meaning

In response to the question: *“Do you have spiritual beliefs that help you cope with stress?”*

Beliefs/Faith

- *“present existence is part of a plan”* (H1)
- *“believe soul goes on somehow”* (H2)
- *“I do believe that some of my prayers do get answers”* (S4)

Prayer/Rituals

- *“Rituals, e.g., slaying of goats, praying to my ancestors” (S2)*
- *“Prayer – speaking to the Almighty directly” (S3)*

Relationship

- *“believe in God and love. Love from other, unconditional from grandmother” (H3)*

Love

- *“before I used to love God” (T1)*
- *“Love – from God and people who care for me help me cope” (C1)*

5.1.1.2 I – Importance and Influence

This group of questions explores how their beliefs influence how they cope with stress and looks at any specific beliefs that might influence their health care decisions:

Beliefs/Faith

- *“I believe in my ancestors” (S1)*
- *“My faith helps me to uplift my expectations”, “ I believe the disease I have is unnatural and therefore it needs scientific intervention. I do not believe natural medicines, for example herbs, would help me” (S4)*
- *“Yes, because gives hope. Can influence body in way that doctors can’t” (H2)*
- *“still believe God can make me well...handing over to God” (H3)*
- *“it influences the way I live my life – the decisions I make in life” (C1)*
- *“I feel the strength, courage and knowledge in trusting God is important in my life (C3)*
- *“I believe in the hospital” (T4)*
- *“I believe in God. It is important” (T6)*
- *“knowing that there is a living God helps me” (C5)*

Prayer/Rituals

- *“When I pray I can be healed” (T3)*
- *“I believe in the hospital. I pray at night” (T3)*
- *“like using muti (traditional medicine used by traditional healers) as it is against many medical practitioners” (S2)*

Relationship

- *“interacting and sharing with other people influences the decisions I make” (C2)*
- *“I communicate holistically with people around me.” (S2)*

5.1.1.3 C – Community

The questions help to elicit information about being part of a spiritual or religious community, or if there is a group of people whom they really love or who are important to them; and whether that is of support to them.

Beliefs/Faith

- *“I get more support from the congregation. My family also play an important role” (S1)*
- *“The church choir is very important, their singing brings spiritual healing and nearness to my Jehovah who loves me” (S3)*
- *“yes, if not able to go to church (they) will come to home” (H3)*

Prayer/Rituals

- *“wife’s church...came and prayed for him and made him better” (T4)*
- *“the church members pray for her and give her ZCC tea” (T6)*
- *“because at church we sing, dance do rituals so it works with my beliefs” (S2)*

Relationship

- *“I belong to mothers union where I grew in my faith.” (S3)*
- *“friends are everything” (H2)*

5.1.1.4 A – Address/Action in care

This question is intended to help the doctor with a care plan that takes into account the patients' spiritual needs. From the answers to this question, a sub-theme of respect strongly emerges under the theme of relationship.

Beliefs/Faith

- *“...our health care centres should involve our spiritual and religious beliefs” (S1)*
- *“I think they should work hand in hand with traditional healers” (S2)*
- *“spiritual care providers and clergymen to be involved in health care centres” (S3)*
- *“balancing the spiritual beliefs with the healthcare issues” (S6)*

Relationship

- *“attitude and support of staff is valuable” (H1)*
- *“nice to have a doctor who is also a spiritual person” (H2)*
- *“call the church group” (T2)*
- *“I'd like to be motivated all the time by all the care providers” (C5)*
- *“be able to talk to me about me, and me and other people” (C2)*
- *“I pray that God be with you as you care for me and we discuss things openly” (C3)*

Respect

- *“my beliefs should be respected e.g. they should be written in the file so that whoever treats me should respect them and behave accordingly” (S4)*
- *“always treated with dignity and respect – if conscious or not” (H3)*

5.1.2. Patients and Caregivers Opinions on Spiritual Care and the FICA Assessment

The topics which were considered important in evaluating the assessment tool are listed below. These were covered during the patient and caregiver interviews:

- Comfort with Questions
- Questions Appropriate/helpful
- Any Changes Needed
- Time Appropriate?
- Patient felt more understood
- Patient Doctor relationship changed
- Improved on Patient's care/ Useful
- Provoked any further thought

This information from the interviews is presented in Table 5.2. Some of the patients' opinions, expressed during the interviews, are quoted to clarify the information in the table.

Table 5.2 Summary of the Patients and Caregivers responses to questions about the usefulness of the FICA Spiritual Assessment Tool.

Characteristics Evaluated	Patients Responses				Caregivers Responses			
	Yes	No	Other	Total	Yes	No	Other	Total
Comfortable with Questions	18	1	1	20	4	0	0	4
Questions Appropriate/helpful	18	0	2	20	3	0	1	4
Any Changes Needed	6	13	1	20	2	2	0	4
Time Appropriate?	11	9	0	20	4	0	0	4
Patient felt more Understood	16	2	2	20	4	0	0	4
Patient Doctor relationship changed	6	12	2	20	4	0	0	4
Improved on Patient's care/ Useful	18	0	2	20	4	0	0	4
Provoked any further thought	9	11	0	20	2	1	1	4

- **Comfort**

Eighteen patients felt comfortable with the assessment.

One patient (S2) felt uncomfortable, saying that the questions were provocative; *"Doctors don't believe in spiritual being, always thinking that your life depends on them"*.

One patient (T6) was *"surprised as she has never been asked these questions before"*.

- **Appropriate**

Eighteen patients said that the questions were appropriate, or helpful in a spiritual enquiry.

One (T1) was unsure and one patient (T6) *“can’t understand why the questions were asked”*. None felt the questions were inappropriate.

- **Changes to Spiritual Assessment**

Thirteen patients did not have any suggestions to change the assessment. Six suggested some changes and one was not sure.

The three patients from Soweto all made suggestions with regard to conducting a spiritual assessment in general; *“in the consultation there could be someone to help if the person need immediate help when it comes to spirituality. Cause it can be very emotional to others to talk about spirituality. It can be done while waiting by somebody else, people are so impatient, especially when they are sick”* (S6).

“I think a doctor must refer you to a priest with your own spiritual.....” (S5)

“Involving, spiritual guidance in all sectors of hospitals. Primary, tertiary, secondary health care” (S2).

Patients at Tintswalo made suggestions about the FICA: *“Yes, 2 questions only, about religion and people who are important”* (T3)

“maybe take out the 3rd group of questions” (T7).

- **Time**

Eleven patients felt that the time spent on the assessment was appropriate.

Four felt that it was too long; *“if its being done by the doctor it will take too long because there are other patients waiting for the doctor”* (S6),

“during initial assessment I am in pain needing possible immediate relief” (S1).

Five said that it was too short, *“too short because it has anything with healing and it takes a long tome too heal”* (S5),

“because it is only once a week like day care or only on Sunday at church” (S2).

- **Understanding**

Sixteen patients thought that their doctor had a better understanding of them as a result of the enquiry.

“because he related to me on a spiritual level and on a personal level” (S3).

“you were able to tell if you do need help or do you have support or not. Do you have any other problem other than you came for. Sometime you are sick because you have lost hope.” (S6)

“Yes, he sees the doctor as a spiritual person herself” (H2).

Two said no to this question,

“doctors belief in Western medicines” (S2),

“some of my spiritual matters he/she does not understand” (S5).

- **Relationship**

Six patients felt that the assessment may have affected their relationship with their doctor.

“the doctor understood me as person with my belief system which I think would help in the healing process.” (S3)

“in terms of understanding me as a whole person better” (S4)

“I will respect him/her because I will know that he/she is consent with my spiritual or believer religion.” (S5)

“I have gained confidence to him and trust, openness.” (S6)

- **Improved Care**

Eighteen patients thought that the assessment was useful in improving their overall care.

“the doctor saw me in totality” (S3)

“it will improve my thinking of other things and change my life of thinking” (S5)

“it shows that he/she cares for me, not only the money I’m bringing in” (S6)

“...more secure” (H2)

“doctors will have a better insight of my life” (C1)

“can relate to the doctor openly. Can make adjustments if and when necessary by understanding my spirituality.” (C2)

“for better health” (T1)

One patient felt it was too early to say and one did not understand the question.

- **Thought Provoking**

Eleven patients found that the assessment had provoked further thought on spiritual matters.

“it enabled me to understand the importance of spiritual, emotional and physical aspects of my totality” (S1)

“it has made me to look in my inner being and change my behaviour towards life in general.” (S5)

“it has helped me to be in touch with my inner self and evaluate my life. It has reminded me of people I care about (my kids) that maybe because of my illness I have gave up living or hope to survive.” (S6)

“has uplifted my spirituality” (C2)

“it’s making me to look deeper into my into my own spirituality” (C4)

5.1.3 Caregivers Responses to using the FICA Assessment

The caregivers’ responses were tabulated so that they could be more easily compared. The responses could be divided into two groups: Ease of use for the caregiver and impact on the patient - caregiver relationship from the caregiver’s perspective. The responses are shown according to site.

An abbreviated transcription of their responses is presented in Table 5.3 and Table 5.4.

Table 5.3 Ease of Use for Caregiver

Facility	Houghton Hospice	Soweto Hospice	Chatsworth Hospice	Tintswalo Hospital
Comfort of caregiver	Quite comfortable	Very comfortable	Quite comfortable	Comfortable
Time to do FICA	10 – 15 minutes	Depends on patient	20 minutes, patients need to think	10 – 15 minutes
Would familiarity with FICA change the time taken?	Quicker with experience but depends on patients	Would change, easier, quicker	No, different patients still need to reflect	Yes, would develop explanations
Appropriateness	Appropriate	Appropriate	Appropriate	Depends on patient.
Most/Least appropriate questions	Most: Importance	Most: Faith, Community	Most: Faith (both questions) Least: Address	Most: Faith Least: Address
Any changes to FICA for their use?	No, would use as mnemonic to aid in history	Formulate questions for better understanding	No. use as is.	Simplify language. One question per category.

Table 5.4 Impact on Caregiver and Patients (caregiver's perspective)

Facility	Houghton Hospice	Soweto Hospice	Chatsworth Hospice	Tintswalo Hospital
Patient responses as perceived by caregiver	Enjoyed, welcomed discussion	Positive, willing.	Very good, felt very good.	Varied. More educated valued it. Less educated; intimidated, bizarre
Improved understanding of patient?	Yes, greater understanding	Think so, better understanding.	Yes, definitely.	Yes, relationship more in depth.
Useful or not?	Useful	Useful	Very useful	Useful
Use in any other consultation?	Yes, can be kept very brief	Don't think at the clinic; associated with death.	Definitely, pain can be spiritual.	Definitely, at appropriate time.
Effect on Caregiver and relating to patients?	Helpful guide as to what to ask	Deep thinking, deep thoughts. Not much change in approach to patients.	Better understanding about spirituality.	Improved relationship, another dimension, trust.
Continued use?	Yes, as useful guide	Yes, choose specific questions depending on individual.	Yes, as it is.	Yes, use 4 headings but keep it simple.

Themes Derived From the Caregiver Interviews Regarding the FICA Tool

Using the questions as a guide, it was possible to derive some important themes relating to the caregivers' ease of use of the FICA spiritual assessment tool:

- Comfort in using the tool
- Appropriateness of the tool
- Time taken to administer the tool
- Improved Understanding of Patients
- Improved Carer-patient Relationship
- Usefulness of the Tool

▪ Suggested Changes to the Tool

The quotes supporting these themes have been recorded verbatim.

Comfort Using the Tool

- *“I’d had time to build rapport with the patients....I had sort of addressed their needs” (H)*
- *“we’re already doing the history and the genograms, it’s too much, so perhaps in the 2nd or 3rd ...you’ve got that trusting relationship, then you do it” (C)*
- *“But I guess it also depends on your rapport, the more rapport you have with the patient, the more they will appreciate it. The less the rapport, the more strange it will be...it’s like inappropriate to get to this level of discussion with a patient you don’t have a rapport with...if I had been treating the patient before then it seemed the normal thing to do but if it was a patient I hadn’t seen before, then it, you can’t start with this” (T)*
- *“at the first assessment would be uncomfortable and intrusive....build a relationship first”.(P)*
- *“a few questions I would rather use in a follow up consultation with a spiritual worker and not a doctor at first consultation, for example, F(iii)” (P7)*
- *“it would be a good thing that would be in one’s 2nd consultation with a patient or at the end of the consultation” (T)*

Appropriateness of the Tool

- *“the first question, faith, belief or meaning... that was fine. Patients are quite, in our setting disempowered, so they’re quite taken aback if you ask them for the last question; A...they are really confused by the last one” (T)*
- *“The ‘I’ question was quite difficult for them, that I think got the most blank looks” (T)*

- *“it is something that is assumed, not spoken about much” “the ‘I’ part of it... we often found that one hard to do, not because of difficulty of the question, but just because no one had given much thought to it...that was a wonderful question to have” (H)*
- *“‘What importance’ is on a spectrum and it’s difficult to express, what do you mean by what importance...also that complex question , ‘have your beliefs influenced how you handle your stress?’ What is stress? It’s not really a concept (in this community); that needs to be explained...one needs much simpler questions... conceptually.” (T)*
- *“one woman who was probably more deep rural... she thought it was totally bizarre to be asking these questions. She couldn’t understand why the doctor was addressing this. Particularly as a doctor, I think. Maybe if a nurse could have addressed it more, because they were from the same community.” (T)*
- *“How we can address these issues...most people said they didn’t think that we could do anything other than just being non-judgemental, I don’t think people see that as for us to get involved, other than to be respectful of their beliefs” (H)*

Time taken to Administer the Tool

- *“we took seven to ten minutes”. (P)*
- *“it didn’t take long, about ten to fifteen minutes” (H)*
- *“we all do these questions in some form or other in our consultation...then actually at that point it probably is done in two or three minutes unless there’s something specific that comes out that then needs to be discussed” (H)*
- *“how many doctors are really going to do this?” (C)*
- *“I think the time was fine because generally in a palliative care setting you want to take a bit of time to chat to the patient and it’s not something one does everyday” (T)*

Improved Understanding of the Patients

- *“Very useful...it made me understand the patients better...seeing their inner feelings and their inner selves...how they cope, that was important” (C)*

Improved Carer - Patient Relationship

- *“definitely (improved understanding of patient) And I think it’s important, especially with a patient you often are with for a while, and it’s appropriate to kind of make one’s relationship with the patient more in depth” (T)*
- *“Some of the patients, I have hang ups when I see them, and definitely improved, added another dimension to the relationship and trust and they feel that you’re really interested in them as a person” (T)*
- *“the thing about asking the questions is that it builds a rapport and it does build that connection” (H)*

Usefulness of the Tool

- *“That really is worthwhile, these are the four things that are important that are sure to be covered when doing a spiritual assessment” (H)*
- *“They weren’t difficult, language was simple, it was easily understood” (C)*
- *“the part that was difficult about it; was trying to explain some of the concepts even to the nurse who was interpreting for me or just to the patient if they did speak English, sometimes I got some blank looks from them....but talking about spiritual stuff, most people were fine about it” (T)*
- *“it’s very helpful, even though we are aware, we still need guidelines.” (H)*
- *“The FICA assessment provides a good framework and basis for the spiritual assessment for doctors to begin with, but as they become*

more experienced they will develop their own questions and techniques and in a narrative history will recognise the issues that have been covered and clarify those that have not” (T)

- *“But for impaired doctors, who are not good at approaching these things, you do need a guideline” (T)*
- *“it has been very helpful, absolutely, to both me and the patients” (C)*
- *“I think we should do this with every patient” (C)*
- *“it was useful, because even those patients that were not there as yet but managed to, you know, to see, like in a broader perspective...” (S)*
- *“having problems with their spirituality, it can cause a lot of pain...deep pain...give them permission to look within themselves...find what’s causing this pain, ...people are waiting for that permission” (C)*

Suggested Changes to the Tool

- *“FICA to be more meaningful and clear for people who don’t know English (simplified)” (P5)*
- *“if we continue this then we might have to formulate perhaps, some of the questions in a different manner or in a more understanding way to the type of people that, not to the language” (S)*
- *“It might almost be interchangeable, ‘F’ and ‘C’, because when you ask ‘spiritual or religious’ it’s hard for them to really....sometimes an easier starting point is ‘are you going to church?’” (T)*
- *“I would use it in a different form...I must remember my FICA and I’d start with the first question and take it from there...I think the four headings are important, I just have to have a way of keeping them simple...I guess that ‘I’ question is the most complicated one to simplify” (T)*

5.2 The Need for Spiritual Care

Three major themes emerged from the interviews with the caregivers - relationship, healing and learning experience. The theme, relationship, could

be broken down into four sub themes; respect, understanding, deeper connection and feeling valued.

5.2.1 Relationship

The importance of the quality of the relationship between carer and patient emerged from the data.

5.2.1.1 Respect

The caregivers respect for the patient and his beliefs was important to the patients

- *“It’s about being respected and hearing what they say”* (H)

5.2.1.2 Understanding

It was important to the caregivers that they understood the patients and that the patients understood their reality.

- *“the more you know the belief system of the patient the better understanding...it is very important that from the outset we work together and we know where we are”* (S)
- *“gave them time to reflect, look within themselves and to get to understand themselves”* (C)
- *“I think it really helps me see where they’re at. Because my question is always, how are they coping with this process? If one understands how they are managing it spiritually one can really see where they are at and you can get a better sense ‘this person’s ok’, they’ve got an acceptance...they can be held in a particular way...”* (H)

5.2.1.3 Deeper/ inner connection

Spiritual care is seen to be taking the relationship to a deeper level: the patient – carer relationship as well as the patient’s relationship with self.

- *“in palliative care, we’re really about connecting with the patients on a much deeper level, trying to figure out where the issues are and people need the space to be listened to”* (H)

- *“seeing their inner feelings and their inner selves...how they cope, that was important”* (C)
- *“and it’s appropriate to kind of make one’s relationship with the patient more in depth”* (T)

5.2.1.4 Feeling valued

Offering spiritual care made the patients feel valued in terms of the greater interest shown and of the time the caregiver invested in the relationship.

- *“who wants to seek spiritual counsel with a Dr who wants to rush out the door”* (H3)
- *“they also valued that time spent with them, they felt now there was somebody more interested in the inner self, someone who wanted to understand them better”* (C)
- *“the ones who could communicate well and speak English, they really valued it as a way of the doctor taking more of an interest in them.”* (T)
- *“ They really welcomed that sort of a discussion, in a sense that a healthcare worker had a greater interest in them, their being, rather than just their pain and their nausea it really brings out a whole different aspect of the consultation. People say ‘I’ve never been listened to like this before’ and this discussion, I think is really helpful at this stage of their lives to be so recognised...this holding...I mean people really do appreciate this stuff, because it’s a big part of it for many people; it’s a very large part and they become more spiritual, religious whatever with time.”* (H)

5.2.2 Healing/ coping of Patients

Patients find strength and wholeness through spiritual care and healing.

- *“because in bad times we turn to pray or use muti (traditional African medication) so spirituality is diverse”.* (S2)
- *“these that did have faith and believed in something, it helped them cope with their stress”* (C)

- *“it was emotional but, at the same time helping the person to cope, even grow more, you know, taking it from the patient herself” (S)*
- *“pain is not only physical, it can be spiritual. And when people are having problems with their spirituality, it can cause a lot of pain, and deep pain, and then if you give them permission to look within themselves and to fine this feeling within themselves and to find what’s causing the pain, I think that it helps them, you give them permission to talk about it. Because often they’ve got this hole in their stomach, they describe it as a hollow feeling in their tummy, isn’t it? And it’s often spiritual pain, not really physical, and once given permission, they open up and they feel better after that.” (C)*
- *“One lady in particular, she really opened up, she was in remission for a long time, has now relapsed, has disease again and is on treatment. Once she looked within herself, she took a whole different approach to this relapse. It wasn’t just that ‘oh I’ve been a bad person or something’. She’s realised that these things do happen and she looked within herself and she didn’t blame herself anymore for the relapse, she felt that it was no fault of hers that it came back...not a punishment” (C)*
- *“the one with the ascites was deemed terminal, he got up and he started walking...he couldn’t move off his bed onto the wheelchair and then slowly there was this determination...I really believe that this had an effect on him” (C)*
- *“one man died, such a peaceful death...his wife...she couldn’t believe how he could be so serene and so peaceful. That search within himself might have helped quieten his spirit” (C)*

5.2.3 Learning experience of Caregivers

- *“some of the patients I was interviewing, they were deep and which made me realise that...life is short...it’s the unknown that is scary, so it made me really; gave me some fears and some deep thinking...” (S)*

- *“it was also a learning experience, for myself to see how far other people can view, you know, what is going on in their lives...it was quite an inspiration” (S)*
- *“what happens after death? You cannot work in this area without ever having given that question a thought, without ever having considered your own mortality...we’re really working at life’s edges, which you can’t do without having some spiritual awareness and questioning or whatever it is” (H)*
- *“even an atheist has a spirituality...he has feelings, he can touch, he can feel” (C)*
- *“right now, spiritual counsellors are really religious leaders that come and they just pray, their ministers in the church, and I wonder sometimes if they even have an idea of what spirituality is” (C)*
- *“it’s given me such a better understanding about spirituality...this now gave me a new perspective. We don’t help people spiritually; we help them find their spirituality, that search within themselves” (C)*

5.3 Spiritual Care for the Caregivers.

From the workshop to train the research assistants, it became clear that spiritual care for the caregivers is vitally important. Time alone as well as time to share within the group was considered helpful.

5.3.1 Group Work

- *“Would be good to do workshops at individual hospices – help staff to reflect. Can be useful in recognising burnout” (P4)*
- *“Discussion of personal experiences. Good reflection” (P1)*
- *“maybe some sharing of personal spiritual self to group so gives more a sense of diversity and wholeness in our unique approaches to our own spirituality” (P3)*

5.3.2 Personal work

- *“Absolutely loved the personal reflection...”* (P2)
- *“Personal reflection combined with presentation was able to better inform my role play use of FICA”* (P3)
- *“Personal reflection – renewal of the spirit within myself”* (P4)
- *“A look at our own spirituality. It is soul searching and gives us a chance to have introspection and improve thereon”* (P5)

Chapter 6

Discussion

The results of this study provide strong evidence to support answers to the research questions. The quality and richness of the data is almost overwhelming. The courage of the patients is inspiring and the depth of their spirituality revealed through their responses is incredibly moving and evokes a strong spiritual response in those who involved in this project. The initiation of a spiritual enquiry using the FICA tool is successful in a number of ways, some of them unexpected. It is clear that the caregivers themselves require ongoing care and time to invest in their own spiritual renewal and growth.

6.1 The Need for Spiritual Care in South Africa

It is evident from the richness and quality of the patient responses that there is a deep spirituality amongst our population and that spiritual care is needed and indeed welcomed by the patients. This sense of the spiritual need and the patients' appreciation of the opportunity to talk about it were strengthened by the confirmation of the initial responses with each new package of responses that was read. The patients' clearly stated spirituality confirms the assumption made that although there are no studies of this nature in South Africa, we all are spiritual and that spiritual growth is accelerated at the end of life. As with patients elsewhere in the world where spirituality has been studied, our patients have spiritual needs and these needs should be addressed as part of our total care plan.

6.1.1 Relationships

The patients all identified relationships as being very important. These relationships had been affected by their illness, often adversely, but could also be a source of strength and support for them. They had an opportunity to look at their relationship with God as well as themselves. Many found that they

were able to re-evaluate their relationships with others in their lives and make important positive changes.

6.1.2 Beliefs/Faith

Their beliefs and faith were also very important in helping them cope with their illness and in coming to terms with their mortality. Those belonging to a religious group found comfort in the collective and personal rituals practiced within their faith. Their spiritual needs were often non specific, requiring respect for their beliefs and rituals. They had few specific needs that were beyond the scope of the caregiver's ability to meet. Some did say that they would appreciate referral to somebody of their own faith for counselling and raised the point of having a professional available to help if they needed further assistance.

Traditional African patients, usually residing in the more rural areas of South Africa, often consult more than one practitioner when they are sick. Some will visit a sangoma (a traditional healer) who will explore existential causes for the illness, and the hospital will be visited for relief from physical symptoms.³¹ These patients may become confused when spiritual care is brought into a context of traditionally purely physical care, which would explain the statements in this context "I believe in the hospital"

Many of the urban patients may discontinue their traditional spiritual practices and culture and adopt a traditionally western spiritual approach to life. Some have incorporated other religious beliefs and rituals into their traditional spiritual view as is seen in the Traditional African Churches. However, in times of stress or illness, especially terminal illness, some patients may be seen to return to their traditional spiritual roots³².

6.1.3 Conflict in Spirituality

Sometimes, patients are pressurized by older members of the family or community, to return to traditional spiritual practices. With a strong culture of respect for the elders, this brings in an area of conflict in spirituality for the

patient. This spiritual conflict adds to the patient's suffering as he struggles with the dilemma of respect for his elders and his spiritual beliefs.

One sees similar conflicts in many patients where there is a different practice of spirituality within the family. This brings suffering into a very sacred area of the patient's life. Spirituality, with its potential to be life affirming, should be of support to patients in their illness and yet under these circumstances of conflict this support is not available to them. These conflicts in spiritual beliefs and practices potentially cause immense suffering and pain for patients and families alike. Addressing these spiritual needs will hopefully resolve the conflict and restore the vital support that they need at this time. In fact, one could argue that spiritual care **is** the most important care that can be given. It is **only** through the spiritual dimension that the patient can truly come to peace and acceptance about his physical illness. It is **only** through the spiritual part of self that one can find meaning in death and that is that patient's immediate reality.

6.1.4 Death: A journey into the Unknown

Terminally ill patients are about to embark on a journey into the unknown. They have to face it. Even those who deny it will still have to face death at the point of their last breath. It is inescapable, inevitable. Surely the best that we actually could do for these patients is to help them by being prepared to talk about death, discuss their fears and expectations and help them prepare for this journey. Any explorer who journeys into the unknown would surely talk about it at length with friends, family and colleagues. They would discuss their fears and expectations; possible dangers; possible 'discoveries'. They would prepare themselves for the unknown, physically, mentally and spiritually. In fact, without a strong belief that what they are doing is to be beneficial, having faith that they would be safe, and hope for a positive outcome, they would not choose to embark on such a journey. Even the love and support of their family and friends is vitally important. However one cannot choose not to journey into the unknown through death. How much more important to the patient, then, is the support and love of those around them, faith and hope, in the circumstance of their terminal illness?

6.1.5 Facing Death and Finding Hope³³

Maybe, if we could escape death ourselves, it would be easier to talk to a terminal patient about his death. Is it not our own fears about our own mortality and our choice to rather not think about it that make us uncomfortable about discussing this life threatening journey? Talking about death raises fear in each of us and that makes us feel uncomfortable. It is easier to avoid the discomfort, in effect denying the reality of death. And yet, facing the reality of our own mortality is life-giving. When we confront our fear, accepting the fact that we could die at any time, life becomes more precious; our loved ones become treasures to enjoy every day. Maybe we wait until our deathbeds to heal relationships because we do not appreciate the fragility of life every day. It does not mean that we must be morbid and think about our own deaths all the time but by accepting that death is a reality and is a part of our lives, we will live more fully and love more deeply and enjoy life more. What more could we ask for?

Even patients, who believe that there is no life after death, need to come to an acceptance of that belief, possibly through having found meaning in their life. I have personally seen a patient who was very comfortable and peaceful, believing that there was no life after death, that it was the final end to life. She had enjoyed her life but was ready to die. She was not in denial and was fully aware and ready to talk about her death. There was no need to change her beliefs as that is not our mission. The caregivers are to accompany patients with compassion and respect for their beliefs. She died peacefully.

6.2 The use of a Spiritual Assessment in Addressing Spiritual Needs

The use of a spiritual assessment tool assists the doctor to open up the discussion of spirituality and sensitively explore any areas of spiritual need. In this study, doing a spiritual assessment gave the caregivers a lot more information about the patients. Caregivers could assess how the patient was coping with their illness. They felt that the relationship became more

meaningful with a greater mutual understanding. All the patients in the study had had an initial consultation with the caregivers.

During the first consultation, the usual history and examination was completed. The spiritual assessment was done at a subsequent meeting or immediately after the initial consultation. After the spiritual assessment, the caregivers felt that they had developed a deeper rapport with the patients. They also felt that they had a better understanding of the patients' coping with their illness. It can be concluded that the spiritual assessment had been helpful in adding to the insight gained by the caregiver into the patient's wholeness. The caregivers commented, on occasion, that they also benefited from the interaction on a personal level, learning from the patient's experiences.

It is important that there is a caring respectful relationship between patient and doctor. It seems that even doctors, who are comfortable with discussing spirituality, feel more comfortable doing so once a relationship has been established. Personal experience has shown that using a spiritual assessment in the first visit is more exploratory with very basic information requested to assess the patient's spirituality. Later, in subsequent consultations, the spiritual issues can be revisited with more depth if both patient and doctor are comfortable with this level of relationship and discussion. As always in palliative care, the caregiver follows the patient's lead. Sometimes due to the terminal state of the patient, it may be appropriate, with the patient's permission, to go deeper into these issues and help the patient with closure at this time at the first meeting.

6.3 The Art of Presence as Spiritual Care

It became clear from the data that there are two dimensions of spiritual care. The spiritual assessment tool is important to open up dialogue with the patient and evaluate their spiritual needs specifically. The other dimension we all have the potential to offer is the art of presence. The findings of this study are congruent with the findings of T.P. Daaleman⁷ who proposed three primary

components of a conceptual framework of spiritual care: being present, open eyes and co-creating. The doctor is present to the patient in need, providing a safe space for the patient to be in his pain. With empathetic listening and being open to the patient's story, the doctor becomes aware of the patient's story and real needs. Together with the patient and any significant others, there is a co-creating of a plan of care.

Being present requires an intention to be open and vulnerable on the part of the doctor. This quality is inherent in all of us but needs awareness, willingness and practice. These intentions require no specific training. We can all do it if we are prepared to open ourselves to another's pain and be available as support to them. We may already do this with family or friends in times of suffering. However, it does require awareness and willingness on the part of the caregiver who will themselves may require support when offering this depth of care.

While being present is an important aspect of spiritual care and should be inherent in the relationship, dealing with specific spiritual needs is a professional task which requires specific training. A doctor may be able to enquire about spirituality, eliciting any needs but few are trained in spiritual care counselling. It is important to recognise our limitations and to refer a patient to a specialist in the field of spiritual care when appropriate.

With active listening and by using a spiritual assessment, the doctor will be able to refer to a counsellor who will be appropriate to help the patient. While doctors do not need to have in depth knowledge of the various religions and forms of spirituality, it is desirable that a doctor is aware of the important beliefs of the population of patients most commonly encountered in their scope of practice.

6.4 Spiritual Care as a Healing Intervention

The potential of the spiritual assessment to be used to initiate healing became clear from some of the experiences recounted by the caregivers. There were

patients who realised, from participating in the study, that they could make some positive changes which enhanced their lives. Some discovered an untapped source of strength in their spirituality discovered meaning in their suffering. One patient, who had been considered terminal, improved to such an extent that he was discharged to go home, with new hope and a sense of purpose in life. Some patients were able to re-evaluate their illness and heal broken relationships with family. One woman reviewed her beliefs about her own role in the cause of her illness, and was able to find peace and acceptance. Another patient was able to come to an acceptance of his terminal illness and died very peacefully which was helpful to his family in their bereavement.

Many of the changes of patients' attitudes and their healing took place with the help of the spiritual assessment and with the care offered by the caregiver by being open and prepared to hold the patients in this difficult time. While these caregivers usually work within an environment that is open to spiritual care, they are not qualified as spiritual counsellors. Yet their willingness to be available to the patients and to do the assessment, allowed for spiritual healing. If more difficult spiritual issues arise, the patients are to be referred as required. In the face of overwhelming losses, the patients felt much better; more whole.

Not only did the patients experience healing but the caregivers benefited from the interaction too. They felt better about being able to offer the patients true holistic care and gained insights into their own spirituality too. These outcomes of healing in patient and healer were unexpected. The positive results of healing show the power of a simple tool to open up conversation and present an opportunity for growth.

6.5 The Usefulness of the FICA Spiritual Assessment Tool in Assessing Spiritual Need in South Africa

The FICA assessment tool was generally well received by the patients and caregivers. The primary problems seemed to be with translation into the local vernacular. Some of the concepts had to be explained. The rural community

struggled with the assessment, however it was still felt that FICA was useful and patients felt better understood by the caregiver or doctor. The caregivers all would continue to use the FICA, either as it is, or in a simplified form. The FICA spiritual assessment tool is very useful and easy to use as it is for some of the communities in South Africa. In some communities, a direct translation of the FICA tool may not be readily understood but the tool could be used as a guide for the caregivers to develop their own spiritual assessment guide based on the language and culture of the community they work in.

6.5.1 Time

The spiritual assessment using the FICA tool in this study took a lot longer than the proposed 2-3 minutes.²⁵ Generally 7-15 minutes were required, depending on the group of patients being interviewed. Some of the time was needed to translate and paraphrase or explain the questions. Some of the patients needed longer to answer the questions and some wanted to deepen the discussion. Where translation contributed to the time, the caregivers felt that it would become quicker with repeated use. For others, it was felt that the same time would be required, even as caregivers became familiar with the assessment because each new patient would require a similar time to answer the questions.

6.5.2 Appropriateness of Questions

The questions were thought to be appropriate although one caregiver commented that it depended on the patient. The "Faith" question was most appropriate at all sites. A spiritual assessment is essentially about a patient's beliefs or faith, which is generally understood across cultures. The "Address" question was considered least appropriate at Chatsworth and Tintswalo, perhaps because patients did not feel empowered to make suggestions regarding their own health care. The community question was thought to be least appropriate by the patients at Soweto. The reason for this response remains unclear as community is considered very important in African culture. Often decisions regarding health care are communal, at least within the family. It may be possible that the "western" influence has disrupted this

aspect of African culture. Further study would be required to accurately explain this unexpected response.

6.5.3 Effects of Culture

The FICA assessment was well received by the patients at Houghton, Soweto and Chatsworth with a varied response from the patients at the rural facility at Tintswalo. The responses at Tintswalo depended on the individual patient's education level and understanding of the process. The concept of "Stress" had been difficult to explain and translate into the local language. The differences in responses may highlight the differences in culture and degree of "westernization" of the participants. At the three urban sites, the patients have been exposed to more western (non – African) culture and forms of spirituality. These patients have often absorbed western ideals and norms into their world view and are more familiar with traditionally western spirituality. At the rural site, patients are more likely to continue their traditional practices in terms of spirituality which is integrated much more in their daily life. Spiritual practice may not be seen as something separate which is only practised at appointed times.

6.5.4 Patient – Caregiver Relationship

The caregivers all felt that the assessment improved their understanding of the patients and found it useful in their care for their patients. This was also reflected in the effect it had on the caregivers themselves. Some felt that it had helped them to try to understand their patients better. One caregiver felt that it did not change her approach to the patients significantly because she usually considered spiritual issues in her consultations. Despite initial concerns about the assessment being too intrusive, caregivers never felt uncomfortable and nor did the patients.

6.6 Ethics of Research in Vulnerable Populations

6.6.1 Respect

Prior to commencing this research, there was much discussion about the ethics of research in a vulnerable group of people as well as the ethics of researching a topic that was considered very sensitive and could be

construed as being intrusive. The research assistants were concerned about the ethics of discussing spirituality with patients. There emerged a clear pattern of thought regarding this aspect. There must be respect for the individual reality of patients. Love must be unconditional and there needs to be real compassion for patients and families with in depth commitment to the relationship and one's work in general. If this research had been conducted in any way that was disrespectful it would have been unethical.

When doctors are working with patients who are facing death, it is often necessary to forge a deeper relationship and to ask questions and grapple with issues that may seem intrusive in a different specialty of medicine. Doctors already have the privilege of getting closer to a patient than any stranger would by the very nature of their profession. A doctor patient relationship is very intimate and should be held sacred by the doctor who is already bound by rules of confidentiality. All patients should be approached respectfully right from the start of the consultation.

6.6.2 Beneficence

Terminally ill patients are facing death and topics that may be taboo in other situations of society, become very important. In general, the issue of our own mortality is not raised in social interactions. When consulting a doctor for a sore throat, a discussion about death would be inappropriate, but it is appropriate at the end of life. Trying to hold a meaningful conversation, avoiding the obvious distress of the patient, is virtually impossible.

With the understanding that a sensitive approach to spirituality in terminally ill patients is appropriate, the question of conducting research in this group of patients remained. The decision to continue was justified by the patients' responses. None of the patients felt uncomfortable and they felt that a spiritual enquiry had been appropriate. In fact most of them welcomed the opportunity to discuss spiritual issues and some even found it to be therapeutic. This would confirm the premise that if the research is appropriate and is honestly and sincerely addressing the patients' needs in respectful manner, it can be

helpful and indeed justified in a vulnerable group of patients. The outcome of such research is improved care of patients who are terminally ill.

6.7 Limitations of the Study

This study evaluated the use of a spiritual assessment tool which had not been translated. The main objective had been to introduce a tool for use by the doctor in consultation. Doctors in South Africa are familiar with English and should have no problem with the tool themselves. Where a doctor does not speak a patient's language, there is a translator, usually a nurse, to help. However, at the rural hospital, the nurses had not attended the training workshop. Some of the concepts may have been difficult for them to understand and to try to translate. The meaning of the questions may have altered with translation from English to the local language and back to English. Similarly, the interview guideline was intended to guide the interviewer, but may have been used to conduct a more structured interview. The intended meaning of the questions may also have changed slightly in translation. Despite these possible problems, the spiritual assessment was favourably received, and the data was relevant to the intention of the study.

The study focused on carefully chosen sites to reflect the cultural diversity of our country and enhance the depth of information collected, making the information more representative. The differing roles of the caregivers, within their respective palliative care teams, could have resulted in potential bias in data collected as each is relating to the patient in different professional capacities. This may have added confounding factors to the data. The analysis of the data did take the possible bias into consideration. Bias is a weakness of qualitative research; however, this methodology enriches the data gathered specifically as it focuses on the individual patient's response and feelings.

6.8 Improving Caregivers Confidence in spiritual care and use of an assessment tool

6.8.1 Workshops

Interactive workshops are very useful to introduce a spiritual assessment tool to doctors. Puchalski uses workshops to equip doctors to offer spiritual care and to use the assessment tool. The experience of this study was that the presentation and interactive discussion on spiritual care was well received and helped clarify issues of spirituality. The participants felt quite intimidated by the thought of offering spiritual care and felt ill-equipped to offer such care. During the discussions it became clear that there was a need for spiritual care and that it was not being addressed appropriately. Spiritual care has historically been given a low priority probably through unawareness or through apprehension. Medical care and spiritual care are traditionally seen as separate spheres of care. However there is a growing realization that healing is not just physical or spiritual but an integrated process.

6.8.2 At medical school

With the important insights gained in this study which add to the accumulating evidence from other studies, it is important to introduce spirituality and training in providing spiritual care into the medical schools. As the technology in medical care increases, compassion in care seems to have diminished.⁶ Doctors are being drawn more and more into managed health care with financial considerations becoming more prominent than caring. The art of medical care is being replaced by the technology and commerce of medicine.

Doctors need to be given the space to become aware of the importance of spirituality in medicine. They would then be empowered to offer spiritual care with confidence. It is important to introduce spirituality in medicine early in the careers of medical students to run parallel with technical training thereby producing balanced healers. Training in medicine is very demanding. An opportunity to discuss spirituality and spiritual care for patients and caregivers would provide the students with coping strategies. Topics such as spirituality vs. religion, spiritual care and ethics, use of a spiritual assessment tool, own spirituality/mortality and self care, effective communication with chronically ill

and dying patients, and including spiritual counsellors and chaplains as members of the multi-disciplinary team, as suggested by Puchalski^{Error!} Bookmark not defined. could be included in the *curricula*.

6.9 Support for Caregivers and Their own spirituality

The doctors who are willing to engage in this art of care would be at risk of being overwhelmed by the emotional work involved in healing. It is therefore important, that these doctors are aware of the effects on themselves of offering empathetic care. They need regular care and support themselves either in the context of their work or through activities outside of the workplace. Through fulfilling, self nurturing practices renewal can take place. At the training workshop the participants recognised the importance of their own spiritual care and how helpful the workshop had been in providing an opportunity for self care.

The time for personal reflection was considered very worthwhile to recharge as well as to clarify their personal beliefs. The interactive discussion also allowed time to debrief with participants recounting experiences with patients and even their own spirituality within the safe space of the small group facilitated by a spiritual counsellor. Hospice care is very demanding as staff care deeply for their patients. Besides the day to day clinical care offered, hospice staff give a lot of themselves, emotionally, to the patients and the patients' loved ones. The opportunity to sit and reflect, in a calm, caring space gave them time for themselves to be supported by the facilitators and their peers. One participant felt that this service should be extended to all hospices on a regular basis.

6.10 Recommendations

6.10.1 Spiritual Assessment and an Assessment Tool

Hospices and institutions offering palliative care should incorporate a spiritual assessment into the case history of each patient.

Hospices should ensure that they have access to the services of several spiritual counsellors as are available to refer patients to if required. The

spiritual counsellors should attend training in hospice care. They should be sensitively screened to assess their appropriateness for work in a hospice setting. Care should be taken to avoid proselytising or the potential for lack of respect for the patients' spirituality.

The FICA spiritual assessment tool should be used as is for doctors doing a spiritual assessment in communities where it would be easily understood. For communities who have difficulties with the tool, it should be used as a guide to develop a simple spiritual assessment tool in a language that is easily understood by the patients and caregivers and that is culturally appropriate.

6.10.2 Training and Support for Caregivers

Hospices should include, as part of their in-service training, spiritual care and the spiritual care assessment tool to be used by that institution. They also need to ensure sufficient support or opportunity for staff to debrief and revitalise their own spirituality.

6.10.3 Introducing Spirituality into Medical *curricula*

Introduce spirituality into the medical *curricula* to help students become more aware of this aspect of healing. Training in spirituality should be offered in each year of the course. Clinical students should have access to spiritual counsellors to help them cope with the realities of working with very sick patients.

6.11 Conclusions

Spiritual care is a vitally important aspect of patient care. Given the immense suffering of terminally ill patients these needs are especially important to address. Hospices are increasingly aware of the need for spiritual care but often struggle to address this area of care adequately. A spiritual assessment tool would make it easier for caregivers to open up the discussion of spiritual needs with patients and these needs can then be addressed adequately, with referral to specialists as required. The FICA spiritual assessment tool is suitable for use as it is or may be used as a guide to formulate a suitable assessment tool for a specific community.

Care is an innate spiritual quality in the practice of medicine and healing. However with advances in the technology of medical care, the spiritual aspects of care are being lost. Introducing spiritual care into medical *curricula* to be taught alongside the physical aspects of care will result in medical doctors with a balanced education and added skills to treat patients holistically.

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27 May 2009

Dear Liz,

Re: MPhil Dissertation

I have made the corrections to the dissertation as recommended by the examiners:

Dr H. Conradie:

2. She demonstrated appropriate knowledge of and practice of the qualitative research methodology she used.
 - a. It would have been useful to refer to the appendices in the text e.g. pg 30 4.5.2.3. interview schedule for carers
 - b. Pg. 62 6.5.1. line 2; reference required for ..2-3 minutes...
3. The interpretation of the data is extensive with numerous quotes from interviews which illustrates the conclusions she makes.
4. There are a few minor typographical errors which in no way distract from the quality of the thesis.
 - a. Pg 20 (J.K. Hallenbeck(2003) and pg 27 (C. Puchalski,1999) change to different reference system.
 - b. Pg 32 line two (confidant ? confident).
 - c. Pg 46: the references to (P) and P7) was not clear.
 - d. Pg 56: line 5 (?delete who).
 - e. Pg 61, paragraph two line 3; ..to (be) available....
 - f. Reference 9 – source not clear.
 - g. Reference 33 "Facing Death and ?Finding Hope".

2a I have inserted references into the text to the appendices with regard to FICA spiritual assessment tool, the two interview schedules and the patient information leaflets and consent forms:

- Pg 29 para. 4.5.2.2 FICA Spiritual assessment tool (appendix 1) and patient interview guideline (appendix 2)
- Pg 30 para. 4.5.2.3 Caregiver interview guideline (appendix 3)
- Pg 32 para 4.7.2 Participant information and consent (appendices 9 -13)

2b Pg 62 para 6.5.1 I have referenced the "2-3 minutes" to reference no. 25; Puchalski C. 1999.

4a Pg 21 and pg 27: I have corrected the referencing so that it is consistent with the rest of the document

4b Pg 32 corrected spelling to read "confident"

4c Pg 46 corrected "P7" to read "P"

4d Pg 56 changed "those who belong to" to "those belonging to"

4e Pg 61 inserted "be" to read "to be available"

4f Reference 9: added "conference" to Palliative care – Mind, Body and Spirit to reference, to clarify source

4g Corrected spelling of "Finding"

Dr F. Rawlinson:

Apart from two very minor typographical errors,

- **abstract : ‘curricula’ in the penultimate line**
- **p22 9th line down – feel(s)**

the project was very well presented, with appropriate use of tables and quotations.

- In abstract, changed “cirricula” from italics
- P22 Changed “feels” to “feel”

Yours sincerely

Dr C.L. Blanchard

University of Cape Town