

***THE RESEARCH AND DEVELOPMENT OF A PALLIATIVE CARE  
MEASUREMENT TOOL.***

**by**

**Hendrik Johannes Loubser**

**Submitted in fulfilment of the requirements**

**for the degree of**

**MASTER OF ARTS**

**in the subject**

**Health Studies**

**at the**

**UNIVERSITY OF SOUTH AFRICA**

**SUPERVISOR: Prof Micheal C Herbst**

**December 2008**

**Student Number: 43349138**

**é estudo é dedicado a Antonio ...**

**COPYRIGHT**

The copyright in this published edition is owned by Unisa. No part of this document may in any form or by any means (including without limitation: electronic, mechanical, photocopying, recording or otherwise) be used, copied, reproduced, amended, adapted, or transmitted. No express or any implied right or license to use, copy, reproduce, amend or adapt or transmit the whole or any part of this document is granted to any person or other legal entity.

The work embodied in this document is proprietary material of South African Database for Functional Medicine (Pty) Ltd and is covered by RSA patent application 2008/09086 and no part of the work may in any form or by any means (including without limitation: electronic, mechanical, photocopying, recording or otherwise) be used, copied, reproduced, amended, adapted, or transmitted, without the prior consent of South African Database for Functional Medicine (Pty) Ltd. No express or any implied right or license to use, copy, reproduce, amend or adapt or transmit the whole or any part of this document is granted to any person or other legal entity without the prior written consent of South African Database for Functional Medicine (Pty) Ltd. (see Annexure 1)

**DECLARATION**

I declare that *THE RESEARCH AND DEVELOPMENT OF A PALLIATIVE CARE MEASUREMENT TOOL* is my own work and that all the resources used and quoted by me have been indicated and acknowledged by means of a complete reference list and that this work has not been submitted before for any other degree at any other institution.

Hendrik Johannes Loubser

## Acknowledgements

My sincere appreciation to Sue Janse van Rensburg – CEO of CANSA - with her extra ordinary abilities of lateral thinking and creative mind that lead her to ask me to conduct this study. She believed that there must be an outcome for the informal care-giver when rendering palliative care to the dying person, and she wanted that outcome measured.

To Dr Carl Albrecht – head of research at CANSA - for his sharp mind, dedication, encouragement and guidance in the study.

To all the informal caregivers and staff of CANSA that contributed in one way or the other to the outcome of this study. My wish is that the final product may enrich your and your client's lives.



To my supervisor Prof Micheal Herbst who set me free to explore, to find and to record and then gently guided me to apply the research science tools to bring about the richness of this accomplishment. The pleasure of enjoying this steep learning curve I owe to Michael.

To Prof Vasi van Deventer (UNISA) for his data analysis and psychometric testing of the data and support.

To my friend Daleen Casteleijn for her infinite wisdom and enthusiasm in the research and design of clinical measurement tools and her willingness to help me.

Finally, to my friend AJ Teixeira for moral and technical support throughout this study.

***RESEARCH AND DEVELOPMENT OF A PALLIATIVE CARE MEASUREMENT TOOL.***

**STUDENT NUMBER: 43349137**

**STUDENT: HENDRIK JOHANNES LOUBSER**

**DEGREE: MASTER OF ARTS**

**DEPARTMENT: HEALTH STUDIES, UNIVERSITY OF SOUTH AFRICA**

**SUPERVISOR: PROF MICHEAL C HERBST**

**Abstract**

The study sought to research and develop a universal palliative care measurement tool that will track the performance of informal caregivers to dying persons across the diversity of the South African cultural and religious groupings.

The major inferences drawn from this study was that a generic domain, sub-items and intervals could be identified for palliative care; that a reliable measurement tool could be developed and that outcomes of care programs for dying persons in terms of effectiveness and efficiency could be numerically quantified.

With the ability to measure now been realised, the ability to manage the outcomes became the new challenge.

**KEY CONCEPTS**

Palliative care, measurement tool, outcomes management, informal caregivers

<b>Tabel of Contents</b>	<b>Page</b>
<b>Chapter 1 .....</b>	<b>10</b>
<b>INTRODUCTION AND OVERVIEW OF THE STUDY .....</b>	<b>10</b>
<i>1.1 INTRODUCTION .....</i>	<i>10</i>
<i>1.2 BACKGROUND TO THIS RESEARCH.....</i>	<i>12</i>
<i>1.3 BACKGOUND INFORMATION TO THE RESEARCH PROBLEM .....</i>	<i>14</i>
<i>1.4 AIMS OF THE RESEARCH .....</i>	<i>22</i>
<i>1.5 OBJECTIVES OF THE RESEARCH.....</i>	<i>23</i>
<i>1.6 SIGNIFICANCE OF THE STUDY .....</i>	<i>23</i>
<i>1.7 SCOPE AND DELIMITATIONS OF THE STUDY .....</i>	<i>26</i>
<i>1.8 WORDS, EXPRESSIONS OR TERMS USED IN THE STUDY .....</i>	<i>27</i>
<i>1.9 ORGANISATION OF THE REPORT .....</i>	<i>28</i>
<i>1.10 SUMMARY.....</i>	<i>29</i>
<b>Chapter 2 .....</b>	<b>30</b>
<b>LITERATURE REVIEW .....</b>	<b>30</b>
<i>2.1 INTRODUCTION .....</i>	<i>30</i>
<i>2.2 PURPOSE AND SCOPE OF THE LITERATURE REVIEW .....</i>	<i>31</i>
<i>2.3 CURRENT UNDERSTANDING OF THE QUESTIONS IN THE STUDY .....</i>	<i>31</i>
2.3.1 Questions on qualitative research techniques .....	31
2.3.2 Questions regarding existing tools.....	32
2.3.3 Questions on basic tenets (or doctrines or teachings) of the .....	33
palliative (or end-of-life) care process.....	33
2.3.4 Questions on how to develop a clinical measurement tool .....	38
2.3.5 Questions on the psychometric properties when developing a .....	42
measurement tool .....	42
<i>2.4 STRATEGY THAT EMERGED FROM THE LITERATURE REVIEW .....</i>	<i>47</i>
<i>2.5 STRENGHT AND WEAKNESSES OF THIS LITERATURE REVIEW .....</i>	<i>49</i>
<i>2.6 SUMMARY .....</i>	<i>49</i>
<b>Chapter 3 .....</b>	<b>51</b>
<b>RESEARCH METHODOLOGY.....</b>	<b>51</b>
<i>3.1 INTRODUCTION .....</i>	<i>51</i>

<b>3.2 APPROACH TO THE RESEARCH.....</b>	<b>51</b>
<b>3.3 RESEARCH STRATEGY.....</b>	<b>54</b>
<b>3.4 FIRST PHASE:- THE QUALITATIVE METHODOLOGY.....</b>	<b>57</b>
3.4.1 Qualitative: Research population .....	57
3.4.2 Qualitative: Research sample .....	60
3.4.3 Qualitative: Sampling criteria used.....	60
3.4.4 Qualitative: Data collection.....	62
3.4.4.1 First visit .....	64
3.4.4.2 Second Visit .....	66
3.4.4.3 Third Visit .....	67
3.4.4.4 The logistics to assemble the focus groups for data collection.....	67
3.4.5 Qualitative: Data Analyses .....	69
3.4.6 Qualitative: Trustworthiness of the data .....	72
<b>3.5 SECOND PHASE : THE QUANTITATIVE METHODOLOGY.....</b>	<b>73</b>
3.5.1 Quantitative: Research population.....	74
3.5.2 Quantitative: Research sample .....	76
3.5.3 Quantitative: Data collection.....	77
3.5.4 Quantitative: The logistics to collect the data .....	78
3.5.5 Quantitative: Data analyses .....	79
3.5.6 Quantitative: Data objectivity.....	80
<b>3.6 ETHICAL CONSIDERATIONS.....</b>	<b>81</b>
<b>3.7 SUMMARY.....</b>	<b>83</b>
<b>Chapter 4.....</b>	<b>84</b>
<b>PRESENTATION AND DISCUSSION OF THE DATA.....</b>	<b>84</b>
<b>4.1 INTRODUCTION.....</b>	<b>84</b>
<b>4.2 THE GATHERING AND ANALYSIS OF THE QUALITATIVE DATA.....</b>	<b>85</b>
4.2.1 What was the profile of participants? .....	85
4.2.2 Information gathering process .....	86
4.2.3 Data collected in the first round of meetings .....	89
4.2.4 Data collected in the second round of meetings .....	96
4.2.5 Designing and developing the measurement tool .....	102
4.2.6 Verifying data at the third round of meetings .....	104
4.2.7 Analysis of the quantitative data.....	107
<b>4.3 SUMMARY.....</b>	<b>110</b>
<b>Chapter 5.....</b>	<b>112</b>
<b>CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS.....</b>	<b>112</b>
<b>5.1 INTRODUCTION.....</b>	<b>112</b>



<b>5.2 DISCUSSION OF THE IMPLICATIONS OF THE STUDY</b> .....	<b>112</b>
5.2.1 Implications of the study in general terms .....	113
5.2.2 Implications to the dying person.....	114
5.2.3 Implications to the dying person’s family and loved ones.....	115
5.2.4 Implications to the CANSA caregivers.....	116
5.2.5 Implications to the CANSA supervisors .....	118
5.2.6 Implications to the training and development of CANSA caregivers. ....	120
5.2.7 Implications to CANSA .....	122
5.2.8 Implications to the health industry.....	122
5.2.9 Implications to further research opportunities.....	123
<b>5.3 RECOMMENDATIONS</b> .....	<b>125</b>
<b>5.4 LIMITATIONS OF THIS STUDY</b> .....	<b>126</b>
<b>5.5 PERSONAL AND EMOTIONAL EFFECTS OF DOING THIS STUDY.</b> .....	<b>127</b>
<b>5.6 FINAL CONCLUSION</b> .....	<b>127</b>
<b>Bibliography</b> .....	<b>129</b>
<b>ANNEXURE 1</b> .....	<b>133</b>
<b>ANNEXURE 2</b> .....	<b>134</b>
<b>ANNEXURE 3</b> .....	<b>145</b>
<b>ANNEXURE 4</b> .....	<b>147</b>
<b>ANNEXURE 5</b> .....	<b>150</b>
<b>ANNEXURE 6</b> .....	<b>154</b>
<b>ANNEXURE 7</b> .....	<b>158</b>
<b>ANNEXURE 8</b> .....	<b>162</b>
<b>ANNEXURE 9</b> .....	<b>163</b>
<b>ANNEXURE 10</b> .....	<b>166</b>

## Chapter 1

# INTRODUCTION AND OVERVIEW OF THE STUDY

## 1.1 INTRODUCTION

*“Birth and death are the only two certainties in life..... what happens in-between is unpredictable.....” HJL*

Dame Cicely Saunders founded St Christopher's Hospice in London in 1967, the first palliative care research and teaching institute that included home care and family support to dying persons. The St Christopher's Hospice paved the way for the palliative care movement internationally (Doyle, *et al.* 2004). As palliative care evolved over the years, it took on different meanings and definition to various healthcare workers depending on the field of their speciality, care setting they work in or country of origin. In 2007 the European Association for Palliative Care (EAPC) Task Force on the Development of Palliative Care in Europe published its report of their findings on the status of palliative care development - as defined by the World Health Organisation (WHO) – in 52 countries covering a population of 879 million people (Centeno, *et al.* 2007). The report confirmed that there is not only a huge diversity in the types of services rendered under the notion of palliative care, but that there is also a lack of standards and universally accepted definitions for the different palliative care services that they render.

What is understood by the term palliative care or how it is defined, or quantified or interpreted varies considerably between the 52 countries, and even between the regions within countries. However, irrespective of the lack of a common language in defining palliative care services, there seems to be universal consensus that people with life threatening illnesses are subjected to a basic trajectory of decline with the following characteristics (Eagar, *et al.* 1997:16)

- a. *Stable* phase where the diagnosis of the life threatening condition is made e.g. cancer etc;
- b. *Unstable* phase where the patient is receiving life-prolonging therapy or medication with or without adverse side effects e.g. nausea, etc;
- c. *Deteriorating* phase where no therapy or medication have any life- prolonging effect and where services are directed to psycho social distress.
- d. *Terminal* phase where all services are directed to render comfort and peace for the dying person.
- e. *Bereavement* phase follows death and counselling is directed to the remaining family.

Palliative care in this dissertation - and from here forward - will refer to the caring service that provides comfort to the dying person\* (see operational definition in Chapter 1 paragraph 1.7) during the “deteriorating and/or terminal” phases of decline. The care for these persons is unique as it finds ways and means to allow a person to die in peace rather than in distress and do not haste or postpone death.

In my 20 years experience as a family practitioner, palliative care have been described by pragmatists as a nebulous, indefinable and a holistic service and by the devoted as a service of the heart, the soul and the body. The Hospice Movement seems to have consensus that the service is complex, and that those that render the service must be an all rounded person with a unique combination of clinical, spiritual, psycho-social and physical skills.

Traditionally, when asked for evidence to the effectiveness of palliative care, the providers used descriptive evidence elucidating the processes involved in delivering the care. In support of this informal feedback they tend to refer to pictures, anecdotal stories and produced thank you cards from grateful families as evidence of a job well done. This mode of reporting seems to satisfy the needs of the donor funders to the service but the formal healthcare funders such as medical schemes are more sceptical as to whether the service meets the dying persons and their loved one’s needs and expectations in a cost effective manner. The providers of palliative care are increasingly reminded by the formal healthcare funders to provide ongoing valid and reliable evidence that their services are based on meeting the needs of patients

and their families and to render proof that they are successful in doing so. (Carson, et al. 2000)

The lack of auditable proof, lack of consistency in evidence and invalid indicators creates a barrier for future healthcare funding of the services. The literature also reveal very little, if any, valid and reliable patient based research tools to be used routinely in researching the dying persons needs, monitoring the patient's acceptance of the care and the outcomes of the care on the patient's wellbeing. Granda-Cameron, et al. (2007) warns that the viability and future expansion of the palliative service indeed will depend on well structured scientific research proofing that it meets both the dying person and their family needs. They conclude that it now becomes a critical issue to develop a measurement tool that tracks the dying person and their family's outcomes over time.

A palliative care performance measurement is, therefore, needed to determine whether a particular palliative approach is working according to a planned outcome or not. If such a tool is achievable to produce valid performance data, it will provide the information decision makers require to monitor the palliative goals, progress and quality of care a dying person receive. It may also provide the data researchers and managers need to formulate the strategic questions and conclude the right answers and decisions. If it will have the capabilities of being routinely implemented, it will not only fulfil the funding and research needs of a new emerging healthcare service, but it will also fulfil the clinical governance needs of a the service. (Arya & Callaly. 2005.)

## 1.2 BACKGROUND TO THIS RESEARCH

*“Although we must be committed to life saving interventions ..... we cannot neglect the support to those for whom these interventions come too late”.....HJL*

A crippling pandemic of HIV/Aids, multi-drug resistant tuberculosis and cancer is sucking the life out of the rural communities of Southern Africa. This pandemic is leaving millions of victims dying daily an undignified death; full of fear, in agony,

anxious of what is to become of their children, depressed, stigmatized and grappling with unresolved issues. These devastating experiences are generally playing out in poor, hidden settings and are far removed from the notion that all lives have equal value. These victims are mostly at the mercy of home based palliative care workers, and during this study my personal observation was that workers have case loads of up to 10 or more dying people to care for at any point in time. These “angels of mercy” go about their vocation receiving a meagre but grateful government stipend of about R800 per month for their services. However, there is no national information system and evidence-based framework in place that will enable us to collect data, learn lessons and to discern and to disseminate the best practice of what constitutes a dignified exit for the victims.

One needs to put this task of caring for the dying people into an operational framework that will give direction and specificity to the care-workers and to benefit the dying persons and their families. At the same time one should be able to measure the performance of these palliative care workers, capture their outcomes data in a robust database, and retrospectively analyse their effectiveness in going about their tasks of caring for the dying persons. For this we need a palliative care measurement tool.

In the research to develop a measurement tool we will have to confront and seek answers to the following questions: What is end-of-life care all about? What are the critical components of caring for the dying person? What value is added by these informal palliative care workers? What are the care-workers hoping to achieve and are they successful in achieving that? Which worker is adding more value than his/her peers? What determines this? What can one learn from those workers that are adding the most value and bringing dignity to the terminally-ill? Where can we intervene with minor interventions that may achieve major outcomes? If so, what will that value-adding intervention be? Can this process of care for the dying be “managed”? Can we add value with a goal-driven management strategy? Will that value impact positively on the dying person? How can we secure equal value and dignity for the dying person in this pandemic? If we can succeed to develop such a tool, and the tool can be routinely implemented, we might be able to also fill the clinical governance issues whereby healthcare services are accountable for

continuously improving the quality of their services and safeguarding high standards of care. (Arya & Callaly, 2005.)

### 1.3 BACKGROUND INFORMATION TO THE RESEARCH PROBLEM

*“All of us will die one day..... some of us will be lucky to get a early warning that our time is up..... the unlucky one’s life will be stolen from them without them even knowing it..... while the lucky ones will have time to prepare a legacy ..... and it is our job to help them create that legacy”. ..... HJL*

While the above discussions are about gathering data to develop a measurement tool, the following questions will require answers to give background information where by the data can be contextualised.

#### **Is there a uniform definition for palliative care?**

The WHO (2002) defines palliative care as “an interdisciplinary team approach that improves the quality of life of patients and their families living with a life-threatening illness through early identification, assessment, and treatment of pain and other physical, psychological, and spiritual problems”. This definition may refer to a huge spectrum of care that, *inter alia*, include people at the (1) end-of-life (terminal or dying), or those (2) that might need care for chronic illness or it may include those (3) persons on life-prolonging curative therapies. The European Association for Palliative Care (EAPC) Task Force on the development of palliative care in Europe has published its report in 2007 (Centeno, *et al.* 2007) and was immediately criticised for its failure to take a stand in developing a uniform language over the terms, definitions and meanings for basic operational words such as “palliative care”, “hospice”, “homecare” “inpatient unit” etc. Instead the taskforce opted to render tables of what these words relate to in the 52 countries that they covered in their project. As mention above, for this study palliative care will refer to the caring services that provide comfort and peace to the dying person in his deteriorating and terminal phases of his decline. The care is unique as it allows the person to die with dignity rather than in distress and without hastening or postponing death.

### **When does dying begin?**

The Encyclopaedia of Death ([Kastenbaum & Kastenbaum, 1989:103](#)) offers six philosophical answers to this question:

- the moment we are born;
- when a fatal condition begins;
- when a fatal condition is diagnosed;
- when a patient is told that he has a fatal condition;
- when the patient realises and accepts the implications of the fatal condition, and
- when nothing more can be done to reverse the fatal condition and preserve life.

From this studies perspective palliative care for the dying person should be implemented when patient realises and accepts the implications of the fatal condition.

### **When should the end-of-life “announcement” be made?**

[Khoo, \(2003:143\)](#) states from his experience as head of a palliation team that there are many false beliefs amongst doctors, nurses, dying persons and their families about when the “announcement” should be made. Many medical professionals consider the announcement to be telling the patient that this is the “end of the road medically” and that that this announcement is also the end of their service. They believe that they are telling the patient that there is no more hope except only pain relief if needed. The truth is there is a hope of improving the quality of life during the remaining time available to the dying person. This means that there is plenty to be done: a new project is about to be launched with the dying person put in charge of new plans to be positively and purposefully structured. And there are palliative care workers and specialists that will assist the dying person to successfully complete their project. For this reason it would be ideal if doctors could refer patients at least 6 months before death to palliative care to enable the palliative workers to establish a good rapport with the dying person. The doctor seems to be the gatekeeper of announcing when the patient is “dying”, and unfortunately this often purposefully delayed as the modern medical systems are increasingly supporting the notion that a person is not dying until nothing more can be done to reverse the condition and

preserve life. This attitude of not rendering a prognosis or arriving late at a decision prevents a patient valuable time to progress through the palliation project. [Bartholomew, \(1999\)](#) wrote that most people assume that their doctor will tell them when they are at the end-of-life, but research showed that in the majority of deaths this did not happen, thereby robbing patients of a dignified death. [Christakis, \(1999\)](#) found amongst Chicago physicians a common belief that without a clinical certainty and/or a timeframe in hand; they should not give an end-of-life prognosis as it will rob a patient of hope for recovery.

### **How do we know when palliative care should start?**

This is a problem with persons nearing the end-of-life phase, we do not always know when “dying, terminal or end-of-life” starts and we cannot always assume that the patient are aware that they have arrived at “the end-of-life” or that they are “dying” or that they are “terminally ill”. Unless their doctor will tell them what their status is, we can mostly assume that they are unaware. What is even more ambiguous is that many people will die without ever being considered by care workers or family as “dying”. These patients would then have missed out on receiving palliative care and the opportunity to close important relationships and make financial and legal arrangements that could have benefit themselves and their survivors. For all these reasons should the option of early palliative care interventions be upfront in any care givers mind. Start rather too early than too late with honest, frank, open communication to provide a safe way for the individual to address their distresses and to find closure, peace and comfort during their last days being “alive”. ([Bern-Klug, 2004](#))

### **What are the perspectives on the dying person's family?**

The wellbeing of the family members of a dying person is intimately linked to the care and wellbeing of their loved one. A terminal illness deeply affects both the dying persons and their family members. Negative recollections during those final months, weeks, or days of the dying process complicates the grief of the family members and may leave them with feelings of regret that leaves scars on their psychological and



spiritual health. For this reason the primary goals of palliative care is to facilitate wellness and harmony between the dying persons and their families. This becomes the challenge of the palliative worker who is to know which early interventions might lessen family distress, increase family satisfaction and quality of life. To achieve this, both the dying person and family, should be approached as a unit of palliative care giving. (McClement, *et al.* 2007) One can thus assume that improving relationship and dignity issues in the palliative care program would have far reaching benefits for both the dying persons and their families through out the terminal phase and may also show beneficial results towards the bereavement phase. (Chocinov, *et al.* 2002)

### **What is known about the psychological distress in palliative care?**

Kelly, *et al.* (2006) defines the psychological distress experienced by dying persons undergoing palliative care as “a unique, discomforting, emotional state experienced by an individual in response to a specific stressor or demand that results in harm, either temporary or permanent to the person”. A distressed dying person can act out in numerous ways such as anger, aggression, isolation, passiveness, withdrawal, upset etc. Kelly pleads that palliative care workers be trained to identify the symptoms of distress, attend to the underlying causes, monitor the changes in behaviour and seek to understand that distress is due to not being “at peace”.

Steinhauser, *et al.* (2006) developed a single item approach to identify spiritual distress in the dying person and they would rate the extent to which the person would be “at peace”. They found a strong correlation with being “at peace” and emotional wellbeing and an absence of psychological distress. For this study this was a vital observation.

Kelly (*Ibid*) explains that psychological distress in patient with terminal illness is best understood as existing on a continuum from mild to severe. While some persons will experience fear, grief, or sadness in responds to their situation other may progress to psychological morbid conditions such as depression, anxiety or adjustment disorders. In cancer patients the incidence of these morbid conditions is between 35-50%. Distress, often described in terms of suffering, hopelessness, spiritual crisis,

can undermine the capacity for pleasure, take away the sense of meaning, diminish the ability to connect with others, and overall have a negative effect on the wellness, comfort and dignity of the dying person.

Kelly (*Ibid*) calls for action to find ways and means to routinely measure, track and record end-of-life distress, stating that if one can identify and manage distress of the dying person one can manage wellness, peace and dignity in the dying person.

### **What are the facts and fallacies in palliative care?**

Palliative care neither hastens nor postpones death. The overriding principle is that any treatment can be considered for palliative care, providing it is not used for life-prolonging or curative intent, but rather for improving the quality of life or allowing death to occur with comfort and dignity. Khoo, (2003:146) warns that when the dying person is in palliative care, the change in dynamics often prove doctors wrong in the prediction of a time frame to death due to numerous variables that are the effect of palliative care and not fully understood yet. It is advisable not to set any time frames during palliative care because wrong predictions may cause a lot of anxiety for the dying person as the time approaches or may mislead caregivers in their management plans.

Khoo, (*ibid*) provides evidence that palliative care, for the vast majority of dying persons, can be very successfully managed outside acute care hospitals. He states that cancer pain can be managed effectively through relatively simple means in 90% of patients. He continues to explain that hyper-alimentation to improve cachexia is a fallacy as anorexia is more likely to be the result of the catabolic process in dying persons rather than the cause. Also intravenous rehydration should be guarded against as the disadvantages - such as hydration that causes increase in the size of the tumour masses, further obstruction and pain, creating barriers to mobility, fluid overload that results in pulmonary and ankle oedema, predisposition to infections, and round the clock nursing care - far outweigh the advantageous. Force feeding the dying patient with a "Ryles-tube" to prevent starvation will make the dying person more uncomfortable and is of no benefit. Hunger is less of a problem at this stage – despite severe protein-calorie malnutrition, and thirst tends to decrease as death

approach - despite a state of dehydration. It is more important to allow the dying person to talk freely than to insert a tube down his throat for feeding and drinking, a need that in any case declines when death approach. Khoo, (*ibid*) also advise that oxygen is often considered to only have placebo value and the same can be achieved with the flow of cool air on the face. Oxygen therapy causes discomfort, a sense of claustrophobia, and more importantly it creates a barrier to valuable time for last minute communication. Also emergency surgery is contra-indicated in patients with intestinal obstruction caused by extensive *carcinomatosis peritoni*. Morbidity and mortality rates are high at this stage and there is no need to subject the patient to post operative pain, infection, and wound dehiscence and the adverse effects of general anaesthesia.

Khoo, (*ibid*) advise that healthcare professionals must at a certain stage of a life-threatening illness recognise and accept death as inevitable. At this point in time priority must be given to relieving symptoms while opening all channels for the last opportunities to communicate between the dying person and the person that he selected to make the journey easier. Kiernan, (2006:1208) supports Khoo (*ibid*) above, by concurring that that *“There is a fundamental problem in the quality of end-of-life care in America. The very peoples (read modern medical system) that dying persons rely on to provide this help (read end-of-life care) do not know how to do it!”* He continues to argue that over the past 30 years the causes of sudden death have declined, while the causes of gradual death have grown exponentially. Most people today do not die suddenly, they die incrementally, but the modern healthcare industry still recognize and react to gradual dying as a medical emergency instead of a natural process. Kiernan, (*ibid*) continues that the modern healthcare industry does not react favourably to natural processes that lead to death. For them “dying” is still a reflex jerk that calls for action to put on a “fight-for-life” at all costs; and when they loose the battle, they internalise it as a professional incompetency. The effect this has on the dying person’s dignity is disastrous, but it is not understood by the medical system as they only contextualise it from within their own personal agony of having “lost the battle”.

### **Is palliative care currently an art or a science?**

[Granda-Cameron, et al. \(2007\)](#) raised the question if palliative care is an art or a science. The [National Palliative Care Research Centre, \(2007\)](#) suggests that without more outcomes research palliative care is still an art, not a science. What is needed to convert palliative care into a science is more well designed studies to increase the knowledge base on: (1) the effectiveness of palliative care, (2) more defined patient populations likely to benefit most from specific palliative interventions, (3) outcomes research on efficiencies, (4) evidence based research relating to patient experiences across spectrum of care, etc.

Another barrier to the science option is the lack of a uniform language underpinning the science. Without it we cannot have a common understanding of the concepts and cannot express a similar meaning. Without it we also have a disregard to other interpretations for the same theories and we continue to bedevil conversations and comparisons. We also bedevil progress. ([von Gunten, 2007](#))

The other main hurdle to overcome is the availability of routinely used measurement instruments. There seems to be numerous standardized instruments around, originally designed to measure the outcomes of palliative treatment protocols, now being adapted and tested to be used routinely for all the palliative care populations – but it does not seem to fit. With so many different definitions and meanings together with irrelevant questionnaires and tools, clinicians struggle with when, what, and how to measure in palliative care programs. In the meantime, due to a lack of a structured scientific framework, palliative care seems to remain more of an art than a science. ([Granda-Cameron, et al. 2007](#))

### **Is there a drive for accountability in palliative care?**

South Africa is in the midst of a pandemic with fatal consequences for many South Africans. The current climate of economic constraint in the healthcare system demands from healthcare workers that they will be held accountable that the services rendered will firstly meet the patient's need, and secondly will be of high

quality and cost effective. No more will services be developed out of a sense of mission and perceived needs of patients and families. (Carson, 2000) Gone are the days that informal feedback was sufficient evidence that a good job was done. This asks the question how can palliative care workers evaluate and render proof that their service is based on meeting patient and family needs and expectations. (Jocham, *et al.* 2006)

### **Can questionnaires be used as a performance outcomes tool in palliative care?**

There is an ethical problem in subjecting dying patients to demanding questionnaires and structured interviews when putting outcomes measures into practice. Emotional upsets at the time of the completing the questionnaire that may be caused by mood disturbances, unwanted settings, unease with caring personnel, family conflict, basic fatigue, etc may impact negatively on the validity and reliability of the evaluation. Of special concern is the burden of completing most of these existing questionnaires. The Cancer Rehabilitation Evaluation System (CARES) has 139 questions and its short form has 59 items. (Schag, *et al.* 1991)

There are 13 different research questionnaires described in the literature that are used as instruments to measure quality of life during palliative care. Their items range from 5 (Spitzer quality of life index) to 139 (Cancer Rehabilitation Evaluation System – “CARES”). The average number of questions per assessment is 38. Additional to these 13 questionnaires are also 3 questionnaires to determine the dying person’s functionality during the palliative care. These functional questionnaires are not as extensive – they number about of 14 items per questionnaire – but these three assessment tools do not give any indication on the dying person’s ability to maintain his dignity. They rather refer to the functionality of the dying person in his environment and the increasing burden of disease and dying with little-to-no reference to record the dying persons ability to leave a legacy and thereby decreasing their sense of suffering and bolstering their sense of meaning, purpose, dignity and quality of life. (McClement, *et al.* 2007) Due to the extent of most of the questionnaires there seems to be a significant amount of irrelevant

and/or redundant questions put to dying persons that may be out of context, not applying to the target population or outside the experience of the patient that might add to the burden and/or distress of the person. ([Granda-Cameron, et al. 2007](#))

Finally, the reporting time frame of most of the questionnaires is 7 days and the question might well be asked how many dying persons in distress will have sufficient memory, endurance, ability or inclination to participate in routine questionnaires spanning over the past 7 days to establish how the patient's life has been affected by palliative care interventions.

For all these reasons, at the December 2004 National Institute of Health (NIH) State-of-the-Science Consensus Conference on Improving End-of-Life Care, consensus was reached to call for action in putting greater emphasis on practice based models that incorporate outcomes measurements in routine palliative care. The conference also recorded its consensus that there are significant gaps in science and knowledge related to evidence based outcomes within palliative care. ([NIH, 2004](#))

Questionnaires have a place in gathering information about a selected group of dying persons, under going a selected mode of treatment, in a selected care setting etc. It can not be used routinely, across all dying populations, across all settings and across all treatment modalities to understand the outcomes of palliative care services. Questionnaires can also not be used as a clinical governance tool.

#### **1.4 AIMS OF THE RESEARCH**

This study aims to develop an objective measurement tool to be used routinely by palliative care workers in quantifying the effect of palliative care on dying persons. By doing this the study will achieve three aims namely: (1) to create a scientific framework to solve the problem of referring to end-of-life care as a nebulous and vague concept, riddled with diversity that has very little structure and framework, (2) to create a universal language for the care worker that will fast forward the palliative end-of-life care sciences, and (3) to create a measurement tool that will allow provider and funder organisations to monitor and manage the palliative process.

## 1.5 OBJECTIVES OF THE RESEARCH

The objectives of the research is to find solutions to the three research questions posed above by trying to understand the dying persons needs and the appropriate skills required to address those needs. When that is clearly understood and defined, it will be possible to design, develop and construct a scientific framework, universal language and a measurement tool. With this in mind, the main objectives are to search for the following basic information needed to achieve the objectives:

- Does palliative care have a single measureable objective or domain?
- Does this single objective or domain have different sub-items or constructs that are internally consistent?
- Can each of these sub-items or constructs be subdivided into equal measures or intervals?
- Can such an instrument be used as bases for a scientific framework and a universal language to demystify the issues around end-of-life care?
- Can such an instrument with a (1)single domain, (2) internally consistent constructs and (3) equal intervals be used to routinely measure palliative performance, and as such be sensitive enough to be used as a outcomes measure?

## 1.6 SIGNIFICANCE OF THE STUDY

The successful outcome of this study will be to the benefit of the whole palliative care industry dealing with the dying process, but five groups of beneficiaries can be immediately identified namely the dying persons, the sciences of palliative care, the palliative care workers, the palliative care organisations, and finally the funders of palliative care.

### **The benefits to the dying persons**

Firstly, the dying persons should benefit most from the palliative tool. It is anticipated that a continuous quality improvement process will come into motion once the

performance of palliative care can be measured and monitored. With the tool a caregiver should get a clear understanding of what exactly the objectives of caring for each individual dying person are. A framework will be in place to convert the effort of rendering basic care into the objective of improving the outcome of the palliative care. A universal language will also be in place to communicate outcomes and to compare dying person's responses against a specific care programs. This will go a long way to repeat successes and place warnings against palliative care mistakes that have negative impacts. The principle of building on successes over and over again will ultimately benefit the dying persons. With this in mind the quality of palliative will improve and the patient will be the ultimate benefactor.

### **The benefits to the science of palliative care**

Secondly, the sciences of palliative care can be expected to be a beneficiary. The patient response to care will be quantified routinely and imported into a database. If such measured responses can be linked to different care modalities then evidence based numerical response to a specific treatment can be established. This is called benchmarking and will be a breakthrough for the relatively new care sciences of palliative care.

Another significant benefit will be the outcomes analysis. With the numerical response are in an electronic database it will be statistically possible to calculate the effectiveness of care by comparing the admission score from the discharge score. If the admission score represented say 20 points and the discharge score represented say 50 points then the effectiveness of the service rendered will be 30 points on the palliative care measurement tool. The value of these calculations is never ending, but what is significant is that benchmarks can be developed for different case-mixes or groupings of dying persons such as diagnostic groups (e.g. HIV/Aids, Cancer, TB etc) cultural groups, socio economic groups, belief groups and race groups or mixtures of the groups. Once benchmarks have been established statistically, the unpredictability of palliative care can eradicated in future.



### **The benefits to the palliative care workers**

Thirdly, the palliative workers will also benefit as the tool will help them to clarify the aims and objectives of palliative care better as it will become more tangible and specific. They will also understand the successes and lack of progress within the context of the science and will not internalise it as weaknesses from their side easily. Within a scientific contextualised approach to the palliative process the chance of burnout is less likely.

### **The benefit to the palliative care organisations**

Fourthly, the organisations that specialise in palliative care will benefit because a uniform language will develop between the management and the palliative workers. Both successes and problems will become quantifiable and performance calculations will now become a basic management skill. Quality control and improvement will become easier as it will be possible to identify those palliative workers that have the good skills and expertise and those that need it.

### **The benefit to the healthcare funding industry**

Finally, the funders of palliative care will benefit. Palliative care is waiting to be recognised as a healthcare specialty service and prospective providers of palliative are requested to seek recognition and funding from the medical schemes industry for the unique holistic care that they are rendering. Community based organisations such as Cancer Association of South Africa (CANSA) and the Hospice Association will want to register as service providers, but they have to proof that their performance in terms of quality and cost effectiveness is the same if not better than the care dying people currently receive in registered hospitals. State funded organizations, such as Non-Governmental Organisations (NGO's) will have to proof to the state that the holistic care that they render are not only of an acceptable quality, but is continuously improving and therefore they qualify to be granted funding for the work that they doing.

Overall, the contribution of such a tool will be comprehensive. It will create a framework for continuous quality improvement, a uniform language for caregivers to better understand the sciences of palliative care, a framework for the organisations to manage the palliative process and it generate the evidence for the funders to understand performance issues that they are willing to fund or continue funding.

## **1.7 SCOPE AND DELIMITATIONS OF THE STUDY**

### **Scope of the study**

This study is designed to explore through qualitative methods if a generic tool can be developed to measure the performance of palliative care. This will be done on a national level across the different cultural, belief, racial and educational divides of the South African populations. The tool must be sensitive enough to measure the changes over time of the dying person's needs to be comfortable and at peace during his end-of-his-life care, irrespective of the care settings such as hospice, hospital, home or custodial care. Through quantitative methods the designed tool will be subjected to psychometric testing for validity and reliability.

### **Exclusions to the study**

- a. The study will focus on adult dying persons over the age of 20 years, as it is the believed by the Child Hospice International organisation that dying children and adolescents have different care modalities to dying adult because as they have different needs and issues, require different abilities to manage the care, their families present with different behaviours and have a different pattern of responding to the phenomena of death. ([Child Hospice International, 2008](#))
- b. A dying person who has lost his cognitive skills to interact with his environment, as well as those that lost their ability to respond and behave to stress factors will leave very little opportunity for an outsider to assess their comfort levels. The study will include only those dying persons who are cognitively alert and interactive.

- c. The study will only include persons that have been informed that they have a terminal irreversible illness and are predicted to die within 6 months.
- d. The study will not evaluate extensively the ability of the tool to be used as an outcomes measure as this is considered to be a further research objective that does not fall in the scope of this study.

## **1.8 WORDS, EXPRESSIONS OR TERMS USED IN THE STUDY**

**“He, his and him”** is used throughout this dissertation for ease of writing and has no sexism intend. If otherwise stated, the following will still be true:

He - refers to her and vice versa.

His - refers to hers and vice versa.

Him - refer to her and vice versa.

### **“Dying Person”**

The dying person has a terminal irreversible illness that does not respond to any medical intervention and is expected to die within 6 months.

### **“Dying process”**

The dying process refers to all the different modalities of support required to successfully guide the dying person and his loved ones through the deteriorating and terminal phases of decline.

### **“End-of life care”**

The end-of-life care refers to the care rendered to a dying person during his deteriorating and terminal phases of decline. For this study it includes both support and counselling to be “at peace” and care to ensure his “comfort”.

### **“Palliative worker”**

Palliative worker is an informal care giver that guide and support both the dying person and his loved ones through the end-of-life care.

**“Domain”**

Domain is the content, realm or range for a particular topic. Domain refers to the knowledge that is locked up within these questions: what is palliative care, why is palliative care done, and what are we hoping to achieve through palliative care?

**“Constructs” (also known as sub-items)**

The constructs are those collections of concrete or abstract images or ideas that identify, support and describe the domain. The constructs refer to the knowledge that is locked up in the question: what are the most important activities or functions in rendering palliative care?

**“Intervals”**

The intervals are the set of equally spaced numbers on a linear line, consisting of all the numbers, including both endpoints. The intervals refer to the knowledge that is locked up within this question: what are the logic steps to be followed when rendering palliative care?

**1.9 ORGANISATION OF THE REPORT**

This study is outlined as follows:

In Chapter 1 the development of palliative care is noted. The lack of a scientific framework and a uniform language to communicate across the care providers is also mentioned. The need for palliative care to become a registered healthcare service depends on its ability to provide evidence of the value that the service add to the dying person. There is no such evidence other than anecdotal and the author makes the point that an objective measurement must be developed to generate such evidence.

In Chapter 2 a literature study is conducted to explore the existing knowledge available to be used in guiding the research design and methodology.

In Chapter 3 the research design plan and methodology is documented.

In Chapter 4 the data, themes and groupings and the development of the measurement tool is discussed.

In Chapter 5 a summary of the findings, conclusions and recommendations are tabled.

In the bibliography is documented all the references used in this document.

In annexure 2 training manual, testing with four case studies and a graph with patient profiles are presented.

## **1.10 SUMMARY**

In Chapter 1 information is provided about the complexities and nebulosity of palliative care phenomena and the need to have this care service transformed from an art to a healthcare science. To achieve this I suggest that a palliative care outcomes measurement tool be developed to measure routinely the dying person's response to the palliative care rendered. If successful, I suggest that such a tool will create a framework for care givers to set goals and objectives to work towards. It will also be possible for the care givers to develop a uniform language to communicate strengths and weaknesses. Furthermore I explained the current conflict between the modern healthcare system and the palliative care that needs to be overcome before a harmonious and respected relationship can develop between the role-players. I also explained the aims and objectives of the study.

In Chapter 2 a literature review to establish the existing knowledge for the guidelines in constructing a measurement tool will be discussed.

## Chapter 2

### LITERATURE REVIEW

*Being a close friend of a dying person means you do not have to ask "How are you?  
..... and he does not have to answer "I am OK!"*

*Dying people choose a close friend to escort them thru the end-of-life  
journey.....HJL*

#### 2.1 INTRODUCTION

A literature review involves finding, reading, understanding and forming conclusions about all the published research and theory and presenting it in an organised manner. (Brink, 2008) In Chapter 2 the outcome of the review is discussed to establish the existing knowledge available for guiding the study. Conceptually the research design will be a mixed model combining qualitative and quantitative approaches. The qualitative section will be used to gather information in a systematic manner to understand what the universal domains and sub-items of caring for the dying person within the South African (SA) context is, taking into consideration that the SA communities are not homogeneous regarding race, culture, language, customs, belief systems and social economic status. Thereafter the quantitative section will be applied to collect data with the designed instrument and conduct the psychometric testing of the data to quantify the reliability of the instrument.

As the greater component of the research has a qualitative approach, care has been taken in the literature review not to be influenced by the findings of other published studies as there is a real danger of polluting the outcome of this study. The literature review will, therefore, be limited to explore current research evidence that will guide me through the different techniques to apply in designing a clinical tool rather than seeking information that might influence the outcome of this study.

## 2.2 PURPOSE AND SCOPE OF THE LITERATURE REVIEW

The purpose and scope of this literature review is to do a review of journal articles and other published works for the current understanding of:

- qualitative research techniques to develop a clinical measurement tool,
- the existence of any routine performance measurements in palliative care,
- the basic tenets of palliation care,
- guidelines on how to develop a clinical measurement tool, and finally
- the basic methods of ensuring validity and reliability of a measurement tool.

## 2.3 CURRENT UNDERSTANDING OF THE QUESTIONS IN THE STUDY

### 2.3.1 Questions on qualitative research techniques

**What qualitative technique(s) is relevant to develop a concept or a theory into a clinical measurement tool?**

[Nyamathi & Shuler \(1990:1282\)](#) established that the focus group technique is particularly valuable to be used for instrument development, illustration, sensitisation or conceptualisation and allows the researcher to investigate a multitude of perceptions in a defined area of interest.

[Kingry, et al. \(1990:124\)](#) defined a focus group as a scientific research method whereby a discussion group is carefully planned to obtain perceptions on a defined area of interest in a permissive, non-threatening environment. He continues by saying that focus groups are particularly useful for the development and validation of the domain and sub-items of qualitative measures. This information confirmed my belief that focus group techniques will be the best research methodology to gather information on the domains and sub-items of the study.

[Freeman, \(2006\)](#) wrote a valuable article where he warned that although there is broad agreement over the general use of focus groups as a particular form of

group interview intended to exploit group dynamics in gathering knowledge; statements of 'good practice' in terms of its application are varied. These differences are principally related to the practical implications such as sampling techniques, composition of groups, the perceived role of interaction and the nature of inference. He encourages researchers to use focus groups extensively in clinical research, but to apply the appraisal criteria appropriate to the stated intentions of the research. Freeman's criteria will be used extensively in this research.

In a systematic review, [Halcomb, et al. \(2007:12\)](#) identified the core considerations in conducting focus group research with culturally and linguistically diverse groups. They found that the success of focus group research in this context is primarily dependent upon the cultural competence of the research team and the clarity of the research question. Secondary findings from this review revealed several key issues related to successful focus group implementation; such as recruitment, sample size, data collection, and data analysis. They concluded that focus groups are a useful technique to expand knowledge about service delivery and understanding patient needs within multicultural populations. Focus groups are (1) relevant to clinical practice; (2) beneficial to increase knowledge of different perspectives of culturally and linguistically diverse groups, and (3) shape clinical practice to better meet the needs of these groups.

There seems to be consensus in the literature that the focus group technique is a popular and accepted technique which can be used to explore the phenomena of palliative care and to gather the information required to develop a measurement tool. This is more so when the research has to be done across different cultures, belief systems and racial divides.

### **2.3.2 Questions regarding existing tools**

**Is there any evidence of an existing objective palliative care measurement tool and has its use as a routine assessment tool been established?**



A review of the literature could not find any evidence of an objective palliative care measurement tool. The relevant search was done on a range of healthcare electronic databases such as Medline CINAHL Psych Info, using the search terms 'palliative care', 'measurement tool', 'objective assessment' and 'routine assessment'. Hand searching of reference lists and relevant journals was also undertaken. However, numerous references to the need for such a tool were recorded, of which the most prominent ones are mentioned or referred to later in Chapter 2.

### **2.3.3 Questions on basic tenets (or doctrines or teachings) of the palliative (or end-of-life) care process**

A systematic literature review was conducted to collect evidence on the basic teachings and policies of care of the dying person in an attempt to understand the domains and sub-items of the dying process. More than 100 references were found alluding to the basic tenets of palliative care. The overwhelming majority of the results approach the basic tenets from a service delivery paradigm and they discuss at length the measurements required to manage **quality inputs** to secure a "holistic physical, spiritual, psycho-social and physical care and comfort service rendered to the terminally ill patient and his family, including a bereavement program after death". Very little evidence had been found of providers stating the tenets to be **outcome based**, such as aspiring to maintaining "quality of life, dignity". As this study intends to develop an outcomes based measurement tool on outcomes based performance indicators, only the most relevant literature contributions in this category were included in the review and are listed below under the following questions.

**Which tenet is the fore-runner to become the domain of palliative care?**

[Chochinov, \(2002\)](#) wrote a classic article whereby he concluded that the basic tenets of palliative care may be summarised as “the goals of helping dying people to die with dignity” In 2002 it was considered a breakthrough in the search for a common doctrine and the term “dignity” may provide an overarching framework that may guide the care-worker, the dying person and his family in defining the objectives and therapeutic considerations that are fundamental to end-of-life care. Chochinov proposed the “dignity-conserving” model as the new teachings for palliative care and, thereby, set the scene for dignity as the domain of palliative care. He did not go further by proposing performance measures to the outcomes of his dignity conserving model of palliative care. Chochinov’s study was not only ground breaking, it also opened the phenomenological debate on how all the role players experience dignity.

**What is the current understanding of dignity amongst nurses, dying persons, care-workers and family?**

[Walsh & Kawanko, \(2002\)](#) says that despite the fact that it is generally agreed that the maintenance of patient dignity is an important element of nursing care, dignity is seldom defined and there are few guidelines that nurses could use in their practice to safeguard individual patient’s dignity. In their study they tested the concept of patient dignity on both the nurses and the patients, based on the nurses’ and patients’ experiences. The characteristics nurses associated with dignity were many and varied but the eventual consensus was the characteristics of respect, privacy, control, advocacy and time. The patients attributed dignity to respect, privacy, control, choice, humour and matter-of-factness, but were differently ranked according to needs than those of the nurses. This study confirmed that nursing and patient perceptions may be similar in some aspects, but do differ in others. Significantly, the study suggested that patient needs must guide the nurses when they seek to objectively score patient dignity.

Hack, *et al.* (2004) used a factor–analytic and regression method to analyse dignity data gathered from 213 questionnaires completed by dying patients. The explanatory factor analysis yielded six primary factors considered by the persons that affect their dignity: pain, depression, informal intimate dependency, hopelessness/ support network, formal support network, and finally quality of life. The authors developed a “dignity-conserving” model of palliative care using these six factors as the main indicators. It is important to note that this model is based and practised in a state-of-the-art oncology unit in Canada and must be contextualised within this locus and the services to be rendered.

Aspinal, *et al.* (2006) found seven themes to be most important for the dying person, his care-workers and his family. These being: choice and control, dignity, quality of life, preparation, relationships and coordination. The bereaved family and the professionals prioritised symptom management, relationships and quality of life issues whilst the dying persons were more interested in issues involving preparation for death. This finding was very relevant to this study.

## **Discussion**

These three key studies were all done by collecting data from questionnaires in clinics with relatively homogeneous dying persons in hospices. Although there is value in identifying and tabling the relevant core issues for these palliative care practices, it fails to clarify the definitions and understanding of the core issues involved. The boundaries between dignity and quality of life remained vague, and the dimensions of preparation for death (Aspinal, *Ibid*) were also not clearly defined. The studies also did not attempt to put a performance measure against these aspects. Although these studies attempted to clarify “dignity” as practised in end-of-life care, they failed to present the reader with an operational clinical model or framework.

### **Is there an existing structured palliative care framework to guide care workers, or can such a framework be developed?**

Clayton, *et al.* (2005) stated that there is a lack of research evidence in the literature to guide the clinical practice of palliative care workers and, therefore, did a qualitative study to explore a possible framework whereby a structured discussion between the palliative worker, the dying person and the family can take place. They found that it is possible to identify distinct content areas and has set strategies to go about discussing end-of-life issues in preparing the dying person for the death experience. Again, the structure was limited to the cultural group, level of education, and setting of care where the research was done. They also did not go further to develop a measurement tool for the framework.

### **What about quality of life issues, and can that be measured?**

Jocham, *et al.* (2006) did a review on nursing literature between 1990 and 2004 to get insight into the international standards of how nursing researchers define and assess the quality of life during palliative care. The conclusion was that although the definition is very wide and multifaceted, nurses do believe that they improve the quality of life of dying patients, but there are still no systematic standards of measuring the quality of life in palliative care. The finding that the nurses was convinced that they add quality-of-life value but can not define or measure it was significant for this study.

### **Where does quality of care fit into the scenario?**

Ellis, (2006) reviewed the literature for benchmarking activity to encourage the quality of care - also known as the Essence of Care (launched by the Department of Health, England in 2001). Ellis concluded that benchmarking quality of care services is of vital importance to the management of healthcare. However, benchmarking of quality of care is not always accepted or supported by the health service organisations as its validity is questionable. This is due to its immeasurability and subjectivity.

## Discussion

The existing body of knowledge on the above issues can be summarised as follows:

- The domain of palliative care seems to be either dignity or quality of life as these two tenets appear in most of the findings either together or as the one representing the other. It is not clear from the literature where the boundaries are between dignity and quality of life. [Chochinov, \(2002\)](#) developed a clinical care model named the “dignity- conserving care model’ and thereby made a strong case for dignity to be a contender in becoming the domain of a palliative care measurement tool. In his follow-up articles and up to his 2004 study he finds that quality of life is a tenet of his dignity-conserving clinical care model and thus indirectly elevated dignity as the domain of palliative care. No evidence could be found to challenge Chochinov with his finding or with an alternative domain.
- The proposed sub-items of dignity in the literature review seem to be numerous (such as respect, privacy, control, advocacy, pain, depression, preparation, coordination, and many more) and their definitions seem to be nebulous and vague and inconsistent. There is also a real threat that these sub-items might represent the institutional situation where the data was gathered for each study and that it cannot be applied universally. This poses a particularly challenging situation for this study as the SA populations, in terms of their socio-economic groupings, cultures, belief systems, treatment settings and treatment modalities are diverse and the effects may differ significantly.
- The literature is uniform in their concern that the outcome of palliative care still remains immeasurable and is mostly subjective by way of self-reporting in questionnaire format. This, [as discussed in Chapter 1](#), is not ideal for routine performance assessment and reporting.
- No evidence in the literature could be found where an objective measure for palliative care has been reported on - or even attempted.

### 2.3.4 Questions on how to develop a clinical measurement tool

A literature review was conducted to collect evidence on the current knowledge of the basic principles to be taken into consideration when developing a palliative care measurement tool. Only the most relevant contributions to this study are listed below under the various questions that are posed:

#### **Generally speaking, in healthcare, what should we measure?**

[Rodgers & Holm, \(1994\)](#) wrote a classic article where they explained the different steps in developing a clinical measurement tool. They suggest the first step is to seek and select a prominent behaviour, ability or function of a patient that is reasonably expected to change due to a healthcare intervention, and then analyse the behaviour, ability or function to detect a sensitive measure that will record the observed change. That is the foundation of what must be measured.

#### **What is an outcomes measure?**

[Dobrzykowski, \(1998\)](#) says that an outcomes measure is the tool that can consistently measure the minimum points a patient has achieved on admission and again on discharge. The difference between these admission and discharge totals is the outcome scores achieved on the measurement tool.

#### **What are the key principles of an outcomes measure?**

[Kilgore, \(1995\)](#) also wrote a timeless article when he explained that the universal outcomes measurement principles are four fold: Firstly, it is the *extent* where by you can locate a patient's ability (or behaviour or functionality) on a linear measuring instrument and allocate a numerical value to that location. Secondly, it is the *difficulty* that you experience to use the measurement tool in locating the patient's ability. Thirdly, it is the *targeting* of the measurement tool whereby the tool is sensitive and appropriate enough to measure the intended ability of the patient. Targeting can also be explained as the process of matching the difficulty

of the tool with the ability of the group of patients intended to be measured to prevent either a “ceiling or a floor” effect. The fourth principle is about the *precision* of outcomes measures. Outcomes measures are designed to measure key sub-items across large numbers of patients and not the detail of each individual patient. Imprecision on detail is to be expected. For specific domains of interest, additional instruments with greater precision and perhaps even additional items specific for that detail may be used. Detail instruments will have fewer outcomes research value but greater therapeutic research value.

[Carson, et al. \(2000:27\)](#) felt that a palliative care outcomes tool must fulfil the requirements of being nonintrusive, easy to complete and cost effective. But even this becomes problematic in the dying patient where their physical and mental health is deteriorating to a point where they can not contribute to measuring outcomes. With this in mind, [Sprangers & Aaronson, et al. \(1992\)](#) studied the option of using proxy raters. Healthcare professionals, lay palliative workers or “significant others” has been asked to continuously track and evaluate the dying persons outcomes. The results were as follows:

- All proxy raters are inaccurate in the dying persons quality of life and pain intensity evaluations by consistently underestimating these values;
- When the “significant others” live close to the dying person the ratings tend to be more accurate, but these values tend to become biased again if they are the caregivers;
- However, the proxy ratings become accurate across all proxy raters if the information sought is within a concrete, observable and structured format.

[Unsworth, \(2000\)](#) stated that a key principal of an outcomes measurement tool is its sensitivity to notice and the change of patients’ behaviour (ability or function) and its ability to record such change. A classification tool, as opposed to a measurement tool, is not sensitive to change, it only group similar patients with similar characteristics and can therefore not be used as an outcomes measurement tool.

### **What about user friendliness in the application of the tool?**

[Granda-Cameron, et al. \(2007:69\)](#) suggests that doing assessments on a target population of dying persons calls for a low item burden of application. Little research has been done to address the relevance of item burden, but some factors that can reduce the item burden are:

- Absolute relevance of the sub-items to the target population.
- Ease of administration, minimum number of items, and minimum time of completion.
- Maximum patient acceptance.
- The assessment can be routinely embedded in the care plan.
- The risk on the overall impact on the dying person should weight less than the risk of doing the assessment.

### **What else should be considered in the development of a measurement tool?**

[Grimby, et al. \(2005\)](#) reported on the outcome of an international symposium arranged by the Journal of Rehabilitation Medicine in September 2004. The symposium reviewed the methodological aspects of outcomes measurement tools to date. Almost 180 specialist in the field of measurement design and evaluation from 24 countries participated. The follow relevant conclusions emerged from the symposium:

- Outcomes measurement tools must be psychometrically tested before use,
- The World Health Organization's ICF (International Classification of Functioning) is not a measurement tool but merely a conceptual framework from where tools can be developed,
- Research into outcomes measurement tools must not only focus on the outcomes of group-orientated populations, there is value to also better understand systemic variations among individual patients in context,



- Principal problems are been experienced with patient-generated assessments (e.g. questionnaires completed by patients) and such subjective methods are advised to be avoided.
- Mixed method designs e.g. combining qualitative and quantitative methods into outcomes measurement tool development should add value and be promoted.
- The sciences of outcome measures should form a integral part of the education of health professions.

Tennant, *et al.* (2004) studied the cross validity of measurement tools that have been translated into other languages. They found in a significant number of translations a problem in that the items in the tools does not work in the same context as the original and thus makes group analyses across languages unreliable. Tennant stressed the importance of using modern psychometric techniques to ensure that test items in the tools work in the same way irrespective of the language group assessed.

## **Discussion**

From the above literature review the following key principles was identified to be taken into consideration in this study when developing a palliative care outcomes measurement tool for the informal care givers:

- The accuracy of data collected by proxy raters depends on how concrete, observable and structured the format of the measurement tool is that they use to gather the information with. The tool's format must also be user friendly to the raters. Accreditation programs that involve ongoing training and testing of the raters should accomplish user friendliness.
- The tool should be an objective measure where the palliative care worker will observe the dying persons behaviour, ability of functioning and score it against a linear measure.
- The difficulty level of the measurement can be problematic as the lower the difficulty the lower the sensitivity and vice versa. The scope of this

study requires that the palliative care tool be used uniformly across the diversity of all SA population groupings. This asks for a low difficulty rating, but also a high sensitivity rating. This in-congruency will need attention.

- The targeted population for this tool is the dying persons of SA. This research protocol's working definition (see chapter 1:1:7) will be the dying persons whose death is predicted to be within 6 months. The tool will not be recommended for use for people outside the target grouping as the tool might not be considered sensitive enough for them.
- A fine balance will need to be considered between "detail" and "sensitivity" when developing the tool. Too much detail in the architecture of the tool may negatively influence its value for outcomes research, and not enough detail may negatively influence the tool's sensitivity to pick up and record change. This becomes more complex as there seems to be an emerging need to also better understand systemic variations among individual patients - within their demographic context - as revealed by routine data collected by outcomes measures.
- Patient-generated assessments (e.g. self reporting questionnaires) and such subjective methods should best be avoided in outcomes measures.
- A combined qualitative and quantitative research method is the study of choice for the development of an outcomes measure tool. The qualitative component should establish the domains, sub-items and intervals of a measurement tool and the quantitative component should take care of the psychometric issues.
- A training manual should form an integral part of a measurement tool.

### **2.3.5 Questions on the psychometric properties when developing a measurement tool**

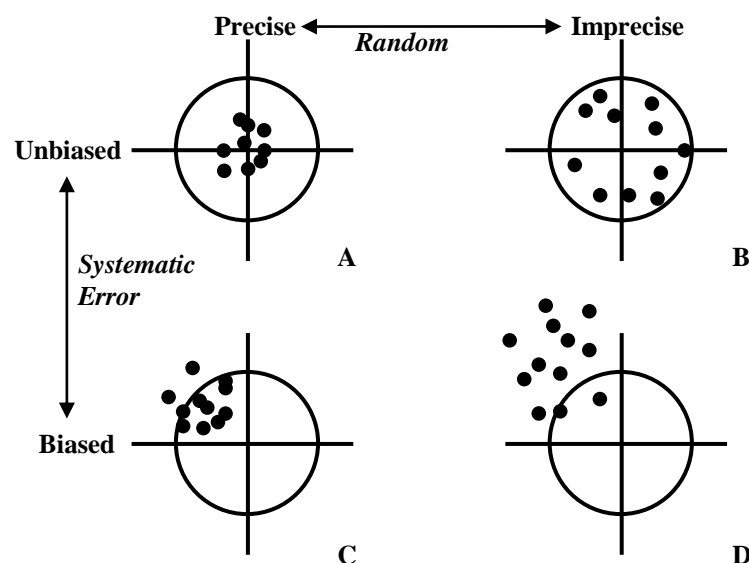
A measurement tool's psychometric properties relate to its validity and reliability. Together, these two indicators refer to the usefulness and appropriateness of a measurement tool in a given environment, context or situation. Validity and reliability clarify the core attributes of a clinical measurement tool such as accuracy, precision, un-biasness, sensitivity, one-dimensionality and efficiency. Although, many studies have been developed to establish validity and reliability, it

is still problematic to predict and harness the variability's that confront all clinical measurement tools. Also problematic is the language used to phrase validity and reliability, which is understood by a handful of people. The results are not familiar and commonplace with the clinical public for whom researchers invent or adjust measurement tools.

[Pickering, \(2002:356-364\)](#) wrote a valuable baseline article to guide researchers on how to publish their new measurement tools and in the process he clarified very complex issues to those who need the information. Most of what follows below is taken from the Pickering article, unless otherwise stated.

### What is understood by the “accuracy” of a measurement tool?

In *Illustration 2.1*, Pickering clarifies accuracy in terms of “precision”, “bias”, “true value” (the cross within the circle) and “repeated measures” (the dots).



*Illustration 2.1 - Precision and bias (Pickering RM, 2002)*

The situation in A shows high precision (as the repeated measures showing very little scatter at the true value) and no bias (as the scatter falls central in the “true value”). This measurement is considered very accurate when it is very precise and has no bias.

The situation in B shows moderate precision (as the repeated measures show scatter) but it still has no bias (as the scatter falls within the boundaries of the “true value”) This measurement is still considered accurate when it is moderately precise but with no bias.

The situation in C shows precision (as the repeated measures show very little scatter – same as in A) but it is showing bias (as the scatter systematically falls outside the “true value”.) This measurement is considered not accurate as it is not measuring what it purports to measure, even though it shows precision.

The situation in D shows lack of precision (as the repeated measures show scatter) and bias (as the scatter falls mostly outside the “true value”) This measurement is considered inaccurate – it show no precision and it is hugely bias.

### **What is true value, and how do we establish were it is?**

The true value of an instrument lies in the degree to which a measurement measures what it purports to measure, and thereby being able to distinguish between material and negligible issues that surrounds the true value. An important point about Figure 1 is that one can recognize bias in situations C and D only because the figure establishes where the true value lies. In practice one does not know where true value lies and in some instances the idea of locating true value is difficult to comprehend. The search and eventual recognition of the true value of a measurement will unlock all the validity and reliability studies on the measurement. This important statement by Pickering guides researchers developing measurement tools to first seek to understand what the true value is of a new measurement before they seek to understand the validity and reliability of the tool.

### **What is the validity of a tool?**

The validity of a tool usually equates to the “accuracy” of the tool, as stated above. What follows from this statement of Pickering is that a tool can only be

valid if the true value is established, and based on this knowledge the tool's measures is then proven to be precise and is not-bias.

**How can we prove the validity (or accuracy) of an existing tool if we do not know the “true value”?**

Pickering suggests there are basic three options available to establish a tool's accuracy in the absence of its own proven true value, namely:

- To compare the new tool's values with another established and valid tool that purports to share the same true value as the new tool (e.g. “*gold standard*”). If, it can be proven that the gold standard and the new tool's true values and measures are close together then Criterion Validity has been demonstrated.
- In the absence of a gold standard; the second option is to calculate how the tool's values and measures interact with other known factors that are known to be related to the underlying true value (e.g. patient is getting better and the tool's values also show similar improvement). If it can be proven that the tool's values show a relationship - or conforms to expectation - with the known underlying values of the “true value”, then Construct Validity has been demonstrated.
- In the absence of both of the above two demonstrations, a third option would be possible to subject a new tool to the peer review of known experts to assess subjectively the relationship between the tool's values and measures to that of the true value it purports to assess, then Content (or Face) Validity has been demonstrated.

**Tools usually have more than one sub-item (or construct). How do we know that the sub-items contribute equally to the same true value?**

A measurement tool is designed to measure different aspects of the true value and each different aspect are taken care of as a sub-item. In a well designed tool all the sub-items should contribute jointly and equally to the true value. The more sub-items that are included in the tool the more different aspects are measured and the more sensitive the tool become in measuring the underlying true value.

Cronbach, (1951) developed the classic formulation to establish - the now known - Chronbach's Alpha coefficient that establishes if there is redundancy amongst the sub-items whereby some of them are not equally contributing independent information to the true value. The extent to which sub-items are interrelated and contributes equally to true value is represented by the idea of Internal Consistency. Values on the Chronbach's Alpha coefficient close to the maximum value of 1 suggest that there is little or no redundancy of the sub-items.

### **How can one scientifically establish if a tool has an inherent weakness to render reliable information?**

Reliable results and data can only be produced if one is assured that a measurement can be applied by different *observers* over different *times* and different *places and the results will prove to be the same*. To achieve reliability a tool must be robust. Reliability issues of an instrument, therefore, relates to its inherent robustness to produce consistency across raters, time and place. To quantify an instrument's robustness (or stability) the following reliability studies (also known as repeatability studies) must be done to calculate the Reliability Coefficient *R*: (Carson, *et al.* 2000:28)

- The first study uses the *same* individual observers (or raters) to score individually, on the same situation, the same way, on two or more different occasions and evaluating their individual ability to get the same results would be testing the tool's Intrarater Reliability.
- The second study uses *different* individual observers (or raters) to score individually, on the same situation, the same way and evaluating their ability to get the same results, would be testing the tool's Intrarater Reliability
- The third study uses the *same team* of observers (or raters) to scored as a team, on the same situation, the same way, on two or more different occasions and evaluate the team's ability to get the same results would be testing the tool's Test-retest Reliability.

In the clinical environment it is rare that patient situations remain stable over time, and great care has to be taken to ensure that observers (or raters) are exposed

to same scenarios and situation on two or more different occasions. To achieve these simulated situations might be used.

## Discussion

From the above literature review the following key psychometric principles was identified to be taken into consideration in developing a palliative care outcomes measurement tool:

- Primarily the tool must measure what it purports to measure, in other words it must have a clearly defined “true value”. When the true value is in place the other validity (accuracy) issues can be established and adjusted, such as precision and bias. (Pickering, 2002)
- All the sub-items of the tool should contribute equally to the true value. (Cronbach, 1951)
- When the reliability issues are in place, then the consistency of use should be addressed with credentialing programs for observers or raters to ensure uniformity. (Carson, *et al.* 2000:28)
- With all of the above in place, it is important to ensure that the external issues are also addressed such as:
  - “Targeting”, where the tool is applied on the group it is designed for; “Difficulty”, where the tool can be used routinely by palliative workers who attend daily to the patient; and finally
  - “Item burden”, where the time and effort to do the assessment is reduced to very little and/or imbedded into the care plan by replacing existing useless information. (Granda-Cameron, *et al.* 2007:69)

## 2.4 STRATEGY THAT EMERGED FROM THE LITERATURE REVIEW

Firstly, I would like to provide a brief summary of the research considerations to be addressed:

- a. First and utmost, a tool must be developed for a selected *target* group of patients, namely the persons receiving end-of life care - defined in Chapter 1 - as the care rendered to a dying person during his deteriorating and terminal phases of decline. For this study it includes all of the following 4 points:
- *He is 20 years or older.*
  - *He is cognitively aware.*
  - *He is aware that he has a terminal irreversible illness.*
  - *He is aware that he is predicted to die within 6 months.*
- b. The tool should attempt to be an objective measure where the palliative care worker will observe the dying person's behaviour, ability of functioning and score it against a linear measure. A questionnaire will not be considered, as principal problems are been experienced with patient-generated assessments (e.g. questionnaires completed by patients) and such subjective methods are advised to be avoided. ([Grimby, et al. 2005](#))
- c. The tool must be used in future as an outcomes measurement and for this reason it must have the ability to be embedded as a routine assessment into the end-of-life care plan.
- d. With the tool being considered as a routine outcomes measurement tool, a fine balance needs to be developed between:
- Achieving the maximum amount of information with the minimum amount of "difficulty" to collect the information;
  - Including the minimum amount of detail to allow meaningful performance analyses for the target group; but not forgetting that individual patient variations also needs to be reported on.

Secondly, the design issues to be addressed:

- a. A *domain* (also known as "true value or principle concept, theory or tenet") must be found for end-of-life care. The qualitative approach of using focus



groups seems to be the best methodology to gather information across cultures, races and belief systems in establishing the domain. The *sub-items* (or also known as constructs) of the domain should also emerge simultaneously from the focus group techniques.

- b. The sub-items must be designed to contribute equally to the domain.
- c. The reliability considerations must be addressed with clear and concise accreditation material, not losing focus from contributing factors such as lowering difficulty levels, and applying only to target populations.

## **2.5 STRENGTH AND WEAKNESSES OF THIS LITERATURE REVIEW**

Consistently, the lack of a uniform language pertaining to end-of-life care is raised by all researchers. This problem bedevils systematic reviews as there is a lack of unified standards and universally accepted definitions of the types of services rendered.

Jocham, *et al.* (2006) did a literature review and reported that there seems to be an obsession in the literature with evidence based measures, referring to self-reporting instruments where patients complete lengthy questionnaires. In the same vein these subjective methodologies to obtain information from the dying person is criticised as ethically not sound and also inaccurate as it is influenced by too many external variances. Yet no objective outcomes based measures have been found that is accurate and can be routinely implemented as a predictive tool.

## **2.6 SUMMARY**

In Chapter 2, I reported on the findings of the literature review which I conducted. This review was done to find guidelines in establishing a robust, but yet sensitive, objective measurement tool for the end-of-life group of persons, that can be used as an outcomes management tool, and therefore must have a low difficulty rating to be used as a routine measurement.

In Chapter 3, I will discuss the methodology of the research project that follows from the literature review.

## **Chapter 3**

# **RESEARCH METHODOLOGY**

## **3.1 INTRODUCTION**

This chapter explains the research methods that I applied to develop a palliative care measurement instrument for the use of the informal caregiver in assessing the dying process as discussed in Chapter 1. In Chapter 2, I reported on the findings of the literature review to reveal the existing knowledge and the scientific guidelines to be considered when applying the research methodology.

In Chapter 3, I discuss the research methodology I applied in the study. I will initially explore the basic principles of a research methodology and follow through with the specific designs and techniques I applied in this study. This includes a discussion of the research population under consideration, describing the sampling methods I used plus the data collecting and analysis techniques I have applied. Finally, I will describe the methods I implemented to ensure the objectivity of the data and the ethical considerations as applied to this study.

## **3.2 APPROACH TO THE RESEARCH**

[Cresswell, \(2003:18-19\)](#) states that there are three basic approaches available for a researcher to use in a study; namely a qualitative approach, a quantitative approach and a mixed methods approach which is a combination of qualitative and quantitative.

- A quantitative approach is the traditional or narrow approach where the researcher uses a predetermined instrument and observation strategies to collect statistical data on a predetermined method. The method is based on predetermined close-ended questions as used by the instrument to generate numeric data. This numeric data may be used, as in this study, as standards for validity and reliability of the measurement instrument by employing statistical and mathematical practices. ([Cresswell, 2003:18](#))

- A qualitative approach on the other hand, is considered the non-traditional or holistic approach available to a researcher who requires studying social phenomena by using text and image data as oppose to the statistical data used in the quantitative approach. To collect and analyse the text and image data the qualitative approach use different designs, each suitable for each specific research goal. (Brink, 2008:110) The qualitative approach is suitable for exploring cause and effect thinking through open-ended questions to test theories, hypotheses and variables within specific groups of respondents that represent the social phenomena under study. (Cresswell, 2003:18) The researcher usually explores the individual experiences and knowledge from participants in their natural setting to fully absorb the detail of their perception on the research question. The qualitative research is essentially of an emerging nature and the research design may evolve over time to keep up with the data collection process as the new knowledge unfolds. As a result a multitude of interactive and humanistic research methods may be implemented to track the flow of the emerging information. In essence, the researcher will help the participants to focus on a single concept or phenomena and then collaborate with them to mine their individual and collective meaning and value of the focused item. Through interviewing and holistic observing the researcher discovers the emerging information in narrative and descriptive data format. From this he develops themes, theories or patterns that reveal and describe the hidden phenomena. He would then verify the emerging information within the context or setting of the participants, validates the accuracy of the findings, makes interpretations of the data and creates an agenda or instrument for reform. (Ibid:19)
- Finally, a mixed method approach is also available to a researcher whose research assumptions are based on more pragmatic or problem-centred knowledge claims where diverse data is required to resolve the problem. There might be a need to integrate the different data sets during the research, or the reasoning may be, as is the case in this study, to first develop an instrument with the qualitative set of data and then use the designed instrument to resolve the original problem with the quantitative set

of data that was collected with the newly designed instrument. In the mixed method the researcher will therefore employ the practices of both qualitative and quantitative research. (*Ibid:19*)

This study requires diverse data sets to produce the data required for the study objectives as set out in [Chapter 1 paragraph 1.5](#). The mixed method that involves both qualitative and quantitative approaches therefore became the methodology of choice when the research approach was considered. To achieve the study objectives, the following seven core research questions was asked to determine the research approach and the corresponding design to the study:

- a. *What is palliative care all about?* The answer to this question should identify the true value (or domain) of palliative care and the research approach to this question will be of a pragmatic nature using open-ended interviewing in a participatory environment and a narrative approach.
- b. *What are the core reasons why palliative care is being rendered?* The answers to this question should identify the sub-items of palliative care and the approach will be the same as in research question 1 above.
- c. *What are the basic processes involved in palliative care?* The answers to these questions should help to identify the basic intervals for all the sub-items which will form the bases of the scoring method. And again the approach will be the same as in research question 1 and 2 above.
- d. *Can the variance in the SA population groups be accommodated in a single palliative care outcomes tool for SA?* The SA population is varied regarding race, culture and believe systems and a palliative care tool must be able to measure across these variances. Information gathering on how to accomplice this will require the same approach as in research question 1, 2 and 3 above.
- e. *Can such a tool be developed?* The information gathered from questions 1-4 above should be the building blocks to develop the tool. Analytical methods

will be used to interpret and rank the gathered data and again these techniques are all of a qualitative nature. The final design of the tool with the refined data will require the analytical and social engineering skills of the researcher.

- f. *Is the tool sensitive enough to measure change?* With the tool finally in place, the sensitivity of the tool needs to be established. Testing involved the implementation of the tool to collect more than 200 sets of data over periods of time. This data will be used to practically test the tools sensitivity to detect change on the same persons over time. This testing phase will involve a quantitative approach with the new tool where pre-determined close-ended observations of behaviour in a dying population are measured. It is expected that these observations should change over time and it is expected that the tool will be sensitive enough to pick up these changes.
- g. *What about the tools psychometric properties?* The final step will be to test the newly designed tools reliability with statistical analysis. This will also be a quantitative approach by subjecting the data gathered by the tool to vigorous psychometric calculations and testing.

### **3.3 RESEARCH STRATEGY**

Cresswell, (2003:16) identifies two different strategies available to the researcher who selected the mixed method approach; namely the concurrent strategy and the sequential strategy. The concurrent strategy is required where there is interdependence between the data collecting processes of the qualitative and quantitative data. Therefore the data must be collected simultaneously. As a result of the interdependence between the two sets of data, the one data set is not dominated by the other and both have equal priority in the data analysis.

In the sequential strategy the second data set is dependent on the interpretation of the final data analyses of the first data set and therefore can not be implemented concurrently. In the sequential strategy first data set has the priority over the second as it must deliver the results for the second data set to build its research

methodology on. The sequential strategy can therefore be seen as two methodologies within one study, with the first data set being the dominating data set in the mixed method design. (*Ibid:210*)

Further more, if the first data set in a sequential strategy is of a qualitative nature then the strategy is referred to as a “sequential exploratory design” and if the first data set in a sequential strategy is of a quantitative nature the strategy is referred to as a “sequential explanatory design” (*Ibid:213*)

For this study I selected the mixed method sequential exploratory design, as the research required both qualitative and quantitative data in the same study. The qualitative data was the dominant data set as the quantitative phase was dependent on the final interpretation of the qualitative data analysis.

The design of this study is therefore based on two independent studies that are integrated sequentially into the final study design. For this reason, and for order and continuity, I will describe the methodology from here forward sequentially with the dominant qualitative approach being first.

Research question	Method	Approach	Design	Population	Data Collection	Sampling	Analysis
<i>What is palliative care all about?</i>	<b>Mixed method sequential exploratory</b>	<b>Non-traditional - qualitative</b>	<b>Case-study</b>	<b>Informal care givers</b>	<b>Focus group</b>	<b>Non-probability Judgemental</b>	<b>Thematic content analysis</b>
<i>What are the core reasons why palliative care is being rendered?</i>							
<i>What are the basic processes involved in palliative care?</i>							
<i>Can the variance in the SA population groups be accommodated in a single palliative care outcomes tool for SA?</i>							
<i>Can such a tool be developed?</i>							
<i>Is the tool sensitive enough to measure change?</i>		<b>Traditional - Quantitative</b>	<b>Non-experimental design</b>	<b>"Dying persons"</b>	<b>Structured observation</b>	<b>Convenience sampling</b>	<b>Cronbach Alpha</b>
<i>What about the tools psychometric properties?</i>							

Table 3.1 - The blueprint of this study (Adapted from Cresswell (2003), Brink (2008), Babbie & Mouton (2007) and De Vos (2007))



### 3.4 FIRST PHASE:- THE QUALITATIVE METHODOLOGY

In the first phase of the study I used the Qualitative Methodology approach. I will describe this approach in detail from here forward under the headings of the research population that was selected, the research sampling and the criteria I used to do the sampling, the techniques used to collect and analyse the data and finally the trustworthiness of the data.

#### 3.4.1 Qualitative: Research population

The term “research population” refers to the entire group of persons that is of interest to the researcher and meets the criteria as set up in the study. (Brink, 2008:123) The term also set the boundaries to the various points of references pertaining to the subjects under investigation. It is clearly not possible for the researcher to access all South Africans that qualify to be included into the “research population”, but those subjects who are accessible to be included in a study is referred to as the “study population”. (Babbie & Mouton, 2007: 174) As the findings obtained from the study population will be generalised to the research population, the conclusions drawn from the study population must be valid and generalise able to the research population. It is therefore dire that the “inclusion criteria” (Brink, 2008:124) for the study population must be correctly defined and stipulated to allow this process to be accurate. The researcher must use the inclusion criteria as the basis for his decision whether an individual would be classified to represent the research population in question.

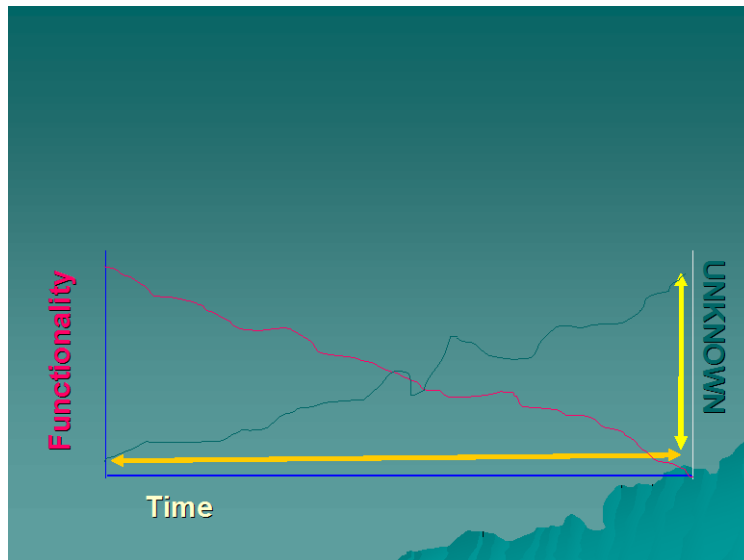
In the qualitative section of this study, the Cancer Association of South Africa’s (CANSA) informal care givers was selected to be the research population. They render support and care to the dying cancer victims as CANSA volunteers. This research population is considered by CANSA to be rich in information about the dying phenomena as they have been rendering this service for many years under the auspices of CANSA and is considered by CANSA as the people with the widest experience in all the different phenomena involving the all the cultures, belief systems, races and genders of the dying cancer victims in the South

African landscape. CANSA is a national organisation and their caregivers are well distributed demographically.

However, the term “palliative care outcomes tool” needs to be taken under consideration within the context of palliative care. There seems to be a latent incongruency in the term “outcomes” that needs closer analysis to guide the decision of who would best fit into this research population role. “Outcomes” by definition mean the measurement of change (Kilgore, 1995:SC21) and mostly a positive change or improvement is associated with outcomes, and negative change or decline usually occurs as an unfortunate variable. “Palliative care” as defined for the use in this study (see Chapter 1 paragraph 1) means the holistic care of the dying person, where the term dying indicates that the person is in an irreversible process of decline with death expected to incur within 6 months. So, if outcomes with dying persons are associated with negative outcomes, why do we need to develop an outcomes tool that is bound to measure decline?

The palliative care workers disagree strongly with this line of thought and say they do have positive outcomes with palliative care. The problem is that the outcome is not tangible or specific or easy to explain. Therefore what outcome is one hoping to measure and what is one expecting to improve with a predictable death as the outcome?

When trying to find answers to these questions it becomes clear that it should best be addressed to those people that dedicated their energies to improve or elevate the “outcomes” of the dying persons that they care for. They should know what the difference is that they are hoping to achieve with their dedicated interventions. They should also know how to recognize the improvements that they claim to have brought about. For these reasons it is important that the study population in the qualitative phase of the study is the dedicated care workers that target their skills to bring about some improvement in the final days of the dying persons. They are the people that should tell us what the change that they bring about is and how they recognise the change that they create.



Graph 3.2 – Functionality versus Time versus “Unknown”

Graph 3.2 was designed by me to illustrate the inevitable functional decline (red line) over time during the end-of-life process. However the informal palliative caregivers are of the opinion that the decline of function over time is not the sole reason of going about their daily task of being care givers. They are adamant that through their care they fulfil and open another dimension to the dying person’s wellbeing that has an upward curve (green line) and indicates a positive outcome that can be clearly observed by them. However, they have a problem in qualifying and quantifying the dimension represented by the “UNKNOWN” axis on the above graph. The qualitative study using the informal caregivers as the study population will be used to identify, qualify and quantify the “UNKNOWN” axis through a qualitative design to develop a palliative care outcomes measurement tool.

This approach is in line with the classic [Rodgers & Holm \(1994\)](#) model of thinking when developing a measurement tool, namely to identify a prominent behaviour, ability or function of a patient that is reasonably expected to change due to a care intervention, then analyze the behaviour, ability of function to detect a sensitive measure that will record that observed change.

Based on these assumptions from the CANSA informal caregivers, CANSA has granted this research project access to their national data base of palliative care

workers and in conjunction with their national coordinator of palliative care workers identified the CANSA regional offices throughout SA that has the highest population of “experienced” palliative care workers to participate in the research study.

### **3.4.2 Qualitative: Research sample**

A research sample is by definition a “fraction of the whole or a sub-set of the larger set” selected by the researcher to be representative of the greater research population under investigation (Brink, 2008:130). A sample thus consists of carefully selected individuals from whom information is been collected that can be transferred to the total research population. The sampling process refers to the researcher’s techniques to select the correct group of individuals to ensure that the information gained from them will be trustworthy enough to transferred to the research population.

There are two basic sampling approaches that are scientifically acceptable namely probability (or random) sampling and non-probability sampling. Each has its different techniques and applications (*Ibid:131*). For the qualitative phase of this study a non-probability sampling technique was considered appropriate were the judgement of the researcher was required to select the participating individuals that are especially knowledgeable about the questions at hand. The advantage of this type of “judgemental sampling” is that it allows the researcher to select the sample based on the richest knowledge available of the phenomena to be studied. The disadvantages are the potential for bias, the use of a sample that does not represent the population and the limited generalisability of the result (*Ibid:134*).

### **3.4.3 Qualitative: Sampling criteria used**

The selection criteria used to select the most experienced care givers to represent the “non-probability judgemental” sample included the following:

- Palliative care workers who has cared for and guided at least ten persons on their end-of-life journey are considered more experienced than those that have been involved with less than 10 dying processes;
- Palliative care workers that have a proven track record of dedication through volunteerism might be evidence that they are successful in what they are doing. The assumption is that they will not continue doing the task if they are not aware in-the-self that they are achieving success. Palliative workers that receive a state stipend of R800-00 per month for expenses are also considered as a volunteer worker;
- Palliative care workers who have been a palliative care worker for 5 years and longer are considered more experienced as those who have less than 5 years palliative care experience. The logic behind this statement is that time brings maturity in reasoning and understanding;
- Palliative care workers must be a member of one of the eleven South African cultural groups and he must have a specialised, in-depth knowledge and experience of that particular group's customary routine, beliefs and behaviour patterns during the dying process. The worker must also be able, and declare himself prepared, to reveal and discuss his cultural group's theories and concepts around this subject openly and freely.
- Finally, I also considered to include the selection criteria of "having or not having previous formal training" as there was a real danger that a previous formal training on the methods of rendering palliative care might influence the data as caregivers might regurgitate what they have learned theoretically rather explain what they have learned what they have observed from the dying persons. I was concerned that the rich information of observing without a polluted mind might be overshadowed by what is considered to be "the-taught-right-way-of-doing-things". After deliberations with the CANSA care giver coordinator, it was decided that informal caregivers that have no previous training but have a vast experience of observing and guiding the dying person, is considered more acceptable to the study than caregivers with a vast experience of observing and guiding the dying person through a pre-structured trained approach that may or may not be correct.

A guide score card was designed by me for the CANSA regional coordinators to guide them in recruiting the most experienced care workers available to participate in the study.

Score	Poor (1)	Average (2)	Good (3)	Excellent (4)
<b>Pain management</b> experience				
<b>Family support</b> management experience				
<b>Spiritual needs</b> counselling experience				
<b>Symptom distress</b> management				
<b>Informal</b> <b>network/community</b> <b>support</b> experience				
<b>Biological needs</b> management experience				
<b>Unique cultural</b> <b>group's needs</b> experience, e.g. Zulu, Hindu, rural Venda etc.				
<b>Years</b> of experience	<5 years	5-10 years	10-15 years	15- 20 years
<b>Assisted dying</b> <b>persons on end-of-</b> <b>life journey</b>	< 10 persons	10-15 persons	16 – 20 persons	> 21 persons

Table 3.3 - Score card to identify experienced care givers.

A care worker will only be included to participate in the focus groups if they scored 20 points or more on the experience chart viewed in *Illustration 3.3*.

#### 3.4.4 Qualitative: Data collection

In the health care research environment, focus group techniques is particularly acknowledged to be an ideal method for collecting the data needed for the conceptualising and validation of constructs when developing clinical quantitative measures. [Kingry, et al. \(1990:124\)](#) defined focus groups as a carefully designed

discussion to obtain perceptions on a defined area of interest in a permissive, non-threatening environment. [Morgan, \(1997:6\)](#) describes focus groups as a research technique that collects data through group interaction on a topic determined by the researcher. [De Vos, \(2007:300\)](#) explains three different approaches to focus groups, namely:

- Exploratory focus groups usually serve as an exploratory technique to understand what the future research needs will entail.
- Clinical focus groups usually serve as an in-depth assessment by professional clinicians using their clinical judgement to gain collective professional knowledge about the inner experiences as set out by the participants.
- Phenomenological focus groups are used to qualify and quantify phenomena by mining into the everyday experiences of a study population to whom the phenomena is part of their daily life. This approach to the focus group technique was used in this study and it generated significant data to understand the phenomena of dying-in-peace and what it takes from a care givers perspective to achieve a positive result.

The strength of focus group techniques is their reliance on the group interaction to produce and refine data. [\(Nyamathi & Shuler, 1990:1282\)](#) The interaction between participants also adds value when each one's experiences and opinions become valuable sources of insight into the complex observations and interpretations of the dying process. The synergy between the participants, when together in a secure setting without fear for criticism, has the potential to uncover important constructs which may be lost when data is generated individually. An empathetic environment also helps to uncover dynamic emotional processes and thereby create a fuller and deeper understanding of the phenomena under discussion. The "security-of-being-in-a-group" phenomena generate spontaneous exchanges of ideas, thought, and attitudes that are valuable to the researcher. [\(De Vos, 2007:301\)](#)

On the down side, a focus groups data is just as good as the researcher. Researcher skills include hearing every participant's view, prevent social

posturing, prevent desires to be polite and only say the right things, prevent defending and arguing the current norms, prevent enforced compliance. If a researcher can not withstand these barriers the data may be at risk of being bias. (*Ibid:306*) Other down points to take into consideration is that case study techniques tend to be time consuming and costly. There is also a high risk of subject drop-out if the study is not completed within the set time frames. However, the distinct advantage of the case-study approach is the detailed levels of analyses that can be achieved. (*Brink, 2008:110*).

The palliative care workers, whom comply with the selection criteria set out in [paragraph 3.4.3](#), did participate in the focus groups, with the dates, times and venues as organised by CANSA's national coordinator of palliative care workers.

Three independent visits of 6-8 hours each were planned to each group with one month intervals between the visits to a group. The first visit served to gather information, the second visit served to apply theme content analysis techniques, to rank information, validate the existing information collected through peer review and the third serves to introduce the groups to the tool and use of the techniques to refine the tool.

#### **3.4.4.1 First visit**

The agenda for the first visits is designed to gather information and is planned as follows:

- Introduction and familiarizing with each other,
- Explain purpose of meeting,
- Explain the use of the flip chart and the tape recording etc.
- Table the agenda for the meeting,
- Pose the questions and record the answers to the meeting

The following questions will be asked –in no particular order - during the 6-hour focus group sessions:



1. *Questions asked to reveal the true value (or domain) of palliative care:*
  - a. What is your understanding of palliative care (end of life) care or what comes to mind when you think of end-of-life care?
  - b. Why are you doing palliative care?
  - c. What do you hope to achieve by palliative care?
  - d. When does palliative care start?
  - e. How do you know when you have been successful with palliative care?
  - f. How do you know when you have been unsuccessful with palliative care?
  - g. If you had to select the single most important indicator to measure whether palliative care was successful or not – what would it be?
  - h. Why would you say so?
  
2. *Questions will be asked to reveal the sub-items of the palliative care:*
  - a. What are the 6 most critical contributing factors that impacts positively on palliative care?
  - b. What are the 6 most critical factors that impacts negatively on palliative care?
  
3. *Questions will be asked to reveal the intervals on the sub-items:*
  - a. What do you usually do to maintain the 6 most positive factors to give a good palliative outcome?
  - b. What do you usually do to turn the 6 most negative factors around and give a good outcome?
  
4. *Questions will be asked to reveal the contextual issues:*

- a. Do different cultural or religious groups of clients react differently to palliative care? If so who are they and how different do they respond?
- b. Do clients with different terminal diseases and illness react differently to palliative care? If so what are they and how different do they respond?
- c. Do adult clients in different age groups respond differently to palliative care? If so what are they and how different do they react?
- d. Do clients in different care settings (home, hospice, hospital etc) respond differently to palliative care? If so what are they and how different do they react?
- e. Do clients with different socio financial status respond differently to palliative care? If so what are they and how different do they react?
- f. Any other groups that respond differently?

#### **3.4.4.2 Second Visit**

The agenda for the second visits are designed to peer review on the total data received in all the previous group sessions, to code and rank the collective knowledge gained to date. This was done by asking the participants to evaluate the response items and through open debate:

- Verify the items listed to the questions asked.
- Collapse the similar items in the same list.
- Rank the items listed.

The open debates on these issues were important as it rendered me additional item knowledge, more in-depth understanding of issues involved and a contextualisation of the operational model; such as the:

- The nuances, meaning and context that the items are used within the different cultural groups.
- Words and phrases that are in common use that palliative care workers can better identify with.

- Palliative care situations that occur commonly and have standard responses to same basic interventions.
- The similarities and the differences across the cultural and belief systems of the SA population groups.

From this refined information it was possible to design the first draft palliative care measurement tool for the South African population.

#### **3.4.4.3 Third Visit**

My objective with the third visit was to evaluate across the focus groups a similar trend of comments which may indicate a weakness or strength in the tool design.

In preparation for the third visit, the first draft of the designed palliative care outcome tool was sent to each participant a week before the visit. Each participant was asked to study the proposed tool and note their comments to be raised at the third visit. They were requested to focus on the tools validity in terms of:

- Correctness within their holistic cultural perspective.
- Technically correctness.
- Difficulty level.
- Further contributions with comments, critique and acclamations where needed.

During the third and final visit each group was by then a cohesive group, relaxed and committed to the success of the palliative care outcome tool. They took ownership of their contribution, and they were eager to render their final stamp of approval to a hopefully scientifically correct tool. Each participant received a certificate of gratitude for their valuable contribution to the development of the tool.

#### **3.4.4.4 The logistics to assemble the focus groups for data collection**

As this study was requested and sponsored by CANSA, the logistics of getting the focus groups together was the task of the CANSA national coordinator of palliative care workers. She was mandated to do and oversee the following tasks:

- She used the CANSA database to select the regional offices with the most experienced volunteer care givers rendering palliative care in the region.
- She informed and briefed the selected regional offices and solicited their participation.
- She selected the most appropriate venues at these regional offices that were familiar to the care givers as to oppose no threat of being foreign territory.
- She selected a regional coordinator of caregivers to coordinate all regional logistics for the focus groups e.g. dates, times, refreshments, transport, etc.
- She assisted the regional coordinator in the selection criteria as set out in paragraph 3.4.3. and helped to create groups that have minimum 6 and maximum 10 participants.
- She handed the inclusion criteria to the regional coordinator of caregivers who selected the most appropriate participants in the region, briefed them why they were selected for the study, explained to them what the study was about and what is expected from them and secure their commitment.
- The regional coordinator also ensured that the care givers received grants for transport to the focus group venues and provided lunch and refreshment during the discussions.
- As all participants were volunteers, none were paid for their times spend in the focus groups.

The selected informal volunteer caregivers were all – without hesitation - available to render their knowledge. Their attendance records during the three visits to the regional offices were 88,7%.

As the facilitator I used the following techniques, also recommended by [De Vos. \(2007:310\)](#)

1. Be interested in the participants and show a positive regard, by acknowledging that they are in possession of the knowledge you seek.
2. Be a facilitator not a participant, by knowing the questions not the answers.
3. Be ready to hear unpleasant views, by acknowledging all different view points on the issue under discussion.
4. Accept that you cannot facilitate all groups, by accepting that in certain situations it is better to use some of the participants to lead the exploration because contextually you are lost e.g. the ancestral belief systems might become too complex to grasp what the real knowledge at hand is.
5. Use you unique talents such as humour and persistent interest in each individual participants point of view on all subjects raised.

[Morse \(1997\)](#) describe field notes as a written account of the things the researcher hears, sees, experiences and thinks in the course of collecting or reflecting on the data obtained during the (focus group) study. During the focus groups the field notes were recorded on a voice recorder and on a flip chart. Recordings, transcripts and memory were used to record the participants perceptions and experiences and the way that they made sense of the process of dying and the needs of the dying persons. As the participants were also available during the second visit in the peer review exercise to evaluate, rank and collapse data the field notes were updated daily after each focus group. The objective for daily updates was two fold; not to rely on my memory for the accuracy of the data and to be ready with fresh updated data at the next focus group meeting.

### **3.4.5 Qualitative: Data Analyses**

It is critically important in analysing open-ended descriptive data that the process be systematic, sequential, verifiable and continuous. Feedback through ongoing comparison within the various focus groups may significantly benefit the quality of

the analysis. This ongoing process requires time, and any delay in the process may jeopardise the outcome of the analysis. (Krueger & Casey, 2000:128-130)

The exploratory data that I collected for this study consisted of a multitude of realities explaining *what* is actually happening during the “dying process” and *why* it is happening. As an experienced general practitioner, who has been at the bedside of many of my dying patients, I never realised that the dying process is such a diverse and complex phenomena. Adding the variances within our South African cultural and belief systems it became a complex task. As a result, I constantly reminded the participants to think and focus on the core basics of the phenomena to ensure that the information apply to all South Africans irrespective of their diversity. As the participants we selected to represent the diversity of the South African population and I was looking for believability in their information based on their coherence and insight, and trustworthiness through a process of ongoing verification between the various focus groups. As each focus group had a different representation of diversity, the final data was subjected through a vigorous and effective peer review for validity. The study was privileged to have participants with not only rich information available, but also a keenness to participate in the analysis and refinement of the data. They responded with their availability to continue within the focus groups to edit my coding of the data (Cresswell, 2003:192) into chunks of similar meaning.

It was important that I use their own language to label such groupings. They were also available to edit my definitions (descriptions or themes) to the codes to ensure generalise ability of the codes across all groupings of South Africans in a language that they and their peers will find “workable”. (*Ibid:196*) From this refined data I could advance to develop a measurement tool and again, when the tool was completed, they were available to edit the final draft to ensure that it fits their concept of what makes a difference between dying in dignity and dying in agony. They also evaluated and refined the final drafts work ability across all the different cultures and groupings that they represented.

The literature did not reveal an appropriate framework to use the narrative data collected from participants into the different components of a measurement tool. I drafted the following general guidelines collected from different sources (Brink,

2008) (Babbie & Mouton, 2007) (Cresswell, 2003) (de Vos, 2007) into specific analyses guidelines for designing this tool. I used these guidelines to analyse the data and then verified my analysis in the focus groups during the second visit.

My guidelines to analyse the narrative data are as follows:

- *Get sense of the whole by browsing through notes, asking one-self what it is all about.*
- *Keep the relevant research objective in mind, which are:*
  - *Is there a consistency in the basic needs of dying persons, irrespective of the race, culture or belief system;*
  - *if so, what are the domain of such an experience;*
  - *and what are the sub-items of such an experience;*
  - *and what are the processes of such a experience?*
- Study the notes and transcripts carefully to identify and cluster opinions by underlying/highlighting relevant phrases.
- Make sure that there is consensus on these clustered opinions across all focus groups.
- Write definitions down for each clustered opinion using the exact words, language and experience used by the research participants.
- Write definitions down for each clustered opinion using the exact words, language and experience used by the research participants.
- Seek and highlight synonyms and similarities in the definitions of each clustered opinion.
- Regroup the similar clusters of opinions with their definitions.
- Collapse the similar clusters of opinions above into a single consensus definition by using the exact wording of the participants. The new collapsed consensus definition will represent a sub-item.
- With the defined sub-items in hand, seek words, interactions, interventions, responses, that might indicate a prominent behaviour, ability or function of the dying person that consistently show change with intervention (Rodgers & Holm 1994). This would represent the process.
- With the sub-items and the processes in place, seek similarities across all sub-items and processes to generate a uniform understanding of the relevance of the sub-items and a sense of uniformity across the respective processes.

### 3.4.6 Qualitative: Trustworthiness of the data

Babbie & Mouton, (2007:276-278) states that the basic issue of trustworthiness is simple: “How can an enquirer persuade his audience (including himself) that the findings of an enquiry are worth paying attention or worth taking account of?” The interpretation of qualitative data can only be claimed to be “*transferable*” to the research population if it is “*credible*”, and it cannot be deemed to be credible unless it is “*dependable*”. All the techniques I applied in this study to secure trustworthiness can be set out as follows:

To achieve credibility:

- Prolonged engagement. Stay in the study until the data is saturated.
- Persistent observation. Keep on searching for new information that counts for this study and what can be omitted.
- Triangulation: Keep asking different questions, seeking different sources and using different methods to refine and test your data.
- Peer debriefing: Use similar status participants who have a general understanding of the study to review the existing perceptions, insights and analysis.
- Member check: Go to the source of the information (care givers) and check both the data and the interpretation thereof for errors, whether it reflects the intention of the respondents and if further information may be volunteered.

To achieve transferability:

- Sampling: The study population must represent the research population. The sampling techniques discussed in [paragraph 3.4.2](#) earlier in this chapter adequately describes that technique used.



To achieve dependability:

- Dependability refers to the evidence that if the study was repeated with similar respondents in a similar context the data gathered would be the same. [Babbie & Mouton, \(2007:278\)](#) states credibility is sufficient to establish the existence of the dependability. It is therefore possible to use the techniques mentioned in credibility to establish that the study has the quality to be dependable.

### 3.5 SECOND PHASE : THE QUANTITATIVE METHODOLOGY

The second phase of this study purposes to collect data with the newly developed tool and to analyse the data. The research question that is under consideration in the second phase of this study is:

- *Is the tool sensitive enough to measure change, and*
- *can the psychometric properties be established by statistical calculations from the data collected by the tool?*

There are two basic designs available for a quantitative approach, namely an experimental and a non-experimental design. [\(Brink, 2008:92-106\)](#) The design selected for this study was a non-experimental design. The non-experimental design differs from the experimental designs in that the researcher does not manipulate or intervene with the independent variable or the settings to study a cause and effect relationship. The non-experimental study is carried out in a natural setting and the observation data is collected as it occurs. The major purpose of the non-experimental design is to describe the phenomena as it evolves and then explore and explain the relationships between the variables. [\(Ibid:102\)](#)

There are two broad categories of non-experimental designs, namely the descriptive and the correlation designs. [\(Ibid:102-105\)](#) A correlational design purposes to describe the existing relationships between variables, and to determine the relationship between independent and dependent variables in a study. This study

does not require relationship analysis and therefore the descriptive design with a time dimension was selected as most suitable. To answer the research question regarding the sensitivity of the measurement tool, I needed to record the structured observations as they happen and change over time. This type of descriptive design that used time as a perspective is referred to as a “longitudinal descriptive design”. The longitudinal studies allowed me the opportunity to collect the measured data of each individual subject at their natural setting at several points overtime to study the changes that happen with a dying person over time. If the instrument is sensitive enough to record those changes that happen in the dying process then the research question would be answered.

The final question was about the psychometric properties of the measurement tool. In this study the reliability was the only psychometric property investigated. [Prof Vasi van Deventer \(2007\)](#) confirmed that a minimum of 200 singular data sets collected with the tool would be adequate to analyse the internal consistency of the measurement tool, e.g. 200 dying persons must be assessed once during the dying process.

### **3.5.1 Quantitative: Research population**

For the second phase of the study the research population are clients of CANSA in their end-of-life phase due to a terminal irreversible cancer that does not respond to any medical intervention and where the subject is expected to die within 6 months. ([refer Chapter 1 paragraph 1.8](#)) As the study was funded and supported by CANSA the research population are clients of CANSA’s palliative care program. They are all dying of cancer and currently in the care of a CANSA volunteer that render the palliative care to these subjects. The research population is geographically well distributed through out the Republic of South Africa and includes all the race, culture and belief systems. The inclusion criteria ([also refer to chapter 1 paragraph 1.7 &1.8](#)) for this research population are dying persons who are:-

- 20 years or older,
- cognitively alert and interactive, and

- aware that they have a terminal irreversible illness, and
- are predicted to die within 6 months.

The cut-off age of 20 years was selected for this population as the study is designed for adults. The operational definition (refer to Chapter 1:7) for this study states that the behaviour, abilities and functioning of children and adolescents may differ from that of adults and it was, therefore, decided not to include data of persons below the age of 20 years into this study.

As the proposed tool will measure the objective observations of the dying person's behaviour, abilities and functions it is a reasonably sound expectation that the dying person must be cognitively intact, allowing the care giver to make a behavioural observation. But what will happen if the dying person loses his cognitive ability during the palliative care process? This question poses a challenge and will be dealt with as follows:

- If the dying person is cognitively unaware on the admission day to the palliative care program, then the care is considered purely physical and no behaviour or ability or functioning is measurable. The palliative care outcomes tool is not to be used, and no palliative care data is collected on the dying person.
- If the dying person is cognitively aware on the admission day to the palliative care program, but at some stage during the program the dying person loses his cognitive awareness, then the palliative care outcomes tool is used and data collected from the day of admission to the day the dying person has lost his cognitive awareness.
- If the dying person is cognitively aware on the admission day to the palliative care program, and maintains his cognitive awareness till the moment of death, then the palliative care outcomes tool is used and data collected from the day of admission to the day the person died.

The criteria of defining when dying begins are operationally problematic. The Encyclopaedia of Death (Kastenbaum & Kastenbaum, 1989:103) offers six philosophical answers to this question: (please refer to Chapter 1)

- the moment we are born;
- when a fatal condition begins;
- when a fatal condition is diagnosed;
- when a patient is told that he has a fatal condition;
- when the patient realises and accepts the implications of the fatal condition, and
- when nothing more can be done to reverse the fatal condition and preserve life.

From this studies perspective palliative care for the dying person should be implemented when patient realises and accepts the implications of the fatal condition.

In the technologically advanced first world areas of South Africa it is not difficult to medically confirm that a person has an irreversible terminal illness and has a predicted lifespan of less than 6 months. This medical evidence is not always available in the rural villages of SA and it is those populations that are currently being devastated by the HIV/Aids and TB pandemics and cancer. However, this pandemic of death has brought forward unusual intuitive skills through experience amongst the palliative care workers to identify dying people and to group them according to the definition above without any medical support. They consider their accuracy in predicting death within 6 months in the medically deprived areas very high.

### **3.5.2 Quantitative: Research sample**

The sampling technique used in the quantitative section of this study is a “convenience” or an “availability” sampling. (Brink, 2008:132) This technique became available to me as the participating palliative caregivers in the focus group section of this study volunteered to collect data from their current CANSA clients. This sampling technique is also considered by Brink, (ibid) as an “accidental” sampling

technique as the subjects in the sample was at the right place at the right time to be included in the sample. However this study population might also be considered to be “accidentally representative” of the research population, because by ensuring that the inclusion criteria for the caregivers to participate in the focus groups studies were representative of the SA population it “accidentally” included their current CANSA clients with the same wide and representative distribution. This study population therefore represents all races, cultures and belief systems in SA, and are geographically well distributed through out SA.

### **3.5.3 Quantitative: Data collection**

The data collections in the quantitative phase of the study used the new measurement tool to gather two sets of data. The first set was data collected by doing a singular observation and scoring with the tool on all their current CANSA clients they care for at the client’s home. These singular assessments were collected and returned to me over a period of about 30 days. With this data set the internal consistency of the measurement instrument was investigated.

Once the reliability of the instrument was established, the second set of data was required to be longitudinal sets of scores during the dying process to understand if the instrument is sensitive to detect change over time and thus to be used as an outcomes measurement tool. The CANSA regional coordinator of caregivers from the West Coast region has volunteered to gather the longitudinal data with her care givers. This group of care givers were not part of the first phase of the study but after receiving training in the use of the tool, assisted me to gather a longitudinal data set of dying persons.

The longitudinal assessments did not replace the standard CANSA methodology of record keeping; it was merely considered as an additional method of assessing the same client. The longitudinal data set on each CANSA client therefore consisted of an “admission”, interim and a “discharge” set of scores. The admission scores were recorded when the observers started using the scores on the client. This might be at any time along the dying process. The discharge scores were done at the last time

the client was considered as lucid and coherent. The interim scores were recorded at any time they visited the dying persons between the admission and discharge dates.

The client names were recorded on the hard copy document for the sole benefit of the caregivers, who kept the score sheets together with the clients CANSA documentation, and need to identify the different scores sheets from each other as most of them had between 5-10 clients that they cared for on a daily bases.

The measurement instrument guided the observers to do a structured set of observations. This entails that they were trained and aware of behaviours or abilities to observe and how to record it. Such structured observations are the technique most commonly used in quantitative studies where the observer simply observes and records certain aspects of the subject's behaviour, ability or functioning. It requires on the part of the observer certain knowledge (e.g. the measurement instrument) of the expected range of behaviours in a given situation. (Brink, 2008:143)

In the healthcare research arena, structured observational studies has several advantages over the use of questionnaires or interviews, as what people say they do and experience is often not what they actually do or experience.

#### **3.5.4 Quantitative: The logistics to collect the data**

For the singular data sets the participants in the focus groups volunteered to become the observers and data collectors. To ensure correct use and reliability of the tool, I asked them to write a four case study test to accredit them as qualified scorers of the tool. They had to obtain 80% or more to be accredited. Only two out of 49 did not achieve 80% due to poor reading skills. The coordinators repeated the test with them verbally and they achieved accreditation.

I also drafted a score document and asked them to write their assessments on the hard copy, return it to the regional coordinator of CANSA, who faxed it through to me. I imported all the singular data scores on the designed excel software and e-

mailed the database to Prof Vasi van Deventer (UNISA) to perform the Cronbach Alpha and establish the internal consistency of the tool.

When the CANSA coordinator of the West Coast volunteered to have her caregivers trained and made available for longitudinal data collection I had to translate the abbreviated tool and the credentialing tests into Afrikaans for the local care giver population (see Annexure 4: Afrikaans Abbreviated and Annexure 7: Afrikaans Test) The regional coordinator undergone a train-the-trainer course by myself and also attended the first training session I gave in the west Coast area on the use of the tool. She trained and tested all her volunteer caregivers (more than 150) in the West Coast Region. They contributed 47 sets of longitudinal data to the study over a period of two months. [\(see their report in Chapter 5\)](#)

### **3.5.5 Quantitative: Data analyses**

Both the singular and longitudinal data sets collected with the measurement tool were expressed in ordinal data. For instance a number 1 under sub item “fear” means that the subject’s ability to find comfort in his spiritual wellness is very poor as he keeps acting out and shows no response to counselling. A number 5 under “fear” would refer to a situation where the subject is comfortable with the support his belief system renders him under the circumstances, but his loved ones thinks otherwise. A score of 3 under “letting go” would indicate the dying person is starting to accept that he must let go family and belongings but at times still acts out when this is mentioned.

The singular data set was used to estimate the internal consistency of the measurement tool by calculating the Chronbach alpha’s coefficient. [\(Cronbach, 1951\)](#)

Cronbach's alpha coefficient indicates how well a set of items (or variables) measures a single one-dimensional latent construct. When data have a multidimensional structure, Cronbach's alpha will usually be low. Technically speaking, Cronbach's alpha is not a statistical test - it is a coefficient of reliability (or consistency). Cronbach's alpha can be written as a function of the number of test

items and the average inter-correlation among the items. Below, for conceptual purposes, the formula for the standardized Cronbach's alpha is shown: (UCLA Academic Technologies Services. 2009)

$$\alpha = \frac{N \cdot \bar{c}}{\bar{v} + (N - 1) \cdot \bar{c}}$$

In the formula N is equal to the number of items, c-bar is the average inter-item covariance among the items and v-bar equals the average variance.

From this formula it became clear that if you increase the number of items, you increase Cronbach's alpha coefficient. Additionally, if the average inter-item correlation is low, alpha will be low. As the average inter-item correlation increases, Cronbach's alpha increases as well.

Therefore - if the inter-item correlations are high (e.g. coefficient > 0,7), then there is evidence that the items are measuring the same underlying construct. What is really meant when referring to a "high" or "good" reliability is that all the items in the instrument measure a single one-dimensional latent construct.

If the Cronbach alpha reveals a low coefficient (e.g. coefficient of <0,6) meaning the data measures a multi-dimensional constructs, a factor analysis can be done to see which items load highest on which dimensions, and then take the alpha of each subset of items separately. (*Ibid*)

The longitudinal data was plotted to overtime to view the sensitivity of the tool.

### **3.5.6 Quantitative: Data objectivity**

The notion of objectivity in the qualitative approach of a study refers basically to two different threats to the validity of the data that the researched must be aware of namely the internal validity and external validity. ([Brink, 2008:99](#))

The internal validity refers to the degree to which the outcomes of an study can be influenced by independent variables (e.g. unexpected negative influences during the course of the study, changes within the caregivers or CANSA clients during the study, assessment fatigue with the observers, selection bias to CANSA subjects in



the study population, etc). (*Ibid:99*) The methods used to limit all influences that might impact on the outcome of data collection can be summarised as follows:-

- The caregivers were trained, tested and accredited to apply the measurement tool.
- They applied it on their own CANSA clients that they are familiar with.
- They were given a 24/7 helpline number to myself to discuss anything related to the assessment or themselves. I received 12 calls in this period. All these calls was to inform me that they enjoy the scoring as it give them a frame work to work from and it empowers them.
- I contacted the CANSA regional care coordinators weekly to check on the progress and received no external influences that might require support.
- The CANSA subjects were not aware that the objective assessments were made.

The external validity refers to the degree that the results of the study can be generalised to the research population. There are two questions to be answered for external validity, namely with what degree of confidence can the study findings be transferred from the sample to the entire population, and will these findings hold true in other places and times? (*Ibid:101*)

The methods used in this study to counter the treats posed to external validity were firstly that subjects were not aware that they have been assessed and therefore no reactive effects from the subjects to the objective observations were experienced. The data therefore could not have been influenced by subject reaction to the study. The subjects represented across the diversities of South Africa and the tool is designed to be a generic measurement tool for all the dying persons of SA.

### **3.6 ETHICAL CONSIDERATIONS**

First and utmost the researcher is responsible for conducting his research in an ethical manner, and in this respect he must: (*Brink, 2008:30*)

- carry out the research competently
- manage resources honestly
- acknowledge fairly those that rendered guidance and assistance
- communicate results accurately
- consider the consequences of the research for the field of study in particular, and for society in general

Secondly the researcher must at all times do no risk or harm to the subjects directly or indirectly included in his research. The human rights that may not be violated at any point or degree in research include:

- the right to self-determination for those that has the ability as well as those that do not have the ability (e.g. children and intellectually disabled subjects)
- the right to privacy
- the right to anonymity and confidentiality
- the right to fair treatment
- the right to protection from discomfort and harm.

With this in mind the following steps were taken to uphold the ethical considerations in this study:-

- a. The study proposal was submitted to the UNISA's School of Health studies for approval of the degree of Master in Health studies. This study proposal was approved and an Ethical Clearance Certificate was issued to proceed with the research. On the UNISA approval of the research project and the issuing of the Ethical Clearance Certificate, the Cancer Association of South Africa (CANSA) gave permission to allow the research for this study to be done using their venues, staff, care givers and the dying people that are under their care.
- b. CANSA debriefed the caregivers about the study, their participation, their responsibilities and their rights as participant in a research study.
- c. At the first meeting with the caregivers I also debriefed them on their rights as research subjects in a qualitative study.
- d. In the quantitative design the care givers were asked to observe their clients in the standardised format of the measurement instrument and record the

data on a hard copy over a period of time. The observations stopped when the client were no more lucid or lost cognition.

- e. The dying person was not be subjected to any counselling techniques from the caregivers, other that the basic care they have been rendering to that date.
- f. The data collected on the dying persons were collected by the CANSA regional coordinator of the service and posted to me.
- g. I transferred the data onto an electronic format and destroyed the hardcopy with the client names on.
- h. Once the tool will be in its final phase of refinement and be ready to be tested, the participating care givers will be trained and tested to use the tool appropriately on the dying persons. This will not be in the format of a questionnaire or any request from the dying person to contribute any energy towards the scoring. The caregiver will only observe the day-to-day behaviour of the dying person as he responds to the items in the framework of the tool and record is as the daily recording of service rendering to CANSA. No invasive methods will be used.

### **3.7 SUMMARY**

In Chapter 3, I discussed the proposed design and methodology of the research project to go about and gather the information that is needed to answer the research question set out in the aims and objectives of the study. I discussed the research population, the sampling techniques, the data collecting and the logistics involved, the methods used for gathering valid and reliable data and my method of analysing the data. Finally I documented the ethical consideration to be adhered to.

In Chapter 4, I will present the data and discuss the results.

## Chapter 4

### PRESENTATION AND DISCUSSION OF THE DATA

*“They observed that a person’s dignity is the spirit within, an attitude of the mind, a possession held close to the heart..... and if you dent it, the heart cries” (“ukulile”)..... HJL*

#### 4.1 INTRODUCTION

In Chapter 1, I introduced the background and the aims and objectives of the study. In Chapter 2, I presented the literature study to understand the existing knowledge and techniques available that would assist me to develop a measurement tool. In Chapter 3, I described the design and methodology on how I will proceed to do the research. In this chapter I systematically present and discuss the data obtained in line with the objectives stated in [Chapter 1 paragraph 1.5](#):

- Does palliative care have a single measureable objective or domain?
- Does this single objective or domain have different sub-items or constructs that are internally consistent?
- Can each of these sub-items or constructs be subdivided into equal measures or intervals?
- Can such an instrument be used as bases for a scientific framework and a universal language to demystify the issues around end-of-life care?
- Can such an instrument with a (1)single domain, (2) internally consistent constructs and (3) equal intervals be used to routinely measure palliative performance, and as such be sensitive enough to be used as a outcomes measure?

Firstly, I will present and discuss the qualitative data, whereby I collected data from the cross cultural focus groups in six of the nine provinces of South Africa. I will make use of verbatim quotations from statements made by the participants to assist in understanding the dilemma of the dying person through the eyes of the care giver. I will also indicate where the literature review confirms the logic of my reasoning in applying the data to develop the tool. I will also point out and discuss the relevance

and importance where the literature review may contradict or not fully support the data obtained in this study. The literature review will also serve as a test of trustworthiness of this study. I will give a complete picture of the finalised measurement tool in the relevant annexure to this dissertation.

Secondly, I will discuss the collection of the quantitative data collected to be submitted for psychometric testing to establish the internal consistency of the measurement tool. I will also discuss the collection of longitudinal data collected to understand if the tool is sensitive enough to detect change over time. This characteristic would allow us to operationalise an outcomes management program whereby we use the concept of dignity of a dying person in routine assessment to facilitate better adjustments in the care to these persons.

Finally, I will present a training and testing manual and a hardcopy data capturing document for the measurement tool to be used for data capturing.

This chapter also illustrates the final product in the relevant annexure.

## **4.2 THE GATHERING AND ANALYSIS OF THE QUALITATIVE DATA**

### **4.2.1 What was the profile of participants?**

The invitation to the participants was structured to include the maximum information gathering, reflecting the diversity of the South African cultural and spiritual landscape. Participants were invited to specifically respond and interact within their cultural knowledge to enrich the data with cultural and belief diversity and to seek answers for behavioural differences. In *Table 4.1*, an indication is given of the various cultural groups and belief systems included in this study within the spiritual realm, the diverse approaches within the different Christian churches was noted and the Muslim, Hindi and Tamil belief systems plus the traditional African ancestral beliefs were equally explored and incorporated.

Region	Size of group	"Experience Rating" in group (out of 32)	Total number of death experiences in group	Cultural entities in group	Belief systems in group	Number of Interviews with group	Attendance
Freestate (Bethlehem)	7	20,25	173	Sotho, Zulu, Swazi	Traditional	1 <sup>st</sup> 2 <sup>nd</sup> 3 <sup>rd</sup>	92%
Freestate (Petrus Steyn)	6	17,16	16	Afrikaans	NG Kerk	1 <sup>st</sup> 2 <sup>nd</sup> *	83%
Eastern Cape	6	21,25	112	English, Coloured, Xhosa	Methodist, Catholic Traditional	1 <sup>st</sup> 2 <sup>nd</sup> 3 <sup>rd</sup>	78%
Western Cape	7	19,14	13	Afrikaans, Coloured	NG Kerk Moravian	1 <sup>st</sup> 2 <sup>nd</sup> *	100%
Kwa-Zulu Natal	7	24,5	131	Zulu, English, Indian	Traditional Hindi, Baptist	1 <sup>st</sup> 2 <sup>nd</sup> *	68%
Limpopo	8	20,25	216	Pedi, Tswana, Venda, Afrikaans, Northern Sotho.	Apostolic NG Kerk Catholic Traditional	1 <sup>st</sup> 2 <sup>nd</sup> 3 <sup>rd</sup>	100%
Gauteng province	8	20,00	83	Tswana, Zulu, Xhosa, Sotho, Afrikaans	Baptist Methodist Traditional	1 <sup>st</sup> 2 <sup>nd</sup> 3 <sup>rd</sup>	100%
Totals	49	19.22	744	11	8	18	88.7%

Table 4.1 - Various cultural groups and belief systems in the study population.

- ❖ The KwaZulu Natal and Western Cape group could not schedule the 3<sup>rd</sup> round of meetings due to CANSA's role-out of preventative care programmes in the community at the same dates, and the Petrus Steyn group had to cancel at the last moment due to a fire in the village.

#### 4.2.2 Information gathering process

##### *First round of focus group sessions*

At the onset of the first round I allowed every participant to introduce himself/herself and explain in detail his experience and skills and allow the participant to select the race, cultural and belief group that he would feel most comfortable representing within the focus group. When they have selected their mandate, those with similar mandates would work together as a team.

This process has generated lively debate and often valuable information was inadvertently rendered that was immediately picked up by me and written down as field notes. I wrote all field notes down, as we progress on a flip chart for all to see, to edit, to correct, to delete, to approve, to change, to rank, to group, to hopefully say *“That is it!! We all agree that is what it is all about!!”* When such a statement was made, I would ask each participant mandated to represent a race, cultural or belief group if the statement is true also for their mandate.

I made sure that every participant representing a grouping would agree at the end and would have nothing more to add. As soon as possible after each focus group session, usually the same evening, the flip chart field notes representing the dynamics of the data gathering were studied and written up as detailed notes by following the guidelines I mentioned in [Chapter 3 paragraph 3.4.5 \(Schurink & Schurink, 1988:93\)](#).

I used this same technique of posing the research questions and simultaneously verify data at all the 18 different focus group sessions. I started each focus group on a clean slate, trying to clear my mind as best I could from previous data and started collecting data from anew. At the end of each group session I updated the previous groups' field notes with latest one. During the first round of sessions I became aware that after the fifth group session I am not getting new information. I have reached a point of saturation. However I continued and completed all 7 groups, confirming that no new information was collected after the fifth focus group.

### ***Second round of focus group sessions***

A month later I conducted a second round of group sessions. Before the second session started, I carefully studied their previous field notes and from there prepared my questioning and probing to check the soundness of their information they gave me on the first visit. This was done in an effort to verify and validate information previously provided by the group. ([Clamp & Gough, 1999:187](#))

Thereafter I also verify with them issues raised in other the groups that, according to my notes, they did not mentioned and asked their opinion on it. I allowed 30 minutes for this “inter-group” verification process.

This process gave me a higher level of clarity and insight as I now understand better how the concepts of end-of-life are aligned with one another. What were different issues to me were in fact the same issues to them, just seen from a different angle. This process help me to bring issues and concepts together across all cultural and belief systems. An example was the two issues of family members that stigmatise the dying person and family members that deny or ignore the dying process. The outcome was that it was the same issue as it has the same effect on the dying person and requires the same remedy.

The remainder of the time allocated to the second round of sessions became in-depth discussions, drilling down on the format gained in the first session. Again I used a flipchart and every participant maintained his mandate to ensure that all cultural and belief systems are equally inclusive and correctly represented on the flipchart. I directed leading questions that were not previously covered with the objective to get as close as possible to the constructs of end-of-life care. I tried to obtain additional, new, information that gave rise to the previously agreed themes by asking the remaining central questions. This assisted in categorising information. (Frey & Fontana, 1993:369)

After the second round of group sessions I had enough data to attempt to develop the tool. Since I could not find literature to guide me in the construction of the tool, the design went through different drafts. When I found it to be sound from all considerations discussed within the groups, I distributed a copy to every participant for study and comment at the following third rounds of group sessions.

### ***Third round of focus group sessions***

The third round of group sessions took on a different format. Every one now had a copy of the proposed tool. We went through the tool design, layout and difficulty level. Most of the time was spent with comments, word changes, editing, corrections, self-appraisals and, very importantly, translations of key words and concepts into the 9 indigenous languages. The translations of the key concepts did generate new insights as some of them could not literary be translate into all the indigenous languages and the group had to agree on the most appropriate



descriptive terms. An example is the term “acting out” which cannot be translated into isiXhosa, but consensus was reached on the word “ukulila” meaning a person’s “heart is crying” which, when placed in this context, is correct.

#### **4.2.3 Data collected in the first round of meetings**

*“The more dignity a person radiates the more respect he earns, and the more respect he receives the more dignity he radiates. A dying person’s final life-line to this world is his dignity” ..... (Carltonville focus group)*

In the first round of meetings my objectives were to meet the teams, build up a sustainable relationship and try to understand why they are doing palliative care as volunteers, what are they hoping to achieve and how do they rate themselves as being successful.

The meetings started off with very basic and reflex answers to questions such as why are you doing palliative care? Answers such to keep the dying person comfortable, pain free, clean, and numerous other basic chores were rendered with sterile attitudes. As the process of probing evolved their responses became better thought through and it become as challenging to me as to the participants. Also their approach towards the process changed. They commended this to be the first time that they had the opportunity to mine individually and collectively into their own experiences in a structured way and find it rewarding that the process is helping them to generate a universal language amongst them for future communication.

The question of what they really try to improve seems to take the discussion to an even higher level. The answers were getting fewer tasks orientated (e.g. basic support, care, errands and cleaning) and more about issues that relate to helping the dying person to be-at-peace. They draw the distinction to dying in “distress” (in pain, fearful, alone and hanging onto life) as opposed to being “at peace” (contented, painless, looking forward, prepared). When asked what qualities, skills or attributes does the “at peace’ dying person have that the “distressed”

dying person is lacking, or vice versa; the debate started exploring the quality-of-life issues.

I probed deeper by questioning the universality of the quality-of-life definition and put it to them that surely the references to quality of life such as happiness, satisfaction, good life-style, being socially and financially successful could not relate to the dying person with a fast deteriorating health situation? They agreed with me and probed deeper into values such as the abilities to accept fate, leave a legacy, take control of the dying process, actively make preparations for yourself and your loved ones for your departure and in the process make sure that every one respects the dying person's leadership in this process.

The groups have agreement that it is this ability of the dying person to achieve control that make the difference between a person dying in "distress" or "at-peace". It was at this point that the teams that have not at an earlier stage exchanged the term "die in-peace" with "die with dignity" made the connection spontaneously. With the term "dignity", the participant's bodily and facial expression of achievement came alive. That indicated to me that there was a sudden awareness of *"we have known it all the time, we just could not labelled it"*.

The dignity translations into some of the indigenous languages were freely rendered: *"isithunzi"* (isiZulu) *"isidima"* (isiXhosa) *"seriti"* (Tswana/SeSotho) and *"menswaardigheid"* (Afrikaans). Across all cultures of the SA population there was a unified vote for dignity and the excitement was tangible. I have tried to persuade them to consider other alternatives for "dignity", but I was not successful. I could not replace dignity with other fundamental wisdoms. There was 100% consensus amongst all 49 participants, across all race, culture and belief systems on this issue of dignity. Although the term dignity is used freely in the literature ([see Chapter 1](#)), these caregivers were not using the notion freely in their day-to-day operations. The experience of working through the motions to arrive at the concept of dignity was for them a discovery and for me a confirmation of the findings in the literature reviews.

This finding was supported by [Chochinov, \(2002\)](#) who wrote that “the goals of helping dying people is to die with dignity”, and [Walsh, et al. \(2002\)](#) who suggests that “maintaining patient dignity is the most important element in care”.

I was satisfied that the data collected up to this stage verified that palliative care have a single measurable objective or domain namely “dignity”, and that I was on the right track to conclude the first objective of the study.

The next step was to try and understand what they meant with the concept of dignity. I questioned if dignity may have different facets and may differ from situation to situation and if different situations have different values or norms? I wanted to know which norms they are referring to in the situation of the dying person. Their collective answer was that every person, irrespective of culture, belief system, age or race has a deep sense of his own dignity. Dignity is an integral part of a person’s make up, identity, personality and who he is perceived to be.

They concluded that there is a link between dignity and respect. The more dignity the patient radiates the more respect he earns. That connection between respect and dignity took the discussions to another level where we explored the possibility that when the person is treated with disrespect, would it affect his dignity? The response was yes, but more so for the dying person as the dying person is in the end-of-life process whereby he is losing on a day to day basis his health, his independence, his earthly belongings, his relationships and possibly his mental capacity. The only thing he still has control over is his dignity, and he will protect his dignity. It is his lifeline to connect to this world. He will only maintain it if this world will treat him with the respect he needs to maintain or regain his dignity.

But does dignity not differ from person to person? The Gauteng group explained that “*dignity is a mindset that feeds on the respect shown towards the owner of that mind*”. The Polokwane group went put it in another way by stating that for the dying person “*the more respect given the higher the dignity the more at-peace the person will be*”. I tested these statements with the other groups and

consensus statement was: “*We are doing care giving to the dying persons to regain and maintain their dignity till the day of their death. We do it through various ways of rendering respect to enable them to die-at-peace*”. All the groups agreed with this statement and I was satisfied that I found the answer to the first research question:

Does palliative care have a *single objective or domain*? Yes, it is dignity.

Horton, (2004:1083) supports this statement by saying “dignity is an attitude of the mind, a property of an individual and all health professionals should treat their patients with dignity with respect.”

At the end of the first round of interactive sessions I could relate the following characteristics to dignity in the dying process:

- Firstly, with the domain in place, the tool must therefore be able to quantify the dignity of the dying person at any point in time during their end-of-life period.
- Secondly, every dying person is actively trying to **preserve or regain his dignity** in the end-of-life journey. This may be a conscious or unconscious effort.
- Thirdly, when a person **died-at-peace** he was able to maintain or regain his dignity till death successfully; when a person did not die-at-peace he was not able to maintain or regain his dignity successfully till death. The informal caregivers stressed that they have developed the skills to regain dignity in the dying person and they do **observe change** through their informal interventions.
- Fourthly, through the language used by the groups in explaining the relationship between respect and dignity, it seems that they refer to dignity as an **ability of the dying person to generate respect** from their environment.

With the above evidence from the groups I could develop the basic framework of the measurement tool. The four evidence pointers fits into the guidelines given

by [Rodgers & Holm, \(1994\)](#) when advising that “the first step in developing a clinical measurement tool is to seek and select a prominent behaviour, ability or function of a patient that is reasonably expected to change due to a healthcare intervention, and then secondly to analyse the behaviour, ability or function to detect a sensitive measure that will record the observed change”.

From the above it was evident that the “prominent ability” in the dying person is to maintain or regain dignity. Further more, there seems to be evidence of change resulting from caregiver intervention as they report that the persons “die-at-peace”.

It was my task at the second round of meeting to explore what are the basic pillars of care giving that would help the dying person to regain or maintain his dignity. If I could identify these care giving models I might relate it to the sub-items of dignity that would support the second objective of the study. I also need to identify how the caregivers evaluate their success in regaining dignity.

The following case studies are examples of how the informal care givers reported on the dying persons they care for.:

Care giver 6:-

“Susan\* het ’n swaar gelewe gehad. Haar man het jare gelede net verdwyn en haar alleen gelos om hulle twee vertraagde kinders self groot te maak. Sy was ’n trotse vrou en het meestal haar eie ding gedoen en nooit iets van iemand gevra nie, maar toe word sy siek en die dokter se vir haar se dis kanker, daarna het sy nooit weer haar mond oopgemaak nie om ’n word te se nie.

So is sy ’n jaar later dood. Sy het haar totaal van alles en almal afgesny. In haar lewe het sy so hard probeer om haar waardigheid te behou, maar die dokter se tyding het alles van haar weggevat. Daar was niks oor waarmee ons dit weer kom herbou nie, nie ’n greintjie nie. Haar waardigheid is dood een jaar voordat haar liggaam gesterf het.”

*Freely translated into English from Afrikaans:-*

*“ Susan’ s\* life was not easy. Her husband just disappeared years ago leaving her to raise their two intellectually disabled children on her own. She was a proud woman and never asked favours from the*

*community but then she became ill and the doctor diagnosed cancer. Since that visit at the doctor she never said one word again. She refused all communication.*

*She died a year later in solitude. She has cut herself loose from the community. During life she tried very hard to retain her dignity; but the doctors tiding took everything away from her. Nothing remained for us to rebuild her dignity. She was totally flattened by the verdict. Her dignity died one year before her body passed away.”*

#### Care giver 23:-

“Oom Joos\* het nooit enige vyande gehad nie, almal was sy vriende en soos hy geleef het, so is hy dood - met waardigheid. Almal het hom respekteer. Hy het net daardie vermoë gehad - tot op sy sterf bed. Daar was nie veel waarmee ons hom kon help nie, hy was in beheer van homself en sy familie. Daar was ook nie nodigheid vir die familie om te rou na die tyd nie, alles was net uitgesorteer voor sy dood.”

#### *Freely translated into English from Afrikaans:-*

*Uncle Joos\* never had any enemies, every one was his friend and as he lived so he died - with dignity He was respected by all. He had the ability - even at his deathbed. There was not much that we could have helped him with. He was in full control of his himself and his family. There was also no need for his family to mourn afterwards, everything was sorted out before his death.*

#### Caregiver 28:-

Susan\* was battling to die. She was in and out of hospice, very demanding and never satisfied with anything. Her husband of 10 years is a dear man and she kept him fulltime involved in her dying process. When the care giver starts probing her on the past she broke down. She had a son from her previous marriage that she lost contact with. We tracked him down and he paid a visit. They spend an hour together. She died two days later with a smile on her face. She had unfinished business to see to.

#### Caregiver 12:-

“Percy\* a 24 year old liver cancer victim could not get through to his wealthy family. His parents would not give up on him, they took him every where to potential miracle healers until his weak body could not handled it any more. He died in the back of their car returning home from another bout of “break through” therapy. Percy could not convince his parents to join him in working through his dying process. They were not there for him. They were in denial. He died alone without closure. After his death his parents were receiving ongoing bereavement therapy. They still do not comprehend what really happened and what went wrong. Percy and his parents got a “raw deal” out of the dying process”.

#### Caregiver 39:-

“Phineas\* was a migrant worker who neglected his rural wife and children..... he returned to his rural home to die with lung cancer..... his family rejected him and place him in the outside shed (*mkuku*)....the care-giver found him there and counselled him to regain his “respect”. After he accepted the wrongs he did to the family and he took control of his dying process, the informal care giver facilitated the interaction between him and his family. The result was a happy one with him and his family bonded and together they managed his dying process. He was moved into the home and there he died .... as he wanted it to happen with his family around him. He found closure.”

#### Caregiver 3:-

“Mary\* was a single parent with two kids age 3 and 5. She was dying from breast cancer and in severe pain, severely distressed and refused medication because she wanted to be alert for the children. She could not let go of the children. The caregiver organised Mary’s aunt to visit, sign documentation that she will care for and raised the children. Mary died peacefully a week later.”

#### Caregiver 47:-

“Kagiso\* was in a hospice dying of prostate cancer. He was extremely distressed and could not die, no medication seems to settle him down. In counselling with the care giver he expressed the wish of being at home with his family and at the place of his ancestors. The caregiver organised transport and he died at home two days later very peaceful and contented.”

#### Caregiver 44:-

“Petra\* was a religious Christian, but she admitted that she fear death because although she had asked forgiveness for all her sins, there might be sins left that she is unaware off! She was dying of ovarian cancer and was not knowing what lies behind death. The care giver asked the reverend to talk to Petra. He did a prayer for her asking God to forgive even Petra’s sins that she might not be aware off and to allow her into heaven as angel. He convinced her that God has answered this prayer. Petra opened her eyes smiled, said Thank you God ..and passed away.”

#### Caregiver 19:-

“Matthew\* was 25 years old dying of leukaemia. He has worked through the dying process with the care giver and was having open and frank debates about the oncoming dying process. However, family and friends avoid being open and frank to him about this process. They did not know how to handle

or address the issues and avoiding it was the best way out for them. This frustrated Matthew and he discussed it with his care giver and together they insisted that the family confront the issues. He succeeded and his dying process became an adventure for all, with him being in the driver's seat. He reported to them on a day-to-day basis how he experiences the decline..... him being the guide, they being the scribes. After his death the family and friends reported that they do not need bereavement counselling, Matthew gave it to them before he died."

#### Caregiver 16:-

"Martha\* belongs to the Methodist church. She was dying of liver cancer. She wanted to have a funeral in the Methodist church. Her "tickets" (invoices issued by the church for members that donates their 10% of income monthly) for the past six months was not updated, and therefore the church would prohibit her funeral in the church by an ordained priest. Her brother stepped in and paid the outstanding to obtain her "tickets" and she was at peace to know that she would have dignified funeral."

#### 4.2.4 Data collected in the second round of meetings

*If the concept of dignity can become the guide of how appropriate our interaction with the dying person is, it might be possible to monitor the degree that we are successful in doing it correctly..... HJL*

With the second round of meetings I put it to the groups that unless we can define dignity we will have trouble measuring dignity, and if we cannot measure dignity how are we going to know if they are successful in maintaining or regaining the dignity in the dying person? Their general response was that if you put a dying person in control of his deteriorating situation, really and honestly and respectfully giving him the power to make his own end-of-life decisions, then you are conserving the dying person's dignity. This led me to probe them on their experience gained from their escorted journeys with dying persons. I asked every one to back-track into their collective experience and to write down the 10 most common end-of-life constraints that they sense to be negatively affecting the dignity of the dying persons in their care.



The results were interesting. There was a difference in profile between the dying persons from a Western Christian community to those from an African Traditional community and finally to those from an Eastern Hindi community. They gave it to me in raw format and with their help we ranked it in a top-down order of prevalence on the flip chart with the participants doing the relevant editing, verifying, correcting and adjusting where needed.

The final table in *Table 4.2* was their answer to the top 10 end-of-life constraints – in ranking order - of dying people they worked with in their mandated communities.

<b><i>Western Christian culture</i></b>	<b><i>African Traditional culture</i></b>	<b><i>Eastern Hindi culture</i></b>
Poor pain control	Stigma	Family problems
Fear for death	Family rejection	Unfinished business
Poor symptom control	Others taking over	Refuse to let go
Family problems	Being overruled	Poor pain control
Refuse to let go	Unfulfilled wishes	Poor symptom control
Unfinished business	Incomplete documentation	Want to be with family
Want to be with family	Want to be at home	Fear for death
Being ignored	Spiritual denial	Incomplete documentation
Others taking over	Poor symptom control	Being overruled
Unresolved financial problems	Poor pain control	Lack of spiritual guidance

*Table 4.2 – The Top 10 End-Of-Life Constraints.*

The information gathering process to create *Table 4.2* gave me insight in the diverse dynamics of the South African populations dying process. It also gave me a baseline to work from.

My first observation was the diversity of problems that seems to affect the dignity of dying persons; secondly the similarity of end-of-life problems amongst the groupings of dying South Africans, and finally, the surprising difference in ranking of these problems by the groupings.

The outcome of the lists also created a surprise amongst the participants when we compared it in the work sessions. The Western participants questioned the very low ranking of pain, symptom control and the absence of fear of death on the African traditional groups list, while the African groups insisted that pain and symptom control is not the most prominent issue with their dying persons.

What is an overwhelming concern to the African traditional groups is the problem of stigma (and the resultant rejection of the dying person by the families) associated with any illness leading to early death not associated to old age. This may be due to cancer, diseases, HIV/Aids or TB. Such “before-their-time” dying persons in the rural communities have traditionally been perceived as being bewitched; or lately, mainly due to the HIV/Aids and TB awareness campaigns, as being contagious. Fear of death is not a concern, as the African traditional belief system originates that human beings of this world will all join the ancestors in the life-here-after. According to traditional African belief their ancestors interact daily with the earthly human beings and joining the ancestors is a transition to look forward to. There is no uncertainty as what the after-death will hold.

The Western Christian groups could not fully explain the reasoning behind their ranking but suggested that it might have to do with the Christian teachings of earthly sins committed and the uncertainty of where transition into the life-here-after would take them. If lack in pain and symptom control could be attributed to this overwhelming uncertainty with resulting distress – e.g. largely psycho-somatic in origin - is unsure.

The Eastern culture was represented by 3 participants and this sample is considered too small for a reliable reflection. However, it was interesting that they also ranked pain and symptom control lower in 4<sup>th</sup> and 5<sup>th</sup> place and fear of death was ranked 7<sup>th</sup>. This can be due to the Eastern culture’s belief that there is no heaven-versus-hell phenomenon.

After the individualised listing of end-of-life constraints I challenged each team to develop generic themes from both their raw material and the coded list provided above. The generic themes were considered to include all the end-of-life

constrains specified in the code list above and each participant must ensure that it is correctly placed under each theme as dictated by their mandate.

Firstly the groups identified the themes and then grouped their raw data under each theme. This process created in-depth analysis amongst the participants to verify each point of understanding. I used this opportunity to listen intensely about the terms and references they use, the processes they describe, the remedies they applied, the anecdotal evidence they produced, and the definitions they introduced. It was very fulfilling for them and I was a grateful for the rich data they made available through this exercise.

At the end of the second round of focus group visits we have compiled, adjusted, verified, edited and unanimously approved a list of themes. Definitions that present the constructs or sub-items of the “*dignity measurement tool*” as it now became known within the focus groups were formulated. The groups concluded with the following sub-items and their definitions:

- **Communication**

Measure the client’s ability to communicate his daily needs and feelings through open, clear, frank, honest and meaningful communication.

- **Family Harmony**

Measure the dying person’s ability to ensure that his loved ones react emotionally appropriate to his dying process; e.g. such as family withdrawal (due to stigma or denial or family that cannot face the decline etc) or a overbearing family (not allowing privacy, space and respect) to allow a peaceful death.

- **Fear**

Measure the client’s ability to find comfort in his spiritual and /or religious beliefs during the dying process.

- **Letting go**

Measure the client's ability to say goodbye to his children, family, friends, property, status, job and other earthy belongings.

- **Unfinished business**

Measure the client's ability to settle old outstanding disputes, regrets, blames, forgiveness, conscience qualms, secrets etc with himself, family, friends or community.

- **Wishes**

Measure the client's ability to finalise all his wishes (e.g. wills, policies, bequests, agreements, funeral arrangements etc) to ensure that those left behind are informed and/or taken care off.

- **Basic care**

Measure the client's ability to find comfort and satisfaction in his

(1) care environment (*home, clinic, hospice, hospital etc*) and the

(2) assistance with daily activities (*eating, grooming, bathing, toileting, bed/chair transfers etc*) and

(3) living conditions (*cleanliness, bedding, temperature etc*).

- **Nursing care**

Measure the client's ability to find comfort and satisfaction with the nursing care to alleviate discomfort such as:

(1) the physical pain control,

(2) vital organ support (e.g. breathing, ulcer managements, bladder, bowl management etc)

(3) symptom relief (e.g. nausea, diarrhoea, odours, rashes, itches etc).

With these sub-items and definitions to describe the dignity of the dying person, I was satisfied that the second research question "*Does this single objective or domain (dignity) has different sub-items or constructs?*" was now answered. Dignity for the dying person consists of eight sub-items and each have a clear operational definition.

During the in-depth discussions to arrive at the eight themes above I observed they refer in a roundabout way to the different emotional behaviours of the dying person and unintentional they refer to it as their barometer of being successful in their tasks as care givers. With probing into this phenomena they revealed that dying persons are emotionally more volatile than normal persons, more so if their dignity is violated.

During their anecdotal presentations and discussions I observed that they have, over the years, developed mutually agreed informal benchmarks to explain their success stories. Success was equated to the person being “at-peace” and not being successful was equated to the dying person been “in-distress” with emotional outbursts or withdrawal. I probed these behaviour benchmarks of the dying persons with them and nowhere could I find any evidence in the literature that this notion has yet been standardised into a numerical measurement.

They volunteered me all the symptoms and signs that they have become familiar with in observing distress. I offered the term “acting out” to them as an umbrella term to describe this cluster of symptoms and signs that represent distress in the dying person. They excepted the term and decided to refer to “**acting out**”, meaning the person is in distress by presenting with a passive or aggressive emotional outburst that is not known to be part of his normal behaviour and is due to disrespectful behaviour towards him. After I completed the list I tried to contextualise it into the meaningful groupings as set out in *Table 4.3*. The list immediately became known as the “Acting Out” guide (isiXhosa = Ukulila, Afrikaans = “uithaak”).

**Shock:**

*Anxiety, Fear, Insecurity, Indecisiveness, Non responsive, not focusing or concentrating,*

**Denial:**

*Lack of trust, Suspicious, Ignore you,*

**Bargaining:** (stand-alone term with no supporting symptoms)

**Anger:**

*Aggression, Obsessiveness, Upset, Impatience, Rudeness, Hatred, Demanding, Discontentment, Irritability.*

**Depression:**

*Isolation, Passiveness, Withdrawal, Rejection, Negativity, Mood swings, Psychosomatic symptoms such as pains, aches, shortness of breath,, hyperventilation.*

*Table 4.3 – The “Acting Out” Guide.*

The “acting out guide” begged for a new question; what techniques do you use, as an informal care giver, to calm a person down that is acting out? I request them to come forward with the basic techniques and I wrote it down on the flip chart. Then we ranked it in a top-down prevalence and found that the informal caregivers - with no trained skills - use the following six basic skills to calm a acting out dying person down and thereby attempts to restore or maintain his dignity. They claim that they have success with it, but they cannot prove it.

<b>English</b>	<i>Listening</i>	<i>Clarifying</i>	<i>Pacifying</i>	<i>Prompting</i>	<i>Probing</i>	<i>Questioning</i>
<b>Afrikaans</b>	<i>Luister</i>	<i>Verduideliking soek</i>	<i>Kalmeer</i>	<i>Aanmoedig</i>	<i>Delf</i>	<i>Vrae stel</i>
<b>Xhosa</b>	<i>Ukumamela</i>	<i>Ukuqinisekisa</i>	<i>Ukuthomalalisa</i>	<i>Ukunyanzela</i>	<i>Incazelo</i>	<i>Ukubuza</i>
<b>Zulu</b>	<i>Ukulalela</i>	<i>Chaza</i>	<i>Ukuthulisa</i>	<i>Khuluma</i>	<i>Ukuzwisisa</i>	<i>Ukubuza</i>
<b>Tswana</b>	<i>Ga Reetsa</i>	<i>Go netefatsa</i>	<i>Go kokobetsa</i>	<i>Go pateletsa</i>	<i>Go utlwisisa</i>	<i>Go botsa</i>
<b>Sotho</b>	<i>Ho Mamel</i>	<i>Ho netefatso</i>	<i>Ho kokobetsa</i>	<i>Ho pateletsa</i>	<i>Ho utlwisisa</i>	<i>Ho botsa</i>

Table 4.4 – Basic Skills to Calm a “Acting Out” dying person.

The “acting out guide” and the six basic skills the informal care-givers use to restore calm in dying person and thereby restore his dignity signalled the end of the second round of focus group meetings. I left well prepared to design and develop the measurement tool. The richness of the data that came from the discussions in the second round of meetings was in the field notes.

#### 4.2.5 Designing and developing the measurement tool

*“If we cannot measure dignity, how do we know if we are successful in maintaining or regaining the dignity in the dying person? .....HJ*

[Doyal & Gough \(1991\)](#) in their book, *A Theory of Human Need* put forward that there are two basic human needs: health and autonomy. These are absolute needs and not related to any particular culture. They are both vital to any type of healthy and dignified social engagement. Further evidence produced by [Marmot, Bosma, Hemmingway, Brunner & Stansfield \(1997\)](#) suggests that health and autonomy are interlinked with one another: lack of control over one’s life and one’s needs leads to worsening of your health. More so in the case of the dying

person where the decline of your health leads to worsening control by the dying person on how he wants to be treated.

Kuper, Marmot & Hemmingway (2002) agree with the link between autonomy, health and dignity and explain at length that human dignity is fragile and it is affected by the way one is treated, especially in circumstances where one's health makes one dependent on other persons. Sen (1992) approached the matter the same, but from a capabilities point of view. He suggests that it is reasonable to suggest that without achieving maximum capabilities to manage and control your environment, an individual cannot have basic freedom; without which he cannot have dignity.

This line approach supports my research findings. It also supports my attempt to measure the domain of dignity in the dying person "as the degree of control and decision making the dying person have over his end-of-life decisions and social interactions". If we can measure the degree of capability of a dying person we will understand and monitor the outcomes of the informal care-givers whose task it is to regain the dying person's dignity. If the concept of dignity can become the guide of how appropriate our interaction with the dying person is, it might be possible to monitor the degree that we are successful in doing it correctly.

I reviewed the field notes to understand the processes and methodologies these caregivers use to pay respect to the "spirit within" the dying persons. In summary the following evidence was now available to me. This evidence also supported the objectives of the study.

- **Dignity** is the single domain of an objective palliative care measurement tool.
- Dignified death is associated with someone who has **died-in-peace**.
- Dying people are actively trying to **preserve or regain their dignity**.
- Some dying people have a better **ability to generate dignity** from the environment than other.
- There are **8 sub-items** (or constructs, or senses) that support or contribute to the notion of the dignity experienced by the dying person.

- There are informal “Acting Out” guidelines used by caregivers to observe and identify when a dying person’s dignity is violated.

In addition the field notes provided me with the following valuable information to use in the design:

- The informal care givers include dying person’s family and loved ones in the care giving process. Maintaining and enhancing the dignity of the dying person is a holistic approach.
- In some cases the dying person is more approachable to the caregiver than the family, and sometimes it may be the other way round.
- The first step to approach a new situation is just to listen, seek common ground, then gently probe in different directions. Allowing the dying person to lead the process is better than the other way round.
- The objective is to win the trust of the dying person and his family and then bond them into a unit or a “team” of cooperation.

With this information I attempted the design of the measurement tool. The design went through many drafts, but I considered the fifth draft of the measurement tool to be as far as what I could take it without further input from the focus groups. I also drafted a training manual and a credentialing examination consisting of four case studies. I sent the training manual of the tool to all the 49 participants for perusal, editing, adjusting, critique and correcting to reach them one week before the 3 round of meetings.

#### **4.2.6 Verifying data at the third round of meetings**

During the third round of meetings every team member attended the meeting with the 5<sup>th</sup> draft of the tool presented as a training manual, and their editing contributions. There was consensus with the general layout, flow, content and logic of the document. Valuable word changes to put it the informal care giver language and adjustments to phrases that would better clarify meaning was the bulk of the editing contributions.



The final measurement instrument can be viewed as annexures, namely:

- [Annexure 2: Dignity \(Omega\) measurement training manual.](#)
- [Annexure 3: English abbreviated version.](#)
- [Annexure 4: Afrikaans verkorte weergawe.](#)
- [Annexure 5: Isi-Xhosa abbreviated version.](#)

I presented the participants with the four case study credentialing test and asked them to write the open book credentialing examination to test their ability to score their current CANSA clients in their homes. However, the result of these case study tests also contributed data to validity the performance of the instrument, such as rendering answers to these questions:

- Does the tool have the ability to be applied to hypothetical patients in a test format? Does the tool generate a reliable format or framework to allow the rater to come to a conclusion?
- Do the raters all come to the same conclusion?
- What is the difficulty level of the tool? How long does it take them to apply the tool successfully?
- What was the raters peer review to the usefulness of the tool?
- Can we use this format of accreditation for future training and testing in the use of the tool?

The four case studies with eight sub-items provided all together 32 (4x8) hypothetical situations to be scored. Of the 49 participating care givers subjected to the test, 47 scored more than 80%, and with this achievement it was decided that 80% should be the “competency rating on the dignity tool”. One scored 68% and another scored 66%. Both these caregivers were currently adult learners in reading and writing skills. A verbal test was done with them a week later by the regional caregiver co-ordinator and they both passed with scores of 84% and 91% respectively.

With this high competency rating it can be assumed that the tool has the ability to generate a reliable format or framework to allow the rater to come to a conclusion. The ability of the raters to interpret the tool correctly was high, as more than 94% of the raters achieved an accreditation score of 80% or more in the first round evaluation.

The four-case-study test was completed between a minimum of 30 minutes and maximum of 75 minutes. The average time it took the 49 raters to complete the four case studies was 52 minutes. This equals 13 minutes per case or 1,6 minutes to assess an individual. This was an acceptable time frame to read and comprehend the situation, then apply the situation to the instrument provided and arrive at a score. If this timeframe is acceptable, then the difficulty level of the tool for informal care giver is also acceptable.

The usefulness of the instrument was considered by the raters to be clear, logical and to-the-point. The outcome of their tests correlates with their view.

With these findings I considered the four case study test to be a useful format of accreditation for future training and testing in the use of the tool. This and similar examinations will serve to credential future care givers being trained in the measurement tool.

The English and Afrikaans case studies can be viewed as annexures, namely:

- [Annexure 6: English Case Studies test.](#)
- [Annexure 7: Afrikaanse Gevalle Studies toets.](#)

Finally, I handed a patient score sheet to them for each patient in their care. They were requested to use these sheets to complete a singular score on every patient in their care and then return the sheet to the CANSA coordinator who would fax it through to me. They have collected singular data of 260 dying persons. This set of singular data was used to calculate the internal consistency of the measurement tool.

The West Coast group, who came on board after the calculation of the internal consistency of the tool, volunteered to apply the tool to their clients to produce data over time to test the sensitivity. They collected longitudinal data from 47 dying persons in their region within the allocated time. They were asked to stop the assessments when their clients have lost their cognitive functions or have died. At discharge from the palliative care program the sheets must be returned to the CANSA co-ordinator, who will send it to me.

#### **4.2.7 Analysis of the quantitative data**

Thirty days after the last focus group meeting the participants have provided me with 260 singular data sets collected with the tool. I loaded the data from hardcopy to the software database access and send it electronically to Professor Vasi van Deventer at UNISA for internal consistency. He reported a Chronbach's alpha coefficient of 0.915. This provided evidence that the measurement tool has a good degree of reliability and that the scale is internally highly consistent. This further means that the eight sub-items contribute to the total score in a highly reliable manner.

A stepwise regression analysis to explore how each of the 8 sub-items contributes to the total score shows a very even contribution from each item.

*Professor van Deventer went further to examine the basic constructs of the scale in light of its good internal consistency. The principal component analysis clearly shows the tool has a single main domain with each of the items loading fairly strongly on this domain. This finding supports the notion that the scale has good internal consistency. The loadings below indicate that "Letting Go" is the strongest indicator of dignity and "Nursing Care" is the lowest.*

Sub-items	Indicator 1
Communication	.706
Family Harmony	.847
Fear	.848
Letting Go	.892
Unfinished business	.854
Wishes	.822
Basic Care	.729
Nursing Care	.607

*Table 4.5 - Results from the stepwise regression analysis of the sub-items and their loadings*

With this report ([Annexure 8](#)) of Prof van Deventer there is good evidence that the scale has a high degree of reliability as well as constructs validity.

To view the sensitivity of the measurement the longitudinal data of the 47 patients that died (case studies) were presented in two graphs. Unfortunately it was very difficult to comment on the change in scores over time as there was no consistency in the periods or time lapsed between scores. The periods between scores in each case study varied between daily to weekly. This made the plotting over time difficult. This irregularity is typical due to the circumstances in the rural areas that do not always allow regular visits. However, the scores were taken and recorded sequentially and the time axis are represented by the sequential scores, irrespective of the time lapsed between the scores. The graph illustrated in *Diagram 4.5*, represented the data received from sequential observations on 47 case studies over a period of 60 days. The horizontal axis represented the sequential scores, and the vertical axis represents the total scores on the sub-items of the measurement tool (minimum 8/56 and maximum 56/56).

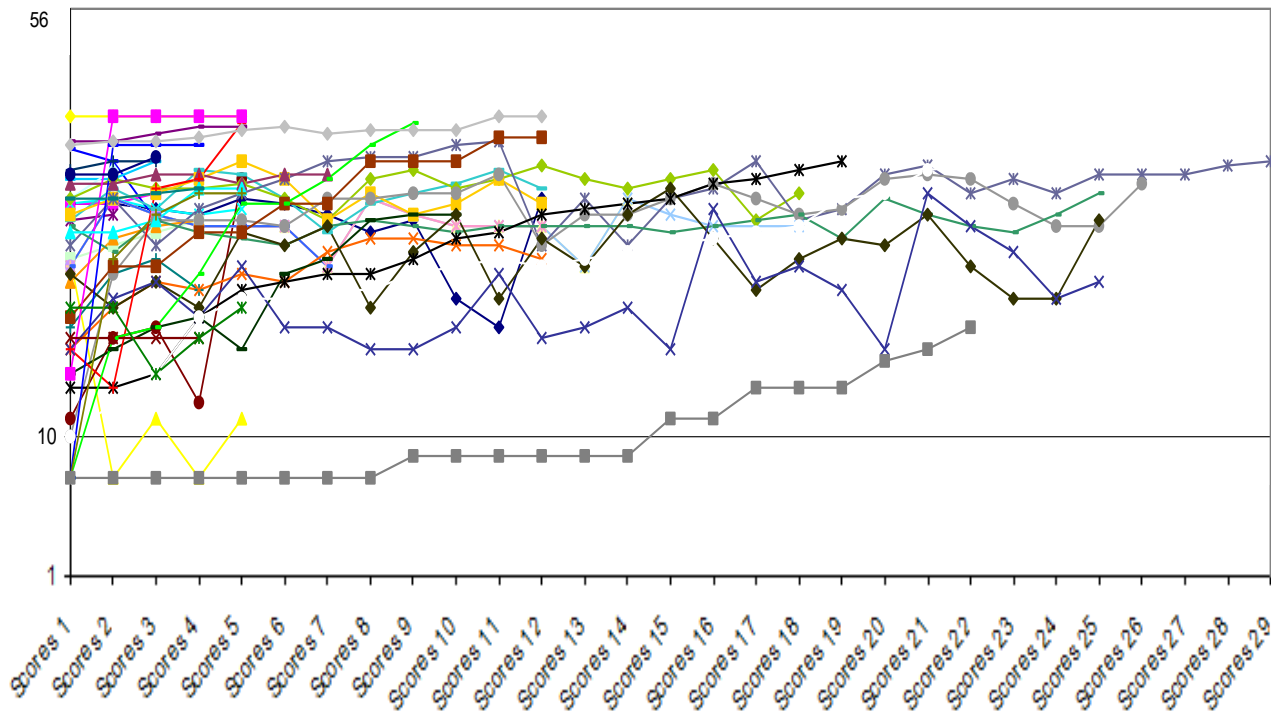


Diagram 4.5 – Time vs. Scores on the measurement tool

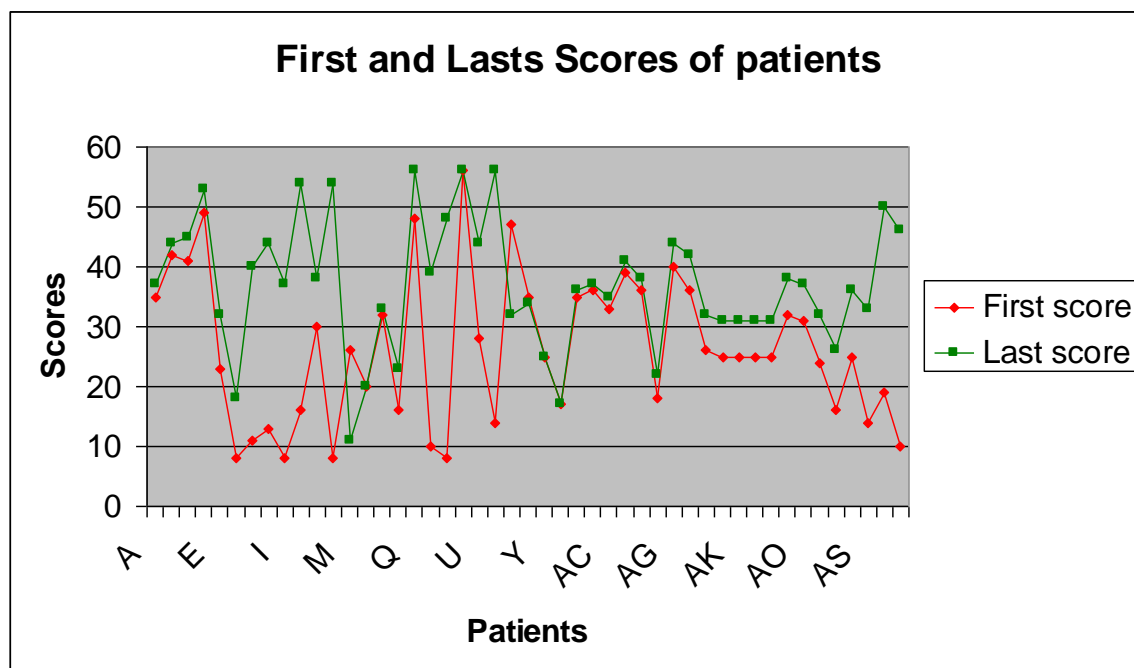


Diagram 4.6 – The individual case studies versus their total first and last scores on the measurement tool

In *Diagram 4.6*, the total scores of the first and last data received per case study (e.g. the admission and discharge totals out of 56) are represented in the vertical axis. The 47 case studies are represented in the horizontal axis. By plotting the

first and last total scores of every individual case study in this format, a preliminary attempt is again made to illustrate the sensitivity over time.

The conclusions derived from *Diagrams 4.5 and 4.6* must be considered preliminary as not enough data could be collected within the allocated time and the data was not within fixed intervals to provide a meaningful statistical analysis. However, the overall impression created with these graphs is that there is an indication of change over time.

In [Chapter 3 paragraph 3.4.1](#), I discussed the latent in congruency with the term outcomes measure when referring to palliative care. The notion is that with palliative there is a overall decline in functionality and that palliative care is all about supporting the dying person as he loose his functions. The care givers claimed that their task was not only to support the declining functionality but through their intervention they generate an outcome, meaning they cause some phenomena to improve. Their perceived sense of improvement they could not explain, define or quantify. However, this study has unlocked their minds and discovered the dignity perception with all its constructs including a format to measure it. Most of the individual graphs in the diagram 4.5 are fluctuating up and down as it reflects the status of the patient's dignity at the time of recording. There is also an early indication that the individual graphs increases at the end-of-life (graphs 4.5 and 4.6) as the function decrease towards death.

This may be the preliminary signs reflecting the sensitivity of the measurement tool. It also seems the graphs reflect an upward trend towards the end-of-life. This might be the first indication that "dignity" represents the unknown phenomena that the care givers were aware of but could not identified.

### **4.3 SUMMARY**

In Chapter 4, I presented the data and the logic and the systematic approach to develop the measurement tool. I described the outcome of subjecting the tool to reliability testing and presented the data that indicates that the tool may be sensitive to change and that there is a real possibility that it might succeed to become a outcomes measure.

In Chapter 5, I will summarise the findings and discuss the conclusions. I will also make some recommendations for future studies. I will also add, as an annexure, the training manual used in the training of individuals to empower them to correctly administer the measurement tool.

## Chapter 5

### CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

*When a person dies in distress the family grieves in access, but when a person dies with dignity the family celebrate his vivacity ..... HJL.*

#### 5.1 INTRODUCTION

In Chapter 4, the data obtained from the in-depth focus group sessions was presented. I also discussed the logic and methodology of how I applied the data to design and develop the measurement tool. It can be considered as an inclusive tool, meaning it can be used with the same success across the diversity of the SA population. The first data collected by the tool was psychometrically analysed for its reliability and the results were presented. Finally the data collected over time was also plotted longitudinally on a graph to detect the sensitivity of the tool to be used as an outcomes measurement tool.

In this chapter I will provide a summary of the findings of this research followed by a discussion of the implications, recommendations, limitations and a final conclusion to the study. In the annexures I will present the training material of the measurement tool.

#### 5.2 DISCUSSION OF THE IMPLICATIONS OF THE STUDY

In the introduction to Chapter 1, end-of-life care is described as a nebulous, immeasurable indefinable and holistic service referred to by the devoted as a service of the heart, the soul and the body.

When asked for evidence to the effectiveness of palliative care, the providers used descriptive evidence elucidating the processes involved in delivering the care. This mode of reporting seems to satisfy the needs of the donors that fund the service but the formal healthcare funders such as medical schemes are more sceptical as to whether the service meets the dying persons and their loved one's needs and



expectations in a cost effective manner. The providers of palliative care are increasingly reminded by the formal healthcare funders to provide ongoing valid and reliable evidence that their services are based on meeting the needs of patients and their families and to render proof that they are successful in doing so. (Carson, *et al.* 2000) This research provided a measurement tool to reveal this sought after evidence during end-of-life care.

Following the guidelines of Rodgers & Holm (1994), the study identified a prominent ability of the dying person that is reasonably expected to change due to an intervention. This proved to be the dying person's ability to maintain or regain his dignity, and so the concept of dignity became the domain of the measurement tool. The research further identified the eight sub-items (or constructs) and also identified the seven (7) intervals on each of the sub-items. With the tool completed, data was collected, the psychometric testing for reliability was done, and the tool was found to be highly reliable. These findings and development have implications on various levels for all involved in end-of-life care.

### **5.2.1 Implications of the study in general terms**

In Chapter 1, I stated that a crippling pandemic of HIV/Aids, multi-drug resistant tuberculosis and cancer is sucking the life out of the rural communities of Southern Africa. This pandemic is leaving hundreds of victims dying daily an undignified death; full of fear, in agony, anxious of what is to become of their children, depressed, stigmatized and grappling with unresolved issues. These devastating experiences are generally playing out in poor, hidden settings and are far removed from the notion that all lives have equal value.

There is very little chance that these victims will receive professional counselling and must rely mostly at the mercy of the informal caregivers. These caregivers have carried out their tasks in a haphazard way, trying to do their best in improving the situation of the dying persons, not knowing what the aims and objectives of their task really entails. They have tried their utmost, but could not measure improvement, nor could they comprehend a framework to work within or

a uniform language to standardise successes and failures. Their task was a lonely one, demanding all their energy, with no outcome as all their patients died at some point in time. There was no acknowledgement for the work that they are doing as the term “successful dying” was unheard and not spoken of.

This study has given the informal caregiver a framework to conceptualise his task and a tool to quantify the degree of success he has achieved doing his task. It should give a new meaning of achievement, acknowledgement and a measure of gratitude to this energy draining task given so freely and acknowledged by so few. It has also given the supervisors of these caregivers a uniform language to track, advise, support and counsel them.

With this structure and uniform language and their ability to measure and track their outcomes, there is a real possibility that the burnout of caregivers may reduce substantially. The emotional distress to the caregiver asking “what could I have done more?” for his dying client should now be something of the past, because the framework will plot their task and the measurement will calculate the outcome they have achieved with each dying person. The feed back from the caregivers ([Annexure 10](#)) highlights a new energy within them:-

- *“Thank you for helping me to understand everything, my job is no more only to help with the cleaning; now I feel good to do more for my people”*
- *“Thank you for helping us to help you. Now I can see how I help the person to get his dignity better. I like to go to see my people now every day.”*
- *“The families are thinking I am better than before because the dying persons are now listening and talking to me. I am so happy.”*

### **5.2.2 Implications to the dying person**

The instrument designed is based on the dying persons needs. The assessments are patient-based evidence and the observations are objective. The instrument renders numerical data and it has been psychometrically tested to be reliable. These characteristics are enhancing the trustworthiness of the measurements.

The result of this is that we now have a review system based on the defined needs of the subject and not the assumed needs of those who want to help.

The study revealed that the dying person have a unique set of needs during the dying process. These needs mostly refer to his ability to leaving a legacy and the methods at hand are to sustain and nurture his dignity. This differs substantially from the dignity perceptions experienced by a normal healthy person who do not experience the immediate need to leave a legacy. This unique suite of dignity characteristics is often rejected by the loved ones as they are mostly in denial and not prepared or ready to accept or participate in the legacy based dignity processes of the dying person. It is difficult for the dying person to persuade the world around him to consider otherwise, more so when his physical and emotional powers are becoming unreliable and his energy to convince otherwise is running out.

The concept of dignity-conserving care (Chochinnov, 2002) now becomes available to the dying person where his dignity becomes the overarching framework to define and guide the objectives and therapeutic considerations that is fundamental to end-of-life care. With this awareness by the loved ones of the dying person's unique set of needs and processes the dying person can now save his energy and efforts to keep his dignity intact till the last day. The battle to be understood has now been won.

### **5.2.3 Implications to the dying person's family and loved ones.**

*“Taking ownership of ones life destination is fundamental to human dignity – it is exercising autonomy and control..... but loved ones tend to determine the extend to which a one is offered that opportunity” ..... HJL*

The dying person's family is always confronted with the feeling of hopelessness and desolation and an overwhelming feeling of being out of control or directive. When different family members and have different emotions at different times the family situation can become very volatile and hot-blooded, especially so when

there are agendas and unfinished business at play. Every family member may have a different opinion on solving the problem of the moment and these solutions is not in sync with the needs or wishes of the dying person.

The root of these regrettable situations is mostly due to a lack of understanding, goal setting, common objectives and cohesiveness in their loved one's dying process. To them this is all new and very daunting. They have no reference to previous experiences and are not sure who to rely on to give guidance. Every one is trying his best, but in a different direction. The medical doctor or the nursing sister is expected to understand and guide them to fully understand the needs of the dying person, but the clinicians are non-the-wiser other than their field of expertise namely pain control and physical bodily care.

This study has provided these loved ones a "quick guide" to have an understanding of the all over needs of their dying loved one. The guide will also help them to focus on the dying person's dignity and coordinate their collective efforts to achieve that. It will help them to help the dying person to die with dignity, and when they have achieved that, they will have a feeling of accomplishment, a task well executed and delivered.

It is also my opinion that if a family was successful in rendering the dying loved one to die in complete dignity, the need for grieve counselling after death would be minimal. There should be loss, but not grieve if the dying person left this world with dignity and the family have achieved this as a team with the dying person. There should not be grieve if all the eight sub-items of dignity as stated in the measurement tool have been thoroughly explored between the loved ones and the dying person before the dying day. Grieve can and must be resolved before death not after. The instrument will help them to achieve that.

#### **5.2.4 Implications to the CANSA caregivers**

*“Without a clear vision of what the care to the dying person should be, there is a risk that administering may be become lost amongst the demands of the different stakeholders” ..... HJL*

It is the role and place of the informal caregiver to provide the knowledge and know-how in the homes of the dying person. She must be enabled to explain and facilitate the phenomena of dignity within the families. It is her task to assess the situations from day to day and guide the dying person on his journey and develop a cohesive family to support and endorse the dignity needs of the dying person. By doing so, she will not only encourage the family and the dying person to establish new relationships, but also to move towards a dignified death. She will set the goal orientated objectives for this dying person and his family team and continuously back it up with assessments. The team will improve overtime and together they will address all the items that are crucial for a dignified death. If she is successful, the family should experience loss but should not grieve after the funeral, as grieve has been dealt with successfully in the dying process. Everything has been concluded and nobody should be at a loss for a sense of meaning or significance. It was sorted out before death.

Previously the caregivers were not capable, empowered or skilled to render this service. Through their experience they became aware of what needs to be done, but they did not had the know-how, neither were they empowered, nor had the ability to assess these situations and to set goals. Due of all these short comings they were never considered to be anybody more than doing the basic chores around the dying person. In their presents the disjointed families would severely dent the dying person’s dignity without knowing better and the care worker would have no status or knowledge at hand to help them, and finally when the person dies in distress the family grieves in access.

The new measurement tool will empower the palliative care givers to assist dying persons and their families from hereon. The feed back from the caregivers (Annexure 10) highlights their new ease to work with the families:-

- *“When I tell the families about dignity they think I am a teacher. They respect me for what I know and listen to what I say how to help the dying person. I am feeling so good because I can score the dying person every day.”*
- *“Thank you – it is so much easier now.”*
- *“I do not feel so tired any more; I look forward to visit my patients. I want to see every day if their dignity gets better. I want their dignity to be very high when they die. I help the family to help me to get dignity high.”*

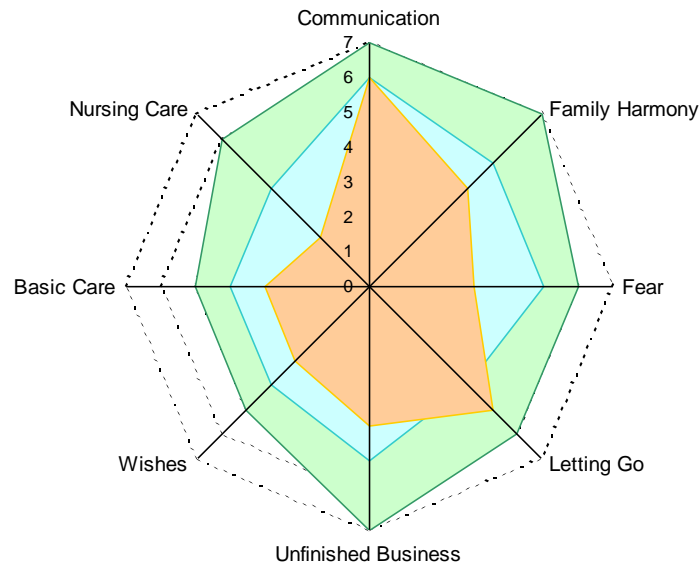
### **5.2.5 Implications to the CANSA supervisors**

*Whenever I lack structure, insight and words to supervise a caregiver in difficult situations ..... I send her away with a hug and some reinsurance to trust their instincts..... but as she walks to the problem, I have to live with my failures. (CANSA Caregiver co-ordinator, Qwa.Qwa)*

For so long the communication amongst the palliative caregivers and the supervisors consisted of questions that was unfocused, ambiguous and unrelated and the responses were vague, unconnected and woolly. This method of saying a lot about nothing and expecting people to follow through with a nebulous plan and report back is in itself degrading and tiring. Overtime the communication on these vague issues became more and more restricted to basic understandable items that can be discussed and assessed such as basic care needs (e.g. bodily care and home chores) and the job-descriptions was degraded to levels where the communication were not at risk of confusing anybody.

Working an environment where one is taking responsibility for the needs of a dying cancer victim and his family and the links of communication, directives and advice from the supervisor is only about the basic needs must be daunting, tiring and sucking the energy out of one. The quality of such a service must also be meagre and of a low level. From a supervisor point of view the service can only be upgraded to higher levels of involvement if a uniform language about the

essence of palliative care underpins it and a reliable method of assessment supports it.



Graph 5.1 – Dignity Scale showing three sequential assessments on a “Spider Graph” © SADFM.

This study has provided this uniform language and the assessment method. Not only will the supervisors be able to communicate appropriately with the care givers and vice versa, but also a uniform assessment is in place to discuss goals, objectives, methods and techniques to secure a successful outcome. (See graph 5.1) The feed back from the caregivers (Annexure 10) highlights their new experiences to work with their supervisors:-

- *“I feel like a queen, I can now explain the patient’s problems to others, now it is so easy because Thomas (CANSA regional coordinator: Free State) looks at my scores only and then he know.”*
- *“The tool has given me a new frame work to work in; I can now see how things relate to one another. Thank you for the opportunity to be part of the research.”*
- *Every time we have group meetings, I can tell other caregivers what the problems are, and they can help me because we talk now about the dignity tool scores, and now we all understand now”*

### **5.2.6 Implications to the training and development of CANSA caregivers.**

From a care giver training point of view the study has provided CANSA with a framework to guide their caregivers into the phenomena of the dying process. By using the measurement tool in their training programs they will give the caregivers the insight that the dying requires much more than just caring. They will now have to apply different techniques and methods to enable the dying person to have a positive outcome. These techniques are based on the eight sub-items of the measurement tool. The sub-items are all inter-dependent and none of them have a higher priority than the other.

The dying person must face all these situations and be able to close-the-book on all the sub-items successfully. If he hesitates, stumbles or fails, the guide must make it possible for him to continue in such a way that he has done it himself. The triumphant caregiver will anticipate those situations and find timely ways and means whereby the dying person addresses it himself successfully. In other words the dying person must find the strength from the guide to enable him to face and overcome all the obstacles in the path to a successful death. In the end his dignity will depend on him making the right decisions to find inner peace and earn respect in his last days. Precisely how the caregivers will be enabled by CANSA to follow this process across the diversity of the SA population is reserved for a future study. This study has only given the broad directives to assess if they are successful, nothing more.

The apparent lack of a uniform language prevented the development of the care givers of dying persons. Their training was restricted to the peripheral needs of basic care and support, while the core need of dignity preservation was not addressed as there was no uniform language to describe it or no instrument to assess it. It remained a phenomenon that is too nebulous to qualify or quantify.

This study has now developed clear definitions, constructs and principles to describe and assess the dignity of the dying person, and is available to be trained to the CANSA care givers. About two hundred has already been trained and the



care worker coordinators have reported back that they would like the dignity tool to be implemented nationally.

Mrs Maree Lambrechts, the CANSA regional manager of the West Coast, who have trained more than 150 care givers in 20 rural villages, produced an interesting report on the CANSA teams and caregivers experience during the training process:- ([Annexure 9](#))

- They identified the constructs of the dignity tool as representing their daily challenges.
- They enjoyed and were excited about training received.
- They were “up beat” to be able to measure their progress.
- CANSA staff predicted that the training will have a very positive effect on service delivery.
- Some caregivers were quick to learn and grasp the concepts while others could not conceptualise the notions of dignity or its sub-items.
- The older care givers that are set-in-their-ways of rendering only physical care felt threatened by the idea of including new concepts into their curriculum, while the younger trainees experienced the tool as applicable, valid and meaningful and were anxious to participate.
- Overall the CANSA personnel were 100% in agreement that the instrument and its application will be of major use in the future training and development of CANSA caregivers.

The feed back from individual caregivers ([Annexure 10](#)) highlights how they experienced the training of the assessment tool:-

- *“The tool is so easy to use, it sits in my head and I know what to listen for and what to look out for to make a score. I am very good now”*
- *“I use the tool on all my people now. It just comes as if I have done it all my life. It is so easy and I feel like I am the best.”*
- *“I always though I had lots of experience with the needs of dying persons and that I was good at it; but the Dignity scale proved that I knew only half of what it was all about.”*

- *“Thank you so very much for asking me to help with the study. We always new what was dignity, but you helped us to measure it and now it works so much better.”*
- *“I would not have missed this opportunity to learn so much in such a short time.”*

### **5.2.7 Implications to CANSA**

CANSA renders an advocacy service to cancer victims in SA. Broadly speaking their service includes preventative, supportive and rendering care to cancer victims who need it. Currently, the care rendering division of CANSA is mostly - but not entirely - based on end-of-of life care with the informal caregivers. CANSA found it problematic to set-up and manage such an end-of-life service if the outcomes can not be measured and managed appropriately.

As this study has now defined and made assessments possible on end-of-life care, the development of care services to persons dying of cancer has been taken to new levels. CANSA can now formalise the management of these services. This includes setting up training programs for the informal care workers to quantify what they are doing, instituting a uniform language to communicate between care workers and their supervisors, develop a routine system of data collection on hard copy that will explain the progress in numerical terms, develop a web-based software to enter the data and keep a national database of all end-of-life cases. With such a database, analysis of the data will reveal the different management indicators available to CANSA such as the benchmarks and trends related to palliative care. (Pirkis, *et al.* 2005)

### **5.2.8 Implications to the health industry**

The preliminary studies on the sensitivity of the designed instrument are promising to use it as a outcomes measure. The medical scheme industry is moving towards outcomes based medicine. This implies that patient based evidence is used in an objective format to collect data that would indicate if the

service rendered to the medical scheme member has added any value to the needs of the member. If such value can be quantified the medical scheme would be interested to register the service as provider of health care to the schemes members and such a service will be paid for. (Crump, 2005)

The medical scheme industry is also moving towards the alternative-to-hospital-care approach. The model for end-of-life care suggested by this study is home-based care by the informal care giver. If such a home-based-service can also be rendered as an outcomes-based-service where the patient improvement can be calculated and compared with other similar cases, then the palliative care services will be registered as service providers as they can proof their value adding to the healthcare continuum. (*Ibid*)

### **5.2.9 Implications to further research opportunities.**

The next step will be to put the tool into operation on a national level. CANSA has committed itself to implement the tool amongst all its caregivers and collect the data into a national database for analyses and reporting. The opportunity to have large amounts of sound data in one database will open new opportunities for research calibration to understand:

- How do the different belief systems manage their dignity during the dying process?
- How successful are the informal care givers in achieving dignity in the dying persons by applying only their cultural experience and the measurement knowledge, and how will the situation improve given basic training in professional counselling skills?
- Can data of outcome measures be interpreted as indicators of quality of care and can medical scheme organisations now verify the quality of care given to their members?
- What are the benchmarks in regaining dignity for different groupings such as genders, social-cultural groups, age groups, diagnosis related, etc?

In Chapter 1 paragraph 1.3, I asked the questions about the palliative care phenomena that await answers and this study provided new insights into the phenomena with a significant amount of responses to those questions. By unlocking the caregiver's insight on the phenomena we now have a better understanding of how to define and measure palliative care. We have a better perspective of what is required from the person selected by the dying person to escort him on his "never-travelled-before" journey. There are impediments in the end-of-life journey and the study has identified the main ones. It also explains the prevailing conditions to determine if the dying person is successful in overcoming those hurdles.

If all the data collected is entered into a database, CANSA will be able to explore a diverse set of management information e.g. CANSA will be able to establish benchmarks for the following:-

- Understand and record the complexities of the tasks of a care-worker and the burden of care associated with each case.
- Calibrate how to establish the criteria for being a successful care-worker.
- Identify through statistical peer review which workers have the knowledge and who needs that knowledge to enhance dignity.
- Analyse the different patterns of how the sub-item improve and how it differs amongst the different populations in SA, e.g. progress pathways for different groupings.

The data will also help CANSA to set up a palliative care governance plan to secure equal value and dignity for all persons dying of cancer in SA by following through on these questions:-

- How can CANSA learn from those workers that are consistently adding more value to bring dignity to their dying clients?
- Where should CANSA intervene with minor interventions that may achieve major outcomes, and what will that value-adding intervention be?
- Can this process of care for the dying really be "managed"?
- Can CANSA add value with a goal-driven management strategy?

### 5.3 RECOMMENDATIONS

- 5.3.1 The psychometric properties of the measurement tool have not been fully explored yet. I suggest that when adequate data has been collected, further studies must be done to establish the construct validity. Ways and means also needs to be explored to establish the tool's inter-rater reliability characteristics.
- 5.3.2 The fresh information suggests that the caregiver can not be considered to be merely the supporter, the devotee, the caregiver to underpin functionality as death approaches; she is also considered the guide, the facilitator the counsellor. Originally seeking and securing comfort for the dying person was admirable but not entirety.
- 5.3.3 The tool must be used to gain experience in caring for the dying person. It will be of benefit if the data collected will be analysed to seek those care-givers who persistently over perform against the standard benchmarks and those that under perform. If such caregivers can be identified and they pass an audit of scoring patients correctly, then the over achievers and the underachievers must be identified. They will represent those that have the informal counselling skills and those that need the informal counselling skills. A process should then be in place to allow those who need help to learn from those that can render help. With this process the quality of informal care giving will evolve overtime and a process of care giving governance will be in place.
- 5.3.4 The informal caregivers at this point in time only understand the framework of the tool and some self taught skills that came from years of experience. I strongly recommend a follow-up research study to fully exploit the valuable services of the informal care givers. This must include a informal care giver guide to explore the basic counselling techniques to be applied for the different peoples of SA. By identifying the over performers on the database would be a good point to start was the knowledge vests.

5.3.5 The tool has been designed to measure the ability of the dying person to maintain his dignity **and the inverse** namely the burden of the care of the care giver. With this tool it is possible to now quantify the care givers burden of care and to understand when his burden becomes too much. By managing the caregiver burden appropriately the incidence of burn out should be significantly less. I suggest that the a caregiver burden of care study be undertaken to establish the maximum amount of burden of care score a care giver can manage at any point in time with out showing signs of burn-out.

5.3.6 The letter (*Annexure 9*) from CANSA highlighted a valuable point. During training of more than 150 care givers, some informal care givers could not grasp the concepts. These care givers are more comfortable to do the basic chores for the dying person without applying the basic counselling skills. There is nothing wrong with this and the dignity tool must be used to assess the different qualities of the caregivers. I would suggest that they might work in teams of two where one is more focussing on informal counselling and the other is more focussing on errands.

#### **5.4 LIMITATIONS OF THIS STUDY**

5.4.1 The dignity scale is not designed to replace the existing professional tools used by professional counsellors during the dying process. The dignity tool is designed with the informal care givers for the use of informal care givers to help them. It makes no claim that it can be used for in-depth counselling by the professional counsellors. It is, however, hoped that professional counsellors will use the framework and language used by the dignity tool when they consult to and advise the informal caregiver. The framework created is therefore limited to the care givers.

5.4.2 The dignity scale only measures the dignity of adult dying persons over the age of 20 years. The study was limited to adult dying persons and it is

unknown how valid and reliable the study will be for people under the age of 20 years.

5.4.3 The study did not include the Muslim community due to unavailability of the group in Cape Town. However, I tried to explore the few Muslim cases presented in the groups to understand if there were any major deviations that we should have included in the data and I could find nothing.

## **5.5 PERSONAL AND EMOTIONAL EFFECTS OF DOING THIS STUDY.**

For me it was a hugely rewarding experience to work and explore new knowledge with these dedicated people that is always prepared to be available for the dying persons and their families any time of the day and night. They were prepared to also spend time out with me, because they believed that in this way they were adding value indirectly to the dying persons. Such dedication I have not experienced yet in the health care world. As a general practitioner who wrote morphine prescriptions and certified people clinically dead after a long illness, I was left humbled by what they taught me. I was not aware what the dying persons went through when I wrote those pain stilling prescriptions.

This was a whole new world that opened for me and I only wished I could have had this opportunity when I started in general practise. It could have meant so much more for my dying patients.

## **5.6 FINAL CONCLUSION**

The research questions posed in Chapter 1 were used as basis for obtaining information and the guidelines from the literature review in Chapter 2 was used to develop the measurement tool. The psychometric properties of the tool appear to be sound and the tool seems sensitive enough to show change over time.

In Chapter 5, I concluded that the tool also appears to be user friendly, can be implemented as a routine measurement, and has a very low difficulty ratio, meaning the trained informal caregiver can master its use. It was thus possible to explore the

domain and construct of the phenomena of the dying person and come up with a measurement tool for such an abstract and complicated concept.

*“It can never be right to act for the sake of a purpose that is not the purpose of those we have the power over”.....* Isaiah Berlin referring to dignity as a function of autonomy.



## Bibliography

- Arya, D. & Callaly, T. 2005. Using continuous quality improvement to implement a clinical governance framework in mental health services. *Australian Psychiatry*.13 (3):241-146.
- Aspinal, F. & Hughes, R. & Dunckley, M. & Addington-Hall, J. 2006. What is important to measure in the last months and weeks of life? A modified nominal group study. *International Journal of Nursing Studies*. 43(4):393-403, May.
- Babbie, E. & Mouton, J. 2007. *The practice of social research*. Cape Town: Oxford University Press.
- Bartholomew, W.G. 1999. Meditations:Lessons from the angels of death. *Bioethics Forum*.16 (Special Issue)
- Bern-Klug, M. 2004. The ambiguous dying syndrome. *Health and Social Work*. 29(1):55-56, Feb.
- Brink, H. & van der Walt, C. & van Rensburg, G. 2008. *Fundamentals of research methodology for health professionals*. 2<sup>nd</sup> Edition. Cape Town: Juta.
- Carson, M.G. & Fitch, M.I. & Vaschon, M.L.S. 2000. Measuring patient outcomes in palliative care: a reliability and validity study of the Support Team Assessment Schedule. *Palliative Medicine*. 14:25-36.
- Centeno, C. & Clark, D. & Lynch, T. *et al.* 2007. Facts and indicators on palliative care development in 52 countries of the WHO European region: results of a EAPC task force. *Palliation Medicine*. 21(6):463-471.
- Child Hospice International. 2008. Difference between adult hospice care and children's hospice care. <http://www.chionline.org/resources/difference.php>. (accessed 27 March 2008).
- Christakis, N.A. 1999. *Death foretold: Prophecy and prognosis in medical care*. Chicago: University of Chicago press.
- Chochinov, H.M. 2002. Dignity – conserving care, a new model for palliative care. *Journal of the American Medical Association*. 287:2253-2260.
- Chochinov, H.M. & Hack,T. & McClement, S. & Harolos, M. 2002. Dignity in the terminally ill: An empirical model. *Social Sciences Med*. 54:433-443.
- Clamp, C. & Gouch, S. 1999. *Resources for nursing research: An annotated bibliography*. 3<sup>rd</sup> Edition. Newbury Park, CA: Sage
- Clayton, J.M. & Butow, P.N. & Arnold, R.M. & Tattersal, M.H. 2005. Discussing end-of-life issues with terminally ill cancer patients and their carers: A qualitative study. *Support Care Cancer*.13(8):589-599, Aug.
- Cresswell, J.W.2003 *Research design: Qualitative, Quantitative and Mixed methods Approaches*. 2<sup>nd</sup> Edition. Nebraska, Thousand Oaks: Sage.
- Cronbach, L J. 1951. Coefficient alpha and the internal structure of tests. *Psychometrika*. 16:297-334.
- Crump, B. 2005. How can we make improvement happen? *Clinical governance: An International Journal*. 13 (1):43-50.
- De Vos, A.S. (ed). 2007. *Research at grass roots*. 3<sup>rd</sup> Edition. Pretoria: Van Schaik.
- Dobrzykowski, E.A. 1998. *Essential readings in Rehabilitation Outcomes Measurement*. Maryland: Aspen Publishers Inc.
- Doyal, L. & Gough, I. 1991. *A theory of human needs*. London: Macmillan.

- Doyle, D. & Hanks, G. & Cherny, N.I. & Calman, K. 2004. *Introduction to the Oxford Textbook of Palliative Medicine*. 3<sup>rd</sup> Edition. New York: Oxford University Press.
- Eagar, K. et al. 1997. *The Australian National Sub-acute and Non-Acute Patient (AN-SNAP); report on the national sub-acute and non-acute case-mix classification study*. Centre for Health Service Development, University of Woolagong. Sydney. Australia.
- Ellis, J. 2006. All inclusive benchmarking. *Journal of Nursing Management* 14(5):377-383, July.
- Freeman, T. 2006. 'Best practice' in focus group research: making sense of different views. *Journal of Advanced Nursing* 56(5):491-497.
- Frey, J.H. & Fontana, H.A. 1993. *The Group Interview in Social Research* in DL Morgan (editor) *Successful Focus Groups*. Newbury Park, CA: Sage
- Granda-Cameron, C. & Viola, S.R. & Lynch, M.P. & Polomano, R.C. 2007. *Measuring patient – orientated outcomes in palliative care: Functionality and Quality of Life*. *Clinical Journal of Oncology Nursing*.12(1):65-77, July.
- Grimby, G. & Eckholm, J. & Fisher, A. & Stibrant – Sunnerhagen, K. 2005. Editorial: Measurement and evaluation of outcomes in rehabilitation. *Journal of Rehabilitation Medicine*. 37:1-2.
- Hack, T.F. & Chochinov, H.M. & Hassard, T. & Kristjanson, L.J. & McClement, S. & Harlos, M. 2004. Defining dignity in terminally ill patients. *Psycho-Oncology* 13(10):700-708.
- Halcomb, E. & Gholizadeh, L. & Di Giacomo, M. & Phillips, J. & Davidson, P. 2007. Literature review: Considerations in undertaking focus group research with culturally and linguistically diverse groups. *Journal of Clinical Nursing*.16(6):1000–1011.
- Horton, R. 2004. Rediscovering human dignity. *The Lancet* 364(9439):1081-1085, Sept.
- Jocham, H.R. & Dassen, T. & Widdershoven, G. & Halfens, R. 2006. Quality of life in palliative care cancer patients: A literature review. *Journal of Clinical Nursing*. 15(9):1188-95, Sept.
- Kastenbaum, R. & Kastenbaum, B. 1989. *Encyclopedia of Death*. New York, USA: Avon Books.
- Kelly, B. & McClement, S. & Chochinov, H.M. 2006. Measurement of psychological distress in palliative care. *Palliative Medicine*. 20:779-789.
- Khoo, S.B. 2003. Facts and fallacies in palliative care. *Asia Pacific Family Medicine*. (2):143-147.
- Kiernan, S.P. 2006. *Last Rights: Rescuing the End-of-Life from the medical system*. New York. USA: St Martin's Press.
- Kilgore, K.M. 1995. Measuring outcomes in the post acute continuum. *Archives of Physical Medicine* 26:Sc21-26. American Congress of Rehabilitation Medicine. USA.
- Kingry, M.J & Tiedje, L.B & Friedman, L. 1990. Focus groups: a research technique for nursing. *Nursing Research*. 23(2):124-125.
- Krueger, R.A. & Casey, M.A. 2000. *Focus groups: A practical guide for applied research*. 3<sup>rd</sup> Edition. Thousand Oaks. Sage.
- Kuper, H & Marmot, M & Hemmingway, H. 2002. Psychosocial factors in the aetiology and prognosis of coronary disease: A systematic review. *Semin Vasc Medicine*. 2:267-314.
- Marmot, M. & Bosma, H. & Hemmingway, H. & Brunner, E.J. & Stansfield, S.A. 1997. Contribution of job control and other contributing factors to social variations in coronary heart disease incidence. (Whitehall study) *The Lancet*. 350:235-239.

- McClement, S. & Chochinov, H.M. & Hack, T. & Hassard, T. & Kristianson, L.J. & Harlos, M. 2007. Dignity therapy: Family member perspectives. *Journal of Palliative Medicine*. 10(5):1076-1082.
- Morgan, D.L. 1997. *Focus groups as qualitative research*. 2<sup>nd</sup> Edition. Thousand Oaks: Sage.
- Morse, J.M. 1997. *Completing a qualitative project: details and dialogue*. London: Sage.
- National Institutes of Health State-of-the-Science Conference Statement. 2004. Improving end-of-life care. *Journal of Pain and Palliative Care Pharmacotherapy*. 19 (3):75-83.
- National Palliative Care Research Centre. 2007. [http://www.npcrc.org/about/about/\\_show.htm?doc\\_id=374963](http://www.npcrc.org/about/about/_show.htm?doc_id=374963). (accessed 25 January 2007)
- Nyamathi, A. & Shuler, P. 1990. Focus group interview: a research technique for informed nursing practice. *Journal of Advanced Nursing*, 15:1281-1288
- Pickering, R.M. 2002. Statistical aspects of measurement in palliative care. *Palliative Medicine*. 16:359-364.
- Pirkis, J. & Burgess, P. & Coombs, T. & Clarke, A. & Jones-Ellis, D. & Dickenson, R, 2005. Routine measurement of outcomes in Australia's public sector. *Australia and New Zealand Health Policy* 2005, 2:8
- Rogers, J.C. & Holm, M.B. 1994. Accepting the Challenge of Outcomes Research: Examining the Effectiveness of Occupational Therapy Practice. *Australian Occupational Therapy Journal*. 48(10), 871 – 876.
- Schag, C.A. & Ganz, P.A. & Heinrich, R.L. 1991. Cancer Rehabilitation Evaluation System-Short Form (CARES-SF): A cancer specific rehabilitation and quality of life instrument. *Cancer*.68 (6):1406-1413.
- Schurink, WJ & Schurink EM. *Focus groups as qualitative research*. 1988. Beverly Hills: Sage.
- Sen, A. 1992. *Inequality re-examined*. Oxford: Oxford University Press.
- Spranger, M.A.G. & Aaronson, N.K. 1992. The role of healthcare providers and significant others in evaluating the quality of life with chronic disease; A review. *Journal of Clinical Epidemiology* 45:743-760.
- Steinhauser, K.E. & Voils, C.I. & Clip, E.C. *et al*. 2006. "Are you at peace?" One item to probe spiritual concerns at the end of life. *Arch Intern Med*. 66(1):101-105.
- Tennant, A. & Penta, M. & Tesio, L. & Grimby, G. & Thonnard, J-L. & Slade, A. *et al*. 2004. Assessing and adjusting for cross cultural validity of impairment and activity limitation scales through Differential Item Functioning within the framework of the Rasch analysis model: The PRO-ESOR project. *Med Care*. 42(suppl):125-136.
- Van Deventer, V. Department of Psychology, University of South Africa. (verbal communication at UNISA on 20 November 2007)
- Von Gunten, C.F. 2007. Editorial: Humpty-Dumpty Syndrome. *Palliative Medicine*. 21:461-462.
- Unsworth, C. 2000. Measuring the outcome of occupational therapy: Tools and resources. *Australian Occupational Therapy Journal*. 47:147-158.
- UCLA Academic Technologies Services. 2008. <http://www.ats.ucla.edu/stat/Spss/faq/alpha.html> (accessed on 10 October 2008)

Walsh, K. & Kawanko, I. 2002. Nurses and patients perceptions of dignity. *International Journal of Nursing Practice*. 8(3):143-51, June.

World Health Organisation. 2002. *Cancer pain relief and palliative care*. Geneva, Switzerland.

**ANNEXURE 1**

**From:** Peyper, JAD  
**Sent:** 14 February 2008 12:12  
**To:** Herbst, Michael  
**Cc:** Van Wyk, Jan; Van der Merwe, Karin; Van Wyk, Dawid  
**Subject:** RE: Request by student

Dear Prof Herbst

As far as I know, only copyright in the dissertation is reserved by UNISA.

In my view, possible Patent or Design rights that may be embodied in the subject matter of the dissertation falls outside the above copyright reservation.

In any event, the LSO at UNISA has no capacity to review all dissertations and to conduct novelty searching for patenting purposes, neither the infrastructure to administer the commercialization of student research.

I suggest you obtain the confirmation of the Dean that UNISA has no interest in the industrial rights resulting from the student's research, should the student insist in receiving a formal reply.

regards

Johan AD Peijper  
Director: Legal Services:  
Agreements & Intellectual Property Law  
UNISA, ORT Building 11-21  
Preller St, Muckleneuk Ridge, PTA  
Tel: 012 429 6904  
Fax: 012 429 8902

## DIGNITY (OMEGA) MEASUREMENT SCALE TRAINING MANUAL

### INTRODUCTION

The **DIGNITY SCALE** is used on persons who face imminent mortality and required the interventions of a counsellor to guide them through the dying process. The counsellor's objective is to secure the dignity of the dying person by providing comfort, meaning and purpose of the transition. To achieve this, emotive and physical interventions between the counsellor and the person are required on an ongoing basis. The DIGNITY Scale measures the effectiveness of the counsellor's interventions by recording the value added to the person's dignity.

**The DIGNITY Scale measures the need for counselling to the dying person and the response to such interventions. As the dignity of the dying person improves so shall the burden of counselling decreases.**

The need for counselling to the dying person is measured on the following constructs:

- Communication
- Family harmony,
- Fear,
- Letting go,
- Unfinished business,
- Wishes,
- Basic care,
- Nursing care.

The following rules need to be considered:

“He’ refers to “She” and “His” refer to “Her” and vice versa.

The DIGNITY Scale neither describes nor diagnoses any cognitive or physical disorder and does not prescribe any therapeutic approach or treatment to the dying person; the scale merely asks how the dying process impacts on the dignity of the person and measures the accompanying need for counselling to the dying person.

The DIGNITY Scale can only be applied by credentialed scorers doing direct observation and/or proxy observation.

The DIGNITY Scale requires cognitive interaction between the dying person and the counsellor.

If the person has lost this ability then the DIGNITY Scale must not be used anymore and professional nursing burden of care must then continue on the Alpha scale, and caregiver burden of care must continue on the Beta Scale.

The definitions for each construct do not pretend to be comprehensive, but is pointing to scenarios in the broadest sense.

“Counsellor” refers to any skilled person that restore dignity of a dying person and his family, through guidance in resolving personal conflicts and emotional problems, using the techniques such as listening, clarifying, pacifying, prompting, probing, questioning etc.

“Family” refers to the loved ones of the dying person.

“Supporter” refers to any person skilled to maintain dignity of a dying person in support groups, individual support and care giving.

“Acting out” refers to the any of the following symptoms and signs that reflect the dying persons frustration.

1. **Shock:** *Anxiety, Fear, Insecurity, Indecisiveness, Non responsive, not focusing or concentrating,*
2. **Denial:** *Lack of trust, Suspicious, Ignore you,*
3. **Bargaining**
4. **Anger:** *Aggression, Obsessiveness, Upset, Impatience, Rudeness, Hatred, Demanding, Discontentment, Irritability.*
5. **Depression:** *Isolation, Passiveness, Withdrawal, Rejection, Negativity, Mood swings, Psychosomatic symptoms such as pains, aches, shortness of breath,, hyperventilation.*

#### **Scoring rules of the Dignity (OMEGA) Measurement Scale:**

1. Always score the actual response of the dying person, not the potential response. E.g. record the score of the dying person at the time assessment, not what you think the score should be.
2. If in doubt between 2 scores (e.g. between a 2 and 3/ or a 3 and 4) record the lowest score.
3. If the family is “on board” (e.g. score 5), but the dying person is only discussing the issues with the counsellor at this stage (e.g. score 3), then the lowest score (e.g. score 3) must be recorded.
4. If the support systems and the family is in place and well functioning (e.g. score 6) but the dying person is still acting out all the time (e.g. score 1), then the lowest score (e.g. score 1) is recorded.
5. If an issue (say “Unfinished Business”) has not yet been raised with the dying person, or the dying person has not referred to any such issues, then a score of 1 is recorded. This would necessitate the counsellor to open the discussion on all issues, deal with it and score it appropriately to prevent low scores.
6. Scores 1- 4 deals with the relationship between the dying person and his counsellor. A trained or skilled CANSA counsellor may develop such a relationship. However it may happen that a family member, friend or confidant may develop a close and intimate relationship with the dying person and such person become better suited to guide the dying person - a substitute counsellor. The CANSA counsellor can still do the dying persons scores through an interview with the substitute counsellor.

#### **Sub Items of the Dignity (OMEGA) Measurement Scale:**

##### **1. Communication**

There is a risk of a communication breakdown between the dying person and his loved ones mainly due to the fact that people tend to steer away from emotional issues. The dying process is loaded with emotional traps and a breakdown in communication is a very common occurrence.

##### **2. Family Harmony**

The dying person and his family must at all time function in harmony to secure optimal dignity to the dying person. Unfortunately, behaviour such as family withdrawal (due to stigma, denial, and family that cannot face the decline) or overbearing families (that prevents privacy, space and respect) puts the family harmony ideal at risk.

##### **3. Fear**

Fear for death is a universally acknowledged. However, some belief systems are better equipped than others to overcome the “fear” issue and the fear-factor has therefore different angles to it. E.g. the traditional African people, on the whole, may be looking forward to death as they may be joining their ancestors, a higher level of existence. The Christian and Muslim people may fear death as they may not be sure

about their salvation. The evolutionists may also look forward to death as they may return as a higher spiritual being.

**4. Letting Go**

Letting go of the loved ones is always difficult for the dying person. In this context we also must acknowledge to letting go of a lifestyle that was developed and accumulated over years (e.g. status, job, property, money etc).

**5. Unfinished Business**

Dying people have unfinished business to attend too. This includes anything that the dying person would still like to settle or achieve before their death.

**6. Wishes**

Dying people have wishes of how they want to be disposed off, distribute their belongings and how their loved ones should be taken care off after their death.

**7. Basic Care**

Dying people are experiencing a decline in their activities of daily living. Their daily activities need to be assisted during this decline in a dignified way.

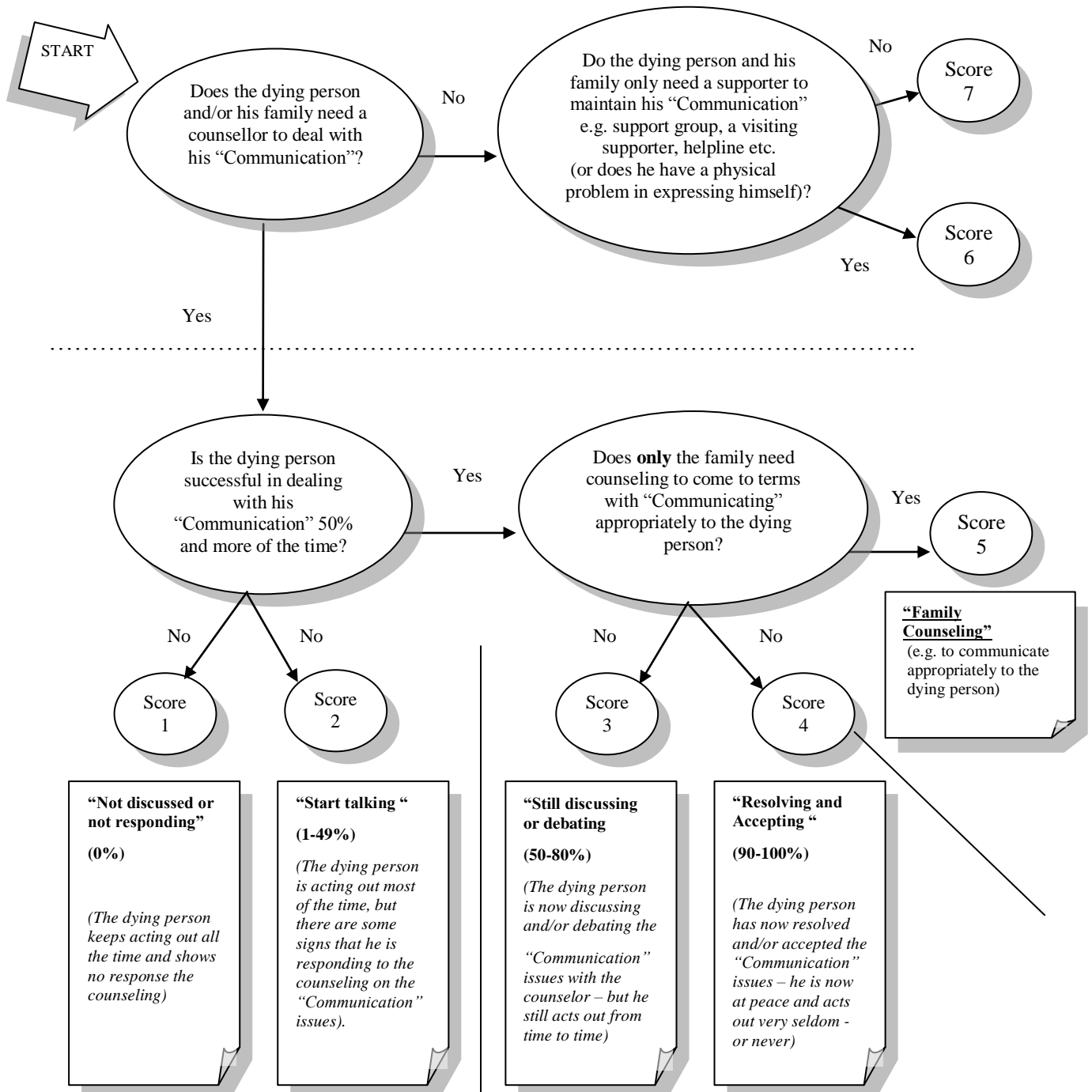
**8. Nursing Care**

Dying people experience a decline of the functioning of the bodily organs and systems. Their organs and systems needs professional assistance in a dignified way.



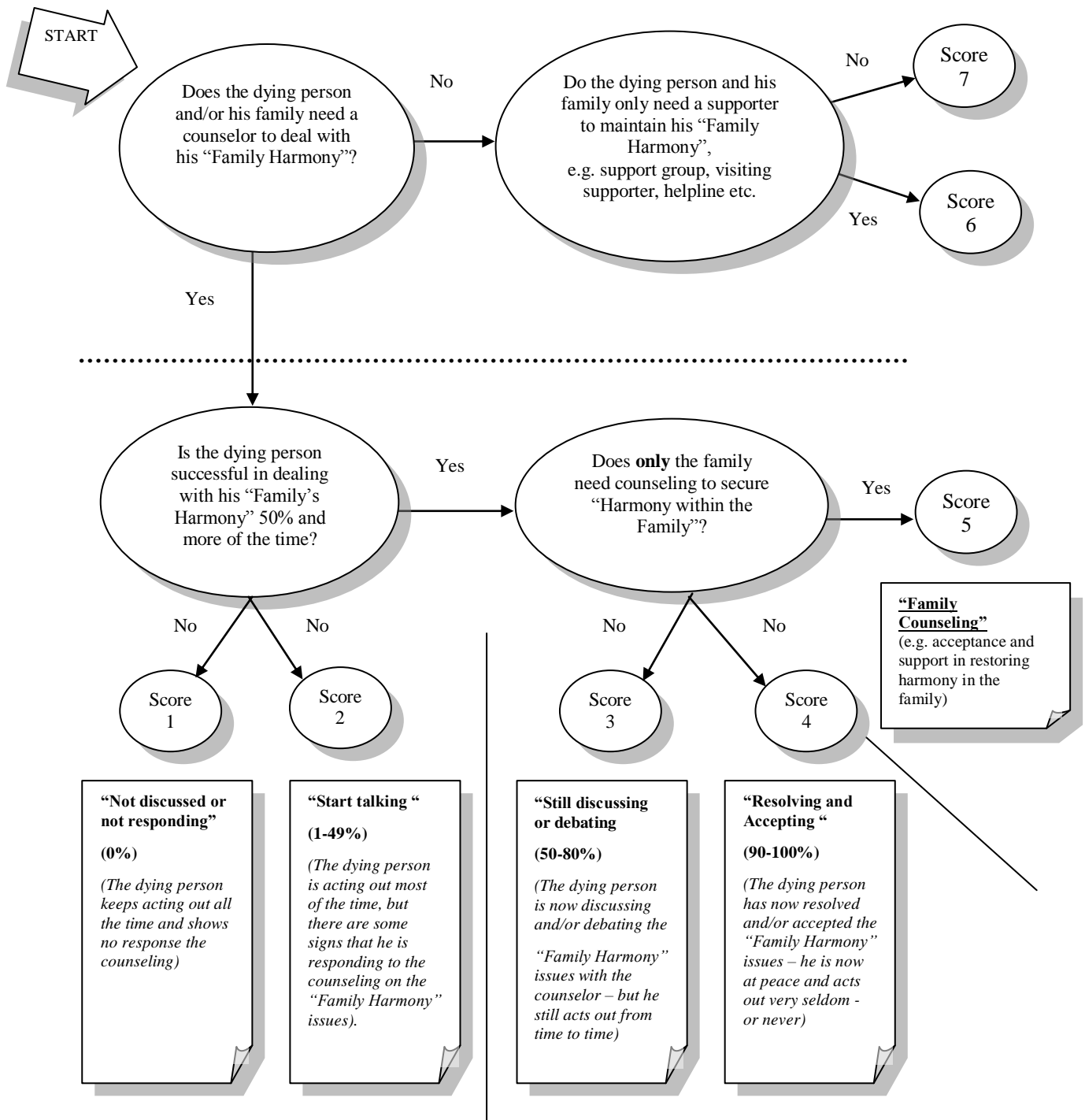
# 1. COMMUNICATION

**Definition:** Measure the dying person’s ability to appropriately communicate with his family his daily needs and feelings through open, clear, frank, honest and meaningful discussions so that he could die in peace.



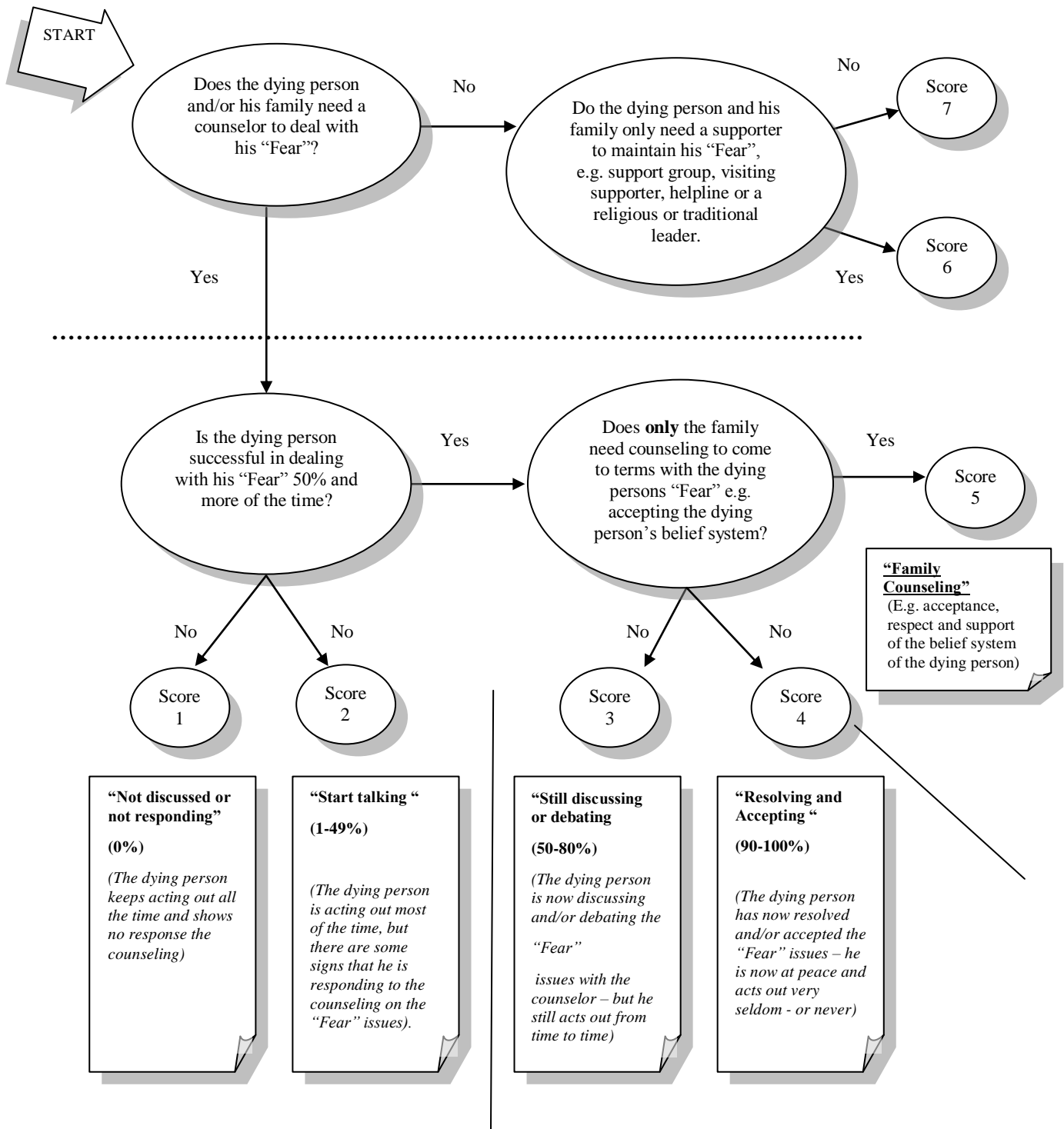
## 2. FAMILY HARMONY

**Definition:** Measure the dying person’s ability to ensure that his loved ones react emotionally appropriate to his dying process such as family withdrawal (due to stigma, denial or family that cannot face the decline etc) or a overbearing family (not allowing privacy, space and respect) to allow a peaceful death.



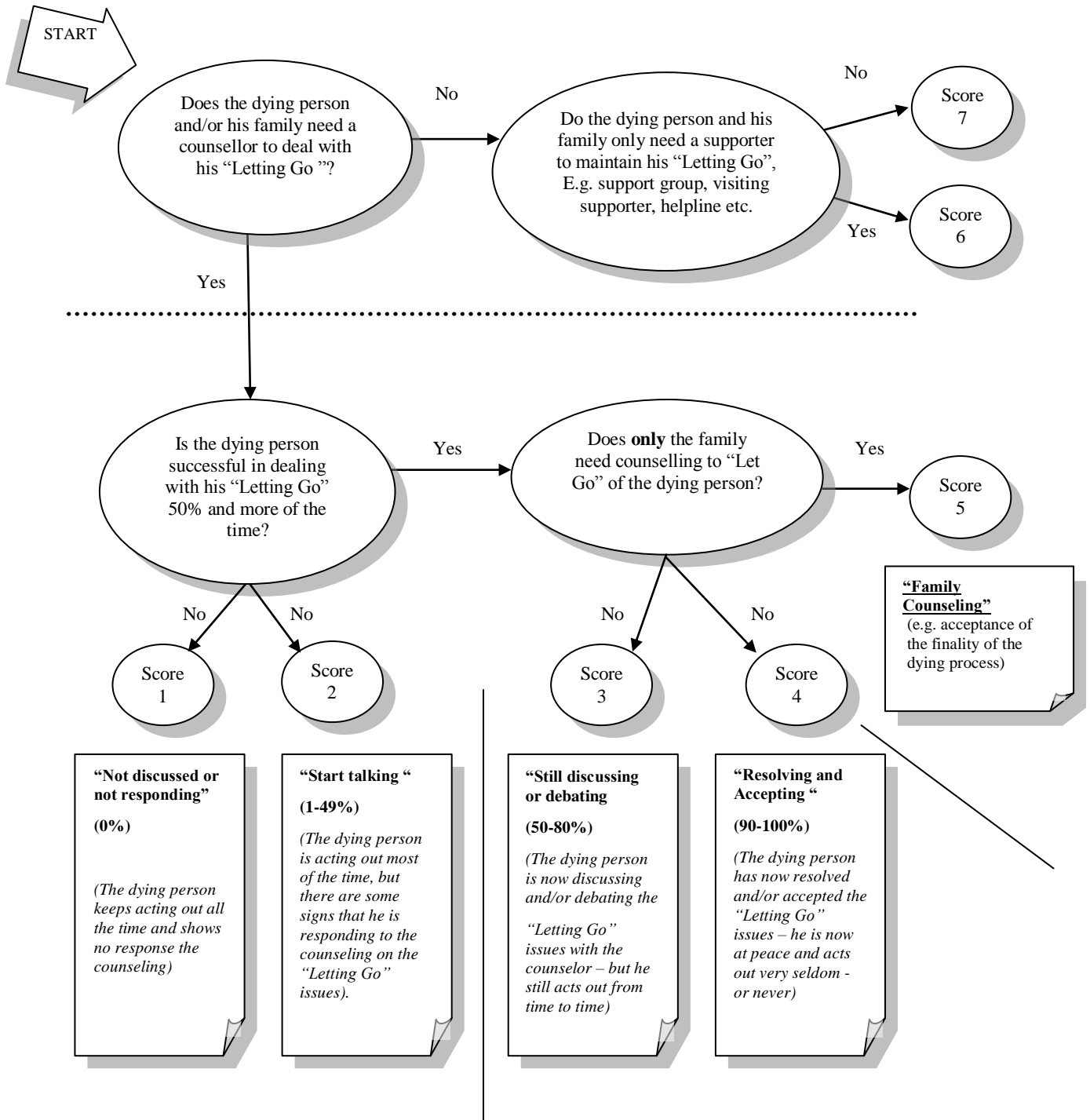
### 3. FEAR (“OPHA”, “CHABA”, “TSABA”, “SABA”, “NDIYOYOIKA”)

**Definition:** Measure the dying person’s ability to find comfort in his spiritual and /or religious beliefs so that he can die in peace.



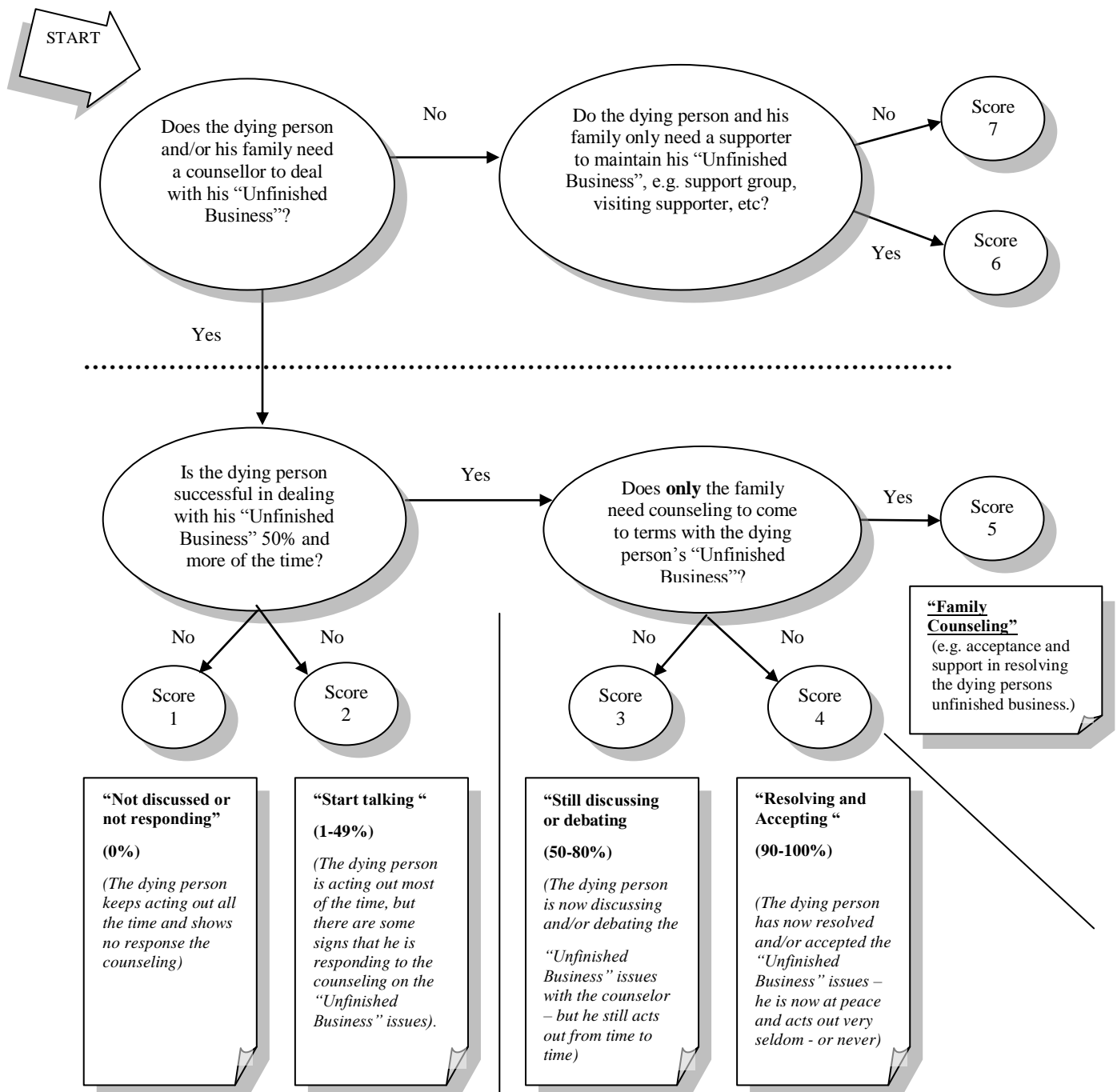
#### 4. LETTING GO ( KAROHANO, KUKULUKANA, KAROGANO UKUHLUKANA)

**Definition:** Measure the dying person’s ability to say goodbye to his children, family, friends, property, status, job and other earthy belongings so that he can die in peace.



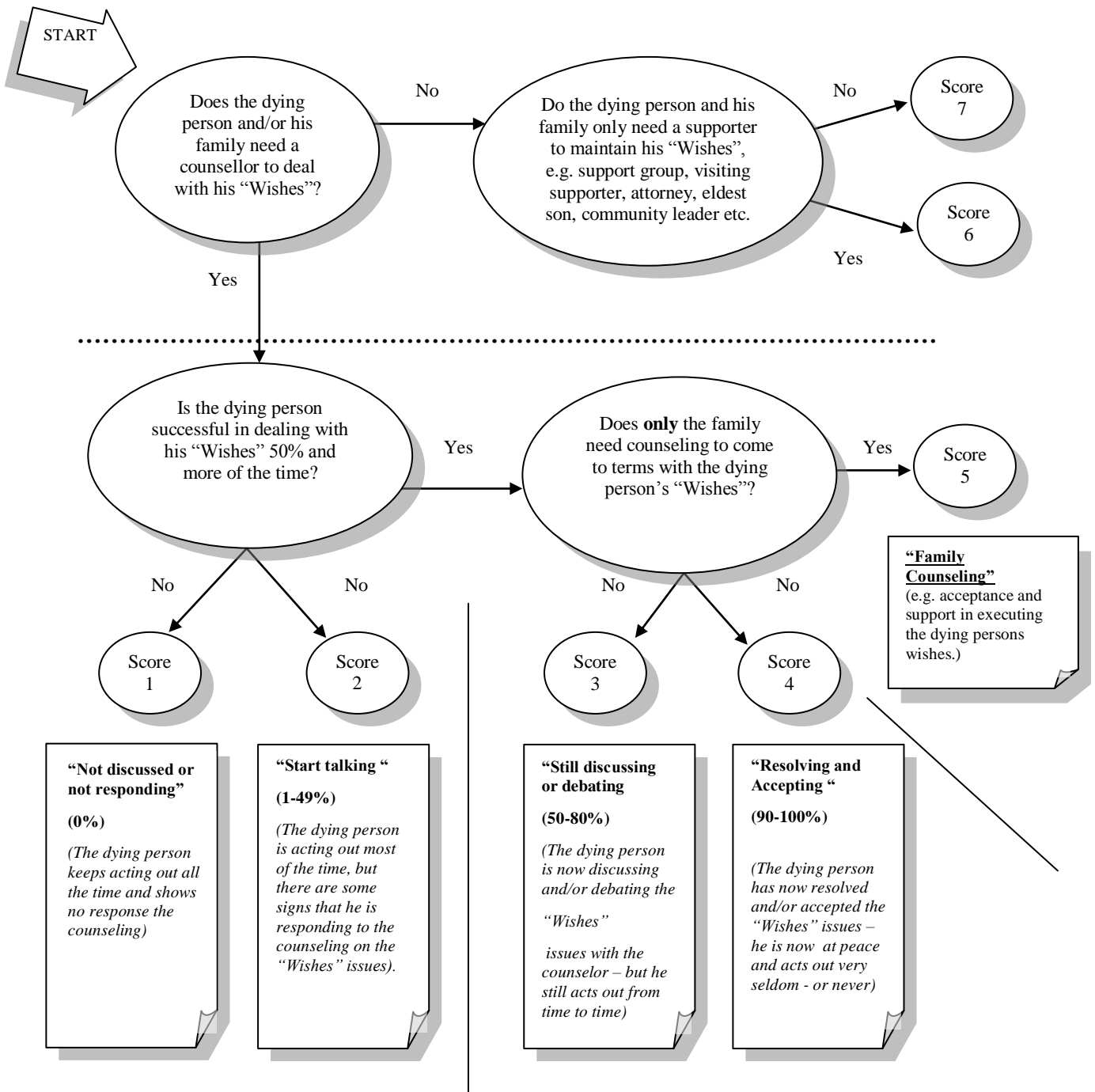
### 5. UNFINISHED BUSINESS (UKUBHOBOKA, UKUXOLELANISA)

**Definition:** Measure the dying person’s ability to settle old outstanding disputes, regrets, blames, forgiveness, conscience qualms, secrets etc with himself, family, friends or community so that he can die in peace.



## 6. WISHES

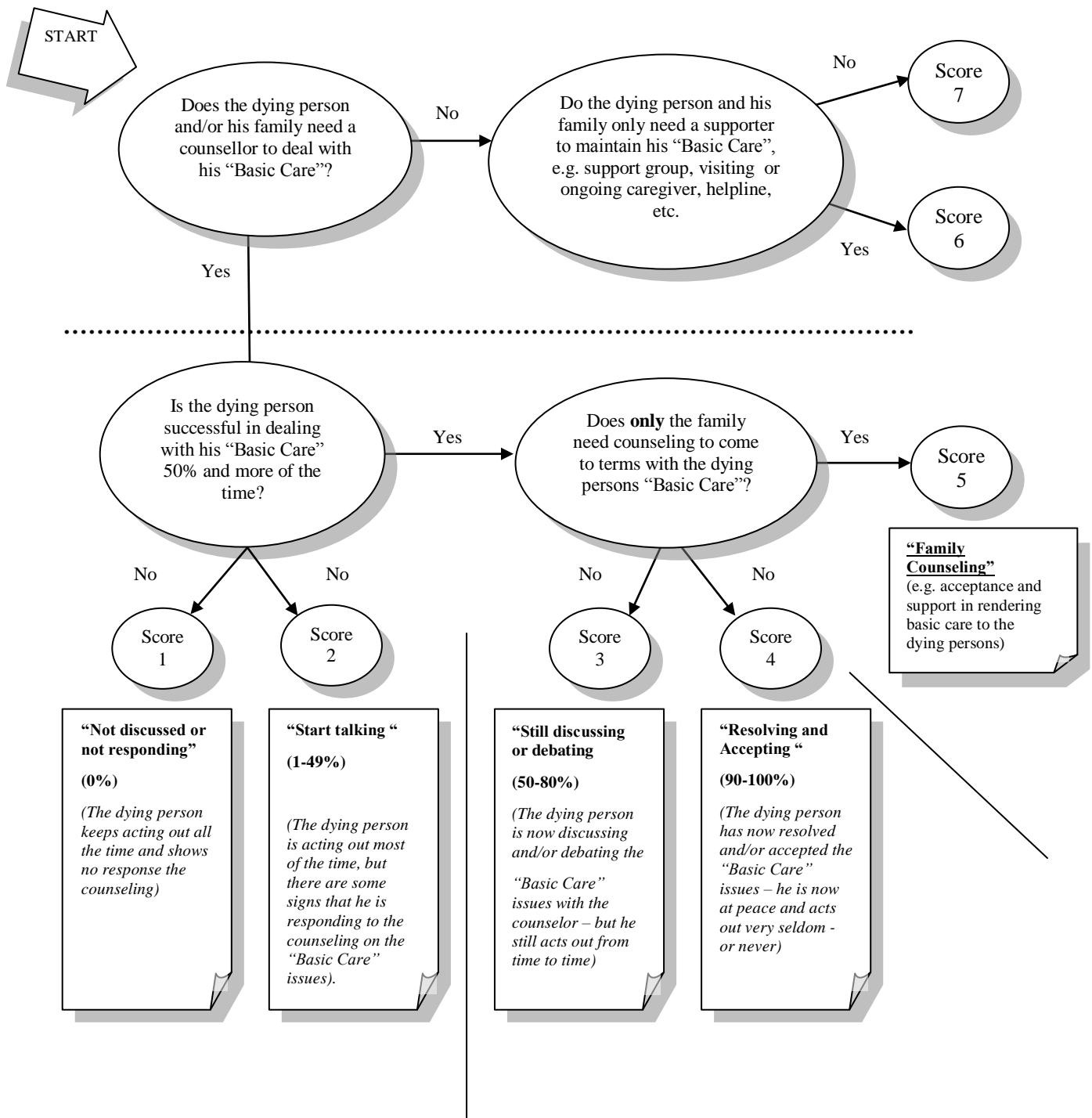
**Definition:** Measure the dying person’s ability to finalise all his wishes ( e.g. wills, policies, bequests, agreements, funeral arrangements etc) to ensure that those left behind are informed and/or taken care off so that he can die in peace.



## 7. BASIC CARE

**Definition:** Measure the dying person’s ability to find comfort and satisfaction in his:

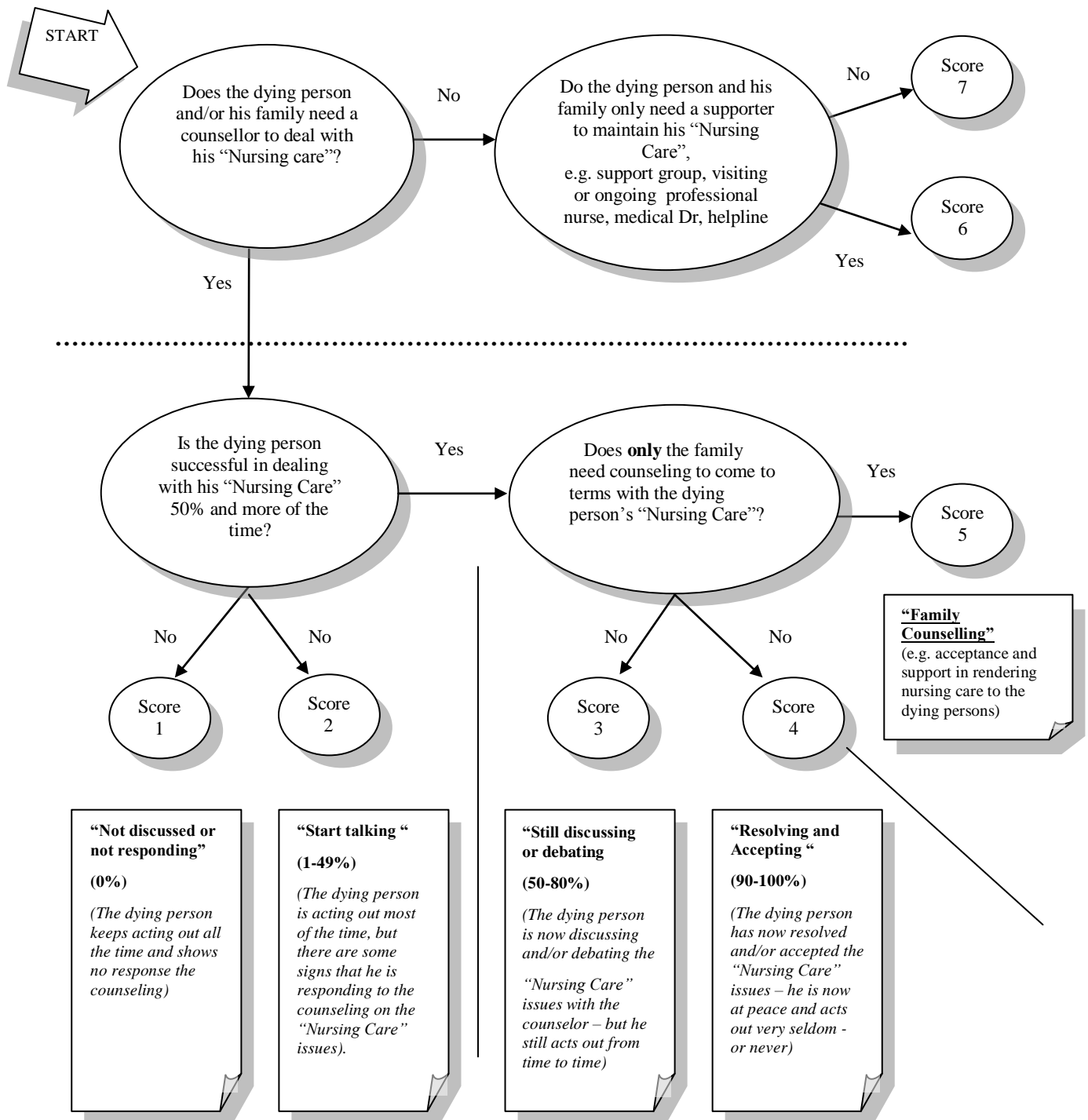
- (1) care environment (*home, clinic, hospice, hospital etc*),
- (2) assistance with daily activities (*eating, grooming, bathing, toileting, bed/chair transfers etc*)
- (3) living conditions (*cleanliness, bedding, temperature etc*).



### 8. NURSING CARE

**Definition:** Measure the dying person’s ability to find comfort and satisfaction with the nursing care to alleviate discomfort such as:

- (1) the physical pain control,
- (2) vital organ support (e.g. breathing, ulcer managements, bladder, bowl management etc)
- (3) symptom relief (e.g. nausea, diarrhoea, odours, rashes and itches etc).





**Abbreviated Dignity (OMEGA) Dignity Measurement Score**

**ANNEXURE 3**

Definitions	Score 1	Score 2	Score 3	Score 4	Score 5	Score 6	Score 7
	<i>“Not discussed or not responding” (0%)</i>	<i>“Start talking” (1-49%)</i>	<i>“Discussing or debating” (50%-80%)</i>	<i>“Accepting or resolving” (81% - 100%)</i>	<i>“Working on family cooperation”</i>	<i>“Only follow-up support needed”</i>	<i>“OK”</i>
<b>1. COMMUNICATION</b> <b>Def:</b> Measure the client’s ability to communicate his daily needs and feelings through open, clear, frank, honest and meaningful communication.	The dying person keeps acting out all the time and shows no response the counselling	The dying person is acting out most of the time, but there are some signs that he is responding to the counselling.	The dying person is now discussing and/or debating the issues with the counsellor – but he still acts out from time to time.	The dying person has now resolved and/or accepted the issues – he is now at peace and acts out very seldom - or never.	“Helping the family to communicate appropriately and meaningfully with the dying person”	The dying person and the family is OK and the counsellor is not needed. A follow-up support group (or supporter) can now manage the client’s dignity program.	No counsellor or no follow-up support program is needed.
<b>2. FAMILY HARMONY</b> <b>Def:</b> Measure the dying person’s ability to ensure that his loved ones react emotionally appropriate to his dying process; e.g. such as family withdrawal (due to stigma or denial or family that cannot face the decline etc) or a overbearing family (not allowing privacy, space and respect) to allow a peaceful death.	The dying person keeps acting out all the time and shows no response the counselling	The dying person is acting out most of the time, but there are some signs that he is responding to the counselling.	The dying person is now discussing and/or debating the issues with the counsellor – but he still acts out from time to time	The dying person has now resolved and/or accepted the issues – he is now at peace and acts out very seldom - or never.	“Helping the family to respond emotionally appropriately and with respect to the dying process”	The dying person and the family are OK and the counsellor is not needed. A follow-up support group (or supporter) can now manage the client’s dignity program.	No counsellor or no follow-up support program is needed.
<b>3. FEAR (“OPHA”,CHABA”, “TSABA”, “SABA”, “NDIYOYOIKA” )</b> <b>Def:</b> Measure the client’s ability to find comfort in his spiritual and /or religious beliefs during the dying process.	The dying person keeps acting out all the time and shows no response the counselling	The dying person is acting out most of the time, but there are some signs that he is responding to the counselling.	The dying person is now discussing and/or debating the issues with the counsellor – but he still acts out from time to time	The dying person has now resolved and/or accepted the issues – he is now at peace and acts out very seldom - or never.	“Helping the family to accept and support the dying persons beliefs”	The dying person t and the family are OK and the counsellor is not needed. A follow-up support group (or supporter e.g <b>religious or traditional leader</b> ) can now manage the client’s dignity program.	No counsellor or no follow-up support program is needed.
<b>4. LETTING GO (KAROHANO, KUKULUKANA, KAROGANO UKUHLUKANA))</b> <b>Def:</b> Measure the client’s ability to say goodbye to his children, family, friends, property, status, job and other earthly belongings.	The dying person keeps acting out all the time and shows no response the counselling	The dying person is acting out most of the time, but there are some signs that he is responding to the counselling.	The dying person is now discussing and/or debating the issues with the counsellor – but he still acts out from time to time	The dying person has now resolved and/or accepted the issues – he is now at peace and acts out very seldom - or never.	“Helping the family to accept the dying persons goodbye”	The dying person and the family are OK and the counsellor is not needed. A follow-up support group (or supporter) can now manage the client’s dignity program.	No counsellor or no follow-up support program is needed.
<b>49% - 50%</b>			<b>Dying person OK .....but Family needs counselling</b>		<b>Dying person and Family OK with each other..... Only needs support from time to time.</b>		

Definitions	Score 1	Score 2	Score 3	Score 4	Score 5	Score 6	Score 7
	<i>“Not discussed or not responding” (0%)</i>	<i>“Start talking” (1-49%)</i>	<i>“Discussing or debating” (50%-80%)</i>	<i>“Accepting or resolving ” (81% - 100%)</i>	<i>“Working on family cooperation”</i>	<i>“Only follow-up support needed”</i>	<i>“OK”</i>
<b>5. UNFINISHED BUSINESS (UKUBHOBOKA, UKUXOLELANISA)</b>  <b>Def:</b> Measure the client’s ability to settle old outstanding disputes, regrets, blames, forgiveness, conscience qualms, secrets etc with himself, family, friends or community.	The dying person keeps acting out all the time and shows no response the counselling	The dying person is acting out most of the time, but there are some signs that he is responding to the counselling.	The dying person is now discussing and/or debating the issues with the counsellor – but he still acts out from time to time	The dying person has now resolved and/or accepted the issues – he is now at peace and acts out very seldom - or never.	“Helping the family to forgive the dying person for what happened in the past”	The dying person and the family are OK and the counsellor is not needed. A follow-up support group (or supporter) can now manage the client’s dignity program.	No counsellor or no follow-up support program is needed.
<b>6. WISHES</b>  <b>Def:</b> Measure the client’s ability to finalise all his wishes ( e.g wills, policies, bequests, agreements, funeral arrangements etc) to ensure that those left behind are informed and/or taken care off.	The dying person keeps acting out all the time and shows no response the counselling	The dying person is acting out most of the time, but there are some signs that he is responding to the counselling.	The dying person is now discussing and/or debating the issues with the counsellor – but he still acts out from time to time	The dying person has now resolved and/or accepted the issues – he is now at peace and acts out very seldom - or never.	“Helping the family to agree to the dying person’s clients wishes”	The dying person and the family are OK and the counsellor is not needed. A follow-up support group (or supporter eg <b>attorney, community leader, eldest son</b> etc) can now manage the client’s dignity program.	No counsellor or no follow-up support program is needed.
<b>7. BASIC CARE</b>  <b>Def:</b> Measure the client’s ability to find comfort and satisfaction in his <u>(1) care environment</u> (home, clinic, hospice, hospital etc) and the <u>(2) assistance with daily activities</u> (eating, grooming, bathing, toileting, bed/chair transfers etc) and <u>(3) living conditions</u> (cleanliness, bedding, temperature etc).	The dying person keeps acting out all the time and shows no response the counselling	The dying person is acting out most of the time, but there are some signs that he is responding to the counselling.	The dying person is now discussing and/or debating the issues with the counsellor – but he still acts out from time to time	The dying person has now resolved and/or accepted the issues – he is now at peace and acts out very seldom - or never.	“Helping the family to acknowledge and facilitates the dying person’s basic care needs”	The dying person and the family are OK and the counsellor is not needed. A follow-up support group (or supporter e.g <b>home caregiver.</b> ) can now manage the client’s dignity program .	No counsellor or no follow-up support program is needed.
<b>8. NURSING CARE.</b>  <b>Def:</b> Measure the client’s ability to find comfort and satisfaction with the nursing care to alleviate discomfort. such as: (1) <u>the physical pain control</u> , (2) <u>vital organ support</u> (e.g. breathing, ulcer managements, bladder, bowel management etc) (3) <u>symptom relief</u> (e.g. nausea, diarrhoea, odours, rashes and itches etc).	The dying person keeps acting out all the time and shows no response the counselling	The dying person is acting out most of the time, but there are some signs that he is responding to the counselling.	The dying person is now discussing and/or debating the issues with the counsellor – but he still acts out from time to time	The dying person has now resolved and/or accepted the issues – he is now at peace and acts out very seldom - or never.	“Helping the family to acknowledge and facilitates the dying person’s nursing care needs”	The dying person and the family are OK and the counsellor is not needed. A follow-up support group (or supporter e.g. <b>professional nurse or medical practitioner</b> ) can now manage the client’s dignity program.	No counsellor or no follow-up support program is needed.

49% - 50%

Dying person OK .....but Family needs counselling

Dying person and Family OK with each other..... Only needs support from time to time.

## Verkorte Dignity (OMEGA) meet instrument

### ANNEXURE 4

	Score 1	Score 2		Score 3	Score 4		Score 5		Score 6	Score 7
<b>Definisies van probleme</b>	<i>“nie met hom bespreek of hy wil nie daaroor praat”</i> (0%)	<i>“begin effens te praat”</i> (1-49%)		<i>“gesels of bespreek”</i> (50%-80%)	<i>“aanvaar of vrede gemaak”</i> (81% - 100%)		<i>“kry die familie se samewerking om ‘n span te vorm met die sterwende persoon”</i>		<i>“die span het net af-en- toe ondersteuning nodig”</i>	<i>“OK”</i>
<b>1. KOMMUNIKASIE</b> <b>Def:</b> Meet die sterwende persoon se vermoë om sy daaglikse <b>behoefes en gevoelens</b> te kan bespreek deur openlike, eerlike, toepaslike en sinvolle kommunikasie.	Die sterwende persoon will glad nie oor die probleem praat nie, hy haak uit <b>aanhoudend.</b>	Die sterwende persoon begin effens te praat oor die probleem, maar hy haak uit <b>meeste van die tyd.</b>	<b>49% - 50%</b>	Die sterwende persoon gesels of bespreek nou die probleem, maar hy haak nog uit <b>van tyd tot tyd.</b>	Die sterwende persoon het nou aanvaar of vrede gemaak met die probleem en hy haak nou uit <b>seldse – of ooit.</b>	<b>Sterwende persoon is OK ..... maar die familie benodig nou berading</b>	“Help die familie om openlik, eerlik, toepaslik en sinvol met die sterwende persoon te kommunikeer”	<b>Dying person and Family OK with each other..... Only needs support from time to time.</b>	Die sterwende persoon en sy familie is nou ‘n span wat goed saamwerk.  Die span het net af en toe ondersteuning nodig om kommunikasie weer op lyn te bring en te hou.	Die span het geen verdere hulp nodig vir kommunikasie nie.
<b>2. FAMILIE HARMONIE</b> <b>Def:</b> Meet die sterwende persoon se vermoë om te sorg dat sy familie se emosies toepaslik bly teenoor hom tydens sy sterwens proses; byv. family ontrekking (agv stigma of ontkenning of familie wat nie kan vrede maak met die agter uitgang nie) of ‘n oorheersende familie (laat nie privaatheid, respek of stilte tyd toe nie).	Die sterwende persoon will glad nie oor die probleem praat nie, hy haak uit <b>aanhoudend.</b>	Die sterwende persoon begin effens te praat oor die probleem, maar hy haak uit <b>meeste van die tyd.</b>		Die sterwende persoon gesels of bespreek nou die probleem, maar hy haak nog uit <b>van tyd tot tyd</b>	Die sterwende persoon het nou aanvaar of vrede gemaak met die probleem en hy haak nou uit <b>seldse – of ooit.</b>		“Help die familie om nie te ontrek of oorheersend te wees nie teenoor die sterwende persoon “		Die sterwende persoon en sy familie is nou ‘n span wat goed saamwerk.  Die span het net af en toe ondersteuning nodig om familie harmonie weer op lyn te bring en te hou.	Die span het geen verdere hulp nodig vir familie harmonie nie.
<b>3. VREES</b> (“OPHA”,“CHABA”, “TSABA”, “SABA”, “NDIYOYOIKA”) <b>Def:</b> Meet die sterwende persoon se vermoë om rustigheid te vind in sy spirituele en/of geloofs oortuigings gedurende die sterwens proses	Die sterwende persoon will glad nie oor die probleem praat nie, hy haak uit <b>aanhoudend.</b>	Die sterwende persoon begin effens te praat oor die probleem, maar hy haak uit <b>meeste van die tyd.</b>		Die sterwende persoon gesels of bespreek nou die probleem, maar hy haak nog uit <b>van tyd tot tyd</b>	Die sterwende persoon het nou aanvaar of vrede gemaak met die probleem en hy haak nou uit <b>seldse – of ooit.</b>		“Help die familie om die sterwende persoon se geloofs oortuigings te aanvaar”		Die sterwende persoon en sy familie is nou ‘n span wat goed saamwerk.  Die span het net af en toe ondersteuning nodig om familie weer op lyn te bring en te hou tov die sterwende persoon se geloofsoortuigings.	Die span het geen verdere hulp nodig vir doods vrees nie
<b>4. AFSKEID (KAROHANO, KUKULUKANA, KAROGANO UKUHLUKANA)</b> <b>Def:</b> Meet die sterwende persoon se vermoë om afskeid te neem van sy kinders, familie, vriende, eiendom, status, werk en ander aardse besittings	Die sterwende persoon will glad nie oor die probleem praat nie, hy haak uit <b>aanhoudend.</b>	Die sterwende persoon begin effens te praat oor die probleem, maar hy haak uit <b>meeste van die tyd.</b>		Die sterwende persoon gesels of bespreek nou die probleem, maar hy haak nog uit <b>van tyd tot tyd</b>	Die sterwende persoon het nou aanvaar of vrede gemaak met die probleem en hy haak nou uit <b>seldse – of ooit.</b>		“Help die familie om die sterwende persoon se afskeid te aanvaar”		Die sterwende persoon en sy familie is nou ‘n span wat goed saamwerk.  Die span het net af en toe ondersteuning nodig om die afskeids proses weer op lyn te bring en te hou.	Die span het geen verdere hulp nodig vir die afskeids proses nie.

	Score 1	Score 2		Score 3	Score 4		Score 5		Score 6	Score 7
<b>Definisies van probleme</b>	<i>“nie met hom bespreek of hy wil nie daaroor praat” (0%)</i>	<i>“begin effens te praat” (1-49%)</i>		<i>“gesels of bespreek” (50%-80%)</i>	<i>“aanvaar of vrede gemaak (81% - 100%)</i>		<i>“kry die familie se samewerking om ‘n span te vorm met die sterwende persoon”</i>		<i>“die span het net af- en- toe ondersteuning nodig”</i>	<i>“OK”</i>
<b>5. ONAFGEHANDEL DE SAKE (UKUBHOBOKA, UKUXOLELANISA)</b>  <b>Def:</b> Meet die sterwende persoon se vermoë om uit die weg te ruim. ou agtergeblewe geskille, veroordelings, rusies, geheime, vergifnisse, gewetens probleme ens met homself , familie, vriende of gemeenskap	Die sterwende persoon will glad nie oor die problem praat nie, hy haak uit <b>aanhoudend.</b>	Die sterwende persoon begin effens te praat oor die problem , maar hy haak uit <b>meeste van die tyd. .</b>	<b>49% - 50%</b>	Die sterwende persoon gesels of bespreek nou die probleem , maar hy haak nog uit van <b>tyd tot tyd</b>	Die sterwende persoon het nou aanvaar of vrede gemaak met die problem en hy haak nou uit <b>selde – of ooit.</b>	<b>Dying person OK .....but Family needs counselling</b>	“Help die familie om die sterwende persoon te vergewe vir wat in sy verlede verkeerd gegaan het”	<b>Dying person and Family OK with each other..... Only needs support from time to time.</b>	Die sterwende persoon en sy familie is nou ‘n span wat goed saamwerk.  Die span het net af en toe ondersteuning nodig om die sterwende persoon se onafgehandelde sake weer te aanvaar.	Die span het geen verdere hulp nodig vir onafgehandelde sake nie.
<b>6.WENSE</b>  <b>Def:</b> Meeet die sterwende persoon se vermoë om al sy wense na sy afsterwe te volbring sodat die wat agter gelaat word ingelig en /of versorg is. (byv testament, skenkings, ooreenkomste, begrafnis reelings ens.)	Die sterwende persoon will glad nie oor die problem praat nie, hy haak uit <b>aanhoudend.</b>	Die sterwende persoon begin effens te praat oor die problem , maar hy haak uit <b>meeste van die tyd.</b>			Die sterwende persoon gesels of bespreek nou die probleem , maar hy haak nog uit van <b>tyd tot tyd</b>		Die sterwende persoon het nou aanvaar of vrede gemaak met die problem en hy haak nou uit <b>selde – of ooit.</b>			“Help die familie om die sterwende persoon se wense na sy dood te aanvaar en uit te voer”

<p><b>7.BASIESE SORG</b>  <b>Def:</b>meet die sterwende persoon se vermoë om vrede te maak met sy (1) <u>Versorg omgewing</u> (<i>huis, clinic, hospice, hospitaal ens.</i>) (2) <u>Versorg hulp</u> (<i>eet, bad, toilet, aantrek, oortel ens</i>) (3) <u>Lewens toestande</u> (<i>netheid, beddegoed, temperatuur ens</i>)</p>	<p>Die sterwende persoon will glad nie oor die problem praat nie, hy haak uit <b>aanhoudend</b>.</p>	<p>Die sterwende persoon begin effens te praat oor die problem , maar hy haak uit <b>meeste van die tyd</b>.</p>		<p>Die sterwende persoon gesels of bespreek nou die probleem , maar hy haak nog uit van <b>tyd tot tyd</b></p>	<p>Die sterwende persoon het nou aanvaar of vrede gemaak met die problem en hy haak nou uit <b>seld</b> – <b>of ooit</b>.</p>		<p>“Help die familie om die sterwende persoon se wense vir sy basiese versorging te aanvaar en uit te voer”</p>		<p>Die sterwende persoon en sy familie is nou ‘n span wat goed saamwerk.</p> <p>Die span het net af en toe ekstra hulp nodig om die sterwende persoon se basiese versorging te hanteer.</p>	<p>Die span het geen verdere hulp nodig vir basiese sorg nie</p>
<p><b>8VERPLEGING SORG</b>  <b>Def:</b> Meet die sterwende persoon se vermoë om vrede te maak met die verplegingsorg om ongemak te verhoed soos:  (1) <u>fisies pyn beheerl</u>,  (2) <u>ondersteuningt</u> (byv asemhaling, wondversorging, blaas en stoelgang versorgingens.  (3) <u>symptoom verligting</u> (e.g. naarheid, maagspoel, reuke, uitslagte jeuke ens).</p>	<p>Die sterwende persoon will glad nie oor die problem praat nie, hy haak uit <b>aanhoudend</b>.</p>	<p>Die sterwende persoon begin effens te praat oor die problem , maar hy haak uit <b>meeste van die tyd</b>.</p>		<p>Die sterwende persoon gesels of bespreek nou die probleem , maar hy haak nog uit van <b>tyd tot tyd</b></p>	<p>Die sterwende persoon het nou aanvaar of vrede gemaak met die problem en hy haak nou uit <b>seld</b> – <b>of ooit</b>.</p>		<p>“Help die familie om die sterwende persoon se wense vir sy verpleging versorging te aanvaar en uit te voer”</p>		<p>Die sterwende persoon en sy familie is nou ‘n span wat goed saamwerk.</p> <p>Die span het net af en toe ekstra hulp nodig om die sterwende pasient se verpleging sorg te hanteer.</p>	<p>Die span het geen verdere hulp nodig vir verpleging sorg nie.</p>

## iSikora sokuLinganisa iSidima esiShunqulelweyo (i-Omega)

## ANNEXURE 5

linkazeli	Isikora 1	Isikora 2	Isikora 3	Isikora 4	Isikora 5	Isikora 6	Isikora 7	
	<b>“Akuxoxwanga okanye akasabeli” (0%)</b>	<b>“Qalisa ukuthetha” (1-49%)</b>	<b>“Ukuxoxa okanye ukuhlafuna” (50%-80%)</b>	<b>“Ukwamkela okanye ukuzazulula” (81%-100%)</b>	<b>“Ukusebenza ngentsebenziswano yosapho”</b>	<b>“Kudingeka ukulandelwa kwenkxaso kuphela”</b>	<b>“KULUNGILE”</b>	
<b>1. UQHAGAMSHELWANO</b> <b>Inkc:</b> Linganisa ubuchule bomxumi bemihla ngemihla ekuqhagamshelane izidingo novakalelo lwakhe ngoqhagamshelwano oluvulekileyo, olucacileyo, olunyanisekileyo nolunentsingiselo.	Umntu obhubhayo uqhubeka nokulila ngalo lonke ixesha kwaye akabonisi kusabela kwicebiso.	Umntu obhubhayo uyalila ngalo lonke ixesha kodwa kukho iimpawu zokuba akasabeli kwicebiso.	Umntu obhubhayo ngoku uyaxoxa kwaye/okanye ukuxoxa imibandela nomcebisi – kodwa usalila ixesha nexesha.	Umntu obhubhayo ngoku uyixazulule kwaye/okanye uyamkele imibandela – useluxolweni kwaye ulila manqapha-nqapha kakhulu - okanye akasoze.	<b>Umntu obhubhayo ULUNGILE .....kodwa usapho ludinga ukucetyiswa</b>	“Ukunceda usapho luqhagamshelane ngokufanelekileyo nangentsingiselo nomntu obhubhayo”	Umntu obhubhayo nosapho balungile kwaye umcebisi akadingeki nganto. Iqela lenkxaso yokulandelisa (okanye umxhasi) ngoku angalawula inkqubo yesidima somxumi.	Akukho mcebisi okanye akukho qela lenkxaso yokulandelisa idingekayo.
<b>2. IMVISISWANO YOSAPHO</b> <b>Inkc:</b> Linganisa ubuchule bomntu obhubhayo ukuqinisekisa ukuba izithandwa zakhe zisabela ngokufanelekileyo nangovakalelo kwinkqubo yokufa kwakhe, umz njengosapho	Umntu obhubhayo uqhubeka nokulila ngalo lonke ixesha kwaye akabonisi kusabela kwicebiso.	Umntu obhubhayo uyalila ngalo lonke ixesha kodwa kukho iimpawu zokuba akasabeli kwicebiso.	Umntu obhubhayo ngoku uyaxoxa kwaye/okanye ukuxoxa imibandela nomcebisi – kodwa usalila ixesha nexesha.	Umntu obhubhayo ngoku uyixazulule kwaye/okanye uyamkele imibandela – useluxolweni kwaye ulila manqapha-nqapha kakhulu - okanye akasoze.		“Ukunceda usapho lusabele ngokufanelekileyo nangokovakalelo nangembeko kwinkqubo yokufa”	Umntu obhubhayo nosapho balungile kwaye umcebisi akadingeki nganto. Iqela lenkxaso yokulandelisa (okanye umxhasi) ngoku angalawula inkqubo yesidima somxumi.	Akukho mcebisi okanye akukho qela lenkxaso yokulandelisa idingekayo.
<b>3. ULOYIKO ( “OPHA”, “CHABA”, “TSABA”, “SABA”, “NDIYOYIKA” )</b> <b>Inkc:</b> Linganisa ubuchule bomxumi ekufumaneni intuthuzelo kwinkolelo yakhe yasemoyeni kunye/okanye yonqulo ngexesha lenkqubo yokufa.	Umntu obhubhayo uqhubeka nokulila ngalo lonke ixesha kwaye akabonisi kusabela kwicebiso.	Umntu obhubhayo uyalila ngalo lonke ixesha kodwa kukho iimpawu zokuba akasabeli kwicebiso.	Umntu obhubhayo ngoku uyaxoxa kwaye/okanye ukuxoxa imibandela nomcebisi – kodwa usalila ixesha nexesha.	Umntu obhubhayo ngoku uyixazulule kwaye/okanye uyamkele imibandela – useluxolweni kwaye ulila manqapha-nqapha kakhulu - okanye akasoze.		“Ukunceda usapho ukuba lwamkele kwaye luxhase unqulo lomntu obhubhayo”	Umntu obhubhayo nosapho balungile kwaye umcebisi akadingeki. Iqela lenkxaso yokulandelisa (okanye umxhasi umz inkokheli yaselunqulweni okanye yasekuhlaleni) ngoku bangalawula inkqubo yesidima somxumi.	Akukho mcebisi okanye akukho qela lenkxaso yokulandelisa idingekayo.

Umntu obhubhayo nosapho BALUNGILE omnye nomnye...Udinga kuphela inkxaso ixesha nexesha.

linkcazeli	Isikora 1	Isikora 2	Isikora 3	Isikora 4	Isikora 5	Isikora 6	Isikora 7
	“Akuxoxwanga okanye akasabeli” (0%)	“Qalisa ukuthetha” (1-49%)	“Ukuxoxa okanye ukuhlafuna” (50%-80%)	“Ukwamkela okanye ukuxazulula” (81%-100%)	“Ukusebenza ngentsebenziswan o yosapho”	“Kudingeka ukulandelwa kwenkxaso kuphela”	“KULUNGILE”
<p><b>4. UKUKHULULA AHAMBE (KAROHANO, KUKULUKANA, KAROGANO UKWAHLUKANA)</b></p> <p><b>Inkc:</b> Linganisa ubuchule bomxumi bokuvalalisa kubantwana bakhe, kusapho, kubahlobo, kwilifa, kwisikhundla, kumsebenzi nakwezinye izinto zasemhlabeni.</p>	Umntu obhubhayo uqhubeka nokulila ngalo lonke ixesha kwaye akabonisi kusabela kwiicebiso.	Umntu obhubhayo uyalila ngalo lonke ixesha kodwa kukho iimpawu zokuba akasabeli kwiicebiso.	Umntu obhubhayo ngoku uyaxoxa kwaye/okanye e ukuxoxa imibandela nomcebisi – kodwa usalila ixesha nexesha.	Umntu obhubhayo ngoku uyixazulule kwaye/okanye uyamkele imibandela – useluxolweni kwaye ulila manqapha-nqapha kakhulu - okanye akasoze.	“Ukunceda usapho ukwamkela ukuvalalisa komntu obhubhayo”	Umntu obhubhayo nosapho balungile kwaye umcebisi akadingeki nganto. Iqela lenkxaso yokulandelisa (okanye umxhasi) ngoku angalawula inkqubo yesidima somxumi.	Akukho mcebisi okanye akukho qela lenkxaso yokulandelisa idingekayo.
<p><b>5. UMCIMBI ONGAGQITYWANGA (UKUBHOBOKA, UKUXOLELANISA)</b></p> <p><b>Inkc:</b> Linganisa ubuchule bomxumi ekupheliseni iimbambano zakudala ezishiyekileyo, ukuzisola, ukuxolela, isazela, amahlebo njl</p>	Umntu obhubhayo uqhubeka nokulila ngalo lonke ixesha kwaye akabonisi kusabela kwiicebiso.	Umntu obhubhayo uyalila ngalo lonke ixesha kodwa kukho iimpawu zokuba akasabeli kwiicebiso.	Umntu obhubhayo ngoku uyaxoxa kwaye/okanye e ukuxoxa imibandela nomcebisi – kodwa usalila ixesha nexesha.	Umntu obhubhayo ngoku uyixazulule kwaye/okanye uyamkele imibandela – useluxolweni kwaye ulila manqapha-nqapha kakhulu - okanye akasoze.	“Ukunceda usapho luxolele umntu obhubhayo ngento eyenzeka kwixesha eladlulayo”	Umntu obhubhayo nosapho balungile kwaye umcebisi akadingeki nganto. Iqela lenkxaso yokulandelisa (okanye umxhasi) ngoku angalawula inkqubo yesidima somxumi.	Akukho mcebisi okanye akukho qela lenkxaso yokulandelisa idingekayo.
<p><b>6. IMINQWENO</b></p> <p><b>Inkc:</b> Linganisa ubuchule bomxumi ukugqibezela yonke iminqweno yakhe (umz imiyolelo ebhaliweyo, iipolisi, amafa, izivumelwano, amalungiselelo omngcwabo njl) ukuqinisekisa</p>	Umntu obhubhayo uqhubeka nokulila ngalo lonke ixesha kwaye akabonisi kusabela kwiicebiso.	Umntu obhubhayo uyalila ngalo lonke ixesha kodwa kukho iimpawu zokuba akasabeli kwiicebiso.	Umntu obhubhayo ngoku uyaxoxa kwaye/okanye e ukuxoxa imibandela nomcebisi – kodwa usalila ixesha nexesha.	Umntu obhubhayo ngoku uyixazulule kwaye/okanye uyamkele imibandela – useluxolweni kwaye ulila manqapha-nqapha kakhulu - okanye akasoze.	“Ukunceda usapho luvumele iminqweno yomntu obhubhayo”	Umntu obhubhayo nosapho balungile kwaye umcebisi akadingeki. Iqela lenkxaso yokulandelisa (okanye umxhasi umz igqwetha, inkokheli yasekuhlaleni, unyana omdala njl) ngoku angalawula inkqubo yesidima somxumi.	Akukho mcebisi okanye akukho qela lenkxaso yokulandelisa idingekayo.

Umntu obhubhayo ULUNGILE .....kodwa usapho ludinga ukucetyiswa

Umntu obhubhayo nosapho BALUNGILE omnye nomnye.... Udinga kuphela inkxaso ixesha nexesha.

linkcazeli	Isikora 1	Isikora 2	Isikora 3	Isikora 4	Isikora 5	Isikora 6	Isikora 7
	“Akuxoxwanga okanye akasabeli” (0%)	“Qalisa ukuthetha” (1-49%)	“Ukuxoxa okanye ukuhlafuna” (50%-80%)	“Ukwamkela okanye ukuxazulula” (81%-100%)	“Ukusebenza ngentsebenziswano yosapho”	“Kudingeka ukulandelwa kwenkxaso kuphela”	“KULUNGILE”
<b>7. UKHATHALELO OLUNGUNDOQO</b>  <b>Inkcz:</b> Linganisa ubuchule bomxumi ukufumanisa intuthuzelo nolwaneliseko (1) <u>kokungqongileyo kokhathalelo lwakhe</u> (ikhaya, iiklinikhi, ikhaya labagulela ukufa njl) kunye (2) <u>uncedo ngemisetyenzana yemihla ngemihla</u> (ukutya, ukubrasha iimpahla, ukuhlamba, ukuya ngasese, ugqithiselo lwebhedii/situlo njl) kunye (3) <u>iimeko zokuphila</u> (ukucoceka, umandlalo, iqondo lobushushu njl).	Umntu obhubhayo uqhubeka nokulila ngalo lonke ixesha kwaye akabonisi kusabela kwiicebiso.	Umntu obhubhayo uyalila ngalo lonke ixesha kodwa kukho iimpawu zokuba akasabeli kwiicebiso.	Umntu obhubhayo ngoku uyaxoxa kwaye/okanye e ukuxoxa imibandela nomcebisi – kodwa usalila ixesha nexesha.	Umntu obhubhayo ngoku uyixazulule kwaye/okanye uyamkele imibandela – useluxolweni kwaye ulila manqapha-nqapha kakhulu - okanye akasoze.	“Ukunceda usapho luggale kwaye kwenze zibe lula izidingo zokhathalelo olungundoqo zomntu obhubhayo”	Umntu obhubhayo nosapho balungile kwaye umcebisi akadingeki nganto. Iqela lenkxaso yokulandelisa (okanye umxhasi umz umnikezi-lukhathalelo lwasekhaya) ngoku angalawula	Akukho mcebisi okanye akukho qela lenkxaso yokulandelisa idingekayo.
<b>8. UKHATHALELO LOKONGIWA</b>  <b>Inkcz:</b> Linganisa ubuchule bomxumi ukufumana intuthuzelo nolwaneliseko ngokhathalelo lokongiwa ekunciphiseni ubunzima. Njengo: (1) <u>lawulo lwengqaqambi yenyama</u> (2) <u>inkxaso yamalungu omzimba abalulekileyo</u> (umz ukuphefumla, ukulawulwa kweesilonda, isinyi, ulawulo lwelindle) (3) <u>ukudanjiswa kophawu</u> (umz isicaphucaphu, isisu esihambisayo, amavumba amabi, irhashalala norhawuzelo njl).	Umntu obhubhayo uqhubeka nokulila ngalo lonke ixesha kwaye akabonisi kusabela kwiicebiso.	Umntu obhubhayo uyalila ngalo lonke ixesha kodwa kukho iimpawu zokuba akasabeli kwiicebiso.	Umntu obhubhayo ngoku uyaxoxa kwaye/okanye e ukuxoxa imibandela nomcebisi – kodwa usalila ixesha nexesha.	Umntu obhubhayo ngoku uyixazulule kwaye/okanye uyamkele imibandela – useluxolweni kwaye ulila manqapha-nqapha kakhulu - okanye akasoze.	“Ukunceda usapho luggale kwaye kwenze zibe lula izidingo zokhathalelo olungundoqo zomntu obhubhayo”	Umntu obhubhayo nosapho balungile kwaye umcebisi akadingeki nganto. Iqela lenkxaso yokulandelisa (okanye umxhasi umz unesi okanye ugqirha) ngoku angalawula inkqubo yesidima somxumi.	Akukho mcebisi okanye akukho qela lenkxaso yokulandelisa idingekayo.

49% - 50%

Umntu obhubhayo ULUNGILE .....kodwa usapho ludinga ukucetyiswa

Umntu obhubhayo nosapho BALUNGILE omnye nomnye....Udinga kuphela inkxaso ixesha nexesha.



<p>Izakhono zokucebisa nezixhobo ezisetyenziswa ngumcebisi:</p> <p>IsiNgesi: ukumamela, ukucacisa, ukuxolisa, ukukhuthaza, ukuphanda, ukubuza, ,          Afrikaans: Luister, Verduideliking soek, Kalmeer, Aanpor, Delf, , Vrae stel,          Xhosa: Ukumamela, Ukuqinisekisa, Ukuthomalalisa, Ukunyanzela, Inkcazelo, Ukubuza,          Zulu: Ukulalela, Chaza, Ukuthulisa, Khuluma, Ukuzwisisa, Ukubuza          Tswana: Ga Reetsa, Go netefatsa, Go kokobetsa, Go pateletsa, Go utlwisisa, Go botsa, .          Sotho: Ho Mamela, Ho netefatso, Ho kokobetsa, Ho pateletsa, Ho utlwisisa, Ho botsa,</p>	<p>Iimpawu “zomntu obhubhayo olilayo” ngenxa yokuswela isidima okanye udano:</p> <p><b>Umothuko:</b> uvalo, uloyiko, ukungabinakhuseleko, ukungakwazi ukwenza isigqibo, akukho kusabela, akukho kuqwalasela  <b>Ukuphika:</b> Ukuswela ukuzithemba, ukukrokrela, ukungakukhoyi,  <b>Ukuxoxa;</b>  <b>Umsindo:</b> uhlaselo, amaxhala, ucaphuko, ukungabinamonde, ubukrwada, intiyo, ukubanga, Ukungoneliseki, ubucaphucaphu  <b>Udakumbo:</b> ukuba wedwa, ukungenzi nto, ukunikezela, ukwaliwa, umoya ongemhle, ukungatyhileki, iimpawu zengqondo nomzimba, Njengeengqaqambo, iintlungu, ukuphelelwa ngumphefumlo, ihayiphaventileyishini.</p>
--	---



## **DIGNITY (OMEGA) SCALE Credentialing Exam, Version 0**

This credentialing examination contains three case studies. Each case study contains 8 questions. Record your answers on the scoring sheet provided to you. This is an open book examination – you may use your manual.

This credentialing examination expires December 31, 2008.

Study carefully the behavior of the dying persons under each definition and score accordingly:

### **Case Study #1**

The dying person John is 55 years old. He has pancreas cancer and is in the terminal phase. He lives at home with his family (wife, 18 years old son and 21 years old daughter). John does not have the services of a CANSA counselor.

#### **1. Communicating**

John is communicating his daily needs and his feelings appropriately to his wife, but the rest of the family (especially the daughter) is still very emotional and avoids communicating to John.

#### **2. Family Harmony**

John is discussing his imminent death with his wife, but he is still acting out from time to time with withdrawal, negativity, isolation etc. Both his children are also avoiding him as they do not want to see him deteriorating.

#### **3. Fear**

John is a Methodist; he is starting to talk about life after death, but will not engage into discussion or debate yet.

#### **4. Letting Go**

John is acting out all the time when the issue of saying goodbye to his family arises. He refuses to talk about it.

#### **5. Unfinished Business**

Nobody has managed to open the discussion on “unfinished business” with John yet. He responds with aggression to anyone who dares to talk in that direction.

#### **6. Wishes**

John is discussing with his wife his funeral arrangements and his will. He still acts out from time to time by refusing to sign the will.

#### **7. Basic Care**

John is at home and cared for by his wife. Both him and his wife are happy with this arrangement. A care giver visits every day for a few hours to give his wife some time off.

## 8. Nursing Care

John has abdominal pain, and it is controlled by a morphine pump. John seldom acts out when he complains of pain.

### Case Study #2

The dying person is Mary age 32. She has breast cancer - spreading to the liver and lungs. She is taken care of in a hospice bed. She has a husband and a 12 months old baby. She is receiving counseling from a CANSA counselor

#### 1. Communicating

Mary is communicating all her daily needs and feelings to her CANSA counselor but she is not yet honest to her husband. The CANSA counselor is now assisting her and the husband to communicate appropriately about her daily needs and feelings.

#### 2. Family Harmony

Mary cannot get her husband to talk to her about her dying. He cannot accept her dying. She is frustrated and is debating with the CANSA counselor about her husband's denial of her dying. She acts out from time to time.

#### 3. Fear

Mary is Catholic and she has accepted and resolved the Catholic belief system to help her into the afterlife. Her husband is also a devoted Catholic and is actively supporting her in this process. The CANSA counselor has asked the Catholic priest to keep on supporting her and her family in their religious journey.

#### 4. Letting Go

Mary is acting out continuously when her husband and child visit her. She would cry, be obsessive with the child and keep on promising the child that she will come home soon.

#### 5. Unfinished Business

The CANSA counselor has probed Mary for unfinished business. Severe emotional trauma in her childhood was discovered.

She is now debating these issues with the counselor, and she is still acting out from time to time with anger and resentment.

#### 6. Wishes

The CANSA counselor has finalized all Mary's wishes with her. This included her funeral arrangements, her will, taking care of the baby etc. Her husband has agreed to everything. All documents have been signed, and there is no need to address the issue further.

#### 7. Basic Care

Mary is lying in a hospice. She is not happy and wants to go home. She is discussing it with the counselor, and from time to time she is acting out by crying.

## 8. Nursing Care

Mary and her family are happy with the nursing care. She has no pain. The hospice nurses supervise her care every day.

### Case Study #3

The dying person is Sizwe age 42. He has terminal lung cancer and returned from Johannesburg to his traditional rural village to be with his family (wife, 3 children and his parents). The relationship between him and his family deteriorated over past 6 years that he worked in Johannesburg as he neither support nor visited his family over that time. He is receiving counseling from a skilled CANSA counselor.

#### 1. Communicating

Sizwe is still debating with the CANSA counselor about the value of open frank and honest communication with his family, but his family is not yet prepared to join in this debate. Sizwe is acting out with anger and frustration from time to time.

#### 2. Family Harmony

Sizwe's family believe he is bewitched and is therefore stigmatizing him. They do not accept him in their home. He is living in a shack behind the family home. When the issues of family harmony are raised to Sizwe by the CANSA counselor, he acts out most of the time, but the CANSA counselor is slowly making progress as Sizwe is starting to talk about his conflict with his family.

#### 3. Fear

The CANSA counselor has opened the issues of fear with Sizwe. Sizwe has responded and they are now discussing the issue. Sizwe is still acting out from time to time by ignoring the CANSA counselor when he raises the issue. Sizwe has a traditional belief system where he will join his ancestors.

#### 4. Letting Go

The CANSA counselor and Sizwe are helping his family to accept his goodbye. He has no problem with accepting that he is dying and to say goodbye to his family.

#### 5. Unfinished Business

The CANSA counselor has counseled Sizwe to accepted that there is unfinished business that he must resolve. It is all about apologizing to the rural family for the neglect over the past 6 years. The issue is not resolved yet as the family is still distancing them from Sizwe when the topic is raised.

#### 6. Wishes

The CANSA counselor has helped Sizwe to draft a will and to determine his funeral arrangements. Policies were also finalized. The family is happy with this arrangement and the community leader was called in to be informed about Sizwe's wishes and to support him and his family with any further changes.

#### 7. Basic Care

Sizwe is not happy to spend his last days in a shack behind the family home. He is discussing it with the CANSA counselor and he is acting out from time to time.

#### 8. Nursing Care

Sizwe is not in pain but he is receiving medication to help him breath. He says he is OK and he is happy with the medication. The family is not yet prepared to collect his medicine, but Sizwe is helping the family to agree to collect his medicine weekly.

## Case Study #4

The dying person is Josy age 65. She has terminal ovarian cancer and lives in her own home. Her two married daughters and their families live close by in the same village. She is receiving counseling from a skilled CANSA counselor.

### 1. Communicating

Josy is starting to talk to her daughters about her daily needs and feelings but there are not responding enough to form a team yet. The CANSA counselor is helping Josi and her family to improve communication.

### 2. Family Harmony

Jozy is acting out from time to time as her daughters are in denial of the terminal condition. They will not accept her imminent death. Jozy is discussing these issues with the CANSA counselor.

### 3. Fear

Jozy is a fully paid up member of the Methodist church. She has her “tickets“ to proof it. She has accepted that as long as she remains a paid-up member of her church she has no fear of dying. Her daughters and their families are not supporting her in her religious belief.

### 4. Letting Go

Jozy will not discuss her imminent departure with her daughters and grand children. She is still debating and discussing with the CANSA counselor, but she cries from time to time, saying that she is not ready to say goodbye to her family.

### 5. Unfinished Business

The CANSA counselor has asked Jozy on the unfinished business issue and she has started talking about something in the past that she still needs to deal with before she dies, but most of the time she gets very emotional when the issue is raised.

### 6. Wishes

The CANSA counselor is still discussing and debating with the Jozy her funeral arrangements and her will.

### 7. Basic Care

Both Jozy and her daughters are very happy about her care in her own home. The daughters are rendering all the care. No further support is required.

### 8. Nursing Care

Jozy is receiving pain medication and she and her daughters are satisfied with the outcome. The community nursing sister is rendering the nursing care support when ever needed.

## **DIGNITY (OMEGA )SKAAL Toelatings Toets nommer 0**

Hierdie eksamen bevat 4 gevalle studies. Elke gevalle studie het 8 vrae. Beantwoord elke vraag met 'n nommer van 1-7 op die antwoord dokument. Hierdie is 'n ope boek eksamen - u mag u handleiding gebruik.

***Bestudeer die gedrag van die sterwende persoon deeglik onder elke probleem en ken 'n gepaste punt toe.***

### **GEVALLE STUDIE 1**

**Die sterwende persoon, Johan, is 55 jaar oud. Hy het kanker van die pankreas en is terminaal. Hy bly by sy huis saam met sy familie (vrou, 18-jarige seun en 21-jarige dogter). Johan se vrou is sy berader.**

#### **Probleem 1: OOP KOMMUNIKASIE**

Johan kommunikeer sy daaglikse behoeftes en gevoelens op 'n gepaste manier met sy vrou. Sy vrou help nou die res van die familie (veral die dogter) wat steeds baie emosioneel is en dus alle kommunikasie met hom vermy.

#### **Probleem 2: FAMILIE HARMONIE**

Johan bespreek sy naderende dood met sy vrou, maar van tyd tot tyd haak hy uit deur homself te onttrek, baie negatief te raak en homself te isoleer. Beide sy kinders vermy hom ook, want hulle wil hom nie sien verswak nie.

#### **Probleem 3: VREES**

Johan is 'n Metodis; hy begin nou effens te praat oor die lewe na die dood, maar hy haak nog meeste van die tyd uit deur sy vrou te ignoreer aangesien hy nog nie regtig daarvoor wil gesels nie.

#### **Probleem 4: AFSKEID**

Johan haak aanhoudend uit as daar voorgestel word dat hy moet begin afskeid neem van sy familie. Hy weier om daarvoor te praat.

#### **PROBLEEM 5: ONAFGEHANDELDE SAKE**

Niemand kon dit nog regkry om oor onafgehandelde sake met Johan te praat nie. Hy raak aanhoudend kwaad vir enige iemand wat dit waag om in daardie rigting te praat.

#### **PROBLEEM 6: WENSE**

Johan bespreek nou al sy begrafnis reëlins en sy testament met sy vrou. Hy raak van tyd tot tyd met haar geïrriteerd, veral as sy hom vra om die testament te teken en dit agter die rug te kry.

#### **PROBLEEM 7: BASIESE SORG**

Johan is by die huis en word deur sy vrou versorg. Hy en sy vrou is 'n goeie span en is tevrede met hierdie reëling. 'n Tuisversorger besoek hulle daaglik vir 'n paar uur om vir sy vrou 'n blaaskans te gee.

**Probleem 8: VERPLEEG SORG**

Johan het abdominale pyn wat gekontroleer word met die hulp van 'n morfiën- pompie. Johan haak van tyd tot tyd uit wanneer hy pyn ervaar.

**GEVALLE STUDIE 2**

*Die sterwende persoon is die 32-jarige Marie. Sy het borskanker wat versprei het na haar lewer en longe. Sy word in 'n hospitiüm versorg. Sy is getroud en het 'n 12 maande oue baba. Sy ontvang ondersteuning van 'n berader.*

**Probleem 1: OOP KOMMUNIKASIE**

Marie het aanvaar dat sy openlik en opreg haar daaglikse gevoelens met haar berader moet bespreek, maar sy is nog nie eerlik en openlik teenoor haar man nie. Die berader ondersteun haar sodat sy en haar man mekaar kan vind om 'n span te vorm om oor haar daaglikse behoeftes en gevoelens te kan praat.

**Probleem 2: FAMILIE HARMONIE**

Marie se man ontken nog dat sy op sterwe lê. Sy bespreek met die berader haar frustrasie oor haar man se ontkenning. Sy haak nog van tyd tot tyd uit deur te huil hieroor.

**Probleem 3: VREES**

Marie is 'n Katolieke en sy het hierdie geloof ten volle aangeneem om haar te help met die hiernamaals. Haar man is ook 'n toegewyde Katolieke en hulle is 'n goeie span in die verband. Die berader het die Katolieke priester gevra om haar en haar man te ondersteun soos nodig.

**Probleem 4: AFSKEID**

Marie haak aanhoudend uit wanneer haar man en kind vir haar kom kuier. Sy sal huil, die kind aanmekeer styf vashou en belowe dat sy een van die dae huis toe kom.

**Probleem 5: ONAFGEHANDELDE SAKE**

Die berader het Marie aangepor om oor onafgehandelde sake te praat. Erge emosionele trauma in haar kinderjare is so ontdek. Sy bespreek nou hierdie sake met die berader en haak nog van tyd tot tyd uit met woede uitbarstings en openbaar gevoelens van gekrenktheid.

**Probleem 6: WENSE**

Die berader het Marie gehelp om haar wense te realiseer. Dit sluit haar begrafnis reëlings, haar testament, die versorging van haar baba, ens. in. Haar man stem met alles saam. Alle dokumente is geteken en daar is geen rede om hierdie saak verder te bespreek nie.

**Probleem 7: BASIESE SORG**

Marie lê in die hospitiüm. Sy is nie gelukkig nie en wil huis toe gaan. Sy bespreek dit met die berader en haak van tyd tot tyd uit deur te huil.

**PROBLEEM 8: VERPLEEG SORG**

Marie en haar familie is gelukkig met die verpleegsorg. Hulle vorm 'n goeie span. Sy het geen pyn nie. Die verpleegsters by die hospitiüm hou daagliks toesig oor haar versorging.

### **GEVALLE STUDIE 3**

*Sizwe is 42 jaar oud en sterwend. Hy het terminale longkanker en het vanaf Johannesburg teruggekeer na sy tradisionele plattelandse dorpie om by sy familie te wees (vrou, 3 kinders en ouers). Die verhouding tussen hom en sy familie het die afgelope 6 jaar, wat hy in Johannesburg was, versleg. Gedurende hierdie tydperk het hy hulle nooit besoek of geld huistoe gestuur nie. Hy word ondersteun deur 'n opgeleide berader.*

#### **Probleem 1: OOP KOMMUNIKASIE**

Sizwe debateer nog met die berader oor die waarde van oop en eerlike kommunikasie met sy familie en van tyd tot tyd haak hy uit in woede en frustrasie buie omdat sy familie nog glad nie met hom eerlik en opreg wil kommunikeer nie.

#### **Problem 2: FAMILIE HARMONIE**

Sizwe se familie glo hy is getoor en hulle verwerp (stigmatiseer) hom daarvoor. Hulle aanvaar hom nie in hulle huis nie. Hy bly in 'n hut agter hulle huis. As gevolg van die verwerping, lok gesprekke oor sy familie se houding meeste van die tyd uitbarstings by Sizwe uit, maar die berader is stadig besig om te vorder aangesien Sizwe begin om effens te praat oor die probleem.

#### **Probleem 3: VREES**

Sizwe het 'n tradisionele geloof waar hy glo dat hy by afsterwe sal aansluit by sy voorouers. Die berader het die probleem van vrees vir die dood begin ophaal en Sizwe reageer daarop deur met haar daarvoor te gesels, maar van tyd tot tyd haak hy uit met stilstuipe en hy ignoreer die berader dan totaal wanneer sy die probleem aanraak.

#### **Probleem 4: AFSKEID**

Sizwe het geen probleem om sy dood te aanvaar en afskeid te neem van sy familie nie. Die berader is besig om Sizwe te help om sy familie te ondersteun met hul afskeid proses.

#### **Probleem 4: ONAFGEHANDELDE SAKE**

Die berader het Sizwe gehelp om te aanvaar dat daar onafgehandelde sake is wat hy moet oplos. Hy is nou besig om sy familie oor te haal om hom te vergewe vir die afgelope 6 jaar se verwaarlosing. Hierdie probleem is nog nie afgehandel nie aangesien die familie hulle nog distansieer van Sizwe wanneer hierdie kwessie opgehaal word. Die berader help Sizwe ook om die familie te oorreed om 'n span te vorm.

#### **Probleem 5: WENSE.**

Die berader het Sizwe gehelp om 'n testament op te stel en om sy begrafnis reëlings in orde te kry. Polisse is ook afgehandel. Sizwe en sy familie het die probleem uit die weg geruim en hulle werk as 'n span saam. Die gemeenskapsleier is ingeroep en ingelig oor Sizwe en sy familie se wense en die leier sal ook vir Sizwe en sy familie ondersteun met enige verdere behoeftes.

#### **Probleem 5: BASIESE SORG**

Sizwe is glad nie gelukkig om sy laaste dae in die hut agter sy familie se huis deur te bring nie. Hy bespreek dit met die berader en haak van tyd tot tyd uit.



### **Probleem 6: VERPLEEGSORG**

Sizwe ervaar geen pyn nie, maar ontvang pille om hom te help met sy asemhaling. Hy sê hy is tevrede met die pille. Sy familie is nog nie bereid om sy pille weekliks te gaan haal nie, maar Size is besig om hulle te oorreed om saam te werk as 'n span en die pille weekliks te gaan haal vir hom.

### **GEVALLE STUDIE 4**

**Die sterwende persoon is Josy wat 65 jaar oud is. Sy het terminale ovariële kanker en bly in haar eie huis. Sy het twee getroude dogters en hulle families bly naby in dieselfde dorp. Sy word ondersteun deur 'n bekwame berader.**

#### **Probleem 1: OOP KOMMUNIKASIE**

Josy het haar dogters begin oorreed om eerlik en opreg te luister en te praat wanneer hulle met haar oor haar daaglikse behoeftes en gevoelens praat terwyl sy sterwend is. Daar is nog nie genoeg reaksie van hulle om 'n span te vorm nie. Die berader is ook besig om Josy en haar familie te help om eerlik met mekaar te wees.

#### **Probleem 2: FAMILIE HARMONIE**

Jozy haak van tyd tot tyd uit deur te huil omdat haar dogters haar terminale toestand ontken. Hulle wil nie haar naderende dood aanvaar nie. Jozy bespreek hierdie sake met die berader.

#### **Probleem 3: VREES**

Jozy is 'n ten volle opbetaalde lid van die Metodiste kerk. Sy het haar "tickets" om dit te bewys. In haarself het sy *aanvaar* dat sy geen vrees vir die dood hoef te hê nie, solank as wat sy 'n opbetaalde lid van haar kerk is. Haar dogters en hulle gesinne ondersteun glad nie haar geloofs-oortuigings nie.

#### **Probleem 4: AFSKEID**

Jozy bespreek haar naderende afskeid met die berader en dan haak sy nog van tyd tot tyd uit deur te huil en sê sy is nie gereed om afskeid te neem van haar familie nie. Sy will die probleem nog glad nie met haar dogters en kleinkinders bespreek nie.

#### **Probleem 5: ONAFGEHANDELDE SAKE**

Die berader het Jozy gepols oor enige onafgehandelde sake en sy het begin praat oor iets uit haar verlede wat sy nog moet afhandel voor sy sterf, maar die meeste van die tyd haak sy uit en word baie emosioneel wanneer daaroor gepraat word.

#### **Probleem 6: WENSE**

Jozy en die berader *bespreek* haar testament en begrafnisreëlings. Dit gaan stadig, want sy raak *van tyd tot tyd* geïrriteerd en bedruk as daar oor die probleem gepraat word.

#### **Probleem 7: BASIESE SORG**

Jozy en haar dogters is baie tevrede met haar versorging by die huis. Die dogters verleen die sorg en saam vorm hulle 'n goeie span. Geen verdere ondersteuning is nodig nie – selfs nie eens af-en-toe nie.

#### **Probleem 8: VERPLEEGING SORG**

Jozy ontvang pyn medisyne en sy en haar dogters is hoogs tevrede met die resultate daarvan. Hulle vorm 'n goeie span, maar die gemeenskap-suster lewer af-en-toe'n verplegingsdiens wanneer dit nodig is.

2008-05-20

Dear Hennie

This is just a brief summary to let you know my findings concerning your Dignity Scale.

The sample

The calculation is based on a sample of 260 cases. The data set was exceptionally clean and it was not necessary to ignore records due to missing values. I did not explore the sample characteristics.

Scale reliability

Your request was to calculate the scale's Cronbach Alpha as an estimate of its reliability. The Cronbach Alpha for the eight-item scale is 0.915. The coefficient is high (i.e good) especially in light of the scale being fairly short the Cronbach Alpha increases as the number of items increases. In light of this there can be no doubt that the scale is internally highly consistent. This means that the eight items contribute to the total score in a highly reliable manner. A stepwise regression analysis (exploring how each of the 5 items contributes to the total score) shows a very even contribution from each item.

Construct validity

Although you did not request any validity information, I was curious to explore the basic constructs of the scale in light of its good internal consistency. Principle component analysis clearly shows that the scale has a single main component, with each of the items loading fairly strongly on this component. This finding supports the notion that the scale has good internal consistency. For interest sake I include the loadings below:

Item	Component 1
Communication	.706
Family Harmony	.847
Fear	.848
Letting Go	.892
Unfinished Business	.854
Wishes	.822
Basic Care	.729
Nursing Care	.607

The component is described in terms of the loading items. From the above it is clear that "Letting Go" is the strongest indicator of 'dignity', with 'Nursing Care' the lowest indicator.

In summary

The Dignity Scale has a high level of internal consistency, showing an alpha value of .915. As can be expected the scale consists of 1 component, attracting high loadings from each of the constituent items.

Kind regards

Prof Vasi van Deventer  
Department of Psychology  
University of South Africa

Beste Hennie

Hiermee graag terugvoer oor die Dignity Scale Meetinstrument soos in ons streek getoets.

Ons het meer as 150 mense opgelei in alle munisipale areas van die Weskus Distriks Munisipaliteit. Dit sluit die volgende dorpe in: Malmesbury, Yzerfontein, Moorreesburg, Piketberg, Koringberg, Velddrif, Eendekuil, Redelinghuys, Vredenburg, St Helenabaai, Langebaan, Hopefield, Citrusdal, Clanwilliam, Graafwater, Vredendal, Klawer, Lutzville, Leipoldville en Elandsbaai in. Ons het ook tuisversorgers na hierdie opleiding uitgenooi en kry reeds ook van hulle punte terug.

Die opleiding is baie positief ervaar en kursusgangers was baie opgewonde oor die feit dat hulle kan meet waarmee hulle besig is. Almal was dit eens dat die probleem areas soos opgestel, die areas is waarop gefokus moet word. Personeel van CANSA wat dit bygewoon is, is geweldig positief oor die effek wat hierdie instrument op die kwaliteit van dienslewering kan hê. Dit was ook interessant om te hoor hoe vinnig kursusgange gevalle waarmee hulle gewerk het kon oproep wat in spessifieke kategorieë geval het.

Daar is egter 'n groot gros van die vrywilligers wat na afloop van die opleiding sukkel om die punte toe te ken. Dit wil voorkom asof dit die vrywilligers is wat al jare by CANSA betrokke is en "set in their ways" is. Skielik word daar van hierdie vrywilligers verwag om aspekte aan te spreek wat andersins nooit aangeraak is nie en hulle vind dit erg ongemaklik. Ek dink ook dat hulle ietwat bedreig voel dat hulle ook in die proses gemeet word en dat 'n blote "Dit gaan goed" nie meer goed genoeg is nie. Van hulle glo dat slegs maatskaplike werkers hierdie inligting kan insamel...

Die jonger vrywilligers vind dit aansienlik makliker om te punt en het eenvoudig gehardloop met die ding. Hulle terugvoer is ook baie positief. Ek het ook 'n oud-arbeidsterapeut wat rasend opgewonde is oor die instrument en by hulle opleiding ander kursusgangers aangepor het om te oefen en te oefen totdat hulle dit baas geraak het aangesien dit hulle werk net soveel meer betekenis sal gee,

Dit is duidelik dat daar nog baie tyd aan voortgesette opleiding gegee sal moet word, maar al die personeel is dit 100 % eens dat dit die moeite werd sal wees. Ons het ook as 'n span besluit om hierdie opleiding deel te maak van ons huidige opleiding vir Pasientediens vrywilligers en so vrywilligers van die begin af gewoon maak aan hierdie manier van doen. Dit gaan egter tyd neem voordat ons die totale impak van die implementering van hierdie projek sal smaak. Dit wat ons reeds ontvang, maak ons egter opgewonde oor wat wag en hoop voorwaar dat CANSA hierdie werkswyse nasionaal sal implementeer.

Mareé Lambrechts  
CANSA Weskus: Streeksbestuurder  
Malmesbury  
Tel: 022 - 482 1111 / 082 922 3227

(A free translation from Afrikaans to English)

Dear Hennie

Herewith I keenly render feedback on the Dignity Scale measuring instrument as tested in our region.

We had more than 150 care givers trained in all municipal areas of the West Coast district municipalities. It included the towns of: Malmesbury, Yzerfontein, Moorreesburg, Piketberg, Koringberg, Velddrif, Eendekuil, Redelinghuys, Vredenburg, St Helenabaai, Langebaan, Hopefield, Citrusdal, Clanwilliam, Graafwater, Vredendal, Klawer, Lutzville, Leipoldville and Elandsbaai. We also invited home based caregivers to these training sessions and already are we getting their scores back.

The training was very well received and trainees were excited about the possibility that they could now measure what they perceived to be their core business. Everyone agreed that the areas as set out in the instrument are the key areas that must be focused on. Staff members of CANSA that also attending the training sessions were upbeat of the effect that this instrument might have on the quality of service delivery. It was also interesting to note how speedily the trainees identified and even scored some of their cases with the study material at hand.

However, following the training sessions some volunteers had problems in scoring cases. It was specifically prevalent with volunteers that been with CANSA for many years and are set in their ways. It seems that if expected from these volunteers to address aspects that they never had part off, they became uncomfortable. I also think that they felt somewhat threatened as being measured in the process, and that an "OK" is not satisfactory any more. Some of them believed that only a social worker can collect this information.

The younger volunteers experienced the tool to be much easier to score and simply ran with it. Their feedback was also very positive. I also had an occupational therapist in one of the training sessions. She was extremely excited about the tool and during the training she continuously prompted the trainees to keep on exercising with the tool until they have required the needed skills as the tool will give their tasks so much more meaning.

It is clear that much more time will be required for continuous education, but the personal is 100% in agreement that it will be worth the while. As a team we also agreed to make this training part of our current training program for Patient services volunteers. The objective is to make our volunteers from day one aware of this way of approach. It will take time before we will experience the total impact of implementing the project. The feedback that we have received to date makes us very excited about the future and sincerely hopes that CANSA will implement this method on a national level.

Mareé Lambrechts  
CANSA West Coast: Regional Manager  
Malmesbury  
Tel: 022 - 482 1111 / 082 922 3227

*Responses from Palliative Caregivers after 3 months of implementation of the tool.*

- *“Thank you for helping me to understand everything, my job is no more only to help with the cleaning; now I feel good to do more for my people” (12)*
- *“Thank you for helping us to help you. Now I can see how I help the person to get his dignity better. I like to go to see my people now every day.” (8)*
- *“The families are thinking I am better than before because the dying persons are now listening and talking to me. I am so happy.”(3)*
- *“When I tell the families about dignity they think I am a teacher. They respect me for what I know and listen to what I say how to help the dying person. I am feeling so good because I can score the dying person every day.” (7)*
- *“Thank you – it is so much easier now.” (9)*
- *I do not feel so tired any more; I look forward to visit my patients. I want to see every day if their dignity gets better. I want their dignity to be very high when they die. I help the family to help me to get dignity high.”(10)*
- *“The tool is so easy to use, it sits in my head and I know what to listen for and what to look out for to make a score. I am very good now” “I use the tool on all my people now. It just comes as if I have done it all my life. It is so easy and I feel like I am the best.” (19)*
- *“I feel like a queen, I can now explain the patient’s problems to others, now it is so easy because Thomas (CANSAs regional coordinator) looks at my scores only and then he know.”(22)*
- *“The tool has given me a new frame work to work in; I can now see how things relate to one another. Thank you for the opportunity to be part of the research.” “I always though I had lots of experience with the needs of dying persons and that I was good at it; but the Dignity scale proved that I knew only half of what it was all about”(38)*
- *“Thank you so very much for asking me to help with the study. We always new what was dignity, but you helped us to measure it and now it works so much better.” (44)*
- *“I would not have missed this opportunity to learn so much in such a short time.” (47)*
- *Every time we have group meetings, I can tell other caregivers what the problems are, and they can help me because we talk now about the dignity tool scores, and now we all understand now” (16)*