HOPE THROUGH THE VIEWFINDER: PATIENTS WITH CANCER AND THEIR CLINICIANS

CAROLYN A. RICHARDSON
BN, PG Dip (Endorsed) Credit, MHScc (Endorsed)

Submitted in fulfilment of the requirements for the degree of

Doctor of Philosophy

Deakin University

June 2012
DEAKIN UNIVERSITY

ACCESS TO THESIS – A

I am the author of the thesis entitled *Hope Through the View Finder: Patients with Cancer and their Clinicians*

submitted for the degree of **Doctor of Philosophy**

This thesis may be made available for consultation, loan and limited copying in accordance with the Copyright Act 1968.

'I certify that I am the student named below and that the information provided in the form is correct'

Full Name  
Carolyn Ann Richardson  
(Please Print)

Signed  
Signature Redacted by Library

Date  
25/5/2012
I certify that the thesis entitled (10 word maximum)

Hope through the viewfinder: patients with cancer and their clinicians

submitted for the degree of

Doctor of Philosophy

is the result of my own work and that where reference is made to the work of others, due
acknowledgment is given.

I also certify that any material in the thesis which has been accepted for a degree or diploma by any
university or institution is identified in the text.

'I certify that I am the student named below and that the information provided in the form is correct'

Full Name: Carolyn A. Richardson
(Please Print)

Signed: [Signature Redacted by Library]

Date: 25th May 2012
ABSTRACT

Title: Hope Through the Viewfinder: Patients with Cancer and Their Clinicians

Introduction:

The inspiration for this PhD research developed out of previous research and I became interested in the concept of ‘hope’ when I interviewed a patient who was dying of cancer. Statistically ninety-five percent of people with her type of cancer die within five years. However, that patient tossed aside statistical probability to invest considerable amounts of time, energy, faith and money in the hope of treating her untreatable and unbeatable cancer. I was driven by a scientific endeavour to understand the difference between hope, optimistic expectations, faith, courage and the will-to-live.

The aim of the research was to

- Define a concept of hope particularly that was perceived by both the patient diagnosed with terminal cancer and a clinician who cares and treats people with terminal cancer.

- Understand if a health professional even consider hope or is it more fundamental as having optimistic expectations for patients with terminal cancer.

- Begin to develop a method of reading symbolic photographs in order to analyse them as a trustworthy and authentic form of narrative data collection.

Methodology:

Interpretive phenomenology is the research method used in this research. Edmond Husserl’s phenomenology (1913) and Edith Stein’s (1891-1942) approach to phenomenology and empathy have been used to underpin the thesis. In the descriptive and interpretive tradition of phenomenology, I have used mixed media to make explicit the twenty participant’s being of and in the world of palliative care. As well as photography the traditional mode of describing phenomenological narrative themes of the lived experience is used.
Results:
Two groups of participants were invited to share their experiences. One group was clinicians who had direct care of patients with non-curative terminal cancer and included surgeons, oncologists, radiation oncologists, general practitioners, medical consultants, and specialist consultants. The second group of participants consisted of ten people who had non-curative terminal cancer. These were identified within a particular district health board and during their patients’ appointment.

The data collection captured the understandable meanings of the participants’ experiences and essential meanings or the ‘essence’ of the experience. Thus several broad open-ended questions were asked to understand if there were changes in hope across the illness phase. The study found four key themes and five sub-themes from both cohorts of participants: For the clinicians hope was described as anticipation, motivation, positive optimism, a driving concept with the sub-themes of hope being contextual, spiritual and preparedness. For the patient participants’ their hope themes were anticipation, positive optimism, realism and resignation with the sub-themes of spirituality and humanity.

Conclusion:
Hope-work is a vital part of palliative care and education will help to understanding how hope works. Greater support and supervision are necessary within the practice of self-reflection in all areas of palliative care including older adult facilities, rural communities and impatient wards. The examination of emotional tolerances and finding meaning in living and dying, and the grief process across all areas within medicine and nursing needs to be considered. Health care professionals also need to have a greater understanding of the processes of how their own hopes and hoping processed are entwined with patient’s emotional desires. The area of cognitive behaviour processes underlying motivations, emotions and anticipation needs to be studied in greater detail to understand the significance of adaptive learning systems with respect to people living with life limiting illnesses.
ACKNOWLEDGEMENTS

This research has been a culmination of ten years involvement with nursing, bioethics and palliative care, and the desire to undertake research to improve the health care and education. I wish to thank Deakin University, Melbourne for the wonderful nurturing environment and vision it demonstrates towards new researcher. Professor Bridie Kent has challenged, supported and assisted me throughout this process. I owe her a debt of gratitude through the process of challenging my thinking and ways to understand phenomenological research.

I also thank Professor Rod MacLeod, my second supervisor in this work, especially through the ‘artistic phase’ and palliative care knowledge. He has been a passionate and an enthusiastic advocate about my photography at the work has matured and taken on a life of its own. His wealth of knowledge, and rich and varied experience within palliative care has been invaluable and an inspiration.

My family have been supportive and enabled me to work through despite challenging circumstances, and I thank them especially Charmaine, Lynette, Harry and Sam who helped in the final post production phase amid the chaos that life throws at us. I would also like to thank Roz McKechnie and Natalie McDonnell for being there to support and encourage the production of this thesis.

Finally I wold like to thank each of the participants for allowing me into their lives for a brief moment in time. Science has taken us on a wonderful journey or clinical discoveries bit it has left behind the key essence – behind each medical and nursing encounter is a thinking, breathing person who has not just a physical body but one full of emotions such as sadness, joy, desires and hopes that need to be supported. There was an expression of genuineness and unconditional positive regard for the patient participants by the clinicians with hope becoming a driving concept within the care trajectory. And I was immensely heartened by this. This research makes me see that people are probably people all over the world bit it is our unique individuality that provides all of us with the ability to strive for different things. Just as we are all individuals, doctors and patients remain a matchless distinctive group of people in their own right. Without their generosity and support research could become very dull and meaningless.
Preface
“Even when photographers are most concerned with mirroring reality, they are still haunted by tacit imperatives of taste and conscience” Sontag 1979, p.6
# TABLE OF CONTENTS

Abstract iii

Acknowledgments v

Preface vi

## CHAPTER 1    INTRODUCTION
- Background 1
- Research Question 2
- Research Topic – Toward a Concept of Hope 3
- Structure of Thesis 4
- Definition of Terms 6
- Summary 7

## CHAPTER 2    LITERATURE REVIEW
- Introduction 8

**Section I: What is known about the concept of hope** 8
- The Science of Hope and Quality of Life 14
- Medicalisation of Hope 16
- Philosophy of Hope 18

**Section II: Philosophers of Hope** 19
- Arthur Schopenhauer 19
- Gabriel Marcel 23
- Existentialism 24
- Marcel’s Theory of Hope 27
- Truth Telling and the Possible Destruction of Hope 29
- The Hopes of Others 31
- Summary 32

## CHAPTER 3    BIOETHICS AND HOPE
- Introduction 35
- The Meaning of Bioethics 35
- Ethical Responsibility in the Context of Hope 37
- The Sanctity of Life Ethic and the Terminally Ill 40
- Foucauldian Ethics 41
- When Dying Becomes a Medical Dilemma 42
- Crossing the Line Between Curing a Benign Illness and Hastening Death 44
- Narrative Ethics 45
- Micro-ethics and the Clinical Encounter 46
- Summary 48

## CHAPTER 4    METHODOLOGY AND DESIGN
- Introduction 49
Clinician Participants’ Pyramid of Hope 128
Clinician Participants’ Circle of Hope 129
Patient Participants’ Pyramid of Hope 130
Patient Participants’ Circle of Hope 131
Hope Described as Motivation 132
Motivation and Co-construction 133
Hope and Anticipation 139
Anticipatory behaviour 140
Hope and Positive Optimism 143
Hope as a Driving Concept 148
Being Realistic and Resigned to Living with a Life Limiting Illness 151
Hope is Contextual and Spiritual 157
Hope and Preparedness 161
Section II 163
Hope and Empathy 163
Steinian Philosophy on Empathy 164
Representing Empathy, Hope and Willing 166
Dissonance between Aesthetic Empathy, Sympathy and Compassion 167
Being Empathic in the Face of Death 169
Hope as an Essence of Basic Humanity 171
Medicine and Nursing in Step with Liminality 173
Limitations of Research 174
Further Research 175
Summary 176

CHAPTER EIGHT  READING PHOTOGRAPHS 177
Introduction 177
The Photograph as Metaphor 180
Getting in Behind the Photograph 182
Hope as a Driving Concept 179
Together and Connections 180
Reading Photographs 186
Creating a Style 188
Photography as Phenomenology 190
The Conception of the Photograph 192
The Meaning Behind the Photographs 193
The Picture Theory of Meaning 206
Photography as a Conclusion 208

CHAPTER NINE  CONCLUSION 211
Phenomenology as a Mixed Media 214
The Very Least You can do in Your Life (Poem by Kingsolver) 223
As Long as We Hope… (Poem by Pulsifer) 223

REFERENCES 224

LIST OF FIGURES
Figure 1  Concept Mind-map 57
Figure 2  Conceptual Graph 58-59
Figure 3  Collective Mind-map 61
Figure 4  Touch Ginger ‘Etilinger elatior’ 63
Figure 5  ‘Forever waiting’ 71
<table>
<thead>
<tr>
<th>Figure</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Figure 6</td>
<td>‘Making connections’</td>
<td>74</td>
</tr>
<tr>
<td>Figure 7</td>
<td>‘Maintaining life and aliveness’</td>
<td>79</td>
</tr>
<tr>
<td>Figure 8</td>
<td>‘Window of opportunity’</td>
<td>81</td>
</tr>
<tr>
<td>Figure 9</td>
<td>‘Stark reality’</td>
<td>82</td>
</tr>
<tr>
<td>Figure 10</td>
<td>‘Reflections and dreams’</td>
<td>85</td>
</tr>
<tr>
<td>Figure 11</td>
<td>‘The spirituality of hope’</td>
<td>86</td>
</tr>
<tr>
<td>Figure 12</td>
<td>‘Sun rise gives way to optimism I’</td>
<td>88</td>
</tr>
<tr>
<td>Figure 13</td>
<td>‘Sun rise gives way to optimism II’</td>
<td>88</td>
</tr>
<tr>
<td>Figure 14</td>
<td>‘Sun rise gives way to optimism III’</td>
<td>89</td>
</tr>
<tr>
<td>Figure 15</td>
<td>‘Feeling alive’</td>
<td>90</td>
</tr>
<tr>
<td>Figure 16</td>
<td>‘Hope through the eye of the beholder I’</td>
<td>91</td>
</tr>
<tr>
<td>Figure 17</td>
<td>‘Hope through the eye of the beholder II’</td>
<td>92</td>
</tr>
<tr>
<td>Figure 17a</td>
<td>‘Bright star’</td>
<td>93</td>
</tr>
<tr>
<td>Figure 18</td>
<td>‘The Ring Master’</td>
<td>94</td>
</tr>
<tr>
<td>Figure 19</td>
<td>‘East meets West’</td>
<td>95</td>
</tr>
<tr>
<td>Figure 20</td>
<td>‘Togetherness and connections’</td>
<td>97</td>
</tr>
<tr>
<td>Figure 21</td>
<td>‘Hope and the end of life’</td>
<td>100</td>
</tr>
<tr>
<td>Figure 22</td>
<td>‘Places and spaces’</td>
<td>101</td>
</tr>
<tr>
<td>Figure 23</td>
<td>‘I believe in miracles’</td>
<td>103</td>
</tr>
<tr>
<td>Figure 24</td>
<td>‘Getting away from it’</td>
<td>106</td>
</tr>
<tr>
<td>Figure 25</td>
<td>‘Fading blooms I’</td>
<td>110</td>
</tr>
<tr>
<td>Figure 26</td>
<td>‘A tramping we will go’</td>
<td>111</td>
</tr>
<tr>
<td>Figure 27</td>
<td>‘Optimism amongst the undergrowth I’</td>
<td>112</td>
</tr>
<tr>
<td>Figure 28</td>
<td>‘Exercising away the cancer cells’</td>
<td>113</td>
</tr>
<tr>
<td>Figure 29</td>
<td>‘Reflecting on life’</td>
<td>116</td>
</tr>
<tr>
<td>Figure 30</td>
<td>‘God understands’</td>
<td>121</td>
</tr>
<tr>
<td>Figure 31</td>
<td>‘Desire cometh, it is a tree of life’</td>
<td>122</td>
</tr>
<tr>
<td>Figure 32</td>
<td>Clinician Participants’ Pyramid of Hope</td>
<td>128</td>
</tr>
<tr>
<td>Figure 33</td>
<td>Clinician Participants’ Circle of Hope</td>
<td>129</td>
</tr>
<tr>
<td>Figure 34</td>
<td>Patient Participants’ Pyramid of Hope</td>
<td>130</td>
</tr>
<tr>
<td>Figure 35</td>
<td>Patient Participants’ Circle of Hope</td>
<td>131</td>
</tr>
<tr>
<td>Figure 35a</td>
<td>‘Hope as a driving force’</td>
<td>151</td>
</tr>
<tr>
<td>Figure 36</td>
<td>‘Alone in the wide blue yonder’</td>
<td>177</td>
</tr>
<tr>
<td>Figure 36a</td>
<td>‘Caedicia simplex’</td>
<td>179</td>
</tr>
<tr>
<td>Figure 37</td>
<td>‘Fading away II’</td>
<td>181</td>
</tr>
<tr>
<td>Figure 38</td>
<td>‘Fans of Hope’</td>
<td>181</td>
</tr>
<tr>
<td>Figure 39</td>
<td>‘Hope as a driving concept’</td>
<td>184</td>
</tr>
<tr>
<td>Figure 40</td>
<td>‘Together and connections II’</td>
<td>185</td>
</tr>
<tr>
<td>Figure 41</td>
<td>‘Positive optimism’</td>
<td>187</td>
</tr>
<tr>
<td>Figure 42</td>
<td>‘All night vigils’</td>
<td>189</td>
</tr>
<tr>
<td>Figure 43</td>
<td>‘Beginnings and endings’</td>
<td>191</td>
</tr>
<tr>
<td>Figure 44</td>
<td>‘Forever waiting’</td>
<td>192</td>
</tr>
<tr>
<td>Figure 45</td>
<td>‘Soul Searching’</td>
<td>194</td>
</tr>
<tr>
<td>Figure 46</td>
<td>Torch Ginger II ‘Etlinger elatior’- Pink</td>
<td>195</td>
</tr>
<tr>
<td>Figure 47</td>
<td>‘When East meets West I’</td>
<td>196</td>
</tr>
<tr>
<td>Figure 48</td>
<td>‘Looking to the other side of life’</td>
<td>197</td>
</tr>
<tr>
<td>Figure 49</td>
<td>‘A sliver of hope through a window of opportunity’</td>
<td>198</td>
</tr>
<tr>
<td>Figure 50</td>
<td>‘Optimism amongst the undergrowth II’</td>
<td>199</td>
</tr>
<tr>
<td>Figure 51</td>
<td>‘Reflecting on life’</td>
<td>200</td>
</tr>
<tr>
<td>Figure 52</td>
<td>‘Marooned’</td>
<td>201</td>
</tr>
<tr>
<td>Figure 53</td>
<td>‘End of the Line’</td>
<td>202</td>
</tr>
<tr>
<td>Figure 54</td>
<td>‘Gone Bush’</td>
<td>202</td>
</tr>
</tbody>
</table>
Figure 55 ‘A Tramping We Will Go’ 203
Figure 56 ‘The Doctors’ Visit’ 204
Figure 57 ‘Cupid and the Butterfly’ 205
Figure 58 ‘Cycle of Life’ 210
Figure 59 ‘Last Flight’ 217
Figure 60 ‘Joined in Quiet Contemplation I’ 218
Figure 61 ‘Hope is like a Thing…’ 219
Figure 62 ‘Reflections and Dreams’ 220

LIST OF TABLES
Table 1 Questions for Clinician Participants 52
Table 1a Questions for Patient Participants 53
Table 2 Data Analysis – Themes 61
Table 3 Clinician’s Essential Themes 77
Table 4 Rendered Thematic Concepts of Clinicians 104
Table 5 Patient’s Essential Themes 105
Table 6 Rendered Thematic Concepts of Patients 121

APPENDICES
Appendix 1 Multi-Region Ethics Committee Approval Letter 257
Appendix 2 Multi-Region Ethics Committee Extension of Time 258
Appendix 2 Information Sheet for Clinicians 259
Appendix 3 Introductory Letter for Clinicians 261
Appendix 4 Information Sheets for Patients 262
CHAPTER ONE  INTRODUCTION

Whose was that gentle voice, that, whispering sweet,
Promised me thought long days of bliss sincere!
Soothing it stole on my deluded ear,
Most like soft music, that might sometimes cheat
Thoughts dark ad drooping! 'Twas the voice of Hope,
Of love, and social scenes, it seemed to speak,
Of truth, of friendship of affection meek...
(Bowles, W. L., 1793, p. 101).

Background
When we set out to undertake a research project we have little idea where it is going to take us or the journey that is required to get to an end point, and I expect this thesis will reveal more questions than I will have answers by the time I type the last word. My interest in the concept of ‘hope’ began when I interviewed a patient for a research project when she was dying of cancer six years ago. Statistically ninety-five percent of people with her type of cancer die within five years. However, that patient tossed aside statistical probability to invest considerable amounts of time, energy, faith and money in the hope of treating her untreatable and unbeatable cancer. She knew that she would never be cured but she was still hopeful right until the end. The latter part of her ‘treatment’ phase was what naysayers call unconventional, God playing or quackery, all in the name of hoping or creating a will-to-live.

I needed to understand why and how this patient stayed hopeful despite her diagnosis. I was driven by a scientific endeavor to research the difference between hope, optimistic expectations, faith, courage and the will-to-live. Did health professionals have the same hopes as patients who were dying in three months or two years? Or did they offer active palliative treatment because the art of statistical probability and mathematics might give the person a fighting chance at a nominal numbers of weeks to months or years? Or was it as fundamental as the clinician providing treatment because it is what they are trained to do or because they can?

Within this chapter and thesis we journey through the hopes of people with a terminal cancer and discuss the importance of acknowledging and being empathic towards their concept of hope along with the bioethics of having and giving hope.
Tenacity, artistry and patience are three of my strong inherited traits, so armed with these and my nursing career that has veered off on a bioethical tangent, and because one research project often begat another, I decided to take up the challenge and traverse the ‘beginning earth’ of hope. I do this to understand hopes philosophical inception and to try to undo some of those knotty ethical issues surrounding hope. I have also undertaken this research because I am particularly interested in how hope is experienced within the “culture of palliative care” and to learn about how congruent the hopes, dreams, courage, faith and desires are between those living with cancer and the clinicians who care for those with terminal cancer in an attempt to invigorate our current knowledge.

Research Question
How is hope defined and captured within the context of palliative care? What importance does it hold for patients who have terminal cancer or clinicians who care for such patients?

Many research articles have been written on how essential it is to maintain some form of hope throughout life even when facing death. But there is a paucity of knowledge about the philosophy of the verb, noun or adjective called hope and what underpins its meaning. Hope can be seen as “a source of disruption in the care” (Bresnahan & Merrill, 1999, p. 43) or broadly defined as a subjective probability from the ‘possible’ to the ‘very likely’ of a good outcome. However it is a difficult concept to articulate and understand because of its “complex intangible nature” (MacLeod & Carter, 1999).

Many previous research projects have focused on futuristic goal setting, complicated models for maintaining hope and a hope of being cured. MacLeod and Carter (1999) challenged health professionals to look beyond the disease process and engender different hoping capabilities through all stages of illness, particularly near the end of life. Thus, a major research challenge is to be able to capture the intangible inner experience of hoping as described by a group of people living with cancer and a group of health professionals caring for those with cancer.

Open, purposeful sampling have been used to obtain a study sample of ten individuals living with terminal cancer and ten health professionals to look at the personal experience of hope or the optimistic expectations and its core meaning between the patient and clinician. I have chosen a study whereby all of the participants are deliberately selected in order to obtain a series of ‘information rich’ interviews pertaining to hope and cancer.
Toward A Concept of Hope

A search of the literature has failed to find any articles describing how or if health professionals consider their own hope or the hopes of patients suffering from cancer or if they even consider the concept of hope and cancer in the same sentence. But one small study recently published looked at ‘hope-work’ and three physicians were interviewed (Wong, 2007). However, “the doctors acknowledged that their limited interaction with patients distanced them from patients’ psychosocial issues” (pp. 88).

MacLeod and Carter (1999) write:

A challenge for palliative care is to develop ways to change health professionals’ conceptualization of hope as a static entity to one where hope is viewed as a dynamic process. In this way, patients’ hope may progress from an initial goal of ‘cure’ to one of enhancing or maintaining a quality of life (pp. 309).

They go on to provide an overview of the literature on health professionals’ perceptions of hope with particular reference to care at the end of life in the article (pp.309). Generally oncologists and surgeons do not use the word hope implicitly or even explicitly instead describe the concept of hope in terms of a patient’s statistical probability of surviving the disease process or having a reduction in cancer symptoms before, during and after treatments. To date I have not found any studies that have combined the hope or the optimistic expectations of the clinician and the patient in an attempt to understand hope as a human experience when people are facing death.

Interpretive phenomenology is the research method that I have chosen. Edmond Husserl’s phenomenology (1913) and Edith Stein’s (1891-1942) approach to phenomenology and empathy will be used to underpin the thesis. In the descriptive and interpretive tradition of phenomenology, I have decided to use mixed media to make explicit the twenty participant’s being of and in the world of palliative care as described in detail in chapter three. Photography as symbolic and iconic footprints stencils a pictorial story for the reader. This method has been used in a previous study (Richardson, 2005) where a variation on the descriptive theme revealed snapshots of impressions through poetry and photography. As well as pictures the traditional mode of describing phenomenological narrative themes of the lived experience is described textually.
Structure of Thesis

Chapter two unravels more about what we know about what it is to ‘hope’ in the literature review. The use of phenomenology as a research method and the literature surrounding this is discussed at this point. Paley (2005, p. 106) suggested to us that the “literature on ‘nursing phenomenology’ is driven by a range of ontological and epistemological considerations intended to distance if from conventionally scientific approaches”.

As already discussed many have written about hope, but little has been written about the underlying philosophy of hope and where it comes from. I introduce the philosophy of hope using the work of Gabriel Marcel (1889-1969), a French philosopher who describes his theory of hope, unhope, and high and low hopers. And the work of Arthur Schopenhauer to understand the connection between hope and willing or if in fact there is a connection, especially that of the Schopenhauer’s World as Will and Representation (Young, 2005). This work has been read as a way of understanding the philosophy of hope from a willing context. As a nineteenth century philosopher (1788-1860), Schopenhauer wrote extensively about wishes and desires and his work will optimistically help to provide a greater philosophical understanding of the topic hope.

Existentialism is discussed within this thesis because much of Marcel’s work relates to existential attitude and content. Tillich (1962) holds the view that existentialism, as an expression, underpins the character of philosophy, art and literature. He considers it to be that all-pervading anxiety of doubt and meaninglessness of human life or of a human being’s situation during a particular given historical point or context. Existentialism has been described as the one philosophy that we can live by (Murdoch, 1959). To what extent existentialisms influence how we think and function in the here and now of palliative care is explored as a way of comparing Marcel’s hope with the participant’s potential hopes or unhopes. “When Sartre uses the term ‘existentialism’, it refers not to an aspect of the method of phenomenology but to one if its foremost results; the idea that human beings do not possess a pre-given essence. He expresses this claim by saying that existence precedes essence” (Morris, 2008, pp. 34-35).

Chapter three discusses the methodology used for this research. The data collection areas in New Zealand extended as far north as the Central Districts and Otago in the south with many of the participants living in urban areas. In this chapter I describe the work of Edmund Husserl and Edith Stein in an attempt to uncover the lived experience of all of the participants.
I discuss the difficulty of underpinning the work using Husserl’s phenomenology. Because of my strong interest in bioethics and bioethical issues I examine the bioethics of hope to understand if we should even consider hoping as a legitimate feeling or expression as health professionals within chapter four of this work. I wanted to understand how hope works between people who have different agendas, namely the doctor and the patient.

Chapter five introduces the clinical participants from the two cohorts. The themes and results of the ‘experimental’ part of this work is introduced and discussed in chapter five and six to inform and improve our education surrounding the notion and concept of hope albeit this will not be the final definitive word on hope. So many questions will be left unanswered and for other researchers in the future. These chapters have symmetry because the same questions were put to both groups of participants but I have decided to keep their transcriptions quotations separated because while there are similarities both groups are singing from different song sheets.

Chapter six introduces the patient participants and their themes while there are one or two themes that are identified in chapter five there is significant difference between the two cohorts of participants to make each of the voices heard differently. You will hear the voices of the patients and while they seem not to dominate the conversation as much as the clinicians they still speak with a powerful voice.

Chapter seven is the discussion chapter which pulls together the treads of what it was to hope for the participants and the implications that it has for both health professionals and patients who have non-curative terminal cancer.

Chapter eight ‘reads’ the pictorial photographs using Thom’s method of analysis as already stated and the final selection of pictures. I have used a mix of symbolism, style and object to describe the phenomenological nod that Max van Manen speaks about. I have used photography as an extension of the voice and unspoken things that happened while collecting the data, and Thom’s way of looking at photographs.

Chapter nine is the concluding chapter where the contributions of the participants have been acknowledged, especially those who have gone before us. This chapter concludes with a recommendation for further research.
Definition of Terms
I have used the terms ‘non-curative terminal cancer’ and ‘life limiting illness or disease’ throughout this thesis and this warrants an explanation. ‘Non-curative terminal cancer’ is defined by it very title. All of the participants had been told that their particular type of cancer was terminal and was non-curative in nature. They were all offered treatments such as surgery, chemotherapy, radiation therapy, palliative care. Life-limiting illness or disease is used to describe those that have a non-curative illness that describes all terminal illness including cancer. All of the patients understood that they were going to die in the coming months post their interview with me.

Selective internal radiation therapy (SIRT) is a form of radiation therapy used to treat cancer. It is generally for selected patients with unresectable tumours particularly in the liver. It was once seen very much as an alternative approach but over the last few years has developed into a reasonably conventional treatment modality. The patient participants talk about this throughout their transcripts.

Palliative care according to the New Zealand Palliative Care Strategy (2001) is “a holistic approach to care, informed by the knowledge and practice of palliative care principles and which promotes a person’s physical, psychological and social well-being” (pp.2).

The World Health Organization (2005) describes palliative care as:

An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Hospice care is usually instigated when a person is believed to have less than eighteen months to live so many of the patient participants were ‘on the books’ at their local hospice but only three out of the ten were receiving active input from a hospice.
Summary
Phenomenological research allows the examination of the minutiae of a particular human experience at a given moment in a person’s life. It is about lifting the lid and discovering themes from the reflective processes that have awoken inner moral impulses in us. Capturing the phenomenological nod is the key object of this research project so that we might better understand and capture the nature of hope in patients receiving active or palliative care. It is about being able to meet their hope needs with a greater awareness and accuracy.

It is anticipated that through the course of this thesis a definition or definitions of hope and how hope is perceived by patients diagnosed with terminal cancer and clinicians who care for them, will be found. How important is hope for patients with terminal cancer and their clinicians? Do health professionals consider hope or is it more fundamental than this concept? How do we read photographs in an attempt to analyses them as trustworthy forms of descriptive data when using phenomenology? These questions will be discussed and answered as the participants take us through their journey across middle earth to define their concept or notions of hope.
CHAPTER TWO  LITERATURE REVIEW

This chapter discusses the concept of hope as it pertains to this current study and examines the literature about different levels of hope from unessential to essential psycho-physical-spiritual hoping.

Introduction
The literature review is divided into two sections. The first section reviews what is already known about the verb to hope, the science of hope and its effect that it has on quality of life, particularly on those who are facing death. This section also looks at the philosophy of hope to try and understand more of where the concept originated from and how it is perceived with the context of medicine and caring. The second section reviews the theorists and philosophers of hope, in particular Gabriel Marcel. The philosophy of willing as described by Arthur Schopenhauer’s standpoint is also reviewed. The philosophy existentialism has been expressed as being concerned with everyday human existence as social beings and the role of our choices and values in our life forces and personal histories. These theories are included within this section to support notions of hope and hoping as an emotion.

Section 1

What is known about the concept of hope

I felt terribly disempowered in the hospital setting. Just going for a checkup and I would come [out] and thank God. I then would ask myself “how am I supposed to keep my hopes up when things were so grim?” (Mrs. V. transcript 2005)

Hope has been described as a multidimensional dynamic life force characterized by a confident but uncertain expectation of achieving a future good (Dufault & Martocchio, 1985; Lam, 2003) and the degree of hope a person possesses can be inextricably linked to help and caring (Forbes, 1994). Hope is said to thrive in the context of a caring relationship and can be broadly defined as a subjective probability of a good outcome (Herth, 1990). Clinicians, on the other hand, may think more analytically and pragmatically when talking about hope. They may not use such a term but instead talk about statistical probability or of optimistic expectation. Mrs V quotes her oncologist “that if she (Mrs V) was treated aggressively then she could probably expect only to live for another five years after treatment”. This gave her
much to live for but sadly she died in spite of all the treatments endured. Hope is said to be the “confusion of the desire for a thing with its probability: He who is without hope is also without fear” (Schopenhauer, 1851,6:168).

Groopman (2004) sees hope as the “very heart of healing. For those who have hope, it may help some to live longer and it will help all to live better”; and further, “Hope, unlike optimism, is rooted in unalloyed reality… True hope has no room for delusion…Hope, I have come to believe, is as vital to our lives as the very oxygen that we breathe” (pp.199). Green (2004) however points out that not all would agree that hope “is a sturdy golden bough sustaining the ill or downtrodden” (pp.1514). The Rubáiyát of Omar Khayyam, translated in English by Edward Fitzgerald (1859) written in 1120 CE contrasts hope as a transient flicker. In his Persian epic Khayyam writes that the worldly hope men set their hearts on either turns to ashes or prospers “like snow upon the deserts dusty face/Lighting a little hour or two – is gone.” Khayyam’s perspective inevitably reflects the pre-modern wisdom of the inescapable collective suffering that was happening when it was written and things hoped for often happened brutally or did not.

Bloch (1959, 1986) argues that from an early age we are searching “all we do is crave, cry out. Do not have what we want” (pp. 21). Medicine and medical science has been elevated to one of the highest social standings over the last century because potentially it controls life and death and we crave this. Oncologists and other clinicians who care for patients with cancer and other non-curative terminal illnesses speak about the probabilities of surviving if certain treatment modalities are given.

Until the beginning of the twentieth century many deaths were attributed to unsanitary conditions, poor drainage and sewage systems. Large scale outbreaks of diseases such as smallpox have not been seen since world-wide vaccinations were available. The last known case of this was in America was in 1949 but in Somali as recently as 1977. There is rarely a need to vaccinate people against this disease because it has been eradicated. Other diseases such as typhoid and cholera have been largely eliminated because of the refrigeration of food and better sanitation around the world. HIV, once a deadly threat, is now a chronic disease for those who have regular access to medical care and medications. Diseases such as tuberculosis, which had almost been eradicated, have re-emerged because of poverty, poor living conditions and large numbers of people living in undersized homes. Over the course of
time many pathogens and microbes have developed ways of reinventing themselves to avoid detection and destruction by antibiotics. The likelihood of conquering all infectious diseases is impossible and Marc Lappé (1994) writes that the “evolutionary message is that we remain at risk for disease in spite of our medical advances. The interconnectedness of all living things on earth... is the basis of our continuing peril” (pp. 211).

The desire to survive a non-curative terminal illness is in the lap of the Gods and modern medicine as many new medications, diagnostic measures and vaccinations are being offered. Cervical cancer may be one of those diseases that could disappear with the development of a vaccination to be given to adolescent female to stop the spread of the virus herpes simplex (HSV) which is a sexually transmitted disease that can lead to cancer of the cervix and surrounding areas. This is a vaccine that could see the end to smear testing (Szarewski, 2004).

Patients have to believe that there is a small probability of surviving a non-curative terminal illness because the greatest threat to the self is death and life is the foundation of all other human possibilities (Callahan, 1998). Historically death was just an inevitable outcome of life and it took people from all walks of life across the life span from infant to elders. However, death has become the ‘elephant in the room’ with modern medications and treatments stretching the probability of living, and overtaking comfort and palliation (Callahan, 1993). Little and Sayers (2004) believe that probability is a mental state “in which the probability of an event, as judged by any given individual., is a statement of that person’s degree of belief in the occurrence of that event” (pp. 1330). Lam (2003) believes that there are six dimensions of hope:

1. Affective dimension whereby a person focuses on sensations and emotions which are part of the hoping process. 2. Cognitive dimension where a person thinks, imagines, perceives, learns, interprets and judges in relation to hope. 3. Behaviours that lead to the action orientation process of the hoping person. 4. Affiliation dimension where the hopeful persons’ sense of relatedness or involvement goes beyond the self. 5. Temporal dimension where past, present and future experience contribute towards hope and hoping. 6. Contextual dimension where hope or hoping is brought to the forefront because of what is going on in a persons’ life (pp. 2).

This article is one of the few that attempts to analyse what is going on philosophically behind the scenes with hope and hoping. Modern society has an attitude of denying mortality but
instead focuses on physical health, beauty and fitness. When people are faced with mortally extreme dilemmas the experience makes both the patient and their support crew hope for life over death (Forbes, 1994). Those sitting on the side line as observers hope for a return to normality and use terms like “moving on”, “getting back on ones feet” and “getting back up on the horse”. While some of those living with either having had cancer, or still with the disease, find it hard to carry on with life (Forbes, 1994, pp. 3-4). Thus, the hopes and discourse of survivors, clinicians and observers may follow distinctly different trajectories. Hope is said to be “a feeling of the possible, an inner readiness, and as an unused resource” (Rustoen, 1995, pp. 356).

Hope has been recognized as a valuable human response (Buckley & Herth, 2004) and that it is an important factor in enhancing the quality of life for those who are dying (MacLeod, & Carter, 1999). Watson (1979) in her seminal book “Nursing: The Philosophy and Science of Caring”, identified faith and hope as one of ten curative components in a humanistic model of nursing. Is theology where we will find out about hope and if so, should we use the word faith instead of hope? Hippocrates writes that before illness can be attended to, a person has to have restored their mind and soul (Illich, 1994, pp.4). Watson (1979) believes that faith and/or hope builds on and draws from a humanistic-altruistic value system to promote holistic care and this in turn will produce positive health.

“Nurse researchers have been more focused on hope than on the lack or loss of hope” (Holt, 2000, pp. 1116). Since 1980 researchers have conducted studies exploring the meaning of hope within different patient populations (Herth, 2000; MacLeod & Carter, 1999) and recent studies agree that to have and maintain hope is to live well (Back, Arnold, & Quill, 2003). In some studies nurses attempted to define the major attributes of hope and then developed tools for measuring hope (Hinds, 2004; Herth, 1990). It begs the question that if someone is content to ride out their disease process with appropriate palliative care and accept no active medical., surgical intervention or chemical or radioactive treatment does this mean that they have no hope? Or is it that they have found hope sitting in the sun, stroking the cat, and hoping for a comfortable future which includes accepting and embracing death?

Hope has long been associated with giving meaning and value (Marcel, 1962) to someone’s life but what is really understood about being hopeful and hoping? People are lauded and encouraged when they appear brave while battling diseases (Little, & Sayers, 2004). It seems
that everyone has an opinion on how to live with cancer, just as everyone is an expert when it comes to parenting or child rearing. Lupton (2004) noted that cancer brings out the worse and best in those that are not living with the disease themselves (Lupton, 1994). Sufferers that never allow themselves to “give in” are described as “incredibly brave” (Lupton, 1994, p. 67). Lupton argues that there is an emphasis on “will” and “if one has enough hope, one may will a change in the course of the disease in the body...” You might say that hope is a belief state with no certainty (p. 67), an uncertainty that moves along its own continuum because it is not dichotomous (Little & Sayers, 2004, p. 1330).

The Latin derivative of speare means ‘to hope’, along with despair and desperation (Stephenson, 1991) and is used as both a noun and a verb (Marcel, 1962). Marcel looks more philosophically at hope as being defined as a response of a person to the “Infinite Being”. Other definitions include Fromm (1968) who talks of hope as “a sense of the possible and a stage of being or as a sort of inner readiness and an unspent activeness or potential activeness” (p.1460). Implicit within any descriptive terms of hope are the two attributes of desiring good and the ability to look to the future with optimistic or sanguine expectations. Such euphemisms as Utopia, castles in the air and Pollyanna days suggest that hope can be tentatively defined as desires, expectations and in anticipation of a positive future (McGee, 1984; Stephenson, 1991).

Stotland (1969) contests that the more a person can visualize a goal and desire it the more likely they are to achieve that goal. He also supports the idea that the more visualization, anticipation and action that a person has towards the hoped for object or state, and because there is an increase in thinking and believing in the hoped for, people are more likely to achieve their hopes. In health care, Mayeroff (1971) and Watson (1979) both believe that hope has been incorporated into the concept of caring and that it is a factor in maintaining and regaining health and accepting illness-related limitations or dying. Hope and wishes are often seen as synonymous however, wishing may be part of hoping but a wish is not a hope. Wishes have little currency because of the limited investment or personal commitment one makes (Fromm, 1968). If a wish comes true there can be an element of surprise where hoping brings with it a calmness, reassurance or a sense of encouragement (Fromm, 1968; Stephenson, 1991). The manner and delivery of a prognosis may influence the way patients diagnosed with incurable cancer perceive themselves, their situation and their well-being. However, that this has little to do with wishing, but instead about the creation of essential

12
hope, expectations, unhope, hopefulness, anxiety and despair (Ford, Fallowfield & Lewis, 1996; Miyaji, 1993; Miyashita et al., 2008; Renz, Koeberle, Cerny & Strasser, 2009).

In our “techno consumptive” modern world we insist on having the irresistible ‘best and latest’ that health care has to offer, much like the call of the Sirens in the Greek classic Odysseus (Lamb, 1808). The seductively beautiful Sirens mythically appeared and called to passing sailors from their treacherous watery enclaves. Ships’ captains were lulled by their call only to be lured into very perilous conditions because the Sirens turned out to be pathological monsters. Many of the ships and sailors were washed upon the rocky outcrops with tragic consequences. Odysseus, however, outsmarted the Sirens by filling the ears of his sailors with wax and binding himself to the mast of the ship to heed the Sirens plaintive wailing and calling. Thus, they were able to stay off the menacing rocks by ignoring the Sirens (Lamb, 1808).

One can imagine that when a person’s diagnosis is terminal and they choose, along with their clinician, to change their treatment tack to good palliation, it can be likened to Odysseus where a person sails away towards death without the lure of the modern tinkers or having the fear of being washed up on the rocks of medical advances amongst the human mechanics, or the constant need to ‘do something’ other than good pain medication and honest caring. Coming to terms with nature has become a demanding task. While nature can nurture and woo us in to submission, mother nature, or the cycle of life, can sicken and kill us through no fault of our own or because we have smoked, eaten or drunk too much.

Advertising and publicity propaganda pikes our imagination into believing in the value, usefulness and success of many first world medical treatments, medications and surgeries like vultures to a carcass (Deyo & Patrick, 2005). We try to cheat death by believing that being alive is an alternative to being cured (Callahan, 1998). People with a non-curative terminal cancer often have to choose between aggressive versus conservative management depending on their gambling strengths, where they live, their finances, availability of treatment and the sensibility of their clinicians, along with what the patients want. Conservative treatment is often summarily dismissed because of the desire many have to add a few more weeks, months or years on to their life despite the ramifications. Aggressive treatment options often win out because conservation is considered ‘giving up’, ‘conceding defeat’ or ‘accepting a life sentence’.
The play *Wit* (Edson, 1998) is an example of this. Performed as a single continuous act without intermission, it is structured around the last few hours of life of Dr Vivian Bearing, an English Professor, who has been diagnosed with Stage IV metastatic ovarian cancer. Vivian recalls undergoing tests by various medical technicians and being the subject of research and grand rounds. Much of her stay in hospital is as a ‘patient’ or the ‘metastatic ovarian cancer’ in bed three, and not as a person. The play ends as Vivian, unclothed after her death, walks from her hospital bed "toward a little light" (p.9) after the clinicians tried valiantly to save her life by giving her cardiac compressions (CPR).

People seem unable to trust their instincts and believe that false hope is better than no hope. The only type of hope that is important for some people is ‘medicalised hope’ where the doctor does everything to save their lives, often in an attempt to cheat death, irrespective of the side effects or obvious benefits (Callahan, 1998). *Doing* gives a person a sense of eternal and everlasting hope that is apparently not available to those who go home to live out the rest of their lives with loved ones. In a place that they want to be without any radical chemical or surgical intervention other than good end of life care (Callahan, 1998), and not in some hospital room dying with hideous complications from extensive and exhaustive treatments.

Death has been described as the principal evil of human life, following a series of preventable diseases, (Callahan, 1998; Singer, 1995) and has at times seemed to be decidedly optional when people have a terminal disease. This is an integral part of Western world hoping (Callahan, 1998) and where it might be intimated there cannot be hope without fear, humiliation, anger and anxiety. More health care dollars spent per head of population is theoretically meant to equate with a long and healthy existence, increased hoping, less fear and anxiety (Callahan, 1998; Deyo & Patrick, 2005). The skeptics, however, suggest that we have reached a plateau and more, newer and bigger does not equate to better health outcomes (Deyo & Patrick, 2005).

**The Science of hope and quality of life**

Eliott & Olver (2002) purport that hope is primarily maintained by interactions with health professionals such as doctors but Flemming (1997) found that nurses, social workers and chaplains or clergy were less likely to influence patients’ hopes or hopefulness. Farran, Herth & Popovitch (1995) support the notion that undertaking hope work or ‘hope therapy’ is believed by health professionals to be necessary if patients are to sustain hopefulness but
there is no understanding about health professionals’ concept of hope so it is difficult to draw any conclusions about this work.

Lam (2003) speaks about hope as “an essential experience of human condition” and that there are two forms of hope that exist when patients are facing death and these are “particularized hope” and “generalized hope” (p. 1-3). In the former, Lam describes as being associated with hoping for specific goals while the latter refers to the “intangible inner experience of hope not attached to any specific goals” (p.3). The first corresponds to such things as a perceptible hope for cure or relief from symptoms while generalized hope is much more personal and generally only accessible through stories, images, motifs and similes. Hope is said to be the ballast that keeps us steady and on an even keel, and tempers fear so we can be ready for potential dangers either to pass us or tolerate them (Groopman, 2004, p.199). Psychologists have shown the more hopeful a person is; the less pain and stress will be encountered or experienced. (Cheavens, Micheal & Snyder, 2005; Wong, 2007). Fostering hope in patients living with a non-curative terminal illness is supported by having successful relationships, maintaining positivity, holding a belief system or faith, having access to good symptom control and being able or permitted to achieve short-term goals (Duggleby & Wright, 2004, p.358).

Duggleby and Wright’s study also revealed quite unique themes of “leaving a legacy, ‘turn your mind off’ and symbols of hope” (pp. 358). Having something to leave friends and families such as a tangible legacy was said to improve the quality of life and foster hope (Bensien, Norgberg, Saveman, 2000; Duggleby, 2008, 2001; Duggleby & Wright, 2007; Duggleby & Wright, 2004; Thomas & Retsas, 1999). Symbols that represent hope have been incorporated into hope interventions by Herth (2000, 2001) and Bensien et al., (2000) write that nature in the form of sensory impressions was essential for maintaining a good sense of wellbeing.

Hope is arguably entrenched in meaning. As long as there is meaning, hope will exist (Parker-Oliver, 2002; Tang, 2008). Wong (2007) found that the journey from hopelessness and despair came when death became a reality with a life-limiting diagnosis. Fallowfield & Jenkins (2004) stated that clinicians are only able to maintain hopefulness in patients after many years of honing their communication skills when it came to truth-telling and being
honest about a person’s prognosis. Remaining hopeful with patients was only possible when giving information and offering possibilities of different treatment options (Simpson, 2004). Wang (2007) reports that balancing hope and the omnipresent apprehension between hope and unhope cause people to “confront living with ambiguity” (p.93). The constantly shifting sands caused the greatest angst for both clinician and patients while they searched for realistic hope or essential hopes.

**Medicalisation of hope**

Because hope is difficult to quantify it often goes unnoticed and is only superficially regarded. It is not a resource that is regarded highly by any of the health professions (Wang, 2007) because it cannot be captured by an empirical method of scientology. In reality, because of the unpredictable and chaotic nature of hope, it has often been placed in some ‘otherness’ so it does not have to be dealt with. Thorne, Hislop, Kuio & Armstrong’s (2006) study found that numbers can be characterised as a powerful story book tool and can represent a person’s life sentence because they often foretold life changing events or diagnosis. Thorne et al. (2006) described the numbers game like people visiting a tarot reader in that integers had the ability to sustain, destroy or create hope (p. 333). Numbers can be such things as; how many years or what is the percentage of living or dying, or what is the carcinoembryonic antigen (CEA) number this time? CEA is a complex glycoprotein whose specialized sialofucosylated glycoforms serve as functional colon carcinoma L-selectin and E-selectin ligands, which may be critical to the metastatic dissemination of colon carcinoma cells and other such as pancreatic, stomach and breast (Kumar, Cotran & Robbins, 2003). Therefore for many of the patient participants treatments would reduce the CEA number if successful and increase if unsuccessful. There is a powerful need for humans “to find hope within their perception or reality”:

...the underlying effort on the part of all of the patients...to develop, retain and sustain hope. Whether that hope specifically referred to disease survival or to some other desired aspect..., numerical information was powerfully associated in the patient’s accounts with the desire to be hopeful and to have that hopefulness supported through reference to grounded, credible, and “reality-based” possibilities (Thorne, et al., 2006, p.327).

The greatest difficulty with health care providers is that many of us want to fix things in that we expect to quantify a person’s hoping levels (Wong, 2007) and there is an assumption that we know what someone might be hoping about or for. Hope, however, is like empowerment
in that we are unable to make people more or less hopeful as suggested by Ridgway (2005). Such statements as “hope instilling practice will empower people” is a nice thought, but Wong contests that this is a biomedical paradigm and not possible (2007, p. 39). Groopman (2003) writes in the context of doctors being challenged with the concept of hope:

Hope can be imagined as a domino effect, a chain reaction, each increment making the next increase more feasible... There are moments of fear and doubt that can deflate it... I feel that I have to do everything better just to be judged as okay. It is something I wish I could let go of. It’s something that I wish just wasn’t there... omniscience about life and death is not within a physician’s purview. A doctor should never write off a person a priori... I had learned that every patient has the right to hope, despite long odds, and it was my role to help nurture that hope (p. 102-214).

So we must consider the immense challenges that face modern clinicians today as they are challenged to provide more and more interventional treatments to affect cure or prolong life, even with long odds (Closs, 2002). The introduction of clinical governance, making medical care a business or using a business model of ‘care’, has enhanced the desire for good outcomes (Closs, 2002). But when patients die before their time Closs argues that many doctors see this as a sign of failure, thus leading to conversations about death and things hoped for left unspoken. Death has become something that happens to other people or in convenient circumstances – when someone is tired of living.

Autonomy and patient choice put increasing pressure on the clinical team who even with the recognition that the doctor’s duty of care is to the patient, still endeavour to take into account the wishes of the family. Frustration and the perception that the “profession or service has let them down” and a misplaced understanding of “rights”, now frequently are vented in aggressive behaviour towards the doctor (Closs, 2002, p.9).

David Morris (1998) talks about the medicalisation of care and hope as patients being trapped between two evils with runaway technology that enables people to be kept ‘alive’ indefinitely and physician-assisted- suicides as the only other alternative to living with a life-limiting illness. A study investigating the perceived quality of life and palliative care outcomes is quoted as saying “dying during the study period is a strong indicator of patients who entered the palliative care intervention in very poor health conditions. We expected and observed a worst quality of life outcome for patients like these” (Paci, Miccinesi, Toscani, Tamburini, Brunelli & Constantini et al. 2001, p.186).
Clark (2002) asks us to consider if this is how we have medicalised death. If palliative care means providing extensive chemotherapy and radiotherapy then it would seem that notions of hope have been turned into medical therapy or, as Clark suggests, that the medicalisation of palliative care “opens up a space somewhere between the hope of cure and the acceptance of death” (2002, p. 907). In all reality hope is practically sustained because medicine has put up an immense fight and “set its face against death” (Callahan, 1988, p. 59). When we speak of advances in medicine and science the impossible is unimaginable with the possibility of death being an anathema in most modern societies.

**Philosophy of hope**

Many have written about hope but little has been mentioned about the underlying philosophy of it and where it comes from. Arthur Schopenhauer, a nineteenth century philosopher (1788-1860) writes extensively about willing, wishes and desires. He does not however, use the word hope in his major work *Prize Essay on the Freedom of the Will* (1818) but of people ‘willing’ something and he describes people as being ‘willers’. However, Schopenhauer, in *Essays and Aphorisms* (1851) discusses the difference between man and a lower order animal when he states that animals lack the ability to become anxious or hope and are only capable of living in the present. Man, on the other hand, is frequently restless, bored and discontent with his condition or environment. The quest for seeing what is on the other side of a mountain or on the moon barely quenches man’s never ending appetite for dreams, desires and often obsessive imagination.

Using a Darwinian approach comparing humans and other species, Schopenhauer argues that we are all put on the earth simply to procreate and continue the human species. While other animals, birds and insects hunt, fish, procreate and provide shelter for themselves in elaborate fashions and in changing adaptations they appear never to have emulated primitive man’s ability to master the complexity of making fire or tools. At our most primitive level finding food, shelter and procreating was our prime motivation for waking up each day. However man soon became discontent with cave dwelling and a diet of raw meat, herbs, roots, grasses and fruits. His powerful imagination and the intensification of thinking thus began the journey of desiring and trying to realize and actualize dreams by imagining, ingenuity, fear and hope. Max Scheler argues that a will can never be empty “willing isn’t willing unless it wills something and also wills that something as realisable” (Cited in Sawickici, 1997, p.32)
Once they have been aroused [(desires] make a far stronger impression on men than do actual present pleasures or sufferings, to which the animal is limited. For, since it lacks the faculty of reflection, joys and sorrows cannot accumulate in the animal as they do in man through memory and anticipation... (Hollingdale, 1970, p. 44).

Section II
Philosophers of hope

The two most notable scholars of hope are Schopenhauer (1788-1860) and Marcel (1898-1960). Described as a Kantian Schopenhauer’s philosophical reflection asks that we look deeply into ourselves to discover not only our own essence, but also the essence of the universe because the basic energies of the universe flow through us just as they flow through everything else. He writes that if we come into contact with the nature of the universe we will come into contact with our own nature. Schopenhauer’s position on Will and representations stand in relationship to each other, and the relationship between the thing-in-itself and our sensations is like two sides of a coin, both of which are of the same coin and coinage (Wicks, 2008).

Gabriel Marcel (1889-1973), a philosopher and playwright, wrote about issues of death, religion, mortality and immortality, faith, fidelity, hope, and love. As a child he was forbidden to mention religion but became intensely drawn to Catholicism by François Mauriac. During World War I one of his duties was relaying news of death to soldiers' and civilians' loved ones. This inevitability made him consider concepts of love, hope and faith.

Arthur Schopenhauer (1788-1860)

It can be argued that the greatest of artists born within a cultural period or epoch get to “reap the harvest” of all that is new and for those who follow get only to pick over the remains or reap empty fields, or at least wait until the spring for seeds left behind to germinate (Shaw, 1901, 1962). What is the use of writing plays or painting frescoes if an artist has nothing more to say or portray than has already been written by such people as Shakespeare, Michelangelo, and Raphael? (Shaw, 1901, 1962) The effect of this barrenness forced intellectuals with original ideas out into such fields as philosophy instead of literature.

The world figures of Germanic literati after Goethe are not found as lyricists, novelists or playwrights but as philosophers and along with Schopenhauer are such thinkers as Nietzsche, Hegel, Schelling and Marx, to name a few (Hollingdale, 1970, 2004; Magee, 1983, 1997;
Singh, 2010). Under a different climate Schopenhauer’s philosophy may well have been expressed as works of fiction or in plays. Instead he uses the ‘language of metaphysics’ which deals with a particular type of philosophy of the apparent and the real world to tell his story through bisecting these worlds (Hollingdale, 1970, 2004; Magee, 1983, 1997).

Schopenhauer’s bifurcation of the ordinary world and the transcendental real world: I am and I think (Hollingdale, 1970, 2004, p. 12) provides us with his second world, our thinking and dreaming humanity (Magee, 1983, 1997. Descartes’ (1637, 1970) two worlds were substance or soul, and matter. Spinoza (1677, 1985) saw the metaphysics of soul and matter not as substance but as God; thoughts and imaginations; soul and matter really belonging to God (Hollingdale, 1970, 2004). Locke (1690, 1970) agreed with Descartes as his two worlds were collections of material things and mental compilations. The metaphysical basis for Schopenhauer’s philosophy was the duality of will and idea (Hollingdale, 1970, 2004; Magee, 1983, 1997) and he understood Kant’s philosophy within this framework. Schopenhauer’s metaphysical writings: The world as Will and Idea can simply be said to be a new interpretation of Kant’s a posteriori from our sensory perception and a priori, applied to sensory perception but not abstracted from it.

Kant (1781, 1954) argues that the thing in itself signifies that which exists independently of our perception, that which actually is. Democitus, a Greek philosopher and the founder of atomism (cited Cole, 1967) states that the thing in itself was matter; fundamentally this was what it was for Locke (cited Ward, 2010); to Kant, it can be simply stated as = x; to Schopenhauer, the thing in itself is will. His chief work World As Will and Representation begins with the bold statement “this world is my representation” (p.10) and he believed that he was the only one to understand Kant in the correct sense (Schopenhauer, 1907-1909).

While Schopenhauer is seldom cited, he provides a significant contribution to our understanding of such emotions as desire, will, and willing objects and thingingness (Magee, 1977; Murdoch, 1978). But who was he? Theodor Adorno (Wicks, 2008) called Schopenhauer a bit peevish and even malicious. Bertrand Russell (Wicks, 2008) describes him as a shallow and not a very sincere person. Iris Murdoch (Wicks, 2008) however, believes him to be a sincere and generous person. Barry Magee (1977) describes him not only as a great philosopher but as one of the “great writers in the sense of great literary artists” (Magee, 1977, p. 3) and Robert Wicks (2008) writes:
A person of developed aesthetic and moral sensibilities, cosmopolitan sophisticated and religious sensibility who harbored a dim view of common humanity, and despite his adequate material surroundings, endured a fair share of frustration and disappointment in his personal affairs and long-life hopes (p.188).

Whatever his personality type Schopenhauer’s philosophical writings have been underestimated by many (Hollingdale, 1970) especially when he describes us as knowing ourselves humanely or objectively in the same way that all objects in the world project themselves in a place, space and within a time period. Yet it is our inner consciousness, or knowing ourselves subjectively as someone possessing emotions, desires and sentiments; i.e. this inner world that Schopenhauer calls ‘will’. The underpinning of his philosophy is “my body and my will are one” (Schopenhauer, 1907, p.18).

Gonzales (1992) states Schopenhauer describing “willing” as an emotional state of our inner most natural desires and intentionality. “Willing can have many degrees, therefore, from the mildest wish to most passionate desire and it refers to any desires or striving, to rejoicing, to lamenting, to loving and hating” (p.52). Wittgenstein (1961) took a particular interest in intentionality and he calls this an essential characteristic of many mental phenomena, such as beliefs, fears, expectations, desires, wishes or intentions, and hopes. His work follows closely that of Schopenhauer’s, in particular the notion of representation. Centrally Schopenhauer’s main interest relates to language and will (Wittgenstein, 1961).

As far as Schopenhauer is concerned the notion of will is a phenomenological occurrence or psychological episode. As such, all phenomenal willing is in every instance a will to live and directed at the living. “We have therefore called the phenomenal world the mirror, the objective of the will, and what the will wills is always life…the will-to-live” (Schopenhauer, 1907-1909, p.275). We learn from this that every living thing is driven internally in all its actions by a will to live. “…For this knowledge the individual receives his life as a gift, rises out of nothing, and then suffers the loss of this gift through death, and returns to nothing” (p.275). Schopenhauer’s reflective scheme or method is similar to that of Descartes with the exception of not doubting his own personal bodily presence. The awareness of his selfness and bodily being remains fundamental with Schopenhauer’s philosophy resting upon the scrutiny and analysis of this awareness (Wicks, 2008, p.53).
To the subject of knowing – which appears as an individual through his identity with the body – this body is given in two completely different ways: first as representation in intelligent perception as an object among objects and as prone to the laws of these objects. It is also simultaneously given in an altogether different way, namely, as that which is immediately known to every one of us, which the word will indicates (Schopenhauer, 1907-1909, § 18, p.100).

Stuart Hampshire (1967) contests that because power is a function of will it is a function of desire. He disagrees with Schopenhauer’s doctrine by stating that “believing and intending are active states, whereas desires (passions) and fears, unless they depend on beliefs, are passive states” (Murdoch, 1966, 1997, p.194). However, Paul Hoffman (2008) argues that “passions or desires could be regarded as providing reasons for action on the grounds that the mere fact that we have a desire or passion provides a reason for satisfying it”. Descartes (1637, 1970) also ascribes to the belief that passions might cause us to make judgments that are not free thereby putting our actions into active or intending states. We are driven by a passion or an ardent desire to perform an act or acts that are not ones we choose freely, but the desire overtakes our sensibility and makes us act or ‘do’ intentional things (Hoffman, 2008, p.45).

Hoffman (2008) contests that when we are weak-willed we are acting out of desire, but that desire provides a reason for our choices, because it is represents objects as good, nice or pleasant. Just like the emotions of lust, anger and greed drive us to want and to take. Thus it can be said to act in view of desire whenever a desire influences our choice we are acting on and for that desire by operating as a reason for it, and that instances of acting proper or improperly in view of what we desire are quite common (Hoffman, 2008). Willing a hope can make it an essential hope or an active intended state, one that is acted upon that may produce a goal or a desired end-point. What gives human subjects the key to understanding themselves is will. This alone gives man the key to his own world or phenomenon, revealing significant things within the inner mechanism of his being, his actions, movements and both the subconscious and conscious thinking (Schopenhauer, 1918, p. 100).

Human beings differ in this aspect from animals despite them being embodiments of the will to live – such as recoiling from danger, they are obviously not aware of any moral status or rules of morality, as far as we understand them. Death became one of Schopenhauer’s central issues or problems in his philosophical system and his metaphysical reality revolves around
the single fundamental world of a person’s will-to-live. Arthur Schopenhauer a philosopher of death – a thanotologist in a true Socratic tradition (Singh, 2010).

**Gabriel Marcel (1889-1973)**

Gabriel Marcel can be described as an energetic French philosopher who probably belongs at the other end of the spectrum from Schopenhauer. His work on hope exudes happiness as he writes extensively in the context of high and low hopers. However, on reading his autobiographical essay life was sometimes very dark. His mother disappeared from his life when she died before Marcel was five. Although he had little visual memory of his mother, her spiritual presence influenced his thoughts during his youth. His father remarried the young boy’s aunt and Gabriel was sent away to live in a dreary apartment with his grandmother and another aunt. By the age of eight years of age he began writing plays and in later years he achieved a reputation as a playwright as well as a philosopher (Bollnow, 1983). Playwriting at an early age was thought to help his dour environment with two elderly matriarchs and a very dim environment.

Over the years as he went on to develop a philosophy he described our place in the world in terms of such fundamental human experience as relationships, love, fidelity, hope and faith (Bollnow, 1959, 1984). His brand of existentialism was said to be largely unknown in the English-speaking world, where it was mistakenly associated with that of Jean-Paul Sartre (1946/1957). Marcel’s view of the human condition was that "beings" are beset by tension, contradiction and ambiguity. He was also interested in the religious dimension of life and was considered the first French existentialist philosopher (Bollnow, 1959, 1984). Marcel became a leader in French Catholic intellectual circles after converting to Catholicism, and his Paris home was the locale for stimulating discussion among leading European intellectuals of all persuasions. During World War II Marcel lived in Lyons and afterwards he lectured in France and other countries with his "Christian existentialism" arousing sharp contrasts between his work and the atheistic existentialism of Jean-Paul Sartre.

During the war years he and his wife Jacqueline worried for their adopted son who joined the French army. This boy was the Marcel’s only child who thankfully was finally discharged injured from the front in 1940. In this same year Marcel’s wife developed terminal cancer and died after being in relative remission for several years in November 1947. At this time many Europeans faced significant cultural and political events concerning hoping, hopelessness and
hoped for things that shaped their lives forever such as the First World War, the 1929 share market crash and subsequent depression, and finally the Second World War that killed many of Marcel’s friends, families and philosophical peers.

It was during 1942 that Gabriel Marcel describes the “world’s alien and threatening character had overcome people with overwhelming force… One felt totally abandoned in a world that seemed ultimately absurd” (Bollnow, 1959, 1984, p. 177). It seemed that existentialism – in its predominant form in Germany appeared to be the tenable position to face up to “the uncanniness of existence” (Bollnow, 1959, 1984, p. 177). It is in Marcel’s “sketch of a Phenomenology and a Metaphysic of Hope” (1949) where hope is closely linked to life and that is what our soul is made of. Quite early on, while developing his philosophy, he recognized that love and joy were important emotions, “everything that is done in joy has religious value” (1949). Objecting to ‘normal’ existentialism Marcel’s basic argument was that anxiety renders us egoistic and unavailable. Bollnow (1959, 1984) contests that Marcel developed the concept of availability in the early part of his philosophical thinking and was not influenced by existentialism because this had not developed or acquired any distinction at the time he first penned the metaphysic of hope.

At the beginning of his philosophical writing Marcel speaks on Existentialism in general and Christian Existentialism in particular, his work moves from the origins of existentialism represented firstly by Sartre (1943), Kierkegaard (1835, 1996), Heidegger (1962) and Jaspers (1971) to Marcel’s theory on hope. At this point I will briefly describe existentialism, distinguish between the existential attitude and the existentialist content “with the latter asserting that man is able to transcend in knowledge and life the finitude, the estrangement, and the ambiguities of human existence” (Tillich, 1962, p.125). Because there is not the space to indulge the reader in this facet of philosophy this is very much a superficial look at the concept of existentialism.

**Existentialism**

This philosophy has been expressed as being “concerned with our everyday human existence, our social being, and the role that the choices we make and our values have on our life forces and our personal history” (Woodruff Smith, 2007, p. 24, 408). Viktor E. Frankl, the father of existentialism, (Allport, 2004) teaches us about this from his autobiographical recollections during the Second World War spent in various concentration camps (Frankl, 1959, 2004). Frankl suddenly realizes that he “has nothing to lose except his ridiculously naked life”
(Frankl cited Allport, p.9) where hunger, humiliation, fear, deep anger, and anxiety are rendered tolerable by the images and thoughts of loved ones, either on the inside or outside of Auschwitz (Allport, 2004, p.9).

By some sort of religious faith and hope, as well as a grim sense of humour, and even glimpses of mother-nature at her best amid the grey stench of suffering, the central theme of Frankl’s existentialism becomes apparent: to live is to suffer. To survive is to find and make meaning out of the suffering (Allport, 2004). Therefore the question that must be asked is whether there is a purpose in life at all? And if so, there must be a purpose in suffering and in dying (Frankl 1992, p.9). Nietzsche (1966) writes “he who has a why to live can bear with almost any how” (x p28). Existential attitude and knowledge is described by Tillich (1962, 1973, p. 125-126) as:

...you may have a precise detached knowledge of another person, his psychological type and his calculable reactions, but in knowing this you do not know the person, his centered self, his knowledge of himself. Only in participating in self, in performing an existential break-through into the centre of his being, will you know him in the situation of your break-through to him.

Tillich (1962) describes this as the first meaning of existential as the attitude of:

Participating with one’s own existence in some other existence there were always choices to make. Every day, every hour, offered the opportunity to make a decision, a decision which determined whether you would or would not submit to those powers which threatened to rob you of your very self, your inner freedom; which determined whether or not you would become the plaything of circumstance, renouncing freedom and dignity to become molded into the form of the typical inmate... this spiritual freedom – which cannot be taken away – that makes life meaningful and purposeful (p.86-87).

Existentialism can be described as a protest against the society that evolved in the second third of the nineteenth century in Europe, and as such has been the building blocks for much of twentieth century philosophy (Morris, 2008). Tillich (1962) holds the view that existentialism, as an expression, gave character to philosophy, art and literature during the period of the Great World Wars (1800s to 1940s), as this was a time of all-pervading anxiety and seemingly meaninglessness for all things human. The meaning of despair is interwoven in the meaning of man as man, his mortality and finality, and his estrangement. The etymology of the word despair is to be without hope. However, in the light of having to face
the experience of dying or being told that one is going to die in a few months or within the next year or two, Tillich (1962) contests that people experience the concept of dying differently. Once a terminal diagnosis has been shared between the patient and their family and friends, life becomes different.

Nietzsche, described as the most important of all the Existentialists, gives a description of European nihilism as he paints a picture of a world and human existence that has fallen into utter meaninglessness and despair with not a hope in sight for many of the world’s people. Sartre, on the other hand, is noted for his work and themes on our “ultimate freedom of choice”, ascribes to the ideal of “acting in good faith as an existential honesty” (Woodruff Smith, 2007, p. 408). As with much of philosophy there is a great deal of cross pollination with regard to existentialism as to who developed the idea in the first instance. As the philosophy was introduced touch by European philosophers, particularly German philosophers such as Husserl (1913) and then Heidegger (1962), it is thought that Sartre went on to develop his theory of existentialism. Foucault (1971) and Derinda (1981) separated it yet again from Sartre to continue on with the European and continental tradition and flavour (Woodruff Smith, 2007, p. 409).

Sartre (1948; 2001) writes that existentialism comes before our essence as an ‘atheistic’ existentialist where man exists first and foremost. That “man simply is” and “man is nothing else but that which he makes of himself” (p. 28-29). He describes man as a subjective being and responsible for his or her being. Unlike a stone or a table, a human can propel themselves into the future. Humans are not made of just matter, but of substance and can implicitly and explicitly make their way in the world (Sartre, 1948, 2001. A stone cannot choose to shift itself to someplace else unless by a force of nature such as a land slide, earthquake, the human hand or a shifting water course but man invents his or herself by taking certain courses of action (Morris, 2008, p. 34-35).

Sartre describes man not having a predetermined human essence. There is no recipe of how humans are meant to be, unlike a fruit cake. If the stated recipe is followed, then we should be able to predetermine what the cake is going to turn out like. Human nature is not fixed, nor is there an apparent ascribed prescription for how we will “turn out” apart from our pathophysiological being that is decided by our genetic heritage. Obviously this philosophy does not fit well within the doctrine of man’s imagination in relation to Christianity. “Our essence would precede our existence because the idea of what we are would exist in the mind of God
and predate our existence and if Sartre is right then this theological view must be false” (Priest, 2001, p.25) Loosely interpreted, existentialism is said to be about optimism and a “doctrine of action” (Sartre, 1948, 2001, p. 46). Humans are shaped initially by circumstances and also by our own free choice:

He [man] realizes himself in realizing a type of humanity- a commitment always understandable, to no matter whom in no matter what epoch- and its bearing upon the relativity of the cultural pattern which may result from such absolute commitment” and “man is nothing else but what he purposes, he exists only in so far as he realizes himself, he is therefore nothing but the sum of his actions, nothing else but what his life is (Sartre, 1946, 2001, p.36).

There is not the space here to debate the history of modern existentialism in this thesis but it became apparent that existentialism could not be regarded as the final word (Bollnow, 1974). Marcel (1951) tried to pull this philosophy from “the solitude of existence” where he believed that a meaningful life within the confines of existentialism was not possible. He writes that all people “engage in our existence; it is not in our power to step out of it” (p. 39). Marcel distinguished explicitly between his own position and that of existentialism. He had us believe that anxiety is at the centre of Kierkegaard (1844, 1980) and Heidegger’s (1962) philosophy. He insists that “anxiety is always an evil…it keeps individuals from giving themselves unselfishly to their fellow-beings” (p.38).

He wrote that anxiety “renders us egoistic” or totally self-centred and unavailable and that “the misery of the believers in existentialism could only be saved by way of reflecting on hope and joy, instead of deep seated anxiety” (1951, p.38). Marcel recognised quite early in his philosophical writing of the metaphysical importance of joy. “The truly genuine radiation of being… it reconciles us with life and the world” (1951, p.39). For Marcel, the fundamental presupposition of a fulfilled human life is “hope”. He can be seen as dragging the depressing works of some of the German philosophers into more happy and hopeful works of prose.

**Marcel’s theory of hope**

Illnesses can make us focus on ourselves to the extent of being into ourselves “the unavailable man does not want to go beyond himself” (Marcel, 1951, p. 188). The hopeful man is always open and available. Availability can be seen broadly in the context of “the temporal character of human life” (p. 188) and this is where Marcel’s philosophy points to
hope as the sustaining foundation of life where it unfolds in accordance with its distinctive nature. Much of his work on hope comes from *Das Prinzip Hoffnung* (Bloch, 1959). First published in German by Verlag in 1959 and further translated by Ernst Bloch (1986) into English in three volumes as *The Principle of Hope*. Marcel’s entire philosophy is grounded in commitment (*engagement*) and in an important passage in *Homo Viator: Philosophie der Hoffnung* (Marcel, 1949, 1951). He distinguishes between two forms of hope, namely an absolute ‘I hope’ and an ‘I hope that’ (p.43). His uses of the word unhope is a word he coined from Thomas Hardy. Hardy used it in one of his poems where he excellently expresses the state of someone’s soul “black is night’s cope; But death will not appear. One, who past doublings all, waits in un-hope” (*In Temebris*, 1880, 1984).

Bollnow’s (1969) interpretation of anxiety is the “the nothing, the uncanniness of the world itself, that comes to light in anxiety” (p.189). Where fear tends to broaden into uncanny anxiety, hope tends to crystallize in concrete forms and defines itself in terms of them. Kierkegaard (1984, 1980) makes another different comparison between fear and anxiety. Fear can be portrayed as being fearful of something or someone. People, on the other hand, are not able to specify an anxiety. Where the first form of hope “an absolute ‘I hope’ is restricted by aiming at a particular idea, or by allowing itself to be hypnotized by it; the second form ‘I hope that’ exceeds the imagination and determines that I abandon the attempt to imagine what I hope” (Marcel, 1949, p. 60).

It is not only a juxtaposition of the two forms of hope, but also a relationship between false hope and true hope. Marcel describes this as a person clinging to a certain idea as “a paralysis of the soul” (1949, 1951). He is of the view that a person should overcome the enticement of false hope in order to attain genuine hope. He uses the illness of a person to illustrate his point when he states “so long as he clings to the idea that he will be well by a certain time, he can be disappointed if things do not work out as he has imagined them” (Marcel, 1949, 1951, p. 189). He asks that there be a purification and transformation of a person’s inner attitude where everything is not lost even if the person is not fully restored back to full health. It is this “somehow” sustained by an all-encompassing presence that becomes part of the innermost nature of genuine hope (Bollnow, 1974, p. 190).
Truth telling and the possible destruction of hope

Being clinically deceptive to protect a person’s circumstances has been considered a necessity within the realms of medicine since the time of antiquity (Jennings, Baily, Bottrell & Lynn, 2007; Toscani, & Farsides 2006). In the 1930s truth telling was considered noble but a Pollyanna or utopian act that was seldom carried out because of the mantra of doing no harm (Henderson, 1935; Toscani & Farsides, 2006). Juth & Munthe (2006) purports that the less people know about their disease process the less likely they are to interfere with the natural progression of the illness path. A person’s ethnicity, religion and place in the world all have a part to play when or if accurate disclosures or beneficent withholding happens when they are diagnosed with a terminal illness (Hofmann, Wenger, Davis, et al., 1997). Pope Pius XII is reported as saying that even if physicians were asked to tell the truth, in many instances they would not communicate the bad news because he contested that often patients were not strong enough to bear truth-telling (Toscani & Farsides, 2006).

Clinical deception is still defended as the result of the consequentialist perception truth-telling causes both harm and the abandonment of hope (Mosconi, Meyerowitz, Liberati & Liberati, 1991; Toscani & Farsides, 2006). Conflicts arise between issues of modern and common sense morality shared by both medicine and the public, depending on values and mores. Gordon (1990) describes non-disclosure as a ‘major mechanism’ for keeping terminally ill (the condemned) in some other place or social world, and death in the ‘other’ world. Informing a patient of cancer means condemning or forcing them into what Gordon calls a social death (p. 275).

Kant’s (1781, 1954) philosophy is built on truthfulness as being the absolute virtue for all rational beings, as he distinguishes between knowing the truth and understanding what to do with that knowledge. It was his analysis on the idea of duty that bore more significance than Aristotle’s notion of happiness. His famous maxim ‘ought implies can’ means one must to be free to perform one’s duty or speak truthfully (Husserl, 1913). This however, is strongly entwined with acting autonomously. As he argues in Critique of Pure Reason:

> the autonomy of will is the sole principle of all moral laws, and all duties which conform to them; on the other hand, heteronomy of the will not only cannot be the basis of any obligation, but is, on the contrary opposed to the principle thereof, and the morality of will (p.43).
But what of the question of religion? Despite teaching that death is an important transition from one life to the next the Catholic Church holds contradictory views on truth-telling, relishing and cherishing “illusory safety” (Toscani & Farsides, 2006). Letting a patient hope might be a good thing, but going beyond illusion could take that person to a different type of hopeful place. Truth and faithfulness however, give loyalty and soundness to any relationship, particularly to the doctor patient association. Toscani & Farsides (2006) provide a version of a contemporary Catholic variation on truthfulness when telling a patient he or she is dying:

- The truth is essential to the patient in order to be prepared for death, and thus, must be told;
- The truth is the endpoint of a relational process between doctor and patients; and
- The truth (in the case of bad news) must be told gradually in order to preserve hope (p.W13).

Thus, disclosing dire news is generally left to the ubiquitous doctor if he or she has the time or skills to undertake this unenviable task (Toscani & Farsides, 2006). However, in reality, the ‘single physician’ is generally a figure of speech because when a person is diagnosed with a life-limiting illness, a multi-disciplinary care approach means that many people care for one person. So the teller, who is metaphorically charged with having ‘the’ talk, may not be present during pivotal points along the trajectory of a person’s cancer continuum. This can lead to misinformation or constant second guessing by family and friends. The literature argues that fostering hope improves a person’s quality of life and supports the attainment of goals and desires (Lin & Bauer-Wu, 2003; von Roenn & von Gunten, 2003). Anecdotally many people cope and have the ability to sustain hope by making plans and setting future goals, whatever the term ‘future’ means for a person who has a terminal diagnosis, when they are told the truth (Gordon, 1990).

If the definition of hope that people ascribe to is as the Oxford English dictionary (2009) states “expectation of something desired, a feeling of expectation and desire combined” or some other description such as “trustful expectation of something one is sure of, or wishes him/herself, is her/his own good, or of something one wishes will happen according to her/his own desire” (Toscani & Farsides, 2006, p.W14). They are both about reality and rely on
Kant’s virtue of ‘ought’ to tell the truth even if it causes angst, sorrow and hurt (1985). By giving someone the benefit of truth-telling about their prognosis this can contestably facilitate the principal notion of hope. Once the shock and hurt have diminished, realistic and achievable goals can be realized in order to achieve a ‘good death’, where everyone lives in the world (Gordon, 1990; Toscani & Farsides, 2006).

Behind full disclosure are matters of autonomy. Fudging of the truth or kind deceitfulness inhibits the self-autonomous person. Dworkin (1988) writes that “autonomy is not just a good thing but it is the best thing that a person has” (p.3). This autonomy equates with dignity, integrity, individuality, independence, responsibility and self-knowledge but you can have none of these things if you are blinded by kindness, because of illusory safety that you might not cope. A terminally ill person cannot make the right choices if they are not armed with all of the tools to support them through their future (Christman, 1991; Gordon, 1990).

The hopes of others
Flemming (1997) concurs that one of the greatest global influences when a person is diagnosed with terminal cancer is that hope is maintained by nurses and the medical staff by ‘being there’, or keeping optimistic expectations alive and showing an interest in that person. The principle of putting in time and being truly present can inspire hope within patients living with a life limiting disease (Kodish & Post, 1995). While a clinician continues to actively treat a person’s symptoms, a positive future still exists for that person in their mind. Conversely, any individual that holds the balance of power or who has the power to inspire hope can bring about a loss of hope, either temporarily or permanently (Flemming, 1997).

Clavarino et al., (2003) write that positive illusions, hope, optimism and despair are all related to a person’s fundamental need to live, the will to live or the need to be alive. Schopenhauer (1907-1909) suggests that most men are destined to strive towards survival or fight for the right to live. Field & Copp (1999) and Schou (1993) report that participants from their studies believe in curability, will-to-live and subjective well-being some three months after being given a life-limiting diagnosis. As death approached the participants who were followed further along the illness phase found that their concepts of hope changed, but as minimal changes were observed during the middle phases of the terminal disease. Mackillop et al., (1988) state that despite being told their research participants were dying, optimism
was a way of practical response to “the demands of a need to cope with living despite an awareness of dying” (p.356).

Wong (2007) writes that “hope is vital for patients’ psychosocial, emotional and likely physical survival” (p.145) and Groopman (2004) contests that without hope nothing can begin, and with hope a person has a chance to reach a better end:

> I would posit that the words spoken and the gestures made by physicians and surgeons, and nurses and social workers and psychologists and psychiatrists, and family and friends, influence the synaptic connections. No one should underestimate the complexity of factors that coalesce in this biological process. But I interpret it to mean that no one is beyond the capacity to hope (p. 190).

The hope model suggested by Wong (2007), as a teaching tool for health professionals enable them to “envision patient’s hopes beyond the biomedical frame of reference” (p.130-152).

- The hope for a cure remains a pervasive hope throughout the disease process
- As the disease progressed a person’s hope shifted
- The hope model acknowledged the patient in context of body, mind and spirit
- Despite hope not being a linear process Wong’s framework implies that hope is psychodynamic
- Hopework focuses and shifts towards ‘realistic’ hopes when cure is no longer viable
- Coping through viewing life incrementally and focusing on relationships was more valid than hoping for tangible objects
- Enjoyment of day-to-day and moment-by-moment improved existential and spiritual connections
- Hopework and hope interventions often occur in the transitions ‘in-between the lines’ along with changes in the disease process.
Summary

Hope has been described as a multidimensional dynamic life force characterized by a confident but uncertain expectation of achieving a future good (Hampshire, 1966; Lam, 2003) and the degree of hope a person possesses can be inextricably linked to help and caring (Forbes, 1994). We are born, develop into adulthood, obtain employment, pay taxes, age, and then we die, in the expectation of that order. However, death has been discussed as a series of preventable diseases and sometimes it appears optional when people have a terminal illness. It is not if we are going to die, but it is when and how, and what part hope plays during our final demise.

The writers and thinkers of the philosophy of hope as discussed earlier, make us consider what this vexing verb or noun is and what effect it has, particularly for those people who are dying. While Schopenhauer (1907-1909; 1970) wrote about the concept of ‘willing’, he failed to mention hope, except in passing (1918, 1970). Gabriel Marcel (1949, 1951) recognized early in his philosophical writing about the importance of joy. “The truly genuine radiation of being... it reconciles us with life and the world” (p.39), for Marcel the fundamental presupposition of a fulfilled human life is “hope”. Marcel’s theory of hope was that because illnesses make us focus on ourselves, the hopeful man is always open and available or receptive to things. It was his relationship between false hope and true hope that makes his work important to this thesis. Marcel describes this as a person clinging to a certain idea as “a paralysis of the soul” (1951). He is of the view that a person should overcome the enticement of false hope in order to attain genuine hope.

Frankl realizes that he has nothing to lose except his naked life in a life where hunger, humiliation, fear, deep anger, anxiety are rendered tolerable by the images and thoughts of love ones, either on the inside or outside of Auschwitz (Allport, 2004, p. 9). By religious faith and hope, the central theme of Frankl’s existentialism becomes apparent: to live is to suffer. To survive is to find and make meaning out of the suffering (Allport, 2004). He makes us think about the importance of hope. This literature review confirms that there are many and varied definitions of hope and the presence of hope is synonymous with a personal future that a person believes that they have (Cutcliffe, 1996). It would appear that one of the greatest global influences when a person is diagnosed with terminal cancer is that hope is maintained by nurses and the medical staff by ‘being there’, or keeping optimistic expectations alive and showing an interest in that person (Flemming, 1997). Wong found that hope was contextual,
spiritual and it was whatever people said that hope was (2007). Groopman's work can have the last word on how necessary it is to hope as he sees it at the very heart of healing and for those who have hope it may help them to live better lives. It is connected to "unalloyed reality" and he argues that it is as vital to our lives as oxygen (2004, p.214). Many thoughts have been spoken about hope and the terminally ill but there is a dearth of literature on health professional's concept of hope.

The next chapter looks at the bioethics of maintaining hope within the context of having a life limiting illness. Is it right to offer patients more and more treatment options just because health professionals can or want to and the person wants this? The first part of this chapter provides examples of ethical issues that pertain to the right to live or die and who should decide. It is a good point within the thesis to examine the doctrine of double-effect as it is sometimes cited as being the potential maleficent aspect of harming some to benefit the greatest number within community.
CHAPTER THREE       BIOETHICS AND HOPE

Introduction

In this chapter I will discuss the ethics surrounding hope as being either an essential or an accidental by-product of medicine and consider if hope should be accommodated within moral ethics. As part of understanding medical ethics, it is important to consider why people choose to have life threatening medical treatments when they have a life limiting disease in the face of so much medical uncertainty. I contest that it is important to understand all facets of hope and hoping, and this means examining why some clinicians appear to provide seemingly hopeless treatments for people approaching death.

The meaning of bioethics

Philosophically, ethics is about the study of morality and moral reasoning (Nodding, 1986). Morality is said to be the product of hard-won wisdom and Anderson (cited Johnstone, 2009) writes that morals are not handed down but that they are “created by people out of the challenges of the time. The morals of today are not the morals of yesterday, and they will not be the morals of tomorrow” (cited Johnstone, 2009, p.123). Although bioethics is occasionally used in an ecological sense it is more commonly ascribed to ethical and moral issues arising from biology, science and medicine (Kuhse & Singer, 1999). The philosophical discipline of ethics is the study of how humans should behave or how to determine the right action to take (Kurtz & Burr, 2011).

One of the earliest forms of correct behaviour was that of virtue ethics based on the writings of Aristotle (384-382 BCE). He believed that everyone had a goal and that a person’s ultimate life goal was “happiness”. Aristotle argued that man would achieve “excellence in performing rational activities and excellence in choosing if he was happy” (1975, p. 6). Kurtz & Burr (2011) state that caring as a virtue could be considered “a mean between extremes on a continuum of attention to and feeling for others” (Kurtz & Burr, 2011, p. 251). Historically Nightingale’s Pledge identified with several virtues for nurses including obedience, purity, loyalty, and willingness to assume the handmaiden role to the physician (Davis & Aroskar, 1991). Modernity however has replaced some of those virtues with such things as assertiveness, critical thinking, loyalty to and advocacy for the client/patient (Benner, 1984; Kurtz & Barr, 2011).
Acting ethically has to do with “the target of action”, who or what are we interested in doing the right thing to, with or for (Kurtz & Barr, 2011, p. 250). The more common application of bioethics is in the field of health care and medicine. It is about asking what is the right, good or the best thing to do and what are our obligations to one another? According to folklore, bioethics came of age in the middle of the twentieth century when theologians, clergy, politicians, judges and philosophers appeared at the bedside to pass judgment on what had traditionally been the clinicians sole jurisdiction, that of making clinical decisions about the care of and for patients (Blake, 1983). At some point during the debate in relation to moral and ethical practices, certain behaviours were brought into question with regard to experiments and experimentation using human subjects for the purpose of data collection. One of the first centers for bioethics was opened in America in the 1980’s to philosophically and legally consider ethical issues that arose in the clinical setting.

Mary Beth Blake, a medical attorney for the University of Kansas Medical Centre, began to see a disturbing trend in that judges from Wyandotte County, Kansas, were being called to the bedside of dying patients to have certain medical decisions authorized (Blake, 1983). The patients in question had moved from active and aggressive treatment to palliation (Blake, 1983). Aggressive measures were no longer deemed appropriate and naturally clinicians began to feel apprehensive about decisions that traditionally had been theirs to make alone, being tested and sometimes interfered with by others. As part of the foundational experience that lead to a doctor, Karen Ritchie, a philosopher, Hans Uffelman and lawyer, Mary Beth Blake, establishing the Midwest Bioethics Centre now known as the Centre for Practical Bioethics (Blake, 2011).

Gillett argues that a sense of life is not just any sort of life with a right to live whatever condition that life might be in but as a person who Thielicke (1970) argues “can be addressed as you” (p. 17). A living person cannot just be a shell or “the empty shell of what once was human” or in a humanly context such as a severely and improperly formed human baby. Gillett (2006) talks about personal identity as being one of the factors that makes us who we are as people who are able to assemble living stories about ourselves (p.247). The questions that concern many ethicists are what it means to be human. Andrews argues “instead of considering the futility of the treatment, the burden of the treatment...Considered the worthwhileness of the patient and the burdensomeness of the patient himself” (Davis cited Andrews, 2009, p. 5).
Gillett (2006) ascribes to the notion that:

_As sense of life seems to embody the idea that the ethics guiding our mortal judgments should be developed in the light of a finely attuned sensitivity to the human condition and a nuanced view of contested situations rather than seen as instancing and applying ethical truths laid down in an extra-human domain somehow immutable and impervious to the particularities of human predicaments (p.244-245)._

Bioethicists ask questions in the context of medicine and draw on historical philosophers such as Plato, St Thomas Aquinas, Aristotle, Descartes, Kant, Mill, Schopenhauer, Wittgenstein and modern thinkers such as Rawls, Brody, Engelhardt, Singer, Beauchamp and Childress, Foucault, Pellegrino, MacIntyre, Gillett and many others to blend humanities such as medicine, nursing, law and philosophy together with humanistic studies, science and technology. Any advances in science and medical technology can and have had an impact on how we experience the meaning of how we live and issues surrounding health and illness (Kuhse & Singer, 2000).

A person’s lived experience is another acknowledgement of personhood as an active, interactive and essentially cognitive being that displays intentional actions with and towards them and others around them (Gillett, 2006). Aristotle wants us to believe that the human soul is a set of functions, capabilities between brain functionality and the reliability of “a unique psychological being.” Thus, the soul of a person in a permanent vegetative state can no longer support the life of that person, therefore the notion of being person “as a person is ended” (Gillett, 2006, p. 247). Life means more than just being a human. Campbell, Gillett and Jones (2005) ascribe to the notion that “the ethical responsibility of the health care team is to make the best decisions they can in the face of medical uncertainty about the unfolding clinical reality (p.12). Gillett (2006) also writes in a later article “Our ethical worries reflect, in part, the widespread and rationally unsustainable belief that life is to be saved at all cost, coupled, for some, with the view that beginning treatment and stopping it is worse than not beginning at all” (p. 251).

**Ethical responsibility in the context of hope**

As part of understanding medical ethics, it is important to consider why people choose to have life threatening medical treatments when they have a life limiting disease in the face of so much medical uncertainty. At the start of this thesis I became interested in understanding
why patients choose to undergo very dangerous and life threatening operations, such as a Whipple’s procedure to gain a few months dogged with serious side effects in the name of something as vague as hope. I was interested to understand bioethically what sustains and stimulates a patient to keep on accepting surgery, radiation and chemotherapy from his or her clinician. Some notable cases will be briefly discussed to look at whether hope has a role in medical ethics and when medicine is pushed to the limits in an effort to cure someone.

In a reaction to such events as the Unfortunate Experiment (Bunkle & Coney, 1987) and a case in which a melanoma was transplanted from a daughter to her informed mother the concept of what it means to create hope has been put under the microscope for both doctors and patients alike (Kodish & Post, 1995). In the case of the transplanted melanoma, the daughter was dead a day after the transplant and the mother died from metastatic melanoma 451 days later (Kodish & Post, 1995). At its very worst, hope has been used to carry out experiments that ethically are reprehensible. Hope has provided the justification for paternalistic ‘fudging’ of the truth and misinformation such as in the case of the transplantation of the melanoma (Kodish & Post, 1995). The procedure was carried out “in the hope of gaining a little better understanding of cancer immunity and in the hope that the production of tumour antibodies might be helpful in the treatment of the cancer patient” (Kodish & Post, 1995, p.1818).

Generally, when judgements are made about a particular treatment or care plan, the health professional’s own moral principles and philosophies are taken into consideration. If someone asks me to harm them, this would be wrong and against the law (Audi, 2007). Similarly, if I purposely neglect or cause another person unwanted harm it would be more wrong than if I neglect or harm myself. Warnock (1971) believes that “the object of morality is to better the human predicament” (p.26) but before we consider more fully common-sense obligation and ethics such things as utilitarianism and consequentialism must be discussed. John Stuart Mill, considered to be the greatest English nineteenth-century philosopher, writes about utilitarianism as choosing “that act from among your opinions which is best from the twin points of view of increasing human happiness and reducing suffering” (Audi, 2007). Utilitarianism is concerned with maximizing the greatest good. The consequences of an act are generally considered to be characterised as a certain type of view-point and utilitarianism deals with the relationship between an act’s rightness and its consequences. The ‘right’ act
must optimise the greatest happiness for the greatest number whereas act-utilitarianism can be described as the greatest good for the most number of people (Audi, 2007).

The idea that the rightness of an act depends solely on its consequences can be completely separate from the idea that the rightness of an act depends on it having the best consequences at the end of the day. “An act is right from an ethical point of view if, and only if, the sum total of utilities produced by that act is greater than the sum total utilities produced by another act the agent could have performed in its place” (Bentham, 1823, 1907, p. 1.1). Consequentialism involves the claim that the rightness of acts depends on whether the consequences are good enough in certain circumstances together with the particular view that only the best possible is good enough. This approach has an Aristotelian component, where Aristotle determined kinds of acts that express virtue. For example, you would feel compelled and obligated to help an injured person rather than keep an appointment with someone or on the way to meeting your friend for coffee if you come across a collapsed person on the street. You might be more strongly obligated to help the collapsed person than meet your friend for coffee (Audi, 2007). The major determinant of an ethical decision is that it “provides the most benefit to the most people or the least harm to the fewest people...the decision to act must be based on a careful examination of all possible actions in the situation and the possible consequences of each action...regardless of consequences, actions themselves must be deemed ethical” (Kurtz & Burr, 2011).

Ethical decision-making is based on the particular values nurses have acquired as individuals and nursing obligation-based ethical behaviour draws upon consequentialist theory from the four principles of beneficence, nonmaleficence, autonomy and justice (Hartrick, Doane & Varcoe, 2007). Obligation-based ethical behaviour and codes have evolved over time as a paradigm to reinforce certain professional behaviours such as the culture, beliefs and duties of nursing (Hartrick, Doane & Varcoe, 2007). Common-sense ethics and nursing obligations focuses on the right and wrong action for what and how we care for people within a nursing context. This assumes that there is a definitive right or wrong response to a given situation. However, the obligation to do no harm is a significant ethical mantra that is inherently part of nursing training and all health practitioners practice (Hartrick, Doane & Varcoe, 2007).

In medical ethics the doctrine of double-effect is sometimes cited as being the potential maleficent aspect of harming some to benefit the greatest number within the community
(Boyle, 1991). Peter Singer (1993) considers the idea of allocating resources to treat patients on the grounds of utility. Treatment would not be given to a person at the expense of others thus allocating limited resources to those deemed medically curable or with more potential to survive (1993). Philippa Foot (1977, 1978) argues that the double-effect doctrine should have a built in proviso when clinicians are morally obligated to help someone. This proviso would allow clinicians to withdraw care where the cost to an organization or company is too great.

The sanctity of life ethic and the terminally ill
Before the 1980s many cancer sufferers were not told the truth about their diagnosis or prognosis (Callahan, 1998; Toscani & Farsides, 2006). They were often unable to make arrangements or say goodbye properly. This lack of disclosure left others holding the greatest secret of their life. In most cases they would know that they were dying when they looked in the mirror, at least in the physical sense. Hope was never taken away from them but they often never had an opportunity to hope for other things.

The ability to keep people away from death has bought the sanctity of life ethic to its knees (Singer, 1995). The issue of allowing people to die because they are in a persistent vegetative State was considered to be an abandonment of traditional ethics but, at the same time, was considered to be one of the great bioethical milestones (Beecher, 1991; Singer, 1995). A competent person has the right to reject treatments or put in place an advance directive, tenuous as it might be when the time comes. Similarly, this does not mean that a patient can demand a treatment that is not being offered (Cantor, 2001). However what about continuing to request treatment when the outcome is bleak or when someone has a reduced quality of life?

Philosophers in general are interested in what is it that gives life its value and choices between life and death (Boddington & Podpadec, 1992). Kuhse & Singer (1985) argued that medical expenditure and resources are more effectively used on those who are perceived to have a higher measure or a greater quality of life (p. 143). However, Landesman (1986) recognized “that the process of defining quality of life and personal life satisfaction is likely to be fraught with difficulties and disagreements” (p. 142). We have attached meaning to quality of life by allowing people who are considered less than perfect, with limited or minimal cognitive abilities, to die because they are not considered to be human in that their spirits have left them and all that remains is the shell of a body (Davis, 2007). The ground
becomes more unsteady and unstable when value of life “has to be attached to some concrete aspect of an individual” (Boddington & Podpade, 1992, p.216). This would mean that philosophically we have to place a stick in the ground and decide, like drafting sheep, which sheep will go in the ‘to live’ yard and which will go on the truck to the freezing works. The irony of this analogy is that the healthy lean lamb goes to slaughter while the others might get turned out to a paddock.

Thomas Sowell (1987) offers an example of “unconstrained vision” (p. 8ff) because there are often no limits to what can be hoped for and obtained or sought after (Callahan, 1998). First world countries have the unenviable image of progress – there are no limits or set boundaries to what people and communities can desire nor facilitating those hoped for treatments, manpower and equipment in the name of modern medicine (Callahan, 1998). The challenge for clinicians and ethical caring is to find a fountain of hope that is not dependent on satisfying unquenchable wants (Callahan, 1998). Once we acknowledge these limits it is important to “recover a more vigorous form of hope, which trusts life without denying its tragic character or attempting to explain away tragedy as a ‘cultural lag’” (Lasch, 1991, p. 43). Callahan (1997) asks can we live without “unbounded and limitless hope...the form of hope inspired by modern medicine” (p. 276).

**Foucauldian ethics**

Foucault’s (1983) ethics are said to be about how human beings “turn him-or herself into a subject” (p.208-209). This makes the central thesis of Foucault’s argument different than traditional ethics which is concerned with obligations to and about others (Prado, 2003), instead we “transform and modify ourselves to attain a certain state of perfection” (Foucault, 1997a, p.177). Foucauldian ethics is about deciding when and how to die, and considering if life is worth living (Camus, 1955; Prado, 2003). We are now in the invidious situation with modern medicine being able to sustain life when ‘normal’ survival would be impossible or not in a person’s best interest (Prado, 2003). Rachel (1968) distinguishes between *having life* and having a life, the difference between being biologically alive and living in a manner where a person achieves “aspirations, activities, projects and human relationships” (p. 5-6).

While we have the right to choose who should live or die when it comes to a person’s diminished ability to cognitively behave human-like with dreams and desires, Prado (2003) interprets scientific developments as clinicians being able to manipulate the terminally ill’s
life or death by enabling a “technologically sustained life or wholly dependent, pointless survival” (p. 209). Societies are said to becoming more resistant to squandering health resources on the sickest and weakest members with people choosing to die in a “timely” fashion adding a new dimension to Foucauldian ethics of forgoing life-sustaining treatment (Foucault, 1986).

There is a fine line however, between allowing someone to die from a terminal disease process than just letting someone die from a ruptured appendix. People, in most instances, are still able to choose to have radical surgery and or chemotherapy after being diagnosed with a terminal non-curative cancer because the treatment is available and the clinical relationships allows for care and attention to happen in a timely manner. But Salem (1999) argues that far from being self-actualized and self-determined by our ability to choose when and if to die, medicine and society have been given the “ultimate authority over this private and deeply personal decision...[the] medicalisation of a private act into a medical event” (p.30). Public health propaganda encourages people to immunize against deadly illnesses but there is a growing resentment surrounding the increasing use of health resources on the terminally ill.

**When dying becomes a medical dilemma**

Prado (2003) supports the notion each person is an individual and not a statistic, and therefore should be treated with fairness and justice, but Steinfels (1997) argues there is tendency to place a greater value on a person who lives autonomously and depreciate a life that is dependent on care. However, not all medical treatments are futile when patients have a terminal diagnosis. Should they receive immunizations or have their ruptured appendixes removed? The matrix of legal and biomedical ethics has evolved over the years in an attempt to justify medical inaction or actions where death becomes a consequence. There is a paucity of information regarding treating terminally ill patients for some other sickness than their specific terminal disease. With the advent of hospices as a place for the dying and for respite care for those referred, for symptom management, and expertise for those with terminal illnesses, another set of medical rules emerges.

Among these rules is the struggle to place people into specialties where they are unable to emerge from, such as palliative care. When moving for curative treatment to palliative care a person steps across a yawning divide of no return, in most instances, which reminds us of Habermas’s approach to rationality and modernity (Higgs & Jones, 2001). If you have a
disease that is terminal then why should you be treated for any other non-terminal disease process other than comfort cares? The struggle between rationing health care is ultimately a political conflict and a Habermas-influenced policy (Longino & Murphy, 1979) accepts that there is a need to reduce health expenditure for ‘undesirable’ people such as the elderly and those receiving palliative treatments so that a more equitable and ‘humanist health policy can emerge’. Much has been written about the futility of care and doctors deciding whether to treat patients or not but little has been said about caring for illnesses that a patient might benefit from, “a benefit, which the patient has the capacity to appreciate” (Schneidermann, Jecker & Jonsen, 1990, p.954-5). The benefit might be that a person will not die from a urinary tract infection if treated in the first instance but their terminal disease will ultimately end in death.

Health care rationing is not a new idea or phenomenon and has been present for a very long time however meeting infinite demands from cash strapped public health systems has become a defining issue (Harrison & Moran, 2000). Taylor (1995) and Scanlon (1997) have suggested that doctors should not have the exclusive right to determine what medical treatment a person should or should not get. Nurses are often at the forefront when discussions about the benefits and limitations of interventions are held for patients (Shotton, 2000). This enables the nurse to act as a patient advocate and support existential choices whatever specialty the person comes from. However, we know that medicine is steeped in charm, romanticism, barbarism, pragmatism and many other nouns. It has its own subtle culture that can be exclusive, sometimes only permitting language and perception in a guarded non-informative manner (Gillett, 1993) sublimely and subversively in certain healthcare settings. Along with this sometimes alien and multifaceted language there is a sense of ‘place’ and what is particular or peculiar to each medical area of expertise.

Our bodies and minds are carved up figuratively into specialties when there are presenting issues. An unfortunate inpatient may be housed in a ward dependant on an establishment’s agenda, the acceptance criteria and the attending clinician’s expertise. Despite modern medicine becoming more politically correct there is still a desire to domicile people by their medical conditions rather than using a first past the post system where people are treated by generalists instead of specialists. Mohammed and Peter (2009) define medical futility as “providing inappropriate treatments that will not improve disease prognosis, alleviate physiological symptoms, or prolong survival” (p. 295). But this narrowly defined classification places medical limitations on certain people within our society because
providing seemingly futile medical interventions “may cause moral distress to health care providers” (Mohammed and Peter, 2009, p. 295), and take much needed health dollars from one group of people and give it to another seemingly “deserving person” (p.295). When a person is referred into a hospice programme unfortunately the road can be precariously cambered and may cause them to drop into swampy grounds between hospital and hospice. Morally they should be able to stand in both camps with equal confidence and surety of being treated judiciously, without discrimination and not as medically futile.

Crossing the line between curing a benign illness and hastening death

Brody and Halevy (1995) have defined two types of medical futility: physiological and qualitative but a third needs to be considered and this I have called rightful care. Much has been written about futility in terms of final outcomes, worst case scenarios and finding an acceptance threshold to withhold or withdraw treatments (Rutland, 2009; Higgs & Jones, 2001). Rightful care allows the use of the moral philosopher, Margaret Urban Walker’s, ‘expressive-collaborative’ model of morality (Higgs & Jones, 2001, p. 143). Walker’s model regards ‘moral knowledge as a communal process that is constructed and sustained in interactions among people, rather than an individual action-guiding theory within people’. It is based on three principles: morality consists in practice, are practices of responsibility; and morality is not socially modular. It is about the distribution of fairness, of responsibilities and the structure of moral life.

We all believe that we have the right to go to any health facility and be treated if and when we choose or have it chosen for us. During a community witnessed cardiac arrest a debate about how much it costs to resuscitate the person is not had (hopefully). In England in the 1930s’ Beveridge anticipated that ‘the development of health and rehabilitation services would lead to a reduction in the number of cases requiring them (Musgrove, 2000, p.845-846).’ Numerous commentators have used Beveridge’s example today to draw attention to how he believed that improvements in health resulting from better health services would rapidly result in a reduced demand for health and welfare services and hence bring about a declining burden on the exchequer (Musgrove, 2000). However, the reverse happened and demand continued to increase so much so that there were serious expenditure crises within Britain’s national health system (NHS) (Jones & Bourne, 1976, p. 92). In 1961, Powell, the British Minister of Health spoke of Beveridge's expectation of declining costs as ‘a miscalculation of sublime dimensions’ (Jones & Bourne, 1976, p. 92).
Yet the Beveridge fallacy continues to capture the imagination of those who believe that health care should be rationed and given to those most likely to survive and be productive human beings. Conversely there are those who believe that everyone should have whatever is available at any time or place. We often seek an account of why and whose life is valuable leading us to examine what makes life worth living and be of an acceptable quality. If we are not careful, there could be a tinge of ‘Nazification’ creeping into the medical profession if assumptions are made about attributing values and quality of life to human lives because they happen to be members of a particular race. A balance must be achieved between what can be rightfully called active treatment and obfuscation, ‘fudging’ the truth, or coercion, because a clinician is unable to stop or say ‘no more’ to continuing expensive chemical therapy. Just because ‘we’ can do surgeries on terminal patients does it mean we should? When is it alright for someone to die from their disease process? Individual clinical decision concerning technical and expensive procedures, thankfully are offered for a variety of reasons and until we are faced with a terminal illness then it is difficult to create a sound argument for or against treatment modalities.

**Narrative ethics**

Within the context of *hospital* a person enters sickness singularly and this signifies uniqueness because no two situations are ever the same (Charon, 2007). It is argued that using narrative discourse and ethics, there is a general consensus and conviction that each person’s story of illness is fundamental to their suffering vis-à-vis the particular community with regard to a given situation, such as the community of oncology (Charon, 2007; Frank, 2004). Narrative ethics allows us to think with stories to understand how essential stories influence our lives within these communities (Frank, 2004). Stories encountered in the clinical setting can show us “complex moral dilemmas” from both sides with the patient empowered enough to control certain situations (Gillett, 2004, p.82). Brody (1994) is convinced that formal moral frameworks need to be supplemented with other ethical approaches based on interpretation and judgment rather than on formal deduction or empirical solutions. On the one hand formal ethics has a small number of very general principles or concepts that provide an ethical solution to an entire repertoire of ethical issues (Brody, 1994; Charon, 2007). Narrative ethics, by contrast, a) uses interpretation of the case and its meaning within a particular context and history, b) reasoning by analogy with other cases so similarities and differences can reveal a resolution to a particular case or situation (Brody, 1994, p. 209).
Narrative ethics offers the kind of knowing that the German neo-Kantians called *verstehen*—a powerful concrete rich sense of the feelings, values, beliefs and interpretations that make up the actual experience of the person who is working through a passage of health-related experiences (Abercrombie, Hill and Turner, 1994). This relationship works because of the mutual sharing that goes on between the clinician and the patient as they deal with the actual moment that reciprocity takes place (Brody, 1994, p. 447). Hartick, Lindsey and Hills (1994) describe this reciprocity as a mutual, collaborative, probabilistic, educative and empowering exchange of feelings, thoughts and knowledge between a practitioner and a person. Patience necessitates waiting for the right time for story telling because it cannot be forced or carried out at an inappropriate time. Narrative ethics attempts to change the patient-doctor or patient-nurse interaction from simply treating the illness to caring for the person.

**Microethics and the clinical encounter**

Cole (1992) provides evidence that spirituality and religious beliefs historically provided philosophical respite for those elderly and the dying that our secular and materialistic culture fails to accomplish. Cole (1992) adds:

*Buoyed by faith and the vision of life as a spiritual journey, early American believers had sought strength and personal growth by accepting frailty and decline in old age. Hope and triumph were liked dialectically to tragedy and death...A society overwhelming committed to material progress and the conquest of death abandoned many of the spiritual resources needed to redeem human finitude* (p.231).

There have been many accounts of patients who appear to die the “good death” that hold on to a measure of hope and a level of spiritual closeness, and narratives help to understand the “nature of a good death” (Schenck & Roscoe, 2009, p. 66). Narratives can become more than just words within words but day-to-day communication can become complex interactions where the nexus of subtle gestures and language nuances bring into focus an issue or issues. Within this context each patient’s dialogue at some point can be a reflection on an ethical problem that can only be revealed through this narrative dialogue. Understanding a person’s experience becomes important. Brody (2003) states that suffering is “produced and alleviated by the meaning that one attaches to one’s experience. The primary human mechanism for attaching meaning to particular experiences is to tell stories about them” (p.8). Wittgenstein
(1953) argues that to speak and understand language we must have an array of capacities to interpret signs in accordance with the rules – such as the language and rules that manifest from the doctor/patient relationship. Komesaroff (1995) calls this ‘micro-ethics’ and he uses it to describe the everyday ethical issues and decisions that can arise from the clinical encounter between a patient and a clinician. Micro-ethics interprets the experiences of each of the participants within any clinical encounter by tone of voice, mood, ideas and lived experiences that each person brings.

These narrative encounters show the reader or listener why certain pieces of information are important to try and redress, and refocus medical ethics on the needs of the participants within each clinical encounter (Wylie-Gibb, 2000). Komesaroff (1995) speaks about the relevance of micro-ethics “...in terms of relevance to the lives of ordinary people, micro-ethics is of pre-eminent importance” (p.70). He talks about it arising from each encounter between participants as being that of the patient and the clinician as between the “sufferer and skilled interpreter” (p.77). Wylie-Gibb (2000) asks us to consider a person’s narrative because hidden agendas often appear with careful listening and with beliefs, attitudes and personalities being revealed within the relationship (p.78-79). Callahan (1998) implores clinicians to engage in discussion using narrative ethics to openly discuss doing other thinks beside offering curative treatments to people who are never going to be cure and who are likely to die sooner than later. While Charon (2006) suggests that:

*Sickness opens the door to knowledge of one’s self and one’s values then a person who cares for the sick has to be prepared to midwife the life scrutiny that inevitably accompanies illness. We had to learn to listen to the multiple registers of the body, the self, and the storyline and how to respond ethically and dutifully to what we hear* (p.185).

Narrative medicine is said to build on the last forty years of medical reform, drawing from person-centred medicine, the biopsychosocial, and from the cultural studies of phenomenology, bioethics, disability studies, narrative theory and anthropological studies of cultural and political differences. So much so, that the future of healthcare policies have to find a way to include “the heritage of narrative medicine...in its internal medical reform” (Lewis, 2011, p. 19).
Summary

Bioethics came about because it was felt there was a need for an ethic that could incorporate our obligations towards each other and the biosphere as a whole. Philosophically ethics is the study of morality and moral reasoning as the product of hard-won wisdom. It is about asking what is the right, good or the best thing to do and what are our obligations to one another. Nursing care is about meeting obligations and being grounded in a humanistic value system and caring is about responding to what a person may become. Common-sense obligation provides a platform for us to promote the good of others; we are obligated to promote good, and trained to support patients to reach their full potential. Nurses have an obligation to provide timely and appropriate care supporting Warnock’s argument that the object of our morality is to better the human predicament of someone (1971). Common-sense obligation morality recommends non-malevolence from us but this is not the same as maximizing the good of something. It is about doing for others, having an obligation to do something, even when this might produce less overall good than certain alternatives like allowing people to continue having palliative care instead of active treatment. However, when patients and health professionals meet there are sometimes clashes between what is right and good for the patient. There are issues of fairness, worthiness, benefits versus societal costs and even clinical prejudices to consider. In particular, when a person encounters sickness and deviates from their chosen life path, empowerment is defined as the personal and political processes patients go through to enhance and restore their sense of dignity and self-worth.

Chapter four describes the methodology used within this present research. The research method of phenomenology and the work of Edmund Husserl (1858-1939) and Edith Stein (1891-1942) have been used to uncover and described systematically the lived experience of ten participants living with terminal cancer and the role ten clinicians play with regard to caring for terminally ill patients.
CHAPTER FOUR METHODOLOGY AND DESIGN

Introduction
This chapter provides an overview of the research process within the tenets of phenomenology. The participants, and the inclusion criteria, and the ethical approval process will be outlined. As part of the methodology, creating and interpreting a text will be described. Structural analysis was used to identify patterns of meaningful connection or the themes, which are reported in chapters five and six. In this chapter the research method of phenomenology and the work of Edmund Husserl (1858-1939) and Edith Stein (1891-1942) are described and the details of how they have shaped the study provided.

Aims and objectives of the study

- To define a concept of hope and how hope is perceived by both the patient diagnosed with terminal cancer and a clinician who cares and treats people with terminal cancer.

- To understand if health professionals even consider hope or is it more fundamental as having optimistic expectations for patients with terminal cancer.

- To develop a method of reading symbolic photographs in an attempt to analyse them as a trustworthy and authentic form of narrative data collection.

Sampling
A purposive convenience sample of ten participants were clinicians who had cared for and threatened those with non-curative terminal cancer to understand their trajectory of hope or whatever noun they used to express hopefulness across time. The second set of participants, also purposively sampled was living with a terminal diagnosis of cancer between the ages of 38 and 80 provided the data for in-depth interviews to understand their concepts of hope. Purposive sampling was used so that a selected sample could be identified which was ‘information rich’, consisting of people that had experienced the phenomenon of interest and were willing and able to articulate that experience concerning the concept of hope.
Participants

As indicated earlier, two groups of participants were invited to share their experiences. One group were clinicians who had direct care of patients with non-curable terminal cancer and included surgeons, oncologists, radiation oncologists, general practitioners, medical consultants, and specialist consultants. These participants were invited from the Southern District Health Board in Otago, New Zealand and the Central District Health Board in the Central North Island, New Zealand during June 2008 to November 2010 through a personal invitation letter sent to each potential participant. These were interviewed at a place and time that suited each of the clinician participants.

The second group of participants consisted of ten people who had non-curative terminal cancer. These were identified from within a particular district health board and during their patients’ appointment. A list of attending people was provided, these were approached and given an information sheet by a clinician, and if they indicated that they wanted to join the project then individual interview was arranged for each one. The researcher was given the names of potential participants and interviews were arranged with all those that chose to take part. There was no particular consideration as to the gender or the type of cancer the participants had, but they were purposely selected because they had a diagnosis of non-curative terminal cancer. All of the interviews took place at a time and place that suited each individual participant during the twelve months from June 2008 to June 2009. Both public and private patients were interviewed according to the following inclusion criteria. All the patient participants have been given pseudonyms to protect their identity and all clinician participants have been given an alphabetical title randomly selected (e.g. Dr B) to protect their identity.

Inclusion criteria

Part 1) Ten potential professional participants, who had direct contact with people who have had terminal cancer. The exclusion criterion was individual clinicians who were pediatric oncologists.

Part 2) Ten potential participants who had non-curative terminal cancer including but not exclusively lung, breast, bowel, prostate, ovarian, cervical, and bone or blood cancer were approached during outpatients’ appointments. Patients with brain tumors or brain metastases who were not lucid or were cognitively impaired were excluded. All the potential participants
were adults over the age of 18 years, whose first language was English, who were judged by the staff or family not to be imminently dying, were lucid and able to sustain a conversation for at least 20 – 30 minutes.

**Data Collection and research method**

Narration is one of the oldest forms of storytelling thus phenomenology, by its very nature as a theory or a research method, asks what is it to be human or enquires “what is the nature of human beings?” It is a science that questions how or in what way we experience the world in which we live as people (van Manen, 1991). The data collection aimed to draw the understandable meanings of the participant’s experiences and essential meanings or the ‘essence’ of the experience. Thus several broad questions were asked in an open-ended fashion with the desire of collecting information rich ‘snap-shots’ to understand if there were changes in hope across the illness phase. The outline of the questions has been described in the objectives of the study.

Herth (2000, p. 1405) talks of the multidimensionality of hope and describes several conceptual models, based on quantitative and qualitative findings, to help us understand the complex construct of hope. Research into hope has explored the experience of hope that involves the past, the present, and the future (Herth, 2000). However, the experience of hope over time remained under researched. Thus this became a focus of questioning and was addressed through interviews with people at different phases along the disease trajectory to understand how or if hope changes over time. To understand if hope has clinician support during the disease process, ten clinicians were interviewed.

A sample of the interview questions put to the clinicians and participants is shown in table 1 and 1a.
Can you tell me a little bit about your current medical practice?

Can you tell me your definition or concept of hope?

How do you maintain hopefulness when a person’s condition seems hopeless?

What do you tell someone when there is no more active treatment and how do you tell someone who wants the have treatments when there are no more treatment options to be had?

Do you believe that you have the ability to maintain or sustain a person’s hopefulness or hopes?

What is your thought on people using alternative therapies with little evidence to support their efficacy?

Do you have any particular faith, spiritual or religious beliefs and if so how does this influence your practice?

How do you support people who are deeply religious?

How do you keep yourself safe?

When do you think is appropriate to talk about dying?

Is it difficult caring for people who haven’t accepted that they are going to die?

What do you think about cure when that is all someone will talk about?

How do you help people who have unrealistic expectations or hopes?

What are your thoughts on alternative therapies?

Table 1: Questions for Clinicians
Can you tell me a little bit about your current medical condition and diagnosis?

Can you tell me your definition or concept of hope?

What helps you to maintain hopefulness when your condition could seem hopeless?

Do you believe that your clinicians help to maintain or sustain your hopefulness or hopes?

Have you considered alternative therapies?

Do you have any particular faith, spiritual or religious beliefs and if so how does this influence your life?

Do you have to support people close to you with regard to them accepting your illness?

How do you keep yourself mentally and spiritually safe?

Have you considered the possibility of dying prematurely or before ‘your time’?

Do you consider the possibility of cure when your clinicians are thinking about your illness as not being curable?

Are the things you hope for realistic expectations and achievable?

Table 1a: Questions for Patient Participants
In creating a phenomenon just a small snap-shot of the participant life at that particular point in time was captured while they were living with cancer or as a clinician. Heideggerian hermeneutic phenomenology presupposes prior understanding on the part of the interpreter, unlike Husserl who believed that we must leave behind any knowledge, or at least acknowledge (bracketing) and put it to one side before we start our interviews. Swingewood (2000) tries to interpret bracketing as a method whereby all ideas about the external world are consciously abandoned but we can never ‘unknow’ what we have learnt about life. As a researcher, I make explicit that I do not know what it is like to live with cancer but I believe that I have been able to stand outside the “research process and have assumed a scientific distance and objectivity” (Lowes & Prowse, 2001, p.471), as van Manen (1990) suggests we do when collecting this type of data. Complete bracketing was impossible because of my existing engagement in the world of some of the people living with cancer as a nurse. However, because at the point when I was collecting the data from the clinicians I did not have any notions or ideas about what their concept of hope might be, I could speculate or try to imagine but no literature informed my knowledge or thinking before I went into the field.

Phenomenological research is a qualitative method that allows for the examination of meaning, exploration, description and understanding of human experience (Dinkel, 2005). It is particularly concerned with delineating the psychological tasks that develop in interpersonal situations. Phenomenology is closely linked to the relationship between the researcher and the participants. It is not about seeking evidence first, as is the gold standard of most randomized controlled trials in quantitative research, phenomenology seeks to disclose the horizons or lift off the lid and uncover the presuppositions (Ray, 1994). These disclosures make prior understanding of Being as already present in the world. Heidegger (1962) refers to this as Dasein or the possibilities of Being in the world or being-there. Capturing the phenomenological nod is the object of this research project so that we might better understand what it is to hope with all one’s might when faced with the threat of terminality.

Bollnow (1974) believes that to produce an excellent phenomenological interpretive piece of scientific data the reflective process must awaken an inner moral impulse. The meaning is revealed by the examination of two processes of integral evidence (Ray, 1994). That is the evidence provided by the person who is engaged in first-hand experience in the world and that experience is deeply reflected and brought to our attention by the experiencing person.
Phenomenology makes explicit our being of and in the world, respectively (Ray, 1994, p. 131-132).

**Ethical Approval**

This research project was submitted to the Deakin University Human Research Ethics Committee, the New Zealand Multi-Centred Ethics Committee, Ngai Tahu Research Consultant Committee and a member of the Chinese community for approval. All issues relating to good conduct in research were addressed. Confidentiality and anonymity have been maintained by the use of pseudonyms or code names, although it must be acknowledged that some of the participants could be identified by their stories. Steps have been taken to minimize this and participants were also aware of this possibility prior to giving consent for participation in the study. Details of the participant’s medical conditions have been omitted, except to name the particular type of cancer (e.g. breast or lung cancer). All stories have been reported in such a way that they could relate to any number of people and places, but pertinent enough that the data collected provided insightful phenomenological data about the concept of hope. Each of the health professionals has had their particular type of specialty identified but only in broad terms. None of the photographs that have been taken reveals any personal information about the participants or where they live or work that could identify them. The photographs are symbolic gestures and metaphors.

**Data Analysis**

From an epistemological point of view, Husserl used applied phenomenology to understand knowledge and how evidence supports our judgments and consists of intuitive characters of certain experience. It is about catching those would be forgotten moments by bringing one person’s experience to the phenomenal present through a sort of act of appropriation which we all experience when we say we have ‘found’ the rabbit in the foliage of a puzzle. The actual process of data analysis clusters similar data that appears to get the phenomenological nod into themes (Streubert-Speziale & Rinaldi-Carpenter, 2007). A theme is used to describe a structural meaning unit of data that is essential in presenting these qualitative findings (Streubert-Speziale & Rinaldi-Carpenter, 2007) while remaining true to the essence of a certain type of experience (Flynn cited Merleau-Ponty, 1973; Marcel, 1951).

All taped interviews were transcribed verbatim and after reading all transcripts and field work notes I gained a sense of the whole text. Structural analysis followed as the second step and
this involved identifying patterns of meaningful connection or the themes. This step has been referred to as interpretive reading (Streubert-Speziale & Rinaldi-Carpenter, 2007). Van Manen (1990) describes the process of gathering themes in the basket of knowledge as "insightful invention, discovery or disclosure" (p. 79). Reading and listening to the participants' descriptions of their concept of hope resulted in time spent dwelling on the data until common themes or essences emerged. It involved a total immersion in the generated data to allow full engagement in this analytical process. Total immersion in the data is necessary to ensure a pure and accurate description (Streubert-Speziale & Rinaldi-Carpenter, 2007).

**Rendering the themes**

After each transcript was word processed and reread several times important and meaningful sentence were revealed. Mind maps were made starting with the doctors transcripts. I very broadly categorized concepts into hope, dying, hopelessness, hopeless, cure, faith, alternative therapies, coping, false or unrealistic hope and abandonment. Figure 5 is an example of one of the mind maps created.
I think to some degree you try and temper it. Although don’t try to kill it altogether

Well you can usually see when it is unrealistic

But I try and be nice about it and emphasize the things that could be done

Even if you don’t give them a seven week course of radiotherapy you might give them two weeks which might give them a little bit of benefit

Again it is emphasizing what one can do rather than what you can’t

I guess you just say but not gloss over it but not emphasize all that. Just try and bring out all the positive and put the plan of attack forward

Obviously you can’t do everything for everybody but there is a lot you can do for

Well I try to be honest but not absolutely negative

Obviously you do give bad news

Yeah it can be difficult and you do sometimes put on a bit of a front

With some people faith and hope will go together

But you don’t necessarily need one to have the other—faith/hope

I have run into people who have been strongly religious and have again lacked hope and have been quite negative about things

Figure 1: Concept mind-map
Hope is the essence of the human mental reactivation which basically motivates what we do.

In essence hope is the driving concept that when the chips are down there is a will to survive to live.

Hope is an inherent desire of the body to live and to maintain life which becomes the personal motivator and protector.

Hope is the one thing that they always, always hang onto.

Hope is to try and relieve pain in the broadest sense not only physical pain but also emotional pain as well.

Hope is preparedness to help patients just redefine their goals.

Hope is about just maintaining positivity towards life and those around them.

Hope is effectively around meaning and how it helps our lives feel good on a day to day basis.

But is about understanding where you are and finding in fact meaning so that whatever stage somebody is at there is always hope.

Hope is about going back to Frankl’s work and it is all about meaning effectively.

And Eric Erikson’s stuff so that hope is necessarily about survival.

Hope might be much more spiritual in a sense or place.

Hope is that there might be a positive outcome that is of importance to you tempered by the realization that it might not happen.

People probably appreciate having hope to hang their hat on and know that something is going to be done even if the chances aren’t that good.

Hope is about anticipation and wanting thing so go.
I don’t consider myself to be a hoper but a fixer

We have to find something else to hope for, like a comfortable death one without pain and suffering

I think a person’s faith has a lot to do with how hope works for each person within their particular culture

Hope is just what it has to be for each person and whatever social and cultural context that it has to be for each

People who are able to sustain hope it is a mechanism for maintaining their emotional equilibrium

The function that hope serves is to make life bearable for people

Dying people construct a whole process or a paradigm around hope that allows them to live in absence of distress or as close as they can to it

You can’t give people hope but you can help them to find it for themselves

I just can offer myself when there is no other curative treatment being offered and this gives hope

There is so much more that you can give and I think that by offering possibilities and offering yourself that people aren’t abandoned and feel more hopeful

My concept of hope is sort of that feeling of this is the thing that you are. It is almost like a wish. You are wishing that it would happen this way with the knowledge it might be that this is the ideal that you are going to work for or hope for.

I don’t really know how to describe hope without using the word

Hope is the feeling of trying to aim or wish for a certain ideal or situation

Everybody’s concept of hope is probably a little bit different in terms of what they see

Figure 2: Conceptual Graph
**Mind map figure 1:** is a small section of Dr X’s transcript and it deals with false hope, enhancing hope and concepts of faith and or religion. After each set of mind maps were completed – seventy in total, a global map was made that included each of the ten participant’s thoughts on hope and the nine other categories. The global map contained between six and ten sentences from out of each participants transcript on an A four size pieces of paper. It was a major mini mind map like figure five but included each of the participant’s significant phenomenal statements or sayings. A similar process was completed for the patient participants. It was very important to keep each cohort of participants separate so that I could clearly ‘see’ the themes without being hindered by mixing up the significant phrases from each group.

Then figure two is an example to how significant statements were taken to create a table giving each of the participants a colour so that I could still identify who had made each piece of conversation without having to code each statement. Each small statement became a box or a balloon of text and from each of those boxes of text conceptual graphs were produced (see figure 2). Sixty-six key statements had been collated about the participants’ concept of hope and from these it was possible to identify each of the above sentences as being very significant. These statements helped to get a better ‘fix’ on the significance of hope. Within that, as suggested by van Manen (1990), the idea of a theme was then put into its own thematic context (p.87). This process was repeated for the patient participants until each sentence was rendered and percolated down so that themes started to appear obvious. The collective mind maps were reduced to an A3 size piece of paper, an example of part of this is shown in Figure 3 from the clinician’s scripts.
I never consider hope as being part of my job.

I think that hope is for people to do peoples hoping for them.

Hoping is about anticipation and wanting things to go well.

I don’t consider myself to be a hoper but a fixer.

I cannot spend time thinking about a patient and what they hope or their hopes. I am an un-hoper.

We have to shift what we hope for, for that person.

No one model or word can describe hope for me.

Things are very complex, contextual, and relevant to what has gone on before an event.

Hope is just what it has to be for each person and whatever social and cultural context that is has to be for each person.

There are those who have no hope of living but then we have to find something else to hope for like a comfortable death, one without pain and suffering.

There are those who have no hope of living but then we have to find something else to hope for like a comfortable death, one without pain and suffering.

I think a person’s faith has a lot to do with how hope works for each person within their particular culture.

I think for people who are able to sustain hope it is mechanism for maintaining their equilibrium.

When you are totally accepting of the fact that you are dying then maintaining hope must become very important.

The function that hope serves is to make life bearable for people.

They construct a whole process or a paradigm around hope that allows them to live in the absence of distress or as close as they can to it.

If you are talking in terms of hope there is aspects of paternalism that affects that.

I think hope is one of those things that is probably pretty difficult to describe.

Everybody’s concept of hope is probably a little bit different in terms of what they see.

My concept of hope is sort of that, that feeling of this is the thing that you are. It is almost a wish, you are wishing that it would happen this way with the knowledge it might be this is the ideal that you are going to work for or achieve.

I don’t really know how to describe hope without using the word hope.

It is the feeling of trying to aim or wish for a certain ideal or situation.

It seems to be one of those things that can change as people go along more what they are hoping for rather than the concept.

I find hope really difficult to define actually.

There is so much more that you can give and I think that by offering possibilities and offering yourself that people aren’t abandoned and feel hopeful.

I just offer myself when there is no other curative treatment being offered and this gives hope.

You can’t give people hope but you can help them to find it for themselves.

You have aspirations and goals and I suppose that is hope and that is what sustains me mentally.

You can’t give people

You try and you can created an environment that allows people to maintain hope.

Figure 3: Collective mind-maps
Each transcript was reflected upon to determine significant phenomenon or if just a bit of incidental conversation had occurred. It is at this point that van Manen (1990) suggests that the use of free imaginative variation to verify whether a theme belongs to a phenomenon essentially or incidentally.

Phenomenology as a research design

Phenomenology is the activity of being in the moment, the study of consciousness from the first-person perspective. It is the science of the essence of consciousness as each act of consciousness is directed towards something or intentionality is at the centre of the essence of our consciousness (Husserl, 1907/1950 § 41). Empiricism has emptied or stripped bare the mystery about knowing by quantifying research so such things as sensation, feeling and judgment have lost their apparent clearness (Merleau-Ponty, 1962). Edith Stein described that the goal of phenomenology is to clarify and find the ultimate basis for all knowledge (p.3) but Husserlian phenomenology looks at more than this as it deals with the phenomena, how we experience objects in our consciousness and with our individual different ways of “relating” to these objects via intentionality. It also deals with how language expresses our thoughts, especially our theories about the nature of things (Woodruff Smith, 2007) and inter-subjective practices pertaining to culture such as communal norms, values, beliefs, morals and politics. It is defined by Husserl (1913/1982) as the study of “essence of conscious experience, and especially intentional experience” (p33-34).

Husserl did not see phenomenology as being about sensory experiences but as “addressing perception, imagination, desire, thought and so on, as we engage the world around us” (Woodruff Smith, 2007, p. 189). As a logician, Husserl’s systematic thinking could be divided up into logic, epistemology, metaphysics or ontology and ethics. A fifth area was phenomenology but his very logistical philosophical thinking moved him from logic to the philosophy of language, to ontology to phenomenology and then to epistemology (Woodruff Smith, 2007). The foundation of logic includes the semantics of how language expresses meaning and represents objects in the world especially truisms within sentences such as “that oak tree over in the field”. Husserl held the belief that logic was about ideal meaning, logical forms, semantics and entailments. He distinguished the sense of an expression with what it’s true meaning entailed or what it represented (Husserl, 1929/1969 § 83; 19/1, p. 359; Woodruff Smith, 2007, p. 51; Moran, 2005, p156).
Phenomenology requires researchers to abstract the structure and content of an experience from observation by our conscious thoughts so that we can reflect on their significant meaning before us (Woodruff Smith, 2007). Qualitative scientific knowledge uses a Kantian form of observation and Husserl describes this as a natural cognition that begins with “experience and remains within experience” (Husserl, 1913, p.51). It is distinguished from the natural sciences by suspending a natural attitude by maintaining a ‘transcendental’ or ‘phenomenological attitude’ or the science of essences (Russell, 2006, p.22). The complexity of his philosophy comes about because of his particular manner of starting a fresh with each new idea but taking it back to the beginning of his first notions of this new philosophy as it was back in the 1890’s. Husserl’s complex philosophy is like the flowering of the ginger plant you see in the photograph below.

![Fig 4 Torch Ginger 'Eilinger elatior'. Pink. Botanical gardens Darwin (Richardson, 2007)](image)

His work does not read like a novel as he takes the reader on a journey as each new idea is built on to make up the entire living flower of phenomenology. Here we see how each petal begins in the middle and is tightly held by the ones that come before and the ones after. Edith Stein (1916-1917) found this to be an incredibly frustrating aspect of Husserl’s work ethos as with each new piece, he always began at the beginning. At the beginning of his career Husserl took arithmetic and overthrew the fashionable psychologicist position that the foundation of arithmetic had at the time and instead, established the “anti-psychologistic, objective foundations of logic and mathematics” (Smith & Woodruff Smith, 1996, p.1). When he went on to become a phenomenologist he never lost the habit of working and reworking ideas as one does when working through a mathematical equation or formula (Woodruff Smith, 2007).
The inspiration of phenomenology indicates a transition period for Husserl between *The Idea of Phenomenology* and *Investigations* where a more radical Husserlian phenomenology was introduced. These new ideas included the phenomenological “bracketing out” (Nakhnikian, 1964, p.xiii), eidetic abstraction, the pure phenomenon, the different kinds of immanence and transcendence, and the theory about what constituted an object within human cognition (Nakhnikian, 1964, p.xiii). From his early work, the imminent-transcendent dichotomy moves through, on the one hand, the pre-critical dualism, “in me-outside me” and, on the other hand, “is the sense in which intentionally inexistent essences that are imminent – their imminence consists in their self-givenness to pure intuition” (Nakhnikian, 1964, p.xvi). Nakhnikian goes on to describe how Husserl refers to these intentional acts as transcendent because their nature and reality are seen as independent of their “being actually in commerce with mind via some mode of mental activity” for example things hoped for, being imagined, desired, believed and so on (Nakhnikian, 1964, p.xvii). But as his work matured Husserl moved through from phenomenology and transcendental idealism into a phenomenology of intersubjectivity and into *ontology* of the life-world that encompassed the social worlds of the culture and history of the day (Smith & Woodruff Smith, 1996, p.1).

**Bracketing**

*The actuality of all of material Nature is therefore kept out of action and that of all corporeality along with it, including the actuality of my body, the body of the cognizing subject...the thesis that there is a natural world of objects of consciousness (things in the surrounding world of nature) to our consciousness of these objects, regardless of whether they exist* (Husserl cited Woodruff Smith, 2007, p. 29).

Casey (1977) describes Husserl’s bracketing as a suspension of the ‘natural attitude’ or the suspension of the natural attitude of all aspects of the lived experience. “We must put out of play our natural and naïve belief in the independent existence of objects of consciousness, and this allows us to realize that the meaning of these objects can be made evident without reference to their being” (p.74). Our conscious mind can be persuaded to perform higher order judgments. Changing one’s mind is little more than a ‘thematic transition’ and is often involuntary or subtle (p.74).
In Husserl’s *Ideas* (§32) he explains his concept of bracketing the existence of the world as:

*We put out of action the general positing which belongs to the essence of the natural attitude; we parenthesize everything which that positing encompasses with respect to being: thus the whole natural world which is continually “there for us,” “on hand,” and which will always remain there according to consciousness as an “actuality” even if we choose to parenthesize it. If I do that, as I can with complete freedom, then I am not negating the “world” as though I were a sophist; I am not doubting its factual being as though I were a skeptic; rather I am exercising the “phenomenological” epoché which also completely shuts me off from any judgment about spatiotemporal factual being* (1913, §32:65).

Husserl’s desire was to get back to an object “to the things themselves” or how objects appear to consciousness. As a way of suspending beliefs, bracketing the existence of the world it allows a reflection of how things within the living world appear to one’s consciousness. Without entering any discussion about an actual object, Husserl was free to look for “limits of that object” and then move on to looking for the “essence, or for that which pertains in every instance of the consciousness of that object” (Parsons, 2006, p.77). Husserl’s use of bracketing is to take something away or put it in abeyance much the same as he dealt with mathematical formulae. He believes that the world did not exist and speaks philosophically of how objects are represented within our living world:

*Absolutely but only relatively in intentional relation to our conscious…any object in the world around us exists independently of our consciousness, but it exists for us – we know and experience it only – in acts of consciousness…the point of bracketing is to turn our attention from the objects that normally concern us to our consciousness of these objects, and to the meanings through which we experience them* (Woodruff Smith, 2007, p. 29).

Over time bracketing has often been quoted as giving a research project more rigour “specifically, the technique of bracketing is often regarded as a way of indicating scientific rigour in the phenomenological approach, yet a precise description of how it is achieved and why it is appropriate in individual studies has sometimes been overlooked” (Le Vasseur, 2003, p. 408). Power & Knapp (1995) believed the technique of bracketing is an attempt to withhold previous knowledge about researched phenomena and to put it into abeyance so as to distinguish it more clearly like the wood from the trees. Husserl (1929) speaks about our
conscious processes as being called intentional, but he believes that intentionality can signify nothing else than this universal fundamental property of consciousness. “To be consciousness of something; as a cogito, to bear within itself its cogitatum” (p. 33). Thus, our change in attitude to philosophical inquiry is reflected in the process of suspending opinion and prejudice to what is the actual essential attributes in the phenomena or lived experience. Consequently we have Husserl’s famous slogan “to the things themselves” (Woodruff Smith, 2007, p. 22).

It is this mental purging to unclutter the actual phenomena of lived experience and the cleansing the mind for the perception of meaning that Husserl called epoch (1929). This is a method of getting the mind to focus on or pay attention to the essences of something or “shifting attention to the actual phenomena in their intentionality and horizontality” (Le Vasseur, 2003, p. 413). By bracketing an experience instead of taking it away for the moment it enabled the formula within the brackets to have more meaning and substance. Husserl states that to bracket something can enhance and focus its structure of meaning (Woodruff Smith, 2007; Le Vasseur, 2003; Husserl, 1931, 1988).

It is from this stand point that Husserl’s bracketing heralds the arrival of “transcendental ego” and it is the conscious behaviour for the apprehending of the phenomenal experience that was devoid of any supposition and assumption surrounding personal history or the position in space or time (Lau, 2007). Here we see the distinction between an empirical ego and the transcendental ego “the purified phenomenal consciousness and the true location of the science of phenomenology” (LeVasseur, 2003, p.413). Husserl articulates that as being the difference between our everyday attitudes and our philosophical reflective and questioning point of view that supports the notion of bracketing. Le Vasseur (2003) proposes that we should consider bracketing when we are curious about something where we lack understanding around a subject and the very nature of investigation or inquiry temporarily suspends any previous suppositions. Husserl suggested this in Ideas I (1929) where he emphasizes a temporary suspension of prior knowledge but this is not as a permanent denial of them. Much of his work is misrepresented at this point when the phenomenologists who followed believed he was creating a separation of thinking consciousness from being or personhood (Wood Ruff Smith, 2007; Le Vasseur, 2003).
Creating a text

Creating a text puts a distance between the researcher and the narrator and allows time to discover the “existential structures of experience”, whilst at the same time distancing us from the rest of the world (van Manen, 1990, p.127). The researcher must become totally immersed in the language of those who own the experience, in the case of cancer and the clinicians caring for patients with the disease. Phenomenological writing allows the invisible that shines through and becomes visible (van Manen, 1990). It is the language bound up in what is said “in and through the words” (van Manen, 1990, p. 130-131). Phenomenological writing is like poetry because it is implicit silence that speaks to us.

Each person’s narrated experience is meaningful and human behavior is generated from and informed by this meaningfulness (Polkinghorne, 1988). Narrative meaning comes within our mental realm of reality and language enables us to understand narrations in new combinations and in new meanings (Merleau-Ponty, 1962). The meaning that a narrative conveys about someone who has cancer requires the use of discourse. Polkinghorne (1988) describes discourse as a unit of utterance that is something larger than just the words spoken in a sentence. He suggests that it is an integration of sentences that go on to produce a global meaning. James Kenneavy (1971) describes five basic discourse forms – referential, expressive, persuasive, narrational, and poetical.

Creating a text, states Polkinghorne (1988, p.130), “serves as a lens through which the apparently independent and disconnected elements of existence are seen as related parts of a whole”, and certain meaning is better expressed how I write than what I write (van Manen, 1990, 2001; Richardson, 2005). Ricoeur (1984) uses a process of opening up the text of experience to “see” the experience as it is in itself and to interpret the experience. By a process of what the text says in itself and what the text is about, the conscious horizon is expanded to appropriate meaning out of the text (Ray, 1994, p 129-130). Themes and meta-themes from the textual discourse illuminate the meaning of an experience as it is lived. Van Manen (1990) writes that “no conceptual formulation or single statement can possibly capture the full mystery of this experience” (p. 92).

Phenomenological reduction occurs after the audio tapes are transcribed, creating a text, and then analyzed to identify essential themes. Husserl (1907, 1950) and van Manen (1990) described essence as what makes a thing what it is (and without which it would not be what it is). The experience itself was then focused on to allow a description of the particular
experience to be constructed (intentional analysis). Van Manen, (1990) stated that “in determining the universal or essential quality of a theme our concern is to discover aspects or qualities that make a phenomenon what it is and without which the phenomenon could not be what it is” (p. 107). Thus, the process verifies whether the theme belongs to a phenomenon essentially rather than accidently or whether it gets the “phenomenological nod” (van Manen, 1990). The more vocative a text the more strongly the meaning is embedded within it, and the more likely that it communicates complex qualitative understandings.

**Interpreting the text: moving from field to text**

Interpreting a text means entering the hermeneutical circle to make sense out of what has been learned from the *art of interpretation* (Denzin, 1998, p.500). Moving from the field to the text and on to the reader is one of the most challenging parts of this type of research. Clandinin and Connelly (1994) have called this “experiencing experience”. When I read the text I hear the voices and nuances, I knew when tears were shed, and when extraordinary deep thoughts contributed to the making of a person’s in the moment story. The transcripts are able to transport me back to where I sat beside the participants and talked about their world. Aside from the words, laughter and tears I have remained faithful and honest to the text. As Sandelowski and Barroso (2002) observed:

> Scholars across the practice and social science disciplines have sought to define what a good, valid, and/or trustworthy qualitative study is, to chart the history of and to categorize efforts to accomplish such a definition, and to describe and codify techniques for both ensuring and recognizing good studies” (cited Rolfe, 2006, p.304).

In an attempt to discover textual descriptions there is a need to make a distinction between what is incidental and what are essential themes. As I listened to the interviews several times I made lists of themes that the interviews contained. At this point nothing was excluded. Cutting and pasting and a computer assisted qualitative analysis (Atlas ti™) were used to sort the material. Case study analysis also provided thematic analysis from a cross-sectional breakdown of the transcripts and field notes, which became an integral part of the research process.

Meaning emerges as the text and the interpreter engage in a dialogue, in a hermeneutic conversation (Koch, 1998). It is the intersection of horizons and where the reader and the participants create the meaning. It is the understanding, reconstruction, advocacy and
activism (Koch, 1998; Gadamer, 1976). Story telling provides a different or other understanding. Parse (1990) calls this “extracting essence” from the translated descriptions or the participant’s language. An extracted essence is a complete expression of a core idea described by the participant (p. 11). As alluded to, the essence of a phenomenon is never simple or one-dimensional and it is always communicated textually when the researcher engages in the reflective activity of thematic analysis (van Manen, 1990).

**Visual art: snapping the moment**

There are two types of humanities enquiry: one enumerates compares and contrasts, creates and tests hypotheses, reads literature and examines the minutiae of materials or systems of one set or another (Kellman, 2005). The other method is engaged in exploring the individual, the idiosyncratic, and the unique, the symbolic and the artful. It is the latter hermeneutic enquiry that can be used to describe how works of art express the lived experience scientifically. At the heart of the phenomenological approach is a critique of the subject-object split of scientific naturalism with phenomenology dissolving the Cartesian distinction between subject and object (Crotty, 1996). Artists have been called “transformers”, in that they symbolically transfigure the invention of symbols within each photo (Kellman, 2005). Critical reflection and action are combined to produce, creative and symbolism, style, (McMahon, 2003) and objects from the spoken words of each of the participants (Kellman, 2005; Zurmuehlen, 1990).

**Reading photographs**

There is a dearth of information on how to philosophically read a photograph especially when a mix of symbolism and object has been used to describe a moment or the phenomenological nod. Much of what has been written about using photographs as a research method relates to some form of therapy. Photography theorists purport that photo therapy works for their clients as the client gets a picture of their life that is worth more than the proverbial thousand words (Weiser, 2001). “As probably the most publicly familiar and emotionally powerful artistic medium, photography has evolved as a natural adjunctive tool to assist not only art therapists, but also for other counselors and therapists who do not usually involve the arts in their work” (Weiser, 2001, p. 10).

Individual photographs, or snapshots, permit people to explore important points of view (and secrets) using a predominantly nonverbal terrain usually in silence. Using phototherapy
clients are able to access information, feelings and memories that words alone cannot describe (Wagner, 2004; Weiser, 2001). However, in this study photography has been used merely as a vehicle for producing unspoken or spoken moments that occurred during the interviewing process. These are metaphors, an invented styles and symbols that occurred throughout the research process and interpretation of the text during the data collection.

**The photograph as some form of style**

The notion or concept of “style” is reported to be central to the philosophy of art history (McMahon, 2003). McMahon described the metaphor as being defined as a resemblance between two signs or images. These signs appear briefly to give credence to meaning through a new juxtaposition or an enduring image that runs through a work like a seam of gold (Derrida, 1930, 1982). Saussure’s theory on the metaphor has value and not just signification as its descriptive justification. The notion of value describes Saussure’s theory as; 1) of a dissimilar thing that can be exchanged for the thing of which the value is to be determined; and 2) of similar things that can be compared with the thing of which the value is to be determined (Derrida, 1930, p. 218).

Style has normally been used to describe particular periods of art fashion such as “Early or High Renaissance”, or the development phase in an artist’s oeuvre, for example Picasso’s Blue Period (McMahon, 2003, p.260) or “a set of formal characteristics that cuts across periods, movements, and individual oeuvres” (p. 260). McMahon calls this “Perceptual Style” (p. 260) and attributed it to artworks in retrospect. She also writes that an artist’s work contains “cognitive stock” where by the artist is contextually aware and living within art theories, histories, ideas and an interpretive period. The photograph, figure 5 called “Forever waiting” depicts an old fashioned telephone, heritage baby shoes, a bird of paradise flower and an open kernel from a large seed. This photo is representative or symbolic how many hours the participants from a previous study (Richardson, 2005) spent waiting for phone calls, family members to visit, babies to be born, and forever waiting on appointment cards to arrive or doctors or nurses to turn up when symptoms became “bad”.
Objects of interpretation and representation

Thom (2000) conceptualizes interpretation into three terms: “object-of-interpretation,” the “object-as-represented” and the “governing concept”. I will use the photo ‘Forever waiting’ to describe Thom’s three themes. “Object-of-interpretation” is how we identify with the objects in their original intended form, such as a telephone, baby shoes, nuts and flowers (Thom, 2000). If these items were laid out freely without any ‘artistic’ arrangement, they would merely be things or artefacts barring little relationship to one another. The “object-as-represented”, on the other hand, refers to taking those same items and creating a picture or artistic representation within a particular significant system. This is normally highly selective, purposeful and the items are arranged to maximize artistic effect or to make a statement.

The remaining trilogy of Thom’s is the “governing concept”. This is where an object is subsumed to make sense out of the context of meaning or “gives them meaning in the sense that the meaning is invented” (McMahon, 2003, p.260-261). In this context or the governing concept, all of the photographs represent hoping, unhope, mortality, aspects within the culture of palliative care, endings or stepping off the mortal coil. According to Solso (1994) we are able to organize categories, themes and schemata within the human brain, thus contributing to our long term memory stores of art information (McMahon, 2003). Kant uses a similar theory in his accounts of aesthetic ideas but he believes that it is because of aesthetic perception or
how we freely imagine things in our minds. It is this hidden agenda that works of art bring or the multifarious ideas that are stored within these artist schemata.

Staying faithful to the philosophy of phenomenology, words or implied meanings from pieces of art-work have been taken as being scientific-thematic-intention that describes the experience of people living in a particular epoch. The objects and subjects have been used to either make sense or invent meaning. The governing meaning for this project represents hope, unhope, and mortality. The pictures in this study represent symbolic intentions as perceptual styles and not simply as historical artefacts or memories.

Summary
Phenomenology is the activity of being in the moment, the study of consciousness from the first-person perspective. From an epistemological point of view, Husserl used applied phenomenology to understand knowledge and how evidence supports our judgments and consists of intuitive characters of certain experience. It is about catching those would be forgotten moments by bringing one person’s experience to the phenomenal present through a sort of act of appropriation through interviewing those from a particular lived experience at a certain timeframe.

Interviews were used to gather a particular type of research material as a source for developing a deeper understanding about what it is to have or maintain hope. The interviews with the patient participants were conducted to understand a snippet of an experience with a person living with a non-curative terminal cancer and to understand what their concept of hope was. Interviews were conducted to gain an insight in what a health professional might consider hope to be in context of patients facing death prematurely. The nature of narrative research is to make meaning by gathering individual sentences and drawing them into a ‘web’ of discourse. It was the meanings behind the instances that produced the themes, and words within words and language buried within the meanings of words that allow us into the world of others.

Reduced to its ‘elemental methodical structure’ phenomenological research is always about a real person and I have set out to make sense of a certain aspect of each participant’s human existence. Nevertheless, a phenomenological description is only my interpretation and no single interpretation of an experience will ever exhaust a richer or more meaningful description that could be undertaken by someone else in the future. Phenomenology is never
the last word but it always begins in the lived experience and eventually turns back to it. A lived experience is about people having that reflexive awareness of an experience that only belongs to that person at a given point within their life journey. Husserl (1913) encouraged people to dispense with taken for granted things within the world around us. A phenomenon of something appears in a person’s mind as having an essential meaning or essence. Phenomenology always begins in the life world as the original, pre-reflective and pre-theoretical attitude and links past, present and future.

When he started to develop phenomenology, Husserl asked two time-honored philosophical questions and in doing so used phenomenological reduction which he maintains is the essence of all science. He asked “what is it that can be known without doubt?” and “how is this knowledge in the most general sense?” (Stein, 1962, p. xvi) His starting point was within the tradition of idealism and he took consciousness to be his starting point to investigation. Before he became too philosophically involved, he posited nothing about the real world or put it out to one side, or in algebraic terms, Husserl put the real world in “brackets” making no use of the material within those brackets (Stein, 1962; Woodruff Smith, 2007). He was not suggesting that the real world did not exist but “it only means that this existence is a presupposition which much be suspended to achieve pure description” (Stein, 1962, p. xvi).

Chapters five and six describe the research results in detail and use excerpts from the participants’ transcripts to support each of the thematic intentions in an attempt to extract the plot or the point of the story from the total line up of text and making connections. Themes merely provide the sign post that gives some order and sense of the research. Figure 6 (p.75) is an example of making those connections and is expanded further in the following chapters.
Fig 6 Dr Q’s photograph
‘Making connections’
(Richardson, 2010)
CHAPTER FIVE  RESULTS AND INTERPRETIVE SUMMARY

Without hope, nothing can begin; hope offered a real chance to reach a better end. Hope helps us overcome hurdles that we otherwise could not scale, and it moves us forward to a place where healing can occur (Groopman, 2004, p. 177).

Introduction

This chapter will present the results and the themes revealed in the data generated by the open-ended interviews with the clinical participants. Narrative medicine has joined many other academic disciplines in recognizing the essential irreplaceable nature of narrative knowledge (Charon, 2006; Bruner, 1990; MacIntyre, 1984). Therefore the dialogue that has been generated helps to enhance narrative knowledge by the respondents desire to make a difference in an open-hearted and compassionate way such as Wong (2007) found.

Identifying Themes and Thematic Analysis for Clinician Participants

Making something of the lived experience through interpretation can be more accurately described as a process of perceptive design, innovation or revelation (van Manen, 1990). It is not rule bound but an act of seeing freely the meaning within spoken words. Ultimately the actual concept of the theme may become redundant over time but exposes the notion of an idea that we are addressing. Themes merely provide the sign posts that give control and order to our research.

Prior to the interviews were conducted with the clinicians, the search of the literature had failed to find any studies where doctors have been interviewed about their concept of hope apart from the work of Helen Wong (2007). The field of medicine reveals a unique self-defined group of people that ‘embodies a historical manifestation of the self’ within each individual clinician (Foucault, 1980, p. 39). The focus of care for many patients emulates from the story of the disease or illness (Wong, 2007). Table 3 (p.76) summarizes the broad themes that revealed themselves when teased out of the many pages of transcripts and mind-maps from the doctors’ conversations into rendered thematic concepts and table 4 (p.76) is the data percolated further to reveal units of language or one word creating the essential themes and sub themes of the clinicians.
• Hope is spiritual in a sense or place and meaning
• Hope is the inherent desire to maintain life
• Hope is very culturally and socially contextually, and it helps people to find themselves
• Hope is about a potential positive outcome tempered by the realization that it might not happen
• Hope is about maintaining an emotional equilibrium and a personal motivator and protector while trying to aim for an ideal or situation
• Hoping for a comfortable death one without pain and suffering

Table 2: Rendered thematic concepts of clinicians

<table>
<thead>
<tr>
<th>Clinician Participant</th>
<th>Essential Themes</th>
<th>Sub Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anticipation</td>
<td></td>
<td>Contextual</td>
</tr>
<tr>
<td>Motivation</td>
<td></td>
<td>Spiritual</td>
</tr>
<tr>
<td>Positive Optimism</td>
<td></td>
<td>Preparedness</td>
</tr>
<tr>
<td>A Driving Concept</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 3: Clinicians’ essential themes
Although there is supporting literature that claims that patients’ hopes are nurtured by their relationship with health care providers (Groopman, 2004; Ridgway, 2004; Larsen, Edey & LeMay, 2005; Wong, 2007), I believe this to be, in some instances an accidental consequence because the doctor’s actions are believed by the patient to help maintain and nurture hope. But in reality he or she is just providing care in a global sense whether that is medicalized or palliative care. Often times this would take into account the patient’s emotional well-being and their whanau but not always. As one doctor suggested that he is “just the mechanic trying to fix something that is broken” (Dr A). Finally it is about caring for an outcome whatever that might have been. One thing that became evident from the transcripts from each of the clinicians was that the concept of hope is not some romantic ideal as stated by Dr A:

…I think that it is for other people to do peoples hoping for them...

But then Dr A goes on to say something unexpected which suggests that that hope is a variable measure that means diverse things at different times:

* Hoping is about anticipation and wanting things to go well (Dr A)

Ultimately each clinician wanted a comfortable death without pain and suffering for patients but there was also that inherent desire to maintain life. Hope was about a potential positive outcome tempered by the realization that it might not happen but in many instances followed a non-static continuum as people presented new and differing stories, and changing circumstances. There were differences within individual patients and often changes happening with every presentation. Sometimes symptoms or conditions may have plateau where treatments helped or tumours seemingly became dormant for a few weeks or months. Hope was expressed by the clinicians as being:

* That there might be a positive outcome that is of importance to you, tempered by the realization that it might not happen (Dr X).

* Is about just maintaining positivity towards life and those around them...it is the preparedness to help patients just redefine their goals (Dr W).

* Effectively is around meaning and how it helps our lives feel good on a day to day basis (Dr Z).
Hope was the feeling of trying to aim or wish for a certain ideal or situation (Dr C).

Hope is just what it has to be for each person and whatever social and cultural context that it has to be for each person (Dr D).

Hope for me is just about anticipation and wanting things to go well but I cannot spend time thinking about a patient and what they hope or their hopes. I am an un-hoper (Dr A).

Hope is much more spiritual in a sense or place, maybe not feeling hopeful but actually just embodying spiritual development (Dr Z).

A good preparation for their death was the professional goal [and hope] and acknowledging that dying is a process and not an event, recognizing that it is a process and you have to get people through it (Dr B).

Through careful reduction and contemplative thinking the following essential themes were revealed:

**Formation of essential themes**

**Motivation**

The first theme is underpinned with Husserl's “bodily selfhood” with its character of intuitiveness or evidentness or intuitive fullness (Woodruff Smith, 2007, p. 327). This idea is further explored with Husserl and the *noematic* sense which presents the object of motivation to us directly or actually. Motivation is located in space-time or in the spatiotemporal setting. This refers to people living contextually in the world they live within, and what and how motivation influences their living context.

For eight of the clinicians hope was about maintaining that emotional equilibrium and being a personal motivator and protector while trying to aim for an ideal or situation. Hope was about being motivated to work at trying to ameliorate symptoms, motivating patients into “good spaces” in their heads and in their selfness so they could tackle the next phase or stage of the illness continuum or journey. Sometimes the disease state would remain stable and other times it was wild and aggressive like a runaway train.
The concept of hope is described in terms of motivation as quoted by Dr Q:

_Hope is the essence of the human mental reactivation which basically motives what we do...In essence it is the driving concept that when the chips are down there is a will to survive [and] to live...it is the inherent desire of the body to live and maintain life which becomes the personal motivator and protector (Dr Q)._  

Figure 7, Dr Q’s photograph, symbolizes this aliveness and of hope being the essence of our basic humanity. Taking time to reflect and consider the world around us was an important aspect of Dr Q’s caring philosophy. As suggested by Dr Q humans are motivated by an inherent desire to maintain life and live. James believes that “death provides the motivation for us to do things and for us to care about these doings” (2009, p.58), but motivation encompasses the direction of behaviour, the activation, instigation or things which makes us spring into action (James, 1850, 1950, p. 555). It is the channelling of certain behaviour in a precise action potential way that motivates us to get up and seize the day or at least brew our first coffee.
I think it is very important for a doctor not to destroy hope...Hope is to try and relieve pain in the broadest sense not only physical pain but also emotional pain...It is always one of the things that they always, always hang onto (Dr S).

By providing some form of action and not destroying hope the patients in this study were motivated to find a place that they felt comfortable and...

[Hope] makes life bearable for people...that allows them to live in absence of distress or as close as they can to it (Dr B).

Trying certain treatment modalities helped to maintain the motivation to keep on living for however many weeks, months or years it may have been. Surprisingly Hedley, a patient said that any treatment that gave him a week longer on this earth was worth having. People are generally motivated to live no matter how grim their situation is unless they have reached that point on the continuum where they are ready to die. As suggested by Dr E who felt that even when things were grim and there were no more treatment options, giving of the self was just as important:

That there is so much more that you can give and I think that by offering possibilities and offering yourself that people aren’t abandoned (Dr E).

Springborg (1981) writes about motivation as “the processes of human motivation are said to be private and to some degree unconscious processes” and the only person in possession of that knowledge about what motivates someone is the individual person (p. 196).

There are those who have no hope of living but then we have to find something else to hope for like a comfortable death, one without pain and suffering (Dr D).

But it is this enabling people to have something to aspire to such as Dr S states:

I have never seen one but miracles can happen and we must not forget that. We cannot take that away from patients... Even if things are hopeless miracles can always happen and they do happen. I have never seen a miracle but I have read of them and I think that it is always important for patients to have that hope available to them (Dr S).
Like many of the doctors Dr D argues that hope is contextual for individual people as he suggests:

*I believe hope to be very contextual and it is whatever it is for each person. We have to shift what we hope for, for that person* states Dr D.

At the particular time that the interviews were undertaken it was a “moment” in the care continuum and as such was a snap shot of each person lived experience when the tape was rolling. Many clinicians had requests by patients about the on-going demands of coping with living despite there being an awareness of death at any time.

*I think a lot of people probably appreciate having something to hang their hat on and know that something is going to be done even if the chances aren’t that good. That there might be a positive outcome that is of importance to you tempered by the realization that it might not happen* (Dr X).

**Fig 8 Dr X’s photograph**

*Window of Opportunity*

(Richardson, 2010)
These words are further represented by Dr X’s photograph *Window of Opportunity* in figure 8 where I have used the theme of an old window with the bright contrast of the ginger flowers. I wanted to contrast beauty with the starkness of the old wooden window with its electrical fittings. These are remnants of human existence, of a life force that once surged through the porcelain cups. The window had had a purpose but now it is derelict with the building no longer in use. Currently the old storage shed is home for pigeons, starlings, swallows and rodents. The ginger flower represents those positive outcomes as its vital vibrant petals remind me so much of a living force, a force to be reckoned with. Dr X shared private moments with me in a very humanistic way. The governing meaning or concept of Thom’s trilogy gives meaning in the invented sense. This photograph represents hoping and against the odds. Such statements as:

*I mean even if they are pre-terminal you know there are always things that you can do in terms of keeping them comfortable and just reducing stress for them and their families*” (Dr X) and he goes onto say:

![Image of snowy landscape with text overlay](Fig 9 Dr X’s photograph ‘Stark reality’ (Richardson, 2010))
You might give them [patients] two weeks which may give them a little bit of benefit but you can offer them good palliation that can improve the quality of life, I think that is important (Dr X).

Figure 9, Dr’s X’s photograph, represents the stark reality of telling people they only have two weeks to live. This bleak scene provides a notion of reality and splendour in the same breath. There is a sharp contrast between the black of the frame and nebulous greyness that hangs about the trees. This fuzziness supports the thought that no matter how bleak a prognosis might be death is a transition from one place to the next and good palliation can still give quality of life and aliveness.

Anticipation

Burning waves of expectation
   In her bosom rose and fell,
   And alone the flowers were heaving
   To and fro upon their swell;
Half her dark hair was up gathered,
   Half in sad neglect it flowed;
While her eager eyes were resting
   On the winding valley road.

(Cary, Phoebe, 1824-1871 [Anticipation (1853)])

This second theme reflects Husserl speaks of the life-world or living world. This constitutes the essence of things in the surrounding world or as van Manen calls it, corporeality; the phenomenological fact that we are always bodily in the world (1990, p.103). This theme was revealed when the doctors spoke in terms of their anticipation of things to come; it was to feel excited, hopeful or eager with the realisation that their patients would be bodily in this world in an enhanced state than before because of some treatment modality. Even, if this was helping to sustain people through the dying process with good palliative care. There was certain anticipation that people would in most instances remain fearless through the dying process as suggested by Dr B:

A good preparation for their death was the professional goal [and hope] and acknowledging that dying is a process and not an event, recognizing that it is a process and you have to get people through it.
Rosen writes about anticipation when he states that “an anticipatory system is a system containing a predictive model of itself and/or its environment, which allows it to change state at an instant in accord with the model’s predictions pertaining to a later instant” (1985, p. 341). However, when we are talking about the future we are thinking about an idea or a promise of something to come. In keeping with the notion or concept of hope many of the doctors talked about the anticipation of things to come. Even clinicians who did not believe in talking about hope still had anticipations for future good for their patients.

*Hoping is about anticipation and wanting things to go well. Some of the patient’s turn to the church and others turn to other things but I don’t even think about hope for them and I am just doing my job (Dr A).*

The image or the ‘thing’ imagined is as a hoped for ideal or a foresight and it is always real as “being a present anticipation of the future. In spite of everything, the future vision is a vision, and is accordingly present in the mode of a mental act. The future, as such, does not have an ontological consistency” (Scognamiglio, 2010, p. 58). Anticipations can bubble below the surface of a person conscious thought and may materialize as purposeful conscious experiences at any given time (Hartmann, 1935; Scognamiglio, 2010). Aristotle asserts that every finalistic action requires a mental vision of the ideal aim, and a non-mental process of realisation. Anticipation for something or an ideal in the future continues to be a powerful motivating force. It is a driving force throughout all levels of existence (Husserl, 1931).

It is with anticipation that eight of the clinicians sought treatment modalities as stated by Dr X:

*Just try and bring out the entire positive and put the plan of attack forward.*

It was this making a plan of attack that held anticipation of things to come. It was always mooting something that gave patients a little glimmer of hope to hang on to and to dream about or desire:

*I think a lot of people probably appreciate having something to hang their hat on and know that something is going to be done even if the chances aren’t that good (Dr X).*
But that then also validate who they are and their strengths and dreams (Dr Z).

Dr Z’s photograph, figure 10, is a representation of reflections, strengths and dreams with the still life of an abalone shell and an araucana feather as he speaks of validating a person’s strengths and dreams therefore acknowledging their hoped for dreams and desires. The doctor-patient relationship is often one sided but many of the patient participants were unaware of this as they had the belief that the clinician has his or her crossfire hair firmly sighted on them or that they were upper in the clinician’s thoughts. When, in fact the patient was just one of many for each of the clinician. The patient, on the other hand, would have one or two doctors treating them at one time so the doctor became that significant other person in their life for the foreseeable future. Whatever story or communication the doctor had with a patient it generally had a lasting effect on that person (Brock, 1991). Clinical anticipation is a powerful form of hope that gives people a vision, something to hang on to and brings about the power of imagination which man does best in dire circumstances (Frankl, 1959, 2004).

If you look at rightly the function of what hope is, which is to keep your goals emotionally intact it doesn’t matter what you hope for with the proviso that whatever the construct is that it doesn’t cause people them harm (Dr B).
Clinicians would wait with clinical anticipation to see if a procedure had reduced the size of the tumours or had had an effect on the CEA. No matter what speciality the clinicians came from they all had a way of anticipating a future or an outcome for their patients whether it was waiting for changing pathology or helping people to sustain them through the dying process. There was evidence of sadness but I did not feel that doctors expressed pity, self-pity or a negativity towards caring for people who were dying as Dr B tells us:

So my goals of care became not keeping somebody alive but just helping to sustain people through the dying process, technical things became good symptom control. ..We are the only animal that really contemplates its own demise for more than five seconds (Dr B).

Throughout the interviewing process and subsequent transcribing phase the positivity and encouragement that many professionals displayed while talking about working with a population of people who were dying emerged. To work day in day out preparing people for their inevitable demise is a very hard job. It is a job that requires tact and sensitivity most of the time because the fear of death oppresses us (Bloch, 1959) and so remains very primal as reflected in Dr B’s photograph in figure 11 *The spirituality of hope*.

Fig 11 Dr B’s photograph
‘The spirituality of hope’
(Richardson, 2009)
Positive optimism

The third theme in the quartet of themes looks at the concept of hope in terms of positive optimism and reflects Husserl’s theory of intentional direction which looks at our relationality towards things (Woodruff Smith, 2007, 232). Van Manen expressed this as “lived human relations” or relationality as “the lived relation that we maintain with others in the interpersonal spaces that we share with them” (1990, p.101). Phenomenology is as already stated a study of the “consciousness from the first-person perspective” thus it is about describing how the doctors experience things in perception, thought, imagination and emotion. It is this subjective idea that Husserl spoke about the way our own conscious experience flows off in relation to things around us (1907, 1950).

Within the doctor-patient dyad there a living relationship that had to be maintained in most instances by each of the participants. This included the interpersonal connections and spaces that were shared between the carer and the cared for, and their family. Dr Q expresses this shared connection that supports positive optimism:

Again it is a wee bit about applying care I think when people are cared for within the context of either friendship or health professional care, that in itself is kind of like a professional hug that is very helpful for a start and then there is a reframing of context required (Dr Q).

It is the ability of each clinician to believe in and have the optimistic expectations for each of their patients that enables them to maintain dreams and desires. Dr E suggested:

But I always believe there is something that I can offer and that there is always something that I can do and things just don’t stop with diagnosis like cancer or terminal illness umm and I guess it is helping the patient find that too (Dr E).
Fig 12 Dr E’s photograph
‘Sun Rise gives way to optimism I’
(Richardson, 2010)

Fig 13 Dr E’s photograph
‘Sun Rise gives way to optimism II’
(Richardson, 2010)
Fig 14 Dr E’s photograph
‘Sun Rise Gives Way to Optimism III’
(Richardson, 2010)
There are things in life that appear to epitomize what constitutes optimism such as never losing sight of the importance of a beautiful sunrise or smelling the rain. It’s often the little things that really matter in life (Coon & Mitterer, 2007). Thus the sight of dawn or sunrise is the quintessence of all things optimistic and things starting fresh but just as the sun’s rays on the edge of the earth is an optical illusion so too can be the concept of a ‘new day’. In keeping with the human science approach Husserl (1913) encourages us to dispense with taking for granted things within our living world and it is his phenomenological approach that gives meaning to the essence of what it is to hope in context of being a medical practitioner. The participants’ stories become expressions of the self and their optimistic expectations are bound within the rules and ethics of the Hippocratic Oath and being as reflected by Dr Z and Dr W’s comments:

*So hope effectively is around meaning and how it helps our lives feel good on a day to day basis… (Dr Z).*

![Fig 15 Dr Z's photograph](Richardson, 2011)
Dr Z’s photograph, figure 15, expresses hope around meaning, feeling alive and being:

*And also when you can treat into their symptoms or speak into their existential need again you know that has an impacted their whole positively (Dr Q).*

*And: What I have come to believe is important for them is that they can maintain optimism with a positive attitude towards life, towards what’s happening to them so they don’t give up early. So it’s really a question helping people find what they can still be optimistic about and not and that won’t be about being alive (Dr W).*

Hope being the last emotion in Pandora’s Box has an air of purity about it but essential hope accepts that life is often unpredictable and messy. As represented by Dr B’s, photographs, figure 16 and 17 that represents hope as a sense of clarity, purity and honesty. It is this looking beyond using a cultural context.

**Fig 16 Dr B’s photograph**

*Hope through the eye of the beholder I*

(Richardson, 2009)
Dr B speaks about the effect that working with Asian communities had on his philosophy of care as he states:

*Working internationally, especially in Thailand, has helped me to understand each person’s cultural and religious context and you have to talk about hope in the context of each particular person. When an Asian person dies many of them believe that they will be reincarnated and come back as a better person.*

His photographs figure 16 and 17 hope is always through the eye of someone else. And the photographs on the previous page represent this looking through the window into someone’s soul and being reincarnated into something or another vision.

It is looking through to the other side onto something different as indicated by Dr W when he speaks about making optimum use of time and finding optimism as he suggests:

*So if it is going to end it is really important that they make optimum use of that time and that requires an understanding of what’s happening and a real open, honesty from their health advisors and that entails realist, they need realism and yet within that they need to find optimism (Dr W).*
Hope – A driving concept

My final theme relates to Husserl’s lived time or lived relationally. Van Manen also spoke of the lived time (1990, p. 104) and this relates to hope being a driving concept. This is very relational to the subjective nature as opposed to the objective accountable actions that each clinician undertook in the care of patients with a terminal illness in the here and now. There was a need for genuineness and unconditional positive regard for the patient participants by their clinicians. This was expressed by the doctors holding on to the subjective feelings as suggest by Dr Q:

And some of that is by helping the person realize the context where they are now living because we as humans don’t like uncertainty and we don’t live well with uncertainty. So actually framing that where the person is and taking out of it the fears they have regarding their future can be so helpful in that person then being able to realign their own horizons and take out of it the gremlins that threaten things that they thought and to better contextualize where they are at, at any one point in time.

It is this realigning of a person’s horizon to better understands their place within the world so that as Dr Q indicated:

By doing it repeatedly it helps the patient realize a) they are cared for and b) they are being given help along the journey to help them see, what is in fact the hope, which they can raise for this next part of the journey (Dr Q).

Fig 17a Dr A’s Photograph
‘Bright star’
(Richardson, 2011)
As suggested by *The Ring Master*, Figure 18, Dr W had been driven by a strong scientific undertaking to create superior chemical therapy, that until recently had only been offered by his clinic and in one other private facility. Because of a belief in this therapy and despite being labelled an originator Dr W has continued to provide this therapy to many patients supporting his notion of what means to hope. He reminds me of being the ring master and a driving force that has supported people’s hopes, dreams and desires for many years.

This is supported by Dr B’s concept of hope as a driving force:

*You try and can create an environment that allows people to maintain hope* (Dr B).
Fig 19 Dr B’s photograph
‘East meets West’
(Richardson, 2010)

The *East meets West* photograph, figure 19, and gives an illusion of contemplative reflection and a stillness that can be seen when you look through the windows in the photograph. This is however, not fluid or parallel as each person reaches the introspective reflective phase at different points in the caring trajectory.

Hope becomes a driving concept within this care trajectory but again each person reaches this at different times in a rollercoaster style as Dr B implies:

*Whatever hope is or the function that it serves is to make life bearable for people* (Dr B).

This is further supported by Dr Q when he speaks of embracive care:

*What I think it is, it’s journeying with them so that you don’t antagonize them, you don’t umm sometimes I try to be affirmative around one particular direction based on balance because I know that there shouldn’t be a lure out there chasing the Holy Grail of cure without that care, that embracive care that I think they do require as well. So when things fall over they have got someone to fall into* (Dr Q).
And he supports this notion further when he states:

*As a medical health professional in front of people that I have undoubtedly injected hope in to them when they come completely dejected and this can be at a time when they feel all treatment options have gone and they go away feeling more hopeful and heading back from this subsequently know that this has sustained them for more than just the visit (Dr Q).*

Undoubtedly the position of a palliative care doctor or generalist who cares for people from birth until death is about solving problems, being supportive and engendering some form of positivity, supporting dreams, desires and essential hopes as a reason to carry on and ultimately it becomes about the good death or the desire for the good death.

*In essence it [hope] is the driving concept that when the chips are down there is a will to survive [and] to live (Dr Z).*

Much of what has previously been written in the other three themes encompasses the essence of hope as the driving concept, however, there are a further three sub-themes to be presented:

- Contextual
- Spiritual
- Preparedness

**Sub-theme**

**The contextual nature of hope**

As already discussed hope is very contextual for clinician and patient or for that matter every human desire is wrapped up with our cultural and moral context for any given time period. Dr D talked about the impact, perspective and importance that Eastern cultures have had on his current practice in the context of how he treated patients, particularly those that were facing impending death.

*You have to talk about hope in the context of each person and things are very time contextual and relevant to what has gone on before an event. I believe hope to be very contextual and it is whatever it is for each person (Dr D).*
[The Asian’s] helped me to understand each person’s cultural and religious context (Dr D).

Dr B talks about dying as being a process but that it is individual and contextual for each person:

*And it is a process not an event and that is what you have to remember* (Dr B).

By being a process he is meaning that it is one that belongs to that person and only that person.

*Hope is just what is has to be for each person and whatever social and cultural context that it has to be for each person* (Dr D).

Dr B talks about hope being very cultural and contextual for some groups of people when he suggests:

*For some cultures that they demand blood transfusions right up until the last day of life and that was hope for the family and not for the patient* (Dr B).

The contextual environment can make it easier for people to maintain hope as Dr Q talks about the hospice and is evidenced by his photograph in figure 20 of these connections and engagements:
So the environment and the philosophy make it far better and easier to engage and that is when spirits can life again and hope can be restored (Dr Q).

The spiritual nature of hope
The second subtheme relates the spiritual nature of hope and much that is written in the literature about hope inextricably links it with faith and spirituality. This is in the broadest sense of spirituality and faith. This subtheme varied for each of the clinician participants. It appears to be a continuum with those at one end who had no concept of spirituality or spiritual care. These were the people who presented as being very pragmatic and slightly paternalistic. At the other end of the continuum were those who had a strong sense of spirituality or who had a religious affiliation. In the middle were those who seemed to have a spiritual dimension about them. Here is an example of a clinician not having a significant faithful or traditional religious thought as Dr B describes in pragmatic manner:

_I think you become fertilizer when you are dead, when you are dead you are fertilizer._

Dr S talks about his spiritual beliefs:

_I always envy people who do have a strong faith and it certainly makes it a lot easier to look after people...No I guess I am a humanist and have not faith (Dr S)._ 

But others had very strong faiths or spiritual beliefs. The percentages of ‘believers’ to that are ‘non-believers’ is consistent with other literature - thirty percent expressing spiritual beliefs. Most of the doctors talked about caring for patients with strong beliefs and their own belief systems:

_I think a person’s faith has a lot to do with how hope works for each person within their particular culture and there are some people who just can’t wait to die so that they can go to heaven (Dr D)._ 

_With some people faith and hope will go together. I have run into people who have been strongly religious and have again lacked hope and have been quite negative about things (Dr X)._
I'm ashamed to say I don't...Possibly some people would call me an agnostic but I don't have faith. I am ashamed to say (Dr S).

We are Jock Tamson's bairns which mean we born on earth and all the same really (Dr Q).

(This means that we are all God's children although Jock Tamson's Bairns is used as a personification of the Scots nation, it is also used to refer to the human race in general.)

Whichever culture and whichever religion we are all the same, we all face fears, we all have to deal with the hope issue and for some of us ah I have got these little diagrams that I drew umm where there is true hope and wishful hope or wishful thinking and it is like a continuum between wishful thinking and hope. And I think hope is initially described in life as an expression that represents that human endeavour and human spirit that will not die (Dr Q).

Dr Z describes his concept of spirituality as:

I regard religion as it has got some lovely ideas. It provides very simplistic answers...So I don't feel like an extra need for spiritual feeling particularly...but it helps people not to think about things if they are not careful (Dr Z).

Faith and spirituality has been a driving force for some of the participants but for many getting on with life and being prepared were significant driving forces as will be discuss in the final subtheme.

Clinical preparedness
This subtheme relates to the concept of the clinicians preparing people to face the next phase in their disease process and the inevitability of dying. Sometimes patients came to the realization that in the process of having a non-curative terminal illness that they were not going to survive and they, in fact were going to die from it. It is this realization that dying is a normal consequence of the disease process. For many of the patient participants it was about adapting in a normal way, to accept that accommodating death was a normal process of living with their disease. This is not to say that they accepted or were content with the idea, it was just they had to prepare themselves and their families for the ultimate end – death.
At a certain point they are going to die so I think that for them it is important for then that they know enough about what is going to happen that they can find the positive things that we are honest enough with them to allow them to formulate some plans (Dr W).

One very important message was that each of the patient participants wanted to understand death for them and not have other people tell them about it as suggested by Ivan Hanson: “I don’t want other people to tell me what death is...What works well is a belief system for me, but I don’t want other people to tell me what to do” (cited Schmele, 1995, p.39). As already stated when discussing positive optimism the message is the same for being prepared for dying and people facing death as Dr W believes:

So if it is going to end it is really important that they make optimum use of that time and that requires an understanding of what’s happening and a real open, honesty from their health advisors and that entails realist, they need realism and yet within that they need to find optimism (Dr W).

The photograph *Hope and the end of life* is this sense of realism as the flower stands out from its black background. Parts of the petals fade and blur into fuzziness as the camera’s eye has focused on the centre of the stem. Life is full of these fussy moments where we are unsure of our next move amidst the stark reality of a monumental event or phase of events such as dying. Dr Z talks about this enabling people to find ‘their place’:
...And exploring people’s relationships and validating themselves through that and their role and then finally getting themselves to a place...at least they have got that [place] to hold onto and other people may need a little bit more encouraging to move through to these other places [or their place] (Dr Z).

For some of the clinicians it was their connections with other cultures that helped them to understand the process of dying.

I am concerned with the palliative care paradigm where we have become too comfortable with death. We are always talking about somebody else’s death. Part of it is how to keep a balance but I do believe that we have become too comfortable with dying (Dr B).

I don’t know of anyone who being given the choice of being cured and returned to normality or being allowed to die would choose to die. People only come to accept that they are dying because they can’t avoid it. I suppose if you ask what do people need hope for but I guess if you have come to that stage when you are totally accepting of the fact that you are dying then maintaining hope must become very important because you are stripped from all the need for it, because the pain from thinking about dying has diminished (Dr B).
At the heart of dying was trying to prepare people for death when it was not considered “their time to die”.

*Well there is a time for everyone to die and you know as a doctor certainly it is my responsibility to preserve life for as long as I can. But it is also not my responsibility to extend the act of dying and that is the way I absolutely look at it. What would I want? I think that is every doctor responsibility* (Dr S).

*So when it comes to the end of life when it arises, the hope is still there albeit framed in different context. And of course hope can extinguish and ultimately for everybody it does generally extinguish but it might just be an hour before dying where there is more of an acceptance, an acceptance of the inevitability that the person then feels as the end of hope which is equal to the extinction of life*” (Dr Q).

Preparing patients for changes in their illness phase and for dying has been said by the clinicians as being an important part of the caring and hope trajectory. It is about each person reaching a level of acceptance in their time and not on someone else’s schedule. This preparation for something is like the flower on page 193. We prepare the soil in a garden for the arrival of spring flowers, summer annuals or autumn splendour and wait expectantly for them enliven us with the fragrance, colour and beauty. Then they die on us. Just like that they wither and drop to the soil to become fertilizer for the next season. Flowers are the very essence of preparedness and hope.

**Summary**

The four themes and three subthemes that have been discussed in this chapter are consistent with Husserl’s lived experience themes of bodily selfhood, life world, lived body or lived human relations and finally lived time or relationality. Making something of the lived experience through narrative interpretation can be described as a process of “insightful invention, discovery or disclosure” (van Manen, 1990, p. 79). The emerging themes revealed themselves as being unique to the phenomenon of concern and these were: anticipation, motivation, positive optimism and hope as a driving concept. For many of the clinicians hope was about maintaining that emotional equilibrium and being a personal motivator and protector while trying to aim for an ideal or situation. Hope was about being motivated to work at trying to ameliorate symptoms, motivating patients into “good spaces” in their heads so they could tackle the next phase or
stage of the illness continuum or journey. The second theme was revealed when the doctors spoke in terms of their anticipation of things to come; it was to feel excited, hopeful or eager with the realisation that their patients would be bodily in this world in an enhanced state than before because of some treatment modality.

The third theme in the quartet of themes looked at the concept of hope in terms of positive optimism and Husserl called this our lived body or lived human relations. Van Manen expresses this as “lived human relations” or relationality as “the lived relation that we maintain with others in the interpersonal spaces that we share with them” (1990, p.101). It is the ability of each clinician to believe in and have the optimistic expectations for each of their patients so the person is enabled to maintain dreams and desires. The fourth and final theme was hope as a driving concept and this related to Husserl’s “lived time” (1907, 1950). The three final subthemes discussed have been that hope is contextual, it is spiritual and hope is about preparing people for each phase in the care trajectory.

The next chapter describes the results and interpretive summary for the patient participants in this study.

Fig 23 Dr S’s photograph
‘I believe in miracles’
(Richardson, 2010)
CHAPTER SIX  RESULTS AND INTERPRETIVE SUMMARY

Hope is a bright shining light which keeps darkness at the bay
Hope is a gentle cool breeze on a hot summer day
Hope is to remain positive when the going gets tough
Hope is seeking more when others think you've had enough
Hope is dreaming of tomorrow and simmering under sorrow
Hope sparkles when tears are in our eyes, tis a beautiful thing and never dies
Hope is as light as a feather and keeps us all together
Hope is ubiquitous and free of cost
And
Hope is the last thing ever lost...

(V. Bansal., 2009)

Introduction

This chapter will examine the results and the themes revealed in the data during open-ended interviews with the patient participants and it follows the format of the previous chapter. The aim of narrative meaning is to make explicit the procedure that constructs a particular type of significance that draws the reader into an understanding of human existence (Polkinghorne, 1988). Individually the participant’s stories are just that, a story but together they represent a concurrence of ideas and themes. As described by each patient participant their essential themes are represented perceptions, remembrances’ or actual thoughts and these have been confined to a handful of meaningful and significant essential words in table 4.

Patient Participant Themes

- Realism, positivity, thankful, good life
- Optimistic, tiny, tiny window of hope, miracles, possibilities and cures,
- Resurrection hope coming back and living on paradise earth
- Leaving early, missing out, resigned to dying, end of a series of chapters
- Anticipation, trying something, attitude and activities, getting back
- Whistling a happy tune, standing in my true self, basic humanity

<table>
<thead>
<tr>
<th>Table 4: Essential Hope Themes of Patients</th>
<th></th>
</tr>
</thead>
</table>
Anticipation
This first theme is similar to the second essential theme that was identified in the previous chapter but many of the patients; expectations were greater and pivotal than those of the clinicians because they related to wellness and bodily reactions to treatment phases. This essential theme explores the lived space of the interpersonal space we share with others, of anticipating something out there or those elusive ‘things’. van Manen is speaking about the spatiality of there something being out there for us to get or be given such as more time with loved ones or anticipating good news (1990, p.182). This theme revealed itself when participants spoke about expecting and waiting for things to happen. The photograph ‘getting away from it’ describes this theme pictorially and symbolically exponentially.

Victoria’s photograph symbolizes wanting to get away from the pain and her undiagnosed disease. She felt that by going to some exotic beach full of anticipation, as figure 24 symbolizes, that her body would ‘be normal’ again when she states:

...I seem to get worse and wasn’t getting any better you know and I was getting a bit depressed really and I was sent off to Australia for a couple of weeks for a bit of time out from my problems...(Victoria).
Victoria and her family had anticipated that two weeks on the sun would help the pain and get rid of the ‘sickness’ or whatever was causing her to feel so bad. For those who have not gone through an experience of anticipating and willing therapies to work, it is difficult to conceive the soul-destroying mental anguish and conflict that may go on in a person’s mind when things were not working.
As suggested by Anna:

I was very depressed about that I thought that I had gone through five treatments and to be told that it is not working I found that very, very hard and then when he rang me on Monday night he said “no you count has come down nicely and it had dropped quite a few hundred” umm I felt good that the doctor came along on Friday to speak with me and he said he thought I was as good as gold (Anna).

Sickness opens different doors such as examining and considering what is important within a persons’ life and hope is strongly connected to patients whenever treatments are offered (Benzein, Norberg &Saveman, 2001) as Fleming tells us:

I have had a very good life but now it is coming to a close and that is sad. I hope to get about six months to a year from this treatment (Fleming).

Anticipating something is an important human emotion and follows that a patient would want or anticipate something after having a treatment phase for non-curative terminal cancer.

Ah the only thing is to try and extend the time that you have got left. And that, that’s the thing that I just hope that I do get a decent amount of time perhaps to do some of the things that I have put off (Fleming).

However, the best known definition of anticipation is Rosen’s “an anticipatory system is a system containing a predictive model of itself and/or its environment, which allows it to change state at an instant in accord with the model’s predictions pertaining to a later instant” (1985, p. 341). Behaving in an anticipatory way is suggested by Scognamiglio (2010) as adjusting present behaviours in order to address future problems. In other words, an anticipatory system takes its decisions in the present according to forecasts about something that may eventually happen as Kowhai tells us:

Ah the doctor said the CEA has come down which was what they were waiting for and he said we will see what happens after the next treatment, and the next blood test, I suppose (Kowhai).

Anna speaks about anticipating things in the future:
But if I can work at having a nice summer tramping and I could get back to doing the things I wanted to keep tabs on things, I could get back to the things that I want to do (Anna).

As does Willkie:

I don’t know what is involved with the radio pellets and whether for instance my system can stand it. At the moment it looks like it might but I don’t know. The Dr is the expert and if it works then whoopee we will go for it and if I get another six months out of it or another eighteen out, then great (Wilkie).

Anticipation is a vital emotion as suggested by Stein (1916-1917, 1989) when she urges other people to be empathic to another’s anticipatory desires or living world. Each patient participant waited with great anticipation when it came to blood results because decreasing tumour markers indicated that treatments were working or things were in remissions. Patients such as Valhi anticipated a good death:

It is my hope and I anticipate that I will sleep for a while until the time is right and I will come back...the Bible talks of death as just asleep that you will wake up in God’s due time for the resurrection hope so I am just going to go away and have a long, long sleep and come back (Valhi).

Kowhai concentrated on anticipating the further trips that she would have been she was feeling better:

The doctor said let’s concentrate on getting you into next year... and I would like to think that my friend and I can do a few more of those trips that we have planned (Kowhai).

Positive Optimism

The second theme was also revealed by both the patient and doctor participants. It appears relational and connected to anticipation. van Manen expresses this as “lived human relations” or relationality as “the lived relation that we maintain with others in the interpersonal spaces that we share with them” (1990, p.101). This theme relies heavily on the relationality between health professionals, patients and their whanau. Optimism has been defined by Scheier & Carver (1983, p. 232) as “the favourability of a person’s generalized outcome expectancy” and within the field of psychology long been associated with better physical
health outcomes and greater longevity and active and effective coping (Scheier & Carver, 1985).

Valhi remained buoyed by her optimistic outcome by saying:

I am still going strong and still able to do things so I am quite grateful for what I have got...I thought if you could give me six months, six months that I can do things...I can still knit and sew so I still keep doing crafts and I still get on the computer. My brain still works so that is good. I can still e-mail my friends (Valhi).

Anna talks about being optimistic enough to go back to camping out with her friends:

If I can get back to going out once a week with that and go away to camp with the friends that I have, yes that is something that I want to do (Anna).

Fleming suggests that when he and his wife spoke of his on-going optimism:

It makes him feel like he is doing something and while there is still treatment going on there is still some room for optimism and hope...He is thankful that he has had two years since his initial bowel surgery and without any treatment he would have been dead in six to twelve months (Fleming became too unwell to finish the interview so his wife helped facilitate the final two pages of his transcript).

Accepting the doctor’s treatment has given him the optimism to carry on with life but he understands that it is not going to cure him (Fleming’s wife).

The figure 25 was chosen because Fleming acknowledged that he had had a good life but he was being asked to leave early. The three blooms represent the fading nature of Fleming’s life. The plants and in particular flowers symbolize dying admirably.
Willkie talked of things coming to an end point but he remained ceaselessly optimistic:

*Well he (doctor) thought it was the end of the line but in the end there are still these other things to consider...He [doctor] never actually slammed any doors, he just gives you the best indication at the time and we will just play it by air one thing at a time* (Wilkie).
Fig 26 Anna’s photograph
‘A tramping we will go’
(Richardson, 2008)

This is represented by the imagery of ‘a tramping we will go’ which was the pictorial image chosen from Anna’s transcript. It represents the anticipation and optimism of getting back into walking around the tramping sites in and around Otago.
The photograph *optimism amongst the undergrowth* describes how Kowhai felt in terms of feeling optimistic. This lone iris stood apart from the rest of the garden blooming in the midst of intense heat where most other flowers had withered and died.

*The more things that you have chucked at you in life I believe it makes you a lot, lot stronger...the only thing is to try and extend the time you have got left* (Kowhai).
Morris believed that his attitude to life made things more optimistic for him:

*I think my attitude and everything I do gives me more hope and optimism* (Morris).

Morris was optimistic that an hour of hard exercise would help destroy the cancer cells each day as portrayed by his symbolic photograph in figure 26. No matter how tired he felt at the end of each day he would complete a rigid exercise regime as he states:

*I believe that if I exercise and keep my body in good shape then the cancer treatment will work better and the cancer cells will be destroyed*” and “*I have been on quite a strict exercise regime ever since I first got diagnosed actually and I just see it as being a way of giving the cancer cells a hard time and they are not going to have an easy time and one day I*
see them [optimistically] saying “oh come on guys we had enough of this lets get out of here (Morris).

Victoria talked about the importance of being offered something to help maintain a positive optimism as she talks about meeting up with one of the only doctors who would do something for her:

_We went and saw him [the doctor] in Christchurch and he gave us a little flicker of hope which was nice and six days later I was up in Auckland having surgery...they did surgery and there was a faint hope that they might be able to excise the tumour but if not they would pop in a port for administering the chemotherapy and the yttrium_ (Victoria).

Victoria also went on to describe her positivism about doing things. She also speaks about her ability to help other people to stay positive:

_We’d go anywhere, spend anything, you know to somewhere in the world. There must be someone who is doing something...I’ve got nothing to lose...because it would get me down if I didn’t have a plan...I am staying very positive and I would like to be able to think that I can do something’s...[T]he pastor came round the hospital and visited me and crikey me I spent most of his time trying to lift up his faith...He couldn’t believe that I was still thinking positive but it was because Jesus was holding my hand..._ (Victoria)

**Realism**

_Suppose nothing else were ‘given’ as real except our world of desires and passions, and we could not get down, or up, to any other “reality” besides the reality of our drives_ (Nietzsche, 1989, p.47).

The third theme looks at the concept of realism because many of the patient participants view of cancer and dying was seen through the eyes of reality. Husserl speaks of “bodily selfhood” and intuitive fullness (1913). van Manen speaks about the _lived body_ or corporeality (1990, p.180). The threat to the patient participants’ personhood and lives was a constant reminder of how tenuous life really is. Realist philosophy is based on the existence of social structures which operate independently of our conception of them, conditioning, being nonetheless dependent on that human activity to endure or change (Archer, 1995; Willmott 1997, p. 97).
N.T. Wright, New Testament scholar and retired Bishop of Durham (Anglican) also writes on this topic:

... I propose a form of critical realism. This is a way of describing the process of "knowing" that acknowledges the reality of the thing known, as something other than the knower (hence "realism"), while fully acknowledging that the only access we have to this reality lies along the spiralling path of appropriate dialogue or conversation between the knower and the thing known (hence critical)(p. 35)

But for the purposes of this thesis realism or reality is about facing what is ahead and accepting the reality of a given situation. van Manen (1990) concludes from a phenomenological perspective we are always bodily in the world. All of the patients without exception understood how grave their realities were as Amethyst suggests:

I went into sort of a doing mode and got all my affairs in order and planned my funeral and everything else (Amethyst).

Morris faced the reality of each day as he had come out of semi-retirement to pay for his ongoing treatment:

I have had absolute control from day one... Dr W said historically there will come a time when all of a sudden you won't be feeling so good but I accept what he says but get on with my life basically (Morris).

Willkie was faced with the reality of dying very soon if his current treatment failed and he speaks of this:

Ah yes the doctor he is utterly honest. He tells you what the most you can hope for is and he can also tell you what the worse scenario is and [people] you will do both (Wilkie).

Willkie knew that he could expect to have some of what he hoped for and he expected realistically the worse scenario that of dying and death.
Hedley appeared to hold realism and being realistic as having a strong practical understanding and acceptance of his world as he said;

*My concern is more about an on-going problem that means if I don’t have any quality life I don’t do anything. I don’t want to be an invalid for the rest of the time that I have. I wouldn’t want that at all. The resection offers the best hope of cure but that has the most risk of dying as a result of the operation* (Hedley).

He spoke about wanting to maintain his fairly active lifestyle and was quietly realistic that his lifestyle would not have to change too drastically:

*...Obviously I would like to be fit and well again, I also realize that I am nearly seventy-seven so how well can you be at seventy-seven. I still like to lead an active life and do the things I like doing* (Hedley).

**Fig 29 Hedley’s photograph**

‘Reflecting on life’

(Richardson 2008)
Hedley became very reflective but realistic about his life and what the future held for him especially drastic interventions such as having a radical resection of his liver. But he also said:

_In between chemotherapy sessions when there have been good days I would go kayaking...It is a big decision to make, it is your life that you are dealing with but on the other hand I have got to make it by Monday so it just might come to the flip of coin_ (Hedley).

**Resignation**

The fourth and final theme is about the _lived time_ or temporality. van Manen talked about this as time being subjective such that the concept of time had taken on a whole new meaning. Time was running out or the participants were living on borrowed time as captured by Victoria:

_I make little plans for myself, little dreams of something that I think that I will be able to achieve in the next week or so. You know go somewhere or make a plan ...even if I wake up the next few mornings and know there is no way I am going to make it but I have these wee dreams... because it would get me down if I didn’t plan, I find that I am doing a wee bit more around the house now_ (Victoria).

Victoria also talked about not wanting the fact that she was dying thrown in her face every time she visited the doctors as she tells us:

_I don’t want a doctor or specialist who is talking about months because I knew it and I didn’t want it spoken about all the time_ (Victoria).

She talked about having only months to live but she didn’t want constant reminders of it. Willkie talks about the being resigned to losing his family:

_I hate the idea of losing my family or them losing me_” and “_at this stage that is the end of one chapter and then we start talking about chapter two which I am hoping the doctor can attack the tumour in some way and perhaps prolong the prognosis a bit_ (Willkie).
Hedley was very pragmatic about dying:

*I'm not worried about death. Either you're dead or that's it and you haven't got much say...well I hope [the treatment works] otherwise I will be annoyed if I am dead by the spring* (Hedley).

Anna spoke openly about dying even if she had unrealistic hopes about the length of time she had:

*I haven't got any fears [about dying] I have a beautiful daughter waiting so I have no fears of dying. I miss her very much but death doesn't worry me* (Anna).

Fleming and his wife talked about being resigned to dying:

*We have just talked about that last night and he thinks he will not live much passed Christmas* (2009) (Fleming).

Morris talked about missing out on seeing the views:

*[The] first thing that flashed across my mind because I was driving around the bays when I was given the diagnosis and I am not going to see these views again and that's really probably the biggest impact it had on me of thinking ahead.*

Fleming talked about being realistic about his future:

*I suppose so, I suppose so but at the end of the day you know it is not going to go on smooth plain sailing for ever so something has got to happen hasn't it and you just accept it. I am tired, a little bit irritable* (Morris).

He went on to talk about accepting and resigned to dying:

*I think I have pretty much accepted it [dying]* (Fleming).

Willkie spoke about the doctor being honest about his prognosis:

*Well he's very honest and doesn't pull any punches...well he thought it was the end of the line but in the end there is still these other things to consider but not until we have got around this jaundice problem which is fading*...(Wilkie).
Valhi also spoke in a matter of fact manner when talking about accepting that she was walking the last chapter of her own book:

*He [the doctor] discharged me from his care and just said it would be palliative from now* (Valhi).

Likewise, Kowhai understood that if her liver stopped functioning that she would also die:

*I suppose it depends on how soon your liver starts to play up and stop functioning and that must be different in every person what happens, how soon it shuts down and how soon you start to fail* (Kowhai).

Amethyst tells us about planning the future:

*I certainly wasn’t scared of death...I went into sort of doing mode and got all my affairs in order and planned my funeral and everything else* (Amethyst).

**Sub-Theme**

**Spirituality**

The term spirituality has been chosen rather than religiosity because they appear to be different concepts and rightly or wrongly spirituality is frequently associated with religion. Narayanasamy (1991) clarifies her concept by saying: “I see it as my being; my inner person. It is who I am, unique and alive. It is expressed through my body, my thinking, my feelings, my judgements and my creativity” (p.4).

However, Burkhardt (1989) uses the term ‘spiriting’ defined as: “The unfolding of mystery through harmonious interconnectedness that springs from inner strength.” Fundamentally it would appear that spirituality is a search for the meaning of life (Greenstreet, 1999, p.656) but it means many things to different people depending on cultural and values systems that people ascribe to. At different times in people’s lives spirituality comes unexpectedly during times of hardship, tragedy or significant points along the human continuum. All of the patient participants had ‘something’ about them. They appeared to give off a vibe or spiritual aura which is hard to describe. They ‘felt’ more spiritually characteristic or spirited than the clinical participants.
The spirituality pendulum seems to swing from the extreme right to the left with three of the patient participant’s being very pious and full of the Glory of God. There were those in the middle who didn’t ascribe to any formal religious affiliation but still had a spiritual aura or spirituality about them and then there was one how believed in channelling a new age ‘belief’ or some higher being directing his life as we read:

_The guy we read on channelling was from a chap called Kyron. There is no flowery religious stuff, none of it is religious. It depends on the channeller how it gets dressed up...No it is not a faith. It’s just knowledge to know how it all works and what happens next_ (Willkie).

For some of the participants praying was an important part of their daily life as Victoria speaks about others praying for her each day:

_I just know it; I just know when a lot of people have been praying for me. I just know when they have been praying because these little mini miracles have happened_ (Victoria).

She talks about her faith helping her:

_I’ve got a good, good faith and a good belief. I’m not God do it all by himself but he is helping me get through this._

Valhi appeared to have a very strong faith and appeared very comfortable with talking about it especially about dying:

_I don’t consider myself terminal because I know I am going to come back in the resurrection...The resurrection, hopes and coming back are as natural as breathing because there are many examples in the Bible of the resurrection of Jesus_ (Valhi).

Kowhai spoke about losing her faith after the death of her second husband:

_[Spirituality] is a moot point. I don’t know what happened but I was alright after Bill* died but after George* died I just have nothing and I don’t know why. It has just gone._

---

* pseudonyms used.
However, despite her apparent loss of faith Kowhai had a spiritual being that came from her love of growing irises which she became very passionate about and she speaks of gaining strength from the adversities that she faced:

_The more things that you have chucked at you in life I believe it makes you a lot, lot stronger...and I suppose there are some of us who are willing to give it a good go..._

(Kowhai)

Morr is talks about the strength of prayer helping him his family:

_Well I pray about the illness every day and that is probably one of the biggest things. It's probably helped our relationship with our children as well because they are spread around all over the place. But I think it has bought us closer, we were always pretty close_ (Morris).

Anna also spoke about the importance of prayer:

_[Along with hope] religion comes into it as well. I believe in prayers_ (Anna).

---

**Fig 30 Morris’s photograph**

“God Understands”

(Richardson 2009)
Fig 31 Anna’s photograph
‘Desire cometh, it is a tree of life’
(Richardson, 2008)

**Humanity**

The final sub theme of humanity has been included because it is a very powerful statement to conclude the themes for both chapter six and seven. Amethyst believed that hope is:

*The fundamental concept of hope is basic humanity because what else is the point if not basic humanity...Basic humanity is the essence of human emotion.*

One definition of humanity I have is: “the quality of being humane; the kind feelings, dispositions, and sympathies of man; especially, a disposition to relieve persons or animals in distress and to treat all creatures with kindness and tenderness” (Anon, 2010). Martin Luther King, Jr. is also quoted as saying “an individual has not started living until he can rise above the narrow confines of his individualistic concerns to the broader concerns of all humanity” (1929-1968).
The presentation of findings finishes with two quotes from Fleming who became too unwell during my second attempt at interviewing him but these two statements leave a lasting effect: *I feel in a way it’s like leaving a party early. It’s like I have been asked to leave a really good party early. You know one of those parties where you are having a really good time but you have been asked to leave before it finishes...As far as being depressed goes I am not really depressed because I hobble up the hall and find myself whistling so things can’t be too bad can they. I am not sure what I am whistling* (Fleming).

Table 5 is the final concepts that reveal themselves as themes from the transcripts. As already stated it is necessary to identify what is essential and an incidental theme. In using the hermeneutic circle the themes reveal themselves as being unique to the phenomenon of concern. Accordingly, intentionality is the central structure in the essence of consciousness (Husserl, 1913 § 13). It is the patient participants’ words, ideas and snatches of conversation that have formed the basis for the Model of Hope Pyramid that you can see on the next page. It is a mirror image of the doctors Model of Hope Pyramid presented in the previous chapter and there are some themes that pertain to both groups of participants such as anticipation and optimism.

**Summary**
The four major themes discussed in this chapter were: anticipation, positive optimism, realism and resigned with the two sub themes of spirituality and humanity. Anticipation explored the lived space with van Manen speaking about the spatiality of something being out there for us to get, of being aware of our relationships with other. It related to expecting and waiting for things to happen.

The second theme was revealed when the patient’s spoke of their positive optimism. Van Manen expresses this as being the “lived relation that we maintain with others in the interpersonal spaces we share with them” (1990, p. 101) or lived human relations. It relates to the relationality that happened between the patients, their health professionals and their relationships with family and friends. All of the patients wanted something positive to happen and it was an important theme for them.

Realism was the third theme because many of the patient participants viewed their disease process with their eyes wide open. Husserl calls this “bodily selfhood” but van Manen talks about the lived body or corporeality. Almost every day people lived with reality that they had
lost the ability to function ‘normally’ or work. There was a constant reminder that life was very tenuous.

Being resigned to dying or discussing death with resignation and having life cut short was the fourth and final theme. van Manen calls this *lived time* or temporality. Most of the participants acknowledge that time was of the essence and that each of them where facing significant losses. This related to only being able to make little plans, or hating the idea of not seeing grandchildren grow up or families losing their loved ones. All of the patient participants spoke very candidly about being resigned to the fact that they were dying or were going to die in the near future. The two sub themes related to spirituality and humanity seems to be a fitting end to the results section of the thesis. Spirituality was used because it connotes with uniqueness and being expressed through selfhood, thoughts and feelings of each individual person. But it means different things to all of us. Humanity related to the humanness of this project and the essence of being and I believe that it is fitting that this theme has the last word as spoken by Amethyst.

_The fundamental concept of hope is basic humanity...Basic humanity is the essence of human emotion_ (Amethyst).

Finally patients came to the realization and became resigned that in the process of having a non-curative terminal illness that they were going to die from it and not survive. For eight of the patient participants it was about adapting in a normal way, to accept that accommodating death was a normal process of living with their disease. This is not to say that they accepted or were content with the idea, it was just they had to prepare themselves and their families for the ultimate end – death.

The primary aim of this study is to discuss the concept of hope between those who live with a non-curative terminal illness and those who provide care as doctors to this group of people. The next chapter will discuss the concept of hope in more depth and apply it to the findings and thematic analysis that have emerged from chapter five and six.
CHAPTER SEVEN    DISCUSSION

Introduction
This research has been influenced by the disciplines of Nursing, Medicine, Bioethics and Humanities in its quest to understand their concept of hope through the narratives of people diagnosed with a non-curable terminal cancer and clinicians who treat this category of patients. It became obvious quite early into the data analysis that the clinicians’ voices were stronger than the patient participants. However when it came to creating the photographs, the patient participants’ pictures were much easier to conjure and develop because their voices were heard more clearly and spiritually than many of the doctor participants. In most instances the patient participants seemed to exude a spiritual being or aura making it easier to summon artistic thoughts or intentions. Meanwhile I have wrestled relentlessly with some of the clinicians’ transcripts to create their symbolistic photograph.

Introduction
This chapter begins with a discussion about phenomenology and the great difficulty in understanding and using Husserl’s philosophy. A project like this has changed my thinking about how we can make assumptions based on historical knowledge, hearsay or questionable anecdotal evidence. In particular there is past evidence to suggest that a number of doctors can be less than caring, sometimes thoughtless and exceedingly busy to the point of neglect, and they reportedly display gender biases and less than professional behaviour (Callahan, 1998; Rosenstein, Russell & Lauve, 2002). While collecting the data from the clinicians, I left behind that diffidence and awkwardness to emerge understanding a passion for knowledge. As Foucault speaks of the value of being passionate about knowing things:

\[\textit{After all, what would be the value of passion for knowledge if it resulted only in a certain amount of knowledgeableness and not, in one way or another and to the extent possible, in the knower's straying afield of himself? There are times in life when the question of knowing if one can think differently than one thinks, and perceive differently than one sees, is absolutely necessary if one is to go on looking and reflecting at all} (Foucault, 1985, p.8).\]

Thus I have strayed into places where it would be easier to have stayed away and I have probed questions that have not perhaps been asked before so that I gain knowledgeableness
that in turn enlightens others. The essence of hope has been captured from many of the participants without holding any preconceived notions about what hope is or was.

Section I

I feel very privileged to have used Husserl’s philosophy to underpin this thesis despite him never describing a method for data analysis. In much the same ways as statisticians use software to analysis and interpret their data I used Max van Manen’s methodology (1990) to construct meaning from the transcripts whilst at the same time trying to remain faithful to the work of Edmund Husserl and other moral philosophers such as Edith Stein and Arthur Schopenhauer, to help underpin the philosophy of the main themes of motivation, anticipation, positivity, positive optimism, realism, resigned, and hope as driving concepts. Within this vein I have also drawn on the work of Christian Wolff (1679-1754), Karl Marx (1818-1883), Erich Fromm (1900-1980) and Gabriel Marcel (1881-1973).

Max van Manen (2007) writes that “phenomenology is a project of sober reflection on the lived experience of human existence” (p.11). By this he means deeply thoughtful, philosophical and “free from theoretical, prejudicial and suppositional intoxications” (p.11). It is, however, an enthralling and alluring methodology because it offers moments of wonderment and “in-seeing” (Rilke, 1987) right into the heart of things such as being able to dwell deeply into the theory of hope. Rilke talks about the essence of the subject as percolating through like a fine cup of coffee that then goes onto permeate and quench our thirst, and finally touch us (Rilke, 1987; van Manen, 2007). Each of the transcripts was allowed to percolate or steep until finally the essence was extracted by being filtered through the pores of time, distillation and thought. Thus, snippets of conversations have been allowed to permeate in a linguistic milieu exposing commonalities that enabled me to extract connotations and essence out of the text.

In using the hermeneutic circle the themes revealed themselves as being unique to the phenomenon of concern. Husserl’s phenomenology has philosophically enabled me to develop a detailed account of how the experience of the participants represented the essence of hope in the world around them at a particular position on their life-map (Woodruff Smith, 2007, p.41). Husserlian phenomenology is about how we live through conscious experiences in a variety of ways: through touch, sight, thought, judgments, desire, willing, feelings and doings. He wants us to see that we are always conscious “of something” (p.56) or that we are
in the business of practicing living (van Manen, 2007, p. 13). Before we traverse the rocky shores of discussing the identified themes it is important to return to my research question of “how is hope defined and captured within the context of palliative care and what importance does it hold for patients who have terminal cancer or clinicians who care for such patients?” Have I answered the question?

While I have only interviewed ten clinicians, as with the spirit of phenomenology I cannot and will not make any major statistical statements but only speak from the transcripts collected. My original questions about hope and clinicians were:

- Did health professionals have the same hopes as patients who were dying in three months or two years?
- Or did they offer active palliative treatment because the art of statistical probability and mathematics might give the person a fighting chance at a nominal numbers of weeks to months or years?
- Or was it as fundamental as the clinician providing treatment because it is what they are trained to do or because they can?

A full set of questions is offered in chapter six and these were determined after three or four interviews. In keeping with the phenomenological method I have expanded and clarified the questions after each interview until nothing new is discoverable and no different questions arise. Further reviewing of each transcript helped to identify the significant phenomena arising from both sets of interviews, in accordance with guidance from van Manen (1990). As a result, the Hope Pyramid, (see figures 32 and 33) was conceptualised. This model contains four essential themes and three sub-themes taken from the thirty essential sentences from the clinician’s transcripts and four essential themes and two sub-themes that also emerged from the patient participants’ interviews.

The Hope Pyramids were developed to pictorially capture hope as described by the participants of this study. This diagrammatical process contributed to identifying key words that describe each theme. It enabled the use of pictures instead of numbers to represent the proportion of participants who spoke about a concept, which then developed into a theme. For example, nine out of ten clinicians spoke about preparing people to face the thought of
dying and death. This is represented by a large box with the words “hoping for a comfortable death, one without pain and suffering”. As this was spoken about by most of the clinicians, so it was placed at the top of the pyramid. Conversely spirituality, which was only considered by less than a third of the clinicians, is only a third as big as the box at the top, and placed at the bottom of the pyramid. Using the boxes in this hierarchical sense helped identify the eight key themes that are further represented by the participants’ Circle of Hope. The Circle represents this fluidity and movement but with no starting or ending points as each theme flows into one another.
Fig 33 Clinician Participants’ Circle of Hope
Hope Is Embedded within

Being resigned to dying, missing out, leaving early and end of chapters

Realism, being thankful for a good life and being positive

Anticipation, trying something, having a positive attitude and being able to complete activities and getting back to ‘normal’

Whistling a happy tune, standing in my true self and hope is basic humanity

Optimistic, tiny, tiny window of hope, miracles, possibilities and cures

My spiritual belief is hope for the resurrection and coming back and living on paradise earth

Fig 34 Patient Participants’ Pyramid of Hone
### Clinician Participant

<table>
<thead>
<tr>
<th>Essential Themes</th>
<th>Sub-Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anticipation</td>
<td>Contextual</td>
</tr>
<tr>
<td>Positive Optimism</td>
<td>Preparedness</td>
</tr>
<tr>
<td>A Driving Concept</td>
<td></td>
</tr>
</tbody>
</table>

### Patient Participants

<table>
<thead>
<tr>
<th>Essential Themes</th>
<th>Sub-Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anticipation</td>
<td>Spiritual</td>
</tr>
<tr>
<td>Positive Optimism</td>
<td>Humanity</td>
</tr>
<tr>
<td>Realism</td>
<td></td>
</tr>
<tr>
<td>Resigned</td>
<td></td>
</tr>
</tbody>
</table>

Table 2: Data Analysis - Themes
Hope Described as Motivation

Human volition is behind all deliberate actions and each person is aware of their own volition or exercising their will, and the power of willing (Husserl, 1913; Schopenhauer, 1818, Singh, 2010). A person generally can identify what motivates them on the grounds of acting one way or another. Schopenhauer maintains that it is impossible to separate a person who knows from a person who wills; “both are part of the sense of ‘I’ that man has” (Singh, 2010, p.27). Singh writes that motivation can be called “causality viewed from within. In this sphere of human volition the principle of sufficient reason assumes the form of ‘principle of the sufficient reason for act’ or as the law of motivation” (p.27). Therefore, willing or wilful acts can be explained as motives or as motivated wills causing an action. Clayton Colman’s premise is that “being motivated to act is, among other things, having a goal” and “having a goal is being in a state with which the world must fit, i.e., a state with world-to-mind direction of fit” therefore “being motivated to act is, among other things, having a desire” (2008, p.128).

Putnam noted that motives can be traced to two different sets of tendencies of 1) our rational aspirations and 2) emotional repressions (1915). Although within psychology motivational systems have been well described over the years with such models as attribution theory of motivation (Kelley, 1972; Weiner, 1985), theory of volition (Gollwitzer, 1999; Kuhl, 1987), and motivation psychology (Heckhausen & Gollwitzer, 1987), little has been written on how people sustain motivation while living with a life limiting disease or illness. Historically religion has played a crucial role in human motivation in all cultures up until recent times. Religion was the paramount reason for living and working with every action regulated by dogma as a “frame motivation”, disregarding many biological and psycho-social needs that communities may have had (Oerter, 2000).

Oerter (2000) describes frame motivation as always connected with “reality construction and with the necessity to act intentionally in the environment” (p.60). It is always framed within a specific situation and the motivation that people feel, express or desire will be particular to that environment, for example that of palliative care or those living within the dynamics of palliation. In this thesis the main thread surrounding motivation comes from the concept of frame motivation since it is critically bound in a person’s need for reality construction in order to achieve security and control. Because it is not a solitary task frame motivation has an outcome of shared activity between two or more people.
This shared activity is evident from the analysis of data from both groups of participants because of the co-construction of the relationships that developed between and around the patient, clinicians, families and other people. Piaget describes this type of motivation by the way humans recognize the world (1967). Lewin (1936) frames it in terms of the person-environment relations by using the term life-space, while Boesch (1980) introduces the terms subjectivization and objectivization to describe it. Motivation that describes the relationship between individuals within their cultural, psycho-social and spiritual realms is described by such terms as reification and internalization and this was introduced by Vygostski and Leontjew in the late 1970s.

Motivation and Co-construction
Frame motivation, from a cultural point of view, in the context of palliative care offers specific affordances and constraints that can be systematically ordered. This type of motivation sees the individual enjoying life for their own sake, achieving as many goals and objectives as possible, and gaining control over their environment (Leontjew, 1978; Oerter, 2000). One of the main features of this motivational psychology is that, in its classification, the person-environment relationship becomes part of the individual’s experience i.e. palliative care. “From the individual frame motivation, specific goals and motives get a systematic position within the whole self-system” (Oerter, 2000, p.24).

Motivationally from the clinician’s perspective, hope was reportedly about maintaining that emotional equilibrium and being a personal motivator and protector while trying to aim for an ideal given situation. It is this use of a two-way self-consciousness that creates a conscious representation of reality through narrative and spatial transformation (Anderson, 1981). The patients found security in what clinicians were ‘doing’ for and to them, enabling them to maintain motivation to get up each day and seize moments that were precious, because time was of the essence. As Schopenhauer reminds us:

Motives only determine particular acts of will of a particular time, place and circumstances. Motives do not determine ‘that’ I will or ‘what’ I will in general; they do not proclaim the maxim of the whole of one’s willing. In other words the whole inner nature of my willing cannot be explained from the motives, but they determine merely it
manifestation at a given point in time. This will itself...therefore the
body itself must be a phenomenon of the will and must be related to
an individual’s will as a whole (cited Singh, 2010, p.31-32).

Each of the participants from both cohorts of people shares common narratives that originally
belonged to the patient. It is the patient’s illness story but treatments or care translate into
spatial transformation – the person can see beyond each day even when active treatment have
moved towards palliation. It gives them a vision or “something to hang their hat on” (Dr X).
The patient participants could mentally visualize cancer cells being beaten into submission
and were motivated to undertake activities that they believe would do this as Morris tells us:

_I made a decision really that while I was feeling OK I would just do everything as I normally
would and I have been on quite a strict exercise regime ever since I first got diagnosed
actually and I just see it as being way of giving the cancer cells a hard time and they are not
going to have an easy time and one day I see them saying “oh come on guys, we had enough
of this lets get out of here_ (Morris).

Motivation as a theme revealed itself from both the clinicians and the patients; the former
being motivated to ‘fix’ things and the latter using motivation to keep going and wanting
things ‘fixed’ to enable that “vital force in us, that is, the will-to-live” (Singh, 2010, p.124).
Living an inspired life takes courage but facing death has that unenviable way of destroying a
person’s dreams and inspiration. It takes an immense amount of courage to rise above feeling
desolate and let down by something beyond a person’s control. “The world is no less in us
than we are in it, and the source of all reality lies within ourselves” (Schopenhauer, 1844,
1907, p.486-487). Each of the patients had to listen carefully for their true inner voice such as
Morris tells us:

_It sort of makes me a bit more determined. If he [the doctor] says ‘you can’t do something’
I say “yes I can.” I take everything he says and retain what I want to and ignore what I don’t
want_ (Morris).

Morris was inspired and motivated to keep going but he never made long term plans:

_I don’t see any reason in feeling sorry for myself or anything because nothing is stopping me
at the moment and I try not to think too far into the future because you tend to just take things
day-by-day... I think my attitude and everything I do gives me more hope_ (Morris).
It was Morris’s small daily actions towards doing things that truly kept him motivated. His strict routine of exercise and prayer were inspired habits that became part of the character he was. To look at Morris he portrayed a person completely in control with life. His strong faith helped him immensely and Tolstoy writes that faith is the power of life and living gives man a belief in something. “Without faith one cannot live…” (1905, p. 20).

Staying motivated for each of the patient participants in many ways goes back to the theory of survival because they wanted to live; this was their strongest desire. Not wanting to go to some ‘other’ place without their family and friends caused a great amount of distress. Desire in this sense is elevated to its highest order in a Maslowian hierarchy of needs. Maslow’s second hierarchy relates to the human motivation of survival and protection of one’s self and others within a community (Papalia & Wendko- Olds & Feldman, 1998).

The key to a person’s motivation is his or her desire to ‘will’. Will and motivation gives people the key to their own phenomenon, reveals who the person really is, the inner mechanism of each person’s being, their actions and movements (Schopenhauer, 1844, 1907, p. 100). Motivation involves a series of psychological subsystems such that which encompasses implicit and explicit cognition, emotion, and arousal. These basic human psychological structures have existed long before we learnt how to write or record language. However, Kant uses an old fashioned term to describe the doctrine of feeling pleasure called motivational hedonism or the doctrine where pleasure is the chief good (Foot, 1978).

The doctors were motivated to support people to live as long as possible. Hope was about being motivated to work at trying to ameliorate symptoms, motivating patients into that good place in their heads and in their selfness so they felt empowered to address or encounter stages of the illness continuum or journey. I am especially drawn to this exert from Dr B’s transcript as it helps to give some perspective to our humanly demise whether it is as a young adult or as an octogenarian. It perhaps goes some way to explaining why we seem to be frightenened of the concept of leaving this earth but not of death itself, as Dr B says:

_No other animal has to put up with knowing that he will be dead in six months and being told to get on with it...we are the only animal that really contemplates its own demise for more than five seconds_ (Dr B).
Schopenhauer (1818, 1969) wrote of this being the point in a person’s life cycle as the “terror of death rest for the most part on the false illusion that the I or the ego vanishes, and the world remains. But the opposite is true…the innermost kernel of the ego endures the bearer and producer of that subject, in whose representation alone in the world had it existence” (p. 500) Fortunately, the individual is not alone with this intriguing but frightening situation because the clinicians, in the main, wanted to help patients from prognosis to death. The doctors talked about the practicality of carrying out their roles as health professionals and fixers but they also spoke about understanding hope. An exception was Dr A who did not believe in the concept of hope or not conceding as stated in a previous chapter, that it was not his job to hope for people:

*I never consider hope. It is not part of my job...Hoping is about anticipating and wanting things to go well* (Dr A).

He was the only one who did not offer his concept on the verb hope. In many cases it would appear that oncologists and radio-oncologists go to great lengths to keep people’s hopes alive. The American Code of Medical Ethics from the early 19th Century placed an emphasis on it being the responsibility of the clinician to sustain hope in whatever amazing technicolour coat hope is dressed as (Post, 2007). Percival once described doctors as the “minister of hope and comfort to the sick” (1803, 1847, p. 2640) and Aristotle suggests that “hope is a waking dream” (C 200 AD) but treatment must be in keeping with what person and personhood means. Pope Pius XII reminds us about what it is to be man when he suggests:

*...Man (and whoever is entrusted with the task of taking care of his fellow man) has the right and duty in the case of serious illness to take the necessary treatment for the preservation of life and health... But morally, one is held to use only ordinary means according to the circumstances of persons, places, times and cultures, that is to say, means that do not involve any grave burdens for oneself or another. A more strict obligation would be too burdensome for most men and would render the attainment of a higher, more important good too difficult* (1957, §4)

Thus medical intervention must not simply be about saving lives, because life is not the greatest good; it is a life that has meaning in human terms that can be called good and worthwhile (Kuhse & Singer, 1999). It has to be said that “offering medical intervention and
maintaining hope is ethically appropriate when there is a reasonable chance that medical procedures will be effective and that their outcome will be meaningful in terms of what it is to be a person” (Kluge, 2006, p. 74).

Much like Schopenhauer, the issue of dying and the will to live became a central problem. A person’s will or the will recoils from death yet it is always to be reckoned with in each person’s mind. It has both an implicit and explicit bearing on a person’s being (Singh, 2010) with us having an “explicitly rational recognition” of death as well as having a gut feeling about our own mortality where we can be inclined to become anxious coping with this “knowledge and feeling” (Singh, 2010, 119). From what many of the doctors said it became imperative, when caring for people who are facing death, that they were enabled towards self-motivation and have their hopes, dreams and desires supported. Dr S talked about miracles but he also added that he would not unnecessarily prolong someone’s life. This is what he talks about in terms of hope:

*I think it is always important never to destroy hope and I always say [to patients] miracles happen that we can’t explain” and it is something that you have got to hang onto* (Dr S).

People like Frankl can attest to life bringing miracles out of the midst of suffering when he was motivated to survive in the concentration camps during the Second World War when he states:

*There is also purpose in that life which is almost barren of both creation and enjoyable and which admits of but one possibility of high moral behaviour: namely, in man’s attitude to his existence, an existence restricted by external forces […]. The way in which a man accepts his fate and all the suffering it entails, the way in which he takes up his cross, gives him ample opportunity – even under the most difficult circumstances – to add a deeper meaning to his life. It may remain brave, dignified and unselfish* (1984, p. 88).

This statement leads us on to think about the Epicurean notion of humans being motivated and being attracted to pleasure while having an equally strong dislike of anything painful. These can be said to be two primary human motivations “all desire implies a want and all wants experienced are painful...A conscious being whose powers were equal to his desires would be perfectly happy” (Rousseau, 1964, p.303-04). *Death is said to be the “real inspiring genius or muse of philosophy” (Schopenhauer, 1844, 1907, p.463) and for that*
reason Socrates defined philosophy as a “practice of death”. Indeed without death there would hardly have been any philosophizing (Schopenhauer, 1844, 1907, p.463). Many of the clinicians were aware that the patient participants were going to die. It was not a matter of if but when, so keeping people feeling self-motivated and positive was sometimes the primary reason for a consultation decision. Fleming was motivated to try and extend the time he had left:

*Ah the only thing is to try and extend the time that you have got left. And that’s the thing that I just hope that I do to get a decent amount of time perhaps to do some of the things that I have put off doing* (Fleming, 2009).

The great written works of ancient, medieval, and early modern periods of history such as Aristotle's *Rhetoric* (350BCE) More's *Utopia* (1516), Descartes' *The Passions of the Soul* (1649), Hobbes' *Leviathan* (1651), and the writings of Jeremy Bentham over a century later, differ as to their application of hedonism or pleasure and being motivated towards attaining pleasurable pursuits or situations. They regard the main human activity next to survival as a self-interested desire to search and seek comfort and pleasure while avoiding discomfort and pain at all costs. Many of these early writers regarded motivation and desire as arising from man's conscious knowing. People were labelled essentially as rational beings and, on the whole, generally able to understand desire and capable of being responsible for any chosen actions (Graffam 1958, pp3-4). The religionists from times of antiquity to the present emphasized our emotional drive as seeking all things good, ethical and holy. Conversely all things labelled evil, unethical and unholy became powerful conceptual motivators that encouraged people to try and behave in the former manner at all times.

Thus hope in the context of being motivated was a theme that revealed itself from both cohorts of participants. The clinicians’ prime motivations were towards fixing things while the patients were motivated to keep going, as a will-to-live and wanted things fixed. Many of the patients were inspired to keep going while never making any long term plans. They were motivated towards small short term goals that were achievable and usually attainable, and in most instances not unrealistic. The key to a person’s motivation is his or her desire to will and this is significant to each person’s own phenomenon, reveals who he or she really is and is central to the inner most mechanism for every human action.
Next the concept of anticipation, which was also expressed in the transcripts by both cohorts of participants, is discussed. It relates to anticipating treatment outcomes and the next bi-clinical phase, move or treatment round, or anticipating the future when things were not progressing as well as could be expected or hoped for.

**Hope and Anticipation**

It can be argued that anticipation is a highly important mental resource that integrates both cognition and affect, with its primary function being exploration, a cognitive process (TenHouten, 2007). Scognaamiglio reports that every human action involves three processes: 1). Anticipation from present to future; 2). Regressive determination from future to present: which selects from current human resources and 3). Realisation from present to future: a real process outside consciousness (2010, p. 56).

In the twentieth-century Husserl (1913-1938) and Bloch (1938-1947) philosophically wrote about anticipation. Husserl talked about things that are actually given are always surrounded by a double halo of what has just happened and what might be going to happen. It is something that has gone but its effects are still being felt and there is an expectation that something is going to happen – anticipation is an emotion where we automatically develop expectations, which may or may not happen as Husserl suggests:

> When experience does not confirm a subject's anticipation, the intention goes "unfulfilled" and demands that the subject revise prior beliefs, thus achieving a degree of objectivity. When experience confirms a subject's anticipation, the intention gets "fulfilled," again achieving a degree of objectivity (1913, 1982, § 13).

Stein also spoke about anticipatory behaviour in her work on “The problem of empathy” (1917/1989) suggesting that being empathic to someone else’s anticipation or living world was vital. Bloch (1938-1947) writes extensively on the anticipation of the future in “The principle of hope.” This book bears the resemblance of an encyclopaedia into the categories of the future where he talks of hidden components or action potentials waiting for triggers to activate them.

However, the best-known definition of anticipation is Rosen’s: “an anticipatory system is a system containing a predictive model of itself and/or its environment, which allows it to change state at an instant in accord with the model’s predictions pertaining to a later instant”
(1985, p. 341). Behaving in an anticipatory way is suggested by Scognamiglio (2010) as adjusting present behaviour in order to address future problems. In other words, an anticipatory system takes its decisions in the present according to forecasts about something that may eventually happen.

\[\text{Anticipation involves classification and analysis of the physical world, that its constitutive events and processes can be understood and predicted. With an explication of anticipation’s cognitive essence, by considering the evolving historical understanding of its main functional component exploration- over the last century (Hartmann, 1951, p.65).}\]

As far as we can understand, the human brain, in comparison with animals and birds, is our conscious state that has the freedom to conjure or represent that which is not yet real, therefore the anticipation of something is always a mental process (Hartmann, 1951; Scognamiglio, 2010). The future is only immanent to consciousness, where it is used to plan and represent actions (Hartmann, 1951).

**Anticipatory behaviour**

Anticipatory behaviour refers to the behaviour that depends on predictions, expectations or beliefs about future achievements and goals. The term behaviour concerns actual and internal decision-making, internal preparatory mechanism along with learning and already learned actions or activities (Butz, Sigaud & Gérard, 2003). The key elements in relation to people who are living with a life limiting illness are looking ahead and acting according to predictions, expectations and aims. For example in anticipating the next round of chemotherapy when a person’s CEA was trending down and other blood results are ‘normal’ as Kowhai tells us:

\[\text{Ah Dr W didn’t say but he said the CEA has come down. Umm, which was what they were waiting for and he said we will see what happens after the next treatment and the next blood test, I suppose (Kowhai).}\]

The patient participants were anticipating what was happening next in the treatment phase; they looked forward to “good numbers” as they talked about their blood results. They were goal-orientated to move to the next lot or round of therapy and they prepared themselves for those bad days.
As Kowhai and Anna tell us:

_The only side effects that I can say that I feel is that lose my taste buds and yeah I think it makes me a bit tired and because you lose your taste buds you can’t be bothered eating_ (Kowhai).

_I seem to have a series, I had 31 weeks and ups and downs with that, vomiting and dysentery ah then they gave me a break for about six weeks and Dr P said we will try a different type of chemo but it wasn’t hitting the spot and didn’t achieve the results and I found that one very hard because it affected all my nerves_ (Anna).

Anticipation has been defined as a “synonym for prediction or expectation – the simple act of predicting the future or expecting a future event or imagining a future state or event” (Butz, Sigaud & Gérard, 2004, p.2).

For the purpose of this thesis I have used Merriman-Webster’s (2008) definition of anticipation:

1. A) A prior action that takes into account or forestalls a later action.  
   B) The act of looking forward; especially: pleasurable expectation.
2. The use of money before it is available.
3. A) Visualization of a future event or state.  
   B) An object or form that anticipates a later type.
4. The early sounding of one or more tones of a succeeding chord to form a temporary dissonance.

These definitions emphasize looking into the future rather than the actual effect of the look (Butz, Sigaud & Gérard, 2004). It is this forward-looking that many of the participants reflected in their narratives. When a new concept is learnt is called latent learning, however the knowledge of this learning is not immediately expressed. Instead, it remains dormant, and may not be available to consciousness specific experiences might need this knowledge to be demonstrated. More recently, cognitive psychology has revealed further evidence of anticipatory mechanisms in learning (Hoffman, 2003; Hommel, 1996), attention processing
(Pashler, Johnston & Ruthruff, 2001) and object recognition tasks (Schubotz & von Cranon, 2001).

Potential future experiences can be said to be anticipated by the experiencing subject at the respective time. Husserl calls these “intentional horizon” of whose intentional content they are anticipated for (Woodruff Smith & McIntyre 1982)

*What will be realized only in the future can influence the present only if in some way it ‘pre-exists’ its realization; and on the other hand this is thinkable only if this pre-existing is intended as the reality of another way of being to which it has first to arrive. It should be also, through an inner strength...Brought into presentness, but without already becoming real in the present* (Hartmann, 1951, p. 65).

From the time of Hippocrates medicine has been seen as a noble activity, one that support peoples hopes, positivity, spirituality where the moral obligation for clinicians is to provide care and treatment to a vulnerable group of people. This responsibility suggests Pellegrino (2000) is:

*The necessity of trusting the physician and relying on his or her character, in the physician's invitation to trust, and in the sick person's moral claim on the physician's competence and on the use of that competence in the patient's best interests rather than the physician's own interests* (p.147).

Rosen (1985) described anticipation as the fundamental difference between living and non-living systems. A predictive model is said to be one that “provides information about the possible future state(s)” (Butz, Sigaud & Gérard, 2004, p.2). Despite many research projects and discussion of anticipatory behaviour, explicit investigations have been undertaken from 2004. Butz, Sigaud & Gérard (2004) suggest the key things that appear to have been identified are that anticipatory behaviours can provide stability in an otherwise chaotic environment and may guide how a person behaves in the future. Anticipatory mechanisms enable “goal-directed focus” with faster reactivity time but more importantly may result in greater adaptability within dynamic and changing environments like palliative care or when a person is faced with a life limiting illness (Boden, 1966; Butz, Sigaud & Gérard, 2004; Gross & John, 2003).

The reciprocity and co-operation needed with groups of people during challenging times, such as those captured during this project, may improve by preventative state anticipatory
behaviours. This is a special kind of anticipation when an anticipated undesired situation makes a person adapt behaviours in order to prevent a situation occurring (Boden, 1966; Gross & John, 2003). An example of this would be putting smoke detectors in a house to alert people of a potential fire or taking an umbrella if the weather looks like it might rain and you want to avoid getting wet and possible a chill from wearing wet clothing (Gross & John, 2003). Physically anticipating a response is reflected in the interviews with patient participants as they were encouraged to take anti-nausea medications in the event that they may develop nausea and vomiting after a treatment phase.

Thus, it becomes clear that anticipatory behaviour, which refers to the behaviour that depends on predictions, expectations or beliefs about future achievements and goals, was evident in the data generated by this project. Cognitive behaviour processes can be beneficial in many and varied forms but for all of the participations it was a significant mechanism for enhancing a person’s will to live when living with a life limiting illness and those who care for such people. The area of cognitive behaviour processes underlying motivations, emotions and anticipation needs to be studied in greater detail to understand the significance of adaptive learning systems with respect to people living with a non-curative terminal illness.

**Hope and Positive Optimism**

Although some doctors see death or patients imminently dying as a technical defeat, the patient may see it as “unthinkable and inevitable”. Alternatively, while other doctors see people as mortal beings that will die after living a long and fulfilling life, the patient, however, may not have developed such concrete ideas on the subject. Seemingly it is always something that happens to someone else (Charon, 2006, p. 22). Although many doctors reacted in a matter-of-fact and very clinical way, this is not the view that the patient participants held, according to their comment provided during the course of this research. Generally patient participants were given honest ‘news’ about their prognosis and they were sometimes given percentages or mathematical probabilities. However differences in human nature and behaviours were evident. Some participants refused to hear any talk of statistical percentages while others wanted all the cards laid out of the table. Furthermore, others just believed that God would support them through no matter what curved ball was thrown as Dr X tells us:
Well I try to be honest but not absolutely negative. Obviously you do give bad news but I think that it is important to try and temper that with some good news and positivity that you can do as opposed to what you can’t do…That there might be a positive outcome that is of importance to you, tempered by the realization that it might not happen (Dr X).

But for many of the patient participants, their focus was being hopeful about maintaining normality and anticipating pleasurable moments. Doctors gleaned their positivity and optimism from a biomedical perspective and intuitive thinking. The vignette below tells a sad story but it also projects feelings of optimism from the life of a butterfly despite the story starting with the word death. This is the same perspective from which eight of the clinicians were coming. They instinctively knew that most of their non-curative terminal patients were going to die in the near future. So, like the butterfly, the story started with the concept of death but positive optimism was still evident frequently.

Death ....is a necessary consequence of the enjoyment of life. If the butterfly were not to die, were he to live only the ordinary age of man, the compass of the earth would not be sufficient for his posterity: but he lives without fear of death, and dies without regretting life...When the rainy Hyades bring back cold and the southern blast, he is not grieved at the short duration of his career; but consigns to Nature the care of his progeny which he is destined never to see. He is content with his lot, having fed on flowers, and having lived until the sun was ready to enter the region of darkness. Finally he seeks the shade at the bottom of his favourite plant, and stretching out his wings, while he fixes his little feet in the ground, he expires in an upright position (Boden, 2004, p.375).

If an optimist is not relying on future change in this life or the next, “then he must claim there is a preponderance of good over evil, happiness over misery, when the world is considered as a whole” (Boden, 2004, p.373). Fromm (1970) speaks of hidden harmonies but in this life sometimes the wicked prosper and the virtuous suffer. It can be argued that this is a genuine form of optimism and resurrection is not the creation of another reality after this life but the transformation of reality in the direction of greater aliveness.

Man and society are resurrected every moment in the act of hope and faith in the here and now; every act of love, of awareness, of compassion is resurrection; every act of sloth, of greed, of selfishness is death. Every moment of existence confronts us with the alternative
of resurrection or death; every moment we give an answer. This answer lies not in what we say or think but in what we are, how we act, where we are moving (Fromm, 1968, 1970, p.29).

From an empirical perspective, in which many of the clinicians were situated, Husserl believes that “empiricism becomes positivism when the model of knowledge is that which is achieved in the “positive” sciences” (Woodruff Smith, 2007, p. 322-23). Fleming’s wife spoke about the positivity of how Fleming maintained his hopefulness:

It makes him feel like he is doing something and while there is still treatment going on there is still some room for optimism and hope. He is thankful that he has had two years since his initial bowel surgery and without any treatment he would have been dead in six to twelve months (Fleming’s Wife).

Micah was a patient who I had cared for and was not a participant discussed my research project in depths with me as well as telling her story. Her example of stoicism, tenacity and positive optimism deserves to be heard in the thesis:

Micah was a fifty year old woman who had been diagnosed with breast cancer some fifteen years ago. At the time only the deranged cells were removed from her breast with Micah declining other formal treatment modalities, but instead used meditation. Just as she was beginning to enjoy life she developed a sore back and a limp. After weeks of physiotherapy and spa baths Micah sought traditional medical advice. CT scans revealed extensive metastatic bony cancer throughout her very elegant and well maintained body. It was only now that she permitted radiotherapy and some oral chemotherapy. For weeks Micah made the pilgrimage miles from her home determined to keep up with her treatment regime with optimism. The four hundred kilometre journey in the back of a car or by ambulance was repeated many times in the desire to live longer. However, Micah died in a hospice with her meditation music chanting in the background.

Hope, according to Fromm, is paradoxical as it is neither passive nor unrealistic forcing circumstances that cannot occur. It is like a crouching tiger that will jump only when the moment for jumping comes (Fromm, 1968, p. 9). When hope has gone, life has ended actually or potentially (p.13). It is, however, the intrinsic structure of life, or the dynamic of a person’s spirit. Faith is the conviction about the not yet proven, the knowledge of the real
possibility. Micah chose to put herself through hours of painful travel because she was possibly trying to make up for not having conventional treatment in the beginning. She had a real sense of guilt about using alternative therapies but she remained ever hopeful that a combination of therapies would give her more time and the doctor made it possible to continue with treatments by sustaining her with optimism and the desire to live and “a shot glass of desire is greater than a pitcher of talent” (Munthe, 2002).

But I always believe there is something that I can offer and that there is always something that I can do and things just don’t stop with diagnosis like cancer or terminal illness umm and I guess it is helping the patient find that too (Dr E).

Brody (1981) believes that disclosure of the truth is almost always coupled with an element of hope; doctors are often “persuasive modulator of patients hopes” (p.1411-1412) since by maintaining active positivism, it can help sustain the doctor-patient relationship (Kodish & Post, 1995). There is, however, a paucity of literature with regard to clinicians remaining optimistic or supporting their patients to maintain optimism so they can have a positive attitude towards life for as long as possible. MacLeod & Carter (1999) suggest that hope “is central to the existence of an individual... the perceived existence of a positive future for the patient and his or her family” (p.316). This is further supported by the findings from the doctor participants in this study which identified that positivity and optimism are important emotions to display when talking to people with a terminal diagnosis.

Our role is to hold the door open so that hope and optimism may enter and to psychologically invigorate and sustain the patients throughout the duration of their illness. Who knows: our attitude and approach may act as an energizing source influencing their immune system. We all respect the small random compliments in our daily lives...For our patients with tumours these compliments assume a special significance...I tell them of our limited knowledge in the biological evolution and leave them to interpret the present crucial situation themselves without deterring them from giving up the fight (Yazagil, 1999, p. 1089).

Christakis & Lamont (2000) believe that many doctors are overly optimistic about how much time terminal patients have. This is further supported by von Roenn & von Gunten (2003) who say, “as physicians, we seem to be systematically miscalibrated toward optimism...in other words we often wait until it is too late to tell the truth” (p.571). But only one of the ten patient participants believed they would live much longer while the other nine were realistic
about the time they had. Furthermore, most of clinicians were honest about how long each person could expect to live. For those clinicians who appear to subscribe to the concept of hope, they are able to “cultivate a practice of identifying realistic goals” and maintain optimistic ideals. However, essential hope oscillates within a “gray zone” of contradictions and despair (Weingarten, 2010, p.9).

Hope was expressed, by five of the clinicians, as being contextual depending upon a person’s cultural, social and belief system. When a clinician offers treatment modalities, this gives patients’ a “medicalized hope”. Positive illusions, hope and optimism, along with despair, are considered to be related to a person’s fundamental need to live and the need to be alive. However, this is tempered by the illness trajectory and, within certain cultures; the concept of the good death can be eagerly awaited.

Husserl (1931) wrote of “transcendent acts” which include emotions like waiting, preparing, having a presentiment, suspecting, being curious, fearing. These emotions were mostly expressed by the clinicians as they spoke of their ability to perform curative and palliative treatments as part of a person’s treatment plan or regime. The more evaluative emotional acts of apprehension, anxiety or anguish were mainly expressed by the patient participants. Anna speaks about her own positive optimism and the following excerpt from her interview captures a sense of excitement:

*I have been back on chemo from February this year and then he [doctor] suggested that there was this new drug that was out. I’ve had six treatments and I have lost all my back pain and I feel wonderful and I had that on Friday. The doctor is pleased about because I must be the longest one that has been on it because most have pulled out after five treatments but I have had six* (Anna).

Furthermore, Dr W expressed his thoughts on the subject, also with a great deal of energy:

*I guess what I see is really important for people or what I think is important for them or what I have come to believe is important for them is that they can maintain an optimism with a positive attitude towards life, ah towards what’s happening to them... So they don’t give up early and so it’s really a question of helping people find what they can still be optimistic about and not, and that won’t be about being alive* (Dr W).
Therefore, the findings reveal that maintaining optimism was a vital concept for many of the participants particularly the patients. It was a state of keeping uplifted and focusing on the positives that could be achieved. That is not to say people were always in this state because there were times for all of them when life was very difficult and it was hard to find things to be positive about. However, at the time of interviewing the patient participants they all talked about remaining in a positive upbeat state so they could tackle each day.

**Hope as a Driving Concept**

This theme reflects hope as a need to drive the illness phase or as hope providing the means to look at each new day with a careful and contemplative mind’s eye. The driving force of hope is like a plan of action where hope is a “cognitive counterpart of planning” (Pettit, 2004, p. 157). It is managing the good with the bad, whilst at the same time being free from the bleakness of thinking about the worst case scenario. This theme can be seen to contrast to optimism because hope as a driving concept makes it an essential desire. Where hope is an intentioned desire that can sustain and support the patient at whatever stage they maybe at, optimism is more spontaneous and perhaps more unconscious. One of the key things that hope as a driving concept does, is that it lifts people out of the quagmire of panic and depression and gives them some direction and a force to carry them through (Boven, 1999; Pettit, 2004). Hope is instrumentally valuable as a driving force and counteracts risk aversion by spawning more “attainable constitutive hopes” (Boven, 1999, p. 670). A hopeful attitude can bring about a successful end even if that end is death.

Hoping is a matter of actively engaging with the limitations that cancer brings and the affect that it has on the future that people want to inhabit (McGeer, 2004). McGeer talks about hope as being “though variously characterized as a cognitive attitude, an emotion, a disposition, and even a process or activity, hope, more deeply, a unifying and grounding force of human agency. We cannot live a human life without hope…” Wiesel (1960) notes that without hope there could be no driving force during the dark days in a Nazi concentration camp: “The instinct of self-preservation, of self-defence, of pride had all deserted us. In one ultimate moment of lucidity it seemed to me that we were damned souls...seeking obligation-without hope of finding it...Within a few seconds, we had ceased to be men...Yet I felt myself to be stronger than the Almighty (p.34, 83).
Aristotle contrasted courage with hopefulness in that it underlies the “confidence involved in both courage and natural high-mindedness, and it underlies the deliberation and self-confidence necessary both to improve one’s circumstances and to cultivate the excellence of character” (Gavlee, 2000, p.477). Snyder contests that hope is a cognitive activity that is about goal setting, finding a way to achieve those goals, and “tapping one’s will power” to move towards those specified goals (McGeer, 2004; Snyder, 1995, 2000). This tapping of will power is the driving concept that is evident from the clinician’s transcripts.

*In essence hope is the driving concept that when the chips are down there is a will to survive, to live* (Dr Q).

Emerging from the twenty participants was this drive to strive for the same goals - that of living longer on this earth but, that when the time came, the goal shifted to being that the actual dying and death to be as comfortable as possible. There was a sense of real genuineness and unconditional positive regard for the patient participants by the clinicians. No one person spoke of despair or disappointment. People were obviously upset and annoyed by being asked to leave their lives early as Fleming wife tells us:

*Accepting the doctor’s treatment has given him the optimism to carry on with life but he understands that it is not going to cure him* (Fleming’s wife).

This is further supported by Fleming.

*I feel in a way it’s like leaving a party early. It’s like I have been asked to leave a really good party early. You know one of those parties where you are having a really good time but you have been asked to leave before it finishes* (Fleming).

Valhi shares a similar sense of being driven when she states:

*I am still going strong and still able to do things so I am quite grateful for what I have got...I thought if you can give me six months, six months that I can do things...I can still knit and sew so I still keeping doing crafts and I still get on the computer. My brain still works so that is good. I can still e-mail my friends* (Valhi).

This was expressed by the doctors holding on to the subjective feelings.
And some of that is by helping the person realize the context where they are now living because we as humans don’t like uncertainty and we don’t live well with uncertainty. So actually framing where the person is and taking out of it the fears they have regarding their future can be so helpful. That person is then able to realign their own horizons and take out of it the gremlins that threaten things that they thought and to better contextualize where they are at, at any one point in time (Dr Q).

It is this realigning of a person’s horizon to better understand their place within the world so that:

By doing it repeatedly it helps the patient realize a) they are cared for and b) they are being given help along the journey to help them see what is in fact, hope. That, they can rise up for this next part of the journey (Dr Q).

Hop ing well has been called an art or a gift – “of character, background, current physical and social circumstances, and other contingencies of nature. However, it is also partly a skill” (McGeer, 2004, p. 125). It is a skill that develops over time with sufficient knowledge and experience and, as a driving concept, there has to be what McGeer called “collective hope”. This is where individuals hold common hopes with others from the community to which they belong. Braithwaite (2004) speaks of community hope as not something that is imposed but that it needs to be tempered by ideas, deliberation, experimentation, and cold analysis (p.11).

Dr X describes this as:

Well I guess you have got an expectation that there might be a positive outcome that is of importance to you, tempered by the realization that it might not happen, I think that is my concept of hope (Dr X).

As a driving force hope has to be seen as being able to “nurture the human spirit in times of disappointment and despair. Fear, like hope, is a contagious emotion”. It quickly robs communities of momentum (Braithwaite, 2004, p. 11). Consequently, this theme was harder than any of the other to formulate, but despite this the inclusion of hope as a driving concept is really a cornerstone, or a lynch pin, supporting or holding the other themes together. Hope drives people’s future goals and it represents a disciplined mental game in which two or more people work to achieve the same outcome. Collectively they are driven to reach the same
endpoint. Thus that the findings from this study illuminate how hope drives people forward, and that this journey is winding and sometimes tortuous, at times disappointing but with open and receptive narrative care patients can have their hopes enhanced and supported.

**Being Realistic and Resigned to Living with a Life Limiting Illness**

*Dr X’s photograph*

‘Hope as a driving force’

(Richardson, 2009)
The death of the poor

It is Death, alas, persuades us to keep on living:
The goal of life and the only hope we have,
Like an elixir, rousing, intoxicating, giving
The strength to march on towards the grave:
Through the frost and snow and storm-wind, look
It's the vibrant light on our black horizon:
The fabulous inn, written of in the book,
Where one can eat, and sleep and sit oneself down:
It's an Angel, who holds in his magnetic beams,
Sleep and the gift of ecstatic dreams,
Who makes the bed where the poor and naked lie:
It's the glory of the Gods, the mystic granary,
It's the poor man's purse, his ancient country,
It's the doorway opening on an unknown sky! (Baudelaire, 1857, 1952)

The themes ‘being realistic’ and ‘resigned’ to dying or reaching the resignation that death was approaching have been merged together because they are so closely entwined and it is difficult to untangle one from the other. These concepts were discussed interchangeably by many of the patient participants as they expressed their view of cancer and dying through the eyes of reality. The threat to the patient participant’s personhood and lives was a constant reminder of how tenuous life really is.

Realist philosophy is based on the existence of social structures which operate independently of our conception of them, conditioning, being nonetheless dependent on that human activity to endure or change (Searle, 1995). Realism, or reality, is about facing what is ahead and accepting or acknowledging the reality of a given situation. Sayer (1992) suggest that realism distinguishes between the real, actual and the empirical. The real exists regardless of our understanding of it, including objects and their structure and powers. The actual refers to what happens if and when these powers are activated. The empirical is the sphere of experience that can refer to the real or actual (Sayer, 1992).

Some real structures may not be accessible or observable, and example of which is the Hubble telescope or the moon, but they can be inferred by reference to the observable through the use of our empirical inquiry. Reality does not just consist of experiences and actual events but it is influenced by structures, powers, mechanisms and tendencies that facilitate the actual events that may or may not be experienced (Searle, 1995; Pawson, 2000). Pawson & Tilley (1997) refer to realism as the: “Embeddedness of all human action within a
wider range of social processes as the stratified nature of social reality. Even the most mundane action makes sense only because they contain in-built assumptions about a wider set of social rules and institutions” (p. 406).

One of the defining features of those prematurely dying or those receiving palliative care is its “morphogenetic nature”, which is its capacity to change shape or its metamorphic ability to become something unexpected or suddenly different (Archer, 1998, p.195). As already discussed death is an all-pervasive and significant part of the moral fibre of many cultures and communities (Callahan, 1998; Field, 1996), however the Westernized notion of death and dying can be seen as “qualitatively different from previous eras and societies” (Field, 1996, p.255). Sontag (1979, 1989) argues that, during different epochs, certain diseases denote particular metaphorical resonances for diverse cultures. Illnesses such as leprosy, HIV/AIDS, tuberculosis, the black plague and swine flu epitomize and encapsulate time periods of grave fears within communities. Cancer, suggests David Field, can be a “metaphor for the fear of death because it typically appeared unexpectedly” (1996, p. 256). Four types of awareness have been identified as significant communication patterns that can occur between the patient and other people that are said to shape the end stage of someone’s life.

Glaser & Strauss (1965, 1968a) and Quint (1967) identified communication patterns between health professionals, patients and families as being pivotal to shaping the dying process for patients. Closed awareness was the communication situation where relatives and staff knew of the patient’s terminal prognosis but the patient did not. Suspicion awareness was where the staff and relatives knew of the diagnosis and or prognosis, and the patient was suspicious that there was something they were not being told. Mutual pretence was where all parties knew of the diagnosis and or prognosis but chose not to discuss and even pretended that everything was alright. Finally open awareness was the circumstances of all parties being open about the situation and acknowledged the terminal process and prognosis.

In this current study open awareness was the awareness context but it still meant that the self-identity was irrevocably changed. Catherine Exley’s study Testaments and Memories: negotiating after-death identities (1999) is notable for the fact that many of her forty participants reported “avoidance” surrounding the discussion of death and dying. Ten years on, this current study found that almost without exception all of the patients understood how grave their realities were and spoke openly about dying and death as Amethyst suggested to us in chapter five:
I went into sort of a doing mode and got all my affairs in order and planned my funeral and everything else (Amethyst).

Morris faced the reality of each day as he had come out of semi-retirement to pay for his on-going treatment:

*I have had absolute control from day one... Dr W said historically there will come a time when all of a sudden you won't be feeling so good but I accept what he says but get on with my life basically* (Morris).

The consistency with which many of the patient participants described the reality of their future in respect to death was remarkable and demonstrated their concept of being realists. All except one person spoke candidly about their prospects and prognosis. Hedley became very reflective but realistic about his life and what the future held for him:

*It is a big decision to make, it is your life that you are dealing with but on the other hand I have got to make it by Monday so it just might come to the flip of coin* (Hedley).

In terms of realism, Killick (2009) writes that death and dying are unexceptional and whoever we are we will all succumb. Much of the conflicting emotions surrounding death and dying is related to the acceptance or being resigned to the inevitable. Somerset Maugham speaks about our inability to accept that death faces all of us:

*It is the tragedy of our day that these humble souls have lost their faith in God, in whom lay hope, and their belief in the resurrection that may bring them the happiness that has been denied them on earth; and have found nothing to put in their place* (1923, 1952, p. 827).

In Maugham’s *Sanatorium* (1923,1952) Mr Chester believed that an early death should only come to those who have “led a wild life, if he had drunk too much, played around with women or kept late hours. He would have deserved it. But he [Mr Chester] had done none of these things. It was monstrously unfair” (p. 823-824). The seminal book on dying by Kübler-
Ross (1969) speaks about the fifth stage of dying as ‘acceptance’ as being a stage that “is almost void of feelings” (p.99-100). As far as the science of medicine goes, death has given it a reason for striving for more technical advances and complex medications in an attempt to put dying on the back burner (Killick, 2009). Aeschylus describes death as “better; a milder fate than tyranny” (*Agamemnon*, 1.1364).

Robin Maugham quotes his uncle (W. Somerset Maugham) as saying that “dying is a very dull, dreary affair. And my advice to you is to having nothing whatever to do with it” (1978, p. 6). It must be said at this point that Maugham was ninety-five at the time of saying this. Chekov (2003) writes in his short story “Ward No. Six” that doctor Andrei Yefimich Rabin holds the view that no matter how bright or famous people have been they will suffer pain, grow old and die and “you will yet be nailed up in a coffin and thrown into a hole” (p.111). Bulgakov (1995), in his *A Country Doctor’s Notebook* takes the death of a patient as a symptom of incompetence or as a health professional lacking the necessary skills to save people after he had travelled through a blizzard to save the patient he writes that he was “tormented by the thought of the dead baby and the mother I had left behind” (p. 102).

Much has been written about the chasm between the doctor and patient when it comes to discussing such things as death, mortality, causality and emotional thoughts surrounding dying; however throughout the transcripts of the patients this was never described. Each patient participant was getting on with their own sense of immortality as if their disease process had written a recipe or prescription for how death would probably come, dressed in a unique clinical and personal way for the individual. With the exception of Victoria there was no evidence of the angry descriptions that can be found in the literature about dying (Jones, 1993; Raunkier, 2009; Tolstoy, 1886, 1960). Instead they spoke of life being cut short but that this was expressed in very matter of fact ways while the clinician participants spoke about realism and being resigned to caring for people who were going to die and having a percentage of their patients die before it was considered ‘their time’ to die. Support for such views is provided by John Donne (1896) in Holy Sonnet Ten “death, be not proud, though some have called thee mighty and dreadful, for thou art not so...And soonest our best men with thee do go.. (p. 162-163).”

All participants spoke about death itself as being something that they were not afraid of. However in reality it was not being ready to die that concerned nine of them, with the
exception of Burt. He was resigned to dying within the next few days to weeks after our interview. He was ready to die because he could see nothing beyond having to take more and more pain relief or sedative medications to keep him comfortable.

*Life is finished for me and I have wrapped up my affairs so I am literally waiting to go upstairs. I’ve had a good life and I have no regrets. When the chips are down you just have to shuffle off. I am no good to anyone and I am very wary* (Burt).

Victoria expressed more emotional suffering:

*I break down from time to time and that’s okay. Like one of my friends came around the other day and just everything seemed to be packing up...and I was an emotional heap* (Victoria).

She was not ready to discuss dying except to say:

*I know jolly well there is no way I am going to make it. But I have these wee dreams* (Victoria).

Willkie spoke about the resignation of closing one chapter of his life and beginning another:

*At that stage that is the end of chapter one and then we start talking about chapter two which I am hoping he can to attack the tumour in some way and perhaps prolong the prognosis a bit* (Willkie).

Furthermore he also talked about the possibility of being resigned to the doctor suggesting that his condition was beyond help:

*Well he thought it was the end of the line but in the end there is still these other things to consider, but not until we have got around this jaundice problem which is not fading fast* (Willkie).

Another patient participant, Valhi, talked about looking forward to her afterlife:

*So yes I am looking forward to coming back and helping to make the earth a paradise. So yes that is my hope that I will sleep for a while until the time is right and Yeah I will be*
back... All the Witnesses believe the same but that is why we are a great comfort to each other because we all have the same kind of hope and the same topic of conversation (Valhi).

In terms of this theme, ‘resignation’ or being resigned to dying is a concept that we all have to consider at some point in our life. It is how we accept it when Dr B described, we are the only animals that have to consider our demise for more than five seconds. For many of the participants had they had two to three years to give dying a thought or ponder over. Fleming’s wife spoke openly about him being dead by Christmas of 2008 and he did die in December that year. There was sadness but not anger or a public display of anguish. He was just getting on with the day-to-day things as best he could albeit in terrible pain. It was not long after his interview that he needed the help from the hospice to alleviate some of the pain. The image generated is of this man hobbling down the hallway to take a phone call from the hospital while whistling a tune with a tear in his eye. He was sad but remained stoically optimistic for a ‘good’ end.

**Hope is Contextual and Spiritual**

Within a spiritual context hoping is about submitting one’s self to the future and opportunities, whatever that might be. It is about exploring our own powers of spirituality as opposed to religiosity. Watson identified faith and hope as one of ten curative components in a humanistic model of nursing (1979). She talks about faith and hope building on a humanistic-altruistic value system that then goes on to promote holistic care that ultimately produces positive health outcomes. In some of the literature, as already stated, hope and faith are inextricably link and synonymous with one and other.

“Now faith is the substance of things hoped for, the evidence of things not seen.” (Hebrews II, 1). Bloch (1958) suggests that no one is ever satisfied with merely wishing (p.1354). Healthcare professionals constantly prepare people for something, for births, for surgery, for this infection to be cured or for that blood test to show if a cancer has stopped growing or has metastasized into something else. The act of healthcare provides us with a social need but it is not solely based upon knowledge and the “art-like application of its practitioners”, but people are at the centre of external determinants (Ten Have, pp 13, 1995). Medicine is very much part of our cultural values and norms as a unified science of disease. Being ill can be seen primarily as being in an existential category and having an illness like non-curative terminal cancer is:
A way of being a human person. When I not only have my life, but also give expression to it, when I not merely have my body, but also am my body at the same time, then it is also the case that I am not only having my disease and suffering it but also make my disease. Thus being ill is a response of the person to his or her own individual existence (Ten Have, 1995, p.11).

Hoping has an “aura of agency about it” (Boven, 1999, p.679) in that hoping may lead us to overestimate the likelihood of the hoped for thing (McGreer, 2004). Hope was made to stay in Pandora’s Box of earthly ills by the ancient Greeks and the Judeo-Christian subscribed to the thought that hope had special powers (Scioli, 2007). Saint Paul placed hope beside faith and love in the scriptures “for now we see in the mirror darkly, but then face to face...So faith, hope, love, abide, these three and the greatest of these is love” (I Corinthians 13:8) and “May the God of hope fill you with all joy and peace as you trust in him, so that you may overflow with hope by the power of the Holy Spirit” (Romans 15:13).

One of the earliest definitions of hope is described in the Oxford English Dictionary as a “safe island in the midst of a wasteland”. William Cowper, an eighteen century poet writes that hope is “an anchor firm and sure, that holds fast the Christian vessel and defies the blast” (cited Scioli, 2007, p.137). Valhi talks about her strong spiritual and religious faith as being the driving force for her still being alive. After only a few weeks of chemotherapy she stopped all further treatment because of the side-effects:

Being a Christian I have got the hope of the resurrection hope so even though I was reading through the information sheet for research participants, you think of terminal cancer. I don’t even consider myself terminal because I know I am going to come back there in that resurrection. There is a promise there in the Bible (Valhi).

Valhi lived the longest of all the participants except for Amethyst who is alive at the time of this publication. Valhi lived for about four years in relatively ‘good’ health until the last few weeks.

The most unusual of the belief systems to be reflected within the transcripts is Kryon of Magnetic Services. Lee Carroll (1989) contests that he began to channel communication with
an entity from a higher dimension called Kryon. Kryon is described as an angelic loving entity from the Source or “Central Sun who has been with the Earth since the beginning” and belongs to the same “Family of Archangel Michael”. The information published by Carroll is intended to help people ascend to a higher vibrational level. “The ultimate goal is the reunion of body, mind and spirit...to cleanse and raise the vibration of the mind, emotional body and physical body to such a degree that they all can be reunited with Higher Self. One's Higher Self becomes more integrated and operative on all levels and you can align more fully with these higher vibrational energies” (Zeramby, 2011, p.2)

This is reflected in an excerpt from Willkie’s transcript where he talks about his spiritual beliefs:

_The guy we read on Channelling was from a chap called Kyron. There is no flowery religious stuff, none of it is religious. Depends on the channeller ah how it gets dressed up. They are all telling the same story and there are thousands of people doing it. But Kyron was straight to the point and it is almost scientific though because he is an electronics engineer and we could relate to it and understand it straight away. I found it absolutely fascinating, in fact it is the only plausible explanation of our reality in everything that religion tried to tell us and screwed up. So I have not time for organized religion at all and so from that point of view I am pretty sure that I know what is going to happen and it doesn’t frighten me (Willkie)._

Within all of the twenty transcripts five of the patient participants and three of the clinicians had strong belief systems. Others talked about religion or spirituality as Hedley describes it:

_I don’t have any religious hang ups and I am not worried, I not worried about death. Either your dead and that’s it, you haven’t got much say. Ah I’m perhaps more concerned about things going wrong and living the rest of my life in pain and destroying what quality of life you have got left. That’s really the situation that I am in at the moment where I have got to make a choice which has got the less risks (Hedley)._

Dr B’s comments on spirituality were similar to seventy-five percent of the others clinicians when he speaks about it as already stated:
My spiritual beliefs? I think you become fertilizer when you are dead, when you are dead you are fertilizer. I don’t think I have any particular spiritual needs that need to be filled (Dr B).

Wright (2002) describes people as spiritual beings with spirituality being expressed religiously or humanistically. He writes that “spirituality transcends the here and now by reaching both beyond and within the self, and has the capacity to search for meaning by addressing the big questions of life and death” (p.127). As such, spiritual care has the ability to cross the borders between faiths, cultures and traditions. Personhood is about seeing people in all their uniqueness, foibles and discovering individual life purposes and internal values (p.130). Spirituality, rather than religion per se appears to be founded on the assumption that we are all spiritual beings, transcending the here and now. Within nursing and medicine, caring for someone both as a spiritual being and ‘spiritually’ is about responding to faithful and religious needs as well as humanistic needs to whatever belief system to which someone ascribes.

Dr Q talked about hope in context of his spiritual beliefs:

*We literally have similar worries and issues world-wide. Whichever culture and whichever religion we are all the same. We all face fears and we all deal with the hope issue...where there is true hope and wishful thinking and it is like a continuum between wishful thinking and hope. I think hope is initially described in life as an expression that represents that human endeavour and human spirit that will not die (Dr Q).*

Victoria speaks about her strong faith sustaining her and her family:

*I’m a Christian and I’ve got a good faith and a good belief...God understands that you can’t be praying all day to him and he knows what you are going through and you thank him and get on with it. I think there is something to be thankful for (Victoria).*

Dr D talked about faith and hope synonymously when he says:
I think a person's faith has a lot to do with how hope works for each person within their particular culture...There are those who are agnostics who don't ascribe to a faith at all and it is different for them (Dr D).

He talked about people of different cultures embracing death:

There are some people who just can't wait to die so they can go to heaven...Asian cultures believe that when they die they will come back as better people (Dr D).

The tendency for the patient participants to be more spiritual than the clinician participants was easier to conjure in their symbolistic photographs. Do people who have a life limiting illness exude a spiritual being that is not there for well people? This question cannot be answered or explained with surety from the data generated by this study. However, this may be due to the small number of participants who shared their experiences.

Hope and Preparedness
All of the clinicians spoke about being prepared for their patients whether it was for treatments or just to discuss a person’s progress. They also spoke about preparing their patients for the next phase of treatment or to expect the next illness phase. There was actual physical preparedness of completing tests before the next round of chemotherapy or seeing if radiotherapy had been successful, and there were times of getting the patient prepared for surgery or a major procedure. Patients were discussed at multi-disciplinary meetings as part of that preparation for the next step.

Is about just maintaining positivity towards life and those around them...it is the preparedness to help patients just redefine their goals (Dr W).

Then there was the spiritual and emotional preparedness about talking with a patient and their families, the nursing staff and other people when it came time to think about moving beyond actively doing things. This was very painful for many of the clinicians as telling someone to prepare themselves for the final phase – death was not or never is an easy task. The patients had to prepare themselves to tell their families when active treatment was no longer viable. Dr B talks about how people are prepared by creating an environment to enable a hopeful state:
It is the same with hope you try and can create an environment that allows people to do that it but you can’t give it to them. It is an emotional state you can’t get somebody to be hopeful. I don’t think (Dr B).

The two cohorts of participants understood the need for both qualitative and quantitative hope. For the doctors this was the particular hope that could sustain their clinical practice while caring for patients with life limiting illnesses. For the patients their particular hope was being able to live in relative peace not thinking or planning too far into the future, mostly pain free and with a positive optimism that could get them out of bed each day.

The themes of motivation, anticipation, positive optimism, resignation, realism, preparedness, contextual and spiritual represent what hope is for the participants. Hope is a basic human response for our desires to want events or things to happen, and it is a basic human emotion and humanity is the essence of all human emotion, therefore hope is a critical element with regard to survival. While people are actively seeking and receiving treatment whether it is traditional cancer therapies, privately funded surgeries and treatments, and palliative care sustained by successful spiritual hygiene, hope and optimism can be maintained and supported until a person has ceased to be a cognitive being. Hope is not what you and I might want for someone, but it is like the notion of individual autonomy or empowerment. These are things we are unable to give someone else, but as health professionals we can support patients so that they might realize their ‘hoped’ for desires and in doing so we must endeavour to find out what they are.

This research focused on gaining an understandable meaning of hope through narration from the lived experiences. Unexpectedly the clinicians’ dialogue reveals that they do not come as a “one size fits all” nor did they bear out earlier misgivings of being like those ‘other’ doctors. There was nothing to indicate traditional styles of paternalistic doctoring. Hope was eloquently described by many of them which would indicate that they have previously considered it as an important emotional commodity.

Of particularly interest was determining if people who paid for treatments were more hopeful. Interestingly many of the participants paid for different aspects of their treatments for a variety of reasons and none of them expressed being more hopeful because they had paid thirty to one hundred thousand dollars for their treatment and care. Eight of the ten patients
had paid for some or all of their treatment for up to a year, or longer in Morris’s case. Private care did not give people any greater longevity but it is possible that SIRT is much easier to tolerate than other forms of chemical therapy with significantly reduced apparent side effects.

While many of the patient participants received active treatment until the disease had progressed beyond treatment, and in some cases within two or three weeks of dying this could be seen as a negative side to hoping in its broadest context, in that it gives people ongoing hope for remission when clearly this was not possible. The one major difficulty that emerged in doing hope-work research is that many clinicians have trouble responding to the truth about a diagnosis and the prognosis or rather the telling of the truth at the right time, there needs to be a greater emphasis during medical training to help support new and emerging clinicians in the future for when it is appropriate to have a truth telling session. There will be some patients, like Victoria, who did not want to have ‘the talk’ but this conversation needs to be held at an appropriate and timely time at some point. Interestingly all of the five participants that were attached to one facility appeared to be more ‘death orientated’ and they all spoke of dying within the next year to eighteen months of our interview.

Finally, while considering the patients’ dialogue and, despite it often not speaking out as loudly or as forcefully as the doctors, it became necessary to consider and explore the concept of empathy within the context of people facing a life limiting illness. Empathy is not a significant theme but I believe it to be an essential component of hope-work. In an attempt to understand the role that it plays within the field of palliative care I have used the work of Edith Stein to briefly examine various facets of empathic caring in the next section of this chapter.

Section II

Hope and empathy

Drawing on the legacy of Stein (1917, 1989) it begins as Sawicki (1997) talks about “a constructive philosophy of empathy” (p.222) as the “human bodily life itself affords direct access to the interplay of natural causality, cultural motivation and personal initiative in history” (p.iv). “Empathy is a process wherein an individual is able to comprehend the psychological state of another” (Travelbee, 1971, p.43). Edith Stein argues, somewhat
controversially, that it is based on the idea that a person’s experiences are given to us (1917, 1989, p.3).

It has been said that there is a tightly woven culture within medicine and nursing that sometimes only permits language and perception in a guarded non-informative manner (Gillet, 1993). This can lead to exclusions and limit displays of feelings and emotions. However, the caring side of medicine is also evident in practice. According to Stein (1917, 1989) this occurs through a blending of the conscious and intuitive effort of touch, presence, thought, empathy and belief together. This happens despite differences in traditions, cultures, the self and others between the doctor and the patient. It is however, well recognized that we live in a multicultural world and while the basis for this section is orientated within Western thinking and philosophies, the concept of empathy extends across many cultures. We must consider empathy from the perspective when clinicians are faced with the hopes of others that may not coincide with their own notion of hoping or within their cultural dynamics when they leave connotations of hope to someone else as Dr A tells us:

_Hoping is about anticipation and wanting things to go well. I leave hope up to the families and friends. I don’t get into hoping at all. I don’t consider myself to be a hoper but a fixer_ (Dr A).

**Steinian philosophy on empathy**

It was Stein’s (1917, 1989) interest in “one’s own experiencing of other people as human beings; that is, how people are available to one another to be understood” that formed the bases of her work (p.2). Stein writes “empathy deals with grasping what is here and now…I know what is expressed in facial expressions and gestures, but also what is hidden behind them” (1917, 1989, p. ix-7). She took the stance that empathy is more than just the foundation of Husserl’s philosophy of Science; it is grounded in the difference in each person’s experience and the paths that individual persons follow in pursuit of truth. “All who seek truth seek God, whether this is clear to them or not” (1917, 1989, p. 272). Stein writes for us her description and interpretation on the subject: “Empathy constitutes for us an experience of another human body being in all his or her complexity: body and member of a body, fallen and redeemed, vulnerable and transcendent, imperfect and loved…” (Stein cited Meier, 1998, p. 135). Parson (2005) writes that the general tenets of phenomenology and Husserl’s brief description of empathy are difficult to understand because of his “parchment for starting over
again”, while previous to this Kolakowski (2000) stated that “his antididactic way of writing” often discouraged readers (p.5). This made the study of empathy from a Husserlian point of view unfinished and complicated.

While exploring notions of hope with patients who have terminal cancer and their doctors who treat them it was necessary to consider the role that empathy plays, particularly in the field of palliative care. Haney (1994) suggests that empathy is a means to the knowledge of humanness and that the knowledge we have surrounding human nature can support and encourage empathy. Stein believes that it is possible to “empathize and sense in” or consider it as “feeling-into” another person even though one does not explicitly experience what another undergoes (1989, p. 15).

As health professionals it is important to be aware of the essential hopes and desires of a person with terminal cancer. Verducci (2000) places empathic phenomena into three distinct concepts: aesthetic, sympathetic and compassionate empathy (p.67) although, here the focus is on: compassionate or epistemological empathy. It is somewhat easy to reflect on where empathy might have a role within the modern clinical setting but it becomes more difficult to understand the ‘what’ and ‘how’ of the concept. At the same time as pondering the perplexing issues surrounding hope it becomes important to consider the significant role that empathy plays in the reality of healthcare today.

Empathy must be considered through its limitations. We cannot presume to know what it is like to have a terminal disease, thus it is impossible to walk in another person’s shoes. Every lived experience is about a lived experience within the healthcare relationship (Stein, 1917, 1989). We can see someone’s pain or an expression of pain in a person’s actions but “pain is not a thing and is not given to me as a thing even when I am aware of it “in” the pained countenance” (p.6). But we can walk beside a person who is suffering pain and provide necessary support as Stein proposes in her complex thesis on the problem of empathy.

There are two sides to the essence of empathy or empathic acts as our own experience announces another experience which in turn may draw us towards this experience or feeling “we may turn toward the foreign experience and feel ourselves led by it” (Stein, 1989, p.19). It is this knowledge gained from a foreign experience that can be called empathic information, from which perceptions of particular feeling or feelings arise. Alongside this an
understanding of a person’s essential hopes and what they ‘will’ to happen as the person experiencing a terminal illness are also needed. In healthcare, the ideal situation is that health professionals are empathic towards the hopes, goals and desires of those facing death if they are achievable and realizable. “Hope is related to dependence on others, choice, wishing, trust and perseverance, and courage, and is future orientated” (Travelbee, 1971, p.78-80).

**Representing empathy, hope and willing**

Empathy has the potential to influence people by increasing knowledge of the self and others (Meier, 1998). Being empathic in the presence of hope acknowledges that a person living with terminal cancer has *their own* particular personal future that a person believes they have (Cutcliffe, 1996). We can see or grasp expressions of pain but we cannot experience the root causes or the origins of someone else’s pain (Stein, 1917, 1989, p.7). Hope can be seen paradoxically existing as an experience in a particular time or in a continuum for a patient who is dealing with their mortality (Tanis & Di Napolit, 2008). In hope there is an alternating balance of things that are possible one minute and impossible at a later time (Tanis & Di Napolit, 2008; Kylma & Vehvilain-Julkunen, 1997; Kylma, Vehvilain-Julkunen & Lahdevitra, 2000).

Where willing just signifies a wanting that may be acted upon or not, an empathic act describes the doing or actualizing a feeling, thought or representation. It is where a foreign thought is given or shared by someone other than me. Empathy can be construed as a feeling-into rather than the willing of something. It is the taking of that foreign experience that is then intuitively picked up by another (Stein, 1989). Therefore maintaining an empathic understanding of the situation, attending to and spending time with patients can inspire and actualize hope for many of them by keeping the notion of achieving goals, desires and wishes alive (Kodish & Post, 1995). Pfänder’s (1899, 1967) sense of will or hope goes further than this by suggesting that “willing is the only kind of inclining that engages the very core of the ‘I’ or that which is willed is always thereby meant as something realizable” (p.8). His work helps to locate the need for Stein’s (1917, 1989) empathy when terminally ill patient’s proffer ideations of *their* hopes and hoping to clinicians. However, the strength of association between hope and the act of willing something requires further exploration.

Murdoch (1966, 1997) ascribes to the idea that there can be no willing intention to act upon. Hoffman (2008), on the other hand, writes that “passions or desires could be regarded as
providing reasons for action on the grounds that the mere fact that we have a desire or passion provides a reason for satisfying it” (p. 45). He does not see passions or desires as passive states but as intended or actual states that can bring into being what we will. It is suggested that one of the greatest influences when a person is diagnosed with terminal cancer is that hope is maintained by clinicians ‘being there’, being truly present, keeping optimistic expectations alive and showing an interest in each encounter to maintain personhood (Flemming, 1997). Being intuitive and perceptive also allows empathic engagements to foster and facilitate those hoped for things by a person who is terminally ill.

While we might expect that the perception and reception of profound empathic moments may happen, clinicians are often faced with more subtle forms of this emotion when patients are receiving treatments and palliative care. Thus, there is a need to know more about how human experiences is empathized or how a shared lived experience from the inside can be acknowledged so that the deeds or actions of another are motivated towards a purpose. Stein (1916-1917, 1989) states it as the means “of inter-subjective access to motivated coherences of all kinds” (p. 105-6).

Dissonance between aesthetic empathy, sympathy and compassion

Empathy can be described as the dermis or a ‘getting below the surface’ of an expressed situation – an act of being perceptive and as previously mentioned, “is the experience of foreign consciousness” (Stein, 1989, p.11). In acknowledging the experience that someone is having, we fully expect that experience or our affect resonates with theirs. With a state of empathic feeling or intuition: 1) we perceive the act or state, 2) internalize this perceived state and 3) acknowledge the state (Stein, 1916-1917, 1989, p.10) and it enables us to self-examine and re-evaluate our states of being as written by Stein (1916-1917, 1989): “By empathy with differently composed personal structures we become clear on what we are not, what we are more or less than others” (p. 116).

It is this standing side by side feeling similar and evaluating the causal situation as separate persons that clearly demonstrates an empathic emotion and “we become clear on what we are not, what we are more or less than others. These, together with self-knowledge, provide an important aid to self-evaluation” (Stein, 1916-1917, 1989, p.105) Stein’s empathy requires that we use affective resonance, cognitive understanding and distance at the same time we
grasp another’s “emotional and situational reality” (Verducci, 2000, p.78). However, empathy is not sympathy or being sympathetic to someone’s thoughts or feelings.

When considering empathy from a clinician’s perspective whilst continuing to actively treat a person’s symptoms, a positive future still exists for that person in their mind. Conversely, any individual that holds the balance of power or who has the power to inspire hope can bring about a loss of hope, either temporarily or permanently when cure becomes palliative.

The function that it (hope) serves is to make life bearable for people and they construct a whole process or a paradigm around it that allows them to live in the absence of distress or as close as they can to it. And so it would have to be intentionally personal in the same way that pain is totally personal. (Dr B)

The capacity to empathise requires the development of theory of mind – an understanding of one’s own and the mind of others. Such development begins in infancy and is propelled by opportunities to interact socially and thereby learn about and reflect on how the mind works (Perner, Ruffman & Leekham, 1994). Closely linked to empathy, compassion involves the additional motivation to relieve the distress that is identified and felt by way of empathy. Demonstration of empathy and compassion predicts a range of valuable elements in the caring relationship, including increased patient satisfaction (Reynolds & Scott, 2000) improved diagnostic accuracy among clinicians, a reduction in negative symptoms and greater patient compliance (Coulehan, Platt, Egener et al., 2001; Lindholm, Uden & Rastam, 1999). Higher ratings of competency among students have been demonstrated (Hojat, et al., 2002) and a reduction in patient anxiety are clearly factors related to a successful empathic relationship (Fogarty, Curbow, Wingard et al., 1999).

To support patients with terminal cancer it is necessary to understand the empathic experience of their hopes not, only as a means to help others but for the therapeutic relationship to succeed between clinicians and their patients as part of the reciprocal care that flows to and from doctors and patients (Janssen, Walker & MacLeod, 2008). As each person has individual levels of hope, these require respect that is addressed empathically not sympathetically. Illnesses can make us focus on ourselves to the extent of being into ourselves as already stated by Marcel (1949, 1951b, p.188) the hopeful man is always open
and available. Availability can be seen broadly in the context of “the temporal character of human life” and sustains what I the self hopes and desires (p.188).

Stein (1916-1917, 1989) describes the world that we live in as not only a world of physical body, “but as a sensitive living body belonging to an I and an I that senses, thinks, feels, wills-hopes-desires” (p.5). Knowing empathically as the ‘I’ grasped in what is in the here and now but a person can never walk in another’s shoes or actually experience firsthand what that person knows and feels. While we have the ability to share someone’s joy we cannot actually (primordially) feel the joy. This notion of joy cannot “issue” from us but in our non-primordial experience we can be led by the actual feeling of joy felt by another, or led by the actual experience we can say that empathy is an act of perceiving from another.

When there is an unintentional agenda that is unknown to patients, especially those dealing with issues that pertain to one’s very existence, more open and supportive dialogue needs to happen. Empathy needs to extend beyond a few willing to be perceptive to emotions, especially towards the hopes and essential hoping of those with terminal diseases (Streubert-Speziale & Rinaldi-Carpenter, 2007). Empathy is being intuitive, and paying genuine attention to and accepting another’s experiences (MacLeod, 2001). “To empathize is to share a lived experience from the inside: to let one’s ‘I’ be led along through the coherent flow of an episode in which an alien or foreign ‘I’ is living originarily” (Sawicki, 1997, p.145). Medicine expects an altruistic response from clinicians when a person faces sickness, hurt and the prospect of dying (Shapiro, 2008). A person with terminal cancer may believe that all of the clinicians that they see share the same beliefs and caring philosophy as they do. Yet this may not be the case, as suggested by anecdotal evidence from clinical practice.

There is a need to understand this dichotomy of beliefs more fully as Valhi tells us.

Yes my faith in the resurrection hope. That I am not going to be tortured or anything when I die and I will simply sleep until the resurrection. Hope, yes so that is the main thing that keeps me going (Valhi).

**Being empathic in the face of death**

Death has been described as the principal evil of human life, a series of preventable diseases, (Callahan, 1998a) and at times optional even when people have a life limiting illness. This is
an integral part of how the Western world hopes and where it might be intimated that there
cannot be hope without fear, humiliation, anger and anxiety (Deyo & Partrick, 2005).
Palliative or conservative treatment may be summarily dismissed because of the desire that
the patient may have to add a few more weeks, months or years on to their life despite the
ramifications. However, it can be contested that some patients seem unable to trust their
instincts and believe that false hope or ‘medicalized hope’ is better than no hope where
clinicians do everything to save their lives but can never cure them (Callahan, 1998a).

That is a responsibility that I have but I don’t think that I have ever said to someone that the
situation is ‘hopeless’; so I would really look at it from a slightly different view point that and
say there is always something that I can do but I would put it in a negative way and say, look
you know it is not hopeless, there are always something that we can do (Dr X).

While we might expect that the perception and reception of profound empathic moments may
happen, clinicians are often faced with more subtle forms of this emotion when patients are
receiving treatments and palliative care. This is in keeping with our Western biomedical
model of caring for people who are dying. Thus, there is a need to know more about how
human experiences is empathised or how a shared lived experience from the inside can be
acknowledged so that the deeds or actions of another are motivated towards a purpose. Stein
(1922, 1970) states it as the means “of inter-subjective access to motivated coherences of all
kinds” (p. 105-6).

The major thing that I can do is to try and relieve pain. Ah and I mean pain in the broadest
sense not only physical pain but also emotional pain as well. And to be reassuring from that
point that medicine can help. I don’t think that the situation is ever, or an actual situation is
ever hopeless because there is always something that you can do (Dr X).

Stein (1916–1917, 1989) believes that empathy is much more complex – by recognising a
lived experience, clarifying another person’s emotional state and then standing side by side
with that person. In practical terms, clinicians are able to transmit this knowledge to enable
and support courage and wisdom in order to reduce feelings of being overwhelmed and
helpless when caring for patients with a life limiting illness. Thus it can be argued that hope
becomes a person’s career when they have been given a terminal prognosis. It becomes their
business to stay alive at all or at most costs. People sustain such amazing courage and retain
high hope that out of all of their suffering they can get some respite and a length of quality time with their families and friends unhindered by ministrations or therapies. Deep down terminally ill people know that there is no cure, but well people can never understand what it is like to live with the constant thought of dying. We can never know what it is like to have just a few months or years to live particularly if the person is considered too young to die. Hope is one of the most important emotions that inspires, encourages and sustains all of us. Throughout this research project I have had the privilege to observe incredible hope, courage and endurance.

Empathy is a complex and difficult concept to understand and health professionals will not always make a connection or share an experience with every person that they meet. It is however, well recognized that we live in a multicultural world and while the basis for this section is orientated within Western thinking and philosophies the concept of empathy extends across many cultures. However, if we remain open and receptive, health professionals can consider empathy as emotional knowing but an experience of solidarity and intimacy that cannot threaten our ego.

Not only is empathy a safe and permissible emotion, it is the lynchpin to a caring patient-clinician relationship and we must embrace this. Empathy has the potential to bond us or support a special relationship regardless of who we are to one another. Despite our own perceived inadequacies, underpinning the ability to empathise is the development of a theory of mind and this can only happen as we continue to build on the interactions that face us each day as health professionals.

**Hope as an Essence of Basic Humanity**

Young breast cancer patients, despite bodies full of bone metastases and unrelenting pain, will themselves to walk, to take a shower and hope that they can go home from hospital in a bid to claw back some sense of normality. Lying in a hospital bed trapped in a body that screams out in pain only dulled by energy sapping and brain numbing opiates and analgesia that constipate and corrode the rest of the person’s system, is imaginably worse than torture. Days of unrelenting tedium broken by ablutions or ‘caring’ are difficult to imagine if a person has no hope. Sometimes when a person has struggled with a terminal disease for many months, and they are finally given the news that no further clinical palliative treatments can
be offered, a person who has gripped on to hope, will die quickly like slipping away from a party early.

Fleming articulated this when he describe his terminal disease and life as though he was at a really good party but that he had been asked by Death to leave the party early. He considered that he had had a good life but it was ending sooner than he would have liked but he was accepting of it. At the same time, he tried the best possible treatments for his cancer that he could afford so that he might ‘put off’ leaving the party too early. He remained hopeful until the end because without hope he couldn’t get out of bed each day. This study has taught me that I can never know what I would do if I was facing terminality or how I would be. I believe that each person has their own hoping level and it must be respected and guarded. If talk about dying doesn’t happen then people are sustained by false hope which is like allowing a person to climb to the top of a steep mountain and pushing them off the top.

Clinicians’ must get comfortable talking about dying even when a terminally ill person wants to be ‘fixed’ continually. It is our duty to make sure someone who has sustained several pathological fractures and who keeps getting put back together by the surgeons just because they can, understands that with each new ‘mending’ surgery the person is potentially getting physically weaker and less able to move about. Those of us who have not lived with a non-curative terminal cancer must never presume what it would be like and how we would react. The participants who went on to have treatment until the last few weeks of life made this choice for their own personal reasons. Their clinicians gave them every opportunity at the possibility of a cure or a miracle but certainly the ‘good death’ was what was wanted by both the clinicians and the patients. Ethically or being medically sustainable appeared never to be at issue or considered.

Of course it would be naive of us to think that each patient doctor consultation was a bed of roses. Moments of hope can be seen as structurally dynamic but generally there were fluctuations as the desirability and feasibility of each hoped for goal was redefined as the nature and course of each person’s disease progressed (Shall, Hall & Leader, 2009). The progression of the disease would wax and wane depending on what stage the treatment phase or tumour growth was at. There were times of great despair such as Hedley tells us:
I was pretty, pretty shocked after when I saw my oncologist and he told me I have only six to twelve months and a few days later I got a visit from the hospice nurse. I was shocked (Hedley).

It was a shock having the hospice nurse calling, because he did not consider that he was terminally ill. It was this face-to-face reality that he was going to die sooner rather than later that affected him. Hedley then went on to say he was being offered an option which gave him the optimism and motivation to try something as he states:

There is a real bit of hope now...I was thinking if I could get one more summer I would be quite happy (Hedley).

For most of the clinicians the patients’ hopes and desires were always paramount even if this was not explicitly expressed in these terms. It was the essence of their care and treatment that amounted to a concept of hope. Treatments or palliative care were offered as olive branches to help ameliorate the dire situations that each of the patient participants found themselves to be in. In this case the motivation towards "peace" has a deeper meaning that includes profound emotions such – hope, anticipation and motivation – not simply just the absence of the symptoms from disease process.

Mohrmann (1995) describes hope as being an emotion as well as an emotional attitude. Regardless of a person’s changing circumstances there are four basic tenets of hope: Desire; a belief that what one hopes for is according to one’s values; the notion of what is hoped for is attainable and achievable; and actions are designed to encourage and sustain hope to achieve the hoped for thing or things (Simpson, 2004). In most instances the health professional and the patient attempted to negotiate some of the hoped for things. These things were as the themes suggest, around anticipation, motivation, realism, spirituality, honesty, basic humanity, positivity, within a cultural and socio-political context and finally a preparedness to die. None of the patients were not frightened of death they just wanted more time on earth and were worried about the process of dying.

Hope has an unintentional and unrealistic side that should not be called hope. This is the hope that is built up by the can do attitude that we have here in New Zealand. After listening to all of the interviews and re-reading the transcripts, all of the participants with cancer just wanted
time. In most instances they were happy to have active treatment because they believed that it would give them more time in this world. There was one exception to this and that was Valhi as she speaks of having no more chemotherapy:

The quality of my life with chemo was so poor. I had been vomiting all the time and was sick and had dysentery and it wasn’t halting the cancer, the cancer (CEA) was still going up. The doctor they had here at the time said if your best friend is your bucket beside the bed then you are better off using what time you have left for a better quality of life which I wholeheartedly agreed. I thought if you can give me six months. Six months that I can do things with rather than lie on a bed vomiting for the next year. There wasn’t really any choice it was a case of doing as best as I could (Valhi).

On the matter of dying Valhi suggests:

I think if you have got a positive sort of hope and not morbid about it and every day is a blessing you do what you can do and get on with it... the Bible talks of death as just a asleep that you will wake up in God’s due time for the resurrection hope so I am just going to go away and have a long, long sleep and come back. So technically I don’t consider myself terminal because I know because of the promises in the Bible that I will be back...So yes I am looking forward to coming back and helping to make the earth a paradise. So yes that is my hope that I will sleep for a while until the time is right and Yeah I will be back (Valhi).

Her pragmatic approach and devotion to Christianity appeared to give her an inner strength that fortified her ability to live happily with what life Valhi had left. In a quiet faithful way she appeared to remain energized but at the same time did not dwell on her life in terms of months or weeks left to live like many of the other participants.

Limitations of Research

What I found in this research is that, while it is not able to be generalized to all people living with a non-curative terminal cancer, it does however fit with what is already known from previous research on the patient perspective of hope. However, because all of the participants were predominantly white European I have only been able to obtain a European perspective.
Another limitation of this research is that I was unable to obtain rural or different cultural perspectives from other clinical practitioners because time did not permit me to pursue this cohort of participants. However, I believe that I have obtained sufficient information to provide a meaningful snapshot of the lives of people living with a life limiting illness and clinical participants who care for this type of patient.

Further Research
The original intention was to follow people from diagnosis to death to understand their trajectory of hope across time however; it was realized after starting this project that more time than was permissible during the data collection phase would have been necessary. I believe that this would be a very valuable piece of research in the future. Because I was not able to reach saturation with the clinicians there is more scope for further research with a greater diversity of practitioners to extend this study beyond the ten participants interviewed.

Research has a role of educating and informing practice about those things that matter to people who are dying and the clinicians who care for these people and this the current research has identified several areas that warrant further investigation. These include:

- How is the concept of hope taught in training institutions for medical and nursing students?
- How is the concept of death and dying taught in training institutions for medical and nursing students?
- How well supported are clinicians who work with patients who have life limiting diseases?
- The area of cognitive behaviour processes underlying motivations, emotions and anticipation needs to be studied in greater detail to understand the significance of adaptive learning systems with respect to people living with life limiting illnesses.
- What is the significance of hope and hoping within other ethnic and culturally diverse communities of clinicians?
Summary

Hope is a basic human response for our desires to want events or things to happen, and it is a basic human emotion and humanity is the essence of all human emotion, therefore hope is a critical element with regard to survival. The themes of motivation, anticipation, positive optimism, resigned, realism, preparedness, contextual and spiritual represents what hope is for the participants. While people are actively seeking and receiving treatment whether it is traditional cancer therapies, privately funded surgeries and treatments, and palliative care sustained by successful spiritual hygiene, hope and optimism can be maintained and supported until a person ceased to be a cognitive being. Talking to people about dying is about admitting we are mortal beings and life is a process that we move through in stages. We must never be afraid to talk about death because it will come to all of us soon enough. Science has taken us on a wonderful journey of clinical discoveries but it has left behind the key essence – behind each medical and nursing encounter is a thinking, breathing person who has not just a physical body but one full of emotions such as sadness, joy, desires and hopes that need to be supported.

Empathy, while not an essential theme became an important emotion that needed careful consideration within this thesis. It is a complex and difficult concept to understand and nurses will not always make a connection or share an experience with every person that they meet. But if we remain open and receptive, health professions can consider empathy on only as emotional knowing but also as an experience of solidarity and intimacy. As part of a nursing experience we have to ability to be empathic to things hoped for by people who are facing life limiting illnesses. Stein had the ability to see us as possessing a pure essence and being capable of demonstrating emotional reciprocity. She speaks of us as being a body that has a soul that individuates us from one another, but that allows personal connections.

Not only is empathy a safe and permissible emotion, it is the linchpin to a caring nurse-patient relationship and we must embrace this. Empathy has the potential to bond us or support a special relationship regardless of who we are to one another. Despite our own perceived inadequacies underpinning the ability to empathise is the development of a theory of mind and this can only happen as we continue to build on the interactions that we face each day as health professionals. The next chapter considers how photography further explores the themes revealed within the thesis.
CHAPTER EIGHT  READING PHOTOGRAPHS

In this chapter I contest that photography is a companionable genre alongside narrative text when phenomenology is the research method. Images connect the universe with people because they are a magical reconstruction of reality turned into simple or complex representations depending on their intention. By using language to philosophically explain the experiential dimensional forms held within photographs, a comfortable marriage between existential and hermeneutic phenomenology can evolve. A mutual joining between text and photographic images as symbolistic intentions can linguistically and visually combine to create and interpret a person lived experience.

**Fig 36 Hedley’s photograph**
*‘Alone in the wide blue yonder’*  
(Richardson, 2009)

**Introduction**
Photography, like Marxism, has a “convoluted history of struggle within the question of abstraction and materiality” (Mills & Muellner, 2006, p. 87). It is the making of pictures from the phenomena of light bouncing off things in front of the camera that causes a pulling together of objects and subjects, the lens, camera, light and colours into an “abstracted space of perpetual stillness” (p.57). It is this quiescence that offers much in a photograph where there is a contradiction between the here and now, the future and a passing moment that is frozen in time by the whir of the shutter. Photographs are a translucent description of the here
and now and reality, and often enhance what has been captured within the frame. The chemical stillness of a photograph is different than that of any other textual medium or art form. Oil paint, for example tends to draw light into its folds and edges and reflect it back hither and yonder while water colours frequently describe subtleness in a mix of fuzzy softness and bleeding tones as if the paint and paper have colluded to create images.

The objects and subjects in a photograph, however, cause subtle changes with light and dark shadows in the moment. Images act as a voice in that they communicate something to the viewer through representation and symbolistic abstraction. Pictures signify that there is something out there in space and of having a “voice” through seeing. Touching or smelling a photograph, on the other hand, is unlike any other art form because it fails to enhance your artistic imagination. They are for your eyes and imagination only, they can become ‘momento mori’ causing the deepening of a person’s sense of reality (Sontag, 2003).

It is the surface of an image that gives it significance. You can skim read the surface with little effort paying superficial notice to the content, or you can scan read them to ‘construct the abstracted dimension’ to provide spaces for intellectual interpretation (Flusser, 1983, 2007; Sontag, 2003). It is the space and time that provides the magic of images. Flusser (1983, 2007 provides a delightful example when he talks about space and time peculiar to an image as being nothing short of magic:

> A world in which everything is repeated and in which everything participates in a significant context. Such a world is structurally different from that of the linear world of history in which nothing is repeated and in which everything has causes and will have consequences. For example: in the historical world, sunrise is the cause of the cock’s crowing; in the magical one, sunrise signifies crowing and crowing signifies sunrise. The significance of image is magical (p. 9).

Instead of taking frozen or fixed images and trying to decode them, images translate states of things into scenes or symbolistic ideations by mediating between us and the world. Today we struggle against image-bound ideologies much like the pagans did during medieval times staying faithful to the text of the bible without allowing idols. Idolatry or images were said to interfere with Christianity. However, with the invention of the pictorial apparatus, namely the camera, text was not the only way to decipher the world. Technical images helped to further
comprehend how the world works (Flusser, 1983, 2007). The curtains were drawn from the windows so we could understand how things worked.

When you look at photographs that lend themselves to scientific discourse there is often only the ‘doing’ nature within the window that you notice. The image of *Caedicia simplex* or long horned grasshopper, a native to New Zealand but also found in Australia, can be seen in the garden camouflaged amongst shrubs and plants as protection from hungry predators such as birds. It feeds on the foliage it lives amongst and jumps or flies between branches and grasses. At certain times during the day it makes a happy chirping sound or a noise like the rubbing of thick organdie fabric between your fingers. As scientific noting, the image gives you an idea of its size, colour and what it looks like. You possibly fail to notice how the camera has focused on the cricket’s left eye ball and that it has blurred the edges of each leg and its wings. The outer leaves and further away branch is completely out of focus giving a subtle fuzzy out thereeness or a leaving behind. It is like the Hollywood lens has been used to romantically fade out the background.

![Image of Caedicia simplex](image)

**Fig 36 Caedicia simplex**

(Richardson, 2011)
In scientific noting you are drawn to look at the grasshopper and nothing else because your brain is looking for something specific – what does *Caedicia simplex* look like? Once you have noted its scientific likeness you will possibly not take the time to look at anything else. It’s recorded in your memory or you might make a photocopy of the image for a more permanent reminder. When you use an image to provide information you are probably not concerned about what is happening inside the window or beyond the intended image. So you can see that images have particular positions within our foci. A picture of ‘how to’ is used for a purpose to describe what is happening – such as the photographs that can be found in cookery books, instruction manuals or text books.

With regard to these sorts of images the reader is generally not concerned by the quality of the image or what else is going on in the picture so long as it offers information or reads like a paragraph. At this point it is worth considering the following saying “a picture is worth a thousand words”. This phrase is believed to have been first used by F.R Barnyard (1921, p. 96) during his time in advertising in the early 1900’s. While working for the trade journal *Printers’ Ink Barnyard* was one of the first people to promote the use of images in advertising on the sides of streetcars. He changed the wording to "one picture is worth a thousand words" (1927, p. 114) and called it a Chinese proverb so that people would take it seriously. However, immediately it was erroneously credited to Confucius (Stevenson, 1948).

It is contested that pictures used for scientific description takes away the magic from what else is happening within the window. This creates what Flusser (1983, 2007) calls a “cheap kind of conceptual thinking” that often fails to awaken any artistic thinking about such images (p. 18). This type of pictorial subliminal magic disables our inquisitive thinking to merely considering the image contextually. You learn what a long horned grasshopper looks like and that is the end of your curiosity. It will be a subject reflected back at you on a smooth surface as a representation of the genus *Caedicia simplex* and any philosophy I offer about the behindness or out thereness will be wasted on those who read image for scientific noting and nothing more (Flusser, 1983, 2007; Sontag, 2003).

**The photograph as metaphor**

An expressive photograph stands on its own and emits a metaphorical impression on the viewer. Through metaphor and symbolism I have used photographs to speak from within and tell variants on a theme through symbols. A passionately created photograph arranged,
captured and produced on paper is meant to elicit emotional reactions from the viewer. I will have achieved a thought provoking piece of art when you, the viewer, have paused, pondered and completed mental gymnastics to think about the subjects before you. As I have read and heard pieces of dialogue that summon my artist intuition and responses, I have been able to create snippets of conversations as visual montages.

Fleming, one of the patient participants, was a vibrant humorous person who had been a fastidious garden and keen environmentalist therefore the photographs of peonies symbolize this vibrancy and aliveness, while fading blooms symbolize the end of life and the life cycle. Peony roses are beautiful strong flowers whether in bud, full bloom or passed their best and dying as shown in figure 37 ‘Fading away II’ symbolizing Fleming’s vibrant and sunny disposition despite his imminent death. He had been a significant figure for both his family and community and at the time of our second interview, though it was evident he was quietly
fading away Fleming had jokes to share, a happy smile, and was an affable host amid the obvious pain.

The photograph *Fans of hope* (fig 38) evolved out of a conversation where a research participant talked about medical professionals working in isolation with regard to her terminal disease. She talked about the doctors and herself being in “silos” standing isolated and individual with the concrete pad around each silo being their only linking or coming together. Instead of photographing a series of lifeless silos I took a large fan tree palm with its individual funnel like leaves to create the effect. Each large fan represents the “silos” but instead of the static effect that metal silos give, you are given the image of things moving from the outer rim of the leaves towards the ground. The leaves give the visual imagery of moving earthward, thus, helping to signify our eventual mortality. Each small fin of the fan indicates to me how a patient with a terminal disease can be touched by many people during an attempt to cure the person and then right through the terminal phase towards the ultimate end - death.

The effect the leaves give of getting smaller and smaller further emphasizes the decreasing circles that living with cancer causes. The concrete pad represents the concretion of cancer, of how it flows and crawls freely like the hot wet concrete that then set solidly around the base of the towering cylinders. The entire process is marked by a ‘defined discontent’ as the metaphor elicits a feeling through the exchange of silent ideas. As my memories and mind images become embodied within my own personal choices in the pictures I have made I have had the opportunity to clarify and realize change through these artist montages. The photographic endeavor is not just about making pretty pictures, as a marker once suggested, but as a further interpretation of the research data and in the creation of a legitimate research tool.

**Getting in behind the photograph**

In a phenomenological sense reading photographs can be similar to the act of phenomenological reduction. Through the process of interpretation and explication, images evoke meanings to become part of the phenomenological theme. It is when the penny drops and a systematic attempt is made to uncover and describe it. Phenomenology has been described as a research method that elicits these ‘telling moments’ (Kirova and Emme, 2006, p.11). It attempts to articulate through the content and form text out of meanings embedded
in the lived experience (van Manen, 1990). Reading a photograph successfully can be seen as giving it the phenomenological nod. It is being able to expand the representation and diversity of the photographer’s voice (Hergenrather, Rhodes & Bardhoshi, 2009) that can be hurried, busy, gentle, romantic, stylistic, and subtle or an actual active event like Hedley’s boat picture at the beginning of this chapter.

Previously I used photography as a way of constructing phenomenological symbols or a sense of being in the moment of participants as they described their lived experience to me (Richardson, 2005). Somewhat naively I thought that the pictures would speak for themselves. As pictures they did this in a reasonable fashion, but as a valid scientific means of data analysis they lacked depth and analytical maturity. The photographs themselves were not at fault but the in-depth reading was left wanting. The photographs previously used were objects and subjects that had come out of the interviews with participants as they describe their experiences while terminally ill. After considerable reflection and with a new research project on the horizon I was greatly concerned that I give future phenomenological images a philosophy, and the legitimate scientific rigor and credibility that they deserve.

Iris Murdoch (1978) believed that art and philosophy were complementary and maintained that “art is far and away the most educational thing we have [because] the statements made by art escape into the free ambiguity of human life” (p. 86-87). Thus the educative effect that art has on people can never be controlled, contained or underestimated. I agree with McMahon (2003) when she suggested that artwork can be represented in several ways and that it is “the artwork-as-represented-as-canonic-schemata-and-perceptual-form” that can be represented as perceptual style rather than art as an historical artifact (p. 261). (The canonic schemata will be explained more fully later).

Photographs are used to deepen our historical characters and a patronizing of reality brings things from outside or “out there” (Sontag, 1977, p. 80). People’s worlds from many cultural and physical settings are “brought inside” in photographs for us to see, to peruse and ponder or in some cases, merely glance at (Sontag, 1977) as you can see from the image ‘Hope as a driving concept’.
Dr Q’s photograph brings the concept of a professional hug and hope as a driving concept to us by this demonstration of connectedness that goes on in the montage between the soft and subtle green tones, and the grasshopper.

So actually framing that where the person is and taking out of it the fears they have regarding their future. [This] can be so helpful in that person then being able to realign their horizons (Dr Q).

I have joined the soft hues of nature, the sharpness of the branches and the subtle form of the grasshopper to describe the blending of things creating a comfortable realigned world. It is about the experience of unfolding our and others natural world, rather than things experienced evidentially. It is making connections, and like a rag-picker as the photographer,
I have collected the outside world's treasures and made them into shapes of usefulness. I have gratified and cohesively joined objects and subjects, framing them window-like for the viewer to consider. The gentle abutment of the young fern fronds helps to create this bringing together similar and like things as Dr Q describes the togetherness of clinical encounters:

*By doing it repeatedly it helps the patient realize... they are being given help along the journey to help them see what is in fact the hope that they can raise for this next part of the journey* (Dr Q).

![Fig 40 Dr Q's photograph](Image)

'Together and connections II'
(Richardson, 2010)

It is this joining together of the fern leaves in the photograph creating connections (fig 40) that helps to emphasize what I am saying about the symbolism that is within the picture. Baudelaire's (Cited Benjamin, 1999) description of a rag and bone man helps to support what it is like to pick away and pull out things while trying to get the perfect photograph:

*Everything that the big city threw away, everything it lost, everything it crushed underfoot, he catalogues and collects... He sorts things out and makes a wise choice; he collects, like a miser guarding a treasure, the refuse which will assume the shape of useful or gratifying objects between the jaws of the goddess of Industry.* (p.48).

Reality is captured in an array of informal pieces in "an endlessly, alluring, poignantly reductive way of dealing with the world" (Sontag, 1979, p. 80). Therefore, life is not about catching significant details because what we happen to see today remains only in our memory.
if we are able to conjure it and many details escape our thoughts like water through a sieve. Life, as in time, is never fixed and moves like a swiftly flowing stream but photographs can hold those illuminated details forever. By capturing an image and holding it within the photographic window it can be a testimony to “times restless melt” (Sontag, 1977, p.15).

Within a cultural context most of us understand and are familiar with a wedding photo; no matter whose wedding it might be we distinctly and instantly understand the meaning of what the people in the picture are about to do, such as the before and after the ceremony pictures. In the same way most of us connect with pictures of tragedies or phenomenal events that have happened in the past but may have little to do with our own small physical world. Photographs continue to educate and inform us of the world. This can be in a dramatic ‘in your face’ way much more effectively than how written words can or may describe an event or happening.

**Reading photographs**

There is a dearth of information on how to read photographs philosophically. This process is made more difficult when the subjects and objects are not historical representations, and when the artist uses a mix of symbolistic meaning, style and object to describe a moment of the lived experience through phenomenology. It was wanting to create, not only pieces of art, but also find a method to more effectively engage with the content and intent than previously has been stated. Much of what has been written about using photographs during research is as art therapy or scientific “how to” or noting, but when images are speaking as though they were written text the scientific evidence is paper thin. The pictures that I have produced not only fill the imagination with emotional responses but also reach out and alter the conscious and unconscious thoughts through subtle implications.

Using Thom’s (2000) object-as-represented I have purposely taken the remains of a window frame, skeletonised it and reduced its contrast to give a stark carcase effect. Dr X often views the patients in their skeletonised forms and I have taken the brightly coloured ginger flower and using slicing techniques and layers to slip it strategically in between snippets of the window frame. It signifies to me the contrast between with the rough-hewn dilapidated wooden window with its disused electrical fittings and the beauty of the crisp jaunty nature the ginger flower seems to exude.
The flower represents the potential positivity that Dr X is offering but this is tempered by the realization that positive outcomes might not happen. The vibrant petals remind me of a living force and of things that once were. The window had once been useful and full of purpose but now it is derelict and redundant.

Over the last decade photographic images have become an accepted method of collecting and analysing data. For example ‘photovoice’ has become a popular method for recording the strengths and concerns of a cohort of people within a given community. This methodology provides a way for participants to present a community-based problem (Hergenrather, Rhodes...
& Bardhoshi, 2009). It gives an opportunity to critically reflect, create critical dialogue and share knowledge to those within the group and the lived experience to others beyond the dynamics of the participants (Hergenrather, Rhodes & Bardhoshi, 2009; McIntyre, 2003). Photovocies are expressed through self-identified images, language and context (Wang, 1999). However, photovoice doesn’t aim to make scientific sense of an image in a phenomenological way. The aim of my own work is rather to understand and use photographs in a way consistent with Paul Thom’s (2000) methodology of reading photographic images from his work “making sense: a theory of interpretation”.

Sontag (2003) argues that artists make pictures or objects of art where the photographer takes photographs (p.41). My photographs, however, resemble something that can be called phototext or symbol-text. The objects have been carefully chosen and arranged to create symbolistic suggestions as a vehicle for producing spoken or unspoken moments that developed during the interviewing process. They are as metaphors, invented styles and symbols that occurred during the interpretation of the text and reviewing field notes. The photographs were sometimes collected during moments where words could not or did not describe what a person was trying to articulate. Sometimes they were intuitive notions that I have turned into pictures to tease out or understand the meaning of a person’s lived experience.

Creating a style

The notion of style has long been associated with all types of art and various photographers have their own oeuvre or opus. Aestheticism comes from the word aisthetikos pertaining to the perception of something or a derivation of the moral principles from all that is beautiful. It is often associated with nineteenth-century romanticism with such scholars as Friedrich Schiller and Friedrich Nietzsche and how we understand artistic styles. The notion of ‘Style’ or ‘perceptual style’ is reported to be central to the philosophy of art and art history, and has normally been used to describe particular periods of art fashion or oeuvre, such as the Early Renaissance or Picasso’s Blue Period. Style can be described as a set of formal characteristics that cuts across periods, movements and individual oeuvres. It is always attributed to artworks in retrospect (McMahon, 2003, p.260). Within my research project I have used the term ‘symbolistic’ style to describe my own opus.
Fig 42 ‘All night vigils’  
(Richardson, 2008)

The idea of the photograph ‘All night vigils’, a still life, while it symbolizes ‘stillness’, this was not my intention. The photograph portrays a movement within the moment or a fluidity of happenings with the flickering flame. It is the intention that viewers ponder over the contextual reality of the objects and are curious enough to ask about the historical and socio-political meaning behind the picture. The tableau on the table cloth represents the all-night vigils that many families, friends and onlookers often undertake when someone is dying. I imagined that many hours of hopeful contemplation, of chewing the fat and soul searching, and trying to understand the meaning of life taking place over a cup of tea or coffee. I wanted it to capture those moments of family and friends laughing and crying, of sharing anecdotes and yarns around the bed of someone dying.

You can see the above photograph has meanings within meanings as a symbolistic arrangement and also as “textotatry” (Flusser, 2000, p.18). Media critic and philosopher Flusser believes that photography is a canny extension of language that represents a transformation in a person’s consciousness, in the same manner as language grows and matures with a person’s age, social and cultural situation. He suggests that literacy is a rationalist response to idolatry (Flusser, 2000, p. 18), therefore photographs are a response to textotatry that can be further clarified by Edmund Husserl’s (1900,1913) phenomenology (Ihde, 1998).
Photography as phenomenology

Stroud (2008) wrote that the narrative has the ability to “move individuals to thought, reflection, action, and belief” (p.19). When using photographs for photo-interviews, they are said to give “birth to stories and be employed as aids to data collection” (Rapport, Doel & Elwyn, 2007, p.534). By using language to philosophically explain the experiential dimensional forms held within photographs, a comfortable marriage between existential and hermeneutic phenomenology evolves. Without using perceptual and hermeneutic phenomenology to explain the meaning behind each print, the images become a collection of things arranged pedantically. A mutual joining between text and photographic images within a phenomenological research context needs to linguistically and visually combine to “communicate, create, and interpret (the) meaning” of a person’s story (Kirova, 2006, p. 23).

The final step from the camera to the page is the manipulation necessary to manufacture the right look or to give the images their artistic licence or symbolistic look. Edmond Husserl (1972) called this reductionism where the objects or subjects become a “phenomenon in a peculiarly new sense” or phenomenological-psychologically reduced (p.244). It is where the phenomena that the participants revealed through their dialogue or implied language is reduced to a theme, and with further reductive engagement and post production manipulation a “collage hermeneutics” is created both visually and textually (Kirova, 2006, p.24).

Because photographs can be called “a transparent account of reality” (Sontag, 2003, p.72), Paul Thom’s (2000) theory of interpretation, although sometimes criticized as being vague and poorly supported (Harold, 2003), supports my own theorising about my photographs. His theory of interpretation has three terminologies or compartments: object-of-interpretation or an intentional object, an object-as-represented, and finally a governing concept. The object-of-interpretation is the object in its original state or objects in their intended states such as the cup, candle and a book on a table cloth. Thom (2000) intended for us to understand that the object of intention is “identified via a set of features believed by the interpreter to apply to it” (p.20).

Therefore, the intentional object may or may not correspond to a physical or external object. We can look at a work of art or a piece of music together but hear or see different things, thus we each encounter a different intentional object or, if we see or hear the same thing or sound then we encounter an identical-intentional-object (Harold, 2003, p.93). Thom’s theory seems to allow that a sole interpretation can involve an infinite number of reflexive acts of
interpretation all happening together (Harold, 2003, p.94). Husserl talked about a similar intentionality when he spoke about the way things are spread around us in space and time or objective things, and subjective “how our conscious experience flows off in relation to things around us” (Woodruff Smith, 2007, p.234).

The “object-as-represented” is the intentional object transformed in to a tableau structured, selected or substituted, such as the manipulation of the articles in the previous mentioned photograph of a still-life (Harold, 2003; McMahon, 2003). What is seen by the viewer is transformed consciously or unconsciously with parts remembered and others ignored. It is the parts that one takes to be relevant and salient or that may hold particular significance to the viewer. Photographs of atrocities shock, inform, as well as corroborate evidence of textual accounts (Sontag, 2003). It is pictures that we often remember better than any written text because they can be encapsulated and unencumbered, even if the meaning behind the content is complicated. Thom’s third category, the “governing concept”, is the concepts that make sense out of the objects or the objects are given meaning. As such I have given the above objects a stated meaning.

Fig 43 Amethyst’s photograph
‘Beginnings and endings’
(Richardson, 2010)
At this point the photograph takes part in story telling or as a thematic centre. The theme becomes the master key to essential matters: place, time, intentionality, memory, aura, privacy, gains and losses (Trachtenberg, 1996). It is a way of “inviting or enticing language” not as a documentary but as “more contingently” or exampleing worldly things into art or photography (Trachtenberg, 1996, p.111). I am guiding you to see what I see through the words I use to state the intention of the photograph. In doing so, I have shifted it from being a piece of art-work to being a piece of scientific-thematic-intention. Scientific-thematic-intentional writing has a way of separating the knower from the known, but at the same time allows us to reclaim this knowledge and turn it into our own pantology or vision (Richardson, 2005, p. 47). Certain meaning is better expressed through how one writes than what one writes (van Manen, 1990), and when an instant or moment cannot be captured textually, a visual medium becomes an important method of recording.

The conception of the photograph
The picture “forever waiting” depicts an old fashioned telephone, heirloom baby shoes, a bird of paradise flower and an open kernel from a large seed. The symbolistic intention is about how many hours the patient participants spent waiting for phone calls, for family members to visit and for grand-babies to be born.

Fig 44 ‘Forever waiting’
(Richardson, 2007)

They were constantly waiting on appointment or doctors and nurses to turn up when symptoms became bad. Retrieving or recalling the essence of pictorial symbols is not a matter of simple analysis or explication, rather it is a reconstruction of a way of life. It shows a willingness to live the images of our lives more deeply and thoughtfully. McMahon (2003)
has suggested that artwork can be represented in several ways and that it is “the artwork-as-represented-as-canonc-schemata-and-perceptual-form” that can be represented as perceptual style rather than art as an historical artifact (p. 261).

Using Thom’s (2000) theory an object is used to make sense out of the context of meaning or “gives them meaning in the sense that the meaning is invented” (McMahon, 2003, p. 261). In this context or the governing concept all of my generation of photographs for this current research project represent hoping, unhope, mortality, and aspects within the culture of palliative care, endings or stepping off the mortal coil. It is about understanding the leaving behind of an evocative image like the last word or “employing photographs as vehicles to knowledge” (Rapport, Doel & Elwyn, 2007, p. 534).

Solso (1994) describes art schemata as information that is stored in our long term memory, such as becoming accustomed to scenes or styles that we remember. According to Solso (1994) we are able to organize categories, themes and schemata within the human brain, thus contributing to our long term memory stores of art information (McMahon, 2003). Kant (1788, 1997) used a similar theory in his accounts of aesthetic ideas but he believed that it is because of our aesthetic perception, or how we freely imagine things in our minds that works of art bring or the multifarious ideas that are stored within these artist schemata.

The meaning behind the photographs
Activities that involve humanness involve epoch and as we move through periods we become creatures of a certain place, time and era. Photography, more than text, retrieves small shards of time and fudges it. Perhaps the measure of a great photograph is its ability to help us experience a priceless relief from mortality as we engage in an intense moment of thought and introspection (Sontag, 1977). The entire process is marked by a ‘defined discontent’ as the metaphor elicits a feeling through the exchange of silent ideas. As my memories and mind images become embodied within my own personal choices in the pictures I make, I have the opportunity to clarify and realize changes through the images. This photo represents the ability of the photographer to facilitate a receptivity that enables the viewer to be drawn into the photographic moment.
The participants that I have interviewed represent more than just words on a page but the eternal moment of visuality. Because the ten patient participants were facing death they spoke of the vigils that families and friends had done with them and of making connections that had sometimes been lost. It was a time for soul searching and confiding in very private thoughts and untold historical facts. When participants were close to dying, there were sometimes “fences to mend” and some wanted to know “what was the meaning or the point of life?” So the photograph ‘soul searching’ represents this. As already mentioned phenomenology invokes themes so that we can make sense of what has been spoken or unspoken. Meaning emerges as the text and interpreter engage in a dialogue, in a hermeneutic conversation (Koch, 1998).
It is this understanding, reconstruction, advocacy and activism that help us to learn (Koch, 1998; Gadamer, 1976). Story telling gives us a different or another understanding. Parse (1990) called this extracting essence from the translated descriptions or the participant’s language. An extracted essence is a complete expression of a core idea described by the participant (p. 11).

In attempting to discover the themes it became necessary to identify what were essential and incidental themes. It was finding out what was left behind when we pare back the narrative so we can get to the core of the ginger flower (fig 46).

**Fig 46** Torch Ginger II ‘Eilinger elatior’- Pink.
Botanical gardens Darwin
(Richardson, 2007)

In using the hermeneutic circle the themes revealed themselves as being unique to the phenomenon of concern. I found that Husserl’s (1913) framework fits very well because it deals with the original. There are two types of humanities of enquiry: one enumerates, compares and contrasts, creates and tests hypotheses, reads literature and examines the minutiae of materials or systems of one set or another (Kellman, 2005). The other method is being engaged in exploring the individual, the idiosyncratic, and the unique, the symbolic and the artful. It is the latter hermeneutic enquiry that can be used to describe how works of art express the lived experience scientifically (Kellman, 2005). At the heart of the phenomenological approach is a critique of the subject-object split of scientific naturalism with phenomenology dissolving the Cartesian distinction between subject and object (Crotty, 1996).
Phenomenology has been described as a difficult and tortuous research method that reminds me of Henry James’ saying about philosophy being “like a blind man in a dark room looking for a black hat that is not there”, (Murdoch, 1959, p. 249), you never seem to get to the end of it or find the back hat. It is the activity of being in the moment, the study of consciousness from the first-person perspective. It is the science of the essence of consciousness as each act of consciousness is directed towards something or intentionality is at the centre of the essence of our consciousness, in order to understand human existence better.

Fig 47 Dr D’s Photograph
‘When East meets West’
(Richardson 2008)
Dr D talked about the understanding of human existences and being conscious of something. His ‘something’ was the impact, perspective and importance that Eastern cultures has had on his current practice in the context of how he treated patients, particularly those that were facing impending death.

*Working internationally, especially in Thailand, has helped me to understand each person’s cultural and religious context and you have to talk about hope in the context of each particular person. When an Asian person dies many of them believe that they will be reincarnated and come back as a better person* (Dr D).

This symbolistic photograph in figure 47 is a mixing together of two cultures. It is his conversation with me about how he loved the view when driving to work and how spiritually motivated felt when he looked at the coastline. This is also the view that many of the early Chinese people got as they steamed up the harbour for the first time as new immigrants. Chinese dragons traditionally symbolize potent and auspicious powers, particularly control over water and rainfall (Wang, 2002). The dragon is also a motif of power, strength and hope (Wang, 2002) and with this in mind I layered this magnificent door knocker over a coastal landscape to create this East meeting the West photograph to gain a feeling of things blending and melding in togetherness, and of hopefulness.
Hope is always through the eye of someone else and for many of the clinicians who took part in my research project, as already stated in this thesis, hope was about maintaining that emotional equilibrium, and being a motivator and protector while trying to aim for an ideal situation. Hope was being motivated to work at trying to ameliorate symptoms, motivating patients into “good spaces” in their heads and in their selfness so they could tackle the next phase or stage of the illness continuum. Figure 48 signifies this looking through the window into someone’s soul and being reincarnated into something or another vision. It is looking through to the other side onto something different and trying to maintain emotional equilibrium and of being at peace with oneself or creating a peaceful vista.

Fig 49 Kowhai’s photograph
‘A sliver of hope through a window of opportunity’
(Richardson 2008)
Figure 49 represents the tiny window of opportunity or sliver of hope that Kowhai believed that she had if she undertook treatment for her type of non-curative cancer. The blue of the iris against the grey of the dilapidated window is my notion of hope as an example of a sliver of hope for Kowhai. As time goes on this sliver of hope gets smaller and smaller and this is represented by the flowers disappearing into nothing. Figure 50 “Optimism amongst the undergrowth II” describes how Kowhai felt in terms of feeling optimistic. This lone iris stood apart from the rest of the garden blooming in the midst of intense heat where most other flowers had withered and died. Kowhai’s images represented to me that standing up against adversity. In her words:

The more things that you have chucked at you in life I believe it makes you a lot, lot stronger” and “the only thing is to try and extend the time you have got left (Kowhai).

Hedley appeared to hold realism and being realistic as having a strong practical understanding and acceptance of his world:
My concern is more about an on-going problem that means if I don’t have any quality life I don’t do anything, I don’t want to be an invalid for the rest of the time that I have. I wouldn’t want that at all. The resection offers the best hope of cure but that has the most risk of dying as a result of the operation (Hedley).

He speaks about wanting to maintain his fairly active lifestyle and is quietly optimistic that his life would not have to change too drastically:

...Obviously I would like to be fit and well again, I also realize that I am nearly seventy-seven so how well can you be at seventy-seven. I still like to lead an active life and do the things I like doing (Hedley).

Fig 51 Hedley’s photograph
‘Reflecting on life’
(Richardson 2008)

Hedley became reflective but realistic about his life and what the future held for him, especially drastic interventions such as having a radical resection of his liver. But:

In between chemotherapy sessions when there have been good days I would go kayaking...It is a big decision to make, it is your life that you are dealing with but on the other hand I have got to make it by Monday so it just might come to the flip of a coin (Hedley).
Hedley states:

*I’m not worried about death. Either your dead and that’s it...Ah I’m perhaps more concerned about things going wrong and living the rest of my life in pain and destroying what quality of life you have got left. That’s really the situation that I am in at the moment where I have got to make a choice which has got the least risks (Hedley).*

Hedley died before I could give him his photographs but they were given to his family and it was reported that he never gave up hope right until he died. Each day he thought there just might be a chance that he would beat his disease. I have chosen to use marooned and becalmed boats in figures 51 and 52 to portray because Hedley life had ground to a halt thus becalmed.
Fig 53 Burt’s photograph
‘End of the line’
(Richardson, 2008)

Fig 54 Anna’s photograph
‘Gone bush’
(Richardson, 2008)
Anna talks about being optimistic enough to go back to camping with her friends:

*If I can get back to going out once a week with that and go away to camp with the friends that I have, yes that is something that I want to do* (Anna).

This is represented by the imagery of *A tramping we will go* (fig 55) which is the pictorial image chosen from Anna’s transcript. It represents the anticipation and optimism of getting back into walking around the tramping sites after chemotherapy for bowel cancer. Each picture elicits a freshness and being out with the world at our feet. Figure 54 and 55 describe for me the strength and stamina that Anna wanted back. The symbolistic meaning is about being a good keen kiwi person enjoying the crisp blue yonder. It reminds us of all things beautiful and not to take anything in life for granted as well as trying to live life as fully as possible despite the odds.
Health professionals, especially doctors, play a central role when a person has a terminal illness and I have chosen to express it by this small still life that I have called *The doctors’ visit* (fig 56). It is one of the few photographs that need little explanation and has been included because many of the participants were ever hopeful that when the doctor visited he or she might give them good news about their test results. Most were ever hopeful that the treatment they were receiving would change “their numbers” thus changing their prognosis. Morris describes his doctor to us briefly:

*Well, I have always been very impressed with Dr W...He’s just like a friend when he sits and talks to you he is pretty honest with what he say’s... My numbers have stayed pretty good and things are progressing well* (Morris).

For Morris and many of the others patient participants the numbers game was a vitally important aspect to maintaining positivity and optimism. It was the facts about numbers going up or down that created an illusion of sustainability and sempiternity, (or lasting forever), and the anguish and despair when the CEA numbers were tracking upwards.

My photographs are a representation of factual illusions or as Diamond (1991) suggests they are “constructions of objects for contemplation” (p.53) that have an everlasting notion of symbolic reality attached to them.
Hippolyte Delehaye (cited Diamond, 1995) made an interesting point when he described what a printer had done with a named portrait:

An old edition of the Aeneid; in accordance with the custom of his time the printer has prefaced it with an engraving representing Virgil. You do not hesitate for a moment; do you, to say that it is not a portrait? And nobody will take you to task for so lightly deciding a question of likeness, which calls for a comparison between the original and the representation (p. xviii-xix).

There are many examples of when we are asked to consider something just because it has been said and it is what it is. Little rosy cheeked cupid with his curly head of hair and his arrow is synonymous with being the God of affection, erotic love and desire. In Roman mythology (cupido) means desire, and he is said to be the son of the goddess Venus and the god Mars.

![Cupid and the butterfly](image)

**Fig 57** ‘Cupid and the butterfly’
(William-Adolphe Bourguereau, 1888 AD)

However, in modern day mythology or popular culture, Cupid is frequently used as an icon for St Valentine’s Day, shown shooting his bow to inspire romantic love. In the current culture Cupid is the personification of love and courtship in general. Hertz (1898) (cited Wittgenstein) states that natural sciences give us *pictures* of reality, i.e. theoretical models
but in “practice language is always more or less vague, so what we assert is never quite precise” (Wittgenstein, 1914, 1961, p. 4.002). According to Wittgenstein the world is composed of facts as inflections of simple objects and these objects constitute the everlasting nature of reality of both form and content.

The picture theory of meaning

Wittgenstein uses an interesting analogy to describe pictorial representations when he describes how Parisian law courts in the 1900s’ utilized toy cars and model figurines to demonstrate the facts surrounding car accidents (Hacker, 1986). It occurred to Wittgenstein that this method of description is not merely an analogy between models representing the facts and the way a proposal portrays a set of circumstances, “but a model, a picture, a proposition are severally special cases of representation and must share certain common features in virtue of which they can represent whatever they represent” (Hacker, 1986, p.56).

These representations must however, co-ordinate with what it represents. Each representation can be true or false but must somehow sense independently or it “must represent a possible configuration of things even if not an actual one” (Wittgenstein cited Hacker, 1986, p. 56) like the model cars.

It is from these thoughts that Wittgenstein’s famous picture theory portrayed in Tractatus is recognized – a proposition is a picture, a logical sequence of events or a coherent and logical picture, of circumstances. The crucial point being, that the proposition “is a standard with reference to which the facts behave” (Wittgenstein, 1914, p. 97). Propositions have a direction or sense, like a sign post or an arrow and a genuine circumstance divides a logical space into two depicting possibilities which we either agree or disagree upon (Hacker, 1986; Wittgenstein, 1961). This he called the bipolarity business and if we understand the representation or proposition of a photograph it belongs to the essence of the picture that should communicate a new sense to us.

Any photograph represents what it symbolizes by virtue of being isomorphic with it and must consist of a diversity of elements which stand for components of the situation which it depicts. Having said that, three distinct corollaries flow from Wittgenstein’s concept of representation:
1. No picture can be a true a priori-knowledge or justification that is independent of experience;

2. There must be an internal relationship between a photograph and whatever it represent;

3. No photograph can represent its own internal relation to what it models.

The use of these photographs along with an accepted explanation of its meaning or sense, against an essential background of human life and activity can lead to them standing for something other than just the depicted objects. They become representations of something. An expressive photograph stands on its own and emits a metaphorical impression on the viewer. Through metaphor and symbolistic meaning, photographs speak from within and tell variants on a theme through symbols. Photographs, in this instance, are a confirmation of the thereness or a person’s ‘theirness’. This rightness of having chosen an object or scene makes it unique to each participant’s moment just the same as words do in a sentence. Unlike other artistic genres that can cry out to the viewer if the work has been poorly executed or improperly worked photographs can capture an essence or a moment despite the talents of the camera operator.

All of the patient participants received a series of three photographs in a wooden frame and a copy of their transcripts within four months of the interviews. Time was of the essence and after I produced the images and processed them they were lovingly swaddled and packed carefully to avoid damage. I drove from one end of the country to the other within eight days, stopping off at each destination. It was a pilgrimage to gift back what I felt was rightfully theirs but it was a nerve racking process because like all art, people have a choice to like or dislike. This gifting process was done with a mix of excitement but it was devastating to discover some of the participants had died. The ten patient participants had all seemed relatively well, considering their prognosis when I first interviewed them and I imagined that most of them would have had at least another twelve months or so, on this earth. I had not prepared myself well for this part of the results dissemination and while nine out of the ten patient participants have died during the writing of this chapter these photographs will live on beyond a research thesis. Because images can portray realism more freely and unencumbered than text it makes perfect sense to include symbolic photographs within a phenomenological research project so they can further describe part of a person’s lived experience.
Photographs, as a scientific tool, must be used to deepen our historical and educative character, and more importantly represent the eternal moment of visuality. Each photographic shot must act as a beginning, middle and an end in itself but must be an extension of language. The nature of framing each picture was just like a sentence that brings things from outside our world to the inside to educate and inform the viewer, to create controversy, understanding and wonder. Each framed piece encapsulates a person’s moment and using the same phenomenological and hermeneutic process that is necessary to reveal textual themes, each picture brings an artistic dimension to the spirit and philosophy of phenomenology. Hermeneutic enquiry is used in this sense to describe how works of art express the lived experience phenomenologically.

Phenomenology allows us to enter the experience of another through reflective revelations. To understand a person living in their world requires a phenomenological sensitivity to the lived experience. Symbols and themes have been produced from modern phenomenology by teasing out themes from webs of words articulated through spoken and written language. This chapter provides access to the intrinsic essence of the lived experience in an attempt to clarify using symbolism and the symbolic look as a form of transparency and clarity so you can hear the voices of the participants.

Photography as a Conclusion
Photography, like Marxism and phenomenology, has had a struggle within the question of abstraction and materiality. In a phenomenological sense reading photographs can be similar to the act of phenomenological reduction and the task of the philosophy of photography is to reflect freedom. It is the only possible way to give significance to our lives in the face of death. Photographs capture our ‘out thereness’ and give it over to others for them to ponder and pause upon. An expressive photograph stands on its own and emits a metaphorical impression on the viewer. Through metaphor and symbolistic meaning I have used photographs to speak from within and tell variants on a theme through symbols. Much the same as a gatherer of artifacts or memorabilia, as a photographer I am driven by an inner passion that is linked to historical events and the past. Photographs in this instance are a confirmation of the thereness or a person’s thereiness. This rightness of having chosen an object or scene makes it unique to each participant’s moment just the same as words do in a sentence. Unlike other artistic genres that can cry out to the viewer if the work has been poorly executed or improperly worked, photographs can capture an essence or a moment.
More often than not it does not prove that the taker of the picture is good or bad at doing the job it just offers up the objects or subjects for people to look at. But it is the picture’s justification and scientific reading that matters most. This intended thereness and theirness also included the final journey of giving or gifting the collected data back to the participants. These excerpts of photo-text are not about my journey or narrative but it is about other people’s theirness, their stories. This photographic method has explored the individual, the idiosyncratic, and the unique, the symbolic, the artful and it was their conclusion in its actual sense. Phenomenology allows us to enter into the experience of another through reflective revelations. To understand a person living in their world requires a phenomenological sensitivity to the lived experience. Symbols and themes were produced from modern phenomenology by teasing out themes from webs of words articulated through spoken and written language. This chapter provides access to the intrinsic essence of the lived experience in an attempt to clarify using symbolism and the symbolic look as a form of transparency and clarity of what the participants spoke about or implied.

The next chapter is the final chapter in this thesis and will bring to a close this discussion by summing up the poignant and salient points.
Fig 58 Amethyst’s photograph
‘Cycle of Life’
(Richardson, 2010)
CHAPTER NINE

CONCLUSION

This research focused on gaining an understandable meaning of hope through narration from the lived experiences in order to understand more fully why and how people stayed hopeful despite a diagnosis of non-curative terminal cancer. Thus it was important to explore further the difference between hope, optimistic expectations, faith, courage and the will-to live. A number of questions had arisen from my experiences of working with patients and clinicians including: did health professionals have the same hopes as patients who were dying prematurely? Or did they offer active palliative treatment because the art of statistical probability and mathematics might give the person a fighting chance at a nominal numbers of weeks to months or years? Or was it as fundamental as the clinician providing treatment because it is what they are trained to do or because they can? Unexpectedly the clinicians’ dialogue revealed that they do not come as a “one size fits all” nor did they bear out earlier misgivings of being like those ‘other’ doctors. There was nothing to indicate traditional styles of paternalistic doctoring.

Of particular interest was determining if people who paid for treatments were more hopeful. Interestingly many of the patient participants paid for different aspects of their treatments for a variety of reasons and none of them expressed being more hopeful because they had paid for medications and care. Eight of the ten patients had paid for some or all of their treatment for up to a year, or longer in Morris’s case. This study found that private care did not give people any greater longevity or greater hopes but it is possible that selective internal radiation therapy (not available in New Zealand through public health care providers), which was given to some of the participants who paid for it, is much easier to tolerate than other forms of chemical therapy as it appeared to have significantly reduced apparent side effects.

I have discussed the ethics surrounding hope to determine whether it is either an essential or an accidental by-product of medicine. As part of understanding medical and nursing ethics, it is important to consider why people choose to have life threatening medical treatments when they have a life limiting disease in the face of so much medical uncertainty. Eight of the ten patient participants received active treatment until the disease had progressed beyond altering tumour pathology to provide some relief from symptoms. In four cases active treatment continued up to two or three weeks of dying and this could be seen as a negative side to hoping in its broadest context, in that it gave people ongoing hope for remission when clearly
this was not possible. However, eight of the patient participants would have given anything for whichever form of treatment could have given them an extra week an earth regardless of the side-effects or how cognitively aware they were.

Because this study could not provide an answer to questions surrounding the political or ethical issues pertaining to providing the greatest good for all people receiving health care, it is worth considering just because we can and do offer end-stage therapy, other than hospice style palliative care, should we? Campbell, Gillett and Jones (2005) subscribe to the notion that the health care team is to make the best decisions they can in the face of medical uncertainty about the unfolding clinical reality. Gillett (2006) in a later article wrote that ethical worries reflect the unsustainable belief that life is to be saved at all cost. Gillett (2006) is of the opinion that ethically and morally it has been expressed by some that beginning and stopping treatment it is worse than not beginning at all. Hope is a basic human emotion and humanity is the essence of all human emotion therefore it is a critical element with regard to survival but should we encourage life at all cost?

While people are actively seeking and receiving treatment whether it is traditional cancer therapies, privately funded surgeries and treatments, and palliative care sustained by successful spiritual hygiene, hope and optimism can be maintained and supported until a person has ceased to be a cognitive being. Hope is not about what you and I might want for someone but it is as individual as self-autonomy and self-empowerment. These are things we are unable to give someone else but as health professionals we can support patients so that they might realize their ‘hoped’ for desires and in doing so we must endeavour to find out what they are. This might mean not offering treatment regimes that can only give longevity with little or no quality of life. We must be able to intellectually, professionally and philosophically move patients towards something other than scientific doctoring towards the prevention and relief of suffering in its broadest context. Clark (2002) has identified a shift in the literature with respect to care of the dying from “idiosyncratic anecdote to systematic observation and research” and clinicians and educators have to deal with “how to reconcile high expectations of technical expertise with calls from humanistic and ethical orientation” when many clinicians may not have specialist training within the area.
Phenomenological research allows the examination of the minutiae of a particular human experience at a given moment in a person’s life. It is about lifting the lid and discovering themes from the reflective processes that have awoken inner moral impulses in us. Husserl asked that we dispense with taking for granted things around in the living world. His phenomenological approach gives things a meaning in that a phenomenon of something appears in a person’s mind as having structural essence. From each of the participants’ transcripts it was possible to uncover the essence of hope, which has been further framed within the themes of; anticipation, preparedness, positive optimism, and realism, resigned to endings or resignation, motivation, and hope as a driving concept. From these results, hope is also contextual, spiritual and a basic human response for the desire to want events or things to happen.

The Hope Pyramids were developed to capture pictorially the key words that described each theme. They depict the eight key themes from the participants’ circle of hope. These circles demonstrate how these could not and did not stand alone at any given time. The circle represents this fluidity and movement bit with no starting or ending points as each theme flows into one another allowing participants units of language to drop in and out at any point within the circle. It is hoped that these models will help to inform the development of a scale that can be used to measure hope and guide appropriate supportive interventions to enhance person-focused care.

Finally, while considering the patients’ dialogue and, despite it often not speaking out as loudly or as forcefully as the doctors, the concept of empathy was explored within the context of people facing a life limiting illness. Empathy was not a significant theme to emerge from the interviews, but it does appear to be an essential component of hope-work. In an attempt to understand the role that it played within the field of palliative care, the philosophical writings of Edith Stein (1916) were used to briefly examine various facets of empathic caring. Health professionals will not always make a connection or share an experience with every person that they meet. However, we live in a multicultural world and, while the basis of empathy for this thesis is orientated within Western thinking and philosophies the concept extends across many cultures.

If we remain open and receptive, health professionals can consider empathy as emotional knowing and an experience of solidarity and intimacy that cannot threaten our ego. We must
consider empathy from the perspective when clinicians are faced with the hopes of others that may not coincide with their own notion of hoping or within their cultural dynamics when they leave connotations of hope to someone else. It has been said that there is a tightly woven culture within the health profession that sometimes only permits language and perception in a guarded non-informative manner (Gillett, 1993). This can lead to exclusions and limit displays of feelings and emotions. However, the compassionate side of medicine and nursing is also evident in practice therefore; empathetic care must be considered as an essential tool in the toolbox of clinical reciprocity and professionalism.

**Phenomenology as a mixed media**

In the descriptive and interpretive tradition of phenomenology, I used mixed media to make explicit the 20 participant’s being of and in the world of palliative care, as described in detail in chapter eight. Photography, as symbolic and iconic footprints, stencils a pictorial story for the reader and is a companionable genre alongside narrative text when phenomenology is the research method. Images connect the universe with people because they are a magical reconstruction of reality turned into simple or complex representations, depending on their intention. By using language to philosophically explain the experiential dimensional forms held within photographs, a comfortable marriage between existential and hermeneutic phenomenology can evolve. A mutual joining between text and photographic images as symbolistic intentions can linguistically and visually combine to create and interpret a persons’ lived experience.

An expressive photograph stands on its own and emits a metaphorical impression on the viewer. Through metaphor and symbolistic meaning I have used photographs to speak from within and tell variants on a theme through symbols. In much the same as a gatherer of artifacts or memorabilia, as a photographer I am driven by an inner passion that is linked to historical events and the past. Photographs, in this instance are a confirmation of the ‘thereness’ or a person’s ‘theirness’. This rightness of having chosen an object or scene makes it unique to each participant’s moment just the same as words do in a sentence. Unlike other artistic genres that can cry out to the viewer if the work has been poorly executed or improperly worked photographs can capture an essence or a moment. It is one of the possible ways to give significance to our lives in the face of death. Photographs capture our outererness and give it over to others for them to ponder and pause upon.
The findings from this research, whilst not generalisable because of the design, do appear to have some degree of transferability. The results add to the existing body of knowledge about hope from the patients’ perspective. They complement conclusions from previous research, whilst also adding understanding about the clinicians’ perspectives of hope. The limitation however is that the results depict a western perspective and there is need to consider how other societies or people interpret or see hope. There was an expression of genuineness and unconditional positive regard for the patient participants by the clinicians, with hope emerging as a driving concept within this care trajectory.

The Hope Pyramids reflect how hope was contextual for clinician and patient, in that it was influenced by cultural and moral context. Hope meant different things to the participants and this makes hope both difficult and straightforward to explain. However, for each of the patient and clinician participants, hope was seen as being situational at whatever stage in the care continuum people were at. These findings are consistent with previous work on the concept of spirituality and spiritual care in that it varied for each patient and clinician participant. In many instances there were no clear boundaries drawn between psychological, existential and spiritual issues and for some it was about having a sense of meaning. However for those where religiosity was a vital part of their life, there were clear boundaries.

Each of the clinician’s wanted a comfortable death for their patients, one without pain and suffering but there was still an “inherent desire to maintain life” but not always at all costs. People are generally motivated to live no matter how grim their situation is unless they have reached that point on the continuum where they are ready to die or accepting of death like Bert, Fleming and Valhi. “The processes of human motivation are said to be private and to some degree unconscious processes” and the only person in possession of that knowledge about what motivates someone is the individual person (Springborg, 1981, p. 196). Even, if this was helping to sustain people through the dying process with good palliative care. Despite eight of the patients receiving active treatment until the last few days of life there was certain anticipation by seven of the clinician’s about leading patients with fearless anticipation through the dying process. Being prepared or preparing patients to face each point along the illness trajectory and the inevitability of dying was critical for nine of the clinician participants.
Hope-work is a vital part of palliative care and education is the key to understanding how hope works. Greater support and supervision is necessary within the practice of self-reflection in all areas of palliative care including older adult facilities, rural communities and inpatient wards. The examination of emotional tolerances and finding meaning in living and dying, and the grief process across all areas within medicine and nursing needs to be considered. Health care professionals also need to have a greater understanding of the processes of how their own hopes and hoping processes are entwined with patient’s emotional desires. This research revealed to me the unique individuality of people and that doctors and patients remain a matchless distinctive group of people in their own right. These findings challenge the thinking that hoping and patients, and doctors with hope should not be said in the same sentence.

Talking to people about dying is about admitting that life is a process that we move through in stages. We must not be afraid to talk about death because it comes to all of us. “For hope to be effective and believable, it must be founded on reality...tempered by kindness” (Wilkinson, 2005, p.86). Wilkinson goes on to say that there is an immense difference between telling a person there is nothing more that can be done to convincing the person that nothing more needs to be done except the doctor becoming a “real doctor, in the old-fashioned, supportive, gratifying, and truly therapeutic meaning of the word” (p.86).

Yazargil (1999) urges doctors to “hold the door open so that hope and optimism may enter, and to psychologically invigorate and sustain the patients throughout the duration of their illness” (p.1089). Nine of the patient participants spoke about not being cured but about living each day and achieving something. This was further illustrated by Brody (1981) “the man who last year hoped for a cure for his arthritis may now hope that, on a good day, he can get in nine holes of golf...hope may mean a pain-free and obvious death...if we were as good at listening to our patients as we are at telling them things, we would learn that hope is not automatically equated with survival” (p.1411-1412). Behind each medical and nursing encounter is a thinking, breathing person who has not just a physical body but one full of emotions such as sadness, joy, desire and hopes that need to be supported, even if, as Burt’s photograph in figure 59 Last Flight we learn that “hope is not automatically equated with survival” (Brody, 1981, p.1411). Burt was no longer able to think about living longer or being around for a few more weeks because he was actively dying. He wanted his last flight to be smooth without too many bumps in the road. In short Burt wanted a peaceful death.
Fig 59 Burt’s photograph
‘Last flight’
(Richardson, 2011)
Figure 60 "Joined in quiet contemplation" reminds us how the doctors considered their philosophical and professional reflections. Just as three fern fronds sit hopefully in quiet repose, in peaceful tranquility in the still of the forest amongst the gentle soft green in the out of focus background. It is a representation of quiet introspective thinking, of one being at peace with the environment. Nine of the doctors talked about having time in quiet reflection to “take stock” of where people’s illness phases was within the care continuum.
Dr C’s photograph “hope is a thing with feathers...” brings together all of the transcripts like singing a tune without the words. It is this environment of quiet consideration that allows people to think about the meaning of life including the doctor and the dying person. It is about understanding and framing where each person is and taking away the fears regarding their future. This is done to help patients see that hope is made up from our cognitive thinking and our affective forecasting, that comforting, energising and elevating feeling of a positive future. So that patients can rise above adversity and take on the next part of the journey in a trustful and more resilient fashion. Many of the doctors believed that hope can arrive or be
maintained only when there are real options and people have genuine choices even if this means choosing to have therapies right up until just before death. Hope is always through the eye of someone else and for many of the clinicians who took part in my research project, as already stated in this thesis, hope was about maintaining that emotional equilibrium, and being a motivator and protector while trying to aim for an ideal situation. Hope was being motivated to work at trying to ameliorate symptoms, motivating patients into “good spaces” in their heads and in their selfness so they could tackle the next phase or stage of the illness continuum.

Fig 62 Dr Z’s Photograph
‘Reflections and dreams’
(Richardson, 2011)

For the patient participants, the lived space was explored; van Manen wrote about the spatiality of something being out there for use to get, of being aware of our relationship with other. Patients’ anticipation related to expecting and waiting for things to happen. Patients then spoke of their positive optimism, which van Manen considered to be the “lived relation that we maintain with others in the interpersonal spaces we share with them” (1990, p.101) or lived human relations. It relates to the relationality that happened between the patients, their
health professionals and their relationships with family and friends. All the patients wanted something positive to happen and it was important for them. Realism was the third theme because many of the patient participants viewed their disease process with their eyes wide open. Husserl called this “bodily selfhood” but van Manen talked about the lived body or corporeality. Almost every day people lived with reality that they had lost the ability to function ‘normally’ or work. There was a constant reminder that life was very tenuous.

Being resigned to dying or discussing death with resignation and having life cut short was the fourth and final theme. Most of the participants acknowledge that time was of the essence and that each of them were facing significant losses. This related to only being able to make little plans, or hating the idea of not seeing grandchildren grow up or families losing their loved ones. All of the patient participants spoke candidly about being resigned to the fact that they were dying or were going to die in the future. The two sub-themes related to spirituality and humanity seems to be a fitting end to the results section to the thesis. Spirituality was used because it connotes with uniqueness and being expressed through selfhood, thoughts and feelings of each individual person. But it means different things to all of us. Humanity related to humanness of this project and the essence of being.

The findings will add to our understanding of the meaning of hope. Clearly, people can lean to live with knowing that they are going to die sooner than later. Currently people can live debilitated and chronically ill for many years without the kindness of pneumonia but in many instances with well-planned palliation. Dying well requires wisdom, skills, patience and prudential virtues (Harwig, 2009; Lynn & Adamson, 2003). We can take heart with the reflections of the patient participants who lived worthwhile, and in some instances restricted lives, but they were living and not just existing. The key to dying well appears to be communication and sharing information between and across disciplines of health professionals and with patients. We must not be afraid to talk about death and dying with people. None of the patient participants were afraid of death but it was the thought of dying that concerned them.

Supporting essential and achievable hopes when people are facing death is a way of facing up to reality. As Charon (2006) suggests by equipping ourselves with “narrative competence” we can use ourselves as therapeutic instruments (p.236). The voices of our dying patients must be part of this therapeutic instrumentation because it is only from them that we can learn
what it is like to engage with the unenviable art of dying. By communicating realism and reality with people who are facing death they can teach us about their anticipations, what keeps them positively optimistic and what supports them spiritually.

For the clinician participants, they gave of themselves, not as oncologists, chemical or clinical experts, radiation specialists or surgeons, but as physicians motivated to listened and support each person at each point on the illness compass. Hope was preparing their patients and families for the reality of each clinical phase, by supporting a person’s hopes as a driving concept to move that person forward. In meeting each person in their own spiritual, emotional and physical context, they supported and recognised hope as a basic humanitarian need. Even when Burt and Fleming were closer to death than any of the other participants they still remained optimistic about their future days. Fleming talked about “whistling a happy tune” even if he wasn’t able to consider what the tune might have been. As far as he was concerned he could still express happiness amidst the pain.

These findings reveal much about the way people deal with a terminal diagnosis and that, as health professionals, we must step outside of ourselves to enter the world of another even if it is a world we would rather not inhabit. It is this “in-seeing” (Rilke, 1945) that offered moments of wonderment right into the heart of people’s concept or theory of hope. Rilke (1945) talks about the essence of the subject as percolating through like a fine cup of coffee that then goes onto permeate, quench our thirst and touch us. The words of each of the participants have each of the participants have steeped and permeated this thesis and provide a rich source of data that should now be used to inform our understanding of hope from the clinicians’ and patients’ perspectives. The following quotes summarise this learning effectively:
The Very Least You can do in Your Life

The very least you can do in your life is to figure out what you hope for.
And the most you can do is live inside that hope.
Not admire it from a distance but live right in it.
Under its roof

(Kingsolver, 2006, p.10).

As Long as We Have Hope

As long as we have hope, we have direction,
the energy to move, and the map to move by.
We have a hundred alternatives, a thousand paths and infinity of dreams...
Hopeful, we are halfway to where we want to go; Hopeless, we are lost forever.

Hope is the anticipation of an event or an occurrence.
Our own individual hopes are our own desires.
Or could be considered our wish for the future.
Hope can give us a feeling of optimism when we are feeling discouraged.
As Diogenes once said “Hope is the dream of a waking man.”
Hope is one of the prime differences between successful people and those who can only
see failure.

Successful people have hope because they can clearly see their goals.
People who only see failure have no hope because they see no light.
They set no goals, and they see nothing accomplished.
Successful people see alternatives and are willing to try different ways.
People who only see failure are unable to see another way and give up to easily.
With hope you are halfway to where you want to go; by setting your goals, and taking
the action to achieve them.
you will see your hope turn into your reality!

(Catherine Pulsifer, 1998)
REFERENCES


Blake, M-B. (2011). Personal communication. MBlake@Polsinelli.com.


Richardson, K., MacLeod, R., & Kent, B. (2012). A Steinian approach to an empathic understanding of hope among patients and clinicians within the culture of palliative care. *Journal of Advanced Nursing, 68*(3), 684-694.


Appendix 1

Multi-region Ethics Committee Ethics Approval Letter
(Copy of Original Letter)

Health and Disability Ethics Committees

Multi-region Ethics Committee
Ministry of Health
120 Wellesley Street
PO Box 5072
Wellington 6445
Ph: (04) 375 8225
Fax: (04) 375 8255
E-mail: mregion_ethicscommittee@moh.gov.nz

Maia Richardson
Medical Ethics Manager
DHBs

Date

A screen of the possible through-the-view reader: The topics of patients with terminal cancer and the applicability expectations or topics of effectiveness within the culture of patients.

Note: Richardson

Richardson Hospital
DHBs

Date

The above study has been given ethical approval by the Multi-region Ethics Committee.

Approved from

Information system and non-personal form version [v.1] (14/0125/2008)

Accreditation

The Committee involved in the approval of this study be accompanied by the Health Research Group and be conducted and operated in accordance with the Otago Standard for Ethics Committees, April 2000.

Progress Report

The study is approved until the date completed. The Committee will review the annual report only if the Principal Investigator is unable to complete. If the Principal Investigator's responsible to forward a progress report covering all sites prior to ethical review of the project to the Health Research Centre.

The report is available on the website of the Ethics Committee.

Please note that failure to provide a progress report may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.

Final Report

The study is approved until the date completed. A final report is required at the end of the study and a form to assist with the in working with the Administration. If the study will not be completed as planned, please forward a progress report and an application for extension of ethical approval one month before the above date. Report forms are available from the administration.

Amendments

It is a condition of approval that the Committee is informed of any adverse events, if the study does not commence, or if the study is altered in any way, including all documentation and amendments, before the prospective participants.

Please quote the above ethics committee reference number in all correspondence.

It should be noted that Ethics Committee approval does not imply any assurance commitment and that the application is subject to ethical best practice. Where relevant, authority for this must be obtained separately from the appropriate manager within the organization.

Emelene Pearson
Multi-region Ethics Committee Administrator
E-mail: emelene_pearson@moh.gov.nz.

257
Multi-region Ethics Committee Approval Letter for Extending Ethics Approval Period to March 2011
(Scanned copy of original)

Multi-region Ethics Committee
Ministry of Health
131 Meeanee Street
PO Box 617
Wellington 6011
Phone (04) 470 8565
Fax (04) 470 8584
Email: multieregion_ethicscommittee@dh.s招呼

12 April 2010

Ms Kate Richardson
40 District Road
Roverewa
DUNEDIN

Dear Kate,

Ethics ref: MEC/09/13/175
Study title: A sense of the possible through the view finder: The hopes of patients with terminal cancer and the optimistic expectations of clinicians within the culture of palliative care.

Thank you for submitting an annual report for the above named study. This document has been reviewed and approved by the Chairperson of the Multi-region Ethics Committee under delegated authority.

Ongoing ethical approval for this study has been granted until 12th of March 2011.

Approved Document:
- Annual Report, dated 12th of March 2010

It is the Principal Investigator’s responsibility to submit an annual report to the Committee before ethical approval for the study expires. This document can be found on our website, www.ethicscommittees.health.govt.nz, under the section ‘Forms’.

We look forward to receiving your next annual report before this date.

Please do not hesitate to contact me should you have any queries.

Yours sincerely,

[Signature Redacted by Library]

Claire Lindsay
Administrator
Multi-region
Appendix 2

Information sheet for clinicians

SCHOOL OF NURSING
Faculty of Medical & Health Sciences

DEAKIN UNIVERSITY AUSTRALIA

February 2009

Following the path of hope with patients who have terminal cancer for clinicians

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate I thank you. If you decide not to take part I thank you for considering my request.

My name is Kate Richardson. I am a registered nurse currently working at Dunedin Public Hospital, in an acute surgical ward. I have chosen this study because I work closely with people who are diagnosed with terminal illnesses, and I want to explore and understand the concept of hope as experienced and described by adults with a non-curative terminal cancer.

The aim is to define a concept of hope and how hope is perceived by both the patient diagnosed with terminal cancer and a clinician who cares for and treats people with non-curative terminal cancer. This is being done to understand the importance of hope for people with terminal cancer and the health professionals who care for these people. This will be achieved by conducting two (or possibly three) face-to-face audio taped interviews.

The second part of this project is to develop a method of reading symbolic photographs that will be used in this project in an endeavour to analyze them as a form of narrative descriptions. The photographs are an extension of the text. They are symbolic photographs taken after the interview during the time when I analyze your spoken words. I will not take photographs of you or your environment or surroundings. (Please view the attached example of photographs). The photographs will be published in a thesis, journal article and possibly in a photographic exhibition.

Should you agree to participate in this project, you will be asked to take part in an interview with me. The interview will be audio taped and involve approximately 30 to 60 minutes of your time. The interviews will be conducted at the hospital or other place of your own choosing and at a time that is convenient to you. I will ask a set of open-ended questions such as:

1.) Tell me about the type of work you do.
2.) Describe your concept of hope for patients who are diagnosed with terminal cancer.
3.) What do you hope for from some of the more complex treatments and therapies?
4.) What do you tell someone if there is nothing more that you can do for them?
5.) What if anything, in terms of hope, do you tell the patient about the treatment?
6.) Do you believe that it is important for other health professionals dealing with the same group of patients to maintain a united style of hoping?

These interviews will be taped and I will contact you when I have transcribed them so that you can read your text. I will provide a copy of the tape, photograph and/or transcript for you to keep if you wish. If any questions make you feel hesitant or uncomfortable, I remind you of your right to decline to answer any question. You can stop at any time and we can resume the conversation at another time that is convenient for you.

The information collected from you will be completely confidential. No one but me will know your name as a participant in the project. When I discuss the text with any of my supervisors or advisors you will be known to them only by your code names. The interview tapes will only be seen or heard by me. Only my supervisors will see the transcripts. All data will be securely stored in such a way that only my supervisors and I will be able to access it. At the end of the project any personal information will be destroyed immediately, except that which is required by the Multi-Centre Ethics Committees research policy. Any health data on which the results of the project depend will be retained in secure storage within Deakin University for ten years, after which time it will be destroyed.

Results of this project will form the basis of my thesis for a Doctor of Philosophy and may be published. Any data pertaining to you will be anonymised so that any information cannot be linked to you or any other participant.

You are most welcome to have a copy of the published findings. You can nominate another person to receive the results if you prefer.

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact a Health and Disability Advocate: Telephone 0800 377 766. This is a free service under the Health and Disability Commissioner Act. Dunedin (03) 479 0265; Telephone (NZ Wide) 0800 555 050; Email: advocacy@hdco.org.nz. If there is a specific Maori issue/concern, please contact Linda Gremell at 0800 3777 7766.

If you have any questions about the project, either now or in the future, please feel free to contact me by phone 09-373-7599 or by e-mail kmerichardson@xtra.co.nz. Alternately contact my supervisors -

Dr Bridie Kent, PhD, BSc (Hons)  
FCNA (NZ), Professor of Nursing  
School of Nursing  
Deakin University  
Health,  
Melbourne,  
Australia  
09-373-7599 Ext 86460

Dr Rod MacLeod PhD, FAccPM  
Honorary Clinical Professor  
Department of General Practice and Primary Health Care, School of Population  
University of Auckland  
09-373-7599 Ext 86525

I look forward to meeting and talking with you.

Kate Richardson, PhD Student
Appendix 3

Introductory Letter for Clinicians

SCHOOL OF NURSING
Faculty of Medical & Health Sciences

DEAKIN
UNIVERSITY AUSTRALIA

Following the path of hope with patients who have terminal cancer for clinicians

I am conducting a study to explore and understand the concept of hope as experienced and described by adults with terminal cancer. The aim is to define a concept of hope and how hope is perceived by both the patient diagnosed with terminal cancer and a clinician who cares for and treats people with terminal cancer. This is being done to understand the importance of hope for this group of patients and the health professionals who care for these people and will be achieved by conducting face-to-face audio taped interviews.

Results of this project will form the basis of my thesis for a Doctor of Philosophy and I am interested in speaking with you for about thirty minutes. I have already interviewed ten participants with terminal cancer. The current literature demonstrates that clinicians have not been considered within any research regarding their perceptions of hope, in particular the hopes that they have for patients who have a terminal diagnosis. Therefore, to give this study balance and increased validity your interest and support would be greatly appreciated.

I look forward to meeting and talking with you.

Kate Richardson, PhD Student,
Deakin University, Burwood Highway,
Melbourne,
Victoria, Australia

If you have any questions about the project, either now or in the future, please feel free to contact me on phone 09-373-7599 or e-mail katerichardson@xtra.co.nz. Alternately contact my supervisors:

Dr Bridie Kent, PhD, BSc(Hons),
FCNA (NZ), Professor of Nursing,
Deakin University,
Melbourne,
Australia
09-373-7599 Ext 86460

Dr Rod MacLeod PhD, FACHPM,
Honorary Clinical Professor,
Department of General Practice and Primary Health Care, School of Population Health,
University of Auckland
09-373-7599 Ext 86525
Appendix 4

Information sheet for Patients

DEAKIN
UNIVERSITY AUSTRALIA

SCHOOL OF NURSING
Faculty of Medical & Health Sciences

February 2008

Following the path of hope with patients who have terminal cancer

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate I thank you. If you decide not to take part I thank you for considering my request.

My name is Kate Richardson. I am a registered nurse currently working at Dunedin Public Hospital, in an acute surgical ward. I have chosen this study because I work closely with people who are diagnosed with terminal illnesses, and I want to explore and understand the concept of hope as experienced and described by adults with a non-curative terminal cancer. The aim is to define a concept of hope and how hope is perceived by both the patient diagnosed with terminal cancer and a clinician who cares for and treats people with non-curative terminal cancer. This is being done to understand the importance of hope for people with terminal cancer and the health professionals who care for these people. This will be achieved by conducting two (or possibly three) face-to-face audio taped interviews.

The second part of this project is to develop a method of reading symbolic photographs that will be used in this project in an endeavour to analyze them as a form of narrative descriptions. The photographs are an extension of the text. They are symbolic photographs taken after the interview during the time when I analyze your spoken words. I will not take photographs of you or your environment or surroundings. (Please view the attached example of photographs). The photographs will be published in a thesis, journal article and possibly in a photographic exhibition. Should you agree to participate in this project, you will be asked to take part in an interview with me. The interview will be audio taped and involve approximately 30 to 60 minutes of your time. The interviews will be conducted at your home, the hospital or other place of your own choosing and at a time that is convenient to you. I will ask a set of open-ended questions such as –

1.) Tell me about your illness
2.) Do you have a concept of hope and can you describe
3.) What helps you to maintain hopefulness when your condition could seem hopeless?
4.) Do you believe that your clinicians help to maintain or sustain your hopefulness or hopes and have you considered alternative therapies?
5.) Do you have any particular faith, spiritual or religious beliefs and if so how does this influence your life?
7. Do you have to support people close to you with regard to them accepting your illness?
8. How do you keep yourself mentally and spiritually safe?
9. Have you considered the possibility of dying prematurely or before "your time"?
10. Do you consider the possibility of cure when your clinicians are thinking about you illness as not being curable?
11. Are the things you hope for realistic expectations and achievable?

These interviews will be taped and I will contact you when I have transcribed them so that you can read your text. I will provide a copy of the tape, photograph and/or transcript for you to keep if you wish. If any questions make you feel hesitant or uncomfortable, I remind you of your right to decline to answer any question. You can stop at any time and we can resume the conversation at another time that is convenient for you.

The information collected from you will be completely confidential. No one but me will know your name as a participant in the project. When I discuss the text with any of my supervisors or advisors you will be known to them only by your code names. The interview tapes will only be seen or heard by me. Only my supervisors will see the transcripts. All data will be securely stored in such a way that only my supervisors and I will be able to access it. At the end of the project any personal information will be destroyed immediately, except that which is required by the Multi-Centre Ethics Committees research policy. Any health data on which the results of the project depend will be retained in secure storage within the Deakin University for ten years, after which time it will be destroyed. Results of this project will form the basis of my thesis for a Doctor of Philosophy and may be published. Any data pertaining to you will be anonymised so that any information cannot be linked to you or any other participant. If you choose not to take part this will not have any implications for any ongoing medical treatment or care.

You are most welcome to have a copy of the published findings. You can nominate another person to receive the results if you prefer. If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact a Health and Disability Advocate: Telephone 0800 377 766. This is a free service under the Health and Disability Commissioner Act. Dunedin (03) 479 0265; Telephone (NZ wide) 0800 555 050; Email: advocacy@hdc.org.nz. If there is a specific Maori issue/concern, please contact Linda Greenall at 0800 3777 7766. If you have any questions about the project, either now or in the future, please feel free to contact me on phone 09-373-7599 or e-mail katerichardson@xtra.co.nz. Alternately contact my supervisors -

Dr Bridie Kent, PhD, BSc (Hons)
FCNA (NZ), Professor of Nursing
School of Nursing
Deakin University
Melbourne,
Australia
09-373-7599 Ext 86460

Dr Rod MacLeod PhD, FAcHPM
Honorary Clinical Professor
Department of General Practice and Primary Health Care, School of Population Health,
University of Auckland
09-373-7599 Ext 86525

I look forward to meeting and talking with you.

Kate Richardson, PhD Student