CRYSTALLISING MEANING:
ATTITUDES OF LISTENING
TO ILLNESS NARRATIVES

Volume One

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Submitted in total fulfilment of the requirements
of the degree of Doctor of Philosophy

September 2008

The University of Melbourne:
Faculty of Medicine, Dentistry and Health Sciences –
School of Nursing and Social Work
and
The Victorian College of the Arts –
School of Dance
Abstract

This study involves listening to illness narratives embedded in in-depth life review processes. The method of multiple interview and multi-modal analysis and reflective responding utilised in the study aims to add to the existing field of research by expanding the understanding of what it is like to be heard or not heard, for people who are either patients, or family members. The study also aims to demonstrate how self-aware, compassionate and reflective listening, particularly in healthcare relationships, can allow meaning to emerge from within the illness experience, thus enriching the wellbeing of patients, family members and their various healthcare professionals.

Stories of disruption arising within healthcare settings often confronted me during more than forty years of nursing experience and also resonated within my personal experiences. These stories express a gulf between patients, family members, or residents in healthcare institutions, and the healthcare organization and its staff. A recurring theme was that these people felt that they had not been listened to by those they trusted to give them care, with a lasting sense of disruption to their wellbeing. In focusing on the dimensions of reflective listening and intersubjective responding, the implications of being heard on the wellbeing of both narrator and listener can be elucidated. An objective of the research became to articulate the attributes and values of compassionate, reflective listening and elucidate the complex nature of the narrating and listening relationship.

Qualitative methodologies such as heuristic phenomenology support personal and interpersonal life descriptions and reflections. These methodological frameworks ensure rigor and validity. The study has a predominantly nursing and medical perspective, grounded in narrative discourse, that utilises experiential creative arts approaches in the search for meaning. To distil meanings and crystallise understandings, multi-modal representations of experiences utilised visual art and poetic forms. These representations formed intersubjective responses offered by the researcher during the processes of dialogue with the participants and the narrative analysis. Several participants died before the analysis process was completed. In these cases a collaborative inquiry partner assisted in the completion of the reflective analysis process. Some participants responded by forming reciprocal responses for the researcher.
The five participants were drawn from a range of life contexts and their narratives were recorded over time, transcribed and processed. Each narrative has a specifically contextualised literature search. I also journalled my own intra-subjective responses as they arose from working with the participants and their narratives. The study thus demonstrates a variety of settings such as aged care, dementia care, and palliative care, where this amplified model of reflective listening and responding to patients', residents and family members' stories could be applied. My study proposes that illness gains meaning when stories of illness are embedded within peoples' life narratives. It argues that the acts of narrating and listening are influenced by the prior experiences, perceptions and cultures of all those involved.

Humans are both meaning seeking and constructors of their own meanings and realities. Four pillars of meaning emerged from the narratives:- finding significance in our experiences, ascribing value to those experiences, forming and narrating a coherent story and finding validation for our experiences by being heard.

The surveyed literature underpinned the process and anchored the study. The narratives and literature suggest that the reciprocal listening component of relationships between patients, families and health professionals can be rebalanced by facilitating a more equal dialogical relationship between healthcare professionals and those for whom they care. It represents a difference from psychotherapeutic dialogues where the healthcare professional controls the meta-narrative and where a changed story would be the expected outcome. The study's amplified model of listening does not require costly or time-consuming interventions, but enables the health professional to see and hear the patient as a person, not just a diseased body. It is a dialogical method of self-aware listening, accepting the ordinary humanness and vulnerability of the care-giver, as well as the care-receiver, an approach that enhances the wellbeing of both.
Declaration

This is to certify that:

(i) The thesis comprises only my original work towards the PhD except where indicated.

(ii) With work carried out in collaboration, the level of contribution of others is indicated.

(iii) Work carried out prior to PhD candidature enrolment is indicated.

(iv) Due acknowledgement has been made in the text to all other material used.

(v) The thesis is less than 100,000 words in length exclusive of tables, maps, bibliographies and appendices.

Signed: ____________________________ (S. J. Foster)

Date: ____________________________
Acknowledgements

Firstly I would like to thank the participants in my study. Without their generosity in sharing their life stories with me my study could not have evolved. After Scott and Sarah died, their family members supported and gave consent for my continuing work with the narratives. I thank Sarah’s brother and Scott’s daughter.

I thank Doctor Sally Atkins for giving me permission to use her poem ‘Tell me, she said’ (Atkins 2003). It was a significant contribution to the development of my thesis.

I would like to acknowledge the encouragement and support of Doctor Warren Lett and Doctor Jan Allen from The Melbourne Institute for Experiential and Creative Arts Therapy, where this study began as a Masters Degree.

I thank Doctor Louise Harms and Doctor Don Asker for their encouragement and superb supervision. I thank Sister Jane Gorey for her friendship and support as my collaborative inquiry partner, and the students and staff in the School of Nursing and Social Work at The University of Melbourne who also gave friendship and support.

I acknowledge Doctor John Williams and the conversations we shared about the nature of meaning. I thank Claire Keith in her role as Drug Information Pharmacist at Austin Health; Doctor Rosemary Milne who read the completed thesis and offered encouragement; and my three sons Terry, James and Richard Griffiths, who shared their computer wisdom. Terry assisted with diagrams, and James with medical information.

I thank my friends who offered enduring encouragement, especially Hilary Robinson, Margaret Dowsett, Margaret and Gerald Stephenson, Beatrice Zuluaga, Solway Nutting, and Peter Kahane. Nicholas Crook contributed computer support, sometimes rescuing me from crisis point. I thank Owen Genat for formatting the thesis.

Finally to John Foster I express my gratitude for his endurance, encouragement, love and support. Without him this study would not have made it to completion.
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Introduction

Listen
In the silence between there is music;
In the space between there is story.

Pay attention:
We are listening each other into being

Atkins (2003)
This study explores how reflective listening, particularly in healthcare relationships, enables the co-creation or crystallisation of meaning between the narrator and the listener. It involves listening to how and when others felt that they had not been listened to, thereby causing a disruption to the person’s sense of wellbeing. It describes dimensions of reflective listening and intersubjective responding, and the implications of being heard on the wellbeing of narrator and listener.

Initially I wondered how I made sense of the experiences in my life, especially those that were painful and difficult. In writing and talking about them, I often found satisfying, coherent meanings. How did these meanings take shape? I wondered about the notion of finding meaning, and if my process of searching for meaning was similar to that of others. I became interested in whether there were fundamental elements or attributes to listening that enabled a sense of meaning to emerge for the other and myself. What happens when there is openness to carefully hearing another’s story, no matter how difficult their story might be? What happens when the opposite occurs, and people feel that others have not listened to them at all? Was it the process of telling, or a special quality of reflective listening that made sense of people’s difficult life experiences?

My present engagement with illness narratives has arisen out of more than forty years of nursing experience, including ten years of palliative care nursing. In 1993 and 1996 I experienced my parents’ deaths, and in 1998 I had my own experience of serious illness. Life review narratives containing significant illness narratives have been a part of my reading for many years, including my study for a Masters Degree in Palliative Care at Flinders University in South Australia, and then Creative Arts Therapy at The Melbourne Institute for Experiential and Creative Arts Therapy (MIECAT).

The Melbourne Institute for Experiential and Creative Arts Therapy is an accredited tertiary institute, with an approach dedicated to the pursuit of meaning. It relies on collaborative person-centred approaches in learning more about reconstructing personal perceptions, learning to understand emotional responses, sharpening intuitions and trusting the reliability of one's being in experience. This results in a strong feeling of being present to oneself as well as to others, a reliance on oneself, as well as a respect for, and trust in, the others with whom one shares one's life (Lett 2001).
MIECAT uses a multi-modal, experiential arts approach to the exploration of significant life meanings. This form of inquiry is based in respect, compassion and commitment to the search for an authentic way of living. The MIECAT inquiry has developed from the epistemological base of phenomenological psychology, heuristic research, experiential therapies and humanistic counselling practice (Lett 2001).

My nursing experiences helped develop my understanding of community and family, and helped me to appreciate how as individuals people are at their best when deeply connected to those around them. In 1986, living in a seaside community, I instigated the development of a voluntary hospice group where local registered nurses offered out-of-hours care. At that time in our community there was no other care available for a terminally ill person and their family outside office hours. The hospice nurses, including myself, were mostly employed in other areas of nursing. In giving this palliative care we were supported by the community, and enriched by a growing knowledge of the issues surrounding dying, death, and grief. Providing palliative care in a small town was demanding. After ten years working with the palliative care group I needed to withdraw, so that I might critically reflect on these experiences and my nursing career. I could not go on being part of the healthcare system without addressing the issues that were beginning to disturb me. I felt great tension with the way nursing was being shaped in the climate of economic rationalisation of healthcare. Nurses Blomberg and Sahlberg-Blom (2007, p.245) describe the tension between the ideal and the reality, that is, the care that nurses want to give and the care that is actually given.

Over the ten years I was working with the group, palliative care became a medical specialty, which was both professionalised and bureaucratised. I shared with families in the care of their dying member, and in the family’s ongoing bereavement. Again and again I heard stories that voiced a gulf between the family’s experience, often full of distress and confusion, and a medicalised ‘case history’ version, dismembered of problems or distress.

Many aspects of these illness stories articulate a gulf between the organization providing care, and the people being cared for. There is a recurring perception of ‘indifference’ and ‘disconnection’ (Habermas 1987; Crossley 1996, p.100; Frank 2002b). Habermas (1987, p.183) describes it as ‘an uncoupling of interaction from the lifeworld’. In many of the
stories, the narrator’s feelings of distress arose when they felt that people had ceased listening to them. These feelings did not dissipate, but in fact often gained momentum in their life-stories and became centred in the narrator’s struggle for some sort of understanding and coherence.

I reflected on the nature of this gulf, disconnection and indifference. I felt angry when I witnessed healthcare professionals practising as if their expertise could manage the psycho-social wellbeing of families and dying people better than the family or person themselves. I was delighted with the rapid development of drugs and protocols to manage symptoms such as pain, nausea, constipation and breathlessness in terminal illness. However, I also felt the anguish and sense of isolation and rupture of values and bonds within the community, caused by heavy-handed healthcare professionals.

Ten years of post-graduate study have honed the direction of this thesis. My study of relevant literature led me to see that my perception of healthcare services and relationships had a clear connection with Buber’s (1923) concept of I-Thou, or Being-to-Being relations. Buber’s philosophy is significant throughout the thesis, and describes I-Thou intersubjectivity, where both partners are equal in the relationship, that is a mutual, respectful recognition of each other’s being (refer Chapter One, 2).

In this light, giving true care requires a generosity of spirit on my part as carer, an acceptance of the other as the intersubjective mirror of myself, and a willingness to communicate in a way that demands my sincere engagement. Understanding and meaning comes from the resonance between us. I share Bérubé’s (1996, p.244) view that people need to seek the ground for human justice through communication with one another. My disquiet arose from witnessing a lack of respect for I-Thou. Instead, there was often a heavy-handed power-wielding I-It, a distinct lack of ‘communion’ with otherness.

I wrote the story of my father’s final illness and death in 1993, and I was surprised by the sense of clarity and meaning this brought me. I was re-membering the story of who my father was for me, our relationship over the years, and my experience of the final years of his life. This written story is an enduring text, a tangible form of the meanings I explored and uncovered. Following my own illness experience I began to write more of my personal stories, inspired by aspects of Moustakas’s (1990, p.179) ‘autobiographical
immersion’. Anderson (2000, p.x) affirms that my process of writing the story was creating and recreating the past in the present moment:

It reaches into the shadows and pulls what cannot be seen or spoken onto the page where it is open to discussion and revision. The page becomes an ‘other,’ offering writers fluid representations of experience and self.

Patients’ individual stories are important. While disease is biological, defined by precise biomedical, physiologically-interpreted information, almost in oppositional tension, our personal stories help determine the meaning of our recovery or emotional healing Kleinman (1988, p.xiv). Kleinman argues that one unintended outcome of our modern health system is that it manages to drive healthcare professionals’ attention away from the individual person’s experience of illness. In my hospital nursing experience I sometimes heard patients referred to by their diagnosis - ‘the small-cell lung cancer in Room Three’. Was there a person attached to this illness, or just the body-to-be-treated?

The ‘problem’ to be addressed by the thesis emerges from these experiences. The many stories of disruption I heard from patients, families and other healthcare professionals were characterised by Habermas’s (1987) and Crossley’s (1996, p.105) ‘indifference’ and ‘disconnection’ in which people’s sense of meaning and wellbeing were disrupted. Disruption comes from the Latin dis-rumpere, meaning to break, shatter, or rend asunder (Macquarie Dictionary 1987, p.520). This heightened my wish to understand more clearly what was happening. To further illuminate the problem, the following two stories from the literature demonstrate quite different approaches and qualities of listening and engagement on the part of a healthcare professional.

As a medical student, Kleinman (1988, p.xiv) was given the daily task of holding the hand of a seven year old girl as she endured painful debridement of shocking burns. She fought and screamed, until one day in desperation Kleinman asked her, mid-scream, to tell him what it was like being so badly burned and to have to endure these awful sessions each day. She stopped screaming, clung to his hand and began to describe to him what her experience was like. She taught Kleinman that it is possible to talk with patients, even
those who are distressed, and that it helps to order their experiences therapeutically. It directed Kleinman’s career towards psychiatry and working with narratives.

The second story is one gathered by Kuhl (2002, pp.45-46), a Canadian palliative care specialist and researcher. ‘Marjorie’ received the diagnosis of her terminal prognosis from her doctor, who stood in the doorway of her room as he told her she had metastatic carcinoma, but not to worry, she could go home the next day, he had booked her into the oncology clinic. Marjorie tells Kuhl that this doctor’s attitude caused her more suffering than the pain of knowing that she was soon going to die.

Cousins (1983, p.135) could be reviewing Kuhl’s story when he states:

> We are accustomed to thinking of iatrogenic problems in terms of the wrong medication, of mistaken surgery, or of harm done in diagnostic procedure. But there are also psychological iatrogenic situations: what happens after a patient is sent into an emotional tailspin with physiological consequences as the result of the exchange with a physician.

Each of these stories highlights a ‘cost’ in listening. For Kleinman being with his patient meant engaging in her pain and suffering, in order to give her the very best quality listening he could offer. On the other hand, Marjorie’s doctor was unwilling to enter her room, sit beside her and engage in the pain of what he had to tell her, although neither he nor Marjorie would realistically expect that his engagement would improve her prognosis. Marjorie felt sure his detachment damaged her wellbeing. She reported to Kuhl that it was harder to deal with than the suffering caused by her illness.

I will now share a story of my own, where my words echo Marjorie’s. In 1998 I was admitted to a city teaching hospital for surgery for cervical cancer. My surgeon and anaesthetist put considerable effort into their plan for managing my chemical sensitivities, chronic bowel disease and previous severe post-operative vomiting.

The surgery went well with no problems over the first night. The next morning, fourteen hours after returning to the ward, I explained to my primary care nurse that I needed to mobilise gradually. I knew that I could not get out of bed immediately because at this
stage it would cause my blood pressure to drop and I would start vomiting. Despite my protests, and my pleading that I did not give consent for this action, the charge nurse and primary care nurse said I was being ‘silly’ and dragged me into a chair, where I immediately vomited and fainted. I was returned to bed with low blood pressure, needing oxygen and intravenous drugs for the vomiting, which continued all that day. The surgeon expressed annoyance with the nursing staff. I felt in a way that I had let her down. Twenty-four hours later I was able to walk and shower. However I felt physically and emotionally distressed and angry. This disturbed my sleep for the remainder of my hospitalisation, and for weeks after I came home.

A number of ward nurses urged me to write to the Director of Nursing to express my distress. They said that they often risked their jobs to do what they believed was in their patients’ best interests rather than adhering rigidly to ward protocol. So I struggled to write to the Director of Nursing the day after I got home.

A week later the charge nurse telephoned me to explain why she had done what she did, yet not to apologise. Ward protocol insisted people were sat out of bed on the first day post-op and owing to staff limitations this had to be done first thing in the morning. She said that if I had told her I was a registered nurse she may have done it differently. In the hospital’s responses to my complaint the administrators interpreted the core issue as me not informing them that I was a nurse. For me, dealing with the cervical cancer was less difficult than dealing with the pain, loss of trust and dignity, and my grief for a deterioration of kindness in nursing care.

A generosity of spirit on my part would accept that the economic rationalisation of healthcare services leads to nursing staff constraints, meaning that protocols must be strictly followed if wards are to run smoothly. However, I was left disillusioned as a patient and as a nurse. In that room with those two nurses, my voice was silenced. According to Guillemin and Gillam (2006, p.38) this is an ethically vital point: ‘decisions and practice in healthcare are deeply influenced by whose version of a story is accepted as authoritative’, in other words, who can or cannot be heard.

My healing was clearly set back, my integrity felt ridiculed. All that I had learned over many years about managing my physiological difficulties, was interpreted by these nurses
as silly. Cousins (1983, p. 24) writes that ‘human uniqueness and individuality are washed away under the indifferent onslaught of rehearsed protocol procedures’. I felt angry that my crisis and additional suffering were preventable, if they had simply listened to me with respect, kindness and care. I was even more convinced that ways of listening are of critical significance. Health professionals not listening with engaged, reflective care lies at the core of the problem that has led to my study. Humans are bio-psycho-social-spiritual beings, and their wellbeing is dependent on their integrity being recognised and respected as a whole. It felt to me as if offering skilled, professional healthcare and engaged, respectful, reflective listening had become mutually exclusive.

A study by nurses Eriksson and Svedlund (2007, p.440) aimed to illuminate patients’ experiences of dissatisfaction with hospital care. They describe these kinds of stories as similar to the battle of David and Goliath:

   It is about people who have not only their disease to fight, they are also forced to strive against those whose duty it is in fact to fight for and together with them … It is about power abuse …

One way of approaching and understanding these stories could be from within discourses of ethics, informed consent and autonomy (Guillemin and Gillam 2006, pp.29-40). This thesis, however, focuses on reflective listening, as discussed by Corradi Fiumara (1990). If healthcare professionals, such as the two nurses in my story, were listening to their patients, their patients’ care needs, rights and autonomy would be better recognised. That is, seen from Guillemin and Gillam’s perspective of ethical mindfulness. At a pragmatic level, this approach could be cost effective for hospitals because there might be fewer adverse events like the one I experienced.

Cousins’ personal experience of serious illness convinced him of a clear connection between patients’ physiological and psychological wellbeing, and the best possible partnerships nurtured between healthcare professionals and their patients. He developed an interest in physician-patient relationships as the result of his illness experience, as well as his interest in the biochemistry of the emotions. Cousins argues that these I-Thou listening skills cannot be taken for granted, and must be taught (Cousins 1983, pp.121-166).
It is my curiosity about the elements that make a difference in these introductory narratives and the narratives discussed throughout the study that are the motivation for this study. I had witnessed, heard and read of many experiences where healthcare professionals controlled the meta-story and had the power to de-stabilise and disrupt the wellbeing of patients. I had also experienced, witnessed, heard and read about better experiences, where engaged reflective listening, kindness and care in its best sense, had a significant positive impact on the person’s wellbeing. Through this study I aim to crystallise what constitutes the differences in care that might have parallels and lead to better encounters in healthcare relationships.

The question arises as to what is good listening. What can people in healthcare relationships be afforded in the way of listening, when they are experiencing a variety of crisis points in their lives? From a pragmatic perspective, Mackay (1998, pp.142-143) suggests that there is a big difference between listening and merely hearing. Hearing involves just our ears. Listening is more active, alert and focused. Mackay continues:

> The difference between hearing and listening is crucial in communication. Hearing involves receiving a message which I may or may not think about. When I listen I am involved in the transaction: I am not just hearing but attending, understanding and interpreting.

According to Mackay (1998, p.145), people need courage to listen. Real listening involves seriously entertaining the ideas of the other person. When people listen they allow themselves to be vulnerable, and run the risk of being changed. To be truly listened to is to receive a precious gift from someone who is saying, in effect

> ‘I am prepared to put my own interests and concerns on hold; I am putting you first; I am going to entertain your ideas.’ That is listening, anything less than that is mere hearing.

There is a philosophy of listening grounded in the Socratic idea of *maieutics*, derived from the Greek *maieutikos* (Corradi Fiumara 1990, p.6). Pertaining to midwifery, the notion is of giving birth to understanding through careful listening:
the vital need to be listened to must coexist as a subordinate with the
derivatives of an increasingly arrogant *logos*, ready even to ignore
anything that does no properly fit in with a logocentric system of
knowledge.

Corradi Fiumara (1990, p.8) is critical of ‘the crushing deafness produced by an assertive
culture intoxicated by the effectiveness of its own *saying* and increasingly incapable of
*paying heed*’. She argues that listening has become alienated from the assertive tradition
of ‘saying’. Gadamer (1982, pp.221, 321) reflects on Buber’s (1923) I-Thou, arguing that
in human relations the important thing is to experience the *Thou* truly as a *Thou*, that is,
not to overlook his claim and to listen to what he has to say to us. These qualities of
listening are examined throughout the thesis.

Mostly, illness narratives evolve within healthcare relationships and settings. Corradi
Fiumara (1990, p.27) argues that a medical culture that knows how to speak yet not how
to listen, establishes tacitly basic principles for differentiating what is useful and what is
damaging. Interpreted by Corradi Fiumara this ‘logos’ is what tells people ‘how they
ought to be happy’. Marjorie’s doctor (Kuhl 2002, pp.45-46) seems to imply that she
ought to be happy that he has booked her into the oncology clinic, and that she can go
home. It seems that after that is said, there is nothing more to be considered. He has
donified what in *his* healthcare setting is useful, and therefore tacitly ignores what is
damaging, that being the extent of his connection to Marjorie’s suffering. What might
have happened if he had waited and listened for her response to his diagnosis?

Finding meaning in illness is another key part of this study. Kleinman (1988, pp.xi-xv),
proposes that illness has meaning, and much to teach people about care and life generally.
It is essential for illness narratives to be embedded as part of peoples’ whole-of-life
narratives in order for them to be reflected on and understood (Frank 1995, 1997, 2000a).
Deeply ill people need to be seen as not simply disease processes to be engaged with, but
rather as individual people with unique life stories, rich experiences, cultures and
contexts, that can be understood in shared, respectful, and reciprocal dialogues.

This thesis explores specific ways people might find meaning in their life’s crises and
epiphanies and disruptions, particularly those arising in healthcare relationships (Guba
and Lincoln 2005, p.205). The thesis therefore considers the implications for listening that are possible in healthcare relationships and settings.

One way of exploring such experience is to listen carefully and reflect on the perspectives of people who have had these kinds of disruptive illness experiences. This model would amplify processes of listening that would firstly enable an understanding of the nature of listening and how it helps shape meaning following disrupting experiences. Secondly, it would uncover parallels between this model of focused listening and any implications there might be for healthcare professionals and healthcare settings. In following this approach, I recorded five people’s life review narratives that each contained illness narratives of disrupted self-identity, coherence and meaning.

1. **RESEARCH AIMS AND OBJECTIVES**

The study aimed to explore:

> What happens when you listen deeply and reciprocally to people's illness narratives embedded within their life review narratives, particularly when their meaning has been disrupted?

The proposition follows that:

> attitudes of engaged, reflective listening to peoples' illness narratives as part of their life review, enables meaning-making for narrators, listeners, and others.

The study consisted of a number of layers, and the format of the thesis reflects and considers the various layers of the process:

- the life review narratives of five people who were recruited from different life contexts, and their multiple expressions as text, poetry, drawings and prose;
- the process of listening to illness and life review narratives and the interventions and reflective responses that accompany that process;
- reflection on the meaning of the process for the narrative partners and their individual surrounding social systems, and for me as listener.
consideration of ways reflective listening might be utilised in broader contexts, especially healthcare relationships, and what the analysis adds to existing knowledge of narrative, life review, and patients' experiences of healthcare. The question will be addressed as to whether anything general beyond knowledge of the individual's story can be inferred.

There is a metaphoric use of crystals and crystallisation throughout the study. Crystals grow, change, and alter. Developing ways to best distil meanings and crystallise sometimes tacit understanding, has seen the emergence of ‘multi-modal’ methods. This can involve rendering experience in visual art and poetic forms and their use and applicability is discussed throughout the thesis. These meanings might become available for all participants including the narrators, their readers, and me as listener-researcher.

2. **SURVEYING THE LITERATURE**

The literature search began years before the study's conceptualisation, flowed through the areas of relevance to the study and continued throughout the thesis writing process. Adopting an attitude of sequential flow in the literature meant that one article and its reference list led to further relevant reading, as well as many more directly focused searches as the issues for exploration arose from within the narratives. Areas of literature searching therefore included:

- Qualitative research, methodologies and methods, especially phenomenology, bricolage, hermeneutics, social constructionism, intersubjectivity and collaborative inquiry
- The search for meaning and self-identity
- Listening and not listening
- Illness narratives, narrative theory and issues of disrupted or sense of lost identity
- Dying, death, bereavement and grief
- Narrative literature and theory especially focused within healthcare professional fields
- Life review, autobiography and memory theory
- Issues involving individual participants, for example:
  - Family relationships: for instance mother's and daughter's relationships
• Dementia/alcoholism
• Ageing
• Abortion
• Dialogical, language issues and interviewing
• Ethical issues

The broad literature searches of this study include references to chronic and deep illness narratives. They are cited throughout the thesis and are gathered into a separate list of autobiographies, biographies and illness narratives in Appendix One. This list encompasses chronic illnesses such as HIV, Alzheimer's Disease, Down's Syndrome, emphysema, progressive and traumatic blindness, severe clinical depression, quadriplegia, recovery from severe injury, Systemic Lupus Erythematosus, Chronic Fatigue Syndrome, cerebral palsy and a variety of cancers. The list includes Bérubé (1996); Ellis (1995); Frame (1980); Hull (1990); Hurley (1996); Lorde (1997); Moore (1991); Murphy (1987); Price (1994); Styron (1992); Torey (2003); and Zola (1982).

The full method of literature searching utilised for the study is discussed in Chapter Two.5. There is some existing research around narratives of living with chronic illness for instance Hart, and Grace (2000), and Whitehead (2006) regarding Chronic Fatigue Syndrome; and Mathieson and Stam (1995) regarding re-negotiating self-identity following the diagnosis of cancer. However, none of these studies approaches listening to illness narratives embedded in in-depth life review processes. The method of multiple interview and multi-modal analysis and reflective responding utilised in this study, aims to add to the existing field of research and literature by expanding the understanding of what it is like for patients who suffer these illnesses, and for their family members. The study also aims to demonstrate how self-aware, compassionate and reflective listening can allow meaning to emerge from within the illness experience, thus enriching the wellbeing of patients, family members and their various healthcare professionals.

3. OVERVIEW OF THE THESIS

I have now introduced the study, described how it evolved, the nature of the problem, and the aim of the thesis. The discussion now outlines the structure of the thesis, which explores a multi-layered, deeply engaged, reflective listening process, focussed on
people’s illness narratives that are embedded within their life review narratives. Five people’s life reviews were tape recorded over time, transcribed, and then processed. In addition I kept a journal of my experiences, noting the emotional impact of working with each person, in each individual’s life context.

Premised on a constructivist worldview that proposes that humans are meaning seeking and constructors of their own meanings and realities, and a social constructionist view that meaning is found through social interaction, Chapter One examines ways meaning can be found in human lives and experiences. It explores the nature, qualities and significance of these meanings, particularly as they arise from reflective listening. These processes of making meaning are basically self centred processes. I explore what can be understood about self, and how inter and intra subjectivity are defined and function from a constructivist perspective. Then follows discussion of the nature of narrating and listening to illness narratives, as they are best embedded within life review narratives in all their complexity.

Chapter Two explores qualitative methodologies that support personal and interpersonal life descriptions and reflections. It considers how particular methodological frameworks allow the study to be rigorous and valid, including collaborative or participatory inquiry as described by Heron and Reason (1997, pp.274-295) and others. The ethical issues involved in this type of qualitative human inquiry are outlined, followed by exploration of the theoretical base for the narrative methods utilised in the study, then a description of the methods themselves. In the study’s amplified process of engaged listening, intersubjectively reflecting back to the narrator the essence of what has been heard is an affirming, valuing experience. My responding, reflecting process has significance and is mapped throughout the thesis. The chapter continues with an introduction to a modified application of van Manen’s (1990) phenomenological method of literature searching that accompanied each narrative’s processing. This is followed by a discussion that prepares the reader to engage with the individual narrative processes.

Chapters Three to Seven describe the five life review narratives’ processes. Each chapter explores one person’s narrative and is self-contained:

- Chapter Three: Listening to Kaye’s narrative;
• Chapter Four: Listening to Sarah’s narrative;
• Chapter Five: Listening to Scott’s narrative;
• Chapter Six: Listening to Bert’s narrative;
• Chapter Seven: Listening to Elizabeth’s narrative.

Following the five life review narrative chapters, Chapter Eight reflects on the processes, findings, effects and problems of the study. The discussion explores what it was like for the narrators to be listened to and why listening made a difference and what it achieved for me to listen with reflective engagement to the life stories and reflections of others. There is further discussion of qualities of engaged reflective listening and situations where listening was not optimal. The study’s model of listening raised a number of difficulties that are examined, and there is discussion of how relevant literature anchored the study. Reflection follows on the process of synthesis, and the notion that the stories are not finalised. The chapter concludes with critical reflection on the methodological frameworks of the study.

Chapter Nine seeks to bind together the multiple strands of the study. I reflect on the nature of meanings and understandings and how they emerged from the study. This includes the intersubjectivity, reciprocal recognition and listening that enabled the meanings to crystallise. The discussion then draws parallels that might enable the study’s amplified model of listening to be beneficially applied in healthcare relationships. The thesis concludes by crystallising the study’s achievements, reflecting on my personal journey through the process, and the ingredients that helped the search to be successful.

The following poetic reflection now introduces my use of poetic-shaped statements throughout the process, as a means of reflection, and as a way of gathering my emerging understandings into a preliminary synthesis.
I see that:

When you describe your life to me
I am deeply inter-ested -
(from inter - esse, to stand in the middle of something).
I stand in the middle of your life story.
To listen to your story is for me a deeply caring act.

I wonder how that helps both you and I
to find meaning, or rather
a temporary crystallisation of meaning,
which becomes deeply satisfying for us both
(for the time being)?

I ask: what was your life like?
What is it you describe about your life,
especially its disrupting experiences,
that shares its essence with me?
I listen care-fully, and respond as we go, intersubjectively.
I listen deeply for my own intra-subjective responses.
Will your story help me to find the essences of my life, and its meaning?

Heuristic phenomenological research
requires me to live this question,
to become this question.
Is this the meaning of this study:
to question experiences by going back again and again
to the stories themselves,
until the experiences that are questioned
begin to reveal something of their nature?
Chapter One: Finding meaning through listening and responding to narratives

1. INTRODUCTION

As previously introduced, a constructivist worldview proposes that humans are meaning seeking, and constructors of their own meanings and realities. This chapter focuses on how meaning might be found in illness and disruptive life experiences, as they are described within the context of the person’s life narrative. It examines the nature, qualities and significance of these meanings, particularly as they arise from reflective listening. The processes of making meaning are basically self centred processes that enable participants to deeply re-experience their life and to see it as a whole. I consider what is meant by self, and how subjectivity, and inter and intra subjectivity, are defined and function from a constructivist perspective. Discussion of narratives follows, with their central position in the thesis: the nature of narrating and listening to illness narratives, embedded within life review narratives in all their complexity. Myerhoff (1979, p.272) characterizes our species as homo narrans, that is, humankind as storyteller, implying that the fabric of meaning that constitutes any single human existence is the story we tell about ourselves.

This chapter is set out as follows:

- Firstly I consider the ways in which finding meaning can be understood, and how it is argued that people make sense of their world. This is followed by discussion of experiential knowing and understanding, and exploration of what can be understood about self.
- Secondly I cover the nature of inter and intrasubjective relationships.
Finally I explore the nature of narratives. I define narratives, discuss illness narratives and life review narratives, and why they are central to humans’ understanding and sense of wellbeing. There is also discussion of the qualities of listening that are proposed as those required in the co-creation of a coherent story.

2. FINDING MEANING

It is argued that humans are beings in search of meaning (Frankl 1978, 1984). Psychiatrist Viktor Frankl was a survivor of a Holocaust concentration camp. He later developed logotherapy, at the core of which is the belief that human beings’ primary motivational force is the search for meaning:

life holds a potential meaning under any conditions, even the most miserable ones … to live is to suffer, to survive is to find meaning in the suffering. If there is a purpose in life at all, there must be a purpose in suffering and in dying. But no man can tell another what this purpose is. Each must find out for himself, and must accept the responsibility that his answer prescribes (Frankl 1984, pp.11-16).

Thus this notion proposes that meaning is what each individual finds for themselves, as they put together the words to describe their experiences (Garro and Mattingly 2000; Gendlin 1982; Greenberg and Saffran 1987; Riessman 2000; Rubin 1996; Robinson 1981; Anderson and Goolishian 1992). Polkinghorne (1988, p.4) argues that the realm of meaning is not a thing or substance, but an action. The process of articulating and reflecting on human experiences enables the dialogical construction of meaning. The implications of this concept are central to my study.

In order to understand the nature of how meaning follows narrating, further exploration of the narrative and constructionist literature proposes that the meanings and truths people construct are neither permanent nor stable. This impacts on the ‘truth’ and ‘meanings’ of the illness and life review narratives in the thesis. Different tellings are created in the context and time of their telling, where they can shape different meanings for different purposes. Freedman and Combs (1996, p.46) discuss Derrida’s exploration of the slipperiness of meaning. Derrida and other deconstructionists argue that it is fruitless to search for one real or true meaning of any text, with all narratives full of gaps and
ambiguities. Derrida (1972, p.250) asserts that there is no clear window into the inner life of a person, for any window is always filtered through the glaze of language, signs, and the processes of signification. Denzin (1989a, p.14), in analyzing Derrida’s view, states that there can never be a clear, unambiguous statement of anything, including intention or meaning. This suggests that there can be multiple interpretations of any story (Kegan, 1982, p.10). The ideas of ‘truth’ and reality, are re-visited throughout the thesis.

My study’s grounding in the notion of meaning arising through narrating and being heard, is supported by an abundance of literature. Despite the gaps and ambiguities suggested by the deconstructionists mentioned above, the value and practice of forming meaning through the narrating of our life experiences continues to be a focus across many disciplines. Like Frankl, Kegan asserts that the activity of being a person is that of meaning-making. ‘Free of disease, warm and well fed, we may still perish if we cannot mean’ (Kegan 1982, pp.11-19). Kegan (1982, p.17) states that ‘our survival and development depend on our capacity to recruit the invested attention of others to us’. Hence the central problem of ‘not listening’, ‘not hearing’, or even ‘not telling’ can be argued as risking our development, and even our survival. There are several other significant dimensions of meaning that need consideration.

- Embodied understanding

An interaction occurs at the time of narrating between experience and concept. Gendlin (1982) proposes that this interaction is a bodily felt sense of meaning. Greenberg and Saffran (1987, p.195) see this body-felt-sense as a rich meaning store, linked to emotional experiences and memories. A person develops this store of experiential knowledge and meaning, containing their view of their identity, as well as their surrounding emotional experiences such as joy, sadness, pain, guilt and anger, contributing to an integrated experience of deeply felt meaning. So in focusing not just on beliefs and judgments, but equally on the experiential structure of our bodily being-in-the-world, the therapeutic autobiographical approach may uncover rich interpretations and insights (Johnson 1989, p.363).
• Meaning in narratives

In the creation of an illness or life-narrative, the meanings are a function of the relationship between listener and narrator, each mutually affecting the other’s meanings and situation (Anderson and Goolishian 1992, pp.26-33). As a sociologist, Riessman (2000, p.145) sees narrative meanings as problematic and ambiguous because they are shaped by the particular interactional context in which the stories are told and by the role of the interviewer in shaping the narrative performance. Rubin (1996, p.9) and Robinson (1996, p.202) suggest that meanings also involve the characteristics of the person and the choices they make.

• Temporal aspects of meaning

The meaning of an experience changes over time. Although different meanings from different times cannot all be accurate, they are all authentic from a first-person’s perspective, that is, they are temporally and locationally specific.

Another way of finding and understanding meanings as they emerge from the narratives in the thesis is to focus on experiential knowing, or what it is that is known following life experiences:

2.1. Experiential knowing and understanding

Experiential knowing involves a direct encounter with an experience, person, feeling, image, place, process or thing, in a face-to-face way that brings an inner resonance with what it is that is experienced. Maslow (1998, p.81) describes ‘full experiencing’, where the researcher’s awareness shifts to become what is known, rather than remaining in the stance of a separate spectator. Orthodox scientific knowledge is like looking through a keyhole, distanced, from outside. There is no involvement with what one is looking at, no loyalty required. Buber (1923, p.59-63) argued that by becoming and being what is to be known, rather than remaining the outside observer, one reaches maturity. It is I-Thou knowledge as experienced and reflected on from within, a connection with self and other
(Moustakas 1996, pp.171-172). This issue will be further illustrated in the narrative chapters of the thesis, especially as I try to understand the narrators’ perspectives as I listen to and reflect on their narratives.

Life-journeys often involve obstacles that must be dealt with and overcome. This gives rise to the basic struggle or tension that gives life-narratives their character. Whatever culture a person belongs to, its narratives have influenced them to ascribe certain meanings to particular life events and to treat others as relatively meaningless. The effects of enculturation are reflected throughout the thesis. Experientially speaking, one’s life narrative is one’s life, and this notion also echoes in the narrative chapters (Freedman and Combs 1996). Stories often centre on some initial harmonious balance that is disrupted and this gives rise to a quest for the lost harmony (Johnson 1989, p.374). People use narrative processes in an attempt to re-create the sense of continuity after unexpected disruptions to their lives (Becker 1997).

Understanding involves finding the essence of our experiences. This means sifting deeper than surface appearances, to reflect on and understand what is there (Peile 1994, pp. 45; 141; Polanyi, 1967). Our explicit knowledge arises from, or is sifted through, our tacit knowledge, which is recorded throughout our bodies. Terms such as ‘it was gut wrenching’, or ‘he was beside himself’ are used to describe experiences.

Having described the notions of knowing, meaning and understanding, I now turn to exploring the nature of self, and then its relationship to the other.

2.2. **What is meant by self, and how is self understood?**

It is argued that people cannot be peeled layer by layer like an onion until a core self is found. Even if the self is made up of many parts - stories, experiences and relationships - these do not together constitute a single self, or the core self (Anderson 1997, p.220). Self and other are created concepts, that is, created by language and stories, and affirmed in relationships and conversations. In this view, the self is a dialogical-narrative self and identity is a dialogical-narrative identity. ‘Who am I?’ according to Georgi (1989, p.75) is discovered by learning the art of meaningful dialogue with another.
‘Dialogue is like a mutual unveiling, where each seeks to be experienced and confirmed by the other as the one he is for himself. Such a dialogue is most likely to occur when the two people believe each is trustworthy and of goodwill’ (Jourard 1968, p.21).

*Self* involves the person viewing themselves from ‘outside,’ or seeing themselves as another would see them. This turning-back process is only possible through the interaction of the person with others. This view is enhanced in the process of narrating one’s life stories, where the self is described as it is explored with another (Crossly 1996, p.55-68). Who a person can be is often a matter of who others take them to be (Nelson 2001, p.81). Nelson argues that:

> Through one’s own and others’ selective, interpretive, and connective representations of the characteristics, acts, experiences, roles, relationships, and commitments that contribute importantly to one’s life over time, an identity makes a certain sort of sense of who one is. It does so because it is essentially narrative in nature (Nelson 2001, p.15).

One might question this notion in regard to hermits or contemplatives. Perhaps their practice rests in the exploration of their sense of interaction with their absolute Other, God (van Manen 1990, p.101-106).

People can be defined as a series of selves by virtue of an ability to become what the situation demands (Spinelli 1989, p.82). Using this argument I can identify myself as nurse-self, mother-self, grandmother-self, illness narrative/life review-researcher-self, wife-self, friend-self, student-self and so on, depending on the circumstances of each experience. Freedman and Combs (1996, p.35) think of a self not as a thing inside an individual, but as a process or activity that occurs in the space between people. Different selves are seen in different contexts, no one self truer than any other.

Personally, I do not picture the selves I have listed above as layers of *my self*, but more as aspects of myself, perhaps more like the facets of a revolving crystal, none more important than the others. Ceglowski (2000, p.95) however, describes how she ‘peels back the layers of her former self’ in her role as researcher. Ceglowski also claims that in
the context of her research work, a caring relationship brings with it a sense of connected knowing that comes from the sharing of self and other, which echoes in my experiences.

Undertaking this study exposes the difficulty for me in separating my researcher-self from my other selves, as noted by Ceglowski (2000, p.95-97). I need to remain aware of the intention of the role I am engaged in, not as palliative care nurse, and not as rescuer, a role I am aware I sometimes assume. My role is that of listener/reflector/researcher. Ceglowski states that the impact of the stories on a variety of one’s ‘selves’ disrupts the notion that the listener/researcher has one identity. I note, describe and reflect on these impacts on myself in my journalling, which is discussed throughout the thesis.

Our individual spiral of understanding, although shaped by evolutionary and cultural forces, is uniquely our own (Skolimowski 1994). It requires the recognition of personal knowledge and personal truth, which can be accommodated alongside what Skolimowski calls universal knowledge and truth. This would explain to me why my siblings, whilst culturally, historically, and genetically similar, have different views of being-in-the-world to mine. Important to this study is how people form, evolve and share notions of themselves.

2.2.1. Stories about our selves
Relevant to the discussion about what is meant by self is the proposal that stories about selves are not just personal inventions. They can be learnt in conversation with significant people in one’s life, such as the stories of one’s birth. These stories are important affirmations of one’s self-knowledge (White, cited in Monk et al. 1997, p.20-21; White 2007).

No life review can contain all the stories that could be told about that life. Over a lifetime, many significant experiences seep into the core of the person’s life, with lasting effects and leaving permanent marks. Denzin (1989b, p.15) calls these experiences the epiphanies of a life. The therapeutic effect of narrating one’s first-person stories is to transform one’s self-identity into one that permits understandings to develop, particularly of significant epiphany experiences.
2.2.2. **Evolving selves**

Some theorists propose that humans are evolving selves and in reconstructing their past, they redefine themselves in an ongoing process that is never finished (Spinelli 1989, pp.78-79, 81, 103; Kegan 1982, p.81). Even after death, others continue to re-story our lives. People live in and through the ever-changing narrative identities that they develop in conversation with one another (Anderson and Goolishian 1992, pp.28, 31). The following section examines the inter and intrasubjective relationships between selves, and how this becomes a significant part of our wellbeing as humans.

3. **SUBJECTIVITY AND INTERSUBJECTIVITY**

No two people can occupy the same place at the same time. They will not necessarily see the same things. There are many factors that might account for discrepancies in one’s various experiences, ranging from social position and cultural history, purpose or mood. There is no single reality to be seen (Crossley 1996, p.30). These different perceptions resonate in stories told, and heard by others.

A fundamental theme arising within an overall constructivist worldview is that of valuing the subjective and the intersubjective. When one shares one’s subjective experience - such as by telling one’s story - one interacts with the subjective experiences of others. Subjectivity becomes intersubjectivity in the social mode of story-telling. Through such processes meaning is shaped. People might assume that a meaning belongs to a community rather than attributing it to a particular person, and according to Crossley this is because all meanings are socially intersubjectively constructed as soon as they reach representational form. It is through peoples’ interactions and dialogues that views of things are developed, and these are continually in flux, overlapping with others’ views, constantly being shaped and reshaped. Thus the world is experienced as an intersubjective world of shared meaning (Crossley 1996, p.4).

3.1. **Voice and empowerment within dialogues**

Another significant way of viewing listening and relationships is proposed. Buber describes I-Thou intersubjectivity, where both partners are equal in the relationship. Crossley calls this *radical intersubjectivity* (Crossley 1996, p.24). Buber (1923, p.113) sees genuine subjectivity as ‘the vibration of the I in its lonely truth’. Buber believes that
meaning forms in the space between people, and each person is therefore de-centred in relation to the whole situation. Each person’s thoughts and experience are dialogically interwoven with those of the other. This means that the stories formed by me with each narrator in my study, belong in the space between us, ‘the inter-world,’ not reducible to either person, but shaped in reciprocal recognition and respect. Don Asker and I tried to find more current language for expressing Buber’s I-Thou, and chose the term ‘Being-to-Beingness’ as having the qualities of human engagement we felt Buber was conceptualising. This term then permits the concept of a less equal I-It, Health Professional-patient, less reflective engagement that my study describes and seeks to change. Throughout the study I continue to use the terms I-Thou or Being-to-Being in preference to Crossley’s radical intersubjectivity, which does not seem to fit so comfortably.

My study seeks to understand how listening enables meaning to be found through the processes embedded in the rich loops of dialogical communication and reflection, where the participants genuinely participate in a shared space (Frank 2005a, p.970). The real lived world is not pure object or data, but more like a tangle of sensations and perceptions. McNamee and Gergen (1992, p.8) argue that it is these loops of communication that bind people intersubjectively together.

4. THE NATURE OF LISTENING TO NARRATIVES

To this point the discussion has argued that seeking meaning is inherently part of being human. It has been noted that dialogical co-creation of meaning lies at the heart of the stories people tell one another about their lives and experiences. The discussion now focuses on the definition of narrative, and the nature of various types of narratives such as illness and life-review narratives, with some natural overlap between them. There is an expanded discussion regarding listening to narratives, and the complexities and difficulties of the narrative process.

There are many perspectives on narratives arising from the many different ways storytelling occurs and is studied. All these perspectives contribute to the narrative understanding that shapes this thesis. For instance, Mattingly (2000), and Good and Good (2000) bring an anthropological view to the understanding of narrative; Frank’s (1991) is
a sociological perspective, coloured by his own illness experience. Charon’s (2002) viewpoint is that of medical ethicist, while Kleinman’s (1988; 2006) is both psychiatric and anthropological. This section defines and examines the significant processes of creating a coherent narrative, and how one listens to narratives, especially those about difficult, traumatic experiences. Encouraging the broad nature of the approach to the study of narratives, Mattingly (2000, p.6) suggests that it makes little sense ‘to band together in exclusionary tribes’ and that ‘cross-fertilisation’ benefits the knowledge-base of narrative studies.

The discussion now moves towards defining narrative and story. Narrative understanding is central to this thesis. It is described as human beings’ most primitive form of explanation. People make sense of things by fitting them into stories. They describe events in a narrative way that satisfies them, and then they think they have some grasp of why the events occurred (Honderich 1995, pp.853-4). The narrative act is thinking with the story, truly listening and attending to the process of becoming which is inherent in this practice (Nelson 1997, 2001, pp.69-105, 2002; Guillemin and Gillam 2006, p.26).

4.1. Definition: Is it a narrative or a story?

The words narrative/narrator/narrating and story/teller/telling are used throughout the thesis. It became impossible to choose one group of words or the other consistently. The resolution of definition for the purposes of the thesis follows in Figure 1. Narratives are one way of reconstructing past experiences. In this way life-narratives provide a framework for the organisation of lived experiences (Norrick 2000, p.6). A story can be defined as a unit of meaning that frames an individual’s lived experiences.

Within the literature, there are multiple uses of narrative and story, and arguments supporting either or both words. Mattingly (2000, p.12) uses narrative and story interchangeably. Mattingly calls story a sequence of actions or events, with discourse being our conversational presentation of these events. Davis (2002) seems to use the words alternately, with no clear differentiation. Ricoeur (1986) describes life ‘as a story in search of a narrative’, applying the Socratic maxim that the unexamined life is not worth living. Polkinghorne (1995, p.5) makes a distinction between narrative, which he sees as a kind of organisational scheme expressed in story form, and story as a single unit that provides meaning to the past events and actions of a person’s life. Frank (2000b) proposes
that ‘let me tell you a narrative’ sounds strange. People do not tell narratives, they tell stories.

Wikan (2000, p.232) argues a distinct difference between narrative and story. Wikan’s argument is that everyone tells stories, but only academics gather narratives. The all important coherence required of a good story is not a crucial criteria for the worthiness of Wikan’s personal illness story, rather it is uncovering the essence of her life, experienced through her efforts to make sense of things that happened. Wikan’s fear is that ‘narrative’ might take her story on a superior flight where its lived experience might be missed. She says that she has no need for a ‘narrative’ to tell her story. All it achieves for her is to create an impression of something fancy. Wikan argues a warning for my study that stories are not ‘neat’, that my approach as listener/researcher needs to be sensitive and responsible, taking care not to take stories on ‘superior flights of academic assumption’.

To resolve the multiple definitions, I utilise Polkinghorne’s (1995, p.5) definition of the difference between narrative and story throughout the thesis, as illustrated in the following diagram:

The drawing together of the narrative:

- stories of families and family relationships
- stories that reflect the values embedded within
- stories of experiences, feelings, epiphanies, grief, suffering and crises
- stories of personal values, testimonios self-identity, hopes and fears

The process of assembling, holding and reflecting.

Figure 1. Multiple stories that form into a coherent life review
Polkinghorne’s definition enables the terms *story* and *telling* to be used throughout the thesis where they appropriately refer to units of telling within the person’s narrative, rather than a consistent, more distanced use of *narrative, narrator* and *narrating*.

In order to understand the structure of the narratives presented in Chapters Three to Seven, the discussion now examines narrative patterns. Some narrative theorists, including Bruner, J. (1986, p.21) and Denzin (1989b, p.37), propose the patterning of beginning, middle and end as the sacrosanct requirements of a narrative, separating them into separate entities. This means a narrative should describe a sequence of events that have happened. Not everyone shares this view.

Others propose that it is possible to choose where to start and end, and stories can be ongoing. Wikan (2000, p.216) protests the view of the orderly narrative that Mattingly proposes (2000, p.181-211), where it is the ending that has a core role in shaping the meaning of the narrated events. Wikan says her story remains unfinished. As far as her illness was concerned, Wikan was strongly aware of before and after. Wikan concludes that what is needed for a good plot is a good beginning, the rest takes care of itself. I sense that the *plot* of the narrative, as described by Wikan, means presenting enough of the complexity and connectedness of individual experience to make knowing or understanding feasible. Wikan argues that stories can remain comfortably unfinished. Frank (2004b, p.132) argues that stories must remain unfinalised. Stories call on us to respond correctly, to meet in a shared *habitus*, ‘a dance of your turn, my turn’. If dialogue is a practice of generosity it must resist the process of conclusion, without reassurance of how it will turn out.

Mentioned in Figure 1, a *testimonio* is an account of a life, in a novella-length printed text, which needs a narrator and an interlocutor, who generally records the account and then transcribes it. The narrator uses the possibility of a writer/researcher’s work to bring the narrator’s situation and dissatisfactions to the attention of those who might change the narrator’s feelings of loss of control. The narrator can be a person who is illiterate or not a professional writer. Several of the narrators in this thesis were terminally ill or demented. Their illness and life review narratives form testimonios - they are told with the purpose of making their dissatisfactions known (Beverley 2000, 2005, p.547-548).
4.2. **Telling life’s stories**

Telling life’s stories can have different structures and intentions, and can be understood in many ways. Different people’s narratives in the thesis demonstrate the different intentions of each narrator. I re-state the significance of narratives in the thesis, especially illness narratives told as part of their individual life review, and re-iterate Kleinman’s (1988, p.xiv) assertion of the importance of patients’ individual illness stories. This re-emphasises the nature of ‘the problem’ that gave rise to the thesis, that healthcare professionals do not always listen well to their patients’ stories. Finding meaning in illness has core significance in this thesis, especially when the person felt that their wellbeing was disrupted by their perception that they had not been listened to well. Kleinman (1988, pp.xi-xv) proposes that illness has meaning, and to uncover this meaning it is important for illness narratives to be embedded as part of people’s broader life review narrative, in order for them to be reflected on and understood (Frank 1995, 1997, 2000a).

The following section begins with discussion of illness narratives, followed by other issues surrounding life review narratives, concluding with a section on listening to both illness and life review narratives.

### 4.2.1. **Illness narratives**

The purpose for telling an illness narrative is proposed by Schweitzer (1957 ed. p.172):

> Whoever among us has through personal experience learnt what pain and anxiety really are must help to ensure that those who out there are in bodily need obtain the help that came to him. He belongs no more to himself alone; he has become the brother of all who suffer.

It is, according to Schweitzer, a membership of the ‘Brotherhood of those who bear the mark of pain’, and gives rise to the need to describe and share the experience. Frank (2000a, p.3) argues that the story serves to convince at least the storyteller of who she or he still is and can become, despite illness.

Today, where medical services are readily available, illness narratives mostly arise in healthcare settings, or have some degree of relationship with healthcare professionals.
Kleinman (1988, p.3) turns to illness narratives to illuminate ‘the innately human experience of symptoms and suffering.’ In telling his own story of serious illness Frank (1991) reshaped his experience into a story that, as he created it, transformed it into the building materials of his own authority of knowing. Then in publishing his story, it became available to be read as part of the building of their own authority of knowing by other ill people.

The following sub-themes describe perspectives of illness narratives. This expands dimensions of understanding listening to illness narratives.

*Stories that balance healthcare professional power*

Many people accept that healthcare professionals enjoy certain privileges over our bodies. Crossley (1996, p.140) argues that people tend to endure this if it helps to alleviate their pain and possibly helps them to live longer. However, the healthcare professional - patient relationship is frequently unequal. Often patients internalise this attitude as a self-diminishing attitude toward their own behavior (Moss 1989, p.197-198). They do not feel heard or acknowledged by their healthcare professionals and this leads to stories of disruption, disconnection and destabilization. In narrating their story and organising the flow of its presentation, the narrator regains their control of what happened. Then it is possible for them to find meaning. Therefore there is a plurality of knowledge around illness and disease, both medical and personal. There is the knowledge that rests with the sufferer of the illness and their extended communities, and then the multiple voices and perspectives of the many varieties of healthcare professionals who become involved in each person’s illness. This point is crucial to understanding the work of listening to peoples’ illness narratives, described as part of their life review narrative (Wiltshire 1995, p.79).

*Stories that help healthcare professionals to understand*

In the introduction to the study, I presented an illness story where Kleinman (1988, p.xiv) says to his patient: ‘tell me what it is like to be so badly burned and have to endure these terrible sessions each day’. Illness narratives provide a ‘window’ into that experience, thereby enabling the healthcare professional to gain insight into illness (Frank 1991,
Frank wanted his illness journey to be recognised. He sought to tell his illness story in a way that could help make the stories of other ill people more highly credited, not only among the ill themselves but also among their carers. Frank says ‘I simply wanted to tell, and I experienced the self-realization I sought in that telling’ (Frank 1991; 2000b, pp.354-365).

Living in deep illness

Living in deep illness places a person in a different culture to those living in wellness, and a different culture to that of healthcare professionals who might be regarded as directing the course and outcomes of these illnesses (Frank 2000b, 1995, pp.141-42; Zola 1982). A dialogical attitude, or recognition, allows existential wholeness to be experienced in relationships with others, despite living in deep illness. Therapeutic autobiographical work focuses on a search for wholeness. The wholeness is never for oneself alone but always for oneself with another. Wholeness here means the ongoing connection between simultaneous differences, such as the difference between healthcare professionals and deeply ill people. The ethical challenge is to live in the space of that tension (Frank 2000b).

Transcendence in terminal illness

My study contains several stories told from the perspective of people with terminal illness. Birnie (1998, p.61) encountered an interesting view. She asked a patient in a palliative care facility to share his life’s story. Amazed, he responded ‘Nobody’s ever asked me that before.’ Morse (2002) also found that many people report that they have never had the chance to tell their stories in their entirety. Often such an opportunity is followed by a genuine sense of satisfaction or closure. People tend not to tell their stories as complete entities, they don’t often pause to assemble their life stories, to look at where they have come from, what they achieved, who they are now, and what they believe and value.
**Illness as punishment for wrongdoing**

In trying to come to terms with her terminal illness, Lindquist (2004) writes that a sense of *sin* still connects illness and punishment and notes the English word ‘pain’ comes from the Greek ‘poine’ which means punishment or penalty. Howell (1998) argues that meaning goes beyond the surface reactions of the individual to the depths of the person’s soul, and can be a source of despair and suffering. Individuals may see two reasons for their symptoms or illness experience: the medical reason and their own private version, such as punishment for perceived wrongdoing. Listening for, and being aware of this view is critical.

**The professional relationship**

Once people subscribe to a given discourse, for instance a biomedical one, they promote certain definitions. Hoffman (1992, pp.14-22) argues that the institutionalised kind of language shared by people in a group (such as healthcare professionals), manages successfully to exclude non-members from participation. One might argue this judgment of the doctor in Kuhl’s story (refer Introduction), who told ‘Marjorie’ that she had ‘metastatic carcinoma’, without inquiring if she understood what this meant. Marjorie tells Kuhl that at the time she did not (Kuhl 2002, pp.45-46). The ‘official’ medical discourse is able to determine which persons or what topics are most important, and what language is to be used.

There is a duty of care in having the narrator’s wellbeing as paramount. It appreciates the possibility that different values or worldviews of facilitator and narrator may impact adversely on the relationship. When listeners share their ways of seeing, understanding, and interpreting the life stories with their narrators, they expose and bridge cracks between their own life-worlds and those of the people with whom they work. By failing to engage in careful conversation I might misinterpret people whose lives and life experiences differ from my own (Larson 1997, p.459). This is an ethical issue that requires constant mindfulness. The risks, difficulties and limitations of reciprocal openness in life review narrative work are discussed in the concluding chapters of the thesis.
4.2.2. Life review narratives

With my aim to embed illness narratives within their individual life review narrative, the discussion now turns to the complexities of this form of narrative. Many perspectives contribute to the practice of life review and life reflection. Bruner proposes ‘Life as narrative’: ‘In the end we become the autobiographical narratives by which we ‘tell about’ our lives’. Encouraging my research, Bruner writes that he cannot imagine a more important psychological research project than one that addresses the development of autobiography. That is, how people’s ways of telling about themselves changes as they tell and retell their experiences, and how these accounts come to shape their ongoing ways of life (Bruner, J. 1987, p.13-15).

My intention is to facilitate each narrator to tell their life stories in their context and situation, within their individual qualities and differences. The process is collaborative. It requires mutual trust, and for the focus to be on co-creating an account that reflects the narrator’s life experiences where ‘it is the connections or relationships among events that is their meaning’ (Polkinghorne 1988, p.6).

Life stories need to satisfy two criteria: firstly the stories have as their primary evaluation a focus on specific points about the speaker, not general points about the way the world is. Secondly, the stories are tellable and are told again and again. A life story consists of:

all the stories and associated discourse units, such as explanations and chronicles and the connections between them, told by an individual during the course of her lifetime (Linde 1993, p.21).

When I began to explore life review narratives in depth, Warren Lett, Director of MIECAT, (refer Introduction) suggested the name therapeutic autobiography for this work. It was personal life-description and reflection. A life review story is not simply a collection of stories or explanations. Instead it describes the relations among them, which sees therapeutic autobiography as an opportunity to tie together the various stories and explanations with coherence that is meaningful for the person whose life is described (Linde 1993, p.25). The life review document itself can then hold tangible meaning as an enduring creation of significance for both the narrator and their family.
There are discussions regarding gathering life review narratives and reflections in hospital or institutional settings, and the benefits of reminiscence therapy, especially for terminally ill patients (Adams 1994; Butler 1963; Byock 1997; Cheshire 2005; Coleman 1986; Gibson 1994; Frank 1998, 2000a, 2000c, 2001). The study’s findings regarding the benefits and ways in which meaning can be found in these situations, is discussed in the concluding chapters of the thesis.

It is argued that it is a universal occurrence in older people to review their lives (Butler 1963; Myerhoff 1994). This may cause depression and sadness, however Myerhoff (1994, p.33) argues that for the elderly Jewish people whose stories she recorded over four years in the 1970’s, there was a greater fear of oblivion than pain or death, and that these mostly Holocaust survivors sought opportunities to become visible, or as Frank (2002a, 2005b) terms it, *narratable*.

The beauty of the life-review-narrative process is that it allows us to tie all the changes in our life together into a broad, comprehensive narrative (Niederhoffer and Pennebaker 2002, p.574). Our stories form, inform, and re-shape our knowledge and our views of reality. In the further discussion of illness narratives that follows (4.3), there is explanation of how illness can destabilise a person’s sense of organisation, and how assembling a coherent narrative can restore some sense of personal organisation (Anderson 1997, p.212).

*Helping with coherence*

Another argument for why listening to life review narratives is important, is that the listener assists the storyteller to produce a coherent story. The storyteller is able to rehearse the experiential material and structure it so that it now represents a coherent series of events (Wiltshire 1995, p.80; Kvale 1996, p.200).

Merely having a story is not enough. The process of constructing the story is crucial, the dialogical act must be coherent. Linguistic coherence includes several characteristics of structure: use of causal explanation, repetition of themes, and an appreciation of the listener’s perspective (Niederhoffer and Pennebaker 2002, pp.573-582).
Coherence is an achievement of the narrator who constructs the story (Conway 1996, pp.109-112). Through an analysis of a coherent life narrative, it is possible to construct the deep motivations that give the narrator a sense of meaningful being, and of being grounded in their present time and space. Our views of human nature and behavior are contained by our descriptive vocabularies, conversations, stories and narratives (Anderson 1997, p.212).

Can life gain coherence through narrative (Mattingly 2000, p.267)? Dreier (2000, p.266) does not worry that life may lack coherence. Rather, in his view, life has plenty of structure and coherence provided by activities and contexts themselves. Kirmayer (2000, pp.171-175), in worrying about ‘broken narratives’, fears that when stories are told, life may appear far too coherent, full of continuities and connections that are the product of the narrative itself. Then the experiential is sacrificed in order to produce a culturally acceptable account. Perhaps it follows that being coherent about an incoherent life is the best possible outcome of one’s life review narrative.

A critical view of the relationship between story as something told, and experience as something lived, argues that there is a discrepancy, even an unbridgeable gap between the two. Mattingly responds (2000, p.204-205) that while no life-as-lived has the congruence of a well-told story, there are strong narrative descriptions that can arise out of these life reviews as they are created by their narrators, that offer an intimate relation to their lived experience. The dominant feature bridging the two is a narrative drama or performance, and the critical phase of reflection. As listener/reflector, I followed the performance with respect.

Memory

The concept of memory is important in the narrating of one’s life review narrative. It has particular significance when the narrator’s memory is shrouded in the fog of dementia. The idea of a core self as now discussed in regard to memory, sits somewhat differently to the previous discussion about self in 2.2, where Anderson (1997, p.220) argued the concept of self constructed in relationship, conversation and situation. Spinelli (1989, p.97) proposes that our picture of our self is tied to our remembered past. ‘If I have no memory of who I have been, I can say very little about who I am today.’ A core self
remembers, and acts upon those memories, defining itself through them. Damasio (2000, pp.174-197) describes a core self, which is based on autobiographical memories. He proposes that the core you is born as the story is told, within the story itself. Damasio argues that our sense of self-knowing is enabled by our working memory.

By placing the life review mostly into chronological order even if the memory is faulty, much fine detail can be remembered and added to the overall complex, intricate picture of the whole life, allowing a clearer definition of who the person has been, and is now at the time of narrating. In several narratives in the study, memory loss and confusion are issues that add complexity to understanding the person’s narrative.

Co-authoring

People tell personal narratives in order to be listened to, particularly when they have the opportunity to be heard. Co-authoring implies shared responsibility for the shaping of the narrative. In co-authoring a conversation, both listener and teller can achieve shared meanings (Winslade, Crocket, and Monk 1997, pp.54-55; Schwandt 1995, p.195). Each person’s story is deeply personal. Listeners cannot know where a story will go and it calls for curiosity and involvement in each segment of the story as it emerges (Freedman and Combs 1996, pp.44-45).

There is something in the creating of a life review and narrating of a personal narrative that enables both teller and listener to feel that they have shared a significant experience (Stahl 1989, p.43). Perhaps this feeling provides the sense of collaboration that Heron and Reason (1997) describe, as discussed in Chapter Two, 2.

Reality/truth

The truth or reality of the five life review stories told for the study, needs consideration, particularly within the impact of dementia or confusion. Each teller of a story is the author of the story, and his or her meanings are brought into an ‘authority of personal knowing’ (Lett 2001, pp.171, 197, 324, 349; Kegan 1982, p.11). The reality is not ‘out there’, but something produced that changes and evolves as the story is told and reflected on. Different stories are possible, even about the same events. How people talk about what
happens to them depends on their starting point and the context of the ‘telling’ (Drewery and Winslade 1997, p.40; Skolimowski 1994). Truth is often a matter of narrative strategies that convey a kind of ‘basic believability’ (Garro and Mattingly 2000, p.260).

A ‘perpetually questing truth-in-flux’ is proposed by Frank (1997, p.142), rather than an eternal ‘fixed-for-ever truth’. Rather than truth, Lett (2001) and Skolimowski (1994, p.306) each name temporary approximations to meaning, which enable the truth or meaning to change as the story continues to be told and re-told. Hoffman (1992, p.22) suggests that an ethic of participation rather than searching for the truth, emerges as a central model for co-operative, co-creative action. Skolimowski (1994, p.298) sees truth as an intersubjective entity, described by Plato as ‘a living dialogue’, that is, words made true in the light of the whole context within which they are embedded at a given time.

**Reciprocity**

Our world-views and lifestyles are intimately connected, and ‘the participatory mind is at the same time an interactive and co-creative mind’ (Skolimowski 1994, pp.xv, 17). This places the narrators, and myself as the listener/researcher in my study, inco-creative, mind-sharing reciprocity.

*Reciprocal* means ‘to give and feel in return, felt by each, expressing mutual relation’ (Macquarie Dictionary, 1987, p.1418). This forms a central philosophical and methodological approach of my study and is further discussed in the study’s conclusions. Murphy (1987, p.201) remarks that the principles of reciprocity are the mainstays of our personhood, and that to be a giver as well as a receiver is a hallmark of maturity. Vafiadis’s (1999) doctoral thesis examines the reciprocity between doctors and patients and their families. His thesis acknowledged that there was clear reciprocal support between the cancer patient and their family, and the general practitioner who was giving them care. A reciprocity in the relational sphere between nurse and patient is described by van Manen (www. 1994/2005) and could apply to all healthcare professionals.

The give and take of social interactions may be used to gain understanding of a particular event or experience. Through sensitive use of self-disclosure, interviews become conversations and richer material is uncovered (Harrison et al. 2001, p.324). However
there is a need to be continuously mindful of the boundaries and tension between what is good for the individual and what is right behavior (Guillemin and Gillam 2006, pp.29-40). The limits and boundaries of reciprocity are untangled in the final chapters of the thesis.

**Conversation**

Conversation, and co-authoring are words that describe the nature of the gathering of the narratives for the study. They indicate a preference for a mutually influenced process between researcher and participant, as opposed to one that is hierarchical and one-directional (Hoffman 1992, p.3). This is a mutual search for understanding and exploration through dialogue, an in-there-together process, talking *with* rather than *to* one another. The therapeutic autobiographer’s role is to develop safe conversational spaces where sharing and exploration can occur (Anderson and Goolishian 1992, p.9).

The narrators and listener do not necessarily take on fixed roles of teller and listener. Instead the conversation shifts back and forth to varying degrees as expected between collaborative partners (Ochs and Capps 2001, p.3). Efran and Clarfield (1992, p.203) argue that conversations are ‘nothing more or less than the everyday, rough and tumble adaptational processes that enable us to live together in the world’, not necessarily fragile events that need nurturing. Conversation is a good metaphor for the social process of meaning-making (Monk et al. 1997)

### 4.3. Illness and life review narratives require good listening for better outcomes

Having explored the nuances of illness narratives and life review narratives, the discussion turns to the overall concept of good listening and ways it can be seen to help, with particular emphasis on illness narratives.

Reflective listening is a central concept in this thesis, as previously introduced. The following discussion expands the nature of this form of listening. It is reiterated that whilst this study leans towards nursing and medicine, it does not differentiate between healthcare professional disciplines. Each can have a beneficial or detrimental effect on the wellbeing of their patients. Figure 12 in Chapter Four illustrates the number and variety of healthcare professionals a patient may see in the course of a serious illness.
Iedema (2008) questions what role communication plays in patient safety and argues that communication is the medium of patient safety, not a component of it. Iedema argues that not enough credence is invested in what communication means in this context, and also argues the financial costs that arise from adverse events in healthcare settings. Iedema discussed a number of reports:

- The Australian Institute of Health and Welfare and Australian Commission on Safety and Quality in Health Care (2007), *Sentinel events in Australian public hospitals 2004/5*;
- The NSW Clinical Excellence Commission (2006/7) *Annual report*;

These reports blame poor communication, among the top three reasons for adverse events and problems. Braithwaite, Iedema and Jorm (2007, p.357) argue that

communication centrally concerns the exchange of information. It involves imparting, receiving and deciphering knowledge. The effective interchange of various signs, signals, information and data, written, verbal and non-verbal discourse connects people together, facilitates collaboration and lays the groundwork for forms of consensus.

Braithwaite, Iedema and Jorm (2007, p.355) also cite The Department of Health (2001), *The Report of the Public Enquiry into Children’s Heart Surgery at the Bristol Royal Infirmary 1984-1995: Learning from Bristol*, which argues that:
Education in communication skills must be an essential part of the education of all healthcare professionals. Communication skills include the ability to engage with patients on an emotional level, to listen, to assess how much information a patient wants to know, and to convey information with clarity and sympathy.

This is the only one of these reports that proposes the specific personal action of *listening* rather than the more impersonal process of *communication*.

Egan (2002) and Silverman et al. (2005, p.9) argue the need for healthcare professionals to have attentive or active listening skills. Listening skills are now being taught to healthcare professionals, with teachers convinced that better communication enhances better outcomes for healthcare professionals and patients alike. As argued by a number of evidence-based studies (Silverman et al. 2005; Beckman and Frankel 1984; Brody 1994; Rider and Keefer 2006; Makoul 2001; Anderson 1998, 2000; Charon 2001; Connelly 2005; Frank et al. 1996; Pennebaker 2000; Smith et al. 1999), the task of the healthcare professional is to listen carefully and attentively without interrupting, in other words, *mindful* or *deep* listening.

However it is argued that ‘the activity of listening’ is more than ‘active listening’ in which one shows that one has understood the other by making a mirroring, empathic response. ‘Rather listening is a responding, a speaking or communicating from the place where I am affected by what you have said’ (Knill, Levine and Levine 2005, p.68). The listener needs to be present psychologically, socially and emotionally. In the stories in the introduction to this thesis, one can identify the engaged presence of Kleinman (1988, p.xiv) with his patient, and the lack of engagement in the case of Marjorie’s doctor (Kuhl 2002, pp.45-46) and ‘my’ two nurses (refer Introduction). This is also different from the perspective of gaining clinical information.

A listening atmosphere is not improvised (Corradi Fiumara 1990). It is the product of a strenuous process of conception, growth, devoted attention and reflection. In listening one is required to be fully present for the narrator. There is a sense of fairness about the need as listeners to demonstrate courage in hearing the story (Winslade, Crocket, and Monk 1997, pp.63-67). After all, the storyteller shows courage in narrating the stories of their
life. Connecting with people’s experience from their perspective, ‘orients us to the specific realities that shape, and are shaped by, their personal narratives. This sort of understanding requires listening with focused attention, patience, and curiosity while building a relationship of mutual respect and trust’ (Freedman and Combs 1996, p.44). It is the capacity of paying heed to a story that allows the unfolding of its meaning.

Empathic witnessing of the patient’s and family’s stories of illness is central to clinical work (Kleinman 1988, p.10). Kleinman seeks to convince his colleagues and students to allocate time to attend to the stories in which patients reveal the meanings they attach to their suffering. He emphasizes that stories are important for the ill person as well as healthcare professionals in the execution of their duty of care. Kleinman is redefining and challenging notions of caregiving. Frank reserves the name ‘caregiver’ for people who are willing to listen to ill people and respond to their individual experiences (Frank 1991, p.48).

The qualities of empathy, reflection and trust are necessary parts of the model patient-healthcare professional relationship (Charon 2001, pp.1897-1902). These qualities arise within narrative competence in healthcare settings where there is empathic listening and reflective engagement between patient and healthcare professional. Charon asserts that along with scientific ability healthcare professionals:

need the ability to listen to the narratives of the patient, grasp and honor their meanings, and be moved to act on the patient’s behalf. This is *narrative competence*, that is, the competence that human beings use to absorb, interpret, and respond to stories.

The healthcare professional equipped with the narrative capacities to fully recognise the plight of the patient and to respond with reflective engagement can achieve more effective treatment than one not equipped to do so (Charon 2001). Attending and listening are ways of translating or implementing the value of respect, thus contributing to good relationships. These attitudes lay the foundation for the healthcare professional’s response to the patient (Egan 2002, pp.73-92).

Specific communication training ensures that healthcare professionals develop effective listening skills so they might create and sustain therapeutic and ethically sound
relationships with their patients. Frank, et al. (1996); Makoul (2001); Smith, et al. (2000); Silverman et al (2005) and Rider and Keefer (2006) each developed tools for teaching communication skills to healthcare professionals. These studies show that interpersonal and communication skills have a beneficial impact on patient care and correlate with improved health outcomes and healthcare quality, and as previously argued, ineffective communication skills are associated with adverse events, malpractice claims and medication errors (Rider and Keefer 2006).

Communication is not just being ‘nice’ but produces a more effective consultation for patient and healthcare professional, producing better outcomes (Silverman et al. 2005, pp.8-9, 46). The healthcare interview that combines the ‘old’ content of biomedical history with ‘new’ content of the patient’s perspective, encompasses the patient’s life-world, as well as the healthcare professional’s possibly more limited biological perspective. With attentive listening, with the aim of mutually understood common ground, both patient and healthcare professional become more equal. Healthcare professionals are often not good listeners, despite knowing that a more humanistic approach to caring for patients leads to better outcomes (Miller and Schmidt 1999, p.801).

Evidence-based research with narratives about distressing experiences led Pennebaker (2000) to argue that turning the experiences into a narrative, whether spoken or written, helped transform the experience. It could move into a less distressing, more organised story where it could be modified with each telling into an integrated narrative that could eventually be set aside. Converting traumatic experiences into language had a beneficial effect on physical wellbeing and health.

### 4.3.1. Difficult stories

Healthcare professionals are often required to listen to painful, difficult stories:

Telling a personal story is a means of giving voice to some experiences that are shrouded in secrecy … Telling a personal story becomes a social process for making difficult experiences understandable and meaningful (Ellis and Bochner 1992, pp.79-80).

Readers share these writers’ personal experience of abortion, which reveals not only how it was for the tellers, but how it could be, or once was, for the readers. It becomes possible
for readers to see the other in themselves or themselves in the other, and this notion is particularly illustrated in Chapter Seven.

Not talking about important emotional events engages negative changes in the person’s sense of wellbeing (Niederhoffer and Pennebaker 2002, p.574). ‘However by constructing stories through writing or talking, these negative dynamics can be reversed’. When individuals experience trauma they temporarily become disconnected from their self-identity. There is anxiety about not having a causal explanation for the traumatic experience. People naturally search for the meaning of events to give them a sense of control and predictability over their lives. This notion reflects in the narrative in Chapter Three.

There are incidences of narrative lack occurring where people who are suffering feel that they have no story to tell (Kleinman 1988, p.9). An example of this situation is described later in the thesis. Kleinman describes ‘vicious cycles that amplify distress’, where the person is isolated in their suffering, so they cannot achieve critical distance from their pain. Autobiographical experiences that cannot be reconstructed and shared produce feelings of existential stress because deep motivations cannot be related clearly to others. Holocaust stories are a prime example of this loss of story (Barclay 1996, p.94).

The whole life story could not be expected to be told. The narratives constructed about lives cannot encompass the full richness of lived experience, but have real effects in shaping those lives (White in Monk et al. 1997, pp.13-14; White 1995, p.13).

As Frank states ‘the story, to be worth that name, is ground on which subjectivities meet in mutual knowing’ (Frank 1998, 2001b). This resonates with a ‘reciprocity of care’ (Vafiadis 1999). Frank writes:

> to give the gift of listening is to appreciate receiving the gift of a story. Not just understanding this reciprocity but embracing it, seems to me to be the beginning of clinical work … The ill person’s whole life has brought him or her to this story ... In these stories there is nothing to fix, only a great deal to listen to (Frank 1998, p.209-10).
In their narrating, the illness and life review narratives in this thesis become dialogical. The dialogical nature of the narratives releases the various voices of the life, and allows them to assert an identity and a way of working from which meaning can be crystallised. Narratives never represent a single voice. There are always many selves and potential selves embedded in our conversations and our relationships. Frank (2000a, p.1-3) argues that polyphony is simply ‘multiple points of view’.

Listening is about ‘turning toward another with our whole selves,’ as described by Buber (1923, pp.34-35). Stein (1998) proposes that just listening is never mere listening, it is listening ‘with all your heart, all your soul, and all your might’. The central task of my study is to listen at this depth to my narrators, and to hear my own meanings as they emerge throughout the process.

Given the dialogical, social nature of story telling and my interest in the value of telling and being heard, it is important to consider conceptual frameworks for the many ways people make sense of the world. There are a number of paradigms identified in qualitative research of which the constructivist - the idea that humans are meaning seeking and constructors of their own meanings and realities - is relevant to this thesis. The following chapter examines the theoretical and methodological frameworks that support the exploration and processes of narrative life reviews, and the methods utilized in my study.
Chapter Two: Methodologies and methods

1. CHOOSING A METHODOLOGICAL FRAMEWORK
As outlined in previously, this study is premised on the constructivist worldview that humans are meaning seeking, and constructors of their own meanings and realities. The nature of these meanings and how they are constructed and understood arises from within this worldview. Also emerging from this worldview are the intersubjective, I-Thou/Being-to-Being notions of reflective listening, as previously considered.

The study is grounded, therefore, in personal and interpersonal life description and reflection. It is a qualitative study of a narrative process that enables the crystallisation of meaning for myself, the narrators of the five recorded life reviews, and for readers of possible publications following the study. It utilises the structure of illness narratives embedded within life review narratives to ask how narrator and listener/researcher inter and intra-subjectively create approximations of meaning. In this study, life review involves the collaboration of myself as listener/researcher, and the co-researcher/narrator who shares their life story with me. These are self centered processes that enable participants to re-experience their life and to see it as a whole. In *Being and Time*, Heidegger (1962 p.171) described this process of personal reflection as making a clearing or space, and as I see it, the life review becomes the vessel Heidegger describes, from which meaning emerges. Qualitative research takes many forms, and reflects a wide range of views (Denzin and Lincoln 1995, pp.1-21, 2005, pp.2-3). However there is a consistent overarching attribute of care and relatedness (Schwandt 1995, pp.204-5).

2. METHODOLOGIES
Some of the key methodological concepts are now discussed. The methodological frameworks that allow this study to be rigorous and valid include collaborative or participatory inquiry, phenomenology, heuristic inquiry, hermeneutics and social constructionism. These methodologies are presented with explanation of how they ensure
the study’s rigor and validity. Methods for understanding or interpreting narratives can be found within the discipline of heuristic phenomenology, with cross-reference to hermeneutics and social constructionism. These blended methodological disciplines utilise the adaptive viewpoints of the *bricoleur*, and therefore this creative adaptation that leads the methodological discussion.

2.1. **The researcher as *bricoleur***


> the interweaving of viewpoints for the incorporation of multiple perspectives, and for borrowing, or *bricolage*, where borrowing seems useful, richness enhancing, or theoretically heuristic.

Thus the perspective of *bricoleur* allows a number of methodologies to be integrated into the unique methodological blend that best suits this thesis.

Bricolage is defined as a multi-method mode of research (Kincheloe 2005, p.323). The qualitative researcher as *bricoleur* uses whatever strategies, methods or materials are at hand. This is a new domain of considerable complexity. The *bricoleur* respects the complexity of the lived world by working within it. If new tools or techniques have to be invented or pieced together, then the researcher does this. The choices as to which interpretive practices to employ are not necessarily set in advance but can be chosen as the work unfolds (Denzin and Lincoln 1995, pp.3-5; 2005, p.4; Kincheloe 2005, p.324).

Using resources that are available, as *bricoleur*, I assemble a participant’s life-stories into a life-narrative document creating ‘a pieced together set of representations that are fitted to the specifics of a complex situation’ (Denzin and Lincoln 1995, p.4). In this study the life narratives have been developed in processes tailored to suit each participant. I might use poetry, art, music, maps, photographs, and other multi-modal forms of accessing and responding to the narrators’ stories of their life experiences. Adopting an overarching attitude of *bricolage* I listened and searched for the most suitable and appropriate method
for developing each participant's narrative. There is no set length or starting point. The narratives can thus include and demonstrate a diverse range of settings and styles. The issue of discerning the most appropriate methods and the judgements involved in that for each individual is reflected on in at length in Chapters Eight.

The methodological bricoleur performs a number of tasks, for example interviewing and intensive self-reflection. My study therefore demonstrates an interactive process shaped by my personal history, culture, life-experiences, gender, social class, and race, and by the narrators, in their own settings (Denzin and Lincoln 1995, p.6, 2005, p.6). It also acknowledges the interaction with the voices of the relevant literature and other contributing conversations.

2.2. Collaborative or participatory inquiry

Emerging from a constructivist worldview is the methodological approach of collaborative or participatory inquiry as described by Heron and Reason (1997, pp.274-295; Reason and Rowan 1981, p.30). My inquiry utilises collaborative ways of co-creating descriptions of life experiences and moves towards a synthesis or crystallising of meaning for both narrator and researcher. Meanings are intersubjective: the precognitive, or that which is not yet fully known, becomes more clearly known or crystallised through dialogue. The meaning is temporary approximate meaning. No perspective is seen as final, there is room for these meanings to expand and move forward (Heron 1996, pp.9-12).

A participatory approach allows the life experiences of all the participants in this study - myself as listener/researcher as well as narrators - to be pivotal in the central ground of being and knowing. Heron and Reason (1997, pp.274-295) propose that a sense of resolution and meaning comes from moving beyond a Cartesian mind-body perspective in order to engage in an experience of participation with others. A participatory form of inquiry shares the quality of self-reflection inherent in constructivism (Guba and Lincoln 2005, pp.192-200), but goes further by enabling an aware, committed, concerned, exploratory, and inquiring relationship. Focused centrally on the reciprocal interactions of researcher/listener and participants/narrators, people become both co-researchers and co-subjects (Reason & Rowan 1981, p.30).
Knowing can take different forms (Heron and Reason 1997, pp.274-295). These can be conceptualised as four tiers of knowing, or four elements that inform one another: *Experiential knowing* comes from the creative shaping of one’s world through the process of directly encountering or perceiving it. *Presentational knowing* arises from this experiential knowledge as a resonance with, and intuitive grasp of the significance of one’s world, as it is symbolised in creative forms such as the stories people tell about their lives. Each narrator creatively describes their way of being in their world, as this knowledge arises from their experiential knowing. *Propositional knowing* is knowing by description that something is the case, emerging as people describe their experiences. It is expressed in statements or life-world theories that help to articulate how the person’s world can be understood more clearly (discussed further in 2.3). *Practical knowing* is knowing how to do something and is reflected in applications resulting from the three earlier ways of knowing. So at the end of the process of telling their story, with me hearing and reflectively responding as collaborative dialogical partner, the narrator has the opportunity to uncover new or not previously understood ways that they might know and live their life.

Our descriptive knowledge of our world can be translated into the development of practical skills for living in the world of our experience, which might be, for example, a world-experience of chronic or terminal illness, experiencing bereavement and grief, or living with deficits after surviving a stroke (Heron and Reason 1997, p.114).

To assist in my study’s collaborative/co-creative nature, Jane Gorey, a fellow Masters Degree student from MIECAT, was given approval by The Melbourne University Human Research Ethics Committee to act as my research partner. I requested Jane’s help especially in several cases where the narrator was unavailable due to death or deteriorating dementia. Within the considerations of ethical boundaries, Jane could share, interact with, support and reflect my process, especially in forming the art conceptualisations that came almost at the end of each narrative’s process. I faxed or e-mailed my thoughts and essence statements to Jane, and she responded reflectively in a way that immersed us deeper into the intersubjective responses. She became a trusted ‘sounding board’ by listening to or reading my reflections, reflecting her responses back sometimes changed, sometimes challenging, extending and crystallising the meanings that
were emerging. There is further description of the nature of our collaborative partnership in regard to the final art conceptualisations, in this chapter, 4.1.1.

2.3. **Phenomenology**

Situated beside collaborative inquiry is phenomenology. It is argued to be the most suitable methodology for the exploration of lived experience (Lett 2001, p.5) as it emerges from the combination of experiencing and reflective understanding through re-experiencing. Forms of interpretation involving the psychological descriptions of experiencing, can then be extrapolated from experiencing into knowing or understanding the meanings attributed to the experiencing. The most open-ended form of reflective phenomenological research is that of heuristic inquiry (Lett 2001, p.7-9). Both descriptions and explanations or interpretations are integral to my study.

The MIECAT form of inquiry developed a blend of phenomenology and heuristic inquiry. Firstly these methodologies will be described separately, and then the differences between them will be outlined.

Phenomenology was articulated by Husserl in the early 1900s, as the study of ordinary everyday phenomena, expressed in everyday terms, through careful focus on the structure of experience without referring to theory. It asks us to engage with the phenomena in our world and make sense of them directly and immediately. It was formed under the banner of ‘back to the things themselves’. Heidegger’s work followed Husserl, seeking what is hidden in ordinary, everyday experience, talking about ‘the structure of everydayness’ (Crotty 1998, p.78). Phenomenology reveals the inner structure or the essence of experiences, through thick, illuminating descriptions.

Crotty (1998, p.82) proposes that phenomenology is about setting our meaning systems aside and, as much as possible, the cultural and language boundaries that limit our understanding. An example here might be that of a health professional trying to understand the person she is trying to help by setting aside her medical language and experience, and thinking about what it might be like from the patient’s point of view. This seems to be what Kleinman (1988, p.xiv) was referring to in his story discussed previously, where he began to listen to what it was like for his distressed young patient. Crotty suggests that our cultural understandings are like masks or blind spots, such as a
healthcare professional seeing a patient from a biomedical/disease perspective, rather than endeavoring to understand the person suffering from the disease. It is deeper, richer meaning that is sought. Phenomenology focuses on the meanings and significance given to experiences by those experiencing them: ‘What was it like? How did you feel and what did you make of the experience?’ (Willis 2004, p.3).

Phenomenological investigation attempts to reveal the nature and meaning of an event or occurrence, just as it appears. In other words, analysis of data must be unbiased. Phenomenological reduction (analysis) is complete when themes or patterns have been distilled from the data and when the essence of a phenomenon is fully uncovered through textural and structural descriptions (Hill 1997, p.1). The shared nature of phenomenological research emerges through exploration of personal experiences and their embedded cultural understandings and meanings (Polkinghorne 1989, p.47). Themes are discussed further in 4.2.

In phenomenological forms of human inquiry, it is important to preclude early conclusions, generalisations, or ranking of information. There are a number of useful ways that one engages with the data in these forms of inquiry. Headings 3 and 4 in this chapter describe some of these processes and methods.

The following two theories add further insight to people’s ways of understanding their world and its experiences:

2.3.1. The lifeworld
There are instances in the narratives where the narrators express their own ‘lifeworld theory’. Listening for and identifying these theories assists in understanding the perspectives of the narrators. Abram (1996, pp.40-1) argues that humans all hold particular views about life and often these are tacitly present. Husserl conceptualised a dimension he named the intersubjective world or the life-world. This helps us to understand what it is to be human. The life-world is the world of people’s immediate lived experience, as they live it and before they have any thought about it. It is present as people live their everyday lives, it is not private; it represents the ordinariness of their lives and the other lives with which they coexists (Abram 1996, p.40).
The members of a given culture live in an experienced world very different from that of another culture with a different language and way of life. An example of such a culture might be a world of deep illness or disability, a world experience not easily understood by those from a well-world. This resonates in the writing of Zola (1982), a physically disabled sociologist who describes two worlds, the valid and the in-valid, and the anguish of his struggle to straddle both.

2.3.2. Lifeworld existentials as guides to reflection

There are differing lifeworlds and realities for each of us. For example the child’s world is different from the adult’s, the deeply-ill world is different from the well-world (van Manen 1990).

There are four themes that provide key concepts and tools for deepening the understanding of the life stories of the narrators in this thesis. In order to study the structure of existential themes they can be separated into themes of lived space - spatiality, lived body - corporeality, lived time - temporality, and lived human relation - relationality (van Manen 1990, p.101-106). van Manen’s themes contribute significantly to the processing and understanding of each narrative, placed in the process according to Table 1, 4.2. Discussion of the four existential themes now follows:

Lived space (spatiality) is felt space. People know the space in which they find themselves affects the way they feel. For example one’s home can be a special space within which one can experience a deep sense of one’s being. It provides, for many, a secure sanctuary that allows feelings of protection and the space to be one’s self (van Manen 1990, p.101-106).

Lived body or self (corporeality) is situated within the phenomenological fact that humans are always bodily in the world. When people interact with another person in their world, that person is met first of all through their body. One’s body reveals something about one, at the same time also hiding something about one. As a personal example, if you meet me, you can see that I have grey hair and wrinkles, you understand that I have lived a fair number of years. A doctor might see my chronic illness. However you cannot know about my life’s experiences, griefs or loves, unless you listen as I describe my life to you (van Manen 1990, p.101-106).
Lived time (temporality) is subjective time, different from clock or objective time. Time speeds up when people are enjoying themselves, and drags when they feel bored, sick or anxious. For example, time might seem to pass slowly for a young child excited about a coming birthday. Lived time describes humans’ temporal way of being in the world. As one evolves, one may reinterpret who one once was, or who one is now (van Manen 1990, p.101-106).

Lived other (relationality) is the lived relationship people sustain with others in the interpersonal space they share with them. As people interact with others they develop a dialogical relationship, which allows them to go beyond themselves. Humans have long searched this experience of the other, the communal and social, for their sense of purpose in life, for meaning, for the basis for living, including, according to van Manen, the religious experience of their absolute Other, God, as discussed in the previous chapter (van Manen 1990, p.101-106).

2.4. Heuristic inquiry

The most open-ended form of reflective phenomenological research is the form of heuristic inquiry, a process initiated by Moustakas after his experience of loneliness during his daughter’s life-threatening illness (Moustakas 1961, Lett 2001, p.9). Moustakas then wrote his doctoral thesis about loneliness. ‘Heuristic’ comes from the Greek, *heuritikos* ‘I find’ (as in ‘eureka’). Heuristic inquiry is a personal research methodology. It aims at ‘self-search, self-dialogue, indwelling, and intuition’ that enable openings towards the illumination of ‘problems, questions, and human concerns’ and ‘self-discovery’ (Moustakas 1990, p.170-171). The aim is not to prove anything, it is concerned with meanings not measurements, essence not appearance, quality not quantity, and with experience not behavior (Moustakas 1990; Douglass and Moustakas 1985).

The heuristic approach involves reflection, and description of the nature of one’s experiences, including one’s perceptions and feelings about those experiences. In life review studies these are verbal descriptions of the experiences of a person’s life as a whole. It involves collaboration between the narrator and listener, who thus become research partners. In the sharing of experiences, richer and more comprehensive depictions are inspired from each of the co-researchers.
In heuristic inquiry there are guidelines but no clear steps that must be taken. The inquiry goes as deeply as possible into the experiences and memories of the life, noting what resonates for each person as they tell the story now: what seems interesting now, and what happens in the process of describing their lives. To know and understand the nature, meanings and essences of any human experience one must empathically appreciate the frame of reference of the person who has had the experience (Moustakas 1990, p.26).

The heuristic process has as its ultimate purpose the understanding of life-meaning or particular experiences. The ‘data’ that emerges is autobiographical, original, and accurately descriptive of the textures of lived experiences (Douglass and Moustakas 1985, pp.39-55).

2.5. **Differences between Heuristic Inquiry and Phenomenology**

There are significant divergences between phenomenology and heuristic inquiry. Central to these differences is that phenomenology encourages a kind of detachment from the phenomenon being investigated, whilst heuristic inquiry emphasises connectedness and relationship. Phenomenology permits the researcher to conclude with definitive descriptions of the structures of experience. On the other hand heuristic inquiry leads to depictions of essential meanings and portrayal of the intrigue and personal significances that drive the search to know. Phenomenology generally concludes with a presentation of the distilled structures of this experience. Heuristic inquiry may involve reintegration of the knowledge as an act of creative discovery, a synthesis including intuition and tacit understanding (Douglass and Moustakas 1985, p.42).

Phenomenological inquiry, in the process of descriptive analysis ending with the essence of experience, may lose sight of the person. In heuristic inquiry the research participants remain visible in the data and continue to be portrayed as whole persons in the essence of the experience, a clear commitment in my study (Douglass and Moustakas 1985, p.42). It is this feature that grounds the study most centrally in the approaches of heuristic phenomenology as its major methodology. The participants must remain present to the end. The heuristic approaches of the thesis also expects my voice, in the first person, to remain as part of the overall discussion, rather than a more objective voice required of other forms of inquiry.
2.6. Hermeneutics

This study embraces some aspects of a hermeneutic methodology. Hermeneutics is defined as the study of understanding, especially the task of understanding texts. The reader discovers and interprets the written word, such as Biblical and literary texts. In the early twentieth century it developed into an approach to interpreting and understanding human behavior, and emerged as a genuine philosophical discipline and a general theory of the social and human sciences (Anderson 1997, p.38; Valle, King and Halling 1989, p.15; Crotty 1998, p.90).

Hermeneutics concerns itself with understanding and interpretation of the meaning of a text or discourse, including human emotion and behavior, and understanding as a process that is influenced by the beliefs, assumptions and intentions of the interpreter. Hermeneutics maintains that understanding is always interpretive and there is no uniquely privileged standpoint for understanding, for example, the standpoint of being a healthcare professional. Hermeneutics does not attempt to arrive at one true meaning and should not be confused with the explanation of causes. The truth is not revealed, there is no one right account of an event; and there is no one correct interpretation. Each account, each interpretation is only one version of the truth (Anderson 1997, p.38).

A double hermeneutic, specific to the social sciences, forms a two-tiered, interpretive and dialectical relationship between social scientific knowledge and human practices (Giddens 1976/1993 edition, pp.2, 9). In this view every action has two interpretations. The first is from the actor, the other is that of the researcher, who tries to find meaning for the action that is being researched. The actor, in the case of this thesis, is the narrator of their life review. They perhaps grasp my interpretations as listener/researcher, and therefore might change their own interpretation of their narrative, or are influenced in their ongoing actions. It also implies that the findings of the thesis can influence the ongoing behavior of its readers, such as healthcare professionals who might modify their practice of listening to their patients.

The shared knowing of personal meanings is confirmed in the moments of joint awareness, a co-creative validation of what is known, from within the experience (Lett 2001, p.8-9). Heidegger’s understanding was that hermeneutics and phenomenology become one in their understanding of human being (Crotty 1998, p.97).
Included in hermeneutic theory is the possibility of gaining understanding of the text that goes deeper than its author’s understanding (Crotty 1998, p.91). This insight is gained through understanding the whole by grasping its parts, and comprehending the meaning of its parts through seeing the whole. In this view understanding is circular because it always involves reference to the known: the part (the local) always refers to the whole (the global) and conversely the whole always refers to the part (Anderson (1997, p.39). This is what Heidegger named the hermeneutic circle. This reflects in the analysis/reflection processes in my study, where the parts of the narratives and their nuances are reflected on separately and brought together, perhaps in a different order or shape, in order to comprehend more deeply the parts and the whole.

2.7. Social Constructionism

As outlined previously, this study is premised overall on the constructivist paradigm or world view that humans are meaning seeking, and constructors of their own meanings and realities.

A similar, but slightly modified, methodological approach is also relevant, that of social constructionism, premised on the view that ‘societies construct the lenses through which their members interpret the world’ (Freedman and Combs 1996, p.16). This methodological stance is both narrative and constructionist: people together construct their realities as they live and narrate them. In other words, there is a shift from

focusing on how an individual person constructs a model of reality from his or her individual experience to focussing on how people interact with one another to construct, modify, and maintain what their society holds to be true, real and meaningful (Freedman and Combs 1996, p.27).

To further clarify this perspective, social constructionism arose from a more sociological perspective, while social constructivism is more psychology-oriented, with the knower and the known seen as more individual. However they share considerable ground. Social constructionism argues a slightly more complex process, that it is not just an individual engaging the world, rather an individual embedded with their cultural information and
inscription, making sense of things. The individual’s considerable experiences and perceptions blend in their engagement with their world.

It is argued that constructionism and phenomenology are closely intertwined, making them both methodologically relevant to this thesis (Crotty 1998, p.12). Phenomenology invites people to engage with the phenomena in their world, and make sense of them for themselves. What is said to be ‘the way things are’ is really just ‘the sense we make of them’. In the act of finding that stance, people might bracket aside their assumptions. In other words they become more conscious of the cultural inscriptions, social values, and personal prejudices that surround them (Freedman and Combs 1996, pp.14-27).

The cultures into which people are born provide them with meanings, similar to Monk et al.’s (1997, p.27) notion of ‘cultural soup’. These meanings people learn in a complex, powerful process of enculturation. They shape peoples’ thinking and behaviour throughout their lives. The birth stories and stories of individual’s core culture are significant in their life narratives, and this resonates throughout the study’s narratives.

One needs to understand that different people inhabit quite different worlds, which constitute multiple ways of understanding, various meanings, and separate realities. When people narrate something, even in telling the story of their own life, it includes the voice or values of their culture, and the contextual nature of their knowledge. Constructions are alterable (Guba and Lincoln 1995, p.111), and my study illustrates this point as narratives change in their telling.

One might state the ontological question as: ‘what is the form and nature of reality and what can be known about it?’ Or ‘how things really are’ and ‘how things really work’. The epistemological question as: ‘what is the nature of the relationship between the would-be-knower and what can be known?’ And the methodological question as: ‘how can the would-be-knower go about finding out whatever they believe can be known?’ These questions can only be answered in ways that reflect our social context, and are always approximations of complex related and often diverse perspectives. Guba and Lincoln (1995, pp.111-113; 2005, pp.113-116) argue that the answers are in all cases human constructions. That is, they are all inventions of the human mind, subject to misinterpretation.
Hermeneutics and social constructionism share an interpretive perspective that emphasizes meaning as constructed not imposed. The meanings people attribute to the events and experiences of their lives, including their self-identities, are created by individuals in conversation and action with one another (Anderson 1997, p.37). To reiterate, the overall constructivist paradigm of the thesis is that humans are meaning seeking, and constructors of their own meanings and realities.

Having described the possible theoretical concepts to be blended as the methodological framework for the study, I now turn to examine the narrative methods utilized, firstly from a theoretical perspective and then how I applied these methods. The discussion begins with how one might measure the validity, rigor and discipline of the study; exploration of the procedures of interviewing, transcription, and the use of oral and written language; I discuss the commitment within phenomenological forms of human inquiry to maintaining openness and avoiding early conclusions, generalizations, or rankings of information, and the tools and processes used for processing the narratives; then the actual methods I modified from this theoretical base. I then introduce my partial application of van Manen’s literature searches that follow each narrative and discuss their structure and contribution to the study. Finally I consider the relevant ethical issues, including the selection of participants and confidentiality.

3. NARRATIVE PROCESSES

In all qualitative research, and especially in this study’s particular blend of methodologies, methodology and method are different entities. Methodology refers to the philosophical and theoretical framework pertaining to a given means of understanding and deepening knowledge. Method on the other hand indicates the techniques and procedures for carrying out the research (Caelli 2001, p.275). The discussion firstly considers the measuring of discipline, rigor and validation, followed by discussion of the theories of interviewing. This leads to further exploration of methods of working with narratives, for example bracketing, description, and amplification.

3.1. Discipline, rigor, validation and replication

The question arises regarding satisfactory ways of measuring the validity, rigor and discipline of this complex form of qualitative human inquiry. Guba and Lincoln (2005,
p.197-205) argue that validity and reality ‘are derived from community consensus regarding what is ‘real,’ what is useful, and what has meaning.’

The concept of qualitative research validity has evolved over time to include communicability, ecological fit, and pragmatic validity (Guba and Lincoln 2005, p.197). Communicability refers to the personal and social value of intersubjectively shared meanings. Ecological fit emphasizes the context-bound nature of research conclusions and their practical implications for the community and culture involved. The latter could be, for instance, those who suffer from dementia or terminal illness. Practical validity is gauged by the usefulness of an interpretation for the participant and perhaps their community. Under these views validation is expected to involve the dialogical relationship between researcher and participant as active collaborators of knowing, and as owners of the uncovered knowledge (Hoshmand 1989, p.10).

This sort of research demands discipline and rigor. For Heron, ‘the rigor is essentially one of mindfulness, inner alertness, knowing what is and is not going on’. It lies ultimately in the experiential discernment of those who take part. What is crucial in attaining validation is ‘the quality of critical awareness’ and insight in evaluating the experiential effects by referring them back to the original understanding (Heron 1981a, p.164).

The core of the validation process and the key to its quality, is provided by the careful and constant intersubjective feedback loops, in which the process is continually re-viewed in the light of the experience of the co-researchers (that is, narrators and listener). The critical skill that co-researchers need, is to be alert to whether the narrated reconstruction of life experiences honors what was actually experienced (Heron 1981a, p.165). This need is significantly embedded in my methodological approach, with constant checking with the narrators that my understanding of what they said is accurate. This checking and responding was sometimes in the form of poetic-shaped summaries that were faithfully and transparently connected to what had been said in the life review narration. Sometimes they were small naïve drawings, which were part of the phenomenological reduction towards essences, but also opened up other intuitions, understandings and further dialogue.
Questions about validity inform whether one has in fact uncovered what one wished to uncover. In the case of my study, this becomes the understanding that emerges from within the narrator’s life experiences (Kvale 1983, p.192). Kvale questions whether there is one correct interpretation of a text, or whether there is what he calls legitimate plurality of interpretation.

There is a change in emphasis from an outside observation of a person, to a conversation and interaction within the person’s world. As Kvale sees it ‘new developments in concepts of knowledge allow clarity of the validation taking place in therapeutic and research interviews’ (Kvale 1999, p.108). These concepts might include the four tiers of knowing described previously (Heron and Reason 1997, pp.274-295).

The participatory view values human wellbeing, knowing, and meaning as ends in themselves. The process of co-creation is valued, and also the emergent meaning that crystallises through the process. The described, presented world is also valued. The rules of language enable people to assert the truth about the world they value (Heron and Reason 1997, pp.274-295). Describing one’s experiences and having them heard contributes to the formation of community values and a shared way of finding satisfaction in, and valuing of the world as it is encountered (Reason and Rowan 1981, p.32).

Qualitative researchers inquire where people’s beliefs come from and what processes of social construction have led people to those beliefs. As researcher/listener I am required to be transparent about my own values, acknowledging that I too am making constructions of meaning from the participant’s constructions; that is, recognising my equally biased role as a constructor of meaning (Freedman and Combs 1996, p. 36).

It is fair to ask if someone could replicate this study’s processes. The methodological structures and procedures are described and could be replicated. However this listener/researcher would not find the same things. Qualitative research is not usually about replication. It would make an interesting study to find someone who would tell their story with interactive dialogue including inter and intra subjective responding. This could be followed by someone else repeating the process with the same narrator, with their inter and intra subjective responses. The differences could then be explored. It would probably demonstrate different modal manifestations, and the particularities of the various
subjectivites and dialogues. There would also be the sense of self-awareness, and the kind of conscious mindful awareness that might grow in each participant.

3.2. Interviewing: listening and responding

There is plentiful theoretical advice available regarding the best practices for recording and transcribing interviews. In Chapter Eight I will discuss how the reality is more contextually difficult and less than perfect. There are three main aspects: firstly, the technology for recording what is spoken; secondly, the stances of interviewer and interviewee; and lastly, the processes of committing recordings to printed word.

3.2.1. Recording interviews

Tape recording interviews allows the interviewer to concentrate on the topic and dynamics of the interview. The words and their tones are recorded in a permanent form that can be re-visited whenever necessary. The audiotape gives a decontextualised version of the interview. It does not include the visual aspects of the situation, the setting, nor the facial and bodily expressions of the participants (Kvale 1996, p.160).

3.2.2. Inter-views

In illness narrative/life-review interviews, in inviting the elaboration of the what and how of the narrator’s lived experience, listener and narrator respond to one another. They reflect on and uncover aspects of their lives including painful experiences, present responses, and feelings (Massarik 1981, p.203). The phenomenological interview is characterised by mutual trust, equality and care between interviewer and participant, and commitment to collaboratively search for shared understanding (Kvale 1983).

Ideas explored at one interview may be changed later through opportunities provided for review and clarification. Empathic efforts to explore the participant’s world are aided by a sense of reciprocal empathy that recognises the integrity of both people, and the environment within which the process occurs (Massarik 1981, p.203).

A well facilitated interview will enable ordinary people to describe their life-worlds, opinions and actions, in their own words. The interview makes it possible for participants to organise their descriptions, emphasizing what they find central. It is literally an interview, an exchange of views in human inter-action (Kvale 1996, 1983, p.173).
Depending on the sensitivity of the interviewer, it is hopefully a positive experience (Kvale 1983, p.174). Interview data are interactional, contextual productions (Denzin 1989a p.57). The narrator is encouraged to describe and reflect on a particular set of life experiences that are then discussed. As researcher/listener I aim for the accuracy and rightness of what was said, and the willingness to change anything requested by the narrator to achieve this accuracy. I am aware that each interview had its own ‘givens’ including contexts and motivations for both interviewer and interviewee.

It is probably not a common experience of one’s everyday life that another person, over a number of hours, is interested in seeking to understand as clearly as possible one’s life experiences. As Bourdieu (1999, p.614; 619) describes it, the interview can be considered a sort of spiritual exercise:

that through forgetfulness of self, aims at a true conversion of the way we look at other people in the ordinary circumstances of life … to take that person and understand them just as they are in their distinctive necessity, is a sort of intellectual love ...

It is this participation in conversation, with both speaker and listener engaged reciprocally, which most clearly distinguishes the style of ordinary conversation used for my study’s approach, from a style of interview in which the researcher, out of a concern for neutrality, rules out all personal involvement. The narratives and transcripts are not one and the same (Caelli 2001, p.277). The interviews should not be seen as transcripts, they are living conversations (Kvale 1996, p.163).

3.2.3. Transcribing

Transcripts are tools for interpreting what was said during the interviews. In my study, they were also a written record of the person’s life-story. Care is needed in moving from the transcript towards themes and meanings. The original face-to-face conversations could disappear by being distilled into fragmented quotes through the post interview processes.

The qualitative interview is transcribed word for word. The typed version, together with the tape, constitutes the material for subsequent interpretation of meaning. This way of co-authoring treats transcriptions as stepping-stones towards a continuing unfolding of the
meaning of what was said. Analysis of the transcribed interview becomes a continuation of the conversation that begins in the interview.

‘From interview to story: writing Abbie’s life’ (Kiesinger 1998), expanded my understanding of my method. Although transcription is a tedious, time-consuming, often frustrating task, Kiesinger found it an invaluable step in the process of writing Abbie’s lived experience. Doing her own transcription forced her to go through the oral history repeatedly. Throughout this process she was able to identify gaps in the conversations, aspects of the story that needed more explanation. Transcribing also allowed her to hear her participant’s voice over and over, and as a consequence she grew to feel closer to Abbie’s experience (Kiesinger 1998, p.92). It is this connection to the narrator and their story as I transcribed it, which brought me deeper into the story and the understandings that emerged. In other words, life-review researchers should make their own transcriptions, despite feelings of tedium (ten Have 1997).

There are considerations of page layout and placement of verbal and nonverbal information in the transcript. Timing, overlaps and pauses, pitch, accent, tone, nonverbal vocalisations, voice quality, inaudible or uncertain portions, environmental noises and interruptions, all require decisions (Lapadat and Lindsay 1999, p.68). The decisions I made are described in their individual contexts throughout the narrative chapters. It could happen that the transcript as text is seen as unproblematic, and is given privileged status in which its authority is unquestioned (Kvale 1996, pp.74,166). This is discussed further in Chapter Eight.

3.2.4. Oral and written language
There are significant differences between oral and written language. In the transcription of interviews, alive, face-to-face conversations are frozen in time and abstracted from their origin in social interactions. A transcript is a transformation of narrative-mode conversation, into the narrative-mode of written conversation. To transcribe means to transform, to change from one form into another (Kvale 1996, p.166).

Interview transcriptions may be boring to read. There may be many repetitions, unfinished sentences and digressions. The apparently incoherent statements may be coherent within the context of a living conversation, with vocal intonation, facial
expressions and body language giving nuances to, or even contradicting what is said. The problems with interview transcripts are due less to the technicalities of transcription than to inherent differences between the way conversation is spoken and written as text (Kvale 1996, p.166-173).

Participants may feel confronted by reading their own interviews. The verbatim transcribed oral language may appear incoherent and confused, even indicating a lower level of intellectual functioning. I have used exclamation marks particularly in the narrative chapters (3-7) to emphasise the way something has been said, or how I have heard it or responded. This is perhaps different to conventional academic writing, but serves to amplify the emotion of the telling and listening, for example:

I want to scream ‘No! You were young men…’ (refer Chapter Six and Chapter Eight, 2).

The question also remains - to delete vocalisations such as ‘um’s’ or ‘blah-blah-blah’s’ or leave them in? This is further discussed throughout the narrative chapters.

The following discussion explores further methods for working with narratives, in their narrating and understanding. The first of these is the technique of bracketing or Epoché.

3.3. Bracketing or Epoché
Bracketing instructs people to set aside their initial biases and prejudices of things, to suspend expectations and assumptions, and to bracket them temporarily, as far as possible, so that they can focus on the primary material of our experience. Bracketing or Epoché was first described by Husserl (Aanstoos 1983, p.253; Spinelli 1989, pp.3;12;17; 153). In other words, to impose ‘openness’ on one’s immediate experience so that subsequent interpretations may prove to be more satisfying.

As listener/researcher I must be aware of the danger of finding only what I expect to find. Bracketing means setting aside my preconceptions, theories, and perceptions that would interfere with hearing the narrator from their perspective, through their eyes and experience. This also requires setting aside my interfering moods and concerns, which could intrude on the development of an open relationship, and may interfere with ‘the immediate and spontaneous’ (Moustakas 1996, p.191). In order to understand the
narrator’s world of lived experience, the listener/researcher must enter into it by suspending or bracketing any presumptions about it (Aanstoos 1983, p.253).

If the listener/researcher simply tries to ignore what they already ‘know’ they may find that the presuppositions persistently creep back into their reflections. It is better that they are explicit about their understandings, beliefs, biases, assumptions, presuppositions and theories, in order not to try to forget them, but rather to turn this knowledge around, exposing what is not seen (van Manen 1984). I used my journalling process to acknowledge my prejudices and presuppositions. This enabled me to find my own meanings in my experience of listening to the stories of the narrators. In the analysis of the benefits for me and the narrators there were a number of strands of understanding: those that belonged to the narrators, those that were mine, and those that might flow on to benefit others (Bradbury and Reason 2001, p.449). This is discussed further in Chapter Eight.

3.4. Description

In focusing on the narratives, and the experiences of listening and telling, there are several important issues, not least of which is gathering descriptions and identifying and describing the essential structures of experience in the life review narrative interview process.

The essence of description is ‘describe, don’t explain’. By describing in their own words the way things appear to them in the moments of their experiencing, people discover their subjective interpretations of reality (Spinelli 1989, p.18). Having opened up possibilities contained in their immediate experience as far as possible through bracketing or Epoché, they are now required to not place new limitations on their experience by explaining or making sense of it in terms of theories. The meanings uncovered are gathered into a structural description. Through the coming together of these meanings it becomes possible to grasp the essential core meaning (Aanstoos 1983, p.257).

A procedure for gathering simple descriptions is proposed by Polkinghorne (1989, p.45). These descriptions are then analysed so that the researcher can grasp the ‘constituent elements’. The elements are descriptions of the experience as they are formed by the narrator. I tried to be constantly aware of three separate sources of the phenomenon:
firstly the narrator’s oral description of their experience. Secondly, my reflections as listener. And thirdly, external descriptions of the phenomenon such as from literature, paintings, poetry, music and so on, from other creative artists. Often these external descriptions were introduced by the participants themselves, such as meaningful poems or books they had read, or a piece of music that had arisen in the telling of the particular story. Each participant was approached ideographically, as becomes clear in the narrative chapters that follow, and their own expressions of external artistic material, when highlighted and explored, enriched and deepened the flow of the narrative descriptions of experiences for the participants and for me as listener. I also made offerings of appropriate external artistic expressions when I felt that it would enhance the description of the experience. On some occasions I critiqued the decision to add external descriptions via my journalling, or in conversations with my collaborative inquiry partner Jane Gorey. This is further reflected on in Chapter Eight.

3.5. Focusing

This process, developed by Gendlin, proposes that attention is paid to the person’s descriptions, whilst also retaining the experiential sense that the person gives to the listener (Gendlin 1982). It is a ‘confirmatory knowing through the body’ (Cornell 1998, p.159). The listener checks by reflecting the description back to the person, asking them to correct the listener/reflecter at each step. Experience is never as it stands, neutral or reliable. Focusing lets new meanings emerge.

Focusing was facilitated through the intersubjective responses I formed while gathering descriptions. There are examples of these responses throughout the narrative chapters and further discussion follows (refer Chapter Two, 4.1). Certain phrases drew my attention and were then highlighted and returned to the narrator as a new way of understanding. This then moved the process forward. In this way differences and discrepancies appear that have never surfaced before, ‘I said this, but I don’t mean it this way, rather that way; it isn’t this but rather that...’ The process is not replacing, rather a collaborative modification of emerging understandings (Gendlin 1999).

For me as listener/researcher analyzing the narratives, in this focusing process there is a felt sense of the body’s particular situation. It feels meaningful, there is a body sense of meaning (Lett 1995/2001). It often felt like a ‘clunk’ of meaning, an ‘aha!’ moment. It
simply ‘felt’ right. Such intuitive confidence may cause concern in some analytical circles. However ‘bodily felt responses’ are supported by the phenomenological/psychotherapeutic literature, for instance Gendlin’s description of ‘felt meanings’ (Gendlin 1982, pp.32-40). There were also checks through journalling, reflecting and conversations with my collaborative research partner Jane Gorey.

3.6. **Pathways into stories**

Connecting with another’s experiences is a process that requires empathic relating to the narrator, and an inner responsiveness to what is happening in the storytelling process. Pathways into stories are found by listening for entry or access points of interest for the narrator. A narrator might recite a meaningful poem, or refer to a book they are reading, or a piece of music they love, or describe a place that has special meaning for them. As listener/researcher I might then use this material to facilitate the life review process by eliciting further stories from the narrator. I might refer to my own knowledge and experience of these points of special meaning to prompt feelings and ideas to surface and encourage the discussion of experiences that are described and shared (Cohen 1994, p.37-39, 41).

3.7. **Amplification**

Throughout the process of gathering narratives, the listener is able to amplify parts of the story, and reflect it back to the narrator for expanded description and illumination. Amplification is like taking a small section of a photograph and enlarging it to make its contents clearer. The listener focuses and amplifies parts of experiences in order to go beyond the immediate, and to enable deeper attention to what was described. Lett (2001, p.260) argues that this process is amplification rather than distraction. It is a way of responsively and creatively enlarging on the experience in order to more fully understand it. It can be as simple as ‘I am interested in your description of what happened then, tell me more about what that experience was like’.

3.8. **Indwelling and intuition**

Indwelling and intuition are closely related. In the process of indwelling, or inner searching, as researcher/listener I immersed myself in the material, reflecting until key
words, key images, gestures and tones became clear. Tesch (1990, p.35) describes this process as ‘like intuitive self-searching’.

Indwelling is a key process in being-with the other. The challenge of indwelling is to direct one’s self beyond the appearance of things, beyond spoken thoughts and feelings (Moustakas 1996, p.84). Feelings are pointers to meaning that exists within the experience. Indwelling is active, conscious, intuitive, feeling, sensing, and beyond facts. As listener/researcher I come to understand the other person’s world through my own awareness and knowing. The process of indwelling swings from cognitive to perceptual-sensing. It is derived intuitively as a response to the texts and their descriptions (Lett 2001, p.339).

Calling this intuition, Andersen (1992, p.55) explains how all our senses are involved in our experiences of life, our skin, eyes, and so on. By being open to what is occurring we can notice answers in our body, from inside. This tells us in various ways how we are reacting to what is happening, and what we might concentrate on. Tesch (1987, p.237) defines intuition as a recognition-producing ability, related to Polanyi’s (1967) notion of tacit knowing, that comes from a deeper source inside us. Tesch suggests that researchers discover themes by intuitively knowing, and sensing what is there.

I frequently formed poetic shaped statements for myself, as I ‘sat with’ the narratives. These often formed part of my journalling process and are discussed elsewhere. They were part of a creative stage that embraced intuitive and tacit things that may not have been articulated to that point. They became another way of drawing things together, the resonance of my own experience towards what I had heard. This was sometimes in different or new words, which were an approximation to something that had until then remained unsaid. It could be argued that these things remained approximate and intuitive, and therefore not scientifically valid, but I always felt they expanded my understanding, making them valuable contributions to the study’s model.

3.9. **Reduction to essence and creative synthesis**

Reduction is described as a process of grasping the essential structures of an experience, by identifying the constituents or themes that appear in the descriptions (Van Kaam 1966). Synthesis, as proposed by Polkinghorne (1989, p.56) is different from a process
that adds or lists elements together: it requires an understanding of the whole. ‘In the grasp of the whole, the elements are understood.’

Years ago I visited a perfumery in southern France. I saw tons of rose petals distilled in large copper vats until rose essence, with its beautiful perfume, became the highly valued, most expensive end result. As the particular parts of an experience are considered:

there emerges an affinity, a structural similarity, a pervading essence.
This permeates the particular phenomena and is expressed through them (Crotty 1996, p.7).

However the word *essence* does not have to mean some ultimate core or residue of meaning. Firstly a good description is needed. This is constructed so that the structure of the experience is revealed. Now the nature and significance of the experience can be grasped (van Manen 1990, p.39; Willis, 2004, p.6). However the essence of the rose is not the rose, the essence statement at the end of each narrative is not the whole nature of the narrator’s life, rather a description of what it was like in its essence:

Creative synthesis, the final phase of the heuristic research process, is an integration of the materials that reflects the researcher’s personal knowledge, tacit awareness, intuition, and understanding of meanings and essences of the experience. The researcher … allows herself to be led to a comprehensive expression of the essence or essential qualities of the experience (Rogers 1998, p.198).

Most researchers reach a point of needing to get away from the data. They consciously ‘tune out’ for a while. It is then that they might see what it is they are searching for, when they have almost stopped looking. However they are still in touch with the search at a deep level (Tesch 1987, p.230). There is a sense of struggle involved in this process, it can take several attempts until the crystallisation from narrative telling to essence reaches a feeling of rightness. It continues to recycle until the point is reached where an approximation of meaning emerges (Caelli 2001, p.274).

Phenomenological reduction teaches us that complete reduction is impossible, that full or final descriptions are unattainable (van Manen 1990, p.18; 42). Hegel equated a thing’s
potential with its essence, or its truth: ‘Underlying the movement of all things is the essence of things’ (Peile 1994, p.32). It involves moving from a ‘natural attitude’ towards a pure, reduced attitude, bringing us more poetically to an essence. There is no end or completion possible (Valle and Halling 1989, p.11). Moustakas (1996, p.30) describes how he allows his intuition and tacit awareness to move him into wholeness that in essence and meaning, answers his questions or leads to the resolution of his problem. This describes the theory of reduction to essence. In the following section I describe how I actually formed and presented these essences as poetic statements.

4. METHODS
The previous section outlined many of the issues of narrative processes. The discussion now moves to further methods and procedures modified for my study, acknowledging that *bricolage* enabled selection of the best methods in each individual narrator’s setting.

4.1. Inter and intrasubjective responses
4.1.1. Intersubjective responses
I begin this section by describing my first experience of intersubjective responses, which I had not heard of at that time:

For three years after my father died, my mother suffered from deep sadness. She died twelve days before Christmas in 1996. Over the following stressful weeks I frequently rang my friend Hilary Robinson, and agonised over my experiences. She always listened patiently. In the New Year she rather diffidently offered me a cluster of what I later learned were called *intersubjective responses*. She was reflecting back to me that she had heard what I said, and understood what I was feeling. I deeply valued her gift. It gave me affirmation and validation and was therefore, in terms of qualitative research outcomes, rigorous and valid. Hilary’s gift exemplified how engaged reflective listening is precious, especially in times of disruption. This is an abridged segment of just one of these responses:

No Flowers or Bullshit By Request.

Condolence cards and Christmas Greetings.
Christmas and funerals,
times for loving remembrance and caring,
pain and platitudes, false emotions.
So, you want the sanitised version?
She didn’t suffer, did she?
it was so sudden.
What a shock!

Who wants the truth?
The slow living death of depression
in a failing body and a shrinking world…

Having attested to personally experiencing the value of these responses, this section now describes the processes I used of intersubjectively responding to what I heard within the narratives. The intersubjective responses mostly formed as I transcribed the narratives after each recording session, and were returned to the narrator at the beginning of the following session, along with the transcription of the previous recording. In the study’s amplified process of engaged listening, reflecting back to the narrator the essence of what has been heard is an affirming, valuing experience. To respond in this way is not always straightforward or possible. My responding, reflecting process is mapped throughout the thesis.

The method of intersubjectively responding to the accounts of another’s experience was developed at MIECAT. In using the MIECAT approach, multi-modal methods were used to form a response to what caught my attention in the narration of experiences. Inherent in the response is the intuitive empathic sense of what lay at the heart of the stories, the associated descriptions, key words and images. My empathic responding moved the work into the space of intersubjectivity. It was an engagement that explored, extended, played with, questioned and connected with the emotional experience of listening to another. For Moustakas (1996) it is: ‘Being-in, Being-for, Being with’. What is returned as my response is filtered, perhaps re-arranged, or worded differently, through a process of intuitive selection. I reflected, indwelled (refer Chapter Two, 3.8), thought, felt, and created my responses, which became reciprocal exchanges when the narrator responded to my material and shared their response with me. This intersubjective exchange enables understanding and clarifies what has been described. It reveals useful new ways of seeing
what has been presented in the narratives. The responses often emerged as I transcribed the interviews and felt the key words and images gain significance (Lett 2001, p.347).

My response may be given in the form of a poetic reflection, or naïve art conceptualisation of what has been said, perhaps accompanied by a poem or piece of relevant illuminating literature. Poetic representations are sometimes preferable to prose. They focus and solidify emotions, feelings and moods in order to re-create moments of experience and draw them together (Richardson 2002). It often makes it easier to capture the essence of what has been said. So whilst the words are those of the narrator, in the re-ordering of the words as I respond to them in poetic form, new understanding and meaning became available. It continues to move me as listener, and often the narrator as well, towards deeper understanding of what is presented. I was aware that the intersubjective responses I returned to the narrator could possibly be confronting and not always affirming. I needed to be careful and respectful if I was to reflect back to the narrator an aspect of their narrative, that is, their own words, perhaps shaped or rearranged differently, so that they might be able to hear, see or grasp them from a different perspective. This was a responsibility that I did not take lightly.

There is an argument against poetic reduction (Atkinson and Delamont 2005, p.823) that warns of:

>a danger of collapsing the various forms of social action into one aesthetic mode - that is, implicitly revalorising the authorial voice of the social scientist - and of transforming socially shared and culturally shaped phenomena into the subject matter of an undifferentiated but esoteric literary genre.

In response to this argument, poetic forms of writing, in order to crystallise the essence of what is there, perhaps represent the speaker better than prose. Poetry concentrates the language by reshaping what was said, deleting extraneous words and clarifying the heart of the matter. The speech used for conversation and storytelling is closer to poetry than it is to prose:

>Settling words together in new configurations lets us hear, see, and feel the world in new dimensions (Richardson 1995, p.933).
Responses that took the form of art conceptualisations were simple visual reflections rather than *art*. They offered representations in various textural aspects and color to what was said. Shared with the narrator, they created valuable non-verbal ways of responding, enriching the verbal poetic-summary responses as well as supporting further dialogue.

I also used a form of ‘art’ conceptualisation to summarise and synthesise each narrative just prior to forming a final poetic essence. With the assistance of Jan Allen, and later Jane Gorey as my collaborative inquiry partners acting as ‘scribe’, working as pre-cognitively as possible, I used felt pens or pastels to draw my perceptions of each theme of the narrative. These art conceptualisations assisted me to grasp the overall essence of the narrative, and they sometimes surprised me with new insights. The use of these multi-modal intersubjective responses in the process of identifying themes within the life narratives is illustrated in the narrative chapters. Having described the intersubjective responses that arose from within the narratives, it was also important to ‘map’ my intrasubjective experience of listening to and sharing these dialogues with others.

### 4.1.2. Intrasubjective responses, mapping and journalling

I also noted and processed my own intrasubjective responses to what I was hearing, exploring the barriers and difficulties in my own responses that prevented me from being fully present to the five narrators as they told their stories. In listening to a narrator’s story I experience a range of thoughts and emotions. These are my intrasubjective experiences. There are occasions when my own reactions to the environment of the recording may impact on the interview. So being aware of and processing that effect, while still entering the process of careful, engaged listening, is a critical element of my inquiry. The reflexive nature of this form of human inquiry, requires:

> a conscious experiencing of the self as both inquirer and respondent, as teacher and learner, as the one coming to know the self within the processes of research itself (Guba and Lincoln 2005, p. 210).

This enables one to do one’s own work and progress in one’s personal growth and development in the context of conducting qualitative research (Braud and Anderson 1998, p.43). All three processes occur simultaneously, and each feeds and enriches the others.
Methodological attention to the interactive field of listening alludes to both the ‘I’ and the ‘Thou’ of the situation (Corradi Fiumara 1990, pp.171-190).

We are led to recognise that listening to oneself and listening to others are synchronic processes that form part of the same interactive function.

Phenomenological mapping is noticing, consciously selecting and recognising small differences, and separating-out or re-grouping what is happening. It sees distinctions between different perspectives of the whole experience. Mapping can only be done well from within the experience, not from a distanced perspective (Heron 1981b, p.160).

My journal was reduced to a summary of four pages (refer Chapter Eight, 3.2 and Appendix Twelve), which evolved into the final poetic essence statement of the thesis. This statement, *Listening to songs of experience*, is found at the conclusion of the study.

4.2. Processing the narratives: themes and reduction to essence

4.2.1. Themes

Following the taping and transcribing of the life review interviews, segments of the text were allocated to themes where they seemed to belong.

Themes emerge from where they lie at the heart of one’s experience. ‘Themes situate the stories, they do not substitute for the stories’ (Frank 2005a, p.969). Examples of themes might be ‘my relationships’, and ‘my mother’. Themes may occur in patterns. By identifying themes a story can be simplified and focus moves to the core of the experience and its meaning. Themes describe an aspect of the concept of the narrator’s lived experience (van Manen 1990, p.87). In trying to understand an experience as a whole, one examines its complexity in fine detail to help gain a clearer understanding (Tesch 1987, p.230).

4.2.2. Further processing

The next step was a process of gradual reduction, aiming to distill the theme’s material to a one-page narrative whilst retaining the voice of the narrator and the essence of the theme. The one-page seemed to be a helpful way to see the theme in one view, even if requiring smaller font size and page margins. These one-page narratives were then each re-formed into one-page poetic statements. Returning to the transcripts, I then formed the
material into van Manen’s (1990) themes of ‘time, space, self, other’, thus experiencing the narrative from a different perspective (refer Chapter Two, 2.3.2). These themes were then each reduced by several stages to one-page poetic statements.

For the first narrative (refer Chapter Three), the next process utilised Denzin’s (1989b, pp.28-29) theme *history*. Denzin suggests that history enters the research process in four ways:

- The events and processes unfold over time, having their own inner sense of history.
- These events occur within a larger historical social structure that includes language, power relationships, and cultural meanings that structure everyday social interactions and experiences.
- History operates at the level of individual history and personal biography.
- The researcher had a personal historical relationship to the interpretive process.

Whilst a valid and relevant method, in processing the narrative in Chapter Three it did not seem to helpfully expand my understanding. This arose more successfully from the other ways of reviewing the themes, such as *time, space, self, other*, and the third person structural form that follows. It was time consuming and therefore I did not repeat this step for the other narratives.

Following this step, each original one-page poetic statement was changed into a third-person, structural form. This brought a distancing from the narrative. I gave myself time to reflect on the themes emerging from all these steps in analysis. Only then a synthesis began to emerge, its timing could not be hurried, expected or planned. This was a process of representation and conceptualising that connected everything, bringing a sense of clarification, so that all the separate parts came together into the best possible creative synthesis. The searching process ended when this unity was achieved. It often brought a sense of relief, achievement, new knowledge, a new way of seeing things, perhaps new possibilities for ways of being. Above all it felt right (Peile 1994, p.220).

### 4.2.3. Reduction to essence – temporary approximation to meaning

For each narrator I formed a poetic statement at the end of processing each narrative. These statements formed through the meeting point of myself as listener, and the narrator.
They arose out of the essence of our meeting at the point of the temporary crystallisation or approximation to meaning we co-created. Each final essence statement is included in its particular narrative chapter.

Temporary approximation to meaning or personal knowing is a concept which allows meanings to form, dissolve and reform over time, in a pattern that continues to move rather than being fixed, final or static. Whilst an effort is made to bring the understandings and meanings into some neat form of synthesis, this does not necessarily conclude within the time frame of my study.

As listener/researcher I approached the narratives with openness to possibility, with a naïvety that allowed me to enter and be taken into each new space, and to be surprised by what I found. I responded with a strong sense of responsibility for the accuracy and rightness that was possible and necessary. By listening reflectively I found individual ways that opened up each situation to the best co-creative and intersubjective possibilities.

Table 1 lists the process procedures for all five narratives, with the outline of my methods and the minor differences between each narrative’s process. They are included at this point in the thesis to enable the reader to see clearly the similarities and differences between the narratives’ processes that follow. Their divergences and individual pathways are discussed later in the thesis.

Table 1. Process procedures across all five narratives

<table>
<thead>
<tr>
<th>Kaye</th>
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</thead>
<tbody>
<tr>
<td>• 6 x 90/60 taped interviews</td>
</tr>
<tr>
<td>• Transcription 93,295 words</td>
</tr>
<tr>
<td>• Tape &amp; transcript returned to Kaye as each tape completed</td>
</tr>
<tr>
<td>• My journalling throughout</td>
</tr>
<tr>
<td>• Many intersubjective responses from Sandra to Kaye</td>
</tr>
<tr>
<td>• Intersubjective responses from Kaye to Sandra</td>
</tr>
<tr>
<td>• Listing of key words/phrases from all tapes</td>
</tr>
<tr>
<td>• Sorting of key words/phrases into clusters</td>
</tr>
<tr>
<td>• Re-read transcript adding more key words/clusters</td>
</tr>
<tr>
<td>• 8 themes formed and named</td>
</tr>
<tr>
<td>• Allocating text to the 8 themes on charts of A3 paper</td>
</tr>
<tr>
<td>• Data transferred to computer</td>
</tr>
</tbody>
</table>
• Distilled to 1 page narrative for each theme
• One theme changed name
• A poem for each of the 8 themes

From this point I worked alone, e-mailing Kaye what I had done for her to read and comment.

• Restructuring of original themes into ‘time space, self, other’
• Document: lifeworld theory [only done for Kaye]
• Re-forming using Denzin’s theme: ‘history’ [only done for Kaye]
• 8 one-page structural 3rd person, past tense narratives
• 1st creative synthesis: 1200 words
• 5 verbs frame further reduction
• Further reduction
• Art conceptualisation [with Jan Allen]
• Literature search
• Final essence statement
• Transfer to University of Melbourne
• Re-writing as thesis chapter
Sarah

- 3 x 90/60 taped interviews
- Transcription 40,000 words
- My journalling throughout
- Two intersubjective responses from Sandra to Sarah

Sarah died

- Conversation with her brother following Sarah’s funeral & his reading of the transcripts prior to his return to Israel
- Transfer to University of Melbourne
- Ethics approval given to continue
- Text re-read, 7 meta themes 23 minor themes, named
- Text allocated to themes, all text used.
- Re-listened to tapes
- Distilled to 1 page narrative for each theme
- A one page poetic statement for each theme
- Restructuring of original themes into ‘time, space, self, other’
- 7 structural narratives: 3rd person, past tense.
- First reduction (1070 words)
- 6 verb creative poetic reduction
- Art conceptualisation [with Jane Gorey]
- Poetic essence statement
- The literature search
- Poem
- Supervision conversations and reflections
- Further poetic essence statement 153 words
- Re-writing as thesis chapter
Scott

- 8 x 1 hour taped interviews
- Transcription 19,000+ words
- My journalling throughout
- A number of intersubjective responses from Sandra to Scott, in the form of poems & classical literature excerpts in enlarged print.

Scott died

- Transfer to University of Melbourne
- Re-listening to tapes, re-reading transcripts, listing subjects as I went, clustering into preparatory themes.
- Formation of 8 themes.
- All material reassembled into these 8 themes on the computer.
- Reduction to 8 one-page narratives
- 8 one-page poetic statements
- Re-structuring into ‘time, space, self, other’
- 8 one-page structural 3rd person, past tense narratives
- First synthetic reduction
- Art conceptualisation [with Jane Gorey]
- The literature search
- Final poetic statement
- Telephone conversation with Scott’s daughter adding one line to the final poem.
- Re-writing as thesis chapter
Bert

- 7 ½ hours taped interviews (7 sessions)
- Transcription of over 69,000 words
- My journalling throughout
- A number of intersubjective responses from Sandra to Bert (ISR’s)
- A number of ISR’s from Bert to Sandra.
- Presentation of the story to Bert at a special afternoon tea

- Transfer to University of Melbourne
- Re-listening to the tapes whilst re-reading the transcripts
- Listing key words & phrases throughout
- Clustering subjects into preparatory themes
- Forming 8 named themes
- Each theme distilled to a one-page narrative
- Each narrative formed into a poetic reflection
- Formation of my intrasubjective responses
- Re-structuring of original themes into ‘time, space, self, other’
- 8 one-page structural 3rd person, past tense narratives
- These 8 themes used as basis of first synthetic reduction
- The first essence statement
- The literature search with special focus on alcohol induced dementia
- The art conceptualisation [with Jane Gorey]
- A further poetic reflection followed
- Re-writing as thesis chapter
Elizabeth

- 6 x 1 hour taped interviews
- Transcription 60,000 words
- My journalling throughout
- 1 page précis of each tape returned to Elizabeth, plus several other intersubjective responses
- Transcriptions, summaries & other ISR’s returned to Elizabeth in folder

- Transfer to University of Melbourne
- Re-listen to tapes, re-reading transcript, listing themes appearing in each tape
- Allocating text to each theme, using poetic form
- Re-naming of one theme
- Clustering of themes from individual tapes into 8 new major themes
- Each theme reduced to 1 page narrative
- Re-structuring of original themes into ‘time, space, self, other’
- Formation of a genogram
- 8 one-page structural, 3rd person, past tense narratives

Elizabeth & her husband both seriously ill

- First creative synthesis 1533 words
- One-page creative synthesis 793 words
- Synthesis/essence: 358 words
- Art conceptualisation [with Jane Gorey]
- The literature search
- Elizabeth requested a further meeting for clarification of her story
- A further poetic essence statement
- Re-writing as a thesis chapter
5. **MODIFIED APPLICATION OF VAN MANEN’S LITERATURE SEARCHES**

My method of literature searching is one way of adding rigor and critique to the analysis of the narratives. There is a comprehensive discussion of literature surrounding the worldviews, methodologies, theories and methods of listening to and working with narratives in human inquiry, reviewed throughout the previous discussions. There is also a literature search undertaken just prior to completing the analysis process for each of the five narratives. This partly meets phenomenologist van Manen’s argument that one should turn to the literature only after attending to the material’s understandings and approximations of meaning on one’s own first. If one attends to the existing literature too early, bracketing one’s interpretations and perceptions might be more difficult. However, van Manen argues, sooner or later one should test one’s insights against those who belong to the tradition of one’s subject of study (van Manen 1990, p.76).

The central place of literature cannot be overstated: in supporting the best ways health professionals’ might engage in reflectively listening to their patients; and in the search for meaning in life’s epiphanies and crises. Hunter (1996, p.312) argues that medicine, (or healthcare professions of any discipline), must search for an understanding of the human condition:

> Literature is unmatched for the access it gives to the experience of others, especially the inner lives of patients and the meaning of circumstances physicians cannot (or do not yet) share.

Such an engagement expands responsiveness to one’s experiences, and affirms what can now be understood within them. Responses might vary from:

- That was similar to how I felt;
- I am relieved to read that someone else felt like I did;
- That’s an interesting way of seeing it;

all of which contribute to deepening understanding (van Manen 1990, p.76).
As van Manen (1990, p.76) proposes, the literature searches should happen after the immersion in each individual narrative. However I had an extensive understanding of illness narratives and especially palliative care literature before I began this project. So it was not possible to say ‘I am not going to engage with the literature until I have finished this particular narrative study’. The reality is more that each narrative stimulated further immersion in particular literature, some more metaphoric and fictional than academic, for example the feminist literature surrounding issues of mothers’ and daughters’ relationships and the experience of daughters when their mothers died. The reality is more of a tangle and a less rigid adherence to van Manen’s instructions.

The literature searches became part of the sorting or sifting processes, whilst expanding and enriching my understanding of the experiences of the narratives. I cannot claim a pure separation of the literature until post-narrative analysis, however I have tried to be transparent by declaring what I had already read. Some of the pre-reading enabled me to cope in the various narrative contexts, and was essential preparation, rather than contaminating the phenomenological process. This was particularly the case in my preparation for working in a dementia unit, which was a new experience.

A phenomenologist values reading widely and deeply, and having an insatiable interest in what he calls ‘truth experiences’ as provided by deep exposure to the creative arts (van Manen 1984). Literature that is searched and absorbed brings awareness of perhaps previously unformed ways of illuminating experiences so that they become clearer. The writings of others become voices in the collaborative search, joining the listener/researcher and the narrators in their discussion of their life stories. As Buber expresses it (1923, p.39):

we must learn to feel addressed by a book, by the human being behind it, as if a person spoke directly to us … It is the voice of You speaking to me, requiring a response.

Throughout my life I have sought literature to guide and inform my understanding. To illuminate this concept, I offer another personal story of how I discovered literature that assisted me to find meaning following a difficult life experience:
As a young nurse, I confronted the normal exposure of healthcare professionals to death and dying. This included some deaths of children I cared for as a staff nurse at The Royal Children’s Hospital in Melbourne. However I was not ready then to fully absorb the reality that this was a normal part of life for me and my family. In 1975, with two very young children, my husband became critically ill. For some weeks there was the possibility-of-death sitting beside us. It did not just happen to other people.

My husband recovered, and shortly after this I heard a book reviewed on the radio. I was moved by how the emotions described by the author were so close to my own intense, confused feelings during this difficult experience. The book was Kubler Ross’s (1970) ‘On death and dying’. It connected strongly to the grief and loss I had experienced through my husband’s illness, even though he survived. It validated my feelings. Reading this book was a pivotal step for me on the path towards palliative care nursing, becoming a starting point for understanding the issues of death and loss. I found literature that supported my need at the time, helping me to make sense of my experience. This allowed me to integrate this new approximation of meaning, and to continue searching for similar reading to expand my knowledge.

In listening carefully, what can be heard in illness narratives in particular, is not people rising above their suffering (Frank 1998). Rather people can be heard as they rise within their suffering, and in the process they teach the rest of society the necessary place of suffering in life. I read and collected many illness narratives. These writers’ courage, resilience, and endurance nurtured my own development of these qualities. A separate list of autobiographies, biographies, or illness narratives that have been significant for me, is found in Appendix One. There were limits to the searches to keep them manageable. There was no way the searches could or needed to be comprehensive. One reference often led to another, for instance around themes of reminiscing, dementia and ageing.

As I worked through the processes of recording, transcribing, reflecting and responding, my own feelings, senses, emotions and thoughts were active and changing. I recorded this movement as transparently as possible by journalling, and slowly my inner understanding emerged and crystallised. This was the beginning of approximation of understanding for me, often then affirmed and validated by the literature I had chosen (Lett 2001, p.346). Thus the voices of the literature become intersubjective resonances to my experience of
the original narrative, giving my experience of hearing the narrative and my subsequent reflections validation and value.

The literature searches occurred almost at the end of the processing of each narrative, with only a final art conceptualisation and essence statement to follow. It was mostly an intuitive selection that guided the literature I chose, ‘asking’ of the search:

- Help me to clarify what I have heard, felt and experienced.
- I need more factual information about issues such as abortion; universal truth; alcoholism; dementia; ageing; family resonances; loss of identity and so on.
- How did someone else feel in similar circumstances?

To help clarify this process in the thesis, each literature search is separated into themes, not necessarily the same as those used in the initial narrative analysis. These themes arise from key words that emerged as I analysed each narrative. These themes are presented as a table examining all the themes and sub-themes across the literature searches for each of the five narratives (refer Appendix Five).

Each literature search is summarised within its narrator’s chapter. The full searches are found in Appendices 7-11. In these individual searches, under the heading of each theme, the comments of the literature are set out in the left hand column in black print, with my reflections on each theme in the right hand column in blue. Thus seen side-by-side there is less confusion about what belongs to the voices of the literature and my reflections arising from the writers’ views.

6. **ETHICAL ISSUES IN QUALITATIVE HUMAN INQUIRY**

As required by the processes of heuristic phenomenology, throughout the thesis I have been mindful of my ethical responsibilities. This was in part to offer, as much as possible, an account that retained the voice and truth of each of narrator, in a form that described the sense of how their experiences felt to them. Like Kiesinger (1998), I worried about what my participants would say when they read my account of their experiences. It was even more difficult when their responses were not available due to death or increasing dementia. I was conscious of others who are involved and affected by the processes of
narrative work. This made me constantly mindful of the ethics of a person telling their story for reading by affected others.

There are major ethical considerations involved in qualitative human inquiry that require careful attention. Ethics is a tension between what is good (for the individual) and what is right (correct behavior within the law of the society). I have addressed this tension throughout my study, to be sure that it adheres to this moral rightness (Ross 2000).

I understood that I needed to treat each narrator with respect and confidentiality. I appreciated the reciprocal benefit of each person sharing personal and private stories, their openness and honesty was something I valued. I was always mindful of Frank’s (2005a, p.966) key question for all qualitative-narrative research: ‘What can one person say about another?’

The following discussion is perhaps more involved with method and selection of participants. It is included here because I identify it as an ethical issue:

In order to select participants for the study, I distributed my Therapeutic Autobiography brochure throughout a variety of healthcare institutions (Appendix Three). Two participants were referred by healthcare facilities: a psycho-geriatric unit and a palliative care unit. Three participants were privately arranged. I selected participants in settings with which I had different relationships or degrees of familiarity. This best represented the possibilities for application of this method in a range of practices settings. I hoped that the nature of the inquiry, and the anticipated depth and detail of each individual study would be adequately served by the selection of five participants.

I gained ethics approval from The Melbourne Institute for Experiential and Creative Arts Therapy as required for my Masters Degree. This included approval from the palliative care and psycho-geriatric units involved. On upgrading to a doctoral program, this approval was then accepted by The Human Research Ethics Committee of The University of Melbourne (Appendix Two). At this point I had transcribed all the narratives and almost completed analysing one. Ongoing family consent was sought from the families of two participants who had died since recording their narrative. Consent was willingly continued in each case.
I met each person prior to the first interview, where we discussed issues such as anonymity, their ability to request changes or to withdraw from my study if they chose at any time. I explained the possibility that the interview process might stir difficult memories for them, and that my counselling training would enable me to assist them, however I would seek other help if it became necessary. None of these issues seemed important to the participants. I outlined the process and they seemed eager to begin. Each participant said that the story they would tell was freely available for my study or for whoever might read their life review document. All willingly signed informed consent forms (Appendix Four).

6.1. Confidentiality
Confidentiality in research implies that private data identifying the participants will not be included. If a study involves publishing information potentially recognisable to others, the subjects need to agree to the release of identifiable information, stated by written agreement (Kvale 1996, p.114). The principle of the research participant’s right to privacy is not without ethical difficulties and dilemmas. There is concern about what information should be available, and to whom. It needs to be made clear before the interview who will later have access to the material.

Who owns or controls the narrative, and what happens to it after the interview (Josselson 1996, p.xiv)? Josselson claims that the ‘I-Thou’ exchange of narrative research is not only ethical but life enhancing for both participant and researcher. Bakan (1996, p.5) expresses his misgiving that narrative research converts what is private into what is public. He worries that this violates privacy and can cause hurt and harm. The most significant truths about human beings are inherent in the stories of their lives. However they need protection in making their stories available to others. Frank (2000a, p.12) reassures us that autobiographical work is ‘always-already constituted as open to others’. My abiding concern throughout my study is that the storytellers feel that their story is their story, told in a form that is ‘open to others’ and more or less self-edited with public disclosure in mind.

One might worry about the intrusiveness of the experience of being ‘writ down’, fixed in print, reduced in some way to just words (Josselson 1996). This seems to express concern about the risk of over-simplification, reducing the complexity of life experience to a
limiting fixity through a single telling or writing down. In contrast, Arnold (1997) tells a ‘good’ story about Vera, who was actively dying. A volunteer presented Vera with her finished life review, complete with photographs. Vera gazed at it in wonder, and kept repeating ‘this is me, this is me.’ She held her story and, early that evening, lapsed into unconsciousness and died later that night. Perhaps for Vera, that her story was told, heard and written, freed her to leave knowing this tangible evidence of her life and her descriptions of its meanings remained. For Vera it seemed neither intrusive nor reductive, it represented completion.

With all narrative work I feel some concern about the telling of family stories and the impact that telling might have on other family members. There is a need to recognize and protect the feelings of discomfort that a family might feel about the publication of family stories (Richardson 1995, p.932; Richardson and St. Pierre 2005, p.966).

There are ethical aspects needing careful consideration regarding the complexities surrounding interpretations that arise within the engagement with another’s story. When a qualitative researcher makes interpretations going beyond the self-understanding of the participant, a series of issues are raised: should subjects be confronted with interpretations of themselves which they may not have asked for? And what should be done about disagreements between the subject’s and the researcher’s interpretations of a theme? These issues need constant awareness and consideration (Kvale 1999, p.106).

In recording the narratives for my study, sometimes painful, meaningful, private conversations took place after the tape recorder was turned off. I do not think the words from these private conversations belonged in the transcripts, or my thesis. However they gave me a sense of the meanings attached to these often deeply personal descriptions and the emotions expressed in these conversations off tape. This raises an interesting question - when does an interview start and stop? It is not clarified in the signed agreement/consent forms. I intuited that these extra conversations were for me alone and I did not breach that understanding, however it was never spelt out. I always clearly announced to the narrator that I was turning on or turning off the recorder.

In the end I come to the same conclusion as Josselson (1996, p.xvi), that with care, understanding, and above all respect, that the I-Thou/Being-to-Being exchange of
narrative research is not only ethical but life enhancing for both narrator and listener/researcher.

7. PREPARING TO ENGAGE WITH THE INDIVIDUAL NARRATIVE PROCESSES

I have to this point introduced the problem, discussed the nature of illness narratives embedded within their individual life review narrative, and proposed how meaning might be found through listening to these narratives in an engaged, reflective way. This chapter has considered methodologies and methods that are suitable for this type of qualitative study. The following chapters (Three to Seven), present the components of the processes of co-creating five individual life review narratives.

Each of these chapters presents specific aspects of one person’s narrative process and is self-contained. It lists a summary of the information I had gathered at the start of the narrative process. This information was acquired differently in each case, reflecting the particular context of each person. (The selection of participants is described in the previous section of this chapter). Each chapter then moves on to introduce the person behind this initial presentation, describe the process of co-creating the life narrative and the meanings arising.

It is a realistic question to consider at this point how my method of working with illness narratives embedded within life review narratives, might be connected to my focus on listening in healthcare relationships and settings. I am not implying that healthcare professionals have time to listen to the 40,000 to 93,000 words of the life narratives, or should write poems in response to their patient’s stories. I address this question in the concluding chapter in particular, but in brief, the next five chapters illustrate and amplify attitudes of engaged, reflective listening, noting both inter and intrasubjective responses, so that the narrator, listener and readers become aware that both perspectives are part of the process of co-creating a satisfying narrative that enables meanings to be uncovered. One of the significant methods for reaching this point of meeting is through the reduction process, where the end point is an essence statement in poetic shape, which represents the narrative that we as narrator and listener have co-created. These essence statements are further discussed throughout the thesis.
Some collegial comments throughout the process have argued that my study does not offer enough of the actual narratives of the participants as they narrated them, in other words, the actual transcripts. There is a desire on the part of the reader to want more of the story. I utilise quotes from the transcripts to highlight points, but have also been aware of the need to protect identities. My aim is for the process to be central to the thesis, rather than the actual words from the transcripts in detail. However this is a conundrum: like St. Pierre (2005, p.973) I hope that readers can still ‘hear’ the voices, perspectives and unique settings of each individual narrator, and that they remain solidly central in their narratives. Verbatim quotations from co-researchers are presented thus:

The intersubjective responses/sentences were amazing, clarifying, for example my fear, ‘I’m scared of being alone’ … I read the intersubjective response and felt the fear in my body, there it was set out in concrete, black and white.

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At the conclusion of each narrative chapter I will address the following questions:

- What does the processing and analysis of this narrative add to the existing knowledge of narrative/life review/patients' or family members experiences of healthcare.
- Can anything general beyond the knowledge of the individual's story be inferred?

These issues are also further discussed in Chapter Eight. In Appendix Eleven I outline possibilities and speculative suggestions that might also add to existing knowledge, and improve outcomes for others who use healthcare services, and for healthcare professionals who provide this care.
Chapter Three:
Listening to Kaye’s narrative

Information provided by Kaye prior to recording her narrative:

She was 35 year old, single and unemployed
Her mother died ten years ago from a ruptured cerebral aneurysm:
Her mother was initially resuscitated by paramedics,
she was declared brain dead after 3 days,
life support was discontinued in the Intensive Care Unit, the family were not present.
In the following ten years Kaye engaged in chaotic behaviour:
she left and re-enrolled at university several times,
she lived interstate much of that time.
Her father and older brother reside in Melbourne.
On the tenth anniversary of her mother’s death
she returned to Melbourne, ending a difficult relationship:

1. in order to reconnect with her family
2. she hoped to develop an understanding of her mother’s life and deal with her confusion about her mother’s death.
1. INTRODUCING KAYE

Kaye was in her mid-thirties, tertiary educated and articulate. We met at a Christmas function in 2000. She told me of her ongoing sadness and despair, which she felt was deepening as the years went by, rather than easing. After ten years she was still struggling to come to terms with her mother’s early death from a cerebral haemorrhage. Kaye’s relationship with her partner was at breaking point.

Kaye felt unable to talk significantly with her family about her mother, and told me that her life was chaotic and self-destructive. She felt that she did not deeply understand who her mother had been, and this weighed on her heavily. She had returned to Melbourne in the hope that she might sort herself out and finally come to terms with her mother’s death, and perhaps reconnect with her family. We talked about my study and she expressed great interest in how it would progress, and how it might help her. We agreed to talk again.

In a subsequent telephone conversation with Kaye I wondered if together we might reconstruct, record and write a life-story of her mother, as a way of her finding some sense and meaning in the difficult ten years since her mother’s death. She was very enthusiastic at the prospect. She was still tangled in the stormy ending of her relationship with her partner. We discussed the parameters and possible difficulties of how we might proceed. I asked Kaye how she would feel about me using the story as part of my study, and she expressed enthusiasm at the prospect. I gained MIECAT’s Ethics Committee’s approval to proceed. Kaye willingly gave her consent, with me explaining the issues of confidentiality and anonymity.

Kaye’s narrative is anchored in the coldly clinical atmosphere of the intensive care unit where her mother’s life support was discontinued after three days. This confronting experience was the trigger for ten years of disrupted wellbeing for Kaye. The story of her mother’s death and Kaye’s inter-linked chaotic journey is an idiosyncratic illness narrative told from a different perspective than the other four narratives in the thesis.

2. THE PROCESS OF CO-CREATING KAYE’S NARRATIVE

The narrative process procedures for Kaye were similar for all the narratives in the study (refer Chapter Two, Table 1). This list is placed at the beginning of this section in order to
act as a guide to the reader as to how the co-creating of Kaye’s narrative, and then its reduction was managed until meaning was uncovered for both narrator and listener.

- 6 taped interviews of 90 minutes = 9 hours
- Transcription = 93,295 words
- Intersubjective responses from Sandra to Kaye throughout processing
- Intersubjective responses from Kaye to Sandra
- My journalling and intrasubjective responses throughout
- Re-reading of transcripts
- Selection of key words and themes (Kaye and Sandra worked together)
- Clustering of themes - 8 major themes (Kaye and Sandra worked together)
- An A2 worksheet allocated to each theme (Kaye and Sandra worked together)
- Transcript cut and allocated to the 8 themes (Kaye and Sandra worked together)
- Theme data transferred to computer
- A one-page narrative for each theme, collaboratively written
- Name changed for one theme
- 8 poetic reflections from narratives
- From now on Sandra worked alone, staying in touch with Kaye by e-mail
- Themes re-formed into ‘Time, space, self, other’ (van Manen 1990, pp.101-106)
- Life-world theory and the value of the process separated from themes
- Time, space, self, other re-written as poetic statements → reviewed by Kaye
- Re-formed as History, using 5 themes (not repeated for other narratives)
- 8 structural third person narratives → reviewed by Kaye
- First creative synthesis: 1200 words
- 5 verb creative poetic reduction → reviewed by Kaye
- Art conceptualisation → reviewed by Kaye
- Further reduction, then final essence statement, 90 words → reviewed by Kaye
- Several further intersubjective responses from Kaye, by e-mail

2.1. **Taping, transcribing and returning the transcripts to Kaye**

Kaye and I recorded six ninety minutes tapes at my home. There were more than ninety-three thousand words of transcription. We used art, music, poetry, jewellery, literature,
photographs, and her mother’s school memorabilia to help access information and amplify the picture of who her mother had been. As we accessed more and more detail, we thereby also created a clearer picture for us both, of the ten years of Kaye’s chaos and emotional pain since her mother’s death. Kaye gradually came to express the possibility of change in her way of experiencing the world, with changes to her approximations to meaning. In *Interpretive Biography*, Denzin (1989a, p.13) explains that the subject matter of the biographical method is the life experience of a person. When written in the first person it is called an autobiography, life story or life history. When written by another person observing the life in question, it is called a biography. For Kaye it was a tangle of her own story, her story of her mother’s life, and her story of how they each fitted into the complex culture of the family they belonged to.

2.2. **Intersubjective responses**

Previous discussion of the nature of these responses can be found in Chapter Two, 4.1. After each taping session, as I transcribed the tapes, intersubjective responses arose in my consciousness, and before we began recording the next session I gave my responses to Kaye. They were sometimes confronting for her, sometimes affirming - she said she found them helpful. Later in an e-mail she said:

The intersubjective responses/sentences were amazing, clarifying, for example my fear, ‘I’m scared of being alone’ ... I read the intersubjective response and felt the fear in my body, there it was set out in concrete, black and white. I could face it, and to a certain extent accept it and overcome it momentarily.’ It was in fact someone sifting through your words and taking some words out. It was significant that in this process the physical document could be returned to you.

There were a considerable number of responses in various modes, and a selection is included here. It is not possible in some of the responses to identify which were Kaye’s actual words and which were my re-arranging of her words. For example in the first response below, Kaye said she had great difficulty when various people suggested that she needed to ‘let her mother go’ - hence my question, did she need to do this, or could it be seen from another perspective.
2.2.1. **Intersubjective responses from Sandra to Kaye**

Following Tape 1: Intersubjective response

Do I need to let go of her?

*I*

and *my mum*

Are bound almost indistinguishably.

How can I lose her

when she is so inextricably

part of who I am?

In such a way that cannot be undone,

or loosened, or disentangled.

Because she was who she was,

I am who I am.

---

Figure 2. Intersubjective response: *The problem*
Following Tape 2:

In order to help clarify for Kaye the clinical details of her mother’s death, in response to her confusion about ‘life support’ and when her mother actually died, I had a discussion with an anaesthetist (my son James Griffiths). The discussion was limited to defining this medical situation. My response to Kaye (Intersubjective Response 3) is found in Appendix Six, 1.

Figure 3. Intersubjective response: An up and down experience
Following Tape 4. Intersubjective response:

\[ \text{My whole life is story} \]

I am a creative person in my essence.
Creativity is one of the really high values.
This is the lesson I have learnt from my mum's death:
I do not avoid suffering now.
From absolutely no choice, to two choices - to sink or swim.

I am strong and brave, I know I will survive.
I want to say 'thanks for my life.'

I am starting to wonder...
Does loyalty (or stubbornness)
mean my life’s work is to pursue her artistic endeavours,
to do what she didn’t complete.
My life’s my life, hard, painful, I suffer a lot -
Love is the only rational act.
I absolutely don’t think pragmatic existence is enough!
The rational is the Love!
Compassionate rationalism -
Until you understand death you don’t understand life!
when faced with two choices, always take the hardest path.
Following Tape 5:

Figure 4. Intersubjective response: This is key: the creative use of suffering

Figure 5. Intersubjective response: I was the one who had the guts to search
‘There’s so many things I want to talk to her about

I’m so helpless because my mum’s dead,
I had this incredible relationship with my mum,
I really wish I had now,
I’ve been missing her really, really badly,
partly because I’m starting very slowly to kick arse.
And if I kick arse, and I do something amazing like I do this project

I want her to know,

I want her to know.

I want her to see it [yells].

I want to be able to talk to her about these people that shit me!
It’s like I was having a conversation with someone
and I can’t have the conversation!

I want to talk to her!
It seems to me that to a certain extent, you’re only going to be free once you accept that you can’t really have security. You can’t really have permanence.

Freedom is when you start to say that’s all you know. And you don’t have fixity in your viewpoint. To be fixed in your viewpoint and to say ‘that means this’. The fear is insecurity. People are scared of being insecure. They’re scared of not having something to hold on to.

Figure 6. Intersubjective response: That means this
Figure 7. Intersubjective response: Klass's (2001) Interactive Web: Modified for Kaye

The modification of Klass’s Interactive Web in Figure 7, for the purpose of discussing it with Kaye, is further described in 2.5 and 2.7, and Appendix Six, 2.

2.2.2. Three intersubjective responses from Kaye to Sandra

1. A reflection on the experience of talking about my mum’s death over 90,000 words ago.

Most probably the anniversary of her death, twelve years ago, although I don’t know, I never know precisely. What I do know is the physical experience of grief that returns to me this week, every year to greater and lesser degrees. And which will do so I suppose for the rest of my life. Today I wonder if when I’m 80 will I still feel ripped off by this? Will I still feel this physical sense of grief? It’s physical. It’s uncanny. Illegitimate? Stored in my gut. When I came back to Melbourne,
running away, running back. I knew I had to come home to find her. It was 10 years since she had died. And I cried on the freeway as I entered the city. I guess I didn't know how I was going to do it but I knew that I had come home to reclaim her back into my life. Because I missed her and she was gone and my life could never be what it would have been if she’d stayed. And I could never know what that was.

The process of sitting with someone who would listen to me. Someone who would listen to me. What mattered was that she was prepared to give me this huge gift. Really the gift of life. I sat and I cried and I talked and talked and talked. Swimming around my life and my mother. Swimming around in this pool of the past. History. My own history. My own sadness. My own life. My life. To see the words on a page reflected back at me, made concrete. To see the meanings emerge and be reconfigured.

To dwell.
To meditate.
To return.
To recreate.
To honour.

I’d known periods of happiness since my mother died but I hadn’t known myself. More than knowing myself now I actually and actively like myself. Sometimes I even love myself. I just never thought I would. I guess it’s a combination of things. Growing up, maturing, growing old, synthesising the experiences into wisdoms.

Acceptance.
Recognition.
Survival.

Pride at surviving and the accompanying knowledge that I can and I did, then I did again and I will in the future.

And knowing myself. The process of sitting with her story, my story, gave me the opportunity to exist. Understanding pain and suffering. Your own suffering becoming legitimate to you. Not anyone else.
That’s enough. When you look at the world and at the suffering and yours seems so minor. To for once have the chance to know that it’s not. It’s a defining moment. She left me, alone. My life had importance to me and to someone else for that time, on that page, in that room. So I’m happier now, more consistently. I have my happiness. I have a sense of being whole and of being free. And I live my life in honour of my mother, in celebration and in pain.

2. To Sandra – here is my spin on this. An intersubjective response:

THE MOTHER:

almost stifles the daughter
by surrounding her
in a powerhouse of spinning creativity.
She is creative in suffering,
in practical things
in building relationships;
Her life is one big creative process.
She was afraid.

THE DAUGHTER:

looks like her mother,
and is interested,
(like her mother), in social issues
art, love and creativity.
She inherited
low self esteem.
She sees both joy and suffering.
The world is mostly grey,
and she suffers a lot.
Although underneath
she knows there lies
something positive.
She wants her mother to see this too.
There is a fine balance here
between hope and despair.

THE DAUGHTER

Struggles between
love
(she had the best ever mother daughter relationship)
and fucked up chaos
(her mother died amongst the shitty, fucked up,
perverse, kookie daughter’s thoughts).

The mother is so much a part of the daughter.

3. The value of the process:

Thank God I’m doing this process with you, because it’s keeping me in
Melbourne and it’s keeping me sane. Because I am a flighty, flighty
person and I’m under a lot of pressure and I feel that the reason that
things didn’t work out with him, is partly because of this process.
Because this is more important, and this is giving me a reason to really
be alive. This is really clarifying for me, it is absolutely what I believe. I
just feel I’ve been given the most incredible gift. It took the most
incredible amount of courage. It caused a huge amount of pain. Yeah,
yeah pain is part of it. It caused a huge amount of pain. Happiness,
growth, the result is I’m sitting here with you and I’m doing this amazing
process and we’re learning this incredible stuff. And we get to sit here
and this incredible privilege, where I get to sit here and crap on to my
heart’s content! [smiles]

I’m learning through this process that what gives me my strength to
exist and be happy isn’t those things   (Tape 5 Side A).

2.3. Re-engaging: steps in processing and understanding Kaye’s story

Kaye’s story was the first of the five narratives processed past transcription, and this set a
flexible pattern for the remainder of the other narratives in my study. With the advice and
support of Jan Allen, my Master’s Degree supervisor at MIECAT, and discussing the
process with Kaye as I went, I inched my way along, seeking intuitively which were the best ways to proceed. I sought to honour the methodological instructions outlined earlier in the thesis, and re-read them as I went, for example Moustakas 1996, Spinelli 1989, and van Manen 1990. I constantly sought to allow deeper understanding to emerge for us both, from within the layers of Kaye’s experiences. From the beginning I processed the experience for myself by journalling my own intrasubjective material (refer Chapter Three, 2.7).

The next step involved the listing of all key words and phrases from all six tapes, selected from my intersubjective responses, prior to re-reading the transcript or re-listening to tapes (refer Appendix Six, 2). Then I read through the list sorting the themes into clusters, after which I re-read the transcript adding a few more themes that I had not yet included. I studied the themes and intersubjective statements, I carefully listened to the tapes and re-read the transcripts again and added yet more themes, which I clustered, including them all, although I was concerned at the volume of material produced.

At this point Kaye and I spent a day together forming the data into 8 themes:

1. Birth, life and death
2. Home and family
3. Feelings
4. Paradox and contradiction
5. My own chaos
6. Idealism and pragmatics
7. Creativity and the creative use of suffering
8. Freedom

We set up an A2 worksheet for each theme and then proceeded by printing and cutting up the pages of text we had each selected, then pasting them to the relevant A2 theme chart. This was clumsy but effective, for the later narratives I used the computer to cut and paste parts of the text into themes.
I then transferred this information to the computer, under the heading for each theme. From these sheets a one-page narrative was written for each theme. The first theme’s name changed. The final theme names were:

1. My Mother Myself / Motherless Daughters / Daughterless Mothers
2. Paradox and Contradiction: a fine balance
3. Idealism versus the Pragmatic: the pearl of great price
4. Feeling
5. The Creative Use of Suffering
6. Home and Family
7. My Own Chaos
8. Freedom ... to be alive
Each one-page narrative was then formed into a poetic statement. Kaye then expressed her discomfort at my process of reduction. My full understanding of Kaye’s challenge of the reduction process did not click with me until well after we had finished the processing of her narrative. I therefore expand on this understanding later, in 2.7, Chapter Eight, 4.9, and Appendix Eleven. From this point on Kaye and I did not work quite as closely together, although I sent her work to read by e-mail. I regularly sought Jan Allen’s wisdom and reassurance in how I might best proceed without distressing Kaye.

The next step involved setting up four sections, one each for *time, space, self,* and *other,* utilising van Manen’s (1990, pp.101-106) concepts. I also created a separate document for Kaye’s descriptions of her personal *Lifeworld* theory:

```
Life is suffering, paradox, ambiguous,
That's what life's like.
Average is dead!
That's what death's like.
Love is about freedom.
I think contradiction is natural and normal.
At a really essential level, the bottom line.

The real joy of having an experience like that in your life
is that it gives you a stark realization of the real nuts and bolts of life.
You had two choices really, sink or swim. Sinking was either suicide or
insanity,
and swimming is just transforming the experience.

I feel that our society has lost its ability to deal with these things so that
when you're in this position you might perform in a certain way. It might
partly be true to yourself, but it might also be true to some sort of
confused idea of what's appropriate in that situation. There's things to
do with a sense of obligation or compulsion, a sense of what one
should do, rather than what one feels that one wants to do, or one
could do. I think that we perform roles, because we have some sort of
idea of how we should perform that role based on what we've seen,
from television.
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Interestingly, Bruner, E. (1986, p.147) remarks that a common reaction of people involved in airplane hijackings when asked how they felt and what they did, was ‘Oh, everything was familiar to us, we had seen it in the movies already.’

This is one of the great things of life,
Happiness comes from knowing unhappiness.
Joy and suffering are inextricably linked, a parallel journey.
Life and survival is contradiction, there is no sense.
there's a fine balance between hope and despair.
I think we misunderstand what normality and abnormality are in this society.
We are all flawed, we all make mistakes all the time.

The unknown is what makes life great.
Inconsistency, contradiction, change,
madness, confusion, loss and pain
are really what make life great.

Each theme of time, space, self and other, was reshaped into poetic statements, the four full poetic statements are included in Appendix Six, 2. They are bulky, however they demonstrate the way the themes were shaped from the text.

I then tried to reform the data using Denzin’s (1989b, pp.28-29) ‘History’ as a perspective, or another way to see the overall story. The clusters for this theme were:

- Grandpa, family trees and connections
- My mum
- Mother and daughter
- My mum’s death
- The daughter after her mother’s death

Whilst this involved considerable time and effort, I did not feel that it enhanced the clarity overall, so I did not repeat this step in processing the other four narratives. I then moved on to rewrite the narratives in structural, third person terms such as the mother, the daughter, the grandfather, she, he, they. Each of the original eight themes became a structural narrative. I have included two of these structural narratives in Appendix Six, 4:
‘Feeling’, and ‘The creative use of suffering’, to demonstrate this process. This brought a feeling of containment and clarity, perhaps due to a sense of taking a step back from the narrative.

2.4. Five verb creative synthesis

Finally a creative synthesis of the whole now seemed possible. It emerged still quite large. From this five verbs were selected to form a further reduction: she creates, she inherits, she sees, she suffers, she believes, and to conclude, ‘it’s fucked.’ The latter assured me that Kaye’s own voice and language were still present. Kaye particularly loved this poem. I have used single spacing to present the poem as a whole, on one page:
She creates:
Her mother’s potential was almost stifled, nevertheless she developed a creative approach to her own suffering. Always actually creating at a practical level, her constant creativity surrounded the daughter, who, valorising creativity, became afraid of not reaching her creative potential. The daughter believes a position can be created; She did this to build good relationships with her family. Her life is a creative process, she chooses to be fully alive, to swim, not sink, a power house of spinning creativity, in her essence, innate, it is actually right inside her.

She inherits:
She inherited some of her mother’s characteristics, she looks like her mother. Her mother’s low self esteem has rubbed off on her. She inherited her mother’s interest in issues of social justice. Art, creativity, value systems and love all inherited from her mother, there’s an energy from her which binds them, honesty is important, and freedom, The mother is inextricably part of the daughter.

She sees:
She sees life as an ongoing parallel experience of joy and suffering. that accepting unhappiness is what being happy is. She sees both sides and flips from side to side, she can see the whole person now. She sees everything as being kind of grey, though she can see the silver lining and the positive side to the experience more clearly. She wants her mother to see it.

She suffers:
Joy and suffering are inextricably linked, an ongoing parallel experience. She suffers a lot, but life is suffering, she doesn’t avoid suffering now. Her mother had quite a creative approach to her own suffering. A fine balance between hope and despair, joy and suffering.

She believes:
She believes in love, and love is about freedom. This is really clarifying for her, it is absolutely what she believes. She will always believe that was probably one of the best mother-daughter relationships that you could ever come across.

It’s fucked!
Ten years ago she had the most profoundly fucked up experience of her life, she believes in love - it’s fucked! It’s weird, kookie, fucked up thoughts, incredibly perverse when someone dies, dark, shit thoughts, honest not callous, shock - bottom line experiences, her own chaos! There is no sense!

A further reduction emerged from the Five Verb Poem, and while it had a better poetic shape, it still did not feel complete to me. Jan Allen assisted me to create an artistic
conceptualisation (refer Chapter Three, 2.6). I shared this with Kaye and she said it was deeply moving and meaningful. About half-way through recording another life review, mildly panicking one morning that I was losing the threads of Kaye’s story, the final poetic essence statement ‘emerged’ and felt right:

‘The gift of being fully alive’

When her mother died,
being a flighty person, she went off
into ten years of her own chaos.
Her idealism struggled with the pragmatic;
Her life was full of suffering, difficulty and pain.

She had to re-create loving relationships with her family
while other relationships perished.
She sees the paradox, accepts that there is no sense in life.
Telling her mother’s story brought clarity
to her own experience, helping her to find
meaning: freedom and validation, strength and happiness.

2.5. The modified application of van Manen’s literature search
(summary)

There was a considerable volume of literature connected to Kaye’s story. Perhaps this was because her story was complex, and so inextricably connected to others, as Crossley (1996, pp.66-68) sees as part of being human. Also to ‘being fully alive’ as Kaye so deeply longed for. So the literature search became like Kaye’s life-search, incomplete, sometimes overwhelming and chaotic, often affirming. As crucially for Kaye as for me, it became an ongoing and evolving search for understanding, meaning and wisdom.

I searched through my own library around issues of grief and bereavement. I did internet searches, for example via google.com and relevant current literature available through amazon.com. I re-read the older feminist writings of Simone de Beauvoir (1974/1985), Collette (1953/1981), and Virginia Woolf (1927/2000), who powerfully describe the
impact of their mothers’ deaths. I sorted the literature into a number of themes, slightly different to the themes used for reducing the narrative.

There are many concepts, and the literature does not always fit neatly into one or another category. The full text of the literature search is found in Appendix Six, 5. Her shouted responses are in bold. Each theme and the literature I searched is presented side by side with the section on my reflections in blue print. I frequently shared the selections of literature with Kaye, who eventually confidently shared the finished literature search with her father.

The literature search was structured around the following themes:

2.5.1. **Theme 1. Mothers and daughters.**
I searched the literature reflecting on mothers and daughters, including understanding this enduring bond of love and blood; motherless daughters; searching for the lost mother; the wild woman; and mothers and daughters as represented in poetry. Manning (2002) pieces together the many tapestry-like shapes that make up mother-daughter relationships, with empathy as the common thread that binds them all into an elaborate quilt, rich with facts and stories. The powerful influence the mother-daughter bond has on a woman’s identity is described by Friday (1997) as affecting a woman’s relationships with men, and her self-esteem. de Beauvoir (1985) suggests that the connection we have with our mothers is sacred.

2.5.2. **Theme 2. Suffering and grief**
A number of aspects surrounding suffering and grief were examined, including anticipatory or preparatory grief, sadness, shock, spirituality, touch and embodied experiences, and continuing bonds with the lost loved one, as described by Klass (1996; 2001). Klass talks about *not letting go* of one’s loved one, and this was an important concept that Kaye eagerly grasped (refer Chapter Three, Figure 7).

This theme is reflected in the writing of Bourdieu (1999, p.4) about *ordinary* suffering. Nietzsche’s *Thus Spake Zarathustra* (1997 edition) was a significant text for us both as we worked our way through Kaye’s grief, still raw ten years after her mother’s death. My selections from C.S. Lewis (1961), Luke (1987), and Frank (1997) contributed to our understanding of suffering, also selections from the work of Haberecht and Prior (1995),

Greenberg and Safran (1987, p.174), Strasser (1999), Spinelli (1989) and Moore (1991) write about the core concept of enduring sadness that shed light on Kaye’s now permanent deeply grounded sadness. McNamee (1992, p.186) illuminated Kaye’s sense of shock, an experience she first learned about when her mother died, and recognised again later when her relationship with her partner came to an end with the terminating letter he sent her. Greenberg and Saffran (1987, p.135) and Polanyi (1967) also discuss this concept.

Haberecht and Prior (1995, p.5) suggest that the focus of Western spirituality is finding different ways of working to expand spiritual knowledge and thus achieve wholeness. This was an important theme in our discussions. Touch, and embodied experiences, are discussed by Abram (1996, p.45) and illuminate Kaye’s experience of her mother’s last days in the coldly clinical intensive care unit.

2.5.3. Theme 3. Re-authoring lives
I searched the literature surrounding the concept of re-authoring disrupted lives. Freedman and Combs (1996, pp.9-12) describe how, through the influence of Milton Erickson, they encountered the belief that people can continually and actively re-author their lives, as Kaye expressed the need to do.

From within a dialogical view, our self becomes a narrative-self and our identities exist in relation to our perspective, a point of view that is related to our purposes. Anderson (1997, p.212) describes a verifiable reality to a narratively formed social understanding or constructed reality of self, asking us to concentrate on understanding how these givens or meanings emerge from our understanding. In this view, with me engaged and open to
listening carefully, Kaye could willingly narrate herself back into a coherent, meaningful life.

2.5.4. Theme 4. Values

I searched for what the literature offered about values as they were revealed by Kaye’s narrative. Some of the values Kaye described included individuality, creativity, courage (and its lack) and concerns about ageing. Freedman and Combs (1996, pp.30-31) suggest that we often inquire about where our beliefs come from and what processes of social construction have brought people into those beliefs.

Conversation is ‘nothing more and nothing less than the everyday, rough and tumble adaptational processes that enable us to live together on this planet’ (Efran and Clarfield 1992, p.203). This felt very much like the cut-and-thrust conversations Kaye and I relished. Bruner, J. (1986, p.41) argues that individuality is born out of the corruption in societies of selves. Kaye was moved by a book she was reading, and this became the focus of some of our discussions of her world views (Mistry 1996).

Creativity was another important concept for Kaye. Bradshaw (1992, p.365) writes that the best environment for creativity is one in which we can respond to reality as it is grounded in the elements of childhood: wonder, curiosity, playfulness, spontaneity, resilience, and experimentation.

Kaye discussed her concerns about ageing, which reflected her mother’s concern. Seedsman (1994) and Luke (1987) write about creative ways to celebrate the acceptance of a peaceful old age.

2.5.5. Theme 5. Paradox and balance

Kaye and I explored the notions of paradox and balance. They became central to our discussions over the weeks of our work together. I then searched the literature surrounding these notions. The two greatest yearnings of human life according to Kegan (1982, p.142) may be the yearning for inclusion, and the yearning for distinctness, that is the self-chosenness of one’s own purposes. These yearnings are in tension. Gibran (1964, p.61) wrote about the balancing of sorrow and joy, laughter and tears, pain and growth. Cecchin (1992, p.88) warns that paradox can be a way to gain control, yet at the same
time it can be a way to bring the battle to a standstill. We could become experts in creating paradoxical situations springing from the intensity of our therapeutic relationship.

2.5.6. **Theme 6. Freedom**

Freedom was a concept Kaye often referred to. Frankl (1984, p.12) suggests ‘the last of human freedoms’ is the ability to ‘choose one’s attitude in a given set of circumstances’.

Being afraid is human, and being able to tolerate our fear is essential (Greenberg and Safran 1987, p.175). It is important for people to recognise that they are afraid, in order to be able to confirm that this is acceptable, and to face and live through what they fear. Kaye was able to name her fears and having named them, to find within them meaning, and places for growth. Heidegger’s definition of freedom as cited by Moustakas, (1996, p.107) is that ‘freedom is the letting be of what is’. Seedsman (1994, p.106) suggests that the fear of freedom is unfortunately real, and like it or not, courage is always required if we wish to be something different from what we have already become. Kaye said that telling her story took a great deal of courage, and caused her a great deal of pain. Estes (1992, p.81) explains that taking on the task of being on one’s own, letting die what must die, allows the new woman to be born.

2.5.7. **Theme 7. Telling the story**

I searched for literature around issues of writing another’s story, such as concerns about equal voices, the collaborative story, methodological issues, and history. We all are made of stories. Cottle (1999, p.14) goes as far as to suggest that they are central to our soul, intellect, imagination, and way of life. It is the story whereby we explain to others how we lead our lives, and what meanings we draw about the lives we have led.

Self is ‘a socially instituted and temporally mediated reflexive process’ (Crossley 1996, p.55). It involves the subject ‘turning back’ upon themselves throughout time, to view themselves from ‘outside’ or rather, as another would view them. The me is often housed in an autobiographical narrative.

Autobiographies identify us both to ourselves and to others, and this was central to Kaye’s task as she worked with me, following the traumatic death of her mother. Claudia Brenner (1995, p.159) says that the more she told her traumatic story, the less power it had over
her, and the more her sense of safety grew. Eventually it began to heal into a memory, and as a memory, it could be integrated into her regular world.

I came to realise the importance of transcription, which was reassuring for me as I embarked on the huge task of processing Kaye’s story. Kiesinger (1998) examined the process of writing the story of a person suffering from bulimia and this paper was important as I learned about the process of working with another’s story. Kiesinger discovered that although transcription is a tedious, time-consuming, often frustrating task, she found it an invaluable step in the process of writing this lived experience.

There is significance and some difficulty regarding the survival of equal voices in the process of listening to, recording and transcribing, and then analysing collaborative narratives (Fine 1998, p.130). Gubrium and Holstein, (2002, pp.21-23) echo this imperative. This theme is also discussed in Chapters 8.6 and 9.3.

To be receptive means to let the other person tell a story in her own way, in its own process and unfolding. Moustakas (1996, p.27) describes how he listens to the range of voices, variations, emotions, body language and silences.

Each individual brings a personal history to the events that are under investigation. Denzin (1989b, pp.28-29) discusses his understanding of history, and its place in the processing of narratives. Firstly the events and processes that are studied unfold over time. Secondly, these events occur within a larger historical social structure. This structure shapes, influences, and constrains the processes under investigation. Thirdly, history operates at the level of individual history and personal biography.

2.5.8. Theme 8. Families
I considered literature regarding the important issue for Kaye of her family and its cultures and structures. Anderson (1997, p.219) describes a family as an interactional process. Tolstoy (1873) begins ‘Anna Karenina’ with the statement that all happy families are alike; each unhappy family is unhappy in its own way. Miller (1997, p.30) suggests that family stories must be told over and over again. ‘That is the way with family stories, they are told and retold to strengthen the tapestry’. Kaye and I spent a great deal of time discussing her many family stories, to ‘strengthen her family tapestry’.
Kaye’s relationship with her father figured centrally in her narrative. Phillips (1991) discusses fathers and their influence on Mother-Daughter Relations. The forgotten factor in mother-daughter relationships is the father. How he relates to the mother influences how his daughter values her mother and herself. While the father plays an important part in his daughter’s self-esteem through his attitudes and behaviours to her directly, research also indicates that fathers may play an influential role in their daughter’s self-esteem through their attitudes to their wives as mothers, as women and as sexual beings.

2.5.9. Theme 9. Language and mirrors
I explored concepts of language, and the image of mirrors, an important issue for Kaye, and one that tangled us in confusion on several occasions. Bruner, J. (1986, p.22) explains that in putting any particular expression together, one selects words and one combines them. How one selects and combines will depend on the uses to which one wishes to put an utterance, the selection of expressions meeting the special requirements of this story. We characteristically assume that what somebody says must make sense, and we will, when in doubt about what sense it makes, search for or invent an interpretation of the utterance to give it sense.

It must never be presumed that our ways of seeing are the same. This was an important lesson for me after Kaye and I tangled over the subject of mirrors. It is in and through language that a person constructs a personal account of the self - who we believe ourselves to be is a linguistic construction (Anderson 1997, pp.108-117). Cecchin (1992, p.90) confesses how in his research, he struggled to give up hypotheses even though they were very attractive and looked like the truth. The hypothesis was a way of constructing a connection with the system and not a step towards the discovery of a ‘real’ story. We use metaphors to construct our conversations. Freedman (Freedman and Combs 1996, p.27) tells how he sees ‘daffodils and azaleas’ as his partner Combs sees ‘beautiful flowers’.

People carefully search for words to express themselves, for the words that are most meaningful for them. This nuancing of their words and language contributes to shifts of the descriptions, understandings, and meanings that the language attempts to clarify (Cecchin 1992, p.64). Moustakas (1996, p.47) also notes this shift in language, which enables the person to move to the language of hope, determination and possibility.
The officially sanctioned or generally accepted meaning of a given text is only one of a great number of possible meanings. This was a lesson for me to absorb as I worked with Kaye’s narrative. As cited by Freedman and Combs (1996, p.46), Derrida explores the slipperiness of meaning and how the meaning of any symbol, word or text is inextricably bound to its context. Derrida and other deconstructionists believe that it is fruitless to search for the one real or true meaning of any text, as all narratives are full of gaps and ambiguities.

2.5.10. Theme 10. Conclusions
I explored the literature around the idea of my being a midwife to Kaye’s stories, as described by Golden (2000, p.30-32), and Corradi Fiumara (1990, p.6). I examined the writings of Kegan (1982) and Skolimowski (1994) in reference to evolving selves, an idea Kaye seemed to be describing. This also fitted into the concept of new knowing Heron and Reason (1997, p.282) describe, which Kaye experienced as a result of this process of finding out who her mother had been, in order to find herself.

The literature search affirmed and validated the many understandings that Kaye and I discovered throughout our work together. Kaye’s mother’s death challenged and redefined her whole sense of health and wellbeing. Her autobiographical/biographical work became a possibility of becoming, a new habitual way of thinking for herself, and in its developing understanding, extends this possibility to others, who must then do their own autobiographical work, as suggested by Frank (2000a, pp.9-10).

2.6. Art conceptualisation with Jan Allen
One colour was chosen to represent each of the structural themes:

Freedom: deep blue
Her mother herself: pink
The creative use of suffering: brown
Home and family: purple
Idealism versus the pragmatic: yellow
Paradox and contradiction: green
Her own chaos: orange
Feeling: red and black
In a free, precognitive way, each theme was represented, starting with ‘her mother herself’ and ending with ‘feeling’. Jan then recorded my relaxed, focussed descriptions of each colour, and what was there beneath each one:

*Her mother herself:*

Centred, dense, tangled, feminine.
Overarching, over the top, not a safe base.
Failed nurturing, disillusioning, shattering of the illusion.
There is no cradle of safety
She needs the holding that was taken away, now she needs to hold herself.
If mother is an angel then she hasn’t got much earthly use.

*The creative use of suffering:*

square structure/form, stable, gives structure to hold her mother
so she doesn’t float away - holds her in a tangible form.
It contains the centre, a grid that holds the family.
(Jan thinks this is like an envelope with a red official seal.)
It hasn’t got feeling, it contains her mother, holds part of her at the centre.

*Home and Family:*

Separate entities, they look as if they lack connection.
Scattered, unstructured position, not supporting one another.

*The ideal:*

Twinkle twinkle star dust, the stuff of fairy tales, not supporting,
good as long as you are not expecting too much. Might dazzle.

*Paradox:*

Follows chaos in the centre and in the ideal.
Feeling:

Hanging off the framework of the container, chaotic in its own way, tangles, unformed, away from the centre, held out by the frame, emotion can’t get into creativity and centre, it does touch the overarching pink.

Chaos:

Gets into many things, is a container, provides safety. Chaos enables her to be free to be flamboyant, wobbly edged, rubbery, unstable, pervading, no firm base, nothing to stand on, all over the place, some boundaries but unpredictable, artistic flare, interesting. Wants excuses, wants chaos to be held, contained, when it isn’t she falls apart. Likes to live in chaos nevertheless not break boundaries.

Freedom:

Container, framework for hanging feelings, could become buried by feelings, square, gives it overall shape. Two fundamental elements: - pink centre, blue square. Freedom, what is it? Kaye? A framework within which all the rest is contained? She says it’s accepting? reality - pain and suffering. Not wanting to know: life isn’t perfect, but I do know life isn’t perfect - [sort of] A fragile knowing, transient knowing, this might be her choice - staying with fragile knowing, ambivalence. This might be the story: a fragile knowing for now, maturity would require all sorts of changes, upgrades, while the knowing is fragile it can remain tentative, ready to run away?
2.7. Journalling my experience of working with Kaye

A meeting of minds and the paradox of reduction

From the outset of my work with Kaye I journaled my responses to the experience: before and at the end of each meeting, and in between as I transcribed, indwelled and pondered our engagement. The journal becomes the vehicle for reflecting on my intrasubjective responses to listening to Kaye’s stories. The title of my journal work with Kaye arose during the process, from the tension of the meeting of minds that Kaye and I enjoyed, and her discomfort with my reduction process. I felt that I could not uncover meaning possibilities any other way, and this caused me anxiety. This tension is explored further in this section. I present a summary of my journalling here in a poetic style. As Richardson (2002) proposes, it is a tool I use frequently that helps me to find greater clarity and understanding. To have included more of the journal as written would raise confidentiality issues.
I often felt confused by Kaye’s chaos, however I eventually sensed this was her way. It was a conversational meeting of equal minds, we enjoyed the sparring, the conversation was free-flowing, pre-reflective, uncontrived, yet I worried it might hinder or slow the deepening of her understanding. I included one quote regardless, I knew immediately it didn’t resonate much for Kaye.

After completing the transcriptions, when we began to work on the process, I began to feel her creative engagement in the story, which I was trying to reduce, causing her discomfort, and me anxiety.

There was paradox in the reduction: I was trying to reduce, distil, abbreviate, précis. Kaye said that she felt that at times my distillations didn’t sound like her voice, even if they were her words. She felt as if her words were ‘going through stages of abstraction’.

Yet she also said that the same sentences selected and produced by me as intersubjective responses, were powerful and meaningful for her.

It seemed to me as if she was creating a beautiful symphony of meaning, and I was trying to reduce it to single notes and snippets of music, disconnected from the whole creation. I worried, heard and understood her point, and continued in anxiety to search and amplify the phrases, with Jan Allen’s support. How else could we deepen the meaning?

I felt concerned that equal voices be heard, a sense that we had really collaborated. Later, I felt encouraged reaching the ‘Five Verbs Reduction’ - Kaye loved it, ‘it felt right’. Kaye said it valued and validated her life, which I felt validated my process.

The emotional and relational investment I had to make to listen, hear and write Kaye’s story was considerable. I wondered (perhaps ungenerously) how accurate Kaye’s description of her parents’ perfected love was. Kaye’s story of her perfect relationship with her mother caused me some envy.

There were risks for Kaye in telling her story, it required her to confront her past traumas and actions. She in turn needed me to willingly confront my past and my story, my relationship with my mother, which was sometimes painful.
It would have felt more uncomfortable had I not already
done so much work on understanding my complex relationship with my mother.
I felt disturbed by her description of the patriarchal emotional abuse
in her mother’s family. I worried how her story would impact on her family now.
It made me conscious of others who are affected by the processes of narrative work,
I thought about the ethics of a person telling their story for reading by affected others.
I decided my own parents’ story was too private, painful,
too related to my siblings to risk publication. Maybe later?

I felt the impact of Kaye’s descriptions of her wild behaviour.
She was proud of her mother’s mild reactions, I journalled:

    I feel confused by her mother’s response.
        You get busted for drugs.
        Your mother says ‘Oh poor you
        I thought that might happen.’
    You get done for drink driving, 0.1050%
        and your mother says ‘Oh my darling
        I hope you’re alright?’
    Even Kaye asks ‘who is this woman?’

I journalled my discomfort at Kaye’s destructive self-punishment.
How would I have responded to the incidents she described,
had she been one of my children? Not so sweetly gentle I think.

Kaye’s distress early on about her failing relationship with her partner
filled me with concern - was she even vaguely thinking self-harm?
I worried about her until session three reassured me she was safe enough.

I found myself swinging with her ups and downs -
her ‘flipping’: Alive - dead; happy - unhappy.
Kaye’s description of herself as fiery and feisty
captured the nature of our conversations.
I felt I said too much that I wanted her to know.
Kaye’s flow of words was like a river in flood,
I needed levy banks to contain the flow.
Yet I delighted in her growing clarity and understanding.
We often shared similar values - but rather different behaviour.

Transcribing felt daunting, totally time consuming.
It was confronting to realise session three had taken over twelve hours to transcribe,
it left me in awe of the demands of this method,
yet how could I sit in the words otherwise?
I asked Kaye for more time to transcribe the next tape.
Kiesinger (1998) helped me see that Kaye and I had become conversational partners.
Kiesinger assured me that whilst transcription is tedious and time-consuming,
it is an invaluable step in processing a storyteller’s lived experience -
there is no other way. That gave me the encouragement and resilience to push on.
I was really pleased when Kaye rang to say she could see a way forward.
She told me she was beginning to understand the paradoxes that make an ordinary life,
and how there are parallel lines of joy and sadness running throughout her life,
[I think: and mine too.]
I said a lot at the start of tape five,
explaining the ‘Continuing Bonds’ paradigm  (Klass 1996).
Jan Allen questioned the use of Continuing Bonds and the Interactive Web model.
She suggested I needed to understand its hermeneutics/constructivist base.
Which meant I had to do more work on what this constructivist approach means.
I eventually named constructivism and social constructionism
as part of the framework in my narrative work.
I felt delighted in Kaye’s pleasure when she ‘got’ what Klass was suggesting,
she had changed, she explained it was due to the changes this process had brought her.
I began to feel an undercurrent of meaning,
and delight with Kaye’s sense of progression in her story, its meanings and possibilities.
The themes emerged with a sense of birthing struggle as we struggled to
anchor the collaboration of the two voices that would satisfy us both.
Even normal birth is a strong, powerful struggle for new life to emerge.
We acknowledged the risk of me making assumptions about her meaning,
I did this at least once - she pulled me up.
Converting one theme into a one page narrative resulted in an reassuring revelation for me. I heard Kaye’s voice resonating clearly. I finally e-mailed her the 90 word essence statement; she replied it was fantastic, she would carry it in her wallet, it would remind her who she was. Thank goodness there was still rich, deeply felt meaning there for her. This felt to me like a relief, a blessing, a benediction, we had managed to create something beautiful and meaningful for us both. Kaye’s e-mail some time later said:

My life had importance to me and to someone else for that time, on that page, in that room.

I could rejoice in the creative temporary approximation to knowing and meaning that was formed by us, and for us both.

As I began the re-processing into the thesis chapter, I re-read Kaye’s and my e-mails to one another to re-experience the feelings of our work. She wrote ‘I feel that I watched her through my life I watched her in her life grow’ She’s talking about her mother, through the window of her own life she could see her mother grow. I think ‘Yes, that is what I have done with Kaye, I have seen her re-enter her life, with her mother better integrated into who Kaye is, fully alive, mostly less chaotic. I am really moved to have been a part of her story, as she is now part of mine.

Kaye later sent me her intersubjective response (refer Chapter Three, 2.2) and I wrote in my journal:

If this is an approximation to Kaye’s meaning for the time being, then I am satisfied, it was a worthy struggle for us both to give birth to a beautiful, rich meaning-for-now.
A short time later I wrote in my journal a temporary ending point:

In ‘What dying people want’ Kuhl (2002, p.242) suggests:

It is meaning that delivers people from despair to integrity. To find meaning we must be willing to embark on a journey - an encounter with the past, with the core of one’s being.

Kaye was not terminally ill, although her spirit was sorely traumatised. Kuhl proposes that for people who do not have the diagnosis of a terminal illness, but who, nevertheless, have experienced a significant disruption to their sense of well being through a dramatic life event, there is the incentive to embark on this journey. This journey of encounter is in order to make sense of the experience and to find integrity. Clearly this was Kaye’s quest, and I agreed to accompany her and to listen deeply and carefully. Kaye expressed a yearning to re-discover where she belonged, and to re-connect the relationships that were so painfully disrupted when her mother died. She agrees that she achieved her goal, even if the crystals of meaning are still changing and life goes on.
3. WHAT CAN BE GENERALISED FROM LISTENING TO KAYE’S STORY?

For others who will experience a healthcare system where there is greater and greater emphasis and pressure on efficiencies, and a shortage of experienced staff, it is perhaps presumptuous to outline possibilities that might be achievable and might make a difference in this dramatic experience of healthcare services.

However it is possible that better and more timely listening might assist family members who face the death of a loved one in an Intensive Care Unit to find a better coherence, a less damaged sense of their own self-identity and less sense of loss of control in this difficult setting. Healthcare professionals could understand that each family member comes to such a difficult experience with their own perceptions and individual ways of coping, and that the leader of a family group may not be able to address the best options for the individual members of the family. This understanding opens up possibilities of listening and support that might permit some beneficial outcomes. The healthcare professionals may well be stretched to the limit, but at least in understanding this one point, they might listen and observe, offer a suggestion (such as one member of the family needing to remain present while life support is discontinued), or summon pastoral care support that could make a difference for a particular family member, and soften the sense of alienation they might be feeling.

Individual follow up shortly after the experience, perhaps by trained pastoral care personnel, might be able to address the questions and confusions of the experience. This contact could offer support, counselling and information if it seemed helpful, and assess the wellbeing of the individual person concerned. This again requires the recognition by the healthcare professional staff of the independent entities of the family members involved in the death of a patient in Intensive Care, and their individual styles of grieving.
Chapter Four:
Listening to Sarah’s narrative

Information provided by the palliative care staff prior to meeting Sarah and recording her narrative:

48 year old female.
Diagnosis: terminal small cell lung cancer
Nationality: Jewish Israeli with Permanent Australian Residency Visa
Palliative care staff describe Sarah as ‘feisty and argumentative’
She has considerably reduced air entry, marked shortness of breath
Recent choking episode with airway obstructed by tumour
requiring emergency treatment for collapsed lung
Endo-bronchial stent inserted
The staff hope that Sarah sharing her stories
might encourage her to be less difficult
1. INTRODUCING SARAH

The nursing staff of a Melbourne Palliative Care Unit asked me to work with a patient suffering from terminal small cell lung cancer. The staff described her as an Israeli Jewish woman who was feisty and argumentative, implying that they hoped this might change. They thought that the work that I was doing with therapeutic autobiography might enable her to be more compliant and less difficult.

In her late forties, Sarah was already very ill, with a serious shortness of breath, a desperate choking cough and husky soft voice that made the life review narrative process difficult. As we talked at our first meeting, she said that her life clearly separated into three stages: her illness story, her early life in Israel and her life in Australia up to the point of her illness. We decided to separate her life-review into three ninety-minute stories, beginning with her illness story, which was causing her great distress. At this first meeting Sarah expressed anger at the way she felt unheard and unacknowledged by her healthcare professionals, except as ‘a difficult patient’. I was amazed by how she was able to yell, despite her voice’s limitations, to let me know how angry she felt. She was depleted but still had an emotional energy and intensity that expressed her anger and frustration. The second story of her early life in Israel, helped me to enter with fascination into some of the painful cultural struggles of her family’s life. In the third tape she described the story of how she managed to acquire permanent residency status in Australia. She was a superb, articulate, zany storyteller and, drawn into her stories, I felt very close to her. We experienced Moustakas’s (1996) ‘long journey of listening, feeling, sensing, trusting, doubting, joining, wandering alone, confronting, loving, supporting, opposing, laughing, weeping.’

I wanted to include Sarah’s rich story in my study because it was so significant in the progression of my understanding of listening and narrative work.

2. THE PROCESS OF CO-CREATING SARAH’S NARRATIVE

Telling me that she desperately wanted her story heard, especially by her healthcare professionals, Sarah said she would be happy for me to use it in any way I wished; her consent was enthusiastic. Her brother also wanted her story published, and was not happy
when I said that if it appeared in print it would have her name changed and the hospital’s identity would not be disclosed. I began to grapple with understanding the complexity of the confidentiality issues of this storytelling process.

![Figure 10. Processing Sarah’s narrative](image)

2.1. Ethics approval

As part of the practicum for the third year of my Master of Palliative Care Degree at Flinders University of South Australia, ethics approval was given for the therapeutic autobiography work I did in the palliative care unit where Sarah was a patient. This approval was then accepted by MIECAT as part of my Master’s thesis in Experiential and Creative Arts Therapy. Approval was then continued by The University of Melbourne Health Sciences Human Ethics Subcommittee, enabling the completion of the processing of Sarah’s narrative. At this point I e-mailed Sarah’s brother in Israel and he e-mailed his ongoing approval and consent for Sarah’s story to be included in my PhD thesis (refer Appendix Seven, 4).

2.2. Taping, transcribing, and returning the transcriptions to Sarah

The three tapes were recorded with Sarah in October and November 1999, and transcribed as quickly as possible, with a sense of urgency because I felt that Sarah’s time was
running out. I discovered how time consuming transcribing is, and how difficult this particular task was given Sarah’s endo-bronchial stent, her cough and breathlessness, and her Israeli accent. I struggled for accuracy in the transcription. I would type in [***] where I was not certain about what she had said. I would listen again and again, it would often become clearer later.

Soon after Christmas 1999, while Sarah was occupied by a visit from Israel by her mother and brother, I visited her to discuss any changes she wanted made to the transcripts of the three tapes. There were few changes to be made. When I pointed out that the transcript was 40,000 words she laughed and said that had she been well it would have been 100,000. It occurred to me later that because of the pressure Sarah sensed of her time running out, she perhaps became an expert at telling a concise life story, pruning many of the colourful stories that might have added to its richness. Was Sarah implying that the extra 60,000 words she could have used had she been well, might have added a dimension that, in the end, I sensed was absent? I finally addressed this issue towards the end of the process.

In my haste to complete the transcriptions, and my early understanding of the process of intersubjective responding, I simply wrote Sarah a letter of thanks after the first tape, and at the end of the transcription of tapes two and three I gave her a poem I did not write myself, but one that I felt expressed what I wanted to say. She said she enjoyed my response. Now in retrospect I wish I had written something myself (refer Appendix Seven, 2 and 3).

Sadly Sarah died before we could reflect together on themes or deeper meanings in her story. She did tell me she was pleasantly surprised by the realisation that emerged while reading her own story, that having previously thought that her life had been boring and uneventful, now she could see she had lived an interesting life and achieved a great deal.

Sarah lived only several weeks beyond the process of transcribing her three tapes. I did not see her again. Her brother rang me to say she had died in theatre whilst having another bronchoscopy. The taping, transcribing and returning of the transcript document to the storyteller was therefore complete at this stage.
I wanted to honour the meanings embedded in Sarah’s story, and to finish with respect the work she and I had started together. Her death made the analysis of her story difficult. The intersubjective and intrasubjective responses are mine alone, apart from one telephone conversation and two e-mail communications with Sarah’s brother who lives in Israel.

After travelling from Israel for her funeral, Sarah’s brother was deeply moved by the unpolished transcripts of his sister’s story that she had propped against the mantelpiece waiting for him to read. He rang me and we had a long discussion about the transcripts. He said that we had captured the ‘essence’ of his sister and that he would be able to take that back to Israel. This reminded me of Denzin’s (1989a, p.9) questioning of the assumption that a biographical method can capture a life and represent it in a text. Sarah’s brother said wryly that he wanted to argue with Sarah about the parts of the story that he had experienced differently, and it was painful for him that it was now too late for that.

Journalling my experiences with Sarah followed the same process as with Kaye (refer Chapter Three), and included the modified application of van Manen’s (1996, p.76) literature search and my subsequent reflections and insights into Sarah’s narrative.

2.3. Steps in processing and understanding

2.3.1. Re-engaging with Sarah’s story

Early in 2004, four years after Sarah’s death, I returned to Sarah’s interview transcript to begin the work of immersing myself in Sarah’s life story. I worked without Sarah’s presence, supported by the reflections of my supervisors and my collaborative inquiry partner Jane Gorey, who accompanied me when I requested help with the intense journey into Sarah’s narrative.

I reconnected with Sarah’s story by re-reading the text, listing themes as I went along, as they drew my attention. Some seemed to be meta themes, with minor themes that sat within the meta themes. The themes were artificial structures I constructed in order to manage and clarify what was there. I worried that there were too many themes but saw this simply as a system of sorting through what was there, enabling reduction as I progressed. I wondered how much emphasis centred in Sarah’s Jewish culture, how much in the embodied chaos of her deepening illness. Even if the themes were wrongly
weighted, I felt this would balance out as I proceeded. Above all, I entered back into Sarah’s story with a sense of respect, and a feeling of moral responsibility for the task. It seemed a tall order to be sure that her voice remained, not knowingly superimposed by my own intrasubjective responses, when she was not available for reflection and review.

2.3.2. Themes
I sensed two overarching themes like paradigms or filters, of humour and storytelling

Meta and minor themes

1. The embodied chaos of suffering a rapidly deepening illness
   • Waiting
   • Dying and death
2. Healthcare professionals: THE EXPERTS
3. Loss of control
4. Being Jewish: the world I was brought up in.
   • The struggle
   • Jerusalem
   • Jews and Christians side by side
   • The Holocaust
   • The Army
5. Family
   • My mother
   • My father
   • My parents as refugees
   • My brother
   • Birth story
   • Discipline
   • Home
   • Education
6. Myself

- Memories
- Sin and punishment
- The problems of rapid maturity
- Humour
- I’m not religious
- Cigarettes

7. Australian Adventure:

- Work in Australia
- The Legalities of Immigration to Australia

I allocated the text to the various themes. Rather than miss anything of significance, I used all the text, not omitting any. Some text overlapped more than one theme and in this case it was allocated to both.

2.3.3. Inter or intra subjective?

As I allocated the text to the theme headings, a first response rose within me, and I wondered whether this was inter or intra subjective. This question arose throughout the processing of Sarah’s story. In the end I decided there was no way to really separate the strands, bracketing only being partly possible, no matter how hard I tried. The responses remained mixtures of intra and intersubjectivity, resonant with most views of bracketing, such as Valle, King and Halling (1989, p.11); Aanstoos (1983, p.253); Crotty (1996, p.44-45, 1998, p.83); Spinelli (1989, pp.3; 12; 17; 153); Ceglowski (2000, p.95); Denzin (1989b, p.23,31); and Moustakas (1996, p.191). I separated as clearly as I could, the strands of intra and inter responding within the realm of collaborative inquiry, with me always trying to ‘hold’ Sarah’s voice and how she might reflect on the work I was doing. One way I did that was to imagine her in her home, reading what I had written, and her feisty rejection of material that she felt wasn’t quite right.

The first intra-inter subjective response was ‘Loss of Control: my life is gone’ a picture of a spiralling vortex, with Sarah’s death at the bottom, her life rushing out of control, with many forces pulling it down. ‘Down the gurgler’ was a phrase I used to title this vortex later. I saw that perhaps it was not simply the healthcare professionals’ power that Sarah
felt had taken control of her life, there were a number of other forces. This was an important glimmer of understanding for me.

At this point I re-listened to the three tapes, allowing Sarah’s voice to wash over and merge into me, re-experiencing being with her in deep engagement while she told me her story. I re-experienced listening to her pain, our laughter, tears, my awe at her compelling skill in telling her story ‘warts and all’.

I then began to write each theme as a narrative, producing two to three pages for each theme. Responses arose as I went along, and I created them as artistic representations as

Figure 11. Inter/intrasubjective response: Loss of control, ‘my life is gone’. Later title: ‘Down the gurgler’
each one surfaced or came to my attention in my consciousness. Sarah’s strong statement that she hated ‘being at the mercy of other people’ impacted on me when I realised how many healthcare professionals and allied helpers one would normally meet in the progression of a serious illness. They felt here like a confronting army that had a strong impact on Sarah, and on me when I created them as a list from her story. They seemed daunting, even though each was there as part of a team, each member sincerely meaning to help her.

From this list a more intrasubjective response flowed - a poem in which I sensed, amplified and interpreted Sarah’s feisty response as her refusal to go quietly, reminding
me of Dylan Thomas’s poem ‘Do not go gentle into that good night’ (cited in Styles and Moccia 1993, p.227) which I called

‘I hate being at the mercy of other people’

She doesn’t run to doctors,
but passed quickly from doctor to doctor, she lost control.
No consistency, no being known.
Her life became a waiting game
with in-your-face, wall-to-wall healthcare professionals.
A thing, a subject. That’s how she felt. No personal touch,
no appreciation of her as a person, no valuing of who she was.
She seems to be saying I’m not going quietly into any good night
as a cancer patient who is compliant, (Shhh!)
who agrees to become the person the healthcare professionals tell her she ought to be.

The next insight emerged as I sensed echoes from Sarah’s early life, that reverberated in her later life, for example the poignant story of her first day at school, her feeling pushed and pulled until she was located in the correct classroom, only to be bullied by the teacher to the point where she needed to be sent home because she was so upset. This seemed to me to echo down the years in the story of her hatred of hospitals, and her description of when she refused further intravenous fluids to flush out the chemotherapy drugs she had been given. I could picture ‘the big kafuffle’ Sarah described with some glee, when she refused the full quota of intravenous fluids that were ordered by the doctor to flush out the chemotherapy drugs, because she felt strongly that she had had enough.

This led me to see Sarah’s description of herself as organiser, perfectionist, a person who prided herself on the achievements she was ‘best’ at, and how her skills bumped into the chaos of the various aspects of her illness, such as the cough, the loss of voice, the reaction to the first chemotherapy, the loss of weight and escalating weakness. I was entering deeper and deeper into understanding the impact of Sarah’s illness on her life, and why she reacted in the way she did.
My next response illuminated for me the tension between the ideal notion of illness as a partnership between healthcare professionals and patient, and the reality of how Sarah felt. I had previously read Arthur Frank’s papers such as ‘Illness as moral occasion: restoring agency to ill people’ (1997); ‘From suspicion to dialogue: relations of storytelling in clinical encounters’ (2000c); ‘Between the Ride and the story: illness and remoralization.’ (2001b); ‘How can they act like that? clinicians and patients as characters in each other’s stories’ (2002c).

I struggled with great difficulty to set aside or bracket my resonance with what I had previously read, as it impacted on Sarah’s illness and resonated in her story. It felt to me, and I think Sarah was saying, that what she was feeling was anything but a partnership. It seemed to be a more equal partnership that she was pleading for. This seemed to be a core impact of her experience. I acknowledged that in part I resonated with Sarah’s story because it so strongly connected with the literature that I had already read. And with my experiences of my own illness, my parents dying and deaths, and my previous palliative
care nursing experiences. Here again was the problem of bracketing (refer Chapter Two, 3.3). However, I could see it all there, and acknowledged the presence of these prior perceptions in my awareness.

Figure 14. Inter/intrasubjective response: *A partnership?*

Then followed the reduction of the narratives to one page for each theme, sometimes ‘cheating’ by reducing the print size and margins to accommodate it into one page. Managing to fit the theme narratives on one page seemed to be important as it allowed each theme to be seen as a whole. I reduced each of these narratives to a one page poetic statement, enabling a further contraction in word volume.

I asked myself how much of the story was coloured by Sarah’s ‘Jewishness’ and early life in Jerusalem as part of a poor squatting family. How did this weight her story, was it the single most important lens through which to view her experience? Supposing she had been Muslim or Japanese, how would the story change? I relished Monk’s (1997, p.27) description of the *cultural pot of soup* that we are all born into, and I began to sense its
importance for Sarah. How would another Jewish person, especially another ‘second generation Holocaust survivor’ read her story? Would they say ‘well of course’. I drew a pot to represent Sarah’s Israeli-Jewish ‘pot of soup’, and added the parts of her story that seemed to belong there. What I began to understand was how we each view our world and our experiences, including deep illness experiences, through the lens of the culture we are born into which colours our early life, and is transmitted from one generation to the next (Myerhoff 1979). Perhaps it is one of the issues that will be present across all the stories, at the end of my study.

Figure 15. Inter/intrasubjective response: Sarah’s cultural pot of soup
Next followed reclassification of the themes into van Manen’s (1990, pp.101-106) time, [temporality] space, [spatiality] self [corporeality] and other [relationality]. From ‘self’ a response was formed called ‘Me’, which allowed me to sense Sarah’s understanding of who she was, and how her nature and personality coloured her world of experience:

‘I'm by nature a perfectionist, and nothing is perfect,
I haven't learned all those years!
I accepted that was what I'd got, my time is come, I've been smoking,
I'm being punished!
I was pissed off with my voice, the world, not concentrating that I've got cancer,
I have to battle that! That was the least of my problems!
It's my nature, its not always good, I attend to minor details,
I'm trying to teach myself to change it.’

All these responses were taking me into deeper layers of Sarah’s experiences, helping me to sense her meanings. In effect I was seeking a meeting with the essence of who she saw herself being, in her world. I was walking around indwelling Sarah’s stories, preoccupied, almost expecting myself to develop a cough. It felt almost as if I was suffering from terminal lung cancer myself. The reflections often woke me at night, and I needed to write them down before I could return to sleep. I created a poetic statement of Sarah’s experience of ‘playing a waiting game’ as she described it. This powerfully illuminated for me how full of frustration and waiting the experience of serious illness is.
A Waiting Game

I said I’m not going to wait till 2 days, I’ll take a partner;
I’ve got an appointment tomorrow then I will probably know what we’re doing,
so tomorrow I find out!
He was trying to get him [the oncologist] we were waiting for a phone call back.
They put me inside, because it was cold, for about 25 minutes,
and I’m just lying there, I was 3 hours down there and nobody knew about me,
they were waiting for me upstairs.
Now I’ve got good news with the voice so I’m kind of biding my time.
Basically I’m playing the waiting game, and um, hopefully I have news.

You’re supposed to take it after dinner, things you’re supposed to take in time,
you come to them and an hour later she comes for you.
I have to sit there and wait when they have time, I mean that really pissed me.
I don’t have to sit and buzz and buzz and wait for them.
Next morning I was waiting to get my new chemo.

I should just sit there and wait for it, I’m not joking, it was just going,
I’m sitting there and it goes, are you finished,
you sit another 5 or 10 minutes and you pish again, and then you pish.
I ask them to show me ... Hey! I’ll probably wait another 2 years before.
I don’t remember which dates so I’m waiting for the bill.
So now I’m waiting because I’ve got my CAT scans on Wednesday,
but I’m only seeing him on the 9th of November.

A powerful cry rose in me as the impact of Sarah’s suffering resonated in me. Her loss of dignity, loss of comfort, loss of control. I extracted one particular illness story, and from it came my own deep cry of understanding how her pain might have felt for her:
'Where was the care?'

She suffered from:
Loss of dignity and privacy.
Loss of the understanding of the healthcare professionals.
Loss of comfort and the feeling of being cared for.
Loss of compassion and empathy. (Couldn’t they bear to see themselves in her place?)
Loss of companionship - she couldn’t receive her phone calls.
Loss of control of her ordinary everyday personal space.
Loss of the right to preserve her energy.
There was no ‘holding,’ no listening, no intersubjective connection. **WHO CARED?**

She had lost everything except her own feisty, resilient spirit,
which produced an explosion of

**ANGER!  and  REFUSAL!**

I was feeling swamped in the material. There was still a great bulk. I moved the themes into a structural form: third person, past tense, then a one page structural poem for each theme, wading through it all in the hope that it would soon clarify and reduce.

I created the first structural reduction using Sarah’s words called:

The embodied chaos of suffering a rapidly deepening illness:

  you’re already on the annoying ride, you don’t stop, its express train…

Later I modified, this poetic statement and it appears complete later in the process. There were loudly ringing connections for me in Sarah’s words about the annoying ride, and Arthur Frank’s paper ‘Between the ride and the story: illness and remoralization’ (2001b) which is further discussed in the literature search in 2.4. Sarah yelled her anguish that she was on an annoying ride that would not stop, and she could not choose to get off.

**2.4.  Art conceptualisation with Jane Gorey**

My collaborative inquiry partner Jane Gorey and I created an art conceptualisation of Sarah’s experience, using the same method used for Kaye’s story. In a free, precognitive way, each theme was represented by a different coloured felt pen. I drew each theme as I
sensed it. Jane then recorded my relaxed, focussed descriptions of each colour, and what I sensed intuitively was there within each one.

The embodied chaos of deep illness: brown
A slippery slide downhill.
Fast, out of control, a progressive loss of herself, and her values.
Her life was gone, shattered, the chaos was so intense she could not work through it.
However at the end point she insisted on retaining her integrity.

Healthcare professionals: THE EXPERTS: deep red
Looking the other way, not at her, not seeing her or listening to her.
They called the tune, they wanted her to play by their rules, do what they said, she didn’t need to know, it didn’t need to make sense or be logical.

Loss of Control: black
COUGH! CHOKE! BE OBSERVED! BE IN HOSPITAL! WAIT!
Like it or not the tumour had obstructed her airway.
She lost control via the disease, via the healthcare professionals, via her family.

Being Jewish: the world I was brought up in: purple
A pot of Jewish cultural soup.
Discipline; Fun; Education; Grief; Suffering; Dislocation;
Being Jewish coloured her view of everything she did, and everything she was.

Family: Blue
Play by their rules. ‘They didn’t care!’
Their idea of care was taking control, they took over,
which compounded her sense of loss of self.
Myself: deep pink

THE ORGANISER: A perfectionist. She saw the small picture before the big picture. She was driven by a sense of duty, and a need to make sense of her world. She couldn’t cope with the illogical.

Australian adventure: green

Adventure. She was sought after for her logic and ‘workaholism’. She let go of her connection to Israel but not to being Jewish.

It is a scrambled, busy, pre-school-like artwork. I needed to remind myself that the art conceptualisations are visual reflections, not art, offering different textural aspects and colour to what was said. I covered the work with clear grey film to represent the filter of Sarah’s humour and storytelling skill through which her whole story needed to be heard. I felt as if I was starting to ‘get it’ - to reach a point of some sort of approximation to Sarah’s meaning, of what her life and illness meant, of how she experienced and viewed her world. I also understood that it could only ever be approximate. I constantly asked myself if Sarah’s voice remained uppermost in the work so far.

Figure 16. Art conceptualisation: Through a filter
After this art conceptualisation I returned to and modified a poetic synthesis I had written previously. It was modified further a little later:

‘The Express-train Annoying Ride’
With minute attention to detail, her recall was crystal clear.
Like her father she was a nervous, workaholic perfectionist called ‘the organiser’.
The Holocaust destroyed 90% of her family.
Visiting a concentration camp was pivotal,
and perhaps became the crossing point for her anger.
Very poor, squatting in Jerusalem,
she had a disciplined but happy tomboy childhood,
physically strong, she kicked the shins of bullies!
She did her duty in the army, trained as a pathologist,
then visited family in Australia,
an amnesty surprising her with permanent residence.
She suffered from fibrocystic breast disease, was disillusioned and raped.
Reverberations echo down the years in the expression of her sexuality,
and still at the end of her life.
On her, she felt, God seemed not to smile.
Her disease scared her, it didn’t look nice, it took control.
She intensely questioned the processes of her care.
She was a person who wanted the facts clearly sorted out and correct;
She expected comprehensive information, accepted logical rules.
However sometimes their rules seemed illogical.
She hated being at the mercy of others,
yet waiting was the game she was forced to play.
Treating her as an adult would have made a difference.

She felt the healthcare professionals’ gaze only saw her cancer, fury, and refusal.
Given her family history and smoking,
hers death from lung cancer could be accepted.
Given her cultural history and experiences,
she would not accept further blows to her sense of integrity as a person.
She wanted her voice back so she could yell her fury -
her lungs full of tumour, she choked instead.
More than anything, she wanted to know what was going on,
and she desperately wanted to sleep.

The chaos of her disease’s rapid progress, the healthcare professionals’ attitude,
and her family, all took over her life;
yet she knew sometimes she did need their help.
She felt she wasn’t trusted in hospital, they made her feel like a subject.
They instructed, and she refused. She was pissed off with everybody!
She didn’t like it.
They didn’t know her,
they weren’t listening,
they didn’t understand.
It would never be the same. Her life was gone.

This was followed by a more contained essence statement:

‘They made me feel like a subject.’

She believed God was the entity that controlled things beyond her control.
There were many things that were controlled for her, not by her.
She was the subject of their attention;
their gaze only saw her cancer, her fury, her refusal.
Not HER! They did not know her.
They were the professionals,
she refused to be a quiet, compliant subject-patient.
She yelled her fury at her disease;
    at her family;
    at the healthcare professionals;
    her life was gone.

At this point I turned to examine the connections to the literature, where the resonances
felt powerful, validating and reassuring for me. Perhaps I hoped for some sort of closure,
however this did not happen for some time. The literature offered a helpful pathway,
rather like finding a map when one is feeling a little lost.
2.5. The application of the literature search to Sarah’s narrative

There are many connections to illness narrative literature in Sarah’s story, particularly in the writings of Arthur Frank (especially 2000a; 2000b; 2001a; 2001b; 2004b). Many of the themes interconnect and are difficult to untangle, so there is some overlap. Much of Arthur Frank’s writing was not new to me, however I re-read it trying to see it as it related to Sarah. There was a strong impact on me when I read ‘Between the ride and the story’ (Frank 2001b) which resonated in Sarah’s description of ‘the annoying ride’ she seemed to be on, which she did not choose and could not stop. This resonance became the starting point of my literature search. I needed to fit Sarah’s story and her role as a patient receiving palliative care into a place where I could shed some light on Sarah’s overwhelming feeling of loss of control of her life. How was it bound together with her prior life experiences and culture, and why didn’t it make sense to Sarah, or later to her brother? The themes I chose to shape my exploration of the literature were:

1. Between the ride and the story
   - Overcoming censorship: telling the story so the pain will not be wasted
   - They made her feel like a subject: medical discourse as power
   - I-It
   - The rise of experts
   - The moral problem of being a patient
   - Those who have the power

2. What is going on here?
   - How can they act like that?
   - Explaining can heal
   - Pseudo participation versus creative participation
   - Standpoint
   - Sarah’s interpretation of her palliative care

3. Cultural soup
   - Untellable stories
4. Meaning
   • Collaborative narrative relationships
   • Storytelling as ethical action in disrupted lives
   • Like a testimonio
   • Life’s normal tragedy: disease as entity

5. Listening to Sarah’s story
   • I-Thou and ‘hot’ texts
   • A shared community of value

6. Conclusions and closure?

The full text of the literature search is found in Appendix Seven, 1. I reviewed my textbook on Oncology (Casciato and Lowitz 1995, p.133-144), to be sure that I understood the issues of Sarah’s small cell lung cancer. This did not seem to need much space in my reflections because they were clinical issues that I already understood. Some of the writers other than Arthur Frank who contributed to my understanding were Audre Lorde (1980, p.14) and her sense of needing her story of cancer to be heard, and ethicist Richard Zaner (2004) and Pierre Bourdieu (1999), each writing about suffering. I considered the intersubjectivity of Sarah’s story from the point of view of Buber (1923) and Crossley (1996), and the pressure she felt from the experts she had problems with. I saw this in the light of Walton’s (2005, p.12) comments regarding the need for reform in healthcare service delivery. Denzin (1989b, p.30) discusses issues of medical and personal knowledge and the exertion of power, especially within healthcare settings.

Medical narrative theorist Charon (Charon and Montello 2002, p.79) asks ‘what is going on here?’ In the context of Sarah’s story, this means with the key stakeholders in her story: that is Sarah, the healthcare professionals, and her family, with here being the setting of her story. As if in response to Sarah’s plea that she simply wanted enough information to make sense for herself of what was happening, van Manen (2002, p.14) suggests that explaining can heal. Sarah knew clearly enough that the healing involved was of her distress, rather than of her cancer.

Skolimowski (1994, p.156) contributed to my literature search with his discussion of the type of pseudo participation that Sarah seemed to experience, as opposed to genuine co-
creative participation in her illness management. It was this loss of control and pseudo participation that Sarah objected to so strongly.

As previously mentioned, I felt a need to explore how Sarah’s cultural background of being a Jewish Israeli second generation Holocaust survivor impacted on her narrative. I came to see how our cultural soup, as described by Monk et al. (1997, p.27) has such a significant place in our perceptions and ways of seeing and interpreting the world. I read LeGuin (1981); Levi (1979); and Barclay (1996, p.94-97) in relation to the horror of the stories in Sarah’s family that were untellable.

Meaning making in relation to Sarah’s story became a theme explored through the writings of Wikan (2000); Anderson (1997); and Becker (1997). I reflected on Buber (1923) and Gilgun’s hot texts (1999) and the impact that listening to Sarah’s difficult story had on me. Winslade, Crocket, and Monk’s (1997, p.39) discussion explained for me how Sarah and I became a community of shared values through the life review narrative she enthusiastically shared with me. I therefore felt that I needed some sort of conclusion or closure to Sarah’s story, since I felt a personal loss that she died before we had finished processing her story. Charon and Montello (2002), and Frank (2000a, 2000b) were helpful readings for me to make sense and meaning from my experience of meeting and working with Sarah in this way. Without the voices of the literature, I would not have gained nearly so much value from this intense narrative.

2.6. Journalling my experience of working with Sarah

I journalled my experiences after each visit to Sarah, and throughout the processing of her story, and continued for quite some time after her death. I sensed that there were a number of themes in what I had written.

The themes in my journalling seemed to be:
Her story was unfinished yet asked to be told.
Me engaged; her in-charge; me saying little.
Me as a healthcare professional or a listener?
The stirring of my own illness experiences.
Strong women who articulate their suffering.
Sarah taught me much about narrative.
The silly nonsensical game.
Engaging with Sarah’s cultural soup helped me to more clearly see my own.
Sarah’s mother - my mother.
I-Thou and non-smoking.
Healing.
Sarah’s continuing story.

I re-wrote my journalling of working with Sarah, encapsulating all these themes in a poetic summary, as described by Richardson (2002), in order to produce greater clarity:

*Sarah’s story was unfinished yet asked to be told.*

In learning about Sarah, I was learning about myself.
Sarah also taught me much about narrative.
She died with me sadly feeling we hadn’t finished.
We both wanted her story told, to bring meaning to her suffering,
to address her silenced voice.
She touched a wish in me to speak for all silenced voices.
In the end the healthcare professionals closed ranks and didn’t want to know.
*I* felt this hurt, as Sarah’s collaborative partner.

I had to meet her full on, be fully present,
honestly and openly accepting who we each were.
Time and again she tested that I was *there*. I said little,
she controlled her story, although she could no longer control her life.
I love the idea of being a midwife to life stories, even sad or angry ones.
I allowed her anger to speak, even when it impinged on me.
I felt she had every reason to feel angry.
I saw myself as listener, rather than as defender of healthcare professionals.
Perhaps it was this that later separated me from the palliative care unit staff.
I did not defend them, though I could understand how difficult they found her.
Sarah knew that I heard her sad and lonely cry for help.
I *agreed* to walk alongside her suffering.
Sarah’s story made me revisit my own illness experience, where I’d felt my voice was silenced (refer Introduction). I had entered into a time of anger, sadness for my perception of changes in caregiving, and grief for the health of nursing as a profession. My own experience was an intersubjective bridge to Sarah’s story. My illusions had been shattered, my trust in my hospital’s ability to give me care. Perhaps my deep engagement with Sarah’s story was in order to oppose the censoring of the things that did not fit the healthcare professionals’ or hospital’s narrative.

I admire strong, determined, courageous women who speak out for themselves and for others. I believe that in communities, who can speak and what can be said, are issues of power. I felt this deeply as it played out in my own family of origin. I hated the secrets and untold stories that riddled my family and tangled them up in knots across generations. To be honest, perhaps my years of study since 1997 have been aimed at finding ways to speak out. I felt that Sarah knew that together, we were engaged in reliving her valued experiences as a partnership. I agreed with Sarah’s view that she hated playing the silly nonsensical game, required when one agrees to the conditions of being a patient. I felt her frustration, at the same time understanding how hospital protocols and rules arise. I struggled with this paradox.

Sarah’s cultural soup became a signpost for me as I worked with her story. In reflecting on my own cultural soup, my understanding deepened for my childhood stories, which had shaped the ways I tackled the rest of my life, and my engagement in this narrative work. I was drawn via Sarah’s stories to re-explore my own story with my mother. Sarah accepted that after years of heavy smoking, her lung cancer was to be expected. I hadn’t yet dealt with my views on this issue. Was I simply a virtuous but judgemental non-smoker? In my deepest understanding, I accepted the elements of life’s normal tragedy.
Now I acknowledged that Sarah’s cultural tragedy was sufficient explanation for me to accept her smoking as *justified*, rather than needing to be *judged*. This acceptance enabled me to enter Sarah’s story honestly.

Unless I saw a *Thou* in Sarah, I couldn’t *be a Thou* for her or an *I* for myself. Our two stories met, enabling Sarah’s story to remain alive in me after her death. I found working with Sarah challenging, working on her story later was a kind of healing balm to her *hot text* because I could hear her voice in the context of her culture and personality, and know that as she insisted, she was a perfectionist and life could never be perfect.

I am sure that if the work we’d done together had included the distilling of this story to its end point, we’d have both willingly struggled to reach a deep, intersubjective understanding.

The dialogue Sarah began continues in me, in the narrative work I continue to do. Sarah still speaks through me, not assimilated, but as a new possibility of compassion, identification, responding to *who was Sarah?* within me. In this ongoing dialogue, according to Arthur Frank (2005b) Sarah and I both remain unfinalised, the experience of our dialogue influences how I see the world. That is deeply satisfying for me.

The ethical challenge for us both included her Jewish and my non-Jewish cultures, her smoking, and my non-smoking, her terminal illness and my recovery from cancer, and ground we didn’t discuss, my never-clarified status as a healthcare professional, beside her as a patient. Perhaps that’s all that can be concluded, and must be enough for me to feel an approximation to meaning for Sarah’s story. I might need to concede my desire to bring order to what seemed to be moral disarray. I celebrate her story, admire her style and courage, and am grateful to have known her.
2.7. Supervision conversations, reflections and final essence statement

Sarah told a complex story, not simply of complaint, but of needing to set her illness into the culture and life values that had shaped her life prior to her illness. She pleaded for her integrity as a whole person to be acknowledged by the healthcare professionals. Perhaps this rose out of her deep need for her culture and prior achievements to be validated and above all respected, rather than the ‘they-don’t-know-me’ that she felt so intensely.

After completing the literature review, I asked both my supervisors, Louise Harms and Don Asker, to wade through my writing. We discussed my deep concern that Sarah’s voice be uppermost and they heard my concern that other voices might now join in. The literature by now had already influenced my interpretations.

A number of issues arose from our discussions, reviewing the work I had done with Sarah’s story so far. Had I focussed on Sarah’s illness, seeing her whole life story through this lens? This was probably what Sarah herself was most objecting to all along. She was not just the sum total of her illness. In fact it should be the reverse - the illness seen through the lens of her whole life story. That had been my aim; now I anxiously questioned if I had succeeded.

We discussed how Sarah’s minute detail of her experiences, which she explained as her small-picture way of seeing the world. She remembered physical, psychological and social experiences with detailed recall of dialogues. The clarity of her recall of events is remarkable, her sequencing detailed, perhaps almost obsessively so?

We discussed the word revulsion one might feel towards one’s own body and illness, reflecting on Sarah’s words (tape one, p.18) ‘I scare myself the noises I make’ and ‘the way I was going on it scares me!’ (yelling). Reading Sarah’s description of the piece of tumour she coughed up and saved in cling wrap to show her doctor caused some discomfort for my supervisors, it did not bother me nearly as much. Perhaps forty-plus years of nursing have taught me to deal with such things with less revulsion.

However I remember enough experiences to remind me I am not entirely immune. Sarah says ‘it didn’t look nice’ and rather than revulsion I think she expressed fear or a strong
need to know what it was. ‘It choked me, it blocked the trachea and bronchi ... what I coughed was part of it.’ So even if the pathology report was not quite as clear as she wanted, she did understand, and wanted to be quite definite about it in her story.

We discussed Sarah’s physical strength, as in her story of kicking boys shins, contrasting with the early stories of loss of control, such as her first day at school. Perhaps these stories were about the shattering of illusions that all children have to experience at some point. Sarah’s school story demonstrated a loss of control and identity that echoes, I think quite strongly, later in Sarah’s illness narrative.

Was it a ‘complaint’ Sarah was making regarding her mother’s silence about her Holocaust experiences (Tape 2, side 1)? I felt that Sarah was not complaining as such rather was more in awe of her mother’s ability to continue to refuse to discuss such an overwhelming story with her children. Sarah and her mother’s visit to the concentration camp a few months before Sarah died, was an important event for Sarah, and impacted heavily on her. She noted her mother’s decision to stay in the bus, as Sarah saw it, to prevent the possibility of Sarah having to witness her mother’s anguish if she had gone into the camp. I think Sarah was expressing admiration for her mother’s role model of strength of will, rather than complaining. I ponder how easily we each perceive and interpret differently, and that there is no correct way to see, no right answer. I think Sarah expressed that she saw some of her illness story as complaining, which therefore, in the light of her mother’s non-complaining, Sarah saw as her own weakness. She wondered whether if she had endured something like her mother had through the Holocaust, she would then not complain so much about what was happening to her in the present. She said ‘I do complain about a lot of things that may be really stupid. But to me they are important’.

We discussed a perception of the tone of Sarah’s story as one of revealing surprises, doors opening. Perhaps Sarah used surprise as a tool as part of her storytelling. Sarah didn’t seem to hear a connection in her distress that her father did not want her to see him so close to death, and her own annoyance with her brother for insisting on coming to Australia when she was in a similar position to her father. She said that for at least twenty years she struggled with the issue of not being in Israel when her father died, as if, she argued, she might have prevented his death. Yet she sees her brother’s visit as a take-over
of her life. Maybe we often don’t want to see the family connections in stories across
generations like this one.

I was surprised and disconcerted that I failed to focus much attention on Sarah’s rape, at
her first sexual encounter (Tape 2). Sarah describes her first experience when she was in
the army, and that it was without her consent, it was ‘virtually what you can even call
rape.’ In my inter-intra subjective response called ‘echoes of the past: then and now’ I
might well have included the rape as then, the now being Sarah’s feeling in hospital as a
‘rape of her integrity’ in the story of the IV and her oncologist, as ‘without her being
willing.’ No wonder she was angry. I wonder is there a cultural rape of Jewish people in
the Holocaust that also reflects her anger?

It was significant in the dearth of meaningful loving sexual relationships in Sarah’s life.
This must also have been made worse by the confronting attention she received for her
large breasts (fibrocystic disease), as she said ‘they attracted boys like flies, and they were
a big hindrance’. She attempted to have a baby alone; even in that the relationship is
contrived and manipulated by Sarah to give her control. Sadly her attempt fails and she
does not try again. Sarah expresses this as God not smiling on her.

As Sarah’s trial of nursing as a career reached six months, she gave up nursing and her
plan to upgrade to medicine, due to her inability to confront patients’ suffering. Sarah
commented that she had to realise that ‘it wasn’t perfect’ as she wished it to be. Does this
mean that death and suffering are in opposition to perfection? My response to this notion
comes a little later.

The next question I asked myself was ‘what should I do with my developing
understanding?’ I needed to integrate the new understandings that evolved as my
processing of Sarah’s stories proceeded. In my view there is not an end point as some of
the narrative literature suggests: that is, beginning, middle, end. Our stories go on being
written even after our death as suggested by Spinelli (1989, pp.78-79; 81; 103) and Kegan

A few days later I wrote: I see Sarah’s anger as a central point in the final experiences of
her life, I see it as the cross-over point of a figure of eight, that directs how the end of her
life will flow or be shaped.
Poetic synthesis

Her life seems to centre in the violation of her early world’s culture:

The Holocaust

The poverty

Her breast disease, and the rape of her sexuality.

She bemoans life’s lack of the perfection she tries so hard to organise,

but in the long run cannot control.

It means she is denied (or denies) loving relationships, and having children.

The violation continues with her lung cancer,

resulting in the ultimate loss of control to the disease,

to the healthcare professionals, to her family,

even to the legalities of death (refer Appendix Seven, 1, Theme 1).

Her life seems to centre around the violation of perfection.

Where is the awe and beauty, the ordinary joy and happiness?

Are they denied too?

Or would they have been contained in the extra 60,000 words

that she would have told me if she’d been well?

She always struggled to hold on to who she knew she was.

To address my disquiet, I wish I could ask her:

Where is the awe and beauty, the joy and happiness?

Is it denied, or simply left out of the story?

Is there a lack of acceptance that to be human means

not to be perfect, to sometimes fail,

thus meaning she might lack acceptance of herself?

Further Insights

Her psyche seemed to be scarred.

The struggle to stay who she was

became harder and harder, against the downward spiral.
It seems to be more a story of struggle than a story of complaint. However perhaps her complaint was that the people who might have supported her struggle, seemed to her to join forces against her, almost like her own personal Holocaust.

A week or so later I attended a public lecture by Arthur Frank, followed by a one-day workshop entitled ‘Working with Narrative Health and Illness Stories’ (Frank 2004a). Sarah’s story was present in my mind as Arthur Frank talked about the twin G’s of narratives. In the story of Beowulf, Grendel is the monster we believe has the power to destroy us. The other ‘G’ is (The Holy) Grail, which has the power to heal us, extrapolated from the mediaeval Christian story of Parsifal and the Fisher King.

So the monsters might be pain, fear, ‘The Cancer’ (often described as The Big C). Frank said that naming ‘monsters’ is an issue. We try to keep the Grendel force outside illness stories by tacit agreement. This really means silence for some people’s monsters, if as Frank says, healthcare professionals only accept stories that do not name what is not allowed, for example mortality.

Suddenly my bells ring! Sarah said to me off the tape at one point that she knew that when she walked up the path to her medical appointments, she set off warning bells for the healthcare professionals she was coming to see. The disjunction between Sarah and the healthcare professionals came very early in her illness narrative. At her initial visits to GP’s to seek help for her constant cough, she says:

I decided then that it was cancer and although the doctor said, ‘Don’t be silly.’ I thought that was how I would cope. If it turned out not to be, then I would celebrate. The next step was a bronchoscopy and biopsy, and that confirmed a lung cancer diagnosis.

Her pragmatic and efficient personality gave her the presence of mind to preserve the piece of tumour she coughed and deliver it to the GP wrapped in cling wrap. She named the monster she had recognised. The cough, her history of smoking, her family history, her weight loss - her monster’s name was lung cancer. And the GP’s response: ‘don’t be silly’. Sarah showed little regard for the healthcare professionals’ preference to leave the
Grendel force out of her story. Here she was suggesting to them that she accepted the worst scenario, even before they officially named it. No wonder she rang their bells. She was a person who would name monsters, and wear the consequences.

In the The Holy Grail story Parsifal needed his own experiences to be able to save the Fisher King by asking the right question. Sarah’s story seems to me to be a complex tangle of a number of wrong questions. Firstly she desperately wanted answers for her questions of what was happening in her disease’s rapid progression. She felt unheard, and unanswered. Perhaps she asked the wrong questions of the wrong people, in the wrong way.

Frank (2004a) says the risk is ignoring the storyteller’s wisdom, and Sarah demonstrates plenty of wisdom about knowing her own sense of moral being. Frank emphasises that the important thing is asking the right question, and he asks ‘what leads these good people (healthcare professionals) to make things worse, when they are sincerely trying to help?’

He suggested that to fall outside the narrative is to become invisible, and Sarah’s not so silent scream was that with her healthcare professionals she felt invisible: ‘all they see is the cancer’. Frank suggests that narrative breakdowns make further work impossible, and surely this is the point where Sarah felt stuck. Healthcare professionals cease to see what does not fit, including the patient, which Frank calls narrative imperialism. Sarah felt that she had indeed fallen outside her own story.

Suddenly I see that if my work with Sarah made any difference, like Parsifal, my own painful ordeals and experiences changed me into a person who has learned how to ask the right question. Parsifal’s name means ‘innocent fool’ and I needed to enter Sarah’s story in an attitude of not knowing so that I might sense what the right question was for her. I think for Sarah, my question needed to be: ‘who are you, as a person who comes to need this care? What has your life-experience been up to this time, so that your illness experience can be told and integrated into the story of your life as a whole?’

My question in the final essence statement was ‘how did the love, the awe, and the beauty, seem to be left out of Sarah’s story?’ There would always be unanswerables, and much of my work was speculative. Frank (1998) suggests that continuing the struggle, and for Sarah this might be seen as her telling her story to me with all its complexity, is a
process of care of the self. For Sarah, it was a story of the very survival of *herself*, within the powerful tension that might have annihilated her voice from her life. As Corradi Fiumara (1990, p.137) and Myerhoff (1979, p.221) would explain it, humans do not so much fear the extinction of life, but rather the extinction of personal significance, or oblivion. ‘And if the ‘meaning of life’ is considered of primary importance, humans want to know that their lives have value in the sense that they do create a significant mark’. The story that Sarah and I created, I believe became the mark that she and her brother could accept as the best possible outcome of her death.

As Frank suggested (2004b, p.62), it was a gift of generosity on my part to listen carefully and engage deeply with Sarah’s story. I think that with respect, I went to the place from where Sarah spoke, and I listened and allowed her pain to voiced, with my deep engagement and encouragement. Frank said that this gift is often not reciprocal, it sometimes cannot be reciprocated. I believe it was reciprocated for me in Sarah’s honest sharing of her deepest story with me, in a truly collaborative way, in the time that was available to us. To use Frank’s words, and those of Bérubé (1996), together Sarah and I made her story narratable:

Like Parsifal, my asking Sarah the right question allowed her story to become narratable:
told, heard, acknowledged, perhaps even healed.

The right question?
‘who are you, as a person who comes to need this care?
What has your life-experience been up to this time,
so that your illness experience can be told and integrated
into the story of your life as a whole?’

Her pain, her culture, her journey, who she had been,
who she was now in her final chapter,
before her life was gone.
There were many unaswerables, speculations, perceptions.
Yet she was able to tell herself
back into the story of who she was.
3. WHAT CAN BE GENERALISED FROM LISTENING TO SARAH’S STORY?

There are immensely beneficial possibilities for healthcare professionals listening compassionately and reflectively over the last weeks of a patient's life, which might allow the patient a more peaceful death. This compassionate listening might make a difference to the person's overwhelming sense of the loss of control of their life.

The listener's task is to demonstrate to the patient that they are known as a whole person and not simply a disease process. Many, if not most people, would like to be treated as equal partners in their terminal illness. The narrative in Chapter Four suggests that it requires empathic, open, engaged listening to the patient and their family members, in order to understand how the person's life experiences, perceptions and culture is an integral part of the scenario, as they face the end of their life. This form of reflective listening will steer the healthcare professional as listener to search for and know how to manage the patient's illness in a compassionate way that is enriching for both.

It involves asking the question, in effect, 'tell me about who you are, as you come to need this care. What is this illness experience like for you?' It is a simple enough question that needs willingness to listen with deep engagement, and a willingness to engage in the patient's suffering and grief. It is a way of listening that reflects reciprocal recognition and trust, and has consequences for both narrator and listener.
Chapter Five: Listening to Scott’s narrative

Information provided by Scott’s daughter prior to meeting him and recording his narrative:

Frail 88 year old male living in special accommodation
Previous stroke, with speech, upper limb, memory, and mobility deficits
Cardiac pacemaker inserted post stroke
Recent bi-lateral cataract removal (needs assistance cleaning glasses)
Poor appetite, some difficulty swallowing, poorly fitting dentures
Needs vitamised food
Wife died some years ago
Visited regularly by daughter and two sons
Family concerned their father is depressed,
He no longer leaves his room to participant in residents’ activities
1. INTRODUCING SCOTT

Scott was an Emeritus Professor of Mathematics. He was born in London in 1912 and when about two years of age came for his first short visit to his grandparents in Australia. He was now in his late eighties, a frail, quiet, private, gentle man, living in Special Accommodation. His wife had died in 1993. His family, a daughter and two sons, were concerned that their father was depressed. He was no longer wanting to leave his room or to participate in activities with other residents.

The stories of his travels seemed to occupy his mind with continuing pleasure whereas other interests were no longer possible. The family was keen that these memories of extensive travels be captured and recorded in some way, as well as helping Scott’s depression by stimulating his interest in life. They heard of my work and asked if it was possible for me to work with Scott, to see if recording his travel stories engaged his interest and gave him on-going pleasure.

In December 1999 Scott had suffered a stroke that left him with speech, upper limb, memory and mobility deficits. This prevented him from continuing his mathematical research, which he had enjoyed until then. Three weeks after the stroke, a pacemaker was inserted to regulate his heart rate. After six weeks in hospital, unable to return to his beloved home, Scott reluctantly began to move from family member to family member. He seemed depressed and spent much time lying in a darkened room. A few days before traveling from one residence to another he would suffer from nausea.

Scott’s vision was not good, partly due to his inability to clean his glasses. Finally an ophthalmology review diagnosed cataracts. His son with whom he was currently living, was also to have surgery, so it was suggested that Scott go into respite care, which he agreed to cheerfully. This brought him to his present abode where, three weeks later, he returned after cataract surgery and adjustment of his pacemaker. Scott had received new eyeglasses and back at the hostel he participated at first with quiet pleasure in activities such as ‘arm chair travel,’ indoor bowls, and quizzes. Soon however Scott withdrew from such activities completely.
1.1. Meeting Scott

I arrived at Scott’s care facility feeling slightly nervous about how I would proceed, and how much Scott would be able to participate. He was sitting quietly in his room in an armchair, gazing into the distance. He told me that he had read my Therapeutic Autobiography brochure (refer Appendix Three) and understood the reason for my visit. He said he felt that recording his travel stories would be a useful and interesting thing to do. I explained that he was in control of the sessions and should tell me at any time if he wished to stop. He understood and signed the consent form that enabled me to use the material for further study, although anonymised. Scott seemed pleased with this idea and we talked about my study plans, which I found encouraging in the light of his university experience.

In order to establish with him that I accepted this was his space I was entering, I began by asking what I should call him. I said I thought of him as Professor, though I had asked for Scott at reception. He smiled and replied ‘I usually warn people that this is how I am addressed here; it is convenient, but you can decide what you call me’. He brightened and seemed pleased to be in control of this detail. He said that as far as his travels were concerned, it was a problem to know where to begin, and he then launched immediately into a starting point, a holiday he remembered in England. I switched on the recorder and without hesitation we were away. We recorded eight tapes, which came to an end due to Scott’s deteriorating health. He died a month or so after we finished recording the interviews.

Scott’s obituary, (unreferenced to maintain anonymity) describes him as a ‘mathematical physicist’. It says that his lectures were legendary models of clarity, accuracy and completeness. One of his former students describes Scott as the most important influence in his academic life: ‘A man of integrity - a true gentleman, who was held in the highest esteem by his colleagues and his students’.

2. THE PROCESS OF CREATING SCOTT’S NARRATIVE

2.1. Taping, transcribing and returning the transcriptions to Scott

I recorded eight interviews with Scott, 408 minutes of taping, almost 20,000 words transcribed. I began with three sessions in the first week, then reduced to two sessions per
week as Scott’s health deteriorated. I also transcribed one tape made by Scott’s wife before she died, which is not included in this study. For me, it added another rich dimension to the family narrative that Scott and I had created, and could be included in the folder that Scott’s family had gathered by this process. I journaled my experience of working with Scott throughout, which is discussed later, and also in Appendix Eight, 3.

My first meeting with Scott has been described. The fourth session began badly with various difficulties. It nevertheless contained some gems of remembering and meaning. Scott didn’t seem quite as well, with clear evidence of hypoxia. Very quietly, almost to himself, Scott recited a favorite verse from Omar Khayyam’s ‘Rubaiyat.’ I decided to find my father’s old copy of this romantic poem and selected several verses to give Scott next time, in enlarged print size so he could read it easily. He seemed pleased with his recitation.

The sixth session began with a minor accident to my car as I entered the driveway to Scott’s care facility. This left me beginning the session feeling shaken and annoyed. Then Scott was not in his room. He had gone for a walk with his carer to a fairly distant sunroom. By the time he shuffled back to his room he was breathless and seemed almost too tired to go on. I thought at times as he drifted off to sleep that morning, that he may not come back, and I looked around to see where the call bell was. I asked myself how I would respond if Scott died while I was present. Would I just sit for a while without alerting the staff, who I was sure would have a protocol to ‘call a code,’ or at least an ambulance. I revisited this scene as I reviewed the literature, and discuss it further in the full text of the literature search in Appendix Eight, 2.

After recording one side of the tape, with some lengthy pauses but some good connected dialogue and re-experiencing, I suggested that Scott should rest before the lunch bell disturbed him again, and he thanked me, I think for allowing him to rest, rather than for coming. However at one point when he appeared to be far away, I made the suggestion that he had developed an ability to work throughout his life alongside the varied customs and cultures of others, without discomfort. He immediately opened his eyes, sought direct eye contact with me, and said firmly, ‘Yes, quite so.’ It was a lovely connection in a morning that felt somewhat damaged, and where engagement had been difficult.
Throughout the course of the taping sessions I gave Scott a number of inter subjective responses. The first poetic statement followed our first session:

*Stories from a Life-traveller*

The voice is quiet
and can no longer sing in the choir,
but it hasn’t disappeared.
‘It’s hard to know where to begin’ -
however England is a good place to start,
you know it so well,
the story is very much alive and well.

Walking is more difficult now,
and seeing is sometimes cloudy,
but the remembered view
from the top of the hill
is as beautiful as ever.

I look forward to the next episode of your journey.
Thank you for sharing it with me.

Scott commented that what I had written were ‘very suitable words about our first conversation’. He clearly read the material I gave him very carefully.

We talked about the significance, for both Scott and his wife, of the play ‘Peer Gynt’, a Norwegian tale written by Ibsen with accompanying music composed by Grieg. I searched for and copied the synopsis of Ibsen’s play from The Oxford Companion to Literature (Ibsen/Watts, 1966). I enlarged the print so Scott could read it comfortably. His daughter also gave him a longer synopsis. The two together seemed to confuse him, however it was another point of access to Scott’s stories.

Scott told me about a trip to Petra, which he described as ‘The Pink City’ (refer Appendix Eight, 1). I remembered that I had read about the Pink City many years ago. Eventually I called to mind four battered, second hand travel books by Richard Halliburton that I had bought as a teenager. In the smallest, most faded of these, ‘The Flying Carpet’ (1950), I
found the chapter entitled ‘The Enchanted City.’ I photocopied it, enlarging the print for Scott. I hoped it might trigger further memories of his trip. Such selected pieces of literature became useful offerings to further access material. Scott received them with obvious pleasure.

After I transcribed the first two sessions I offered copies to Scott to read in large print. At the next visit he told me he had read the transcripts and they were ‘very fair representations of what we said.’

After discussing the bridges of London, we together spontaneously recited Wordsworth’s poem. I typed ‘Upon Westminster Bridge,’ so that I could enlarge the print size and offer it as another remembered gem with which Scott could sit and re-connect. I also gave him three of my own little travel stories of one or two pages in large print, extracted from my travel diaries. However I felt in the end that they simply confused him. I wrote a poetic response for Scott that he obviously enjoyed when I read it to him. It was chosen by his family to be read at his funeral service:

\[
A \text{ good life}
\]

A quiet pacifist sets out to know and understand the world.

Through exploring mathematics;
Through traveling cities, towns and countries;
Meeting, knowing people, cultures, history, politics.
Wisdom was gained,
the world’s body of understanding was expanded.

Though feelings remain difficult to express,
Though heights were sometimes a problem,
Though others’ views were not always understandable.

Quiet places impressed,
England was always a special love,
seen from a bicycle,
Cambridge a centre of learning -
of life, as well as mathematics.
From Delhi to Ingleton, Cracow to The Isle of Wight, 
Dromana to Petra, Sofia and Dubrovnik, Madrid and Lisbon, 
Nottingham to Flom and Narvik, Townsville, Brampton Island, and Jerusalem.

Welcome in Moscow, not so welcome in Leningrad.
Welcome in Germany, not so welcome in France.
You quietly made friends with people of all countries, 
and in so doing, 
you cultivated a life of peace, connection and understanding 
so sorely needed as balm in a troubled world.

I created an art conceptualisation of Scott’s ‘worlds’ as he seemed to be describing them, 
and shared this by mail with his daughter, but not with Scott
I could see various themes starting to emerge in my own response to Scott, and in his responses to his own stories. Dealing with my own intrasubjective response that week I journaled but did not share with Scott or his family:

_I witnessed the tide of residents arriving in the dining room as I walked through to the front door to leave The Manor. All were frail, mostly with walking frames, some in wheel chairs, the embodiment of ‘old’. It was like a bizarre kind of ballet, where the performers all shuffled along attached to up-market walking frames and chairs._

_The dance of the nursing home_

Their bodies are well cared for here  
the surroundings are expensive, elegant  
but what about their minds, their souls?  
Who listens to them?  
Hears their stories? Connects the spaces between them?  
Helps them find knowing and peace?  
Who will listen to me?

This was followed with:

_Old age_

He is eighty nine years old next week  
His memory is failing  
His ability to communicate is almost finished  
I feel he is sad,  
Yet it seems he feels it is too late or too difficult to say so.  
And while The Manor is up-market  
It is not where he wants to be.  
There’s not much joy in the end of his life -  
Even if I see care, and hear rich stories of what has been experienced.  
I don’t think I like this picture of old age  
and seeing myself being like that.
So for me a theme of old age and how it might be for me, was starting to gather central meaning. And reading Yalom, (1999) and Zable (2001a,b) enhanced the later essences and approximation to meaning for myself, and the formation of responses I would later offer to Scott and his family.

Scott’s family was concerned with his depression. I began to ponder:

Perhaps Scott is not ‘stuck’ in his room
Bowed with depression.
Perhaps he is peacefully occupying
One of his other worlds,
Able to do so
By his reduced physicality.
So maybe it’s a depression in his physicality
Rather than a depression in his soul.

I think this might be a comfortable place
for him to spend his time,
as the end of his life approaches.
Perhaps this is a state to be accepted:

Here
feelings may remain unexpressed
Scott can just be,
in a world of his choosing.

2.2. Steps in processing, themes, understanding and essence

In 2005 I re-listened to each tape, whilst at the same time re-reading the transcripts. I listed the topics as they occurred in each tape, clustering them together in preparatory themes. This produced eight lists to be assembled into themes. The next step joined clusters of subjects or topics into eight themes that comprehensively encompassed all the topics Scott discussed as part of his life review, plus one theme that gathered references to the process of Scott telling his story:
The Eight Themes

1. Relationships
2. Places and Travel
3. Mathematics
4. The process of telling the story
5. Remembering and not remembering
6. Literature, poetry and singing
7. World views
8. Feelings

The transcript material allocated to separate tape themes was reassembled into the eight themes from across all the tapes. I did this by moving data on the computer. Each theme was then gradually reduced to a one-page narrative, and then a one page poetic reflection. The one page again seemed important in order to enable visualising a theme represented in one view.

Returning to the original theme allocation of the material, frequently referring back to the transcripts themselves, I restructured the material using van Manen’s (1990, p.101-106) ‘time, space, self, other’. Each of these themes was reduced in several stages to a one page poetic reflection.

Then followed each of the one page narratives from the original themes being re-written into third person, past tense, structural narratives, and these eight pages became the basis of a first synthetic reduction. This remained unchanged after the art conceptualisation other than the line marked * which was added following a telephone conversation with Scott’s daughter, after she had read the poetic essence statement.
‘I have to call myself a mathematician’

Scott’s mind was dedicated to seeking truth,
he lived what he most loved,
mathematics and travel.
Everything in his life reflected his identity as a mathematician,*
mathematics defined and described him,
and his search for the expression of universal truth.

Scott knew that his family was the fabric of his life,
they were the ground beneath his feet, supporting and holding him
so that his mind could soar as far as it could go.

Scott deeply loved beautiful things,
quiet places,
bridges, picturesque villages, country vistas,
people who lived together in peaceful coexistence,
mathematics, things built by hands.

People with a similar outlook could connect with him.
But quite often he was not so comfortable with other human beings
when he didn’t understand their points of view.
It was never difficult to move between the worlds he loved.

He had a pacifist’s view of the world as a whole,
which made feelings difficult to express.
Perhaps he was more of a Dick Whittington than a Peer Gynt.
2.3. **Art conceptualisation with Jane Gorey as my collaborative partner**

One colour was chosen to represent each of the structural themes:

*The Eight Themes:*

1. Relationships: Brown
2. Places and Travel: Green
3. Mathematics: Red
4. The process of telling the story: Purple
5. Remembering and not remembering: Grey
6. Literature: Peer Gynt, poetry and singing: Gold
7. World views: Blue
8. Feelings: Black

In a free, precognitive way, each theme was represented in the art representation. Jane then recorded my relaxed, focussed descriptions of each colour, and what was there beneath each one.

The relationship of family and friends held Scott so that he could reach as far and as high as his mind would allow. He controlled the doors to his separate worlds, and that wasn’t hard to do. His family and friends were a container, or safe base, for whichever world he wanted to occupy. He was a mathematician above and beyond all else.

The door to travel and places began with his lifelong love of England, and continued with his love of mathematics. Sometimes accompanied by his family and sometimes alone, he travelled the world in search of universal truth. He sought and loved beautiful places, quiet places, and places where people lived in peaceful coexistence.

The universal truth of mathematics contained, defined and described him, it was the doorway between his two worlds.

I think he enjoyed telling his story despite the difficulties and limitations. He did seem satisfied with the rich stories that were part of who he was. In a way they were still able to contain who he was, but nevertheless he grieved for his loss of the details, the loss of
temporality and his ability to abstract. He was sad about these losses. I think he knew it was permanent, so many precious memories were gone, obscured by the fog.

Some golden keys of literature and poetry could still unlock the doors to pictures and places.

A pacifist’s view of the world as a whole where people lived together in peaceful coexistence. Being a pacifist means feelings had to be contained. It’s better not to say you are angry most of the time, however sometimes he wondered if it might not have been better if he had said what he felt. That would have changed his life.

Figure 18. Art conceptualisation: *A Pacifist’s world view*
2.4. The modified application of van Manen’s literature search to Scott’s narrative

There was much to be explored in the literature following my work with Scott, illuminating many of the issues that were uncovered by my journalling as I worked. I identified two key themes in Scott’s narrative, each containing a number of minor or sub-themes. These themes and sub-themes became the framework for my literature search. The readings I selected helped me make sense of Scott’s story.

In order to remain within the word limits for the thesis, the full text of the literature search is found in Appendix Eight, 2. In the full text, each theme or sub-theme contains the relevant literature references side-by-side with my personal reflections on how these particular readings have contributed to my understanding of Scott’s life narrative. Under the heading of each theme, the actual discussions of the literature are set out in the left hand column in black print, with my reflections on each theme in the right hand column in blue print. The themes I selected were:

1. Scott’s identity as a mathematician
   - Truth
   - Being a professor
   - Feelings
   - Separate worlds

2. Old age
   - The poetry of growing old
   - Inter / Intrasubjectivity
   - Giving Care
   - The dance of old age
   - The process
   - Asking the right questions
   - Oral hygiene enabling good communication, comfort and nutrition
• Time
• The family
• Meaning
• Isolation? Depression?
• Listening in the silences

This particular literature search demonstrates the bias and intrasubjective leading of myself as the researcher. It is obvious that the literature chosen is quite idiosyncratic. If the literature search following Scott’s narrative had been comprehensive, I would have explored the mathematical concepts that Scott and I had discussed. Because they are outside my ability to comprehend, I did not search the literature around these issues. This could be seen as a significant omission given mathematics’ central position in Scott’s story, illustrated by Scott saying ‘one of the most central parts of mathematics is the Binomial Theorem’. From a more positive perspective perhaps it was simply my intersubjective decision that our connection would be enhanced if I did not spend too much time floundering in my lack of mathematical intelligence, and focused more specifically on Scott’s search for universal truth.

Scott’s identity as a mathematician was the first major theme I explored through the writings of Holstein and Gubrium (2000); Luke (1987); Anderson (1997); and Bourdieu (1999), seeking understanding of Scott’s self identity and the importance of his life’s work in the realisation of the meaning embedded in his life.

Scott’s search for mathematical or universal truth was his lifelong passion. I searched the writings of Frank (1997); Lett (2001) and Skolimowski (1994) around the issue of truth, truth-in-flux, and approximation to truth. I searched the internet and found sites dedicated to the search for truth, one site explaining the importance of Pythagoras and his quest towards universal truth via mathematics, which certainly seemed relevant to Scott’s story (<www.goodwriters.net/apierovichpythagoras.html>). I also considered the work of Caputo (2000) and his references to the deconstructionist position of Derrida that there is no ‘truth of truth’.

Scott told me that he saw himself first and foremost as a mathematician. This was considered in the light of a DVD of the Ingmar Bergman film *Wild Strawberries* around
the theme of ‘being a professor’. This film is also discussed by Coleman (1986); and Butler (1963) in critical examination of reminiscence therapy for elderly people. I then found on Radio National, a program where a West Australian professor whose father was also a professor, comments in a poignant poem about the meaning of being a professor (Radio National Science Show 19/4/2003).

Scott stated that the expression of his feelings was a source of difficulty throughout his life. In view of this I searched the writings of Greenberg and Saffran (1987), and referred to Gendlin’s (1982) discussions on focusing and bodily felt feelings, especially those of sadness, following my discussion with Scott regarding his very reluctant expression of anger.

Professor Arthur Bochner’s (1997) writings about the death of his father helped me to comprehend the gulf between what Bochner saw as his academic world, and his world of ordinary lived experience. I pondered how this related to Scott’s world and the gulf between his academic life and his ordinary life with his family. Bruner, J. (1986) also contributed wisdom that was central to grasping some understanding of Scott’s life.

The second major theme centered in the issues of ageing. First I relished two poems about ageing, by Matthew Arnold (1966 edition); and Judith Wright (1994). Richardson (2002) explains that poetry somehow captures the essence of a situation, and I found these poems moving and illuminating the essence of Scott’s slide into old age and dying. This brought me to face the intrasubjectivity of my own fear of ageing. Yalom (1999) and Zable (2001a,b) were important in my search for understanding, as was Helen Luke (1987) and her poignant descriptions of her own journey into old age. I read Arndt (1992), van Manen (2002), and Skolimowski (1994) about giving care, as it impacted on me in working with Scott. The dance of old age as I saw it in Scott’s aged-care hostel, was helpfully discussed by Chodorow (1991), enabling an intersubjective response that brought a further step of clarity.

I examined the difficulties I had working with Scott, through the work of Norrick (2000), Adams (1994), Anderson (1997), Killick and Allan (2001) and Butler (1963). Each addressed, from their various perspectives, the difficulties and demands of working with someone as old, frail and close to death as Scott. I was able to address the value of the
process for Scott and his family through the writings of Selling (1990), De Salvo (1999), Zable (2001a,b), Murphy (1987), and Reason (1988).

The difficulties of listening through the silences in Scott’s narrative were addressed by the writings of Killick and Allan (2001), Moja-Strasser (1996), Holstein and Gubrium (2000), and Kenyon (Kenyon and Randall 1997). The poetry of William Wordsworth, Kahlil Gibran, Omar Khayyam, the poet who speaks in Psalm 71, and the writing of Richard Halliburton about the Pink City called Petra, each helped lead Scott and I through the process of recording his narrative and through my later searching for its deeper layers of meaning.

2.5. Journalling my experience of working with Scott

I reduced the original version from my journal to this poetic style summary, again seeking Richardson’s (2002) enhanced clarity in this form. To enable comparison and transparency regarding the reduction process, the full text is found in Appendix Eight, 3. Some of this material has previously been described in the process of recording and analysing Scott’s story.

I began my task feeling anxious,
in awe of Scott’s and his family’s intellectual excellence.
I wanted to offer my best, to connect in some way with this frail, quiet, dying man.
He re-connected me to my father’s dying, I wanted [needed?] to comfort and care for him.

I felt pressured by the transcription task, especially with three sessions in one week,
and pleased when I braved invading Scott’s space to reposition the microphone closer,
in order to make transcribing easier for me.
Starting the fourth session I castigated myself for forgetting to turn on the tape recorder.
I was reassured by Warren Lett’s teaching. It worked, I was engaged with Scott,
I could remember what had been said.

As I transcribed, I was increasingly delighted by Scott’s obvious enlivening,
his engagement with the process evidenced by denser conversation.
I was encouraged by his collaboration, despite his failing health.
I was delighted that my knowledge and love of literature, poetry, and my travels,
enriched our engagement. I can see now, one didn’t need Mathematical Intelligence
to hear the philosophical truths and meanings he had reached for through his life of mathematical study.

I agonised that sometimes I was too pushy in trying to get more information, or when I pushed my own stories. I tried to tread gently, with sensitive care. I knew that sometimes I caused him to lose his place.

The connection through The Rubaiyat was like a bridge reconnecting me to my Dad, and his love of this beautiful romantic poem.

I enjoyed Scott’s gentle wit and humour, the twinkle in his eye, the wry grin, his relaxed head-scratchings - it was a lot like talking to my Dad.

I made myself learn to allow the silences to be in comfort.

The possibility of his death while I was there with him, felt like a privileged place to be, in dignity and peace, if the time was right for him to depart. I loved seeing him able to be transported to a transcended place where he was luminously peaceful, seemingly with another beloved presence.

A bridge connected our pacifist ideals, though I don’t think I have much trouble expressing my position or feelings. Through Scott’s story, Yalom (1999) and Zable (2001a,b) helped me to face my own fear of ageing.

This was up-market care, but still felt sad, isolated, almost soul-diminishing to me.

Scott allowed me to be a guest in his life story (Remen, 1996). I could hear and accept the gift of his wisdom, available to me through listening care-fully to his reflections, despite any confusions. As I re-connected with Scott by processing his life review, I saw that the most difficult thing required of me was perhaps the greatest gift he offered me overall: to build a bridge between us, I needed to slow myself willingly and peacefully to his pace, only there could we meet. It meant I had to become slower, older, quieter, if I wanted to hold and know his wisdom, to see and accept that he was able to be in the world of his choosing, as he sat there in his room.
What he seemed to be experiencing was depression of his physicality, not of his soul. This was a much more hopeful view of ‘depression’ for me.
It was a privilege to visit, see and know his place, to be connected to this wise, brilliant, special man.
It was a communion of minds and hearts that I value.

2.6. Supervision conversations and final reflections

After I had finished working with Scott, Warren Lett commented to me in a personal conversation, that what is possible in therapeutic autobiography depends very much on the capacities of the teller, and not just on their memory. Perhaps Scott was not used to reflection to a point of meaning. Lett continued that this was an interesting problem: ‘Should one assist this or just stay with the story as told? And how will you find the answer to such a question except by testing it?’

Scott and I began to work together late in his life. Starting before his stroke may have yielded a different story. He was distressed that he had forgotten so much, and his deteriorating condition left little ability for meaning making. It was almost too late for Scott to be able to draw conclusions, despite the fact that together, we gathered a credible narrative. One of the most significant difficulties for Scott was his loss of a sense of clock or calendar time, and his difficulty with abstraction, both clear deficits post-stroke. However, I believe that the essence of who Scott was, the essence of his life and values, grew through his story and it is there in the end despite the deficits, emerging from the process of listening to what he could still remember.
3. **WHAT CAN BE GENERALISED FROM LISTENING TO SCOTT’S STORY?**

This narrative again highlights possibilities for enhancing care by listening to and reflecting on an individual patient's needs. Again, it involves asking the question, in effect, 'tell me about who you are, as you come to need this care. What is this illness experience like for you?'

By listening to a frail, dying, elderly patient, it is possible to comprehend a comfortable withdrawal into a peaceful inner world. This is not necessarily a clinical depression that needs treatment or needs encouragement to leave. Rather it can be a transcendent place where the person might peacefully prepare for their approaching death.

To reach this understanding took me hours of careful listening, and would therefore necessarily need the healthcare professionals involved with the person's care to build 'the picture' over time spent listening to the patient and family members. The family might be comforted if they can understand that their loved one's apparent withdrawal is peaceful and not necessarily depression, even if it involves sadness for unresolved life issues. This understanding prepares the family for the patient's peaceful death. Other staff might also benefit from this reassurance.

Another understanding that emerges from this narrative is that when a patient is moved from one facility to another unit or level of care, there is a need for the new healthcare professionals to take considerable time to explore, listen to and understand the person's situation and needs. This narrative reveals an individual tailoring of care that requires listening deeply to this individual person and his/her family, and his/her unique way of being in the world. It is this approach that becomes the key to giving better care.
Chapter Six:
Listening to Bert’s narrative

Information provided by the Activities Co-ordinator of Bert’s psycho-geriatric residence, prior to meeting Bert and recording his narrative:

Bert is 76 years old and single
Diagnosis: Alcohol Induced Dementia (Wernicke-Korsakoff Syndrome)
His psychotic attacks are controlled with medication
He refuses to socialise with other residents, preferring to remain in his room
The Activities Co-ordinator would like to see Bert leave his room more often
His oldest son visits occasionally, he is disconnected from his youngest three sons
Bert had been a journalist
He had active service in the Second World War
He is financially supported by The Department of Veterans Affairs
Bert reads and writes copiously.
1. **INTRODUCING BERT**

In August 2001 I was asked to work with Bert, a resident in a psycho-geriatric unit. The activities co-ordinator had heard of my work and thought that the experience of telling his stories might interest Bert.

I visited the unit to meet the activities co-ordinator. She told me Bert was a person with alcohol induced dementia, and his psychotic attacks were mostly controlled by medication. He isolated himself in his room, although he enjoyed people visiting him there to listen to his stories. Now in his mid-seventies, he had been a journalist, travelled extensively, and was actively engaged in the Second World War. He still reads and writes copiously, and loves music. The activities co-ordinator and I agreed that we would plan to record three sessions and then review the situation. She stated that Bert was absolutely able to give informed consent for using his story for my study. Bert assured me that he understood the issues that I explained to him at our first meeting. He seemed clear that if I used his stories in my study that they would be anonymised. Given the nature of his dementia, cognitively unlike that of Alzheimer’s Disease, and with the activities co-ordinator’s reassurance, I accepted that Bert understood what he was agreeing to. His enthusiasm and understanding never seemed to waver over the seven interviews, or cause me to doubt his ability to consent.

The activities co-ordinator told me that she tried many ploys to extract Bert from his room, so after she introduced us, she suggested we use the ‘relaxation room’ to talk and get to know one another. Bert happily agreed to this. It was quieter in there, with a table to use, so an ideal room for recording. I explained to Bert that I was soon going on holidays and could not begin work for another three weeks. He said he was disappointed as he was anxious to get on with it, and had made lots of notes. He said cheerfully that he accepted there was nothing he could do about it. He seemed totally lucid, spoke strongly and seemed quite fit.

We talked about where we might begin. Bert told me his story began with his conception, nine months before his birth, which he said was three days after Valentine’s Day. As he happily scratched his head and shuffled through his papers, intense with anticipation, he told me some beginning stories about his childhood. By this time I was also full of...
anticipation about his stories, wishing we could begin sooner. I felt encouraged and full of enthusiasm for the process, and full of hope that Bert’s family would value the stories we would record.

I came home and began my journalling with:

I felt a sense of excitement and possibility
that I would be drawn into the stories
of this interesting man.
Alcohol induced dementia maybe,
yet his stories are alive and well,
Like fruit, ripe and bursting to be picked.
The taste of the visit lingered with pleasure,
though I pondered his truth,
his confusions
his unrealities.

As I thought about the task ahead, I wondered how much I would need to believe that the stories Bert told me were more or less accurate, or merely fantasies of his dementia. Crisp (1992, 1995) helped me to find a place for my intrasubjective feelings. Her papers helped me to prepare myself for the work to follow, and the dementia unit setting I was to engage with for the first time in my life. Purest phenomenology would require me to bracket these readings as I processed Bert’s story, however some preparation seemed essential. I read Crisp’s papers again later as I searched the literature as part of my processing of Bert’s story. It did not dawn on me at this early stage that I would need to understand the differences between Bert’s alcohol induced dementia and the patients with Alzheimer’s Disease who also lived in Bert’s unit.

I reminded myself that Bert would find value in telling the stories, and I would see this in other ways than his necessarily telling me of this valuing in words. It was not necessarily important that the stories were accurate historically; this was not their most important value.

Crisp (1992, p.49) eventually considered her mother’s confabulations not as lies, but rather as narratives, and this opened them up to the interpretive competence appropriate to
narrative. As I transcribed Bert’s tapes, my process would help me to *indwell* (refer Chapter Two, 3.8) or focus on Bert’s stories and experience their essence, allowing their meaning to be recognised and valued. It was good preparatory understanding:

> the weaving of these narratives out of fragments drawn indiscriminately from the real and the fictional is likely to be seen as evidence of ‘confusion’ rather than as duplicating the process of *bricolage* whereby any narrative, fact or fictional, is constructed (Crisp 1992, p.50).

I considered the word *bricolage* and pictured fragments, or pieces of Bert’s scattered stories, forming together to create a new picture, like lots of torn up fragments of many pictures being used to make a new art work of new value and new meaning. A *bricoleur* is a person who uses only the tools or materials at hand to achieve a creative purpose.

Crisp treated her mother’s narratives as narratives, that is, not to be judged as true or false, rather to be interpreted in terms of a narrative performance with thematic and metaphoric meanings (Crisp 1992, p.50). Much the same holds for the life stories of non-dementing individuals. In telling one’s life story one is engaging in a kind of *mythological rearrangement*. This was really helpful for me as I embarked on working with Bert to record his life review.

To see the narrative as confused or lacking coherence, says as much about the inability of me as listener to extract meaning as it does about the characteristics of the narrative itself. The mythological rearrangement turns an incident into a narrative and enhances it by exaggeration, which makes it worth telling. A narrative is a gift to the person to whom the story is being told. It involves interaction with another: ‘one should regard the sharing of memories, whether fantasised or real, as *a form of personalised gift*’ (Crisp 1992, p.52).

I prepared myself to receive the gift of Bert’s stories. He was clearly enthusiastically willing to share them.
2. THE PROCESS OF CO-CREATING BERT’S NARRATIVE

2.1. Taping, transcribing and returning the transcripts to Bert

We recorded seven and a half hours of interviews. The transcription took about sixty hours, and produced over 69,000 words.

I journaled my experience of working with Bert throughout.

I gave Bert a number of intersubjective responses, from material that drew my attention as I transcribed the tapes. Bert spent many hours pouring over and thoroughly absorbing every word of the maps and internet information that I gave him.

Bert gave me a number of his own responses, particularly two stories he had written on paper towel. Some of this material is included later in this chapter.

*Responses from Sandra to Bert:*

Over the weeks of taping, I gave Bert photocopies of a number of maps of South Australia, Victoria and Darwin. Some of these maps Bert requested, always with a humble ‘if it’s not too much trouble’. They were maps of areas Bert was familiar with. It was as if via the maps he could revisit them in his memory, down to actual street scenes.

A photocopy of a page from the Postcode Book highlighting an outback town in South Australia was a significant validation for Bert, and is discussed later.

My response to Bert after transcribing the first tape:

*Good years for growing up!*

Hallet, Riverton, Burra and Renmark;
Yarcowie, Terowie and The Willdongaleechy Pub.
Cooper’s beer and cans of milk with cream on top;
A pound of butter, a pound of strong cheese,
and bent cans of milk with ripped labels.
Hunks of coal thrown from freight trains,
collected by boys and wheeled in for cooking fuel.
Shunting steam locomotives, just eight years of age,
Beloved engines with names and numbers;
Hot gravel winds, and snow men in winter;
Oxy-acetylene lights and crystal sets,
Learning was easy - always top of the grade.
So much happened, so much you remember.

Ether for splinters, heads through glass windows
snake bites and a bed in the lounge room
beside the railway platform.
Comics from Adelaide, ice for ice blocks
and Coolgardie Safes.

Lancasters and Sunderland flying boats,
not yet 21, yet wireless telegraphist, navigator, observer.
Just a job that had to be done in those days, for good money.

Britain, Tyne, then The Philippines.

Medals for service -
For getting used to malaria and dysentery.

From a push-bike to a railway engine to a 4-engine flying boat.

Finally a car driver’s licence.
What an interesting life.

My response to Bert after transcribing the second tape:

I can remember that!

In those days:

1 foot 11, 3 foot 6, 4 foot 3 and quarter, and the broad 5 foot 3 inches
Smouldering wool bales, Good gravy!
24 hours, 6 for sleeping, 18 to be used.
Always busy? ‘It was just done!’
Working, playing, eating, sleeping.
‘I'll never stop being interested in learning something’.
Sucking snake venom, suck and spit, suck and spit
Not scared - just what had to be done.
Guiding lost Lancasters -
Told in modesty - just a job that had to be done.

I gave Bert his ‘Honeymoon Story’ that I extracted from the second tape and printed separately. This is presented later in the chapter as an example of Bert’s style of story telling.

My intersubjective response to Bert after transcribing the third tape:

_A busy life_

‘It’s not very nice to say this’
telling the truth uncovers painful events:
  loss of relationships, of lives.
Regret, expressed with honesty -
  ‘I did waste a hell of a lot; I was 38 years younger then.’
  ‘Things like that’: bad news, sad phone calls
    Pan America’s flight crashed
    She died later in hospital.

‘I’m interested in learning from what ever I’m doing.’
  Fascinated by Australia’s first computer;
  Leigh Creek and coal mining; diphthongs [sic]
  with enormous tyres, and orderly truck drivers;
    wind-the-handle telephones;
    the 1956 Olympic Games, laps of honour;
    cricket balls hitting painful places;
  and football for the fourths in Wonthaggi;
To USA for President Kennedy’s funeral, and marriage in Boston.
  Remembering hop beer in 50 gallon barrels,
    in a cellar with a gable roof;
    ready to share with visitors;
    A birthday party in the ladies waiting room;
    Daught cars and T-model Fords;
A son’s job to deliver the peeled off pounds for Mum’s supplies.

And a dream wish to return
home to beloved Barossa Valley
South Australia.

I downloaded information for Bert about topics we discussed:

Sir Charles Kingsford Smith
Past Winners of The Melbourne Cup
Harold Holt’s disappearance
The Beaumont Children

My intersubjective response to Bert after transcribing the fifth tape, to acknowledge his keen concern for, and study of the environment:

Resourceful, creative conservation.

Use underground water,
grow things on roadside spaces
(it all has the same sun and rain).

We could take more people in.
Even a place like this nursing home
could grow stuff
left right and centre.
We survived rather well.

Bert’s responses to me are discussed later in the chapter.

2.2. Re-engaging with Bert’s stories: steps in processing and understanding

In 2004 I re-listened to each tape, whilst at the same time re-reading the transcripts. I re-engaged with Bert’s voice, and the nuances that brought back to me his various moods at the time, scratchings and bangings, and the noises of the other residents outside the room, especially Larrie, who yelled and banged on the door and peered in the window on several occasions.
I listed the subjects as they occurred in each tape, clustering them together in preparatory themes. This produced seven lists to be assembled into themes.

The next step joined clusters of topics into eight themes that encompassed all the topics Bert discussed as part of his life review, plus one theme that collected references to the process, and Bert’s confusions and confabulations throughout the process:

*The Eight Themes*:

1. Alcohol
2. Relationships
3. I am a person of value and integrity: a story without mentioning love.
4. Everyone was working: it was natural.
5. Good gravy! I can remember that!
6. Stories
8. The process, the confusion, the intersubjective responses.

The transcript material allocated to the separate tape themes, was reassembled into these eight themes.

Each theme was then reduced by several steps to a one-page narrative, and then a one page poetic reflection. At the time of writing the one-page poems, I was reading Becker’s (1997, p.28) *Disrupted Lives*, about how people create meaning in a chaotic world like Bert’s. An intrasubjective response emerged, gathering what I heard throughout the tapes of Bert’s longings for his future, influenced no doubt by Becker’s powerful writing. My own feeling of distress arose from my understanding that in reality, for Bert, very few of his longings were achievable:

*Bert’s hoped-for end*

I’m 76 years of age. I intend to be well over that hundred mark,  

  don’t worry about that, I know I will get there.  

  My life’s not finished yet either, I’m just on the threshold of it.  

  Life begins when you get up in the morning.
You say what are we going to do today?
What are we going to invent. What's new we can do today.

Even to this day as old as I am, I still get interest out of Channel 31.
Oh yes, yes. I'll never stop being interested in learning something.

I know South Australia very well, I'm looking forward to
getting back there after Christmas,
you always want to go back to your own home town. That is home.
My own home neck of the woods. Not here, home in South Australia.
I'm not going to shoot through, I'm going to do it all legally.
I'm looking forward to next year, getting back [laughing].
My main thing is to settle back in Adelaide. That's where I wish to be.
That's my headquarters, still travel around, but visiting,
then returning home. Gee I'm looking forward to going back.

I can remember Wonthaggi, Kilcunda, Korumburra, Leongatha, Lower Tarwin.
The sea was four and a half miles away at Cape Patterson,
    I haven't been back for so long.
    I might go down there one of these days.
    I'm going to attempt to go to The Cup myself.
well that's another one of the stories I have for you,
I can remember, I'll tell you the story about The Melbourne Cup.

I've always been interested in different languages.
French, German, Latin, I have a very good book of Latin, and I read that.
    I can't speak any of them at all fluently,
I'd love to get into contact with someone who does,
and just speak only the language of that, within about 3 or 4 days,
it would come back.
I read - I haven't been able to get them lately
    but I have two French books in my room,
I read them backwards and forwards, yes.

I can type, oh yes I can still type reasonably well.
    I enjoyed writing, oh yes, still do.
I'm looking forward to getting my typewriter
today being Friday I'll have to wait now till next week some time,
I’m very sure - I know I’ll be getting one soon.
The number of typewriters I’ve had - and they’ve all gone.
Oh, give me a week back with my own typewriter, no one else mucking around,
the last one I had was a Brother, Big Brother is still on the market these days.
I had my last one about a year or two ago.
I haven’t started my book yet. ‘The Two Dozen and a Half.’
Oh no, no, get one thing done on time first.
That’s the plot of it though, I’ve thought about it for quite a long while,
that’s definitely what the plot will be about. ‘The Two Dozen and a Half.’

Returning to the original theme allocation of the material and referring back to the transcripts, I reshaped the material using new themes structured around van Manen’s (1990, pp.101-106) ‘time, space, self, other’. I was still feeling overwhelmed by the volume of material.

Each of these themes was reduced in several stages to a one page poetic reflection.

I rewrote the one-page narratives from the original themes into third person structural narratives, and these eight pages became the basis of the first synthetic reduction:

2.3. ‘Good Gravy! I can remember that!’
The river of his time seems to flow backwards
to times he can remember as if they were today.
Like shunting railway engines at Hallett,
the crystal set, which was something when you had no electricity.
He remembers his father to this day, his dislike of drinking alone.
So Bert grew up in a culture of drinking alcohol
with rules that said you mustn’t drink alone.
He remembers every day collecting the bottle of port for his mother and grandmother,
and one particular birthday party where he and the visiting children
had rather too much hop beer to drink.

In those depression days everyone had their jobs to do.
His mother and grandmother did excellent quality baking,
they bartered with local farmers, their baking swapped for meat;
they had eggs, fruit and poultry, it was all countrified.

He had a job each morning before school helping a farmer with separating,
this provided milk and cream. He remembers [with pride]
that they had a better table than most people, they managed rather well.
He remembers the contribution of his grandfather who loved his beer, he brewed hop beer
in the cellar, things had to be done his way, he was good at outside jobs,
the bantams, splitting mallee roots, railway sleepers and hunks of black coal -
discarded by the engines, which the boys collected and carried in,
all used to keep the fires going.

Everyone was working, it was natural, you had to be self sufficient,
that’s the way they were brought up. He remembers trouble was a second word,
boys weren’t growing up unless they got into trouble.

He enlisted in the airforce at seventeen by putting his age up,
he had his father’s consent to join the air crew,
He didn’t worry about the risks, he was paid good money.
The war affected the rest of his life, naturally.
Sometimes he sees things on television, or reads something, it brings back memories.
He had a cousin who didn’t make it back from the war,
he knows it could have been him.

He was getting good money, but wasted a hell of a lot of it,
though he didn’t gamble all that much.
He had four boys by this stage, the youngest born the year his first marriage broke up.
His children stayed with their grandmother, his oldest son visits quite often,
he doesn’t see the second one much. He doesn’t ever talk about the youngest two.

His main dream is to settle back in South Australia, which is home.
He’s looking forward to getting back there after Christmas, ‘you always
want to go back to your own home town, your own neck of the woods’
He plans to do it legally, but that’s where he wishes to be.
‘Not coming home, returning home, I think that’s a reasonable explanation’.

He is more interested than ever in this process of telling his stories,
he still loves to write.
He studies the information in the evenings, he ponders what’s going on, what happened in those days?
He’s always been interested in different languages: French, German, Latin.
His life’s not finished yet either, he’s just on the threshold of it, he believes you only get one chance. Company’s the main thing, he enjoys getting out and seeing the country the way it is.
Always top of the class, he’ll never stop being interested in learning, he still goes by that today.
He believes, and thinks he will to the day he dies, (in another 30 odd years): do your work, and when you’ve finished, then sit down and relax and have a few beers before tea.

The title of his next story is Two Dozen and a Half, not Two and a Half Dozen. The half is a person, he’s written it in first person tense, he put himself down just for the story as the half, the person in the first tense, just using himself, he’s been promised a million pounds if he could rehabilitate himself, get back to a normal straight course.

His second marriage was in Boston.
The plane she was in crashed, she was injured and died, they were married seven years, he says that was the end of his ‘waywardness about getting married’.

Re-living his stories of the past, he seems able to reconnect with his sense of self-worth. He tries to re-construct a story of coherence from his past, despite the confusions, confabulations, fractures and disruptions of his present. He learned well how to utilise resources, there are stories within his story: of finding tickets for the ‘56 games, of hitching a ride out of the path of Cyclone Tracey, being in the right pub at the right time; surviving a snake bite by ‘sucking and spitting.’ He is master of his story, it entertains me, it has structure: a beginning, middle, and his longed-for end.
From this I wrote the first poetic essence statement:

*Bert: A Lost Life Re-created by the Telling of His Story*

In those days you didn’t drink alone,
alcohol and its rules were part of his growing up,
the expression of Australian mateship.
Now he sees himself as ‘half a person’ -
it would be worth a million pounds
if he could rehabilitate himself.

The war affected the rest of his life ‘naturally’.
However his life is not over yet,
he has more learning to do,
more remembering, more writing.
He learned from his family’s culture
how to use available resources to survive,
now he uses paper towel, because he still loves to write.
But company’s the main thing.

He yearns to return to his beloved South Australia.
That’s where his heart and his hoped for future lies.
His stories re-create coherence, and his sense of self-worth,
which struggles to survive being ‘honkey-tonked’ by his night terrors.

This is his present life, it begins today ‘in this small nursing home’
yet is anchored and secured in his past.
His work today is pondering ‘what’s going on now’,
‘what happened in those days’ he can remember clearly.
2.4. Bert’s responses to Sandra

2.4.1. A Honeymoon Story (extracted from transcription of tape 2, anonymised, and presented here in its entirety)

I can remember we were on our honeymoon over in Hobart. And we were married on Saturday before Melbourne Cup was run on the Tuesday. We were over there. Over here in Victoria (I was living in Victoria at the time) I was down at Wonthaggi, that’s where I got married. Gambling was still illegal here, you used to have the old SP bookmakers, remember those, in their motorcars?

Whereas down in Tasmania, Tasmania and New South Wales it was legal. Both those states it was - they used to have the Tatts remember they used to have the old Tatts tickets in those days - 10 thousand pounds over in Hobart.

When we got there, on the Saturday night before Melbourne Cup, I’d picked out, I’d been following a horse back here called Comic Court, and we’d backed it with the SP bookmakers down in Wonthaggi, I forget now, one of the banks it was, I’d backed it for a pound each way, that was 15 to 1. And we got to, we were down in Hobart, we were on a bus tour, on the Tuesday of the cup, up to Mt Wellington there. The mountain there.

The bookmakers had their own betting shops, a proper booking arcade, each had a betting shop, size of this room but only about this wide. You put your bets on, and I only had a certain amount of money, not like you have now, but still a reasonable amount. As I said to her, ‘Look, Comic Court’s scratched,’ I said ‘there’s one here’, I said, ‘3 starts ago’, I said, ‘it won The Geelong Cup, and then’ I said, ‘it had my favourite figures, a second and a fourth, in 2 Melbourne races,’ I said, ‘you know’ I said ‘I like the way they run a 2/4 and then come into a big race,’ I said ‘there’s a horse here Welkin Sun not Welcome, but Welkin, as in Irish, W.E.L.K.I.N.S.U.N, Sun. She said ‘well how much are you going to put on?’ ‘Well’ I said ‘with spending for the day, I’ve only got 25 shillings.’ She said ‘We haven’t got to Mt Wellington yet, we’re going there this afternoon.’ We were only allowed so much a day to spend till
we get home Saturday, so we worked out our economies so - see we were building a house at the time, it was only quarter finished at this time. We allowed 2 pounds a day to spend on the honeymoon. It doesn’t sound much but in those days 2 quid was 2 quid.

So to cut a long story short, with one of the bookmakers there in Hobart, before we went on the bus trip, later on in the morning I put a pound each way, that was our complete day’s pocket money for the entire day. On Welkin Sun. So we went up to Mt Wellington and had a look out and took a few photographs, and had ours taken I suppose as well. And I remember we called into this particular hotel, a town halfway between the base of Mt Wellington and Hobart, it’s not that far, only about 20 miles, but halfway there was a pub there starting with an ‘L’, and listened to the race, I can remember I had my ticket out, the proper bookmaker’s ticket, all being legal. I had it out and I said what it was for - Welkin Sun, and listened to it on the radio, you know, no such thing as TV, and Welkin Sun tarried on the strait, it dashed out of the pack, and it was about 3 lengths clear half way down the strait - a 3 furlong strait, as you know at Flemington. And Dalray the favourite, came up and beat it by about a long neck. Welkin Sun came second, 200 to 1 was the actual prize. I had 50 to 1 for a place, with a pound each way, I got 51 pounds back! That was more than we left for our pound each way! We were only over there for a week. It was more than we’d left for a pound each way! For 2 pounds a day, a pound each day each, that was our - we were there for a week, we allowed 28-30 pounds for spending money, we got more than that back in the one bet! We had twice that much back in the one bet! We had 51 pounds I picked up in the one bet! Which is a 49 pound profit. Allowing for a pound each way.

I did the right thing - I gave 25 pounds of it to my wife. I can remember, I gave her 25 pounds, I know she bought another suitcase, in those days you could buy a new suitcase for about a pound. And the clothes and that, that she bought from there. And we hadn’t been to Cadbury’s - Cadburys used to have - the only factory was over there.
It was inland from Hobart. it had its own name for Cadbury’s there. Anyway I can remember the clothes that she bought from over there, and the stuff that we got from the Cadbury factory, and - beer, over in Australia it was still hard to get, at the start of the war a lot of hotels and most of them would only have a certain amount of bottled beer in those days, because everyone was getting back into the money, - they used to bottle their own out of the draught. But I can remember I brought back a dozen - I bought a suitcase also, and I put a dozen bottles of Cascade, various types of Cascade, apart from other things I bought for myself, but I still came back with quite a few quid.

2.4.2. **Bert’s first paper towel offerings**

I include several pages to illustrate the nature of Bert’s presentations to me that were part of this booklet.

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Figure 19. *Promoting group harmony*
Figure 20. Map of Hallet Railway Station

Figure 21. A humorous story

TOGETHER III, I BELIEVE
THEY BOTH
WORK
AT THE
LOCAL
MILK AND
DAIRY FOODS ORGANISATION III
This makes me recall "Grazcos", one of Australia's largest sheep-shearing organisations, where, in 1936, whilst in Grade Six, I won a prize whilst hurling, that was my first [17] air-plane ride, at Melrose Place. Melrose Place, Thirty-Seven [37] Miles North-West of Hallett.
MEMROSE PLACE, OWNED BY [1936] THE LATE SIR JOHN MELROSE, WHO WAS BLISHED BY A BEE - STING IN 1925 OR SO. HE OWNED THE "WILLTON GALEBCHY" HOTEL!! THIS WAS LEASED TO MR. STEW HANSEN!!! REGARDING THE SHEEP ON PAGE ELEVEN [11], GRAZCO'S SHEARERS WERE JUST FINISHING SHEARING TWENTY - THREE THOUSAND [23,000] MERINO SHEEP, WHEN A FARMER ON THE EDGE OF HALLOTT, A MR. WRIGHT ASKED THE GRAZCO ENGINEER/MANAGER TO SHEAR HIS SHEEP !!!

"HOW MANY, WAS ASKED ??!!!" TO WHICH MR. WRIGHT REPLIED "SEVENTEEN" [17] AFTER A PAUSE, GRAZCO M/E ASKED "WHAT ARE THEIR NAMES SIR?"
The opening words of this page are not distinct, but read: ‘Melrose Place, owned by (1936) the late Sir John Melrose, who was blidled [sic] by a bee sting in 1929 or so. He owned the ‘Willdongaleechy’ Hotel’ The remainder of the copy is clear enough to read.

2.4.3. Bert’s second paper towel offerings
Some of its twelve pages have been chosen to illustrate how the maps I gave Bert stimulated the production of his reminiscences.

Figure 24. “I am offering a slice”

Figure 25. Map of Hallet Railway Yards
Figure 26. Map of Hallet Township
Figure 27. Hallet Township including Primary School
Figure 28. Hallet Township including Catholic School
Figure 29. “I am recalling Philippine Islands”
2.5. The modified application of van Manen’s literature search to Bert’s narrative

The full text of the literature search for Bert is available in Appendix Nine, 2. To this point I’d had little experience of dementia, so it was a steep learning curve for me to enter Bert’s world and his narrative. From outside Bert’s dementia, I needed to consider the problems and risks in his dementia unit setting, wondering how I might attempt to understand a world I knew so little about, and to see the similarities between Bert’s world and mine, rather than being overwhelmed by the differences. Ethnographer Carolyn Ellis (Ellis and Berger 2002, p.857) reflects on her research writing about the experience of suffering from bulimia, as a participant who did not engage in the bulimic behaviours she was seeking to understand. Because I drink very little alcohol, like Ellis I reflected on my work with Bert from the position of a collaborative inquiry participant who did not engage in his alcohol-induced-dementia behaviour, which I nevertheless set out to understand. The literature was illuminating for me, and in the end I could see Bert’s personhood shining through his dementia, which was a poignant revelation.

I again draw attention to the idiosyncratic nature of these literature searches. I did not research the other narratives’ illness physiologies and clinical perspectives to the same degree that I explored Bert’s alcohol induced dementia. Because of my previous nursing and palliative care experience, with these other narratives I felt that I had adequate understanding of the clinical issues involved.

I focused on books by Killick and Allan (2001) and Kitwood (1997) from the many related specifically to dementia care. John Killick worked for nine years in a dementia unit as writer-in-residence, and his insights were invaluable in my understanding of Bert’s narrative. He refers to ‘people with dementia’ as the one condition, rather than the probable group of conditions, which perhaps could be called ‘dementias’. His partner Kate Allan helped develop this writing from her background of clinical psychology. Crisp’s writing on dementia in the light of her mother’s experience, was also helpful (1992; 1995).

Kitwood (1997, p.1) expresses his concern at the ‘rising tide of dementia’ that is inevitable with our ageing population. His experience with dementia began by meeting a frail old lady who became a friend to Kitwood and his wife. At that time he was an
academic psychologist, and he then began to work with and for people with dementia, finding to his surprise that he liked people with dementia, admired their courage, and could interact with them and understand something of their predicament. As in the other narratives, in the full literature search the ‘voice’ of the literature is presented in the left hand column in black print, and my reflections in the right hand column in blue. The themes, as in the other narratives, are not the same themes as in the analysis of the narrative itself, but rather as I selected and clustered them for my search to bring clarity to my understanding of Bert’s story and experiences.

1. Alcohol induced dementia
   - Definition of alcoholism
   - The development of alcohol induced dementia
   - Wernicke-Korsakoff’s Syndrome
   - Confabulation
   - Differentiation from Alzheimer’s Disease
   - Alcohol and Isolation: non being

2. Narrative identity, personhood or sense of self, its loss
   - Narrative identity
   - Loss of story
   - Careful listening
   - Personhood or Sense of Self; power and disempowerment
   - In-valid: Loss of control
   - Silenced voice: this could be me.
   - To reveal all, or respect doors that need to remain shut.
   - Bert describes himself as ‘Half a person’
   - Humour

3. Emotions
   - Raw emotions
   - Night Terrors and disruptive behaviour
4. Dementia care: Being de-mented - a troubled perspective
   - The in-valid, and concepts of total care.
   - Bert’s confabulations beyond the physiological
   - Time and place, present and past
   - Making sense of dementia
   - Initiating conversations
   - Self disclosure
   - Bert’s future: leaving him and walking away
5. The staff of a dementia unit
   - The dialogues between staff: staff stress and conflicting values
   - The staff’s surprise
6. Reminiscence and life review
   - Reminiscence in dementia
   - The re-constructed past
   - Valuing Bert’s presented world
7. Truth and values
   - A sense of place
   - Commemorating moments of value
   - Work ethic
8. Buber and intersubjectivity
9. Ethical considerations
10. Conclusion
   - Approximations to meaning
   - The poetry
   - The benefits of the process

The literature search for Bert begins in the domain of his alcoholism. The only medical information I was given by the Activities Co-ordinator was that Bert was a person with alcohol induced dementia, and that his psychotic attacks were controlled by medication.

Because this was a new area for me, I needed to explore and understand the clinical issues surrounding Bert’s dementia.
I searched for a satisfying definition of alcoholism, and how alcohol induced dementia might begin. I needed to understand *Wernicke-Korsakoff’s Syndrome* although I only ever assumed that this was Bert’s official medical diagnosis. His confabulations also needed my understanding, as they had a considerable effect on the experience of working with Bert’s life review. I was perplexed by the considerable difference between Bert’s presentation in his unit, and the other patients who were apparently suffering from Alzheimer’s Disease. The literature I selected helped me to separate the differences in cognitive disabilities due to the differing brain functions of the two causes of dementia. I finally understood - they were physiologically not the same. Some of the contributing authors for this section included Dalla Barba, Cipolotti and Denes (1990), Lishman (1990), Oscar-Berman, et al., (1997), Hersh, Kranzier, and Meyer (1997), Oscar-Berman and Marinkovic (2003), Brun and Andersson (2001), and Bloch and Singh (1997).

It was Bert’s isolation in his room that concerned the Activities Co-ordinator and brought me to work with him. I began within this theme to examine Bert’s isolation and my sense of his *non-being*. I found Murphy’s (1987, p.72) description of such intense isolation helpful.

The second theme of the literature search is therefore around the notions of Bert’s narrative identity, personhood or sense of self, and its loss. I searched the writings of Wiltshire (1995, pp.80-81), Freedman and Combs (1996, p.77), Sacks (1985, p.105), and Damasio (2000, p.196). These writers all seem to suggest that our narrative identity is of fundamental importance to our sense of self, and that this identity arises from within the coherent stories we manage to tell about our lives and our experiences. Kitwood (1997, p.9) goes as far as suggesting that there is a real possibility of excluding people with dementia from what he calls the *personhood club*.

I then move to the notion of being *in-valid*, with the loss of control of one’s life that comes with dementia, as well as other chronic illnesses. This concern is central to the writings of Zola (1982), and echoes also in Kitwood’s work. I needed to come to grips with my own intrasubjective response to Bert’s story and with working in the dementia unit. I understood that as I age, it is increasingly possible I might become a person who suffers from dementia. This could indeed be me. I read Holstein and Gubrium’s (1995,
discussion around the issues of silenced voices, and Zaner’s (2004, pp.69-87) particularly poignant understanding of the impact of being silenced by dementia.

Frank (2001a, p.358) helped me to clarify the issue of Bert not wanting to talk about his two youngest sons, and how it was correct for me to allow him to leave this as a ‘closed door’ if that was what Bert needed to do. Murphy (1987, p.92) and Sarbin (1994, p.25) helped me to interpret Bert’s story of being half a person and Killick and Allen (2001, p.86) shed useful light for me on Bert’s dry humour, and its importance in his storytelling.

The third theme addresses the issue of Bert’s raw emotions. Bert’s night terrors were really confronting for the staff, and therefore for me, without any understanding of what Bert knew of them in the cold light of day. Crossley (1996, p.155) argues that as long as people like Bert are denied the dignity of recognition, their situation will remain unstable. Kitwood (1997, p.72) and Moss (1989, p.197) also discuss so-called problem behaviours.

The fourth theme examines dementia care: being de-mented – a troubled perspective according to Zaner (2004, pp.69-87). Zaner, and Zola (1982) each contributed important ideas about the giving of total care. Crisp (1992, 1995) helped me to gain perspectives of coping with the confabulations that permeated Bert’s narratives. Crisp’s wisdom came from her experience with her mother, and this was echoed by Killick and Allen (2001). These writers also helped with my understanding of issues surrounding making sense of working in a dementia unit, such as self-disclosure. I also explored the issue of leaving Bert at the end of our work, and the perspectives and problems of the staff working in his unit. Again Killick and Allen (2001), Kitwood (1997), and Murphy (1987), all contributed to my knowledge and understanding.

I searched for understanding of the value of life review in working with people suffering from dementia. Gibson (1994), Crisp (1995), and Killick and Allen (2001) were helpful. Garro (Garro and Mattingly 2000, p.71) assured me that literal recall was ‘extraordinarily unimportant’. Reason and Rowan (1981, p.32) helped me to see the beauty and the significance in Bert’s love of his ‘neck of the woods’ in South Australia, and how collaborative inquiry enabled him to re-experience his sense of belonging there. I resonated with the writing of Crapazano (1980) about Tuhami, a Moroccan with whom he had an ethnographic encounter. Social commentator Hugh Mackay (2005) cast light on
the importance of the places where we feel we belong. Hillman (1999, pp.53-56) also shed light on the significance of life review and reminiscence in older people.

Central to the methodology of this study is the philosophy of intersubjectivity, which in the light of Moustakas (1990), Buber (1923), and Kitwood (1997) helped me to clarify my work with Bert. There were significant concerns around ethical issues and I found the work of Killick and Allen (2001), and Zaner (2004, pp.69-87) enlightening.

In conclusion I relished the poem ‘South of my days’ by Australian poet Judith Wright, which for me painted a richly colourful image of Bert, the honouring of an old man with amazing stories I was privileged to listen to and understand. I was grateful to the voices of the literature writers and the light they shed for me on Bert’s narrative.

2.6. **Art conceptualisation with my collaborative inquiry partner**

**Jane Gorey**

One colour was chosen to represent each of the structural themes:

*The Eight Themes:*

1. Alcohol: grey
2. Relationships: pink
3. This is my life, who I am, what I believe, [a story that doesn’t mention love.]: red
4. Everyone was working: it was natural: blue
5. Good gravy! I can remember that!: gold
6. Stories: orange
7. Places: I still call South Australia home: green/brown
8. The process, confusions or confabulations and intersubjective responses.
   His hoped for future/end black
   His night terrors and chaos
In a free, precognitive way, each theme was represented, starting with ‘alcohol’. Jane then recorded my relaxed, focussed descriptions of each colour, and what was there beneath each one.

Alcohol

A grey cloud that covers the whole of his life. It zaps him, the alcohol permeates everything, still permeating where he is now because it has destroyed his body and fractured his soul. It can be controlled in the daytime, however it rages free at night. It permeates all his world including now, when he doesn’t have any alcohol (I presume).

Relationships:

His relationships are all outside his present situation. His relationships with his children, brother, staff, they’re all destroyed except in the stories. I didn’t draw myself in the picture [art conceptualisation], which is interesting. I was the receptacle for the stories. So his life could come alive, through me listening to and honouring the stories.

This is my life

His understanding of who he is, is seen through the window of his dreams, into where his heart is in South Australia. Who he is, is in his stories. His stories are what light up his life, and he can talk about wishes, but not love. The stories of who he is are all that are left. Maybe the bombs and the alcohol were what caused his life to implode. The stories are now made bland so that they are manageable in daylight. They rage at night.

Everyone was working

It was natural to work and it was natural for the war to affect the rest of his life, however that work ethic still drives him; it is still alive and strong. Harnessing Bert’s work ethic might give him a sense of integrity and purpose and self-worth. If he was feeling that he was valued through his work and his writing, then he might feel that he has value as a person.
Good Gravy! I can remember that!

Validating the stories of the things he can remember validates him, even if they are confabulations. Some things that touch base with reality, just some things, are enough to make him feel not totally disconnected. It doesn’t have to all be true, as in verifiably true, as long as it touches base in his stories along the way.

Stories

The stories of important connections like President Kennedy, and The Dam Busters, medals, and the snake that bit him, are stories of a person who copes and does well.

Places

He has travelled the world. His family were migrants yet his heart is in South Australia and it has to be through the window of his dreams now, since there is no other way he can be there unless the dream of South Australia can somehow be brought back into his room.

The process

Listening to Bert’s stories together, gave him back his sense of who he was, and the intersubjective responses proved I was listening even through the confusion. Even the confabulations helped tell me who he was however at night he is beside himself. The night terrors are his rage, his scream, the destruction of his relationship with the staff. They [the night terrors, and their chaos and mayhem] white out who he is, so that he is only half a person, as he tells it. It is his only hope that we hear and validate who he is.
This poetic summary followed:

The half is a person, I put myself down as the half, just for the story
A grey cloud covers his whole life,
alcohol permeates everything, even now, when alcohol is banned.
It has destroyed his body, eroded his memory, fractured his soul.
Except in his stories his relationships are distanced, problematic,
he has disrupted connections with children, and siblings.
I became the receptacle for his reconstructed experiences.
He could re-live, and re-experience through his stories.
They light up his life, and describe his journey,
he talks about wishes but never about love, his stories are all that are left.
Maybe the bombs and the alcohol did implode his life.
It was natural to work, natural for the war to affect the rest of his life.
His work ethic is alive and strong, it still drives him.
To harness it might give back his sense of integrity, meaning, self-worth. If he could feel valued through the work of his writing, only then could he feel valued as a whole person.

Validating the things he can remember validates him, even if they are confabulations. Some things that touch base with his reality, simple things like a postcode, are enough to reverse his feelings of being totally disconnected. It doesn’t have to be all verifiably true, if it touches base in his stories along the way. His stories are of connections, as a person who copes and survives rather well. He travelled the world and fought for his country, it was a job that had to be done.

Who he is, reflects through the window of his dreams, returning him home to where his heart is, in South Australia. His story is wrapped in his yearning, his belief that he would soon return to his ‘beloved neck of the woods’. I was locked into my knowing that he is Sectioned, Certified, Secured for the remainder of his days. There is no way he can return home, unless his images of home are re-created in his room in the nursing home.

For me, hearing his yearning and not contradicting it was our collaboration in the expression of his life-story. Listening to his stories gave him back his sense of who he was, my responses affirmed that I was listening through the confusion. Even the confabulations helped tell me who he was. However at night he is beside himself, in his rage, his storm, his scream, and the destruction of his relationship with the staff. The night terrors’ chaos and mayhem white out who he is, so that he is only half a person, as he tells it. It is his only hope that we can hear his stories, and validate who he is.

2.7. Journalling my experience of working with Bert - a reduction

For this summary, again I chose to use a poetic-shaped reflection, as Richardson (2002) suggests, in order to enhance the clarity of my understanding. The full text of my
journalling is bulky with all my intrasubjective responses included. In order to stay within the word requirements for the thesis, the full text is to be found in Appendix Nine, 2.

I began with hope, the possibility I’d be drawn into the stories of this interesting man. Would I need to believe that the stories Bert told me were more or less accurate? I realised Bert was offering me a deeply personal gift, I was aware of my responsibility, however I continued to silently seek my own validation of the facts.

My pacifist self reacted to his almost complacent acceptance of bombs and mayhem in his war stories. I wanted to scream: ‘Our world hasn’t yet found a way other than violent, especially after 9/11’.

Shyly Bert gave me his responses, I accepted with delight. I felt I was gaining his trust. Transcribing, I heard his pleasure and my pleasure grew in listening to him.

Many questions surfaced representing a lack of medical information about Bert’s illness. I found this uncomfortable, unprofessional. I needed to know more from the healthcare team’s perspective.

Did I need to see myself aligned with them?

If I had professional knowledge would that have distanced me from Bert? Surely not!

Next visit I felt more acceptance and acknowledgement from the staff, particularly the Activities Co-ordinator [A/C].

She asked for a copy of what we’ve done so far:

I am concerned again and again about the confidentiality aspects of my work with Bert.

Bert’s dry mouth and poorly fitting dentures disrupt his speech, I long for him to have him better care.

He has called the paper towel book he presented me with ‘Promoting Group Harmony.’ I was slow to notice that. What did he mean? What else is there I’ve missed?

I hear how central alcohol has been in Bert’s life, I think there’s a Post-Methodist voice of disapproval buried in me.

Nuances of sadness and disconnection one day left me feeling disturbed, I felt Bert’s sadness, distress, anger.

My conversation with the AC wasn’t encouraging.

That night I had a powerful and disturbing dream
of tangled images, shattered illusions, I think connected to Bert’s sadness, provoking the dream, set in a period of my own mess and chaos.

I felt comforted by Bert saying that he was more interested than ever in this process. Interruptions to our taping by staff felt like bureaucratic intrusions. Did they want to see what we were doing behind the closed door? I was annoyed. I won’t know unless communication with the staff improves. Is the search for values for me, or Bert? I hear values in there, a work ethic, is this my interpretation? Why do I need to identify his values? Bert is forever locked in this unit without choice. Is it possible to shift closer to his now?

I try becoming him - (Moffitt 1971, p.149; Moustakas 1990, p.173) ‘… you must Be the thing you see’. ‘Becoming’, by being integrated into Bert’s culture of having Wernicke-Korsakoff Syndrome and its dementia and loss of selfhood, in order to hear his story authentically (Corradi Fiumara 1990, p.156). I write:

Locked up, powerless, surrounded, not free to choose, controlled, angry, upset
I disengage from this me in now and flee to me in Hallet, Barossa, my beloved South Australia,
another time in my favourite place where life flows, is creative, resourceful, we survive rather well.

His brisk, witty humour added to the complexity of the day and my subsequent digestion of it. I felt an urge to visit South Australia, a journey of validation; affirmation; confirmation; seeing with my eyes; feeling with my senses; alive to the essence of his place. Bert’s paper towel offering this week is titled ‘I am offering a slice.’ Of himself? There’s the gift (Crisp 1992, p.52).

I went to bed the night before the seventh session filled with horror at the callous, inhumane attitude of our politicians towards refugees. I had another vivid, disturbing dream. I am connected to times when I feel a sense of powerlessness, loss of control, loss of choice, the inability to do what I’d choose, including this visit to Bert,
and what felt like the uncaring attitude of the nursing staff.
I connect strongly again to my dream images
when a new nurse offers to lock us in the ‘relaxation room’.
I feel furious horror at John Howard’s public statement
that we don’t want ‘that sort of person’ in Australia.
[boat refugees reputed to have thrown their children overboard to avoid being caught by immigration officials, later established to be wrongly reported].
The lack of care for Bert suggests Howard wouldn’t want that sort of person either.
*My outrage boils in me!*

Talking to the A/C left me sadly understanding that *her* working life there is difficult,
she also feels unsupported by the nursing staff
who seem to feel little regard for the patients, or if they do they don’t stay long.
I worry about her well being, to survive she’ll have to leave,
as does everyone else who cares. Which of course further disempowers the patients.

Bert’s night terrors impact on me repeatedly throughout the weeks of working with him.
One day I asked Liz [the acting D.O.N] if his missing satchel had been found,
she told me it was thrown out because he’d messed it up. Liz told the AC
that in the mornings the staff go to Bert’s room wearing gloves and gowns
and throw out all his stuff, he’s soiled everything with urine and faeces.
I agonise over this situation.
The AC says Bert has *nothing* left in his room,
which includes loss of all the Intersubjective response’s I’ve given him.
In despair she repeats ‘*Nothing!*’
‘Why can’t they give him a box, get him to pack his things,
mind them for him overnight, returning them in daylight? She says they do -
the things that the staff value most, his clothes.
I stab at the computer keyboard in my anger as I write this,
I feel his disempowerment so strongly.
Do the staff *allow* the rages to destroy his precious papers and books,
or is this a bit too harsh? Liz *is* angry with him and maybe me,
if she feels telling his stories has fed his night terrors.
I feel his fractured soul emerge in my own intrasubjective response,
with the fracture line running through the line between night and day.
I draw a representation of this (refer Appendix Nine, 2), my anger ‘burns’ the page!
I worry that my work with Bert might inflame rather than soothe him.

Next visit the place feels changed, warmer, friendlier, less intimidating.
Is it different staff on duty, or the effect of the new unit manager who I don’t ever meet.
Or is it because I was in the office, and therefore seemingly part of the staff?
For the presentation to Bert the A/C made the room pretty and the occasion special, with cake. A number of staff came, the A/C says
she constantly told them about the work I was doing with Bert,
somehow it was as if it clicked, and they saw (when it was finished).
She says my enthusiasm for the stories was transparent.
The staff almost grabbed the book from Bert, and poured over it with amazement,
and seemingly genuine appreciation, humour and acceptance of the work we’d done.
The A/C tells me the process has given Bert back his identity.
If this process has given Bert a sense of his self worth, identity and integrity,
It has also given me a huge understanding of the impact of dementia.
Reading Killick, Kitwood and Crisp enriched and enhanced my understanding.
Zaner (2004) blew me away with his affirmation of my feelings of distress for Bert.
It has given me a greater understanding of the importance of the stories for the person,
for their integrity and self identity, regardless of their historical accuracy,
I can see Bert through his confabulations; the pure shining worth of the human soul
behind such an obscuring screen as dementia’s mess.
Maybe if a few of the staff see that, and value the people they care for more,
it’s perhaps less bleak for them,
they are cared for even if not by all of society, or even by all of the staff.

For me:

Precious valued golden knowing of life’s colourful, full-blown,
locked away, often noisy, sometimes smelly, mouthfuls of meat-in-cheek reality,
Golden I-Thou/Being-to-Being connection in story,
in care given, care received,
reciprocal humanity.
I wake next morning and click into feelings of let-down, disappointment:
I was conscious of the imperfections of the finished book, still some typos,
the binding isn’t as strong as needed;
Bert would wreck his copy quickly, perhaps has already.
It was a huge task over 10 weeks, 7.5 hours of taping, 60 hours of transcribing.
I felt exhausted relief it was finished.
I worry what will keep Bert together now,
if he is in fact more himself as a result of this process?
It cost me a considerable amount, no one mentioned that I bore that cost completely.
It was my substantial gift to Bert. Was my gift excessive?

Heuristic inquiry and phenomenology, sit happily with my philosophy and beliefs.
I asked Bert ‘how has this process been for you,
have you enjoyed telling me the stories of your life?’
He said ‘it’s not a matter of enjoyment, or non-enjoyment. This is my life’.
Behind his answer, for me is

‘I have told you who I am.
Not the person you see here in this place,
not the wreck you see now, but a person who has lived,
loved and had interesting experiences.’

Could I have presented him with a Questionnaire that said it better?
I needed only to listen carefully, give myself,
hear and understand what was deeper than his words.

2.8. Supervision conversations, reflections and final essence statement
Talking to my supervisor Louise Harms about Bert’s story, I confessed to a feeling akin to
spying on Bert as I searched the internet on more than one occasion. For example,
searching The Department of Veterans Affairs, where records of war service are
available. Why did I need to know? Did my making sense of his story need my sense of
‘truth?’ I’m not sure of the answer to this question even now as I write this chapter.
Louise Harms commented that she could hear/read my anger in my journalling, yet it did
not equate with anger on Bert’s part. She thought that his story was rather devoid of overt
feelings. I argued that I saw ample evidence of Bert’s anger, but that he tried to suppress it as much as he could - which is why I felt that it emerged via his nightly rampages.

Is my anger to do with the annihilation of selfhood in the power grip of healthcare professionals? That would correspond with the dementia texts I selected for the literature search, particularly Killick and Allan (1994) and Kitwood (1997). It also reflects the core problem lying at the heart of my thesis, of healthcare professionals not listening with engaged care to the people locked into their need for this care.

The selected literature helped me to frame and understand my intrasubjective responses to my experience of working with Bert. Ethicist Richard Zaner (2004, pp.69-87) wrote in his reflections about people suffering from dementia in locked units that ‘this is a prison, plain and simple, and to make matters worse, they treat you like a child’. I read this some time after meeting Bert. However as I re-entered Bert’s narrative to process his story I readily managed to re-experience the feelings I had on Bert’s behalf. Or was it simply my fear of ever finding myself in an albeit accredited unit like Bert’s? I was very grateful that my feelings of anger over Bert’s situation were validated: felt and written by someone else, particularly someone of excellent reputation and integrity like Zaner. Perhaps this is a core need in all human beings, to have what they feel, especially disturbing feelings like I had about Bert’s experience in his dementia unit, validated and confirmed by someone else having similar feelings. This seems to be a fundamental triangulation and crystallising that uncovers the meaning of our life’s experience, and is central to the essence of this thesis.

Louise Harms commented on the sense of identity Bert had gained from his alcoholic culture. We discussed my not wanting to take the five voices of my narrators and simply put my filter on them. Or is that inevitable? Am I listening for my experience to be confirmed in their story? How do we make collaborative conversation? These questions seemed more insistent in processing Bert’s life review than with the other participants’ narratives.

I was searching for the threads of meaning, but were they lost in Bert’s dementia? What are these threads of meaning I want to find embedded in Bert’s story? These questions continue to be present as I progress through the study. There are clearly temporary
approximations to meaning, and some crystals of understanding arising from Bert’s narrative. I hope that the final chapter will bring them together into some form of temporary synthesis. The final poetic essence summary for Bert became:

_Bert’s Lost Life Re-created by the Telling of His Story_

In those days you didn’t drink alone,  
alcohol and its rules were part of his growing up,  
the expression of Australian mateship.  
Now he sees himself as ‘half a person’ -  
it would be worth a million pounds  
if he could ‘rehabilitate himself.’

The war affected the rest of his life ‘naturally’.
But his life is not over yet,  
he has more learning to do,  
more remembering, more writing.  
He learned from his family’s culture  
how to use available resources to survive,  
now he uses paper towel, because he still loves to write.  
Yet ‘company’s the main thing’.

He yearns to return to his beloved South Australia.  
That’s where his heart and his hoped-for future lies.  
His stories re-create his sense of coherence and his sense of self-worth,  
that struggle to survive being ‘honkey-tonked’ by his night terrors.  
This is his present life, it begins today ‘in this small nursing home’  
but is anchored in his past.  
His work today is pondering what’s going on now,  
what happened in those days he can remember clearly.

There (but for the grace of better knowledge and understanding) go many more of us, maybe you, maybe me, washed away by Kitwood’s (1997, p.1) ‘rising tide of dementia’.  
Much later, as I edited this chapter, I read a verse from T.S.Eliot’s (1967 Edition) _East_
Coker, and it spoke deeply to me of Bert, and superbly expressed my bleak feelings and fears that I still struggle to reach and express:

The whole earth is our hospital…
Wherein, if we do well, we shall
Die of the absolute paternal care
That will not leave us, but prevents us everywhere.

I yearn that we might see, hear, and understand dementia care differently. I wish this for Bert if it is not too late, and also perhaps for you, and perhaps even more for me.
3. **WHAT CAN BE GENERALISED FROM LISTENING TO BERT'S STORY?**

This narrative raises the issue of listening to dementia patients, especially those whose dementia arises from alcoholism, in ways that honour the person's stories, self-worth and dignity. Practical actions might not only enhance the resident's wellbeing, but also staff morale. This could lead to retention of staff for long enough to gain experience and understanding of the issues of care involved in dementia units.

- Approaches such as protecting the patient's belongings, removing them at night if necessary, bringing some semblance of self-esteem and control over precious possessions.
- Understanding that listening to a resident is valid therapy, equal to drug regimes, a worthy investment of time and resources and more creative than cycles of resident rage followed by staff anger and low morale throughout the unit.
- Listening to resident's stories - with maps, memorabilia and photos on the walls, encourages the staff's interaction with the resident's 'place', validating and affirming the resident's personal value and dignity despite confusions and confabulations.
- Facilitating a resident's still strong sense of work ethic, despite confusions. This needs imagination to find the individual activities that would appropriately meet this need, but might again enrich the sense of dignity and self worth for the resident.
- In processing this particular narrative, I proposed that a one-on-one personal care attendant be employed to be with the resident over the hours when there was an established pattern of destructive behaviour. This would lessen or prevent the behaviour that seriously upsets staff morale and leads to feelings of anger with the resident. Reduced unpleasant cleaning might outweigh perceived costs.

Possible positive outcomes arising from listening to residents: firstly the staff engaged in creating a more peaceful and positive existence for the resident. Secondly the resident is less bored, better occupied therefore sleeping soundly, with less night rages and disruptions, and thirdly the possibility of reduced anti-psychotic medication and its consequent dry mouth.
Chapter Seven:
Listening to Elizabeth’s narrative

Information provided by Elizabeth prior to recording her narrative:

She is in her late seventies.
She suffered a ‘stroke and heart attack’ several months ago, she was close to death
The ICU staff warned her family that her recovery was not expected.
She is married with four children, all but one son living in Melbourne,
Her family gathered at her bedside,
Her fluids were restricted and this caused her enormous suffering,
Her husband was sobbing and so she decided to ‘come back’ if she could.
Deficits from the stroke include weakness and mobility problems,
left arm weakness, double vision, some cognitive deficiency and depression.
She suffers from hip pain due to arthritis, hip replacement is being considered.
1. **INTRODUCING ELIZABETH**

When I first met Elizabeth at a social function, she was in her late seventies, quite frail, having recently suffered a severe and debilitating illness. I sat beside her and she talked to me about an experience she remembered clearly from this illness, which sounded to me like a ‘near-death-experience’. She was very troubled by the loss of function and the ongoing weakness she was suffering, and the changes it made to her everyday living, independence and mobility. She was distressed by her inability to play her beloved piano, or to maintain the independence of driving her car. She was feeling quite bleak about her future. I told her about the narrative and life review work I was doing, and said I would very much like to hear more of her story. Her husband had already recorded his fascinating life story, so she was very happy to participate in my study. She seemed to be the ‘ring-leader’ in a family who relished stories, and I connected immediately to her enjoyment of participating, with her delightful, natural, earthy sense of life’s meanings being able to be told.

I rang to arrange our first meeting and Elizabeth was enthusiastic, telling me that all her family of origin had now died, and that she would love to tell me about the interesting times of her life especially in the early days of her marriage living in Indonesia. We talked about issues of confidentiality and her being able to delete or change any part of the story if she wished. She said that she could not think of anything that she would not want told. It reminded her of Holland, where everyone kept the curtains open at night, and when she commented on this to Dutch women their response was always: ‘what have you got to hide?’ Her stories were alive and well, and she was full of anticipation.

At Elizabeth and Pieter’s home, we recorded six tapes, which transcribed to 56,000 words. With secondary school teaching still in her blood, Elizabeth meticulously corrected my typographical and spelling errors, and we had various telephone conversations about the correct Dutch and Indonesian words and their spelling. Each morning, as we got to the end of the first side of the tape, Pieter would appear with a tray of delicious coffee and Dutch biscuits, served with gentle courtesy. It was a lovely experience to be with them both and share their rich, colourful and compelling stories.
Many older life review participants demonstrate the evolution of such characteristics as
candour, serenity and wisdom (Butler 1963, p.65). Elizabeth’s interesting story is framed
by, and filtered through these characteristics.

Shortly after we completed the tapes, just after Elizabeth’s eightieth birthday, she endured
a hip replacement with determination and courage. She has since returned to a degree of
mobility, and has less pain than before the surgery. She is now engaged with a group
writing poetry and is able to express in this new way, her frustrations with her physical
deficits and memory loss.

2. THE PROCESS OF CO-CREATING ELIZABETH’S
NARRATIVE
2.1. Taping, transcribing and returning the transcriptions to
Elizabeth
After recording and transcribing six one-hour tapes with Elizabeth, I presented her with
the transcriptions, and for each side of the audiotape, a one-page summary, which she told
me was helpful, and enjoyable to read. A number of examples of how these summaries
were shaped are found in Appendix Ten. There was one art representation, as an
intersubjective response from me to Elizabeth, also included in Appendix Ten.

2.2. Re-engaging with Elizabeth’s story: steps in processing and
understanding
I engaged once more with Elizabeth’s narrative in March 2004. I began by listening to the
tapes while reading the transcription. I listed the themes as they appeared to me in each
tape, and anonymised a set of transcribed tapes and responses as I went along. After
reading and listening to each tape, I allocated the text to the various themes. Halfway
through listening to tape 4A there was a ‘clunk’ of understanding and I wrote the
following intersubjective response:
'Faith, determination, resilience and integrity'

Determination, firmness of purpose, resoluteness,
the process of deciding to survive,
Resilience: springing back, resuming your original shape after being bent, stretched, or compressed by difficult experiences.

Having faith, maturing and growing from girlhood,
complete trust or confidence in God and your marriage;
a firm belief without requiring logical proof,
anchored in a soundness and honesty of self.
True to yourself, you listened to your own voice.

Faith, determination and resilience feed on each other,
and come from different aspects of one’s self.
Determination is from the brain, mental, or cerebral.
Faith, a belief - an inner core conviction,
your *ut omnes unum sint* - ‘that we all may be one’.
Resilience, a remarkable strength of spirit.
These three held and undergirded your life,
a mixture of head and heart.
This allowed you to be who you became,
a person of strong, honest, moral character and uprightness.

Having listed all the themes across the tapes, I examined them for clusters of themes, and sought names for these new themes. The text was then gathered together under these eight new major themes, and clustered minor themes within:

1. Relationships (the largest theme, which took six rounds to reduce to a one page narrative)
   - My parents
   - My mother [including her death]
   - My father
   - My sister
• Grandparents and aunt
• My first love
• Pieter: an enduring love
• My dear neighbours
• My four children:
• An enduring reciprocal love and care
• The benediction

2. Faith and values
• Faith
• Alcohol and Rules
• Struggle, determination and resilience
• Resilience of spirit, determination and faith
• A bad thing happened: a soul crisis
• Punishment for the abortion

3. Health Issues
• Menstruation
• Thrombosis of the mastoid
• Malaria and TB
• Hanna’s birth
• Breast feeding in primitive post war Indonesia

4. Life’s difficulties
• A motorcar accident
• Pain
• Nasty - not nice
• Grief
• Second son’s birth/asthma [health issues]
• A sort of nervous breakdown

5. Who or what will I be: searching for a sense of self
• About learning / not learning
• Books
• What was I going to do? or be?
• Not knowing
• Starting to teach
• Mother’s Club
• Back to teaching: a matter of trust?

6. Changing cultures, changing eras and changing times
• The War
• A Different Era
• Across-cultures
• Holland
• Visitors from Holland
• Changing Times

7. Home and journeys away from home
• A very pleasant life
• Location and Relocation
• Journeys
• The Paradox of Adventure
• This was always home
• Travel
• My thinking spot
• At home in Australia and England
• Not being at home

8. Celebrations, ceremonies, and love of music-making
• Music

I focussed on each theme individually and then reduced each to a one-page narrative, often through a number of reductions to enable the essence to filter through each round.

An understanding surfaced in my consciousness as I sifted through the theme of ‘not being at home’. In order to amplify my understanding I formed an art representation:
At the end of this process, two further intersubjective responses were formed:

Figure 32. Intersubjective response: *The Paradox of the dream and the reality*
The next process was to return to the transcript and focus on van Manen’s (1990, pp.101-106) Time, Space, Self, and Other.

‘Time’ produced my intersubjective response:

‘A personal perception of time: a life measured by time.’

Elizabeth experienced lovely, pleasant, happy times,

She loved books and music all the time,

although some times were hard,

there were times of confusion, times she now gets mixed up,

terrible, worrying times, bad times, horrible times,

times so difficult she didn’t want to remember them,

and has almost blanked out their memory.

In the end, she is thankful most of all for loving shared times,

For relationships that have stood the test of time.
‘Self’ produced a number of intersubjective responses, one example follows:

I was good at:

I could read by then, I think I was bright,
I was ten and put up further than usual, always the youngest in the class.
I probably played the piano quite well.
Academically I did well, I’ve a good memory for things like poetry.
I could walk very nicely across planks.

I’d Matriculated, I was obviously brighter than most of them.
I was good at languages, I have always been able to write well,
I passed the English like pffhhhh! I can spout you reams of Shakespeare,
I learned about Bach. It is difficult, I love it, its like a puzzle, its mathematical.
I was very interested in theology and I was searching the background,
I knew what I was going to do.
I had quite a nice soprano voice.
I was very thankful that I could learn so easily.
Someone said I was a flinke meid - a brave girl. A decent girl.
It was just as well I had a flair for languages.
I was proud of my Dutch, I could think in Dutch.

I walked for miles to get things at the cheapest price,
I thought I did very well.
It is what I wanted. I felt that I made it! I did it! I organized it,
I was the main person behind the scenes.

I then did a teaching degree, later I did a librarian’s degree.
I had such plans, I’d done such a lot of work on new systems
I think now I was really advanced.
I had to be organized and efficient,
I was Vice President. Kinder, Kirche, Kuche is the German phrase for a good woman, the good wife.
I did that for some years, while the children were little.
This led me to create a genogram using Elizabeth’s descriptions of her family of origin (abridged):

**Grandfather [Captain in the Boer War] & Grandmother [Nanna] - mother’s parents**

Grandfather was very impressive, a good man, an elder of the church.
The much respected elder statesman in the background.
Nobody would ever speak back to either of them.
My grandmother asked me often to learn large swathes of the Bible, which I still know.
My grandmother was very important to us. In her quiet way she ruled the family.
They were all terribly anti any sort of drink. So was my mother.
(I still don’t like people drinking at all.)

**Auntie Jessie**

Dear Aunt Jessie looked after me. A deal of sadness of maiden aunts.
She died suddenly at about forty, Mother was undone by this.
Aunt Jessie was her elder sister. We think she died from a heart attack.
I was just told that she said ‘Mother I’m going’ and she went.

**Mother**

Mother had been a music teacher, she had never been able to cook.
When she first was married, it was hard for her, she wanted me to go to finishing school
Mother sensibly told me that these poor men outside the hotel didn’t have jobs,
she taught me to be sorry for them, she was out a lot, doing things.
Mother and I fought a fair amount. I always said she spoiled my sister.
She told my sister things she never bothered to tell me because I was too little.
Mother was a musician, I didn’t encourage her, she had a **brilliant** style,
I hadn’t learnt it that way, she didn’t like hearing me practise,
I didn’t like hearing her practise. She stopped, due probably to me.
Mother was very good at homes, making them pleasant places,
she was very hospitable. She said to me
‘I know you won’t take any notice of me, but Pieter is the man for you’.
Mother had a big party, ‘On the occasion of their daughter going to Indonesia.’
No mention of marriage.
From Brisbane I rang Mother and said, ‘I want to come home’. She said
‘Dear, you’ve promised Pieter, get back there!’ which was true. So I went on.
Mother said she didn’t realize she could love such a little scrap as my daughter
so much in just three days.
Pieter said ‘Your mother died, come and sit down. I said ‘not my mother?’
And I wept and wept.

Father
Father was rather disappointed I wasn’t a boy. He found it terrible having his salary cut
because of the depression, but it didn’t make any difference.
Father was a very sports person, I got on fairly well with my father.
My sister said he favoured me, he wasn’t very forward in our family,
it was always ‘ask your mother.’ Father was proud of Mother’s home making.
He was a dear, but he wasn’t the leading light in our family at all.

My sister
Six years is a lot of difference, she had boyfriends, pretty dresses,
and I was at school [sniffs];
We didn’t like each other really, we knew later on we had to get on,
we were the only ones left, we were always entirely different people.
I used to pinch her clothes, when she was home we’d fight.
My sister had to cook for me. It was a disaster. My sister couldn’t cook either.
My sister said to me ‘If you want to get out of this marriage, I’ll back you.’
And I said ‘but I don’t want to.’ My sister had to look after Father,
she resented this a lot, it soured our relationship. She’s long dead.

‘Other’ was complex, and formed into 8 complex pages of text regarding many detailed
relationships formed throughout a long, social life. The next step was to reform the 8 one-
page narratives into third person structural narratives, after which synthesis became
possible. This reduced after several rounds to:
The centre is anchored: the core of a resilient spirit, a strong sense of self

Early anchors and foundations
She had a loved, happy, secure childhood.
A bibliophile, she absorbed the ideas and wisdom of others.
She had a privileged, excellent education for a bright, clever girl
who learned and remembered easily.
The church brought faith and a creed that she still can believe.
She suffered early knowledge of screaming pain and fighting anaesthetics.
Music, literature and poetry were within her and all around her.
She enjoyed fun, romance, and broad social experience, especially at university
She developed an early sense of what she was going to do,
a strong determination of what was right for her; an acceptance of herself.

Her main anchor: her enduring love
Her main anchor then became the love of her life,
she was ready to set off on a dramatic journey of adventure and great change,
to spend the rest of her life with him, both determined their marriage would endure.
Their four children, despite many difficulties
were there with them through rocky health experiences in later years
And are with them now as these experiences continue.

Challenges and life-forming experiences
She willingly set forth into colossal cultural and climate changes, which shaped her.
Difficult births of her babies, traumatic health crises,
tested, challenged and strengthened her resilience.
Inner Melbourne’s drunks extended her family’s abhorrence of alcohol
into her own life-long stance.
She decided to abort a pregnancy that would have kept her in Holland
where she felt unwell and unwelcomed, and this led to life-long guilt and shame.
There were times of fractured resilience
such as when her mother died, shortly after her first baby’s traumatic birth,
coupled with her isolation in Bali.
And around the time of a difficult miscarriage,
which she saw as punishment for the abortion in Holland.
She can hardly bear to remember her injuries from a car accident
and the following premature excruciating birth of her second son.
A nervous breakdown coinciding with her second daughter’s difficult teenage years.
And now, after her stroke, struggling with the deficits
that rob her of her precious independence.

2.3. The modified application of van Manen’s literature search to Elizabeth’s narrative

The full text of the literature search regarding Elizabeth’s narrative is bulky. The full text
is found in Appendix Ten, 2. This literature search occurred after substantial processing of
Elizabeth’s narrative, before the final essence statement was written.

The literature I selected to search following Elizabeth’s story, covers many of the themes
and issues uncovered in her narrative, such as her family and its cultures, influences and
structures; her illness narrative; her resilience; her soul crises and epiphanies; and lately,
her grief concerning her loss of independence. Elizabeth’s story covers complex life
issues and experiences, and it is not possible for the literature review to be
comprehensive, or the themes entirely untangled. In the full text of the literature search,
the texts of the literature are discussed in the left hand column in black print, and my
reflections are in the right hand column in blue. The themes are not the same as those
used to process Elizabeth’s story, rather they are selected and clustered to guide my
search.

1. The narrative
   • A story of intensity
   • The story’s flow
   • A narrative shaped and measured by time and place
2. A sense of self and belonging
   • Different cultures
   • Community support and connections
   • Making choices

3. Family and enduring relationships
   • Family ceremonials

4. Epiphanies
   • Elizabeth’s abortion
   • Elizabeth’s nervous breakdown
   • Elizabeth’s ‘hot texts’
   • Elizabeth’s near death experience
   • ‘It was not nice’
   • A touch of kindness

5. “Fraying around the edges”
   • The deficits after Elizabeth’s stroke
   • Resilience
   • The end of Elizabeth’s narrative

2.3.1. Theme 1. The narrative
The first theme examines the process of recording Elizabeth’s life review. I reflected on the strength of Elizabeth’s story. Frank (2004, p.5) writes that stories are like images that invoke the world of the storyteller with great intensity. Throughout Arthur Frank’s 2004 workshop on narrative, Elizabeth’s story was in my mind, there were so many intense moments in her life review.

Permut (1989, p.56) comments that naming things is a way of owning them. Spinelli (1989 pp.97; 101) comments on the way we retrieve the memories of our experiences. Elizabeth’s story has a remarkable flow, enabling a sense of meaning to emerge that flows from her childhood experiences to her present frailties. She is not afraid to name her experiences, particularly those that were ‘not nice’. In all my literature searches, one reading often lead to another. Frank’s (2004) writing led me to read Damasio (2000) regarding the autobiographical self and the basis of memory. I was intrigued by Elizabeth’s sense of time and place, supported by Bruner and Feldman (1996) and by van
Manen’s (1990, pp101-106) view of time (temporality): I may reinterpret who I once was or who I now am.

2.3.2. Theme 2. A sense of self and belonging
The second theme examines Elizabeth’s sense of belonging. Crossley (1996, pp.65-67) discusses the importance of our self-identity through our citizenship. Elizabeth expressed a strong sense of when she felt ‘at home’; ‘not at home’; and of the communities within which she belonged. She experienced living in a number of cultures. Crossley (1996); Bruner and Feldman (1996, p.302); and Reiss (1981, p.173) discuss similar experiences of living in cultures other than one’s culture of origin.

2.3.3. Theme 3. Family and enduring relationships
Specific shared explanations that families develop are important in shaping the ongoing values of the family members (Reiss 1981, p.173). Elizabeth’s genogram (refer previous section) illuminates her ongoing values and their origins within her family. Reading Reiss shed light for me on Elizabeth’s failure to feel at home and accepted within her husband’s family in Holland. The need to belong had a core role in several life crises that are central to Elizabeth’s narrative, also illuminated by the discussions of Drewery and Winslade (1997, p.48).

The family’s social environment is a factor in its management of stress (Reiss 1981, p.177). This was a helpful perspective in understanding Elizabeth’s experiences. In exploring the theme Making choices (Appendix Ten, 2, Theme 2) I found Robinson (1996, p.21) illuminating in his comments that such major decisions as choosing a career or a partner have irreversible consequences. The reasons for making those choices impacts on one’s sense of identity, and the coherence of one’s life story. Reiss (1981, p.155) proposes that the family serves as the basic organiser of our experience, and as a strong model to follow. Our family influences the framework on which we hang our explanations of the world. This echoes in Elizabeth’s story, within her family structures, the framing of her life’s narrative, and especially within her enduring, loving relationship with her husband. Riess (1981, p.246) also discusses the significance of family ceremonials, and Elizabeth mourns the loss of some of these precious rituals since her stroke.
2.3.4. Theme 4. Epiphanies

Elizabeth describes a number of *epiphanies* or life crises, that were major turning points, (as discussed by Denzin 1989b, p.15), that shaped and directed her ongoing life narrative. She often commented that what sounded to me like horrible experiences were simply ‘nasty’ or ‘not nice’. To me they were like Gilgun’s ‘hot texts’ (1999), which I needed to absorb and cope with.

Finally Elizabeth brought herself to the point of describing the latest of these experiences, her stroke and near death experience. These emotions were more recent and she was able to describe the horror she felt about one particular incident. As a story of not being heard, it sits beside the three stories in the thesis introduction. Bourdieu (1999, p.600) and Frank (2004) illuminate this experience, where a touch of kindness would have made a significant difference for Elizabeth and her family. I saw this experience as Elizabeth’s own ‘hot text’. She left telling this part of her story until the last tape of her life-review.

I wanted to understand as much as I could about the experience of Elizabeth’s abortion in Holland many years before we recorded her story. I could hear that it still aroused painful memories for her. I searched some of the literature regarding this issue. I found Drewery and Winslade (1997), Reiss (1981), Greenberg and Saffran (1987), Lastman (2004), and Nathanson (1989) all made significant contributions to my understanding of the enormous impact that abortion can have on a woman’s life and wellbeing.

In seeking to understand Elizabeth’s nervous breakdown, which she seemed to have described in her life as an epiphany experience, I read Bloch and Singh (1997). I also noted Reiss’s (1981, pp.170-173) comments on family disorganisation and destabilisation. Linde (1993, p.134) describes the loss of coherence brought about by disruption to our life’s story; and Becker (1997, p.107) argues that families may both aggravate disruption and create continuity, engaging in a form of generational continuity. As I read, both Becker and Linde shed light on the dynamics in Elizabeth’s family that brought about her sense of shattered wellbeing. It was reading this point in my literature search that brought Elizabeth to request a further meeting with me, to clarify some of my assumptions that she felt were not quite right (refer Chapter Seven, 2.5).
Theme 4 also examines Elizabeth’s near-death experience. Such experiences are discussed by Becker (1997), Atwater (1992), and Nuland (1993). Byock (1992, p.233) describes a ‘nearing death awareness’ that seemed closest to what Elizabeth experienced.

2.3.5. Theme 5. “Fraying around the edges”
This title uses Elizabeth’s own description to discuss the literature that shed light on her feeling of despair regarding the physical deficits remaining after her stroke. Zola (1982, p.8) describes his own experience of being ‘a diminished person’ in the presence of his physical disability. Murray Parkes (1971, p.103) writes about the grief and loss that arises in situations like those Elizabeth experienced.

Elizabeth and I had a number of discussions about resilience. I had read Deveson (2003; 2004) and her views of what resilience implies. Elizabeth still thought this was ‘too kind’. She ‘just did what was necessary’.

The end of Elizabeth’s narrative concluded with a benediction statement about her gratitude for her life as it had been, fitting Denzin’s (1989a, p.25) description of a narrative device that enables closure. Frank (2004) suggests that the purpose of a narrative is to arrange events in an order that seems to make sense and end correctly.

2.4. Art conceptualisation with collaborative inquiry partner Jane Gorey
Consistent with the method used for all the art conceptualisations, the process was framed by the eight structural themes:

1. Relationships
2. Faith and values
3. Health issues
4. Life’s difficulties
5. Who or what will I be
6. Changing eras and cultures
7. Home and journeys away.

A colour was chosen to represent each theme, and the art conceptualisation was done as Jane announced each theme. She then recorded my ‘pre-cognitive’ response to each
theme, and the notes she took as I talked, formed with little change into the poetic summary that followed. I was conscious doing each of the art conceptualisations of an inadequacy and limit in my artistic ability. However in the long run this was not detrimental to my uncovering the underlying approximation to meaning. I reminded myself they were not art, but rather another way of forming and ‘seeing’ what Elizabeth had described.

Figure 34. Art conceptualisation: *A strong resilient spirit*

### 2.5. A further conversation

Elizabeth requested that I return for a further conversation to finish her story, there was one particular issue she felt was not quite correct. I visited her home and we soon focussed on the issue in question. I had promised that we would continue until the story felt right to her, changing whatever was necessary. It was part of the original agreement for all participants. The issue that was a problem for her was my connection of the abortion she had in Holland to her later ‘nervous breakdown’. The following aims to make transparent the changes that were made, and how they came about.
A segment of the transcript [annonymised]:

‘Then I had a bad thing, I was pregnant. And I couldn’t bear that. I couldn’t stand that. I told the doctor ‘I’m not going to have this child.’ Because I knew what would happen … and so I had an abortion, which was done … by a doctor, but I was very ashamed, I’ve been ashamed ever since. I feel it was purely selfish reason to have it but I never should have done it.’

A later segment of the transcript:

I got ill, I think I had a sort of a nervous breakdown … the doctor said ‘if you go to school I’ll put you in hospital.’ It was a bad time … At one stage I left the family, when I had a nervous breakdown, I went to England to my daughter … It was a terrible time.

In the original literature search that Elizabeth had read I had written:

A sense of loss of coherence, to a degree matches Elizabeth’s story of her abortion and later her ‘nervous breakdown’ (Linde 1993 p.134). What seems to be missing in Linde’s overall view, as it sits with Elizabeth’s story, is my perception, (not suggested by Elizabeth), that at this point in Elizabeth’s life many of her previous losses of self coherence came together in a mass destabilisation. The abortion, the grief over her mother’s death, the struggles with her children’s births and health, the family’s car accident, the struggles with her teenage daughter, all were brought to a head by the girls’ school scenario and her feeling of failure, her sense of loss of trust and therefore integrity.

After she had read what I had written, Elizabeth said that I had made too much of the abortion continuing on to be part of the nervous breakdown. She had squashed the abortion by her confession, and also by going on to have more children. At this extra visit she said ‘it was a pity I had done it, but it wasn’t part of the nervous breakdown’. She went on to explain that her mother’s death probably was part of the breakdown, however mostly it was due to her feeling that she had failed in her job at the private girls’ school.

I asked if she still felt that she had failed as a teacher, or rather that the girls’ school had failed her, that they had not been as advanced as she was in their thinking about teaching.
She said that she didn’t feel now that she failed. She believed that they judged her as a teacher from a high school, who could not fit in to their environment. When she had the breakdown, the abortion was too far away, too long ago to be part of the cause.

She now feels that the things that have happened since have supported her decision to have the abortion. I asked if the emotional scar of the abortion would always be there, and she replied that ‘it is only a scar, ‘it doesn’t do anything’.

She felt, and her priest agreed with her, that she was punished by the difficult miscarriage that she suffered some time after the abortion. She believed that having been punished she could start to get better. It was not a lifelong grief. She doesn’t carry the abortion as guilt, however she still feels it was done for all the wrong reasons. Here she does like the idea of resilience, she got over it. She did it entirely for herself, it was selfish, not as I suggested courageous. She did what was best for her. She felt she simply could not stay in Holland and could not return to Australia pregnant.

I asked her if a strong woman was one who does what she believes she has to do for herself. We debated for a time the difference between (my word) courage and (her word) necessity. From now on she is going to refer to it as a termination, she hates the word abortion, ‘its horrible’.

We discussed the benefit of the process of therapeutic autobiography for her. She thinks that I have credited her with more courage and strength than she had, again because what she did was a necessity. She sums up her story with ‘I did what I had to do, always. The key word is necessity.’

I asked with a smile if there were no ‘pats’ for herself. She replied that she liked what she did, she likes the shape of her life except when it starts fraying around the edges, - and we both giggled. She says her intellect is alive and well, though her analytical prowess is not what it was. ‘But I can still talk.’ She had read her story with a sense of pleasure - ‘this was me, I said that, it was true!’ She said that our conversation had been fun.

I think this further conversation was an example of how re-focussing on an issue can help deepen and perhaps reframe a closer authority of personal meaning that had not been clarified before this point. After the art conceptualisation I had felt, a little uncomfortably,
that Elizabeth and I had not yet reached a *right essence* point in our work together. After this re-shaping of this one experience, I felt that we had reached a clearer *approximation to meaning* that sat more comfortably for us both.

Elizabeth had summoned me back because reading what she had said, and my comments and interpretations, had extended her own understanding beyond where we had stopped, and this further understanding brought an extended sense of completion. It felt more satisfying to us both.

2.6. **Following our further conversation, I wrote the following poetic summary, which I did not share with Elizabeth.**

*Feelings*

She feels that the final essence statement paints a kinder, braver picture than she deserves - though she would like to think it was her.

She feels sad for the world - will we ever learn to talk to one another - and listen?

She feels depressed for the world’s madness,

the blossoms and birds are not enough to ease her pain for a world gone mad.

The pushy Currawongs on the lawn outside the window are black, and loud, and she doesn’t like them.

She feels bad about the social worker who came this morning at her daughter’s insistence, to talk about the *package* she said they needed, to cope with staying at home.

They want to manage the things they can manage,

And have help with the things they can’t manage [like shopping];

not be offered help with things they can do,

and hear that the things that they need help with are *not available* [like shopping].

She feels sad that it is getting hard to communicate with one another because her husband is loosing his hearing, and forgetting his English, however he doesn’t want to talk to her in Dutch.

Her Dutch is excellent, but English is the language they used to establish their relationship in the beginning.
She feels hopeless about grandchildren who are overwhelming,
and eat all her biscuits, when shopping to buy more is so difficult.

She feels sad for a bladder that has developed problems, a surgeon to be seen,
who might not look at her and see all that she has suffered.
She fears falling on the stairs that give the house its character,
And bond it to the land’s slope.
She cannot bear to think that she might need to leave this home of over fifty years.
She cannot bear to think that she might need to lose her love,
he is getting so frail and slow.
If he dies, will I please come to visit so she might cry and cry -
she cannot bear to think of life without him.

Yet I “must not say reducing it down - ‘reduce’ on its own is fine”.
And whatever will your supervisors make of all this?

_She mourns her losses_

She feels grief for the world she has lost faith in;
She feels grief for the loss of independence,
and the failure of others to see her need and feel her loss;
She mourns the loss of deep communication with the one she loves most;
She feels overwhelmed by grandchildren and great grand children,
who cannot see her frailty and do not understand her sadness.
She mourns the loss of body strength that threatens her continence and stability.

Most of all she mourns that she might lose her beloved home,
and above all, her beloved life-companion.
If he dies, she will drown in grief,
she cannot bear to think of life without him.
2.7. **Journalling my experience of working with Elizabeth (summary)**

The full text of my journalling of my experience with Elizabeth is found in Appendix Ten, 3.

I connected deeply with Elizabeth’s story, acknowledging my own intrasubjective responses as they emerged. I admired her courage and loved her openness. She corrected my typographical errors, forever the school teacher. Her fluent Dutch and Indonesian impressed me. Her schoolteacher self slightly intimidated me, only perfect would do. There were connections in our schooling, the similarities evoked my memories of my schooling, especially Elizabeth’s tactics to avoid sport (an art form in which we both excelled). Her mother’s support to go to post-war Indonesia contrasted dramatically with my mother’s anxiety regarding letting me go as far as the nurses’ home in the same city.

My engagement with Elizabeth’s story was not difficult. There were bridges in her story to mine, the intense moments evoked some of my own painful experiences, though there were also many differences. I needed to become clearer about the meanings that were available for me. Particularly while writing the literature review, I sensed deeper connections triggered in me that. Through my own re-experiencing and journalling, I was separating my stories, bracketing as best I could, and responding to Elizabeth’s stories. I walked around for some time indwelling it all (refer Chapter Two, 3.8). I needed to be constantly aware that the inter and intrasubjective responses were interconnected, and that separating them completely is difficult. Her ‘nasty’ and ‘not nice’ confused me, they sounded *horrible* experiences to me. Years of training have taught me to listen to difficult stories, knowing that painful stories needed my attention and my own self-care came later. As one example, the story of Elizabeth’s birth of her first baby in Indonesia’s primitive conditions was shocking. It was not at all like the sterile, drugged Caesarean birth of my first baby, yet I reconnected anyway, to the grief of my experience, the shattering of my illusions as a midwife of the natural beauty of normal childbirth.

It was difficult to immerse myself in Elizabeth’s pain. I could not expect to comprehend it. I asked myself: ‘How did her family survive their traumas?’ This raised the next question for me: ‘How did my family survive its traumas over many years?’ I could hear the long term tolls it took on Elizabeth’s family, as she described their various ups and downs. Now I could sense and identify the bridge this evoked to the tolls on my family.
Her gynaecologist demanded she and her husband take a break after her miscarriage. I felt angry with her gynaecologist’s lack of insight. I identified with Elizabeth’s exhaustion. It took some time for my anger with this doctor to gel with other aspects of Elizabeth’s story and their connections to my experiences and passion, which I was coming closer to uncovering.

Elizabeth describes her mother and, listening to her story, I thought about how homemaking and hospitality were the best aspects of my mother. Elizabeth’s relationship with her sister was strained. My mother’s relationship with her sisters was fraught; my relationship with my sister has taken soul-searching for us both to reach a place of peaceful co-existence. Elizabeth’s family stories stirred up lots of my family memories.

Elizabeth ‘fell apart’ in a teaching position. I felt the connection to a nursing experience where my illusions were shattered. I consciously tried to bracket it out. The rules of the times didn’t worry Elizabeth, she lived within them. Some twenty years later for me, the rules were changing, however I have continuing annoyance with silly rules that in my younger years stifled and suppressed our full development as women (for example not washing one’s hair or swimming when one was menstruating).

I found it difficult to respond to Elizabeth’s story of her abortion. I searched the literature in order to understand what it might have been like for her to make this decision. I tried to immerse myself in Elizabeth’s description, so that I could feel her perspective. It sounded to me like a deep soul crisis. I could hear her pain and guilt yet it was hard to grasp her perspective. I wanted to plead with her ‘please forgive yourself’. It felt to me like a heavy burden she was carrying. I needed to stay with her never. I had to grasp her perspective and bracket my feelings and interpretations. I could not ‘fix-it’ for Elizabeth. I felt angry with her priest’s lack of compassion, I felt that he had cemented her into her guilt. I felt angry that he told Elizabeth she was not to discuss it. He was probably only expressing the view of the day, however it started to emerge and fit together for me, the imposition of power by her gynaecologist, and now her priest, that plugged into my core anger with the negation of the suffering person. The lesser person becomes in-valid and only the voice of authority stands. It is Buber’s (1923) I-It, and my mission has become seeing and telling the stories so that a different way of listening and being might surface. It is at the heart of my passion. Elizabeth said she never got over feeling guilty. I really wanted her to see that
lack of support, and her priest’s judgement, forced her to carry this pain ever since. But that was her story, not mine.

Sue Nathanson’s (1989) narrative helped me to make sense of Elizabeth’s experience, *from my point of view*. We demand that mothers provide perfect care for their children, knowing perfection is impossible. Here again, I can see bridges to my own painful experiences. My mother did not, and could not, protect me from the painful experiences in my life, no matter how distressed I felt with her for not doing so. Neither could I protect my children from the painful things that happened to them.

After her stroke Elizabeth *knew* she was dying, but felt responsible for her husband. She couldn’t leave without knowing he was alright. Somehow she felt that she had managed to turn her dying around before it was too late. This enhanced my understanding of what dying might feel like, I like the idea of knowing when the time is right. I am fascinated by near-death stories, they draw my attention.

Elizabeth’s narrative fell outside the medical imperative. The nurse who upset her only saw what fitted her nursing orders. How could any nurse not see Elizabeth’s ‘agony’ and offer her comfort? The nurse failed to hear her suffering. Again, I feel angry with power assumed by healthcare professionals. Elizabeth links me to my own story of ‘how could they act like that’ (refer Frank 2002, in the full text of the literature search, and Appendix Ten, 3). Here finally was the trilogy I had uncovered: the priest, the gynaecologist and now the nurse, silencing the voice of Elizabeth’s suffering, and challenging me to continue working with narratives to find ways of doing it better.

According to Elizabeth, I exaggerated her spring and bounce. Elizabeth is depressed about how the end of her life has panned out. Perhaps I want to think of myself as resilient. Elizabeth says her faith carried her, as did her loving husband. Sometimes it is simply human to fall in a heap. Elizabeth did, and I resonated with that. I feel blessed to have friends to support me when I fall in a heap. I empathised with her distress that her stroke left significant deficits. At my age I wonder how my health will pan out over the next twenty years, and how I would deal with similar issues. Elizabeth’s grief and struggle to accept these restrictions, impacted on me deeply.
In sadness and depression Elizabeth mourns many losses. I feel sad for her despair. Are these things I will need to mourn in time? How will I deal with my ageing, and find creative ways to cope with change and loss. I think to myself: we mustn’t believe our children should give us care, we must find independent support that frees our children to connect with us as they choose, not as we impose. There will be loss and grief, it is how we deal with it that should be creative.

Post Script

Elizabeth requested the opportunity to modify one part of her story that she felt I had misinterpreted. Commitment to changing the story until it felt right was part of the original agreement, yet I was anxious about how much change would be needed. However, I really enjoyed this further conversation with Elizabeth, and felt encouraged that the change was do-able. I had felt that in the original transcript, after her abortion, Elizabeth’s ‘ashamed ever since’ which I had interpreted/written as ‘life-long guilt’ had felt uncomfortable for her. We needed to change this part of the story to reflect how she saw it now.

After reading and reflecting on the work we had done, Elizabeth felt that I had made too much of the abortion continuing on to be connected to her nervous breakdown. She had quashed the abortion by her confession, and also by going on to have more children. The changes we made are documented earlier (2.5).

For me, overall this felt much closer to the authority of Elizabeth’s own personal knowing. It now sat more comfortably in her story’s meaning. Therefore this was better for me as well; in this latest meeting we were in agreement that the best approximation to meaning for us both had been reached with a sense of pleasure. I felt real delight when she said that she read what she had said and thought ‘this is me, it is what I said, and it is true!’

I asked with a smile if there were no ‘pats’ for herself. She replied that she liked what she did, she likes the shape of her life except when it start fraying around the edges, and we both giggled! I might ask myself how many ‘pats’ I am ever inclined to give myself.
2.8. The final essence statement

A strong resilient spirit

Within the core circle of her resilience was her family,
the values they taught her, the music and the love.
She had a rich, colourful, intelligent, adventurous, literary, artistic, romantic foundation.
She had a very strong sense of herself and what she wanted to do,
a strength of spirit, a robust set of values and a willingness to struggle with life.

So throughout her life the ruptures and fractures couldn’t destabilise her for long.
She had sufficient maturity and determination
to form a strong enduring loving relationship
that held firm throughout the difficulties, challenges, losses,
griefs, not-belongings, pains and agonies.
There’s something overall that I haven’t grasped yet -
there is something more about this person:
a quality, an intelligence, an honesty or outspokenness - what is it?

I am in awe of the richness of her spirit, she is an admirable role model;
She’s anything but locked-in, or locked-up, despite her physical deficits.
a strong resilient spirit, I’d like to be like that when I’m her age.

She’d had an adventurous, colourful life, she could have been a free spirit
simply riding, floating on the top of the waves,
without life’s challenges, difficulties and fractures touching and moulding her.
However she allowed herself to be needy, broken, agonised, suffering.
She allowed herself to be tried by life’s fire and shaped into a rich, creative fullness.
3. WHAT CAN BE GENERALISED FROM LISTENING TO ELIZABETH’S STORY?

This narrative highlights the bitter memories a patient can retain after surviving a critical illness. Painful treatments, however well intentioned and medically worthy and successful, nevertheless require compassionate explanation to the patient and their family. To not respond to a patient's distress, and to not find time for such basic care as oral hygiene, is not acceptable nursing care.

Another issue arising from this narrative is that if indeed patients are able to influence their survival and 'come back', that the deficits and difficulties of their subsequent life might well bring agonies of regret, depression, sadness and grief.

When a patient is deemed to be dying and the family is present around the bed, this narrative highlights that the patient is not cut off entirely from awareness of what is happening. They are able to recognise gentle kindness and care from nurses and family members. Soothing explanations, good oral hygiene for comfort, are surely acts of compassion that are the imperatives that undergird the skills of nursing care.

As I consider the possibilities of listening in these situations, Giullemin and Gillam (2006, p.47) comment:

… what is the remit of health professionals; can they take (equal) care of all dimensions [of care/treatment]? One way to think about this is to consider different health professions as specialising in different dimensions of wellbeing. But we need to be clear that this does not mean they can be cavalier about the others … this does not mean it is ethically acceptable to ignore the possibility that medical treatment might cause psychological suffering.

Healthcare professionals might indeed be pleased that their skill successfully saved a life. But not listening to a patient's suffering leaves lasting distress, and is what is often remembered most clearly.
Chapter Eight:
Reflecting on the process of listening

1. INTRODUCTION
This study modelled and amplified a process of reflective listening, companioning and intersubjective dialogue. It involved adopting a stance of ethically mindful awareness. It illuminated how the crystallisation of meaning, that is, learning about oneself, one's world and one's experiences, can be extended and enriched by these processes of intersubjective, reflective listening. It confirms that there are better ways of listening to people who are ill, which enhance the wellbeing of not only the ill person, but also their family members and healthcare professionals.

This chapter begins by examining the significant findings of my study and how this inquiry expands existing knowledge. These findings are not listed in order of importance, but rather written to indicate their interconnectedness.

1. The processes of deeply engaged, empathic, reflective listening to a person’s illness narrative within the context of their life review narrative, enables meaning to be found in their illness and other traumatic life-disruptions.
2. Meaning is constructed around and through the narrative-telling itself.
3. The narration and dialogue enables coherence to emerge from sometimes chaotic or confusing situations, contributing to the construction of an enhanced self-identity.
4. A person’s story telling, reflections and meaning making can occur within the difficulties and limitations of terminal illness and dementia.
5. Representations of the experiences in a variety of expressive forms, including poetic and visual forms, can facilitate the emergence of meaning. The written record of the life review itself becomes another significant tangible form of meaning.
6. Adopting a respectful, mindfully aware attitude recognises that the whole person is central in facilitating the narrative and meaning making.

7. Respectful, mindful awareness involves:
   • Reciprocal recognition and trust that facilitates descriptions, assisting the person to narrate their experiences.
   • Walking with the narrator, and engaging empathically as an active participant.

8. The narrative processes of the study contributed to the emergence of a sense of the whole person: that is their bio-psycho-social-spiritual being.

9. For each narrative engagement the listener requires awareness and respect for the ‘other’s’ life situation and values, and courage and self-awareness within themselves:
   • The qualities of ethically mindful awareness include the listener’s fully present, empathic, reflective listening: a capacity for intrasubjective and intersubjective responding; and developing appreciation of the social and cultural settings of the ‘other’. This requires remaining within the framework of appropriate ethical boundaries.
   • The listener’s intrasubjective responses throughout the narrative processes add a considerable dimension to deepening meaning within a narrative’s co-creational experience.

10. The study’s narratives reveal that the failure to provide attention to the entire bio-psycho-social-spiritual person produces feelings of anger and deep disruption to a person’s sense of wellbeing. This leaves the person possibly angry, disempowered, uncooperative, rebellious, deeply hurt and alienated.

11. The study, through its range of narrators, suggests that the processes of telling and listening to illness narratives and life reviews are in themselves learning processes for an empathic listener. This has particular benefits for healthcare professionals, such as coming to appreciate something of what suffering deep illness might be like.

The study expands previous research that has relied on gathering patients’ narratives through more traditional interviewing techniques. Throughout this chapter, particularly in Chapter Nine, Section Two, at various points such as at the end of each narrative chapter, and in Appendix Eleven, there are summaries of the study’s expanded knowledge that might be used by healthcare professionals in their everyday practice. The list in the following section proposes the ways in which this model of listening enhances the overall
wellbeing of narrators and might also expand the knowledge and wellbeing of healthcare professionals.

Chapter Eight now explores these findings further by reflecting on the processes, effects and problems of the study. It firstly explores what it was like for the narrators to be listened to in this way and why listening made a difference. It notes what it achieved for me as researcher to listen with reflective engagement to the life stories and reflections of others, and how people’s selves evolved through the process of telling their illness and life stories. It is then possible to list further qualities of engaged reflective listening, and to describe situations in the study where listening was not optimal. The question ‘was it therapy?’ is addressed, followed by discussion of difficulties that were encountered. I note how relevant literature anchored the study. Reflection follows on the process of synthesis and the essence statements that ended each narrative. The resilience of the narrators is discussed, also the notion that the stories are not finalised. The chapter concludes with critical reflection on the methodological framework of the study, including a meta-map of the study’s processes.

2. WHAT HAPPENED WHEN THESE STORIES MATTERED AND WERE LISTENED TO?

There are commentaries on the benefits for each narrator in Chapters Three to Seven. Mutually enriching conversations expanded our knowledge of ourselves, our life experiences and their meanings. The following summary reiterates how the process of narrating their life narratives was significant for the narrators and for me, and some of the values of the study’s model of listening:

- Making sense of suffering
- Creating safe spaces that could be trusted to contain the story with all its emotions
- Enriched self-awareness and self-knowledge
- Affirming one’s values through the life stories of others
- Making sense of, and giving significance to life experiences
- Creating and telling a coherent story that could be valued and validated
- Developing possibilities for fresh approaches to one’s life through a re-told story
- Reassurance in understanding withdrawal in the dying process
• Making stories available for future generations (capturing the essence of the person)
• Transcending unsatisfactory situations such as dementia units
• Recognising possibilities for expanding healthcare staff’s willingness to find ‘good’ qualities in ‘difficult’ patients
• Facilitating expressions of grief enabling amended accounts that are more satisfying
• Listening to stories about different cultural settings expanding knowledge of one’s own cultural background
• Making some difficult and painful stories narratable
• Understanding and respecting that some difficult stories need, in the best interests of the narrator’s wellbeing, to remain un-narrated, lying in tension with many current psychotherapeutic methods.

Part of the benefit of telling one’s life story is developing an understanding of one’s past through the process of articulating aspects of one’s life. What one chooses to bring to consciousness and to share in dialogue is valuable, or gains value in the process. This value is then potentially available for others. For instance Bert’s grandchildren, might come to read and form a different understanding of Bert’s identity and how he fitted into his family’s narrative. The psycho-geriatric unit staff might read Bert’s stories and understand the nature of disempowerment that arises through suffering from dementia and the need to live in a secure unit.

Via empathic, ethically mindful listening, I entered into and engaged with the narrators. Co-creating their narratives built bridges and connections between my world and its narratives and experiences, and their worlds, narratives and experiences. The discussion now explores how each narrator and I created a space for sharing, and how owning and presenting the varied facts and experiences of our lives, leads to new meanings and a freshly conceptualised sense of our self-identities.

The construction of these narratives provides opportunity to reflect on the effect of this model of listening, and why it matters to tell one’s story and be heard. The narrators told stories of particular disruptions in their lives, and how they dealt with the sense of disconnection that these situations brought about. I argue that in each case there was a contribution to the individual’s understanding of their lived experiences.
Emerging from within the disruptions, the narratives describe who each of the narrators saw themselves as being, often in the light of a medical system which Frank argues has neither time nor interest in who people are. ‘Stories tell those things that defy commonsense reciprocal recognition, yet seek to be heard, seen and recognised’ (Frank 2001b). From this perspective, a brief review of each narrative follows:

- Kaye’s mother’s unexpected death disrupted Kaye’s sense of identity. Co-creating her story and thereby validating her experiences, enabled her to gather together a more coherent and stable identity.

- Elizabeth told stories of a variety of disruptions throughout her life. The latest blow happened when she suffered from a stroke and heart failure. Her suffering was told, re-shaped and acknowledged, thereby perhaps making it a little more bearable.

- Bert’s behaviour erupted from his alcohol-induced dementia and disrupted the peace of the unit where he lived. I listened to his stories, and could hear, through the tangle and confusion, his identity as a whole person. The process of narrating his story clearly engaged Bert and enlivened him. The staff also needed to know and acknowledge who Bert was in order to make more permanent changes to his wellbeing and a more peaceful unit for other residents and staff. I am not at all sure this happened.

- Scott was withdrawing from the world in preparation for his death. Accepting this as a natural, peaceful transition rather than ‘depression’ smoothed over some of the disruptions to his tranquillity. When he moved from his special accommodation in the city to a nursing home in the country, the staff there needed to listen and know who Scott was before he was able to settle back into peaceful transcendence.

- Sarah’s life was disrupted by her deep illness and her sense of not being heard by her healthcare professionals. In Sarah’s case, having her experience heard was important to her. As Frank argues, (2004a) it is difficult to express a complaint from a position where complaining is a problem. Sarah said:

  I don’t like to be too complaining especially when I know with what I’ve got and the treatment I’m getting, I’ll be seeing them at least for a few months, if not for a few years … If I antagonize them, complaining all the time … so I try to keep my big mouth shut, but it’s very hard.
One might ask what Sarah’s purpose was in telling her story, and who she expected her audience might be? My response, since she cannot answer for herself, is that she trusted me to make her story known. I think she implied that if I managed to share her story with others, particularly healthcare professionals working in palliative care, then like Lorde (1997), her suffering would have some meaning and not be wasted. Sarah’s story is marked by pain, compounded by her feelings of censorship of her pain (Frank, 2001b, p.6). Whilst she had complained to many people, telling the whole story to me was the only occasion where such a version was narrated and sincerely heard. In that process it was validated and strengthened (Winslade, Crocket and Monk (1997, p.72).

Galeano (1992, p.72) tells a poignant little story of a doctor working late in a hospital in Managua on Christmas Eve. A small child creeps up to him. The doctor can see that the child is dying. The little boy gives the doctor his hand and whispers ‘tell someone I’m here’. Frank (2001b, 2005b) proposes that in co-creating this story, the child is seeking to hold his own. He registers his suffering and seeks recognition from the doctor. Galeano’s story reflects the five narrators of my study, where each narrator was trying to co-create the understanding that they mattered. It was as if, like Galeano’s boy, they were saying ‘tell someone I have had these experiences, tell someone my life feels out of control, tell me that I matter, that my life means something. Tell me that you can see, hear and feel my aloneness’ (Moustakas 1961). These five narrators, like Galeano’s dying boy, remind us that the ill and suffering are there, they are not invisible, and they call on others to recognise what it is like to be there. Throughout the processes of the study, I was challenged by the thought that this could be me - there.

Frank (2002a, p.2), in discussing the dialogical ethics of narrative analysis, asks ‘Why study people’s stories?’:

The stories were about the kind of cleverness necessary to get on in the world, the kind of humour required to persevere, what people and situations to look out for, and what actions were memorable and even exemplary.

This rings true particularly in the narratives of Sarah, Kaye, and Elizabeth, and also in Bert’s confused confabulations. Their narratives remind their listeners or readers who the
narrators were and were not, and why that identity was valuable. Being true to oneself and the things that matter:

requires on-going dialogical recognition from others that one’s life expresses values they share (Frank 2002a, p.5).

Particularly for Bert and Sarah, there was a need to re-affirm who they were via the stories of their experiences. Sarah seemed to understand her need to situate her narrative beside the tacit master narrative of her healthcare professionals who described her as difficult. In Chapter Four there are many expressions of Sarah’s feeling that she was not known by the palliative care team other than as difficult, or as a body with cancer: ‘They only see the cancer, they don’t see me!'

Sarah and I co-created a structure that coherently integrated her dying back into her life narrative (Cheshire and Ziebland 2005, p.21). Bert was confused in his expression of the concept of integrating his dementia into his life stories. As I transcribed and worked with Bert’s narrative however, it produced a strong feeling in me of seeing and reaching the person Bert was and had been, despite and through the fog of his dementia (Nelson 2001, p.71). Sarah told an articulate narrative of a damaged, disrupted identity, and I felt that concept strongly underlying Bert’s narrative. I cannot know how much Bert understood this, other than from his statement ‘this is my life’, when he saw the completed document we had co-created. Nelson (2001, p.15) argues that:

Through one’s own and others’ selective, interpretive, and connective representations of the characteristics, acts, experiences, roles, relationships, and commitments that contribute importantly to one’s life over time, an identity makes a certain sort of sense of who one is. It does so because it is essentially narrative in nature.

The narrators’ cultural values emerged constantly from all five narratives, for instance the strong family values of not drinking alcohol that permeated Elizabeth’s narrative, and the heavy alcohol consumption and values of mateship that coloured Bert’s narrative. Frank (2002a) discusses the work of Bourdieu (1998, p.25) and his understanding of habitus, as ‘the things that matter,’ reflecting the culture where one belongs or has social capital.
Bert’s stories are who he is, as we created the stories dialogically, despite and through the difficulties of his confabulations and confusions. My study affirms that authenticity is interpersonal, and the process of narrative research has the potential to model how people can most usefully listen to and recognize each other’s stories (Frank 2002a).

Bert’s stories set the scene for deeper understandings available within his narrative. His present plight is still terrible. Yet at least I managed to ‘hear’ who he was and is now, at a deeper level than appears on the surface of his non-negotiable existence in the nursing home. Denzin (1989b) argues that to understand a life, with the epiphanies and the personal experiences and self-stories that shape that life, one must penetrate and understand the cultural, ideological and historical contexts. They are what Bert proudly remembered best and described with relish.

Kaye used the phrase, ‘my whole life is story.’ Brody (2002, p.151) argues that narratives ‘stand with both feet on the ground of earthy human experience, be it factual or fictional’. Thus I understand that I am also a storyteller. I learn in stories and by stories. I am grounded in the earthy human experiences of my nursing and personal life, rather than being predominantly persuaded by theories and principles, which is where my sense of discomfort as a nurse demanded my attention a decade ago, as described in the introduction. Here is my own grounding in experiences of disruption. Stories often do not fit comfortably into frantically busy, economically rationalised healthcare relationships and settings.

No two people can occupy the same place at the same time. They will not necessarily see the same things. Throughout Kaye’s stories of her mother’s death, described in the context of their family cultures and values, Kaye saw that her brother interpreted their mother’s death through his perceptions, not hers. He had reacted differently. In Sarah’s brother’s response to Sarah’s stories this notion was also apparent. He said sadly that he was now unable to argue his different perspectives with her.

There are many factors that might account for discrepancies in individual accounts of shared experiences, ranging from family position (Millman 2004), social position and cultural capital (refer above) through to purpose, temperament, and inclination. All these factors lead us to question our environments differently. Nevertheless, ‘we can enter into
each other’s perceptual fields’ (Crossley 1996, p.30). I qualify this, however: only if we are deeply aware and listen with respect.

For several of the study’s narrators, the recording of their life review narratives was limited by their physical or mental illness, layered over their previous ways of dealing with meaning in their lives. Even these limited narratives have overall significance extending beyond their immediate narrating - in terms of the potential understanding and meaning embedded within them. This is available to others as a tangible life review document, for example for Scott’s children and grandchildren, Sarah’s relatives in Israel, and possibly Bert’s family who might later engage with his narratives. The discussion now explores the notion of hope that grew from the processes of reviewing one’s life experiences and having them heard and validated.

*The generation of hope*

Helping each narrator find meaning in their experience and treating each person with respect and dignity, assisted them in finding hope. Engaging in the process of telling me their life stories enabled them to feel they still mattered.

Hope is a belief that something good lies ahead. Themes emerged from my study concerned with the generation of hope, such as connecting with people and finding a common bond. Another significant theme was seeing the person as they were before the illness. This was important in order to hear the stories as they were set in their time, not how the narrator was at the time of telling their story. I could picture Bert as an active, intelligent journalist, rather than the wrecked man residing in the psycho-geriatric unit now. Participating in narrator’s experiences by careful listening and engagement, and affirming their values, for example Bert’s love of South Australia, were attitudes that generated hope (Perry 1996).

Arising from within qualities of reflective listening, the narrator has the opportunity to be care-fully heard (Monk et al. 1997, p.66). An act of ‘attentive reflection’, invites the narrator to hear themselves in a new way and to be audience to their own story. This engenders courage, resourcefulness and hope. Having reflected on the listening processes for the narrators, I now explore the effects and findings from my perspective as listener.
3. ENGAGED REFLECTIVE LISTENING TO OTHER’S STORIES

3.1. Entering other’s stories as a component of reflective listening

Entering into the stories of others is an integral component of reflective listening. I facilitated the building of bridges and connections between the narrators and me, through whatever multi-modal method seemed appropriate.

Throughout the process my dream world rocked with tangled images of the narrator’s stories and mine, with messy, shattered illusions. The literature validated this experience for me. I read of Traylen’s (1994, p.72) vivid dreams as she struggled through the collaborative inquiry process. I was without doubt engaged. I ‘caught’ Kaye’s chaos, the pain of Elizabeth’s birth stories, Sarah’s anger and grief. I sat beside Sarah’s desperate loss of control, and in so doing revisited my illness experience and my silenced voice (refer Introduction). I saw that the most difficult thing required of me was perhaps the greatest gift Scott offered me. To build a bridge between us, I had to become slower, older, quieter, if I wanted to hear his wisdom. I felt despair as I tried to become Bert, I felt locked up, powerless, controlled, angry, upset. I wondered how my health would pan out over the coming years (Moustakas 1990). This was connection at a deeply empathic and engaged level. ‘I see old people now in a new way, as part of me, not they’ (Myerhoff 1979, p.19).

There were significant benefits arising from the life narrative process for me. These were chronicled in my journal. I concentrated these benefits by reducing my journalled experiences to four pages (refer Appendix Twelve).

3.2. The journalling process

My journal’s validity rests in my aim to explore my own resonances with the experiences of all the narratives presented in this study. This includes those in the introduction and Appendix One, and particularly the study’s five narrators. The journal entries bring my voice and responses to the multi-vocal discourses of the narratives, as demonstrated in Figure 35 and Figure 36. My intention in writing the journal was to form, in various modes, my perceptions, reflections and conceptualisations of the experiences of ‘being in’
or part of the narratives’ co-construction. In the end its validity for me was that it ‘felt right’.

The poetic reflections I formed as part of my journalling are creations that embrace intuitive and tacit things that may not have been articulated in the essence statements. They become another way of drawing things together within me, the resonance of my experience, towards what I have heard. The poetic shaped expression might utilise different words, but is a further approximation to something that has as yet remained unsaid. My journalling process is also discussed in Chapter Two, 3.3 and 4.1(b), the poetic reflection process is discussed in Chapter Two, 3.9, and the value of writing in this more intuitive way is reflected in the final poetic essence summary that concludes the thesis. However I now offer several excerpts where my emotional reactions are transparent:

**Bert:**

‘As I transcribed I felt my intrasubjective responses surface. My pacifist self began to react to Bert’s almost complacent acceptance of bombs and mayhem in his war stories and I needed to acknowledge these feelings:

Being just post-New York terror,
I want to scream ‘No! You were young men,
So were ‘the Japs’ as you call them, so were the people of The Ruhr Valley
whose dam walls you biscuit bombed’.
Our world hasn’t yet found a way other than violent.
I feel a sense of drowning in despair for the world,
*my* dam wall breached by terrorism’.

**Sarah:**

A powerful cry rose in me as the impact of Sarah’s suffering resonated in me. I felt her loss of dignity, loss of comfort, loss of control. I extracted one particular illness story, and from it came my own deep cry of understanding how her pain might have felt for her.
This poetic reflection appears in Chapter Four, 2.3, called ‘Where was the care?’ It ended with my expression of Sarah’s explosion of ANGER! and REFUSAL!

My journalling process deepened my own self-awareness, for me one of the most significant benefits of this model of listening.

3.3. **Self-awareness: knowing oneself through the lives of others**

To paraphrase Buber’s (1923, p.54) words, ‘one needs to know one’s I, before one can know the other’s Thou’. This is self-awareness. Yalom (2008, p.1) proposes that

> self awareness is a supreme gift, a treasure as precious as life. This is what makes us human. But it comes with a costly price: the wound of mortality. Out existence is forever shadowed by the knowledge that we will grow, blossom, and, inevitably, diminish and die.

From within in a lifetime of illness and other narratives (refer Appendix One) I have found crystals of meaning such as an enriched understanding of what life is like for others. Listening to Kaye, Scott, Bert, Elizabeth and Sarah enabled me to be more aware of myself, with richer understanding of life’s suffering, experiences and meanings than before I began the study. I could not have engaged at the level I did with each narrator without searching within myself and reaching deeper self-awareness and self-knowledge. I understand that to feel heard and understood is one of the most precious aspects of life, and I accept Yalom’s ‘cost’ - the wound of my own mortality.

There is no story without a listener, be it mine, or others’. Meaning was formed in processes of engagement: mine, theirs, and others who might read this thesis or subsequent publications (Stein 1998). Perhaps the meanings that arise require perception, sensory openness, and a willingness to engage horizontally across the breadth of the experience. That is, having a phenomenological stance, which is an approach to life I find enriching.

There is also a preparedness and interest in reflecting on the experience, a capacity to explore relationships, and willingness to continue to hold all the dimensions of experiences, including one’s conceptualisations, felt senses, and emotional aspects, even when they might confront one’s fears and prejudices.
I knew that my own intrasubjective responses existed and needed to be bracketed as much as possible whilst listening to the narrators. There were occasions where I had quite strong inner reactions to parts of the narratives: Kaye’s and Bert’s descriptions of alcohol and other substance abuse; Elizabeth’s descriptions of abortion, difficult miscarriage and traumatic childbirth; interpretations of religion, issues of ageing and dementia, and my fear of what that might be like for me. In my journal I wrote: ‘Key point: I don’t think I like this picture of old age and seeing myself being like that ...’

I needed then as a separate experience, to bring to awareness what the narrator’s story resonated within me. This often happened while I was transcribing the interviews, and I journaled my responses as honestly as possible. Taboos and judgements are taught well and lodged deeply, and need to be brought to one’s consciousness. Whilst this can be difficult emotional work, it is a satisfying way of working. Each narrative engagement encouraged me to deepen my self-knowledge. Understanding myself was part of the process of understanding others (Douglass and Moustakas 1985).

I came to understand others’ reactions to their life experiences, and this enriched my understanding of the differences of meaning we individually attach to our experiences. I noticed there were myriad ways of seeing the world. In listening to and learning about each person’s life, I was confirming who I was, questioning my fears and strengthening my values and meanings. I loved the feisty feminine narratives told by Kaye, Sarah, and Elizabeth. I was able to clarify and comprehend life’s normal tragedy. In communicating with care, we created the kind of relationships that fulfilled my wish for a community of empathy, balanced participation, respect and I-Thou/Being-to-Being equality, as Richardson proposes:

   Surely as we write ‘social worlds’ into being, we write ourselves into being (Richardson 1997, p.83).

I felt sad that I could not finish the work Sarah and I began just weeks before her death. Her voice was silenced by her disease, her family and her healthcare professionals, and this evoked my anger. Sarah touched a wish in me to speak for other silenced voices. My intense engagement with Sarah’s story stimulated a desire to ‘oppose the censoring’ of the things that did not fit the healthcare professional/hospital narrative (Frank, 2001b). I heard
Sarah’s lonely cry for help, and felt compelled to walk with her suffering. I was her reflective listener, rather than defender of healthcare professionals. In each narrative chapter I describe the emotional reactions that each story stimulated in me.

I came to understand that my postgraduate studies have partly been aimed at ways to amplify silenced voices so they might be heard (Frank, 2001b), and this is reiterated in the concluding section of the thesis where I re-state my a priori values and experiential findings. I felt Bert’s disempowerment so strongly my anger and despair were again called forth. Listening to Elizabeth’s experiences finally brought it together in my journalling. I finally grasped my ‘silenced voices’ passion. It was difficult to bracket my feelings and interpretations. To me it felt like the stories had been engulfed by Buber’s (1923) power-laden I-It. My mission became to listen to, reflect and understand the stories so a different I-Thou or Being-to-Being, more equal intersubjectivity might emerge. This understanding brought a sense of meaning of its own. I finally identified the sources of my anger. This perception becomes the specific focus or direction of the thesis I am proposing, that empathic listening is fundamentally based on I-Thou, or Being-to-Being intersubjective equality.

As mentioned earlier, by listening I facilitated the building of connections between me and each narrator. I felt a sense of delight as I felt the connections strengthen with trust, for instance when I received the paper towel booklets that Bert shyly offered me at the beginning of several sessions (refer Chapter Six). The essence statements, and the narrators’ responses were deeply satisfying, as from each person’s story an undercurrent of meaning slowly emerged.

These processes have enriched my values and integrated crystals of meaning into my life. They enhanced my relationships outside my work, with family and friends. My reactions are different in my relationships, with deeper understanding of the nature of being human.

My nursing experiences and study gradually equipped me over many years to sit with, listen and talk within the unique encounters with suffering and death that occur particularly in healthcare relationships and settings, but also unavoidably in my personal life. It was an important skill for listening to several narrators who were close to death
when we recorded their narratives. I could listen without anxiety and could understand the value of this ability (Brennan 2007, p.239).

I came to see that, as Mackay suggested (1998, p.145, see Introduction), I needed, and found, the courage to listen. I needed to understand that ‘the telling’ was the narrator’s and I was required to allow this to flow in its own way, and not to control or steer it. For example, there was a need for me to stay with Kaye’s chaotic process if she was to grasp the possibilities for change. Kaye said telling needed courage on her part. I needed courage to go with Kaye’s chaotic flow towards changes and not try to order her chaos. I needed to be prepared to sit in ‘unknowingness’, or ‘not knowing’. It required a willingness on my part to maintain the disorganisation of searching for understanding, in order to find clearer crystallisations. It involved being willing to engage in the chaos of collaborative inquiry (Traylen 1994, p.72). By listening with ethical mindfulness I received the gift of the story, and was prepared to risk being changed by it. I am aware that the stories of my narrators changed me.

I also needed courage to be comfortable with the emotions that often accompanied the telling of difficult stories, for instance Sarah’s intense anger because she felt unheard and unacknowledged by her palliative care team.

Self-awareness can now be argued to be one of the qualities that emerged from listening to the narratives. It arose from, and was an essential component of engaged, reflective listening. There are additional qualities of engaged, reflective listening that are uncovered by the study’s model of listening.

4. **FURTHER QUALITIES OF ENGAGED REFLECTIVE LISTENING**

With hindsight I have gained perspectives on many ways of listening, the environment for listening, the types of dialogues I experienced, and how better to maintain them. I reflected on the forms of responding, the multi-modal aspects I used, and ways of extending the concept of narrative to include other forms of expression or language such as silence and body language.
4.1. **Listening to cultural contexts**

I needed to engage with the narrators’ cultural contexts, which also often prompted intersubjective resonances with my own cultural background. Cultural knowledge became a rich resource for connecting with and extending the story. A simple example: Bert and I had a happy conversation sharing childhood memories of helping to ‘bottle’ fruit. Cultural knowledge is uncovered by listening carefully to people’s stories, with their illness stories told in the context of their life review stories. On a number of occasions Bert described his family’s culture of mateship and heavy drinking. This continued through his war experiences, and throughout his life as a journalist. There is evidence in Bert’s and several of the other narratives where prior cultures and experiences seemed to be not known, or not given any credence in the person’s situation.

4.2. **Empathic reflecting and re-iterating**

Engaged listening involves not just hearing but fully attending, in other words, *mindful* or deep listening. By empathic reflecting and re-iterating, the person knows they have been heard correctly, and the multi-modal intersubjective responses were an important part of this reflecting process (Further discussed in Chapter Seven, Chapter Eight, and Chapter Nine, 1.1.1). As a good listener, I needed a sense of responsibility to respond intersubjectively, offering my sense of what I had heard. By listening respectfully because the teller and their story mattered, differences between the narrator and me as listener could sit intersubjectively ‘side-by-side’. Listening to each individual person’s story involved a different quality of listening and reflective engagement in each context. It thus acknowledged the individual’s values without the necessity to share them.

4.3. **Gentle, sensitive and unhurried listening without interruption**

My listening needed to be gentle, sensitive and unhurried, without interruption, with permission given to continue talking until the story was sufficiently told for that particular telling. When there were interruptions to the story, and sometimes I recognised this whilst transcribing, I could return to that point at the next session.

4.4. **The struggle to find the words**

I needed to accept that people might struggle to find the words for their experiences. I noticed how nonverbal language, such as sighing or tears, enriched listening. Silences also
deepen the story and the listener’s understanding. This was something I learned, especially with Scott, who was frail and dying. Sometimes after a long pause, when I was about to jump in, the most precious gems of his wisdom emerged. The times when I did jump in clearly weren’t helpful. As previously stated, with Scott I needed to become slower, older, quieter, if I wanted to hear his wisdom. This reflects Buber’s (1923, p.59-63) argument that by becoming and being what is to be known, rather than remaining as the outside observer, one reaches maturity.

4.5. Allowing the story to change
The story might change as it is told. With careful, empathic, reflective listening, I learned to assist the storyteller to produce a coherent story that made sense. In this way I validated and affirmed the story and its experiences.

4.6. Accepting the risk of being fallible and inviting correction
As an engaged, reflective listener I needed to accept being fallible - the uncomfortable position of knowing I might be wrong. There are a number of examples of this occurring in the narratives, particularly Kaye’s (Chapter Three, 2.5) and Elizabeth’s (Chapter Seven, 2.5). I made mistakes or assumptions and needed to invite correction, or further explanation, another description, or deeper understanding. If I had not run this risk, then I would not have fully experienced that central place of getting it right for the moment. The willingness to be open to making the space for correction therefore becomes one of the qualities of good listening. This acknowledges that everything is approximate, and continuously negotiable.

4.7. Listening to difficult stories
Engaged, empathic, reflective listening made room for descriptions of difficult, painful experiences. It required me to be open to hearing the other’s story no matter how difficult or painful. Respectful listening also required me to accept that some stories are best left untold, for the wellbeing of the teller. This is further discussed in Chapter Eight, 13.12.

4.8. Sharing information
In the process of responding intersubjectively and using literature and internet material to access further stories, I shared various multi-modal offerings with the narrators. I came to understand that good listening required me to offer information gently, in a way that
understood what it might be like to have difficulty remembering, or to be confused. In offering such information, on a number of occasions I was aware that I confused Scott and Bert. With Kaye, I was able to interpret medical language that had confused her for the ten years since her mother’s death. Her confusion had irritated her and it was straightforward to untangle her confusion with precise interpretations of medical terms.

After working in Bert’s dementia unit, I empathise with Zaner’s (2004) concern that Kitwood’s (1997, p.1) ‘rising tide’ of dementia, might include him. It might also include me. The confusions and confabulations of dementia require special understanding to hear what lies at the heart of the often-tangled story. This was a rewarding revelation to me after listening to Bert’s narratives. I found and knew Bert’s essential self despite, and through listening to his tangled confabulations.

4.9. Less than optimal listening

Deeply connected listening - staying immersed in the phenomenological stance of being open to each narrative - allowed me almost always to notice the entire horizon of what had been said. However there were also things that I did not notice, the significance of which did not rise in my consciousness until transcribing later. I cannot imply that I heard everything in the narratives, there were obvious imperfections. Was this bad listening? Were they lapses in my concentration, or are there times when one needs to be aware that one cannot listen deeply due to particular circumstances such as external distractions or lack of time to fully engage in the story being told? Perhaps there are times of fatigue when this depth of connection is not possible to sustain. There are times when one can return later and try to make amends by re-visiting that part of the narrative. Sometimes that is impossible, such as with people like Bert suffering from dementia. Once the moment of telling has passed, it has gone forever.

I now understand that I can never be fully equipped to deal effectively with everything that surfaces in narrative work. One difficulty was knowing when I had not listened or fully comprehended what was said. There is a range of not listening: there is choosing not to listen, there is listening when one is aware that one cannot listen well enough because there is insufficient information, for instance the difficulties I had working in Bert’s unit. But there is also not listening when the listener is not aware that they are not listening (Egan 2002, p.75). That is the disconnection that surfaced as a significant problem in the
illness narratives of my study, particularly Sarah’s, and in many of the narratives in Appendix One. This seems to cause the most disrupted sense of wellbeing. It negates the narrator’s sense of their story mattering.

In order to understand not listening, I now reflect on occasions I recognised when I was unable to listen fully in working with the five narrators. The transcripts revealed times when I did not hear. Then I was re-connected with what was said as I transcribed the tapes, causing me to ask myself why I did not respond immediately. I consider how I might have listened differently, summarised here and discussed fully in Appendix Eleven, 2.

Kaye:

Had I discussed the method of reduction to an essence statement with Kaye in depth before we began, she would not have felt so anxious about the deconstruction or reduction of our precious creation. In other words I needed to get past my ‘system’ and listen to her more carefully. Then I might have understood her perception of the ‘fragmentation’ she objected to, inherent in my process of reduction/analysis. It took me time to absorb how it felt for Kaye.

Bert:

It would have been helpful for me to understand the nuances of Bert’s unit’s structures and philosophies, in other words having more information to work with. It was a difficult setting. It did not permit a relaxed feeling, when I was trying to listen carefully to Bert’s stories. It did not seem to bother Bert, he lived with it, but I could understand why he hid in his room. On two occasions I did not notice the titles of the precious paper-towel booklets Bert gave me until I got home and took time to look at them and absorb their significance. By then it was too late to comment on them - he would have forgotten them by the next session.
Sarah:
Because the staff of Sarah’s palliative care unit interpreted me as ‘siding with’ her, they withdrew from supporting the work we were doing and simply observed from a distance. I needed to clarify for myself what my role was from Sarah’s point of view, and listen from that vantage point, and not as a healthcare professional.

I learned eventually to manage the tape time to suit each narrator and my capacity to transcribe the tapes before each subsequent interview. One-hour tapes were ideal. Ninety-minute tapes lead to listener/transcriber fatigue. I used three ninety-minute tapes for Sarah because of the urgency of her situation, and worked hard to transcribe them as quickly as possible, but this was not ideal. It reduced the time for my inter and intrasubjective reflections to ‘brew’. These responses emerged later during the narrative processing after Sarah had died. This perhaps partly accounts for the fact that I did not respond in the immediate interview to Sarah’s description of rape halfway through our second interview. It was only later in a supervision conversation that its significance dawned on me (Chapter Four, 2.7). I needed to accept that the quality of good, totally absorbed listening has limits, and as practiced in most therapeutic systems an hour is the sensible limit.

Scott:
Scott taught me about deeply listening and waiting in silence for what might possibly emerge. I had to learn especially with Scott to ask open-ended questions, or he would give me simple one-word answers that did not move us anywhere. I then had to extend the question to ‘unstick’ the conversation.

Elizabeth:
The major lesson I learned from recording Elizabeth’s story was how the story could change, and how my intra-subjective responses impinged on my processing of Elizabeth’s narrative. Bracketing helped but was never complete. It eventually became clear that my comments about her ongoing grief were the catalyst for Elizabeth to re-form her story, which was satisfying for us both. But for me at the time it was a disconcerting complexity.
It became clear that *selves* evolve and change through the processes of telling, listening and reflecting, and this finding is now explored.

5. **EVOLVING SELVES: RE-PAINTING OUR SELF- PORTRAIT**

The narratives contain articulate epiphany stories. For instance Elizabeth’s encounter with the nurse who denied her fluids without kindness or explanation, when Elizabeth was close to death and pleading for a drink. This left Elizabeth with the feeling that this was her latest and perhaps worst experience of ‘horrible’ encounters in a number of health crises throughout her life. In reconstructing the past, people redefine themselves (Spinelli 1989, p.103). In the process of forming these narratives a growing awareness emerged of what was significant in the narrator’s life.

Elizabeth inched towards accepting the grief and limitations of her post-stroke life, and her acknowledgement of strong relationships with her family. She described the importance of her family relationships through years of personal stress and trauma. Families may both aggravate disruption and create continuity (Becker 1997, p.107). Expressing her grief at the many losses she had experienced, and fitting them into her narrative with rich explanations of how they occurred, was a way for Elizabeth to move towards a degree of acceptance. The most recent disruption to her health meant she had to come to terms with a significant loss of independence. When expectations about the course of life are not met, people experience inner chaos and disruption, and this reverberated in all the narratives in the study (Becker 1997, p.4).

Elizabeth began to weave the disruptions she had experienced over her life, into the narrative that described who she was and how she dealt with difficult situations. My overzealous interpretation of her resilience (refer Chapter Seven, 2.5) caused her to recall me to further clarify the situation so that it felt absolutely correct. Elizabeth refined her story and the process brought a better sense of continuity in the face of her lifelong experiences of disruption. I noted my own reactions to Elizabeth’s sadness and grief. Appendices 10.5 and 12 describe my own reflections on ageing and loss.
Kaye moved a good distance towards a less chaotic, more connected way of living, as we unpacked the experiences of her mother’s life and death that had impacted on Kaye. I facilitated Kaye’s descriptions, re-connecting her to the physical and emotional circumstances of their relationship, particularly at the time of her mother’s death. We co-created a narrative that gained coherence, enabling calm to replace some of her chaos (Frank 2004a). One cannot help wondering if this conversation had taken place much earlier than ten years after Kaye’s mother’s death, Kaye could have moved on in her life with less anguish (refer Appendix Eleven).

5.1. Finding meaning in crisis

Kaye describes her sense of how at the worst point of a crisis, when chaos surrounds her, she knows from previous experience that she is at the point of significant growth and meaning in her life (refer Chapter Three). For Kaye after her mother’s sudden death, her crisis lasted ten years, until we were able to co-create a changed story. Her new understanding helped her find her way into a fresh way of seeing her world. The individual moves forward through an effortful series of upheavals, reversals and renewal (Moss 1989, pp.199-202). Kaye saw:

… that hopelessness is kind of operating in tandem with something else which is a kind of re-growth, or regeneration or re-birth.

5.2. Owning the facts of one’s life

At the beginning of our work, Kaye said she felt she was heading for self-destruction without some sort of sense-making intervention. Many individuals, like Kaye at the beginning of our work together, are painfully aware of their ‘thrownness’ (Moss 1989, p.204). Our narrative work enabled Kaye to integrate her mother’s death into her life in a less destructive way. It was a relatively simple, perhaps risky, but profoundly engaging way of making sense. I accompanied her by listening through her chaos. It was a special moment when Kaye owned her chaos, realising that it was self-structured, and held her in its own kind of safety net (refer Appendix Six, 3.c). In this way my processes of narrative analysis had uncovered understanding for us both.

The discussion now addresses the issue of the therapeutic qualities of the study’s processes.
6. WAS IT THERAPY?

Whilst the process I was developing had been named therapeutic autobiography, I did not consider myself a therapist offering therapy or counselling, although my qualifications were adequate for this role. I was exploring the process of listening deeply with empathic openness to illness narratives within the context of life review narratives, in order to answer the question ‘what happens when stories matter and we listen differently, especially to stories of disruption?’ It was a slight switch of focus from therapeutic autobiography.

Throughout the process of forming the five narratives there were interventions on my part that might be argued as having therapeutic intention. As an example of what was arguably a therapeutic intervention, each recording session with Kaye was paused at a certain point, where we stopped when Kaye said she was cold or hungry. We shared simple comfort food before we recommenced taping her emotionally laden stories. This would not be possible in a normal counselling/therapeutic one hour session. Other examples are discussed in each narrator’s chapter. Were these interventions simply my response to the needs of the narrators in my ordinary intersubjective relation to them as Other, or Thou? I was never conscious of a more calculated or overt therapeutic intent. I was committed to listening in a particular way, and there was no contract around the notion of therapy.

This raises the question of how healthcare professionals might respond in situations where interventions of engaged reflective listening might make a positive contribution to the wellbeing of both narrator and healthcare professional. The validation of Bert’s stories and my attention to Scott’s care, were arguably further examples of therapeutic interventions, though they felt to me more like ordinary care-giving from within Guillemin and Gillam’s (2006, pp.29-40) ethical mindfulness.

There is clearly a therapeutic effect within the process of telling and listening to life stories and forming them into coherent life reviews. As Kaye said:

The process of sitting with someone who would listen to me … What mattered was that she was prepared to give me this huge gift. I sat and I cried and I talked and talked and talked (refer Chapter Three).
Perhaps there is a tendency to put boundaries around what is perceived as therapy, deciding that certain practices are therapeutic: it happens with a counsellor and there is an intention and so it is therapy. Macquarie Dictionary (1989 edition, p.1760) defines therapy as ‘the treatment of disease, disorder, defect; as by some remedial or curative process’. A therapist is a ‘person trained to give therapy by any of various physical or psychological methods’ and therapeutic as ‘pertaining to the treating or curing of disease’.

There are things that are capable of improving people’s wellbeing that are consciously done. They are therapeutic, but maybe these things sit outside current procedures, and are not necessarily recognised, so their impact cannot be measured easily. I think of therapy as someone doing something to or with someone with the intention of improving the wellbeing of the other.

Does therapy include listening deeply to someone with empathic openness? Figure 35 and Figure 36 show the intersubjectivity of dialogue and its potential to crystallise meanings for people who are prepared to risk being in the central intersubjective space where meanings can be shared. Then therapy is dialogical and reciprocal, enhancing the wellbeing of both. This wellbeing is holistic, not purely physical, including emotional wellbeing and the enriched perception of self (Figure 35 and Figure 36 are discussed later in this and the following chapter).

Helpful contexts and therapeutic aspects emerge from life review narratives, such as stories of one’s mothering (Kegan 1982, p.257). For example Kaye’s narrative rings with her perception of her mother’s ideal mothering, which felt lost to Kaye because her mother died. Through our narrative dialogue Kaye absorbed the notion that her mother’s creativity is innately part of who Kaye is now, despite her mother’s death. The concept of mothering is described in detail in every narrative in my study. Complex, but on-the-whole supportive family contexts are explored in depth by each of the narrators. Perhaps also in describing less than helpful contexts, the rich and thereby therapeutic rewards of helpful contexts are more deeply understood.

6.1. The therapeutic qualities of conversation

The study’s process allowed mutual or reciprocal recognition, thus enriching the wellbeing of both teller and listener. They were good conversations, not necessarily with a
therapeutic imperative, but with intrinsic therapeutic qualities such as mutual respect, sincerity, valuing and validation, within a context of empathic openness. These qualities arose from sharing the experiences of the narrators’ lives, and describing some things that had perhaps been untold through previous years. These descriptions were given respectful attention and neither denied or minimised. The process demonstrated the potential to know someone more deeply. It created a written document describing experiences and feelings about them, which can be read by family and friends.

7. **BARRIERS AND BOUNDARIES**

I offered fully present, connected listening. To question the nature of these connections is important. Was it simply person to person? Was it Moustakas’s (1996) ‘Being-in, being-for, being-with’ or were there differences? Did I manage to adopt a respectful, mindfully aware attitude that recognised the whole being of the narrator, including the intersubjective and my own intrasubjective responding, developing appreciation of the social and cultural settings of the other?

It was a model of listening that had its limitations. It was in some ways still a hierarchical process, with me owning responsibility for the processing, reduction, production of the essence of the dialogical experience and the writing of the life review documents and thesis. Regardless of my aim for equality, there was, nevertheless, a level of power imbalance in my narrative process. I took responsibility to sustain, engage and support the dialogue. In that sense I was powerful, because I knew how to do it, whilst the narrators perhaps did not necessarily have that skill. I went away and processed, reduced, deconstructed. It was this point that brought anxiety to Kaye as we struggled through the process. I then returned the poetic essence statements to Kaye, which turned out to be satisfying for her, but in a sense I had remained ‘in charge’. Perhaps it is this point that parallels most closely the ethical and procedural structures of healthcare relationships. Do healthcare professionals indeed remain in charge of the healthcare story? Is that a necessary stance?

There were crystal clear moments of reciprocity where the narrators and I shared the narrative process in equality. They were points where it was crucial to have reciprocal openness. That is not enough to say this was *reciprocal openness* as a blanket quality that
operated across the dialogues. Perhaps reciprocal recognition is closer (Frank 2001b).

Reciprocal recognition, which is the intersubjective process, allowed mutual trust and respect to create bridges between the narrators as they described the intimate, disruptive experiences of their lives, and me as listener. I also had implicit commitment to my particular skills, although they did not necessarily mean the narrator’s disempowerment. I was deeply committed to be open to their stories. It was a mindfully and self-aware, empathic, engaged listening, bracketing my intrasubjective material within a tacit professional boundary. I tried to set aside my instant reactions, like my dislike of the messy chaos in the psycho-geriatric unit, and to process it later in my journalling. That action itself in some ways denies a permanent state of reciprocal openness. In each of the narratives there were differently empowered structures operating where I needed to have certain attitudes and constraints in order for the cycles of re-experiencing to occur. For instance in Kaye’s narrative, perhaps because we were more intellectually equal or alert, there was more of the feisty cut and thrust of normal conversation than with the other dialogues.

The literature describes equal dialogical relationships that are perhaps akin to friendship, for example Moustakas (1996, p.36-39). Then there is psychotherapeutic literature where the therapist is in control of the agenda (Stern 2004, p.82). My process seems to be situated in between the two. It is neither fully Moustakas’s Being in, for and with, nor is it Reason’s (1994) full collaborative inquiry or Stern’s psychotherapy.

My methodological template is visible in other researcher’s work, such as Reason (1994) and Moustakas (1996). I have drawn on their wisdom, but I have also found that in these engagements there are boundaries and barriers that have parallels with the ethics and moral structures of nursing and medicine. This is discussed further in Chapter Nine, 2.

7.1. **My process was a professionally bounded interaction**

I continued to maintain the stance of a nurse’s professional duty of care to respond to any crisis such as a threat of self-harm. I was nervous about Kaye’s wellbeing for a week, and if she had hinted that she was considering self-harm, I would have had a duty of care to take action. That is a boundary or barrier. In other words my stance was complicated by an underpinning responsibility of care. At the same time I needed openness to my intrasubjective responses and intuition.
Another example of this complexity was in Bert’s unit (refer Chapter Six). It disturbed me that the staff did not see me as part of the professional team, sharing knowledge about Bert’s condition, which would have assisted me to understand his situation. I think they saw me as a volunteer/narrative researcher/listener (which was in fact my role), who perhaps also provoked some variation in Bert’s behaviour.

One could equally describe the narrators’ boundaries. I gave them the right to keep ‘doors shut’ on various subjects they did not want to talk about. There were stories they told me off-tape, which were a kind of line-drawing on the part of the narrator. What can be seen is perhaps what people offer when given the space to tell their stories, with caring feedback in the mode of intersubjective responses that validate their experiences and narration. In other words there were boundaries for teller and listener.

Very little of my story was present in the dialogues. If the task was to listen and to share the other’s story, I maintained, in some sense, a professional boundary.

7.2. Self-disclosure

In doing the intersubjective reflective work, I came away and reflected on my side of the dialogue, especially as I transcribed the tapes, which, to reiterate, was therefore not a fully open reciprocal method. To put that into a healthcare professional context, is that necessary? If I go to my doctor with a serious problem, do I want him to tell me the story of his problem? No, but I would want him to know himself well enough to be able to listen to my story of my problem without being swamped by his own intrasubjective reaction to his own perhaps tacit perceptions, cultures, judgements, experiences and contexts. If he is self-aware, and he recognises his own intrasubjective response, he can bracket it and listen to mine.

The process of engaged, self-aware, empathic reflective listening, is an intersubjective process that includes bracketing. As one develops the qualities of listening, one requires the continuing processing of one’s own self-knowledge. Instances of this are reflected throughout the thesis, as I describe my growing knowledge of the issues of dying, death and grief that were part and parcel of learning to work in healthcare settings. This knowledge continues to stand me in good stead as I move through my everyday life.
It was a flexible model of listening. I nevertheless questioned my interventions, for instance asking a friend to gather photographs of Bert’s places in outback South Australia when she was travelling that way. They are still highlights of his existence, as far as I know. I was also uncomfortable, as described in my journal, that I felt a need to check the accuracy of Bert’s story in web sites such as Veterans’ Affairs. This was a uni-directional search on my part (refer Chapter Six).

Another instance was when I gave Bert a photo of myself as a child beside my grandfather’s Hupmobile car, after Bert mentioned his uncle’s similar car. I wanted to show him that I knew what a Hupmobile was, and that was affirming for him. But I had a prickly feeling that by showing him a personal photo I was somehow breaking the taboo of non-self-disclosure that nurses were taught so strongly.

In other words, I felt professional limits and boundaries to my self-disclosures, which arose from my training in healthcare settings. The boundaries were moments of pulling back or re-directing the flow of the conversation, allowing me the right to say ‘no, we won’t go there’.

At times I de-stabilised the narrative process by offering material that confused the narrator, such as when I gave Scott three of my little travel stories. Scott wasn’t sure if they were his and that he couldn’t remember them. I wished I’d not done it, but as Warren Lett said at the time (supervision conversation), ‘how else can you find out these things, other than by testing them? If you find they are confusing then you pull back’. That suggests one is always riding an intuitive line. In a sense this is saying ‘I’m going to work intuitively, but must listen carefully in that process for my own visceral reactions and the reactions of the other, to be sure that all is well in the process’.

The thesis aims to demonstrate tools that usefully amplify the components of the engaged, reflective, self-aware processes of listening, and how they might be negotiated. Not all of these tools will be useful in every situation, especially in healthcare settings.

There were some difficulties noted throughout the study processes and these are now explored.
8. DIFFICULTIES

8.1. Recording and transcribing extended dialogues

I discussed the theories of interviewing and transcribing in Chapter Two, 3.2. In recording
the narratives it was sometimes difficult to end an interview, particularly with Bert, who
wished to continue the conversation. I noted what was said after the tape recorder was
turned off, usually when the tape ended. I often started the next session by referring back
to this material when it was appropriate.

There were two occasions where the tape recorder was not turned on at the beginning of
interviews with Scott (refer Chapter Five). When the conversation on the tape was clearly
audible with minimal background noise and the microphone close enough to both
participants, transcribing was easier. Transcribing one’s own interviews sensitises one to
the importance of the acoustic quality of the recording, paying attention to asking clear
questions and getting as clear answers as possible. I improved my attention to these
details and it lessened the stress of transcribing. However it is difficult when people are
deeply ill (Kvale 1996, p.169).

Whilst time consuming, transcribing the interviews myself was essential, in order to
deepen my engagement with what had been said. There were difficulties with Bert and the
noisy background of the unit and the impact of other patients. The difficulties of Sarah’s
limited voice strength, accent and cough made her narrative the most difficult to
transcribe.

The transcriptions were returned to the participant as soon as possible after each
interview, in order to clarify and validate what had been said, to allow for any changes,
which were most often to do with dates and spelling of place names. I was always aware
of the need for sensitivity in returning the transcripts to the participants who were deeply
ill or withdrawn. In the case of Scott, once he was too frail to proceed, the
communications and reflections continued with his daughter, who was involved with the
process until it was completed. In Chapter Nine, 1.1.3 I question the suitability of the
process for everyone. In each case this checking-back, along with my responses, helped to
enrich the narrative as the telling proceeded. However this imposed a tension with the
time-consuming task of transcribing and the aim for absolute accuracy. With Scott, I
began with three interviews in the first week, then two the following week. To check my
accuracy I re-listened to each tape with the transcript in hand after each transcribing session, before returning it to the participant. However mistakes still slipped through.

I was conscious of the limitations of my written transcript in reflecting the whole environment, intonations and the gestures of telling. Often theatrical elements of the conversations were lost. I did my best to include descriptions of hilarious asides that might have been missed (Denzin and Lincoln 1995, p.76). This was important for all the narratives, but particularly with Sarah (Chapter Four) with her consummate storytelling style.

8.2. Ethical issues
Throughout my study I did not encounter any reluctance to tell the story, rather the reverse. I recorded intimate details of the narrator’s lives and all were open to sharing their experiences. My offer to delete material or to change a story was sincere. I have worked with stories not included in this thesis, where once transcribed, the story remained private and confidential, owned by the storyteller, helpful to them in telling, available to refer back to, but not open to others besides myself.

It would have been helpful to have been fully aware from the outset that this dialogical way of working might test issues of confidentiality. It may require decisions about one’s capacity to sustain the process, both physically and emotionally. In research such as this it is acknowledged that there is a potential for change for both the participants and the researcher, which may not be recognised prior to embarking on the project (Caelli 2001 p.279). I have previously described the changes I recognised in myself (refer Chapter Eight, 3) as I undertook the process. Kaye’s comments about the process precipitating momentous life changes (refer Chapter Eight, 5), are equally relevant to illustrate this point.

The pragmatics for working with narratives remain constant. If a narrator told me they were thinking of harming themselves or someone else, I had a professional and ethical obligation to intervene. I was conscious of immediate avenues of referral if I ever reached that situation. This defines one boundary to openness. Being ‘the researcher’ was a professional role.
What enabled me to connect with the other? Was it by being completely human? This is one of the complex paradoxical threads to understand. On the one hand I have expressed a tendency to de-professionalise this process and to say it is about listening, but on the other hand there is the contradiction that at certain critical points I needed to pull back into my professional role.

Perhaps it is a kind of filter, or need for a bracketed but continuously cautious awareness of what is happening. Referring to Figure 36 there is still an understanding in my professional filter that influences me differently. Do the narrators also have filters? They have their integrity as a filter in reviewing their own capacity for openness. It is what enables or disables the reciprocal openness at times, whilst still maintaining reciprocal recognition.

8.3. **Voices: Whose story? Whose meaning?**

I was concerned about the impact of the story on the family of each narrator. I saw that there were more voices than the storyteller’s to be considered in this process. I worried about how equal, multiple voices in the stories, could survive the process with integrity. Whilst I felt that the five narratives were largely collaboratively formed in reciprocal dialogue, I worried about me assuming that my meaning was their meaning. Kaye pulled me up regarding our different perceptions (see Chapter Three). This issue is further discussed in 13.7.

8.4. **Issues of confidentiality**

I struggled with issues of confidentiality with every person. Often this seemed to be outside my control, for example some of the staff overtly lacked respect for Bert’s story. A separate copy of Bert’s story was kept outside his room so he would not destroy it. However once I made this copy available I no longer had any say over its protection (refer Chapter Six). However Bert was obviously happy for anyone who was interested to read what he had said. In fact all the narrators seemed happy to share their story with whoever wanted to read it. Maybe one can assume that they only told stories that were available for others to read or had been told previously. The ethical dilemmas in narrative work need to be acknowledged (Josselson 1996).
Treat ing each narrator with respect and confidentiality enhanced my understanding of, and respect for narrative ethics. I appreciated the reciprocal benefit of each person sharing personal and private stories, their openness and honesty was something I valued. However I have not included stories that were shared with me after the tape recorder was turned off (refer Chapter Two, 6.1).

The literature was always a guiding light for my path, adding wisdom in a way that underpinned the entire process.

9. ENGAGING WITH THE LITERATURE

It was quite late in the process of writing the thesis when I decided that I had challenged van Manen’s (1990, p.76) instruction that the literature searches should happen only after the immersion in each narrative (refer Chapter Two, 5). In defence of this unintentional challenge, I acknowledged that I had already done considerable reading prior to the study’s conception. It was partly because of my fascination with the literature that I was drawn to the research in the first place. The prior reading was an essential part of my surviving the recording and processing of the narratives, without it I would have lost my way. In other words I only partly adhered to van Manen’s method of literature searching, I was not a clean slate. I wondered how purely van Manen believed this was necessary or possible. At this point I cannot visualise the prospect of not having had the voices of the literature to inform, support me and anchor the process as I proceeded. More intensive literature surveys also took place towards the end of each narrative’s processing, where I returned to some familiar literature, and added further illumination for the narrative’s understanding.

Later in this chapter I describe how the literature continues to reveal further insights and meanings. It is a continuous process: prior to the study’s conception, in preparation for and alongside the interviews, throughout the analysis processes, and is ongoing. In other words, overall I engaged with the literature in an accumulative way. I was thoroughly immersed in relevant literature as I entered the concluding phase of the inquiry. Perhaps to that degree this meets van Manen’s recommendation.
The dates in my reference list cover many years, such as Buber (1923), and Schweitzer (1933), whilst also including current literature. I searched for literature that encouraged me, affirmed my task, methodologies and method, validated and challenged my work, and sometimes reassuringly echoed my despair.

The literature affirmed that if I was to work in this way with illness and life review narratives there were stringent requirements: I needed not only to be fully present to the narrators, but also to know that my prior experiences and reading enabled me to see things through the lens of my own perceptions. I needed to find ways to ‘bracket’ them as fully as possible, or make them as transparent as I could via journalling. I absorbed a wide diversity of authors and points of view, some more fictional and metaphoric than others.

I think, shape and frame my understanding and philosophy around what many others have written. The literature informed my points of knowledge-lack, helping me to make sense of the narratives for myself. The areas of exploration of the literature were selected by me to find understanding and meaning for myself, not a collective meaning of universal human life and experience.

Did what I read impacted on the narrative dialogues themselves? In response, my palliative care reading started in 1975 with Kubler Ross’s (1970) ‘On death and dying’ (refer Chapter Two, 5). That set me on a different life trajectory as it responded to my immediate experience. By acknowledging other writers in the context of my research journey, it becomes transparent that many other voices have contributed to my knowledge-base, which then become part of me as the person supporting the narrator and their narrative journey.

Thereby an interesting form of triangulation developed: I selected the areas of literature to search, the literature informed me and coloured my final crystallisation of the essence of each person’s narrative and the meanings uncovered in each narrative. In the literature I met other voices such as Kiesinger (1998) Killick (1994, 2001); Frank (1991 - 2005), and Zaner (2004) to name just a few. The literature searches brought me possibilities for making some sense of the narratives, and the validation of my experiences and feelings.
9.1. **Learning to write poetic reflections**

The study encouraged me to engage with poetry and poetic form as one mode of reflecting and responding. The study enhanced my pleasure in expressing myself via poetic statements, although they were not poems. In a written sense the poetic essence statements became the end point of the writing of each narrator’s story, in other words, a poetic shaped, intersubjective summary of the narrative we had co-constructed.

There is a critical argument against poetic reduction (Atkinson and Delamont 2005, p.823) that warns of:

> a danger of collapsing the various forms of social action into one aesthetic mode - that is, implicitly revalorising the authorial voice of the social scientist - and of transforming socially shared and culturally shaped phenomena into the subject matter of an undifferentiated but esoteric literary genre.

In response to this argument, poetic forms of writing, in order to crystallise the essence of what is there, perhaps represent the speaker better than prose. Poetry concentrates the language by re-shaping what was said, deleting extraneous words and clarifying the heart of the matter. The speech used for conversation and storytelling is closer to poetry than it is to sociological prose:

> Settling words together in new configurations lets us hear, see, and feel the world in new dimensions (Richardson 1995, p.933).

Like the meanings uncovered in my study, crystals grow, change, and alter. They are prisms that reflect and refract, creating different colours, and patterns like in a kaleidoscope. The shape and colour of what we see depends on the angle from which we are looking. Richardson (1995, p.934, 2005, p.963) also uses the image of crystal, which ‘combines symmetry, and substance with an infinite variety of shapes, substances, transmutations, multi-dimensionalities and facets, and angles of approach’. This remarkably reflects and refracts the heart and value of my study.

As I struggled to come to grips with the study’s ideas, early in the processing of the narratives, particularly Sarah’s, I wrote a poetic reflection that arose from my thoughts
about being accompanied in equality by health professionals who listen. It is titled ‘I do not know who I am: that is who I am’ and is found at the conclusion of Appendix Eleven. It demonstrates how the poetic form assisted me to find meaning as I searched to find a viable pathway through the study. In consideration of the value of the creative elements of the narrative processing and analysis, I refer the reader to further discussion of the artistic representations that follows in Chapter Nine, 1.1.1.

The discussion now expands the understandings that arose through synthesis and the essence statements.

10. **SYNTHESIS AND ESSENCE STATEMENTS**

My thesis is engaged with co-creating five particular life narrative constructions. The essence statements are one part of the methodological chain I engaged in with each person. The poetic statements formed at the end of processing each narrative are formed through the meeting point of myself as researcher/listener, and the narrator (refer Chapter Two, 3.8 and 3.9). My process of reaching an essence statement is like narrowing to a fine tip of concentration of this meeting, rather than reduction of what was said by either individual.

The narrators and I met, there was an essence of where we met, how we met, and what we created between us, rather than who they as narrators are. It was difficult to reach that point following Sarah’s death, and given Bert’s dementia and Scott’s frailty. Then the essence had to be my interpretation of our meeting point, although I struggled to keep their perspectives and voices alive at the end-point. It would become a reductionist, essentialist process unless it was about our meeting point. It was about the essence of our meeting at that point of the temporary crystallization or approximation of meaning we formed together. I found comfort in Guillemin and Gillam’s (2006, p.10) argument that ‘a reductionist step of some sort is necessary; it is difficult to begin to reflect or gain understanding without it.’

In this form of reduction, every statement needs to be treated with equal care and respect. The challenge is to let everything that appears in the story stand in its own right, accepting and honouring it as it appears. This made the process of reduction for each narrative
stressful, as I grappled with the problem of what to delete and what to leave. This is
amplified throughout each narrative’s analysis (Moustakas 1996).

As previously stated the essence statements are faithful and transparently connected to
what has been said in the dialogues. What was it like for each participant to have an
essence statement developed from their narrative? The essence statements for each
participant crystallised the endpoint of each life review as it was narrated, as much as this
is ever possible. This highlights a difference in the study’s method from an overtly
therapeutic method where a changed story would be the expected successful outcome.
The end point essence statement for each narrator reflects the entirety of the process as it
was, even though there were gaps, confusions and silences. Only some of the final
essence statements were returned to the narrators. Nevertheless each narrator, or the
family member most closely representing them following their death, said they felt that
the essence statement reflected the essence of the person. Sarah had already died, I did not
send Bert his essence statement as I thought it would confuse him, and Scott’s was
received by his daughter. She rang me to add a comment that is indicated in the text. She
also expressed how powerful and moving it was for her, some time after her father’s death
(refer Chapter Five).

Kaye’s essence statement became a pocket-sized, portable version of validating her life
and its experiences. Kaye said this would remind her of who she was if and when her life
became chaotic again. In her case it was more like a final intersubjective response that
summarised our journey together. Following the recreation of her sense of self, she has
something we co-authored to carry with her. I was returning what I felt was the essence of
what we had said, and there were different responses possible due to the different
circumstances of each narrator. They were perhaps poetic summaries that reduced what
was said to these essential things.

My forms of synthesis are a way of gathering-it-all-together into a new place of
crystallised meaning from which to move forward. Did I simply write a neatly crafted end
to their narratives to give ‘closure’? I questioned if I went beyond a collaborative inquiry
position by writing an ending to the stories. Are they endings, or rather a summation of
the best knowledge that these lives have brought to their narratives (Wikan 2000)? My
response follows:
10.1. Points in time

Each essence statement was written at its own point in time in the flow of processing each narrative. For the narrators these poems were of varying significance. I have refrained from editing or enhancing them now at this point in time. To justify this restraint, I offer the following example: When I have finished writing this thesis and it has begun its journey of assessment, I will find further perfect citations, or have ah-ha moments of crystallised meaning that will expand my understanding. I will wish that I had found them in this now time of writing. There is no end to the process other than the submission of the thesis.

The words in the central space in Figure 36 have expanded during various professional presentations and conversations, and as the words suggest, there is no fixity or closure. It is a place of transformation, transition, a fluid space that is everlasting in that it is never filled, it is elastic space with no boundaries, and no finalization or end.

And so it is with my narrators’ stories. Time passes and our stories move with us through time. The words in the central space represent ripples of stories flowing out in time, from the narrators towards whoever is open to receive them. There need be no boundaries or finalization. The meanings shift and re-form in time, not necessarily within the time frame of the study, illustrated by the following example: Kaye (refer Chapter Three) e-mails me occasionally with further insights that have slowly emerged for her, long since we finished our work together. She still finds fresh understanding particularly around the anniversary of her mother’s death. Perhaps the meanings are still precipitating or crystallising, so in a sense each part of the experience has continued to resonate and settle in forms of new understandings.

To further illustrate how ongoing literature, insights and understandings continue to emerge, I recently found a paper by Wros (1994). She describes a study of nurses involved in the care of dying patients in critical care units, and it extended my understanding of what it might have been like for the nurses who were caring for Kaye’s mother when she died in intensive care. Kaye’s mother’s nurses may well have grappled with the separate entities of Kaye, her father and brother, and the difficulties of trying to listen to each of them as they spent the three days before life support was withdrawn. I then became mindful of my suggestion in Appendix Eleven that healthcare professionals
might have listened to Kaye and supported her as an individual. This is perhaps unfairly critical. My reading of this paper moved me to imagine Kaye’s mother’s nurses’ voices and perspectives in these sorts of situations. This allows that they were perhaps more caring and ethically mindful than I imply in Appendix Eleven, but I had not heard their presence represented in Kaye’s telling other than negatively. My understanding has moved. As Lett (2001, pp.135-136) describes it, the meaning is in the experience as the experiencing goes on. ‘The analysis of understanding is cyclic over time, and multi-modal in its presentation’.

10.2. Across the essence statements? Synergies and differences

I intended to explore the essence statements across the five narratives and search for common themes and understandings. I gathered the final statements for each narrative and began to question what was there as the essence of them all. I could examine the key words in each, and explore matching themes. Instead I questioned if there should be a common meeting point. I was looking for commonalities when I had taken so much trouble to individualise these essences to represent each individual person. If each narrative was a kaleidoscope of rotating crystals of meaning, was it important to see that there were matching colours, or patterns of meaning in the other narratives? As previously noted, each crystal’s colour and shape depends on the angle from which we observe them (Richardson 1995, p.934). If the meanings uncovered in the narratives emerged creatively from the intersubjective meeting points of me as listener with each narrator, balanced and expanded with the enrichment of the voices of the literature, shouldn’t that be end point enough?

After reaching a fine point of meeting with each narrator, it felt as if finding commonalities across the narratives and experiences might spoil what we had created up to this point. So I decided not to examine whether the life review narratives were similar or different. My focus is on the process of listening and responding, and what it means for all the participants to have had this experience of being listened to as they described their life’s journey.

However, one significant theme emerged naturally across all the narratives:- the central place that family had in each life review. There seemed to be far more discussion about family than friends. Hirst and Manier (1996, p.272) confirm that families figure centrally
in most people’s autobiographical recollections: how the family processes information and develops their own ‘family paradigm’. Elizabeth’s, Kaye’s, Scott’s, Sarah’s and Bert’s strong family ties resonated in the writings of Reiss (1981), echoing how the family as a social unit strongly shaped their life stories and values.

11. THE RESILIENCE OF PARTICIPATION

Elizabeth protested that I had painted an exaggerated picture of her life-long resilience, saying that she had simply done what was necessary at the time to survive. Discussing resilience, Deveson (2003, p.109) suggests that unless you can revisit the past, you can’t write a new chapter to your life.

These five narratives affirm the resilience of the participants, including mine. For Elizabeth this meant acknowledgement of her achievements and her suffering, and her firm understanding that it was her relationships that had sustained her through her disruptions. Deveson (p.200) argues that resilience is strengthened by a sense of belonging, and that our need for home lies deep within us all. The theme of home and place of belonging is described by all the narrators with their various interpretations. Deveson explains that it is hard to be resilient if there is no safe base from which to journey forth. However home doesn’t have to be brick walls and a picket fence. For Bert, I hope that the photos of his outback childhood home on his bedroom wall helped him feel a little more at home in his nursing home which he cannot leave.

Death and its repercussions resonated throughout the conversations. Deveson writes (p.205):

I have come to realise that although dying might seem to be the antithesis of resilience, it lies at its very core … dying requires its own kind of resilience … we need to share this most profound experience and the universal questions it makes us confront. The meaning of life is connected inextricably to the meaning of death.
12. THE STORIES ARE NOT FINISHED

As previously suggested, there is no ‘finalising discourse’. These five narratives are part of who I have become through embarking on this process and through learning to listen deeply. None of us are finalised, but able to go on in stories that extend beyond our lives with the creative meanings we explore in conversations with one another. Perhaps remaining un-finalised applies especially to Sarah, Scott and Bert (Frank 2005a, p.968). As Frank interprets Bakhtin (1984), each voice always contains the voices of others, and it is a core ethical demand that in Buber’s (1923) I-Thou relationship neither part ever finalises the other. The dialogue Sarah began continues in me, as the narrative we created through our three conversations, and in the work I continue to do. Sarah still speaks through me, not assimilated into me, but as a new possibility of compassion and identification. The experience of creating our dialogue together influences how I see the world, and that is deeply satisfying.

To understand the stories is to understand how and why the successive episodes led to their particular conclusions (Johnson 1989). However Wikan (2000) argues that while stories bring understanding, they are valid even when muddled, unfinished, in-the-midst-of experience. Their only certainties are the beginnings or turning points. A number of the stories in this study clearly lack Wikan’s despised ‘neatly crafted end’.

I did not plan how many sessions were to be recorded and it intrigued me that the storytellers sensed when they had reached the end point, without seeming to see it coming (Johnson 1989). This did not apply for Bert, who had simply gone back to the beginning and started his stories again. I hear he is still telling them to whoever will stop and listen.

The discussion now moves to consider the methodological framework of the thesis, its successes and difficulties.

13. THE METHODOLOGICAL FRAMEWORK

The values of the process of listening at a deeply, empathic level may be extrapolated differently as time and particular circumstances might direct. One of the most helpful aspects that the unfolding methodology allowed was that I could respond intuitively as each occasion directed. I was not constrained to follow a prescribed format that might
have inhibited some of the rich, deeply personal outcomes. This of course has its own implications and responsibilities.

13.1. Validity and authenticity

In considering the points of validity grounding the authenticity of the study, Guba and Lincoln (2005, p.207) provide measures for outcomes in constructivist inquiries:

1. ‘Fairness is thought to be a quality of balance, that is, all stakeholder views, perspectives, claims, concerns, and voices should be apparent in the text. Omission of stakeholder or participant voices reflects, we believe, a form of bias’.

Response:

There are clearly absent voices throughout the narratives, and whilst acknowledged, they could be argued to question the validity of the outcome. For instance the voices of Sarah’s health professionals, and the voices of the staff in Bert’s dementia care unit are present only indirectly. It indicates that in these particular narrative discourses and this study, the voices that were represented were those who had seemed to be left out of the healthcare professionals’ discourse, which was the catalyst for the study’s evolution. In a sense we co-created the narrators’ half of the medical narrative that had been neglected in the original experiences.

2. ‘Ontological and educative authenticity’ were designated as criteria for determining a raised level of awareness, in the first instance, by individual research participants, and in the second, by individuals about those who surround them or with whom they come into contact for some social or organizational purpose’.

Response:
This point is adequately met by the structure of the study and the drawing of parallels that might be applicable in healthcare settings (refer Chapter Nine, 2). There are, as required by Guba and Lincoln, clear moral and ethical overtones in the qualities of reflective listening that are demonstrated to provide the best care and outcomes in healthcare settings.

3. ‘Catalytic and tactical authenticities refer to the ability of a given inquiry to prompt, first, action on the part of research participants and, second, the involvement of the researcher/evaluator in training participants in specific forms of social and political action if participants desire such training’.

Response:

This would also centre in the model’s parallels for possible application in healthcare settings. For instance healthcare professionals might engage in listening differently to their patients as a result of reading the study’s findings. It also resonates in some of the life changes that evolved for the participants in the study.

The multi-model method and methodological approach to the study addresses the critical argument of Atkinson and Delamont (2005, p. 823) that one should not seek to render social life in terms of just one analytic strategy or social form. The forms of analysis should reflect the forms of social life; their diversity should mirror the diversity of cultural forms.

These authors seem to be suggesting that qualitative researchers need to be aware of the organisational conventions and strategies implicit in their approaches. Data analysis needs to be rigorous in revealing this. When various forms or modalities of data are used respect is needed for the particularities of those modes and ways that they are implicitly organised.

There is a caution against tendencies to ignore the organising structures of forms of poetry, visual representations and schema. In other words the task as researcher is to do the extra work necessary to bring those particularities to the surface and to ensure that the
The bricoleur approach was adopted as a framework that allowed flexibility in working in different contexts, with individual narrators in their individual settings. Bricolage has been described as a form of montage, where several images are juxtaposed to or superimposed on one another to create a picture (Denzin and Lincoln 2005, p.4). It is, in a sense, like *pentimento*, where something has been painted out of the picture. Montage, in creating something new, uncovers or reveals what has been obscured by another layer or image, such as Bert as the person he was before alcohol and dementia took over his life, or like Sarah before the cough took over her life ‘like a devil’. These layers were uncovered by the processes of narrating and reflective listening.

13.2. The methodological struggle

The initial methodological difficulty was the struggle to find a ‘home’ for my qualitative study and its methodologies. Inquiries involving experiential accounts acknowledge the subjectivity of telling and the multiplicity and situational nature of ‘truth’. Such approaches, where there is no emphasis on a fixed and provable outcome do not sit comfortably in some research departments.

13.3. How did my model of listening differ from other narrative therapists?

There are obvious similarities between my model of listening and other narrative therapy practitioners. White’s (2007) narrative therapy lists six main areas of narrative practice: externalising conversations; re-authoring conversations; re-membering conversations; definitional ceremonies; unique outcome conversations; and scaffolding conversations, and suggests how to employ them in clinical practice.

In considering how my model of engaged reflective listening differs from approaches such as White’s, I argue that White had an agenda for a therapeutically changed story in its telling. My aim is for a carefully heard and validated story, a stating of life experiences that become coherent through the telling. That is, the four meaning points that follow in Chapter Nine, 1.
Highlighting some similarities, Morgan’s (2000, p.2) definition of narrative therapy describes:

- A respectful, non-blaming approach to counselling that centres people as the experts in their own lives.
- Problems viewed as separate from people, assuming that people have skills and abilities that will assist them to change their relationship to the problem.
- Curiosity and willingness to not know the answers on the part of the therapist.
- No single correct direction for the conversation to take.
- The person consulting the therapist plays a significant part in determining the directions taken.

There are also similarities in the work of Egan (2002 pp.73-92) and his model of Active Listening, where the goal of listening is understanding. Empathic listening ‘hears’ the verbal and non-verbal material, whilst being present to the person and communicating empathy. Carl Rogers’ (1961, pp.62, 262) approach of unconditional positive regard, with its notion of unfailing empathy and genuineness offered by the helper to the client, is also in order to effect change.

My model places the person’s illness or disruption narrative within their life review narrative. That is, the illness or disruption experience told as part of the person’s culture, prior experiences and life story. It offers multi-modal responses that may bring about change, but it does not have a specific agenda to do so. To re-iterate, I was committed to listening in a particular way, and there was no contract around the notion of therapy.

13.4. Agendas

It could be argued that I had an agenda to produce a more positive story, for instance a resilience focus, or to draw out a strength perspective. Did I aim for a slight re-frame in the essence statements? Re-visiting the initial agenda for each narrator might uncover the answer:
For Sarah:

The staff wanted Sarah to be less difficult. My agenda was for her to find coherence in her illness narrative by placing it within her life review narrative, in the hope that she might find a sense of validation, and balm for her anger. Sarah’s was not a positive story. I hope that telling and hearing her own negative story was a positive experience for Sarah, and I think in that process she found coherence (further discussion about coherence follows). Sarah was critical of the context she found herself in, and I did not try to make that any less problematic. If Sarah’s agenda was to make sure that her story was told, warts and all, particularly the illness part, then in fact she achieved her aim.

Kaye:

Our intention and agenda was to describe who her mother was, which Kaye felt was missing from her knowledge. Coincidentally Kaye might also re-discover who she was, thus re-creating a less destructive, more stable self-identity. The double outcome was one that I only vaguely perceived at the outset, it was a process that developed as we proceeded.

Elizabeth:

My agenda was a little more self-oriented. When Elizabeth told me about her ‘near-death’ experience I wanted to hear more. I wished to hear Elizabeth’s illness narrative, described in the context of her life narrative. Elizabeth’s agenda was to tell her life story, not particularly dwelling on her latest illness narrative. Her husband had already recorded his life review, and she felt that she also had an interesting life story to tell. I admit to pushing for a more positive, resilience focus with Elizabeth, and in the end she requested that I tone this down, to clarify how she saw it.

Bert:

The Activities Coordinator’s agenda was to find a way to get Bert to tell his stories, as a ploy to get him out of his bedroom. My agenda was to find a way through the tangle of his confusion and confabulations to see if I could ‘hear’ the person behind the dementia. I
also wished to learn about Bert’s dementia environment, and to understand my own complex responses to Bert’s situation.

Scott:

The request to work with Scott came from his family because they thought he was depressed. My agenda was to see if it was possible to engage this gentle, frail man via his travel experiences, in order to enliven him by the processes of his telling and my engaged listening.

13.5. **Was there an agenda to create a coherent story?**

Macquarie Dictionary (Delbridge 1987, p.366) defines coherence as: natural or logical connection; congruity; consistency; cohering: sticking together; having a natural or due agreement of parts, connected, consistent, logical.

In Chapter One, 3.2 I noted how the listener to a life review narrative assists the storyteller to produce a coherent story. In this study the agenda was different in each case, although in a sense perhaps the overall agenda was to co-create coherence, and then to distil that coherence into an essence statement that was a tangible record of the dialogical meeting that was shared. Perhaps that is a major commonality across the narratives. Layered over any possible push for coherence, came the issues of referral and engagement, or the situatedness that drove the engagement in each case. At the outset of the study I saw the variations and individual situations as having the potential to highlight the amplified processes of engaged reflective listening in more or less any situation. Overall this added to the study’s complexity.

Every setting was different, describing five very different life worlds and circumstances. I noted in Chapter One, that Kirmayer (2000, pp.171-175) fears that when stories are told, life may appear far too coherent, full of continuities and connections that are the product of the narrative itself. Perhaps it follows that being coherent about an incoherent life is the best possible outcome of one’s life review narrative. Perhaps this is the caveat: the agenda was to co-create a coherent story, or at least an understanding of what has *a priori* been incoherent, and may remain incoherent.
13.6. Themes and further processing

This form of experiential inquiry is multi-modal. It allows the resonance of what is there to be seen and amplified. As I processed the stories I stayed with the emerging understandings, focusing and amplifying the expressions of the experience that grew out of the dialogical creation of the narratives. There were months between the completion of the transcriptions as part of my master’s degree, and the remainder of the processing once I began forming this thesis. This allowed the narratives to ‘brew’ or develop depth within me. I then formally re-engaged with each transcript by re-listening to the tapes at the same time as re-reading the transcriptions.

The processes for each narrative differed slightly in order to follow the intuitive sense I had of how meaning was best accessed for each participant. This is presented in Chapter Two, Table 1. As researcher/listener I needed to approach the narratives with openness to possibility, with a naivety that allowed me to enter this new space, and to be surprised by what I found. I responded with a strong sense of responsibility for the accuracy and rightness that was possible and necessary.

Themes are discussed in Chapter Two 4.2. They developed as I listened to the stories and transcribed them. Patterns and themes lie at the heart of, and identify the experience. An example might be where different parts of the conversation talk about ‘mum’ and when gathered together into a theme called ‘mum’, they amplify the picture of who the narrator describes as ‘mum’. After all the themes were listed, I could see that many of them clustered into a key theme such as ‘family relationships’. This was always bulky work owing to the size of the narratives. By forming themes the story is simplified.

Figure 35 which follows, is a meta map or schema of the study’s processes, allowing for flexible, multi-modal and individually shaped, personalised responses, modelled on White (2007, for example p.116). It is an approximation rather than an exact replication of the processes, however it illustrates the major framework of the thesis. It is a temporal process that always flows from top to bottom, it is not possible to ‘rewind’ the changes that are brought about by the telling and listening once they have been experienced. As van Manen expresses this temporal nature, it is
subjective time as opposed to clock time. Past, present, future: the past changes under the pressures and influences of the present - I may reinterpret who I once was or who I now am (van Manen 1990, pp101-106).

Figure 35. A meta-map of the thesis process

13.7. How collaborative was my inquiry?

As stated in Chapter Eight, 4.9, it would have been better if at the beginning I had discussed the method of reduction to an essence statement with Kaye, so she would not have felt anxious about the deconstruction or ‘demolition’ of our precious creation. This
perhaps points to the need for forward thinking, rather than not listening. It challenged my understanding of collaborative inquiry, and concerned me. It became clear that I had modified the notion of collaborative inquiry.

Collaborative inquiry researcher Peter Reason (1994) presents a variety of research projects that used collaborative, participatory research methods to various extents. His discussions were reassuring: about chaos, the difficulties, the ethical issues, take-over bids and power struggles. My study did not fit this methodology entirely, it is not Reason’s perfect collaborative inquiry, nevertheless it was a useful and supportive framework.

I enjoyed engaging in the struggle to rigorously anchor the collaboration of the voices in a way that would satisfy the narrators, me, and the academic requirements of writing a qualitative thesis. As part of the collaborative inquiry process, searching to understand issues such as dementia, alcohol abuse, abortion, ageing and so forth, enriched my knowledge of ‘the nuts and bolts of life’ as Kaye termed it. In the process of searching I was able to find pathways of meaning through these complex issues.

How else could I find the essence of each person’s story in a manageable shape and size without reduction? I invariably had the feeling that reduction was impossible without choosing to delete precious parts of the narrative, followed by a satisfying ‘clunk’ as the essence emerged. Across the narratives, the process moved beyond the time when I returned the life review documents and intersubjective responses to the narrators. Then followed the process of analysis and reduction to essence, which clearly was less collaborative.

From then on, in all but Kaye’s and Elizabeth’s narratives there was little input from the narrators. Scott’s daughter was involved in the processing of her father’s narrative by reading and adding her insights by e-mail or telephone. In each case it was the best I could manage, often dependent on the narrator’s physical condition at the time. Perhaps collaborative inquiry always has limits and points where it moves away from Reason’s model. Maybe the times when I moved away from collaborative inquiry were when I was more engaged with heuristic searching. I read the struggles of Reason’s (1994) co-writers and was reassured (Traylen; Whitmore; Cosier and Glennie; De Venney-Tiernan et. al; Treleaven; Archer and Whitaker). Each of these researchers described tortuous paths
through the difficulties of collaborative inquiry as they tried to follow the rules of convergence and divergence.

In my study I did all the writing, other than valued written responses from Kaye and Bert, and verbal responses from the other narrators (Heron 1981, p.165). I shared much of what I had written with the participants. Scott said he enjoyed the material I gave him to read and that my reflections were accurate accounts of what we had said. I changed and moulded what I had written according to the responses I received, especially in Elizabeth’s case (refer Chapter Seven).

Finally I contacted Peter Reason by e-mail and expressed my concern regarding the difficulties and tensions of collaborative inquiry. His response (personal communication 1/4/08) was:

‘I appreciate the issues you raise … You do what you can in line with the philosophy and principles, and pay attention to the consequences. There is no such thing as a pure collaborative inquiry!’

This means that there is an inherent complexity in any collaborative inquiry. My study more clearly demonstrates a process of co-creation. Bradbury and Reason (2001, p.449) capture the methodological aspirations and achievements of my study by arguing that:

What seems important in action research, which leaves new institutional patterns in its wake, is its ability to integrate the three manifestations of work, of oneself (‘first-person research practice’), work for partners (‘second-person research practice’) and work for people in the wider context (‘third-person research practice’). The integration of these three approaches to action research suggest a logic of continuous change, which supports the work of radical transformation of patterns of behaviour in which support a world worthy of our lives.

13.8. **Selection of participants: the range of settings that this study represents**

There are various ways in which these narratives have been formed, as previously explained, along with the agenda for the selection of participants. The process has allowed
different textures of narration to be demonstrated, where distinctly individual lives were articulated differently. There are significant contrasts between the narrations offered by Sarah, Scott, Bert, Kaye and Elizabeth. These differences enriched the study and made it worth the struggle to work with their diversity. Another approach might have included all palliative care or all dementia narratives. It would be an interesting study to be structured in similar methodological vein, to explore one person’s illness narrative, and to see the experience from the perspectives of the variety of stakeholders in the illness: the person, their family members, and various healthcare professionals.

13.9. The risks in openness
One of the major risks in these differences was that the purpose of each life review could be lost. In each participant’s setting, the aims and risks varied.

For instance, Sarah was a person with little time and a clamouring story to be told. Supposing I had not heard her and had sided with the palliative care staff and carried their story for them. There was the risk that the purpose of hearing and documenting Sarah’s life narrative might have been derailed. I might have lost sight of Sarah’s life review by defending the palliative care system. If I had shared that with Sarah, the life review would have shifted its focus. I think this would have outraged Sarah and I would have immediately lost her trust. My purpose was to listen carefully to Sarah, not to present her with views about healthcare institutions.

The palliative care unit did not respond kindly to Sarah’s story, which she wanted them to read. If they had expected me to work with her in order to defend them, I did not try to do so. It remained after her death exactly as she told it, transcribed as accurately as possible. Perhaps Sarah’s story might have been interpreted as a threat to the structures in which some of these dialogues most need to be heard. I was told Sarah was difficult and feisty. She told it as she experienced it.

Thus some risks might pertain in some healthcare agencies where the voiced experiences of patients might be rejected. That poses the possible risk of punishment. In the two particular institutions in my study, those of Bert and Sarah, the narratives, if received with generosity and empathic reflection, pointed to possibilities for better care-giving that the institution might have adopted with positive outcomes. These views were the honestly
expressed feelings of two people who described how it felt to experience these units’
models of care. For Bert and Sarah as institutionalised participants there was a risk that
their stories would be rejected by their institution.

13.10. Counselling backup for participants
I was aware of the risk of getting into deeper water than I could deal with, although I had
a good safety-net in terms of referral. In my introductory letter to participants I stated that
where I needed additional help I would seek it. I might have sought counselling for
myself or the narrators. Frank (1998, p.200) suggests that ‘staying with a story can be like
finding a usable pathway through a thicket’. This was a suggestion I took seriously when
the going felt difficult, especially in the chaotic confusions of Bert’s dementia unit.

13.11. Personal safety
I felt some tension working in the psycho-geriatric unit recording Bert’s story. At one
stage I was locked in the room with him, according to the nurse on duty, in order to
prevent another patient from entering. She said I could open the door from the inside and
leave if I wanted to. I did check, and the door opened readily. I continued without further
anxiety. Consideration should be given to where the recordings take place in order to
minimize risk, such as that arising from working in isolation.

Other risks might include defamation, libel litigation, and the question of what would
happen if the transcribed documents were disapproved of by the family. It is difficult to
ensure that there is not contentious or defamatory information that might become public.
Bert’s family do not visit him; they have not read his narrative. There is a copy saved for
them when he dies if they collect his belongings from the unit. They could object if there
was a sense of defamation or loss of public face. If, in other words, what Bert confided in
me went into some kind of public domain through publication or anecdotal leaking. Bert’s
family could interpret what I’ve done as being offensive in writing the stories of someone
who is demented, or argue that the stories are not true. They will probably not read this
thesis but might read the transcript, Bert’s account of his life.

In terms of access to the transcript, I returned it to each narrator. From then on it was out
of my hands. I kept a copy for my study purposes, falling within the security requirements
of the human research ethics approval system. My promise was to use sections of the transcripts in an anonymised way, as part of the consent agreement.

13.12. Opening painful stories

Another risk is the pain of re-opening stories. Kaye comments about telling her story:

- It took the most incredible amount of courage.
- It caused a huge amount of pain.
- Yeah, yeah pain is part of it. It caused a huge amount of pain.

Kaye’s pain was supported by my training, careful listening and empathy. Describing her mother’s death moment by moment was painful for Kaye. There was a risk that the pain could have been overwhelming. Kaye was resilient and we could sit with the pain of the description, unpack it as it emerged, and in the end that was helpful for Kaye, but not always possible for others.

The emotional surge that occurs in the remembrance of these sorts of events is powerful and significant and needs respect. For me, there was the pain of stirring my emotions regarding my complex relationship with my mother, (refer Appendix Six, 5, Theme 7), and about experiences of my illness journey that were uncovered along the way (refer Introduction). My journalling and supervision conversations were the supports I used to help me deal with these issues, beside the narrators’ stories.

I was always aware that at some point a need to stop might arise, and this was stated in my initial letter to the narrators. It required my constant awareness of how the narrator was experiencing the telling. I noticed that when it got difficult for Kaye, she would say she was cold and hungry and we stopped for comfort food. The food and time out enabled her to return to expressing what she had experienced.

Miriam, who was terminally ill, was referred to me by her nurses to record her life narrative. They hoped this might bring her some peace. Her Holocaust stories in the end proved to be impossible to articulate. She said it was too painful and difficult to start. She knew she did not have time left to deal with these horrendous stories, and that they would not, as the staff hoped, bring her anything but re-traumatisation. So together we agreed not to proceed, and she died with these stories unable to be told (Barclay 1996, p.94). My
intervention was to respectfully and sincerely acknowledge her choice. The I-Thou/Being-to-Being stance was me saying ‘Yes, I can hear you’.

That was the crucial ethical point I needed to listen for. In discussing the risks or difficulties of this work, it requires being constantly mindful that not telling is sometimes an option. Either narrator or listener should be able to say ‘I don’t want to go there, it is not safe for me.’

The concluding chapter of the thesis explores the crystals of meaning that have arisen from the narratives and processes of the study, the possible parallels and applications that might be seen with listening in healthcare relationships and settings, followed by the concluding reflections of the thesis.
Chapter Nine:
Meanings, Parallels, and Reflections

Tell me, she said:
What is the story you are telling?
What wild song is singing itself through you?

Listen:
In the silence between there is music;
In the spaces between there is story.

It is the song you are living now.
It is the story of the place where you are ...

We are all in this story together ...

Pay attention:
We are listening each other into being.

(Atkins 2003)
This concluding chapter seeks to bind together the multiple strands of the thesis.

Firstly I reflect on the nature of the meanings and understandings that have emerged from the study. I begin by listing four core findings in relation to the nature of the particular meanings that emerged from the life review narrative process. I clarify the use of such words as self-knowledge, awareness, understanding and meaning. I then examine intersubjectivity and the nature of reciprocal recognition, and exploration of how meanings emerged from the co-creation of spaces for narrating and engaged, empathic listening to the narratives; how the additional voices of the surveyed literature and other conversations contributed to the formation of meaning for all the participants; a diagrammatic schema of the study’s central meanings; and the intersubjectivity that enabled the meanings to crystallise. I also review the inter and intra-subjective responses, and how they assisted meaningful attitudes to form. Finally I address the question ‘is this process appropriate for everyone?’

Secondly I connect the emergent findings of the study to parallels and applications in healthcare settings, exploring possibilities for producing better outcomes for health professionals, as well as for their patients.

The concluding reflections explore the study’s achievements as they flowed from their origins in the experiences and stories described in the introduction. I reflect on my personal journey within the study, and the ingredients that were necessary for the search to be successful. At the end of the study, in keeping with its heuristic phenomenological stance, the voices of all the narrators are present. There is discussion of how the narratives reflect the life fundamentals of time, space, self and other as proposed by van Manen (1990, pp101-106). Different times, spaces, selves and others allowed different meanings and values to emerge from each narration.

To conclude, there is a poetic end point that crystallises the study as a model of a different way of listening that enables meanings to change. This occurs by engaging deeply, connecting with the essence of who people are, where they are, and how they are in time.
1. **CRYSTALLISING MEANING**

This section examines how meanings emerged from telling and engaged empathic listening to life review narratives, and how the additional voices of the literature and other conversations contributed to the forming of meaning for all the participants. It also explores the nature of these meanings. There were four core findings in relation to the nature of the particular meanings that emerged from the life review narrative process. This list evolved during a personal conversation with friend and philosopher John Williams in August 2006:

1. Finding significance for an individual’s life and its experiences;
2. Ascribing value to those experiences;
3. Co-creating a coherent story by interpreting those experiences as part of a whole life’s complexity, viewed through the lens of its particular culture;
4. Having the narrative validated by a trustworthy listener.

In order to expand the discussion of these meaning concepts, as a starting point explanation is required for the differences I perceive in words such as *self-knowledge, awareness, understanding* and *meaning*. To illustrate these differences I will use Kaye’s narrative (refer Chapter Three). Kaye told me her story ten years after her mother’s death. Over that time she had experienced enormous grief, whilst living in a state of chaos.

As Kaye told me her complex story over a number of weeks, she expressed appreciation for the space we made for her to articulate her experiences. One of the things she described was how she saw herself as a ‘flighty, flighty person’. This was *self-knowledge*, or *self-awareness*. She then could articulate her *understanding* that as a result, her response to her mother’s unexpected death was to take off. She described how her life over this period involved intense suffering, and that it took great courage to endure the pain of re-telling her story. She came to see that she had the courage she needed. Much of our conversation centred around Kaye’s awe and respect for her mother’s creativity. As the storytelling went on, Kaye came to *understand* that she had inherited her creativity from her mother:
I am a creative person in my essence…
The mother is so much a part of the daughter.
The mother almost stifles the daughter
by surrounding her in a powerhouse of spinning creativity…
Her life is one big creative process.
The daughter looks like her mother,
and is interested, (like her mother),
in social issues art, love and creativity.

Kaye slowly came to express the possibility of change in her way of experiencing the world. These insights allowed her to find a new framework for living her life more creatively. The meanings Kaye found through the processes of telling me her story and reflecting on her experiences, have continued over time to crystallise (take shape and substance, reflect and refract), and to dissolve and change again and again. The poetic essence statement found in Chapter Three, 2.4, gave a particular form to the things Kaye and I dialogically co-created.

It was Kaye’s articulated self-awareness that developed understanding of her reactions to her experiences. This then enabled Kaye to form new meanings that we knew would probably change again in the course of time. They were temporal and temporary, but they allowed Kaye to move towards a safer, happier way to live her life. The self-awareness, understandings and meanings were different, but interconnected. The dialogues allowed metaphoric constructions or self-conceptualisations that came from our reflective stance. It needed both Kaye and I to value the time and space necessary for this intuitive processing. Without this time and space, the meanings could not have evolved.

The concepts of experiential knowing and embodied understanding were described in Chapter One, 2.1. Chapter One, 2.2 explored what is meant by self. Crossley (1996, p.34) uses the example of long division, that a person understands long division, when they can do long division. In this form, understanding is the passing of a performance test. This view argues that Kaye’s understanding was crystallised or made explicit by our dialogical collaboration, and demonstrated by her grasp of what she needed to re-conceptualise and integrate in order to move towards leading a less chaotic life.
Also discussed in Chapter One is Skolimowski’s (1994, p.86) view that the process towards understanding is dialogical. For Skolimowski it is a ‘spiral of understanding’ where people simplify in order to understand. This fits my thesis model where understanding arises out of the reflective dialogical construction of the experiences. In a sense self-knowledge, awareness, understanding and meaning are words that can act as a stimuli for a particular way of thinking.

1.1. Intersubjectivity and Reciprocal Recognition

I used Buber’s (1923) term I-Thou, or Being-to-Being throughout the study, rather than Crossley’s (1996) later radical intersubjectivity. I-Thou seemed to best represent the nature of the dialogical relationships that formed between us. Reciprocal recognition emerged as a core quality of the relationships, which is I-Thou or Being-to-Being, and grounds the intersubjective process that this thesis has examined by using a narrative discourse. It is the quality of reciprocal recognition formed within the Being-to-Being relationship, which expands the opportunities where uncovered meanings might flow outwards towards other subjectivities and new understandings. In our dialogical transactions we recognised something of our selves and each other.

In terms of our individual inner growth as mature and connected human beings, it is, according to Buber (1957, p.104), not so much our relation to ourselves that is significant, but rather between ourselves and others,

in the mutuality of the making present - in the making present of another self and in the knowledge that one is made present in his own self by the other - together with the mutuality of acceptance, of affirmation and confirmation.

One half of the communicative openness allowed the narrators in my study to tell me their stories and for us to co-create their life reviews. The other half of the communicative openness formed through my willingness to listening with respect, and to being aware of and receptive to my own intrasubjective responses that were activated by the issues raised in the narrator’s stories. I engaged in the stories of alcohol induced dementia, ageing, frailty, dying, death, grief, chaos, and struggles in family relationships. These issues provoked my intrasubjective responses, which I brought into awareness to be re-
experienced in my journalling and supervision conversations. Without my willingness to engage deeply in these stories, the openness would have been one sided. As part of my heuristic phenomenological inquiry, I needed to willingly feel ‘as if’, or ‘what it might be like’ to be in a dementia unit, or terminally ill with lung cancer, or dying of old age and so on (Moustakas 1996, p.28; Buber 1923, p.59-63).

The I-Thou/Being-to-Being reciprocal recognition included my deeply empathic-intuitive response to Miriam, the terminally ill patient I described earlier who decided that her stories needed to remain closed (refer Chapter Eight, 13.12). I understood and accepted that in the light of her situation, Miriam’s Holocaust stories should remain locked up, in order for her ‘to hold her own’ (Frank 2004a). By beginning, she might have opened up a Pandora’s Box of horrors she knew she did not have time to deal with. She knew what was the best end point for her. So my reciprocal recognition of her being, accepted Miriam’s closed-ness as being in her best interests.

The narratives in the study demonstrate that the narrators find that meaning is not simply preordained by prior scripts or cultural rules, although these things have some influence. In a sense meaning emerges out of the social interaction of dialogical openness, where the telling is valued, encouraged and intersubjectively responded to.

1.1.1. The Inter and Intrasubjective responses

The intersubjective responses have been previously described in Chapter Two, 4.1, and Chapter Eight, 1.3. These responses were formed throughout the process of working with the narratives, mostly arising as I transcribed the audio-tapes, through until the final essence statement was written for each narrative.

The intersubjective responses, and my own intrasubjective responses could be seen as imaginal expressions arising from within each meeting with each narrator (Heron 1992, p.138). These responses are described throughout the narrative chapters. Kaye described her response to them:

To see the words on a page reflected back at me, made concrete. To see the meanings emerge and be reconfigured … The intersubjective responses/sentences were amazing, clarifying …
My tools were my naïve art conceptualisations of what was said, or re-arranging or collecting together themes I could feel emerging in simple poetic-shaped summaries. It enabled seeing what had been said from a different vantage point, reflecting, re-engaging, echoing. The intersubjective responses created ‘a portrayal which carries the immediacy and impact of an experience rather than any explanation of it’ (Willis 2004).

1.1.2. Understanding the nature of meaning

Figure 36 is a schema for illustrating the nature of the meanings the study unfolded. However creating a diagram assists the discussion, it also reduces beings and their meanings to lines and words. The diagram, along with Figure 35, tries to address the question ‘what was this process?’
The arrow-shape in Sarah’s narrative processing (Chapter Four, Figure 10) represents the narrowing to a synthesis point for her narrative. In Figure 36, narrowing of the meeting point leads to an intersubjective connection of the person, the literature, me, and other conversations, which all open into the intersubjective space. This can occur because:

- I am willing to be aware and notice my perceptions, feelings, prejudices and prior experiences, as I empathically recognise and engage in the other’s stories;
- The narrator’s stories have been willingly told and open into the intersubjective space;
- The selected literature is inherently open and illuminating;
- Supervision and collegial conversations add further insights and voices to the meaning.

Understanding this process adds a significant contribution to my study. Figure 36, whilst similar to triangles, is not triangulation as research triangulation is intended. Research triangulation suggests that the quality of findings is tested through triangulating not only with methods but also with other researchers (Sarantakos 1997, pp.77, 155-56). Richardson (1997, p.92) argues, ‘there are far more than three sides by which to approach the world’.

However it is an adjunct to, or a critical reflection on that process of triangulation. It goes beyond Buber’s (1923) two dimensional *I-Thou* model. They are open-ended triangles, because if they are not open there cannot be a meeting of multiple subjectivities in the central intersubjective space where meaning is to be found. They are perhaps like sieves or filters, moving from broad dialogues to uncovering fine meeting points. Returning to the earlier paradigmatic notion of ‘Man’s search for meaning’ Frankl (1984, refer Chapter One, 2), if a person is closed, perhaps the meaning is therefore unlikely to be available, in other words it remains intrasubjective.
Jourard’s interpretation of Buber reflects the kind of reciprocal recognition that my study describes. Jourard (1968, p.21) suggests that dialogue is like:

mutual unveiling, where each seeks to be experienced and confirmed by the other … such dialogue is likely to occur when the two people believe each is trustworthy and of good will.

It is interesting to note that whilst the overall nature of the study and relationship to the narrators is dialogical, in the instance where I believed that Scott was closer to death than to being present in his room with me, we sat for some time in total silence - it was a special kind of companioning without need for words or action. It was a deeply empathic intersubjective kind of relationship that was not languaged. For me, the meaning here was that I was comfortably willing to quietly companion Scott without language or action, even to the point of his death if it happened then.

In Chapter Eight I considered ‘whose story and meaning was created?’ Did each narrative belong to each narrator? All five narrators chose, (and it is important to state that not everybody would or should make this choice), to open their story to the metaphorical central space in Figure 36. In order to access the meanings in the intersubjective meeting space, I engaged in listening empathically, accommodating, pulling back from ‘doors that were closed’ and opening my own experiences to the possibilities in the stories we shared and co-created. This suggests that my experience of the life reviews opens up as much of my own understanding of life, as it offers this understanding for the narrators who engaged in it with me (Lett 2001, p.159). They thus become co-created, shared meanings.

This could be argued as being a counter-therapeutic perspective. Here one might say one should work with defences such as ‘closed’ stories. One might work with the narrator so traumatic memories become memories that can be processed in some way. In this view, one does not leave these stories closed. I asked myself how I should listen with deep respect when the narrator was saying ‘I do not want to talk about that issue because it is in my best interests not to’. It was not always verbalised, I sensed that it seemed best that I did not probe a situation further. It felt as if I was standing in front of a closed door, and should respect that and move on in the narrative. In other words I was there as an ordinary I-Thou or Being-to-Being, not as the Therapist In-Charge-of-The-Therapy. It was
volitional, co-constructive sharing and responding. I did not feel that I was there ‘to get to the bottom of things’ as a psychotherapeutic approach might perceive as its agenda. In this way it needed respected closed-ness when that was required, as part of reciprocal recognition. It allows Frank’s (Frank 2004a) dialogical *holding one’s own* to be accommodated with respect.

The key finding of my study is centred around the notion of shared, reciprocal recognition and openness, and all five narrators for whatever reasons, had those points of openness or willingness to share their stories with me. I offered my willingness to listen deeply. In the case of Miriam, the Holocaust survivor previously described who could not begin to tell her story, I was open, and the literature supported me in making meaning from within her ‘keeping the lid tightly closed’ on her dreadful stories. *My* understanding of openness or an acceptable, understandable closed-ness was expanded as a result.

This offers an interesting perspective on a current notion of people needing to find ‘closure’. In a sense what I am arguing is different, rather that people need to find an appropriate openness in order to find what is approximate to closure, or meaning, or making sense of their experiences. It is the crystallisation of meaning sought by this process of openness. However it is, in a sense, about meanings for a particular point in time.

Temporary approximations or crystallisation of meanings were discussed in Chapters One and Eight. From a slightly different perspective, perhaps it is like dropping a pebble into the middle of a pond. It sends ripples outwards, it becomes a widening field, and the meanings can be available for others who meet them as part of their own openness. Perhaps they are just moments, crystallisations that appear when and where people are open to them. There is an ah-ha: ‘that’s what it meant’, but not MEANING that is finalised. Some meanings might last a while, and some might change in the telling. Retelling assists in expanding, rotating and re-shaping understanding and meaning, as was illustrated by Elizabeth’s ‘extra’ visit (refer Chapter Seven).

In the study there were uncovered meanings and observations throughout. Maybe there is not a fixed meaning for the ‘narrative of a life’; there are many tellings and many ways of telling, with many subsequent meanings. To re-iterate, the study demonstrates that from
within life review narratives, meaning is constructed through dialogues, helping to form a coherent narrative after disruptive life experiences. The narrative changing is not as important as the capacity to connect life events and come gain an awareness of their pattern. Forming a coherent matrix of stories into a satisfying life narrative can engender awareness of its essential features or essences. However it is not always possible, as was evident in Bert’s and Scott’s situations.

Skolimowski (1994) would perhaps describe the space in the centre of Figure 36 as ‘the space of grace, or sacred space’, which is created by the condition of the mind that experiences ‘ordinary’ spaces in an extraordinary way (p.258). Skolimowski (p.251) offers the schema that:

\[
\text{meaning} = \text{becoming} = \text{liberation} = \text{creativity}.
\]

He also suggests that the most important aspects of the integrated self are being at peace, and being whole. From my perspective this arises for me from understanding and hearing others, and being heard and understood myself, as ‘whole’ people.

My prior experiences made a significant contribution to the narratives. Supposing I had not had prior experience of people dying, then Sarah and Scott, who were close to death while I was recording their stories, could have caused me anxiety. I might not have been able to be calmly present. Although we were not addressing my prior experience, it was there as a ‘holding’ presence.

According to ethnographic researcher Ellis (Ellis and Berger 2002, pp.853-854), interviewing then changes in function as well as form:

The interviewing process becomes less a conduit of information from informants to researchers that represents how things are, and more a sea swell of meaning making in which researchers connect their own experiences to those of others and provides stories that open up conversations about how we live and cope.

In the case of Sarah’s story after she died, one might re-question ‘whose story is it now, and whose meaning?’ All of these stories exist in tangible form as they were written, as
narrative texts of these lives. Some might accept that as people die and cease to utter their narrative accounts, this is where they have ended. However the texts survive and can shape the interpretations and possible future actions that might flow from the characters in the life-stories. The listeners and readers of my study might also experience their own meanings, as I did from the personal illness narratives listed in Appendix One (Mattingly and Garro 2000, p.202).

I think Sarah saw purpose in her struggle to stop her story from being finalised by her bureaucratised disease process. By telling her story, she trusted me to extend the life of her story. Frank (2004, p.46), and Bakhtin (1984), argue that there is no finalising account or narrative, there is no closure.

Some people feel they have things of significance in their lives that are valuable for others to know. For Scott’s family, there is a feeling that his children and grandchildren are enriched by the legacy of their ancestors’ tales. It is an enrichment of knowing the stories of who and where they came from. Sarah was sadly resigned to the fact that she did not have children to fulfil this task. I was her best chance to make her story known.

The meaning is not necessarily fleeting or transient, it might remain stable for some time before it changes. However it is temporal, or at its own point in time. What seems to happen is that by holding the meaning and repeating or sharing it with others, the satisfying, deeply felt value of the process emerges. Transcribing was important. Re-experiencing the words as I was transcribing them, and then forming my intersubjective responses, enabled me to grasp and reflect on what was deeper, emerging from behind the words. I would often transcribe a section of the conversation and then go for a walk. I always needed paper and pen handy to write my reflections. They sometimes woke me at night and I would not be able to go back to sleep until I had written them down.

1.1.3. Is this process appropriate for everyone?
The answer to this question is clearly not. If somebody such as Miriam, whose situation I previously described, does not feel able to share their stories in this open way, that is their prerogative and it needs to be accepted with respect. I do not imply that the openness of the central space of Figure 36. is the one perfect end state for all.
The process highlights the intersubjective meeting that occurs when people feel safe to talk with someone: a feeling of **safe vulnerability**. Perhaps something in the first encounter makes it possible to be vulnerable in reciprocal recognition. The uncertainty and unknown outcomes are a stepping-out process for both listener and narrator. Safe vulnerability is another way of referring to intersubjective openness. The process may involve feelings of vulnerability, but one can go through it and emerge feeling changed and enriched, as Kaye affirmed.

These situations perhaps best illustrate the point of departure from a standard psychotherapeutic approach. In the psychotherapeutic framework it is the psychotherapist who applies the brakes to stop the therapeutic vehicle and inhibit or close the degree of resonance with the other Stern (2004, p.82).

In my study I amplify a system, to use Stern's metaphor, where I had a set of brakes. However I did not see myself as the sole driver in charge of the vehicle. In a sense the narrators had their own set of brakes, the decision to stop would have been a collaborative one. If there was a point where the discussion should not go, it was acceptable for the brakes to be applied by either person in the co-creative partnership. I have reflected on points where the narrator is driving the situation, (such as Elizabeth requesting a further meeting), not as in a psychotherapeutic situation where as driver-in-charge one might be saying ‘I know what is best for this journey, I control the brakes’. My study illustrates some possibilities for a vehicle with dual controls, perhaps more symmetrical than in a psychotherapeutic relationship.

I needed to listen to and understand what the points of safety were, for myself and for the person I was listening to. What is enabled to emerge from the process, is the uncovering of new understandings. For instance Scott was not suffering from a major depressive disorder, as his family feared, but rather was quietly withdrawing into a world of his own choosing prior to his death. It was a world where he could peacefully end his life. It might have embodied sadness, but it did not need interventions that would have disrupted his peace (Horwitz, A. Wakefield, J. Spitzer, R. 2007, pp.3-4).
2. THE APPLICABILITY OF THE STUDY’S MODEL TO HEALTHCARE SETTINGS AND RELATIONSHIPS

In Chapter Eight I discussed the qualities of engaged reflective listening that emerged from the study’s amplified model of listening to peoples’ life review narratives. These qualities included reciprocal recognition, openness and trust. As listener I engaged with the narrators as they constructed their illness and life review narratives, intersubjectively responding to the stories, and noting my own intrasubjective responses. This enabled a sense of meaning to form through the narrative process.

It emerged that as listener I needed courage and self-awareness to be fully present for the other’s telling. I gained perspectives on ways of listening: listening for the cultural contexts of the narrator and how they connected with my own cultural contexts; empathic reflecting and reiterating; gentle sensitive listening without interruption; allowing the struggle to find the right words; appreciating non-verbal language such as silence, which also enriched the story. I learned that the story might change in its telling, and I accepted the risk of being fallible and inviting correction. I learned to listen to difficult, emotional stories. I understood that sharing information also needed engaged listening, to clarify how this information was heard and interpreted by the other. I reviewed the situations where the listening was not optimal, and some of the reasons for these imperfections.

This section aims to explore the possibility of drawing parallels to engaged reflective listening in healthcare relationships and settings, and applications that might produce less disrupting experiences and better outcomes than some of those described throughout the study.

The introduction to the study described how illness narratives often express a gulf between the people needing care and the healthcare organization providing that care through its various staff members. The ensuing perceptions of indifference and disconnection arising from that gulf led to strong feelings of disruption to people’s sense of wellbeing (Habermas 1987; Crossley 1996, p.100; Frank 2002b). Some of the stories of my study express this sense of distress and disruption, arising from a variety of experiences that occurred within healthcare settings and relationships.
I have reflected on some of the ways that the quality of care might have been improved by better listening, contributing to better experiences and outcomes for each of the five narrators and their families, and for the healthcare professionals involved in the situations they describe. Because these ideas are speculative, they can be found in Appendix Eleven, 1.

The findings arising from the narratives, plus some synthesis of the possibilities of better care through reflective listening, enables moving beyond the particular, in order to address broader healthcare contexts. As Guillemin and Gillam (2006 p.27) imply, the narratives in the study might expand the imaginations of healthcare professionals and assist their understanding of those they care for. To listen to a patient’s narrative requires taking a particular theoretical and ethical stance that does not give privilege to biomedical scientific knowledge (Skott 2001, p.250). It sits differently to taking a medical history. As Killick (1994) argues ‘There’s so much to hear when you stop and listen to individual voices’.

Chapter One noted a number of primarily medical, evidence-based studies, that can be applicable to all healthcare professionals. These studies argue that better health outcomes are possible for patients, their families, and for healthcare professionals themselves, when healthcare professionals are mindfully engaged in processes of reflective recognition and listening (Silverman et al. 2005; Beckman and Frankel 1984; Brody 1994; Rider and Keefer 2006; Makoul 2001; Anderson 1998, 2000; Charon 2001; Connelly 2005; Frank et al. 1996; Pennebaker 2000; Smith et al. 1999).

A number of studies proposing reflective recognition and listening argue that this means that there are less adverse events for health systems to deal with, thereby making better listening cost effective, such as Iedema (2008) Taylor, Wolfe, and Cameron (2004) and Braithwaite, Iedema and Jorm (2007), (refer Chapter One, 4.3). This evidence reflects my own disruptive experience (refer Introduction) where better listening on the part of my nurses would have prevented the significant costs of the extra drugs and attention I needed for twenty-four hours.

These studies note that some current student healthcare professionals are being taught to listen and to respond to their patients with care and empathy. These attitudes recognise
patients’ own expertise and understanding of their situations. Referring again to my story, I knew perfectly well what was necessary to prevent the iatrogenic mishap that befell me because two nurses refused to listen.

Nurses Blomberg and Sahlberg-Blom (2007, pp.248-251) argue that a strong sense of personal identity and self-knowledge is important in healthcare professionals’ encounters with patients and their families, in order to trust their own feelings and to be able to engage in others’ suffering. Listening confronts one with the suffering of others and one’s own suffering which has perhaps not yet received one’s attention. Healthcare professionals need to be consciously aware that their own prior experiences, culture and prejudices impact on relationships with patients, and that there is benefit in finding ways to seek a mature self-awareness and self-knowledge. Then the healthcare professional can meet with patients with an intersubjective recognition that is beneficial for both. It is necessary to learn this openness, it does not come as an automatic state. It requires learning to respond in an inter/intra-subjective space of respect and recognition of the entire bio-psycho-social-spiritual being of both those who seek care, and those who give this care.

Whilst the study’s model of engaged reflective listening demonstrates and amplifies lengthy processes of listening to and recording life review narratives, the model of reciprocal recognition and openness has parallels with briefer meeting points between healthcare professionals and patients. The study’s findings argue that the engagements that might enable better outcomes for patients and healthcare professionals, do not rest with time, cost, space or environment. Different levels of listening can contribute understandings that are available sometimes in the briefest of conversations and meeting points. They are more to do with the attitude of being fully present, and the quality of warmth and openness between the dialogical partners, rather than the length of a conversation. They imply that the healthcare professional sees the patient as a person, not just-a-body, in what is, for many people, an alienating, identity-denying situation. Kleinman’s (1988) and Kuhl’s (2002) stories are about qualities of listening. The five narratives in the study amplify and illuminate these qualities.

They arise from a willingness to build a connection to the other, an empathic engagement in an intersubjective space where both parties might meet and hear one another in a more
equal way. Perhaps the addition of merely seconds, with a different attitude of commitment to the scene in which they are players, might make all the difference to the patient’s wellbeing, and to the healthcare professional’s satisfaction in their work. Healthcare professionals, despite the pressures they are under, are clearly caring people who need to find ways to connect with the people in their care, and to listen to their stories of their illness. Sitting beside this willingness to connect, is the paradoxical tension that not everyone is able to be open to this kind of engagement or disclosure.

The development of ethical practice needs stories that give room for doubt, anxiety and hope, as elements of more humane, holistic interactions (Benner 1991). In writing about their personal experience of illness (refer Appendix One), Moore (1991), Frank (1991), Lorde (1997) and Price (1994) among many others, have clear suggestions for the improvement of healthcare provision. This depends on recognition of their experiential wisdom, which is embedded in their personal stories. The literature recounting people’s experiences should be a significant part of healthcare professionals’ development of empathic listening skills.

The nurse’s role might need to be that of interpreter and mediator when ‘the linguistic order of medicine meets the personal experience of sickness clothed in narrative language’ (Skott 2001, p. 250; Wros 1994). Not listening, as it emerged from the study’s narratives, amplifies loneliness and negates any feelings the person may have that they matter. The healthcare professional who is mindfully prepared to engage with her patient assures them that they matter.

I am arguing that there is potential in this model of listening for application within healthcare systems such as aged care, dementia care, palliative care - in fact any healthcare service. The model challenges notions of therapy as being a one-way doing-to by expert for recipient. The process is dialogical, and requires a quality of awareness from the healthcare professional that is alive, dynamic, open and truthful, not necessarily self-disclosing, but recognising the other as an expert in their own experiences.

There are encouraging stories that illustrate a different way of listening. Anderson (1998, p.281) describes teaching medical students how to create the symbolic space crucial to the emergence of more complex narratives, like those told in my study. One of Anderson’s
stories involved a student with a ‘difficult and demanding’ patient who was dying - ‘a smelly, unpleasant woman’. The student realised the woman came from the cotton growing area where he grew up. One day he sat beside her, held her hand, and told her that he had forty acres of cotton waiting to be picked and he was counting on her to get better so she could get started. She began to talk about her life. The student watched her ‘transcend her surroundings’. He noticed that she had no other visitors, and she brightened every time he visited her. Her continence and demeanour improved and the other staff were impressed. This story highlights the unique person-to-person encounters that are possible and enriching. This woman’s illness stories were then understood in the light of her previous cultural environment. Cultural knowledge should be a resource, as it is uncovered by listening deeply to people’s stories of their illnesses and lives (Garro 2000, p.70).

In another setting, application of this study’s findings relate to St. Pierre’s (2005, p.967) argument that listening to life review narratives assists in decreasing violence. This is reflected in remote Australian Aboriginal communities. Alcohol and drug dependency and its related violence is a topical issue. Excellent narrative work is being undertaken by Aboriginal and non-indigenous healthcare workers and counsellors listening with recognition and respect, to Aboriginal people’s stories of disruption and lack of acknowledgement. This respectful, engaged listening helps reframe the stories into ways of seeing positive skills, knowledge and abilities, and in finding more creative stories for survival (Wingard and Lester 2001; Aboriginal Health Council 1995).

The starting point for disseminating the understanding gathered through the study's process is my aim to publish the work in book format. I also see possibilities for publishing the methodological understandings that have emerged, which can extend narrative work utilising multi-modal phenomenological methods.

In Chapter Eight, 13.8, I suggested a study that might be structured in similar methodological vein, to explore one person's illness journey by interviewing and engaging with the experience from the perspectives of the variety of stakeholders in the illness: the person, their family members, and various healthcare professionals involved. A multi-modal, multi interview, dialogical study could, by utilising heuristic phenomenological inquiry reflective methods, contribute to a narrative picture that expands the
understanding of how different perspectives find different meanings in one intense illness situation and experiences.

In early 2009 I am preparing to interview with a similar methodological approach, some of the present and past residents of a hostel that accommodates people from country areas needing to stay in Melbourne for medical treatment, or because a family member is critically ill in one of Melbourne's hospitals. It is run by a charitable foundation and these narratives will hopefully deepen the understanding of the impact of needing to be away from home, family, and friends in a time of crisis, and how staying in a supported, caring facility brings some sense of calm and meaning.

3. CONCLUDING REFLECTIONS

I not only gave space and encouragement to the narrators to speak and be heard empathically. In addition I was concerned about finding understanding and meaning that linked epiphanies and rich descriptions of particular points in one’s life. It was through these junctures and noticings that I tried to facilitate reaching the threads that helped make sense of these five lives and thereby, reflectively, my own. I wanted to find the deepest underpinnings of these qualitative narratives and excavate them. I also wanted to map them back into the literature that had inspired me and shaped my thinking, in order to give my listening and reflections integrity, validity and rigour.

Chapter Two 2.4 introduced the notion that ‘heuristic’ comes from the Greek, heuritikos ‘I find’ (as in ‘eureka’). The following discussion reflects the heuristic heart of my thesis, and the crystallisations of meaning that arose for me from my study:

For reasons outlined early in the study, I was somewhat emotional at the beginning of my tertiary studies, concerning my perception of the failure of healthcare professionals to carefully listen to their patients. As a healthcare professional approaching the end of my career, I was angry, due to my sense that all was not well: this could/should be done better. I hoped that professional care-giving and empathic, reflective listening did not need to be mutually exclusive. Firstly I had to explore what was firing my anger. I finally crystallised that I had an agenda for effecting change in some way that could create a more equal position between healthcare professionals and their patients, rather than
healthcare professionals claiming overt power positions over vulnerable patients who expected care and recognition of themselves as bio-psycho-social-spiritual beings, not just a body with a particular disease.

I needed to take time for reflection in order to understand the experiences, both personal and professional that I had accumulated over many years, as discussed throughout the thesis. This involved ten years of postgraduate study, conversations, reflecting, reading, listening and writing, and finally writing the thesis, for it to gel together into a shape and meaning that was satisfying. My reference point always returned to the disrupted stories in healthcare relationships and settings and my need to make sense of them.

My a priori concerns and values are apparent in the introduction and transparent throughout the thesis. I became committed to listening in a particular way, testing and amplifying a particular model of seeing and hearing what was going on, in these five particular life review descriptions of not listening.

The ingredients that were necessary for my search to be successful were firstly in making a clearing or space and time for in-depth reflection and study, as proposed by Heidegger (1962 p.171). Then I needed willing listeners and support for my search. I found these through my teachers, friends, supervisors, courses of study I undertook, and the literature I absorbed. I needed courage and determination for my journey of exploration because it was never easy and challenged me ceaselessly. Listening to and reflecting on the experiences of others, and being heard by others in return, enabled me to find coherence, make sense, and crystallise meanings for myself. It required me to acknowledge my vulnerability and to place myself openly in the central space described in Figure 36, in order to create and see the ripples of meaning that could flow outwards for others. I needed to pay careful attention to my intrasubjective responses along the way, journalling my emotional reactions, fears and discomforts, and being transparent about my prior perceptions and judgemental stances.

What has crystallised from within the processes of the study is an understanding of the complexity of listening, and the many factors that impinge on it. I have amplified elements where it is possible to protect the space that is needed to talk, listen deeply and
reflect. I also identified how attitudes of reciprocal openness allow connections and meanings to crystallise even in brief conversations and meetings.

In contrast to most styles of academic writing, I included some of my own deeply personal experiences, which was not always entirely comfortable. However if the thesis aimed to amplify a process of engaged listening and responding, I was required to be transparent about my own relevant intrasubjective responses and how they influenced the crystallisation of meaning. Otherwise the process would have appeared to be incomplete. As previously stated, the study’s methodologies and model of listening can be replicated in other relationships and studies, but individual responses to individual stories are not replicable.

The study’s deeply personal conclusion fits the proposal in Chapter One that the thesis has explored ways in which meaning can be crystallised, and how it is argued that both narrator and listener make sense of their world, especially following difficult experiences, which are often located within healthcare settings and relationships. It expands understanding of experiential knowing, and what can be understood about self. My study argues that it is the I-Thou or Being-to-Being reciprocal openness, involving a binding together of self and other via dialogical connection, which allows meanings to crystallise.

My study reveals that it is not simply an either/or position of being a good or bad listener. I have amplified across the spectrum: really good listening to stories of difficult experiences, and contrasting situations where there is an inability, difficulty or refusal to engage with others’ stories of suffering.

In a sense it is an ethic of responsibility. I crystallised the understanding that the adoption of a Being-to-Being, or I-Thou stance involves a commitment to self-awareness and accepting responsibility for one’s own wellbeing. We use the word selfish in a pejorative sense. Perhaps only if one is self-full can one be available to oneself and to others. Figley (1995, p.1) argues that compassion fatigue often comes as a cost to caring. Healthcare professionals who engage with stories of pain, fear and suffering, may themselves feel similar pain, fear and suffering ‘because they care’. For successful, self-full narrative engagement the listener requires awareness and respect for the other’s life context and values, and courage and self-awareness of the complexity within themselves. It becomes a
positive, reciprocally open I-Thou, or Being-to-Being connection that allows both people to crystallise their own meanings.

Perhaps different people search for meaning with different degrees of intensity following disruptive experiences. My study deepened my understanding that I am by nature a person who needs to crystallise meaning to make sense of my life and its experiences. Kaye said that she needed to process the facets of her mother’s life and death and Kaye’s own ensuing chaos, in order to know who she was now in the world of her mother’s absence. Sarah begged for open and engaged dialogue that might help her process and integrate her suffering into her life story. However not everyone will have this need to search so intensely in order to know. I am not arguing that everyone will or should be an intense meaning-searcher, despite the literature’s arguing this universality as presented in earlier chapters of the thesis.

A question then arises as to how people who have an intense need to search for meaning, can survive in a healthcare system when their experiences are exacerbated by tensions involving healthcare professionals who do not appreciate their need to operate in this way. How does an intense meaning-searcher make sense of an indifferent and disconnected relationship with a healthcare professional who does not have time, energy or emotional willingness and resources to build that connection (Habermas 1987; Crossley 1996, p.100; Frank 2002b)? How might attitudes shift so as to ameliorate some of the varieties of disruptive experiences that the study describes? The real world of healthcare services is fast paced, stressful, economically and technologically driven. Even so, healthcare professionals need to understand the lasting effects of indifference and disconnection, in order to reduce the ensuing disruption to meaning that is often the end result.

In concluding this heuristic phenomenological study, as suggested in Chapter Two, 2.3-5, it is important that the voices of all the participants are present at this end point. The creative, collaborative act of shaping these five narratives acknowledges the suffering and experiences of those lives, and those touched by the process, so as to make them available and meaningful. Robert Murphy (1987, p.230), recognising his own impending death, wrote that life has a liturgy that must be continuously celebrated and renewed. Its liturgy is its stories, which Bert so beautifully expressed as he held his life review document: ‘this is my life’. For Bert, it seemed to be a very tangible form of his meaning. Buber
(1923, p.131) interpreted it as ‘They say You, and listen’. It only happens when the Other is recognised as You, not It.

The narratives were created at one point in time in both my life and the narrator’s lives. There is a temporal and contextual anchorage, reflecting much of van Manen’s life fundamentals of time, space, self and other (van Manen 1990, pp101-106). Each of the stories is detailed and complex. It is not just the time, the being, or the place. It also encompasses the narrator’s relationship to the healthcare organisation involved, to others, and to their family. Each individual needed me to listen differently, and resonated differently within me and my prior experiences and stories. Some of the benefits of the study’s narratives sit within this larger frame of the life-world and the value of more fully comprehending the details of one’s own and others’ life-worlds. Each of the narratives was and is valuable differently.

Kaye is able to go on with her life by using her suffering more creatively. Sarah’s story is still alive in me, it still needs to be told, especially in Palliative Care circles, arguing the best possibilities of listening to people who need this care. Perhaps this is particularly the case when these people seem to be difficult. Scott’s narrative enabled his family to understand his withdrawal from the world as he approached the end of his life. Bert’s story changed me. I wish I thought that telling his story had any long-term impact for Bert. It was clear that in the time I visited him he gained value, self-respect and enjoyment from telling and being heard. Elizabeth told a story of adventures, highs and lows that stirred similar stories from my own life experiences. In coming to grips with the frailties she now lives with, she still celebrates the family strengths and support that are so important to her.

For a thesis that has utilised qualitative, phenomenological and heuristic processes it is acceptable to conclude without being conclusive. The stories can go on engaging whoever comes across them and chooses to allow approximations or crystallisations of meaning to emerge at their particular point in time. Even as I write it, it has already changed. The question is whether research that presents itself as part of an ongoing process is evaluated as inconclusive in a pejorative sense, or as open ended, which in dialogical theory is both empirically correct and ethically appropriate (Frank 2005, p.968). In conclusion, and in response to Sally Atkin’s poem ‘Tell me, she said’ (Atkins 2003), and Schwandt’s
(1996a, p.158) interpretation of William Blake’s poems ‘Songs of Innocence and Songs of Experience’, my final poetic essence statement for my study becomes:
Listening to Songs of Experience

I listened and paid attention:
I heard the poignant beauty in the music of the wild sad songs in the stories:
I heard how it felt to be de-mented and honky-tonked;
To be a flighty person who suffered deep grief and chaos,
but who, on being listened to with deep, care-full, self-aware engagement,
could courageously grasp a way to creatively absorb her suffering;
I heard how it was to be sad, old and dying but still searching
in quiet ephemeral worlds for universal truths and departed loved ones;
I heard the anguish of being on the annoying downhill ride,
which did not permit getting off, or being known;
I heard the sadness of fraying around the edges,
that coming back meant suffering griefs and frailties that are almost unbearable.

I learned to listen to my own wild, deep, sad songs - to crystallise their meanings
and know the impact that other’s stories have on my stories and experiences.
Sometimes overloaded with compassion fatigue by the weight of the world’s stories,
I need to acknowledge and honour my own need to say ‘I can’t go there!’

Their stories met with my stories and became our stories,
however bounded by limits of my professional stance and their closed doors.
I came to know me more deeply, as I have come to know them.
My sadness met and recognised their sadness.
We created bridges to the fluid spaces between selves
where understanding could envelop and transform us.
This is who we were, this is how we experienced our lives …
Our crystallised stories could rotate, refract, reflect and go out into the future,
even if we couldn’t always be present to our story’s now,
even if we continue to have difficult or disrupting experiences.
This is the meaning: our stories matter,
There are no boundaries or finalization to the stories - but only as long as we listen.
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Author/s:
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Title:
Crystallising meaning: attitudes of listening to illness narratives

Date:
2008

Citation:

Publication Status:
Unpublished

Persistent Link:
http://hdl.handle.net/11343/39575

File Description:
v.1

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