

**A VOYAGE OF GRIEF AND BEAUTY: A PHENOMENOLOGICAL STUDY OF
THE EXPERIENCE OF SUPPORTING A FAMILY MEMBER WITH AN
INTELLECTUAL DISABILITY WHO IS DYING IN A COMMUNITY SETTING**

by

Susan Anne Marlow

A thesis submitted to the Victoria University of Wellington

**in partial fulfilment of the
requirements for the degree of**

Master of Arts (Applied)

in Nursing

Victoria University of Wellington

2007

Abstract

This thesis reports on a research project which explored the phenomenon of supporting a family member with an intellectual disability who is dying in a community setting. The research purpose was to enhance professional understanding of what it is like to encounter this lived experience. Literature back-grounding the phenomenon and philosophical and theoretical constructs embraced by the researcher are outlined. An explanation is given of the hermeneutic phenomenological methodology which was utilised.

The main method of collecting research data was through conducting five open-ended interviews with participants who had supported a dying child or sibling. The participants' family members were aged between 3 and 52 years old at the time of their deaths. Their specific intellectual disabilities included Down syndrome, a metabolically induced disorder and a non-identified syndrome. The family members had died from a variety of terminal illnesses and in a range of community settings.

Interpretive analysis was achieved through reflexive journaling and hermeneutic intuiting of interview transcripts and field notes. The research findings have been subjected to rhetorical consideration in the light of further literature and poetic texts. Research findings are expressed metaphorically as groups of boulders representing themes and sub-themes. Three major themes were revealed as having impacted on the river voyage shared by participants and their dying family members. These were Interlocked Companionship, Search for New Balance and Permeable Interaction.

An assessment is offered of the strengths and weaknesses of the research project. The thesis concludes with recommendations for reflective practice, evidence based practice, service development and areas of future research.

Key Words: dying, intellectual disability, family member, community setting, hermeneutic phenomenology

Acknowledgements

First and foremost I extend sincere gratitude to each research participant. Your trust and generous sharing of a deeply personal story is at the heart of this research.

Without my academic supervisor Dr Margi Martin this thesis would not have been achieved. Margi, you have perfected the art of offering guidance with one hand and freedom with the other. The depth of your wisdom has inspired me to transcend zones of uncertainty and empowered me to glimpse beneath the edges of existence.

My husband Barry has not merely tolerated the impact this thesis has had on our personal life. He has encouraged me daily. Thank you for giving your love and sharing wise insights as I have pursued this new direction. To our family – each one of you is precious. The interest and belief you have expressed in my academic aspirations has touched me to the core.

Thanks are also offered to every person who has been consulted about this project or considered acting as a recruiter or a participant. I express particular appreciation to actual recruiters. Your courageous efforts have been pivotal to the success of this research. To my two friends who took part in pilot interviews – thank you for your support and willingness to pave the way.

I am indebted to the academics, professional colleagues and librarians who have offered inspiration, knowledge and skills. Special thanks are offered to Dr Kathy Nelson, Dr Chris Walsh, Dr Cheryle Moss, Dr Joan Skinner, Justin Cargill, Margret Westwater, Cindy Johns, Vicky Wall, Roz McKechnie, Kirsty Fraser, Bronwyn Lindsay, Don Carberry, Lynne Crooks, Vicky Trigg, Suzanne Hammond, Jean Parr, Chris Barthow, Krissy Wright, Gala August and Jayne O'Neill. The professional contribution of the transcriber is also warmly acknowledged.

A significant proportion of the operational costs for this research project were met by a grant from the New Zealand Nursing Education and Research Foundation. Receiving this funding and the affirmation of the committee gave a huge boost to the project. I also thank the board and management of Te Omanga Hospice Trust for the provision of study leave and professional services.

So many individuals have shown faith in this project that it is possible some have been overlooked. If so please accept this as personal recognition of your contribution.

Finally, I pause to remember a friend and colleague Larry Lindsay who was profuse in encouragement but sadly did not live to see this project undertaken.

You burn and glow and shine
You are the flicker in the flame my close and distant friend
COME with me and we will shout the cry of justice
Until those who have spent their life dance in the shadows
Can glide with smoothness of helping hand
into their own unique space
in the Great Beyond

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Chapter One

A Voyage of Grief and Beauty: The Research Origins

Introduction

The primary purpose of this document is to present a research report about a project designed to enhance understanding of what it is like to support a family member with an intellectual disability who is dying in a community setting. The complexities and challenges of moving from the role of nurse to student neophyte researcher have also been captured.

This chapter begins by outlining how my interest in conducting this research was initiated and a picture is painted of the forces which drew me further down this pathway. The construction of the research project is described and the research question, purpose and aims are introduced. The meanings of key terms which were applied throughout the project are defined. The thesis structure is laid out, inclusive of an explanation of font style coding. This introductory chapter concludes with a table displaying the core content of each chapter.

How This Thesis Came To Be Written

My commitment to exploring this topic had its roots in inner dissonance which arose while I was caring for terminally ill patients with intellectual disabilities. Sometimes the patient's eyes spoke volumes but their verbal silence was unnerving. Even if we were able to exchange words mutual understanding could be elusive. If invasive interventions were required the patient's family invariably offered explanation and reassurance to them. However once the patient and I were left alone, perhaps in a much loved and personalised bedroom, their pervading sense of bewilderment and vulnerability shook me as a fellow human being. This produced a gut-wrenching sense of imposing upon their personhood. I also cared for dying patients who had a family member with an intellectual disability. In some instances terminal illness shredded parental capacity to support a co-habiting adult child with an intellectual disability. Resolving such situations could be emotionally and practically gruelling.

During these deeply challenging professional encounters I would searchingly ask myself "how is this person with an intellectual disability experiencing this situation and how can I

best assist them?” Van Manen (2002g) posits the view that having concern for others has been devalued in post-modern society and that as a consequence the voices of the most vulnerable population groups have been muffled. As I began to investigate what was known about palliative care provision for people with intellectual disabilities literature confirmed that the dying (Bradburn & Maher, 2005) and people with intellectual disabilities (Botsford, 2004) were two groups of people who fitted into van Manen’s description of hidden population groups. I discovered that application of a ‘personal tragedy model’ to disability had strongly influenced societal attitudes to the deaths of people born with intellectual disabilities. This grand theory which had dominated societal attitudes represented people with impairments and their families as victims. It portrayed them as having been struck a cruel blow by nature, resulting in disability and therefore an automatically diminished social status. Accordingly people with intellectual disabilities were perceived as being socially dead. Because of this and the powerful manner in which death and disability confront society’s fear of human disempowerment the physical deaths of these members of society have been historically denied. These pervasive attitudes devalued the personal deaths of many people who had lived with an intellectual disability and the whole topic was shrouded in silence (Blackman, 2003; Todd, 2002).

My philosophy of nursing is aligned with the foundational hospice approach described by Smith (1990) of offering holistic care to patients and their families. Therefore another outcome of my sense of having inadequate knowledge and skills to comprehensively care for dying people with intellectual disabilities was to question colleagues from palliative care settings about how they thought this aspect of service delivery could be improved. The predominant response was the assertion that as a holistic philosophy existed there were no deficits in the support given to people with intellectual disabilities. I questioned myself about this but felt unable to settle on such a view. The picture I had built up through personal experience, accessing literature and having collegial discussions consolidated my desire to conduct a research project designed to illuminate the phenomenon of dying with an intellectual disability. I equated this with addressing a social injustice.

Driving Forces at Work

This escalating interest received ‘coincidental’ reinforcement through attendance at a postgraduate lecture. A leading advocate for people with intellectual disabilities described her co-facilitation of focus groups of adults with intellectual disabilities which enabled them to inform a report: “To Have An Ordinary Life” (National Advisory Committee on Health and Disability, 2003). The report’s purpose was to describe the degree to which this

group of adult New Zealanders experience community membership and citizenship rights. In doing so it identified extensive deficits within health service delivery. Verbatim quotes formed a framework throughout the document and were disarmingly powerful.

Another unexpected but influential occurrence at this preliminary stage of the research was an intensification of my connection with my husband's late sister Karen who had been born with Down syndrome. Karen didn't quite fit into any of the 'right boxes' to receive carer relief or education while she remained at home and mounting stress culminated in her going to live in a large institution at the age of twelve. Sadly she died suddenly while undergoing a medical procedure at the institution when she was fifteen years old. Karen's gentle footprints, now echoing with fresh clarity, harmonised with the evocative narratives in the document "To Have An Ordinary Life" (National Advisory Committee on Health and Disability, 2003) and intermingled with ongoing clinical encounters. My motivation to find answers to the question "what is it like to die when you are a New Zealander with an intellectual disability?" burgeoned.

One practical step taken was to conduct a systematic analysis comparing the services offered to people with intellectual disabilities by my employing hospice with the obligations and goals (key result areas) contained in relevant national and regional strategic documents. I then sought to gradually realise the recommendations generated within my clinical setting. At the same time I began networking with professionals involved in the intellectual disability support sector in New Zealand and Britain and asked them if they saw justification for undertaking such research. Without exception they encouraged me to step into this neglected research area.

Later, I stumbled across the term back-story, when editing the writing of my daughter who is a theatre student. It seemed back-story referred to the drawing out of stories and character traits underlying what was explicitly revealed through a dramatic plot. This aligned with my view that life is the most authentic and richest form of theatre, where what is openly displayed is always under-girded by multiple influences, truths and realities. Back-story felt like the perfect description of the deep and almost intangible personal perspectives which were at that time driving me as I embarked on the research project. My daughter directed me to the following definition of the term.

"In narratology, a back-story ... is the history behind the situation extant at the start of the main story. ... The dramatic revelation of secrets from the back-story is

a useful term for forming the story, recommended as far back as Aristotle's Poetics” (Wikipedia, 2006).

Although from a non-academic source, the statement perpetuated the notion of back-story under-girding the research project. It spoke of how history strongly influences the current positioning of intellectual disability within society, as well as highlighting how back-stories within my life had brought me into the role of neophyte researcher. As the research evolved the pertinence of sensing back-story at work intensified further because of the close links between phenomenological perspective, literature and theatre. I also became aware of the interviews unfolding as theatrical settings where narratives were laid out and secrets brought to the light.

While contemplating the research project I grappled with my inexperience as a researcher and lack of knowledge about the intellectual disability sector. On this basis I decided that involving people with intellectual disabilities as research participants was not ethically justifiable. A desire to align the research topic to my practice as a hospice homecare nurse was another reason behind the project exploring the experiences of individuals who had supported a family member with an intellectual disability who had died in a community setting. I hoped to create a platform where those who had stood alongside dying people with intellectual disabilities could speak out about a phenomenon which had been erroneously concealed for too long.

As the research focus was clarifying I sought published research about the relationship between terminal illness and intellectual disability with greater intensity. The scarcity of writing on the topic and the explicit statements made by several authors emphasised this issue had been largely overlooked by palliative care and intellectual disability researchers (Read, 2005; Todd, 2002; Todd & Blackman, 2005; Tuffery-Wijne, 2003). Almost all of the research studies sourced were of British or American origin. No New Zealand studies about the deaths of people with intellectual disabilities were found. King (2003) points out eighty percent of New Zealanders are now native born and possess a strong sense of national identity. This aptly describes my personal positioning. This dynamic accounts for the manner in which discovering this absence of local inquiry intensified my desire to conduct research within New Zealand's unique social, healthcare, economic and cultural context.

The reading of available literature broadened my knowledge about intellectual disability and further guided my identification of a specific research focus. It also confirmed my view that palliative care services had historically been under-utilised by this population group but that those services should expect to care increasingly for people with intellectual disabilities who were living within mainstream society. This resonated with the opinion of the advocate, whose lecture about facilitating the focus groups to inform “To Have an Ordinary Life” (National Advisory Committee on Health and Disability, 2003), had acted as an initial catalyst to conceptualising this study. She believed that if my research enhanced the quality of and access to palliative care services for New Zealanders with intellectual disabilities this would protect their right to experience an ‘ordinary death’ (C. Johns, personal communications, June 2, 2004; September 28, 2006). I concluded that enhancing professional insight into the lived experience of supporting a family member with an intellectual disability who is dying in a community setting would undoubtedly contribute to this goal.

Research Structure

Having decided on the specific focus of the intended project a search for the perfect research question began. This involved thinking and speaking with others. The area of inquiry was clear from the beginning but the words “what is it like” were not arrived at until the decision was made to utilise a hermeneutic phenomenological approach.

The Research Question

“What is it like to support a family member with an intellectual disability who is dying in a community setting?”

Research Purpose

- To reveal the ‘inner world’ experiences of individuals who have supported a family member with an intellectual disability who was dying in a community setting.

Research Aims

- To release the voices of families/whanau who have supported a family member with an intellectual disability who was dying in a community setting
- To support the clinical practice of palliative care and intellectual disability sector nurses by revealing the experiential perspective of people who have supported a

family member with an intellectual disability who was dying in a community setting

- To identify palliative care service gaps, thereby enhancing quality outcomes for dying people who have intellectual disabilities and their families/whanau

Definition of Terms

As what is conveyed through words is open to interpretation the meanings of the following terms are outlined below to provide a clear understanding of the context in which they were used within the research question and applied throughout the research project. A definition of palliative care is also provided.

Palliative Care:

Palliative care is the care of people who are dying from active, progressive diseases or other conditions that are not responsive to curative treatment. Palliative care embraces the physical, social, emotional and spiritual elements of wellbeing—tinana, whanau, hinengaro and wairua – and enhances a person's quality of life while they are dying. Palliative care also supports the bereaved family/whanau (Minister of Health, 2001, p. 2).

Support a Family Member:

The offering of any form of practical or emotional involvement in the life of a person with whom one has a biological and/or legal relationship.

Intellectual Disability:

“a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with:

- *a reduced ability to cope independently (impaired social functioning)*
- *which started before adulthood with a lasting effect on development”*

(Department of Health as cited in, National Advisory Committee on Health and Disability, 2003, p. 10)

Dying:

Having a terminal illness (malignant or non-malignant) or having suffered a terminal event (like irreversible aspiration pneumonia) which is likely to limit life expectancy to one year or less.

Community Setting:

Any location, apart from, a large residential institution for people with intellectual disabilities.

Thesis Framework

The chapters of this document outline the research process from inception to completion. They also demonstrate the less structured reflective and interactive spheres under-girding the project. Poetic, lyrical and metaphorical elements surface at certain points in the text. This reflects my engagement with hermeneutic phenomenological methodology. The reasons for assimilating these artistic styles into the study are outlined more fully in Chapter Four. Specific points of note related to this are:

- The application of ‘inverted commas’ when including descriptive terms which are not direct quotes. Some contain evidence of the creative nature of this methodology as they include words which were ‘invented’ by myself in order to adequately convey a concept.
- The altered **font style of headings** in Chapters Seven, Eight and Nine and the insertion of ... at the end of analytical statements is indicative of the rhetorical nature of the writing.
- Textual coding applied throughout the document is shown in Table 1.

Table 1: Textual Coding

General Text	Times New Roman
<i>Cited Quotes</i>	<i>Times New Roman</i>
Transcript: Participant Statement Accentuated statement Omission of word(s) Researcher Statement	Comic Sans MS Comic Sans MS Book Antiqua
<i>Reflexive Journal Excerpts</i>	<i>Lucinda Handwriting</i>
<i>Journal Excerpts</i> <i>Researcher's reflections trailing on in muted form</i>	<i>Script MT Bold</i> ...

Chapter Overview

This thesis has twelve chapters. They collectively present the pathway which led to the research project being conducted, outline the many facets of the research process and present its outcomes. Introductory and concluding passages define each chapter and amalgamate the constituent parts of the thesis. In order to avoid monotony these passages are given varying titles. The key content of each chapter is summarised in Table 2:

Table 2: Chapter Content

CHAPTER	CONTENT SUMMARY
One	<ul style="list-style-type: none">▪ Explains the forces which motivated the execution of this thesis▪ Outlines the research structure, question, purpose and aims▪ Discusses the thesis framework
Two	<ul style="list-style-type: none">▪ Profiles the part literature directly about and relating to the research topic contributed to the project▪ Strategies employed during data searching are described▪ Literature illuminating the phenomenon of interest is profiled and reasons for inclusion offered.
Three	<ul style="list-style-type: none">▪ Addresses methodological selection, outlines the chosen research approach in terms of its epistemological stance and how my engagement with it is representative of researcher pre-suppositions▪ The history of phenomenology philosophy and research methodology are summarised▪ A range of original phenomenological texts is discussed▪ How hermeneutic phenomenological research is conducted and the part which reflexive writing plays in this are explained▪ The interaction between the nursing profession and phenomenological methodology is described
Four	<ul style="list-style-type: none">▪ Paints a picture of philosophical and theoretical scholarly understandings which stand as pre-suppositions due to their innate influence on my psyche as a person and researcher▪ The perspectives of Viktor Frankl, Judith Christensen, Margaret Newman, Jean Watson, Thomas Moore and interpersonal bonds traversing death are discussed, in relation to the project.

Five	<ul style="list-style-type: none"> ▪ This is the first of two chapters providing an overview of the research design and methods ▪ It specifically relates to data collection ▪ Consideration given to the Treaty of Waitangi is described ▪ Ethical approval and related issues, the recruitment process, the challenges of recruitment and participants profiles are all described ▪ The multiple facets of interview implementation and data collection processing are profiled and retrospectively reflected on
Six	<ul style="list-style-type: none"> ▪ Portrays the research methods utilised during data analysis to reveal the meanings contained within and across participant statements, observations, the reflective journal and field notes ▪ The trustworthiness of the research project and findings are examined using a framework which evaluates the rigour of qualitative research
Seven	<ul style="list-style-type: none"> ▪ The first of three chapters profiling the three major themes and numerous sub-themes which arose as research findings. These chapters are written rhetorically and moulded around participants' verbatim quotes ▪ This reflexive style mirrors hermeneutic phenomenological analysis through which these understandings were derived. These chapters are stylised through use of metaphor, lyrical textuality and a different font style for headings ▪ Chapter Seven offers insight into what constitutes the powerful Interlocked Companionship found to exist between participants and the dying loved one they were supporting
Eight	<ul style="list-style-type: none"> ▪ A metaphorical presentation of the second theme Search for New Balance. ▪ This highlights equalising reactions invoked within participants as situations evolved around themselves and their dying family member
Nine	<ul style="list-style-type: none"> ▪ The final major theme Permeable Interaction is addressed through identifying sub-themes. ▪ They pertain to how participants experienced the involvement of other individuals and services within the context of supporting their family member with an intellectual disability

Ten	<ul style="list-style-type: none"> ▪ The research findings are discussed in the light of a broad range of literature sourced following data analysis ▪ Links are drawn between the literature and the research findings ▪ Pretexts set out as pre-suppositions in Chapter Four are reconsidered with reference to the research findings
Eleven	<ul style="list-style-type: none"> ▪ An evaluation of the strengths and limitations of the project is delineated
Twelve	<ul style="list-style-type: none"> ▪ The body of the thesis concludes with a summary of the significance of the research findings ▪ Ideas about implications for clinical practice and service development are shared ▪ Recommendations are made about how future research can build on this research project and its findings
Epilogue	<ul style="list-style-type: none"> ▪ Expresses my personal feelings about the project as the experience of venturing into the role of student neophyte researcher comes to an end

Conclusion

The driving forces and logic behind my decision to research the lived experiences of people who have supported a family member with an intellectual disability, as they were dying in a community setting, have been outlined in this opening chapter. Justification for undertaking the project and for choosing to interview family members is inherent within this description. The research question, purpose, aims and methodology have been introduced and the structure of the thesis has also been outlined. A summary of the core content of the chapters forming the thesis has been tabulated to provide the reader with a mind map.

Accessing professional literature about the phenomenon of dying with an intellectual disability played a key role in guiding my insights in the early stages of this project. A selection of this literature is now profiled in Chapter Two. Data searching strategies are also shared and rationales are offered for the inclusion of the chosen pieces of literature.

Chapter Two

What Evidence Has Informed This Research Project?

Introduction

An overview of how reading literature and communicating with some established researchers informed the research project is offered at the beginning of this chapter. Data searching strategies and a selection of literature which provided preliminary understanding of the phenomenon are then outlined. The chapter closes with revelations of how several authors have identified the urgent need for research in this area.

How Literature Laid Foundations

In my nursing practice I have taught myself to drop deeper and deeper into reflecting on situations which are the most challenging. One strategy for doing this is turning to literature which informs evidence based practice. As scientific knowing always has potential to be flawed (Wilson, 1993) I have also sought to become a discerning research consumer. I therefore critiqued all the literature sourced to provide an overview of the phenomenon I was proposing to research and those which were related to it. The content of each piece of writing was then summarized; with particular reference being made to how it informed the central or peripheral issues of the phenomenon. Van Manen (1990) confirms the wisdom of this strategic gathering of theoretical insights into a phenomenon under consideration prior to entering the researcher role.

When seeking professional literature pertaining to the phenomenon of supporting a family member with an intellectual disability who was dying in a community setting a traditional dearth of research became evident. It seemed however that British and American researchers had recently become more focused on death and dying among people with intellectual disabilities. British literature portrayed this impetus as being collegial and associated with strong networking and collaborative clinical goal generation. For example a book edited by Read (2006) consisted of multidisciplinary contributions by experts sharing a mutual concern that optimal palliative care and bereavement support be available to anyone with intellectual disabilities. The detailed information provided was aimed at empowering intellectual disability support services to provide fundamental palliative care and to foster partnerships with external health providers such as hospices and district

nursing services. Encountering multiple exhortations within the literature for increased research into the circumstances surrounding the dying of people with intellectual disabilities further reinforced my research intent.

Electronic data transfer allows traditional barriers of time and location to be traversed (Newman, 2003). This means clinical research can now be rapidly disseminated to enhance evidence based practice globally. I appreciated the convenience of retrieving publications from databases on the World Wide Web and found that communicating with authors using email addresses included with published articles was fruitful. I was told by more than one source about The National Network for the Palliative Care of People with Learning Disabilities in Britain and was provided with details of forums being held there. I found authors appreciated feedback about the clinical usefulness of their publications, were interested in the corresponding situation in New Zealand and invited ongoing contact.

Data Searching

When seeking literature related to my substantive area of interest initial consideration was given to research explicitly about the dying of people with intellectual disabilities. This focus then broadened to allow exploration of some of the complex peripheral issues accompanying this topic.

Library Catalogue Searching

At the beginning and conclusion of the research project the library catalogues of the following institutions were searched for relevant literature, either independently or occasionally with the assistance of librarians.

- Victoria University of Wellington
- Te Omanga Hospice
- Donald Beasley Institute
- IHC

Database Searching

As a distance student I accessed a wide range of databases from home. The most productive results came from searching Proquest Medical, Proquest Social Science and CINAHL databases. A variety of terms and combinations of terms were inserted as key words in a truncated form when conducting advanced searches. This was complicated by

the diverse alternatives to 'intellectual disability'. Terms used in searching included: intellectual disab*/impair*; learning disab*/impair*; mental retard*; Down* syndrome: palliati*; death; dying; hospice.

Abstracts or full texts were briefly reviewed onscreen and if the content appeared relevant they were downloaded to hard copy. Other articles were obtained through using the 'Journal Finder' facility on the university library web site. Any full-text articles which were unobtainable electronically were requested through university distance librarians.

Literature Illuminating the Phenomenon of Dying With an Intellectual Disability

An overview is now given of selected literature derived through this initial search which preceded the research project. Literature is presented under topic headings. I did not find any research specifically about the issue of family members supporting dying loved ones with intellectual disabilities in community settings. Tuffery-Wijne (2002) did recruit a family member as part of a case study but then they withdrew. This left me seeking insight by reading articles about closely related topics, such as the contemporary situation regarding access to palliative care services for people who have intellectual disabilities. I then delved into the broader issues of living with an intellectual disability in order to anticipate the influence these may exert as a family member was dying.

About Supporting a Family Member Living With an Intellectual Disability

I believed the experience of supporting a family member living with an intellectual disability would provide the 'base course' on which the phenomenon I was seeking to illuminate rested. I found Todd and Shearn (1997) had conducted serial interviews with thirty-three parents of adult people with intellectual disabilities. Findings showed that although parents tended to view their adult children as adolescents they universally believed their offspring deserved to be respected as adults. Several parents felt health professionals imposed adult status in an unreasoned, patronising and insincere manner. Maintaining vigilance in public and limiting social forums reduced families' freedom and so some people felt their family suffered a collective disability and diminished self-identity. Most parents did not discuss their offspring's compromised social status with them, citing a desire to avoid inflicting the type of distress they themselves had experienced on discovering their child's disability.

How People with Intellectual Disabilities Perceive Illness

I had a burning desire to find out how illness is viewed and therefore experienced by people who have intellectual disabilities. This was directly linked to my question in practice “what is this like for you? How do you see this?” At times the same query had been posed to me rhetorically, by relatives seeking to understand the reactions of family members with intellectual disabilities, whose parent or sibling was dying. In particular it seemed actions taken to relieve discomfort could be viewed as the cause of patient distress. In the context of my role as researcher I saw that seeking to understand the conceptual framework of illness held by individuals with intellectual disabilities would be a pre-requisite to comprehending some of the stories I would ultimately hear.

I sourced a study by March (1991) which sought to define what developmental level of illness perception fifty four subjects with intellectual disabilities had attained. It was found most either believed illness was contained within persons or objects close by or that it was held in these persons or objects and transmitted into their own bodies if physical contact occurred. Rote use of medical terminology without underlying insight was also noted. Interviews revealed illness outcomes were widely viewed by participants to be pre-determined and non-modifiable. March concluded that perception of illness and individuals’ cognitive development level correlated. Interestingly perception of age and death are shown to increase as adults with intellectual disabilities age (Lipe-Goodson & Goebel, 1983).

Changing Demographic for People with Intellectual Disabilities

At the time of contemplating the research project the last large institution for New Zealanders with intellectual disabilities was about to close. This reflected the move into community living. I also knew people with intellectual disabilities were living longer lives but tended to die more frequently of different diseases than the general population. I sourced data to ascertain concrete facts about these phenomena and whether they supported my assumption that the need for community based palliative care services by people with intellectual disabilities would escalate. There were numerous texts written about these trends and these are now presented.

Bittles et al.(2002) found South Australians with moderately severe intellectual disabilities now have a median life span of 67.9 years and for people with mild disabilities this was 74 years. Longitudinal studies conducted among institutionalized residents with intellectual

disabilities found cancer death rates were lower than in the general population, although rates identified varied between 13.6% and 31% (Cooke, 1997; Evenhuis, 1997). Gastrointestinal malignancies were found to be disproportionately common but lung, breast and prostate cancers were under-represented. Certain cancers have been linked to particular syndromes, such as a high rate of leukaemia and testicular cancer in individuals with Down syndrome (Tuffery-Wijne, 2003; Yang, Rasmussen, & Friedman, 2002). However heart and pulmonary disease most frequently claim the lives of people with Down syndrome (Yang, Rasmussen, & Friedman, 2002). As most New Zealanders accessing hospice care have cancer and are over 60 years old (Minister of Health, 2001) the findings outlined above collectively indicated a significant proportion of older New Zealanders with intellectual disabilities will require palliative care services. Hospices are increasingly providing palliative care for people dying of non-malignant conditions so I also surmised they should expect increasing involvement in caring for people with intellectual disabilities in the end-stages of cardiac and pulmonary disease.

Palliative Care for People with Intellectual Disabilities

I felt that gaining a comprehensive understanding of the interrelationship between palliative care and intellectual disability services, and how readily people with intellectual disabilities could access support in their dying, would provide a strong reference point as I conducted the research.

Many authors writing about this topic explained how multiple factors have shaped the current palliative care needs of adults with intellectual disabilities. These include abandonment of segregated institutions and a philosophical commitment to normalize individuals' lives within mainstream society (Botsford, 2000; Evenhuis, 1997; Hollins, Attard, von Fraunhofer, McGuigan, & Sedgwick, 1998; Hollis, Attard, von Fraunhofer, McGuigan, & Sedgwick, 1998; Read, 1998; Todd, 2002). The impact of these sociological changes is that increasing numbers of people with intellectual disabilities experience bereavement and terminal illnesses as they age and live as part of mainstream society (Botsford, 2000; Brown, Burns, & Flynn, 2003; Tuffery-Wijne, 1997). Authors noted that families and staff in residential settings where the focus is on providing social rather than medical care frequently struggle to meet the palliative care needs of people with intellectual disabilities (Saunders, 2005).

Literature also outlined how certain population groups are known to have marginalized access to palliative care services and therefore a reduced possibility of dying at home (Grande, Addington-Hall, & Todd, 1998). Poor collaboration between intellectual disability and hospice/palliative care services was profiled as specifically problematic (Brown, Burns, & Flynn, 2003; Lindop & Read, 2000; Read, 2005; Todd, 2004; Todd & Blackman, 2005; Tuffery-Wijne, 2002) despite both sectors sharing key values about participation, self-determination, de-medicalisation, holism, inclusion of family and the entitlement of individuals to receive homecare (Botsford, 2000; Todd, 2002). Alliances between determined groups and individuals seeking to remedy this were however evident (Botsford, 2000; Read, 2005; Read & Papakosta-Harvey, 2004; Tuffery-Wijne, 2003).

The Complexity of Dying With an Intellectual Disability

Another action taken to lay groundwork before conducting the research was to build up a picture of how having an intellectual disability impacted when a person was dying. Exploring this would perceivably sensitize me to seeing how this featured in participants' stories. It seemed like a common courtesy to acquire basic insight before undertaking the interviews and having a preliminary understanding of the phenomenon would perceivably ground me as a researcher. Four issues explored with these goals in mind are now discussed.

A Difficult History

Through presenting a discourse analysis overview Todd (2002) demonstrated how people with intellectual disabilities have traditionally been excluded from death experiences and rituals. Suggested reasons paradoxically included the current emphasis on 'ordinary' living. Historical dynamics such as the 'personal tragedy model' presenting death as a kind escape from disability were other proposed causes. Past practices of concealing illness, disability and death from this population group have been identified as leaving a difficult triple legacy (Botsford, 2004).

Contentious Issues: Disclosure and Consent

Open disclosure, facilitating informed consent and professionally paternalistic reactions to treatment refusal have been presented as uniquely challenging issues when intellectual disability and terminal illness coincide (Brown, Burns, & Flynn, 2003). A major reason for this is that support and care systems have frequently compromised the self-advocacy skills and therefore the lives of adults with intellectual disabilities (Tuffery-Wijne, 2003).

Conflict between ethical desirability of disclosure and fear of inflicting emotional harm generally results in non-disclosure, which disempowers the person from sharing their lived experience of dying (Tuffery-Wijne, 2002). Dilemmas regarding disclosure to other people with intellectual disabilities who are close to the terminally ill person are compounded by the complexity of their own needs and the widely varying ability of such individuals to comprehend information provided (Blackman, 2002; Read, 1998; Tuffery-Wijne, Hollins, & Curfs, 2005). Deciding who should make disclosures and ensuring vigilant control of 'information leakage' in the absence of disclosure are also sources of anguish within support services (Todd, 2002).

The Impact of a Terminal Event on Significant Others

Smith (1990) believes that every diagnosis of terminal cancer produces a severe psychosocial crisis. This may throw their family's uniquely balanced normality into chaos. When an individual with an intellectual disability becomes terminally ill it often profoundly affects those who love them. As a result families may exhibit over-protection, rejection, guilt or over-identification (Tuffery-Wijne, 2002). When observing the painful inability of two brothers to be truthful with their dying sister who had an intellectual disability Tuffery-Wijne (1997) attributed it to a prevailing "conspiracy of silence" (p. 51). She also warned that pre-existing tensions between residential carers and families can become exacerbated in the face of terminal illness and enmesh the dying person in conflicting loyalties (Tuffery-Wijne, 2002).

Several researchers had found residential carers regard hospice care as aligned with the medical and institutional models from which the 'intellectual disability world' has recently emerged. Experiences of people with intellectual disabilities being ignored and misunderstood during hospital admissions has further fuelled resistance to palliative care services (Blackman, 2002; Brown, Burns, & Flynn, 2003; Todd, 2002, 2005). Todd (2002) hypothesised that the inequalities influencing the lives of people with intellectual disabilities would also compromise their dying process and the manner in which they were subsequently remembered. He interviewed fourteen parents whose adult children had died in residential care. A pattern emerged of having experienced rapid dislocation from the 'intellectual disability world'. There was a sense life was now abnormal without their child who had a disability. This created an emotional and social void; especially as parents felt others believed they should not react as having lost a child but as 'relieved people'. Their grieving was self-described as private, unrecognised and unsupported. Todd's research

particularly interested me as it had involved interviewing relatives of people with intellectual disabilities about their bereavement experiences.

Diagnosis and Symptom Management as Special Challenges

Diagnostic overshadowing describes altered behaviour arising from an individual's physical or emotional distress being mistakenly attributed purely to their intellectual disability. It was detected as an impediment to optimal palliation in multiple studies (Astor, 2001; Blackman, 2002; Brown, Burns, & Flynn, 2003; Evenhuis, 1997; Lindop & Read, 2000; Regnard, Mathews, Gibson, & Clarke, 2003; Tuffrey-Wijne, 2002). I felt this was a serious concern as Grande et al. (1998) strongly link late diagnosis in the general population to a reduction in home death rates. Tuffrey-Wijne (2002) provided an example of how diagnostic overshadowing combined with poor prognostic advice to carers impacted negatively on a man with Down syndrome who developed terminal liver disease. His presenting symptom of faecal incontinence was perceived to be 'acting up'. In another study the grief responses of three adults with intellectual disabilities who variously burnt themselves, stopped traffic and engaged in searching behaviors were similarly misinterpreted (Blackman, 2002).

Other studies confirmed that the assessment and treatment of symptoms is a source of concern and conflict in the 'intellectual disability world' (Astor, 2001; Read, 1998). Whether some congenital abnormalities causing intellectual disability also impose insensitivity or indifference to pain is a contentious issue (Tuffrey-Wijne, 2003; S. Gates, personal communication, February 16, 2005). The suggestion that ignorance of the serious implications of pain may reduce the physical sensation must be held in tension with the belief that lack of understanding can amplify fear, anxiety and pain (Tuffrey-Wijne, 2003).

People with intellectual disabilities are often gifted at forming interpersonal connections and it is proposed that their craving for meaningful relationships increases in the face of terminal illness (Tuffrey-Wijne, 1997; V. Wall, personal communication, March 9, 2005). Those familiar with the person frequently understand their unique 'language of distress' (Brown, Burns, & Flynn, 2003; Regnard, Mathews, Gibson, & Clarke, 2003). The importance of including carers in clinical assessment processes (Astor, 2001; Brown, Burns, & Flynn, 2003) and educating them regarding likely disease course and symptoms (Tuffrey-Wijne, 2002) were therefore highlighted as being important.

Urgent calls for Further Research

A final outcome of this preliminary data search was affirmation of my research intent. Responding to the historical lack of research into the terminal phase of life for people with intellectual disabilities Todd and Blackman (2005) and Read (2005) identified a need for more comprehensive statistical data to be gathered. Qualitative methodologies were however proposed as most suitable to remedy the general paucity of phenomenological knowledge (Tuffery-Wijne, 2003). Research about the terminal experiences of non-verbal individuals with severe intellectual disabilities was noted to be totally absent by Tuffrey-Wijne who called for the diversity of intellectual disability to be acknowledged in this context. She pointed out that how intellectual disability support services manage terminal illness, the meaning of dying with an intellectual disability and where and how this occurs remained unanswered questions. How palliative care services could most supportively be delivered to those in residential or family settings was also seen as a pertinent research topic (Todd, 2005; Todd & Blackman, 2005; Tuffery-Wijne, 2003).

Conclusion

This chapter has presented literature obtained through preliminary data searching. Commentary has been offered on why each piece of literature was judged to be pertinent and how fore-knowledge of the phenomenon of supporting a person with an intellectual disability who is terminally ill was generated through reading this literature. Strategies employed during data searching have been detailed. In the next chapter the focus will move to consideration of the methodological approach utilised in the research project.

Chapter Three

Methodology

Introduction

This chapter profiles phenomenology and its derivative hermeneutic phenomenology which was the methodology utilised to conduct this research. This complex approach and its underlying philosophy are outlined in depth along with a portrayal of how it infiltrated my psyche. This is to satisfy the methodology's requirement that understandings which a researcher carries into the interpretive analysis process must be declared as pre-suppositions (van Manen, 1990).

The methodological selection process and an overview of phenomenological history are now provided. The perspectives of leading phenomenologists Edmund Husserl, Martin Heidegger, Paul Colaizzi, Max van Manen and Michael Crotty are also reviewed. The chapter concludes with a resume of the relationship between nursing and phenomenology.

Methodological Selection Process

Due to prior education I was aware that a qualitative approach would be required in order to expand understandings about the experience of supporting a family member with an intellectual disability when they were dying. I also knew that in social science research methodologies arose from specific epistemological understandings of knowledge acquisition and underlying philosophical stances. The methodology would then guide formulation of the research design and methods through offering strategic approaches congruent with itself (Crotty, 1998).

“When using qualitative approaches reality is explored from an emic perspective, understanding life from the perspective of the participants in the setting under study” (Morse & Field, 1996, p. 18).

Any methodological approach selected must allow the researcher to manage self and data in a style compatible with their own personhood and have the capacity to answer the research question (Koch, 1999). These are the factors which guided my choice of research methodology.

As I read about qualitative research I became attracted to phenomenology through recognising that the intensive dialogue involved in such an exploration could provide answers to what it meant to have a certain lived experience (LoBiondo-Wood & Haber, 1998). I discovered that phenomenology enhanced insight into phenomena through accessing the consciousness of another who has lived the experience of interest. Crotty (1998) suggested that epistemologically phenomenology was a derivative of constructivism. This meant it viewed objective knowledge and truth as subjectively derived and formed through individualist understandings. Intentionality, the relationship between conscious subjects and their objects, is the basic building block of phenomenology. Crotty stated “*consciousness is always consciousness of something*” (p. 79) and emphasised that subject and object are interdependent and so mutually define each other.

The phenomenological notion of existentiality denotes the connections between people and the entire universe and cites the two as being inseparable. This is based on the assumption that as people are involved in objective life world situations they instantaneously develop a ‘sense’ about what occurs. As this ‘sense’ is unexposed to subsequent thoughts, self-interpretation, reflection and attribution of meaning, it facilitates a pure (primordial) experiencing of the phenomenon. Within this phenomenological context phenomena are things as lived experience (Streubert & Carpenter, 1999). When this sense about an experience is revealed the phenomenon stands out as the thing itself (Crotty, 1998). These phenomenological concepts rang true for me and I imagined participants sharing what it had been like being in their world during the time they had supported their dying loved one. Perceivably inter-subjectivity would be portrayed through accounts of how participants had interacted with whatever or whoever had entered into their life world during that experience.

In hermeneutic phenomenology knowledge is formed through moving backwards and forwards reflexively between composite parts of a phenomenon and its entirety. In this way new understandings are generated, including the nature of inter-relationships contained within the phenomenon. This contrasts with the positivist social science view that knowledge may be gained by considering various components of an object separately (Crotty, 1998). This methodological characteristic of deriving research findings reflexively attracted me strongly to the hermeneutic form. As a child I was labelled a ‘day dreamer’. As an adult this is more positively viewed as ‘being reflective’. How can this ‘day dreaming’ be described? It is like apprehending a tangible occurrence then holding it in position while also drifting out from it on waves of deliberation. This does not involve

focused cognition but a form of contemplation which inhabits silent spaces; it waits until the next step arises as an impression. This impression is then melded into the original imagery being held, so they reflexively become a fresh configuration. This process rolls over and over until conceptualisation of the matter under consideration reaches completeness. I recognised this way in which I engaged with the world as being conducive to undertaking a hermeneutic phenomenological research project.

Hermeneutic phenomenology seeks to capture the unique multiple realities which all individuals hold within their consciousness about everything they have experienced (Gillis & Jackson, 2002). My innate attraction to individual idiosyncrasy provoked enthusiasm for this phenomenological concept, called perceptivity. Phenomenological interviewing held potential to create a space for research participants to introspectively locate and extrospectively express their unique experiential perspectives. Stories would open a window to reveal insiders' viewpoints (Osborne, 1994) as unstructured interviews empowered participants to draw from their pre-verbal consciousness of experiences (Roberts & Taylor, 1998).

Phenomenology's attention to the body's social world promoted its use as a research methodology by psychologists, psychotherapists and sociologists (Spiegelberg, 1994). After detailed critique of selected nursing research studies (Byrne, 2001; Daly, 2005; Jumisko, Lexell, & Soderberg, 2005; Paton, Martin, McClunie-Trust, & Weir, 2004) I became convinced of phenomenology's capacity to enlighten clinical understanding and service development within nursing. At this point I concluded a hermeneutic phenomenological methodology definitely offered the best access to the experiences of people who had lived the phenomenon which I intended to research. Although I had known what research topic I wanted to explore the research question was not finally worded until the topic of interest was laid alongside the methodology. The phenomenological question which emerged was:

"What is it like to support a family member with an intellectual disability who is dying in a community setting?"

The words 'what is it like' reflected the ontological epistemology on which a hermeneutic Heideggerian approach is based and were also conducive with my personal orientation towards being constantly curious about how others are experiencing being in their own life world (van Manen, 1990).

Gaining Methodological Understanding

Prior to formulating a final research proposal I ‘scanned’ phenomenological horizons through reading a range of texts. This was not limited to the hermeneutic version because I wanted to grasp what lay around this approach and to remain open to questioning whether it was definitely the most suitable phenomenological methodology to utilise. This sifting process showed me which theoretical tenets I should adhere to and which were incongruent with my personhood or poorly suited to decisively answering the research question.

I found that a lack of familiarity with classical philosophers such as Plato, Aristotle, Kant, Hegel and Nietzsche who had collectively informed the modern phenomenology movement (van Manen, 2002c) was a distinct impediment. Another limitation was my cursory and second hand awareness of the contemporary movements and theoretical works which have developed out of phenomenology (van Manen, 2002d). One strategy for consolidating my understanding of the philosophical roots of hermeneutic phenomenology was to compile the following summary of phenomenological development.

Historical Overview of Phenomenology

The phenomenological movement arose in reaction to the dominance of naturalistic science (van Manen, 2002c). Phenomenology was typical of continental approaches of exploring abstract concepts through developing a theory around them; in contrast to the Anglo Saxon practice of applying analysis (Spiegelberg, 1994).

Franz Brentano introduced the concept of intentionality, claiming the conscious mind must always be focused on another, real or imaginary, objective entity (Spiegelberg, 1994). Edmund Husserl, a student of his, was unable to accept that consciousness could maintain a concurrent awareness of two things. This ongoing debate about the exact nature of consciousness is called the ‘mind-body problem’. One facet of this is the ‘double aspect theory’ which refers to mind and body being part of another reality which is beyond them. It has been claimed that Husserl clung to the empirical Cartesian stance that man possessed, rather than lived in a body (Holloway & Wheeler, 1996). Husserl’s search for a rigorous method to demonstrate scientific truth of lived experience radicalised early phenomenology (Spiegelberg, 1994).

Martin Heidegger developed hermeneutic phenomenology with the aim of revealing hidden aspects of phenomena and thereby answering ontological questions about ways of

being in the world. Heidegger introduced existentialism to phenomenology (Colaizzi, 1973). He believed all humans possess a veiled type of pre-understanding of Being and he named this 'fore-structure of Being'. He claimed these structures surrounded human Being and were precursory to existence. Heidegger saw philosophy, phenomenology and ontology as inextricably linked with Dasein, the core way of being in the world located at the centre of Heideggerian hermeneutic intuitive interpretation (Crotty, 1998).

Phenomenology had its origins in Germany. Broader acceptance then began among French academics, despite the recent history of war and perhaps due to a reduction in philosophical nationalism. Groupings sprung up globally, such as the American Phenomenological Society, founded in 1939. Compatibility with popular Marxist philosophy, focused on modern man's homelessness and alienation in the world, may have been a factor in this. Phenomenological existentialism was perceived by some as a left wing revolutionary movement competing with communist philosophy for young post-war adherents. Gabriel Marcel strengthened phenomenology's focus on the encompassing of human existence, as defined by 'being-in-a-situation', through 'participation in Being' and 'in beings'. He claimed 'being-with-others' represented self-hood (Spiegelberg, 1994). Jean-Paul Sartre focused on the tension between objectivity and subjectivity, freedom versus being and elevated the role of the human body. His existential humanism asserted that the universe was constructed by human subjectivity and self-transcendence, views attacked by the Catholic Church and communist authorities. His theatrical and literary background was shared with other notable phenomenologists (Spiegelberg, 1994). Merleau Ponty asserted that existence was a fusion of the difference between consciousness and non-consciousness. Highly regarded academically, he redirected phenomenological perspective towards actual human living, rather than pure consciousness. This rendered it applicable to researching individual and social existence (Spiegelberg, 1994). Paul Ricoeur embraced an existentialism based on man's reconciliation with himself, his body and the world. This presented man as a broken unity with unification being dependent on transcendence occurring (Spiegelberg, 1994).

Review of Original Texts

I was also aware that to build credibility novice phenomenological researchers need familiarity with original phenomenological texts (Streubert & Carpenter, 1999). While seeking to achieve this I discovered the truth of assertions that apprehending the constructs underlying phenomenology's philosophical writings can be frustratingly elusive (Koch, 1999; Streubert & Carpenter, 1999). The phenomenological landscape was complex and

jumped in and out of focus. In another sense it had always been there - a previously unnamed but palpable thread running through life. Trying to capture all the ideas it enveloped was overwhelming but reflections on some key discoveries are presented below.

Edmund Husserl

Husserl's pure phenomenology demands an objective, reductionist approach to be applied in order to find eidetic (general not singular) truths within phenomena. This requires any pre-suppositions which may influence the immediate intuition of what is held in pure consciousness about the phenomenon to be bracketed, as in mathematical problem solving. Husserl claimed this led to pure scientific description (Husserl, 1967). I found reading Husserl's essays was like exploring a fascinating cave with a flickering torch. A good dictionary successfully unlocked the quaint, somewhat dated terminology but the frequent insertions of German words amplified the sense of being in foreign territory. The text tantalisingly encapsulated deeper meanings. Interestingly even translator, Boyce Gibson, stated that he was grateful for the personal support of Husserl when he was attempting to understand the original version of "Ideas: A general introduction to pure phenomenology" (Husserl, 1967). As I read this translated version inner conviction seemed to 'ooze' out of Husserl's words. I considered his supplementation of this English edition with a preface commenting on the writings to be evidential of his own relentless redefinition of phenomenology. Reflecting on sections of Husserl's work certainly seemed more like 'sharing a journey' than 'learning about something' as the following excerpt from my journal demonstrates.

First you say we are continuously able to perceive our body within the world of things and ask if our consciousness can become distinct from our sense of being. Yes I dig this consciousness bit. Living life put in a nut shell - we come into the world and from that moment an interactive dance begins. We are always wondering or think we know where we fit. Why do you then go on about how immanent essences are those occurring within experiential stream of consciousness and how the essential nature of these can only be exposed when a phenomenologist has suspended all transcendent essences, including 'human feeling' and 'soul'? Plonking all the feeling, soul stuff aside for a while - that would be impossible. Basically what is IN me IS me and it HAS to exert influence. Perhaps I would answer your question about separating off consciousness with a "no". Mind you if I had the benefit of your personal explanation I

may see it differently. Am I reacting out of ignorance or the mob mentality that phenomenology has moved on from you?

Although reading Husserl's work was a struggle it was interesting to see the actual writing which Heidegger himself acknowledged to be precursory to the hermeneutic form of phenomenology (Farrell Krell, 2004). This appraisal of Husserl's work also confirmed a pure reductionist phenomenological approach was not congruent with my own view point.

Martin Heidegger

"For Heidegger, hermeneutics is the revelatory aspect of 'phenomenological seeing' whereby existential structures and then Being itself come into view" (Crotty, 1998, p. 96).

Heidegger proposed that the fundamental nature of human Being and existence legitimised the integration of the researcher's pre-suppositions so data analysis became interpretive, rather than merely descriptive (Spiegelberg, 1994). On appraising his philosophical positioning I felt fascinated by it. Heidegger argued that there were metaphysical elements within human existence which transcended pure science. The following statement typifies his existential view point: *"However, what trouble do we have concerning this nothing? The nothing is rejected precisely by science, given up as a nullity. But when we give up the nothing in such a way do we not concede it?" (Heidegger, 2004b, pp. 95-96).* Contemplating this and related concepts took on a life of its own; embedding itself as a reflective energy force seeking a positioning or rejection within my unique blueprint for life. It arose in the midst of my clinical practice as I cared for the dying. I chronicled this invasion of my innermost musings through journaling.

Attunement – reveals our Dasein – how we are among beings as a whole- see big links and how crucial to therapeutic use of self. What was going on with the Dasein of the patient I was with who changed from stable to dying from a pulmonary embolism in the space of five minutes. Did their Dasein travel fast to readjust to how they were among beings or doesn't it matter so near the end? I know it had been in our earlier conversation. They spoke about not always having been so helpless. I didn't need that explained but THEY needed to explain it.

Later

I see you have given thought to the link between Dasein and death. You say death doesn't become an adage on the end point of Dasein but in fact death is a point where Dasein takes everything back into itself. Very fascinating concept. I find it a feasible explanation of how conscious patients near death are commonly 'distancing themselves' from others and their environment. In fact it is like their 'usual selves' are lost to themselves and others. Is this an evaporation of Dasein?

In his definitive work "Being and Time" Heidegger (2004a) describes temporality where time runs ahead of existence and so in a sense becomes its future. My interpretation of phenomenological time was that it is existentially located so 'floats about'. Other concepts pivotal to Heidegger's ontological perspective are spatiality and Dasein. Dasein is essentially man's way of Being. It is spatial in nature with an inherent quality of discovering its own space through looking inwards on itself. I wondered if Dasein is the orientation we intuitively grasp for each time we 'surface' from sleep. I surmised that in asking "what is this **like** for you?" the research question essentially pertained to Dasein. Heidegger's argument that there is no innate spatiality within beings but this is produced by their inter-relatedness with the world was at the core of the research. While reflecting on temporality and spatiality I developed a quiet expectation they would both materialise within the narratives of research participants. I was intrigued whether participants may describe entering into a state of pure anxiety. I understood this Heideggerian concept to portray a realm where concern is obliterated to the point where a person's being almost implodes and they are able to glimpse briefly into life's mysterious chasm.

Before concluding this section about Heidegger it is important to note I am aware of controversy about his National Socialist allegiances (Maier-Katkin & Maier-Katkin, 2006; Milchman & Rosenberg, 1997). Mackey (2005) warns that nursing researchers should not overlook the implications of this. Koch (1999) believes selection of a research methodology must be based on it having congruency with the researcher's self identity. My view was that Heideggerian phenomenology offered a clearly preferential pathway for exploring the research question. Although Nazi perspective is strongly at variance with my own I did not sense these disturbing elements emanating from Heidegger's philosophical writings. After data derived from interviews led to the thesis directly considering the devastating effect the eugenics movement has had on the community of people with intellectual disabilities, I reconsidered this matter. Still, there was no awareness of any pretexts underlying the methodology having denigrated the research data, or its analysis.

On this basis, the application of a Heideggerian hermeneutic approach to an exploration of the phenomenon, was considered to be defensible.

Paul Colaizzi

The thinking of Colaizzi has been aligned by some commentators with a reductionist Husserlian approach. On reading his method of data analysis it did not seem to offer a suitable framework for interpretive analysis of data. I appreciated the ‘sharpness’ of his writing style (Colaizzi, 1973) and a useful comparison was made between individual phenomenological reflection and empirical phenomenological reflection. He projected them to be mutual derivatives of each other. The former enhances empirical data with imagination and the latter is more strongly grounded in real facts.

Max van Manen

Possibly the most acknowledged contemporary phenomenologist is Max van Manen. His commentary offered honest and pragmatic insights. For instance he stated “*phenomenology asks the simple question, what it is like is to have a certain experience ...?*” (1990, p. 44) and asserts that the objective of hermeneutic phenomenology is to “*enrich lived experience by mining its meaning*” (p. 38). The pertinent nature of van Manen’s writing is probably derived from his background as an educator and applied social scientist. The belief that language permeates lived experience is foundational to his theoretical positioning and he translates this into a combination of practical guidance and exposition on how language permeates lived experience. Clear articulation is provided of the four existentials he believes are found in all phenomena. These are: temporality; spatiality, corporeality and relationality (lived time; space; body and relationship). Van Manen linked these with the practice of writing by suggesting they could provide a textual framework for writing up research findings. When describing phenomenological foci he claims they seek clarity regarding both ontic (factual) content and ontological (the core nature) aspects of a lived experience.

Michael Crotty

Australian academic Michael Crotty’s (1998) commentary on social science research offered pertinent considerations of phenomenology. That his explanations were positioned within a broader human sciences context added value, as did his willingness to enter into knowledgeable and fresh critique of phenomenology's legitimacy. He explained that hermeneutics was based on the assumption that the written and spoken word have a

distancing component which extends their meaning beyond pure semantic content so situatedness holds equal importance with the actual words. Within this theoretical basis there is another assumption that meaning is often implicit within conversation and hidden from even the one expressing it. Overall, Crotty's insights into hermeneutic phenomenology strengthened my sense of identification with it. For instance his exposure of Heidegger's opinion that the influence which 'they' have within lived experience should be recognised and questioned was 'music to my ears'. The nebulous but often powerful 'they' element in life had always bothered me.

Crotty (1998) asserted that phenomenology is one facet of interpretivism, a research approach which provides understanding of human social existence through presenting interpretations of 'being in the world'. Its objective is revelation of idiosyncrasy rather than consistency; a process which includes embracing the influence of history and culture. Pondering this feature of phenomenological analysis caused me to wonder to what degree the culture and the historical place of intellectual disability in New Zealand society would be evident in participants' accounts. Crotty cites Merleau-Ponty's view that "*in order to see the world and grasp it as paradoxical, we must break with our familiar acceptance of it*" (p. 80). To phenomenologists culture is a double edged sword. It permits environmental reflection and provides direction through symbolism and social meanings but also impedes a free understanding of humanity. Discussing phenomenological intuition Crotty warned themes must emerge from within data and not be externally generated. The continual self-referral to the 'thing' in question was emphasised as protection against this. In terms of my proposed research I interpreted this as confirmation of the value of maintaining a reflexive journal where my interpretations of data would be explicitly presented to myself and recorded as a trail for others.

The contemporary phenomenological practice of "*putting oneself in the place of the other*" (p. 83) is named 'the great phenomenological principle' (Crotty, 1998). Crotty opposed the post-modern accommodation of situations inherent within this stance, positing that it represented an Americanisation and corruption of phenomenology's original European form. The subjectivism which allocates total emphasis to participant accounts is rejected by him. He insinuates the name phenomenology was adopted by this group for convenience, declaring that the resultant loss of objectivism and criticism diminishes the potency of findings. I thought he was suggesting the researcher becoming too enmeshed in the experiential accounts of participants may diminish the role hermeneutic intuition played in analysis. On the other hand Crotty describes how Heidegger modified

hermeneutic phenomenology himself, such as moving the emphasis from Dasein to Being and the poetic. Crotty claimed that a characteristic of Heidegger was to ascribe ever new meanings to words. I believed these points further legitimised the evolving nature of the phenomenological form named hermeneutics and that it justified my use of whatever variable methods best revealed the nature of the lived experience I was seeking to illuminate, as long as the processes were clearly explained.

Another way I informed the actual research project was to reconstruct information gleaned from methodological commentaries into the following summarised description of hermeneutic phenomenological research and writing.

Hermeneutic Phenomenological Research and Writing

In hermeneutic phenomenological research, unstructured interviews in which participants recount living the experience which is the phenomenon of interest generates primary data, supplemented by field and reflexive journal entries. To extract and faithfully interpret meaningful accounts of participants' life worlds they are guided to subjectively locate and reveal awareness from their consciousness, as they alone possess this knowledge. The methodological strengths of spontaneity and minimal interview structure generate textually thick data (Osborne, 1994). Interpretation of transcripts from interviews influences questions posed in subsequent interviews and directs ongoing analysis. Participant feedback on interpretation is pivotal (Osborne, 1994) and the degree to which unique aspects of participants' experiences are revealed is indicative of research quality.

Hermeneutic research should be circular, free flowing, reflective, reflexive and meticulous (Diekelmann, 2001). Continuous dialogical engagement between the researcher and the data ensures that high quality phenomenological findings are produced (Baker, Norton, Young, & Ward, 1998). Hermeneutic phenomenological analysis includes seeking secluded meanings between words. The detection of essences, or structures, leads to the creation of hierarchical themes through which the 'insider's' experientially based meanings of the phenomenon can be revealed (Osborne, 1994). Considering philosophical texts during the interpretive process challenges and extends interpretive perceptiveness and maintains focus on the phenomena (Diekelmann, 2001).

Declaration of pre-suppositions is pivotal to achieving rigour. The literature review is conducted after data analysis to avoid anticipation of findings (Beanland, Schneider, LoBiondo-Wood, & Haber, 2000). Presenting this literature alongside findings can be 'user

friendly' although situating findings and literature in discrete sections conforms more strictly to research protocol (Burnard, 1991). Van Manen (1990) presents phenomenological writing as a combination of interpretation and narration, describing contemporary phenomenology's epistemological foundation to be the expectation that language and text will reveal ontological knowledge so rhetorical writing becomes a composite part of the analytical research process. Familiarity with phenomenological texts also enhances a researcher's ability to discover meaning embedded in data (van Manen, 2002h). He supports his views by citing Heidegger's assertion that one facet of man's existence is an inherent intertwining of language and thought processes and states each researcher's writing is an authentic created work.

Phenomenology's Relationship to Nursing

The final methodological consideration was the alliance between phenomenological methodology and nursing inquiry. An extensive discussion is not possible in this context; for instance consideration of Benner's sentinel writings could not be included. I did find evidence that application of phenomenological methodologies to nursing research has been the subject of some debate:

The writing in nursing publications around phenomenology and hermeneutics has been prolific, confusing and repetitive... It is important to ask why nurses have turned so strongly to philosophies of Husserl, Heidegger and Gadamer ... Why do we continue to struggle through these impenetrable texts ... it is worthwhile reading German philosophers selectively, but under the guidance of a mentor... so much written about the influence of German philosophers in nursing research is unreflective and regurgitated and often does not relate to the specific inquiry (Koch, 1999, p. 28).

Some commentators believe nursing researchers have used phenomenology in ways which are incompatible with its underlying pretexts. Others assert new directions have arisen from philosophical development, rather than as a disfigurement imposed by nursing researchers for their own purposes. American phenomenology is commended as providing deeper and broader understandings to enhance pre-existing nursing knowledge and through this demonstrates faithfulness to the phenomenological constructionist paradigm. American phenomenology utilises participants' thoughts and interpretations in the data collection and analytical processes. It acknowledges culture as integral to the participant's

world view and experiential account. (Caelli, 2000). What constitutes nursing research is contentious but essential features are: relevance to nursing; focus on a practice area influenced by nurses and with the potential to benefit patients, nurses, the organisation and society (Roberts & Taylor, 1998). Legitimacy of the research question should be justified by explaining why it is worth answering and clearly outlining anticipated relevance to clinical practice (Roberts & Taylor, 1998).

Smith (1999) asserts that phenomenology has a strong fit with nursing concerns because nursing is primarily a human pursuit and phenomenological methodology honours human experience. As an exploration of conscious experience phenomenological research illuminates understanding of personal inner worlds, including health care experiences (Osborne, 1994). Van der Zalm (2000) posits that phenomenological inquiry's relevance to nursing lies not in the generation of practice theory but in its capacity to enlighten practitioners about the experiential human dynamic of the other. This contrasted with the assertion of O'Connor (1993) that nursing is phenomenological in nature as it involves episodes of inter-human encounter. She suggests nursing theory can emanate out of and beyond standard existential phenomenological philosophy.

Conclusion

My deep identification with phenomenological philosophy and hermeneutic phenomenology as a research methodology has been portrayed throughout this chapter. The process of methodological selection has been explained and phenomenological development summarised. An appraisal of some original phenomenological texts has been presented. How phenomenological research and writing are inextricably linked has been outlined. In conclusion the growing connection between the nursing profession and phenomenology was critiqued. This is now supplemented by the disclosure of additional philosophical and theoretical precepts which I identified as pre-suppositions capable of influencing my interpretive intuiting of data.

Chapter Four

Philosophical Underpinnings

In the more philosophical and especially the more historical usage of the term (hermeneutics), there is a certain mystique to be reckoned with. Whether we are speaking of Dilthey's universal spiritual forms that shape social events with human history, or of Heidegger's search for the event that gives being, or of Gadamer's fusion of horizons between past and present, there seems to be a grandeur and profundity, a certain aura, about what is going on. Hermeneutics in this vein, it would seem, is not just any old attempt at interpretation (Crotty, 1998, p. 110).

Introduction

This chapter conveys how theoretical and philosophical frameworks submerged within my psyche surfaced so forcefully at the preliminary stages of this research project that I felt obligated to record what occurred. Subsequent consideration has been given to laying this chapter aside as a private journal entry. My conclusion was that doing so would remove a vital component from the account of undertaking this hermeneutic phenomenological study. Rationale about how the precepts rising up became identified as pre-suppositions is now offered. This is supplemented by a brief overview of the links between each theory and the research question.

The Integral Role of These Precepts

Once the intended research focus and methodology had been finalised it was impossible not to try imagining the meanings which participants may ascribe to their experiences of the phenomenon of interest. I realised these images were based on my second hand knowledge gleaned through 'looking upon' others as they had supported dying family members with intellectual disabilities. During my visualisations of how interviews may unfold I became acutely aware of personal and professional philosophies rising up and colouring these inward deliberations.

In hermeneutic phenomenological studies researchers are the primary instrument through which interpretative data analysis occurs so declaration of knowledge or pre-understandings which may exert an influence during this process is vital if rigour is to be achieved (van Manen, 1990). In Chapter One I disclosed prior experiences of interacting

with people who have intellectual disabilities and revealed information related to the phenomenon sourced through networking and literature. This represents a declaration of important pre-suppositions. (The term pre-supposition is used as it resonates with my perception of this concept.) I also came to see the potency with which I began incorporating certain philosophies and theories into my notions about possible research outcomes meant they also stood out as pre-suppositions. It became important to make them explicit to myself before entering into hermeneutic interpretation. Explaining this influence to research consumers would permit enlightened entry into the realm of research analysis and optimise their capacity to critique the quality of the research findings.

But how does one put out of play everything one knows about an experience that one has selected for study? If we simply try to forget or ignore what we already “know” we may find that the pre-suppositions persistently creep back into our reflections. It is better to make explicit our understandings, beliefs, biases, assumptions, pre-suppositions and theories (van Manen, 1990, p. 47).

Identifying the exact origins of these pretexts colouring and illuminating my standpoints regarding the phenomenon of interest demanded introspective self-awareness; so as deeply ingrained pretexts ‘floated up’ they were captured. These theoretical stances had been initially adopted through reading texts and spontaneously affirming them as truthful. Now wanting to reassess the strength of this identification I resourced the literature. During re-familiarisation with texts I reflected on whether I was thinking along with the writer. I needed to be responding with “oh yes” or “but what about?” If the underlying pretexts did not feel alive or a dissonance existed between my core beliefs and those of the scholar the writing was put aside. Eventually I felt ‘over cooked’ and unable to begin writing. Reconnection occurred with the buried emotions of being ‘overdue’ to give birth in the natural sense. Finally as anticipation got converted into total stress I contacted my supervisor. She wisely reacted to my lack of productivity by encouraging me to journal.

Journaling allowed me to link these inner philosophical precepts to phenomenological theory and the project itself. Their potential to impact as almost subliminal points of reference on my interpretive analysis of participants’ stories became tangible as I conjured up scenarios and envisaged how the philosophical stances may speak into them. These philosophical and theoretical pretexts held within my psyche are now briefly outlined. The ways in which my mind was telling me these theoretical pre-suppositions may inform and show themselves during interpretation are also discussed.

Viktor Frankl

Viktor Frankl was an eminent Jewish psychologist who spent three years in German concentration camps during World War Two. He offers illuminating, clear and ‘from the heart’ insights into life and the nature of man. Frankl confronts the issues of death, dying and suffering head on, integrating them into the wholeness of human existence. Being pushed to the brink of his own existence and watching his fellow man’s intensity of suffering moulded Frankl’s assertions. He also drew on his academic background when developing his theories. In re-reading his book “Man’s Search for Meaning” (1985), prior to undertaking the research, I perceived clear linkages with phenomenological thinking. For example I believed his account of being laid totally bare in the prison camp paralleled with Heidegger’s description of pure anxiety and boredom – wherein lies access to the nothing. Frankl regarded meaning as being pivotal to man’s being in the world, suggesting that death, dying and suffering are integrated into the wholeness of human existence. In this vein he asserted that facing human adversity leads to rich accomplishment and that as every human life is sacred it should be accorded due dignity to the final breath.

Frankl defines existentialism as a combination of: human existence, the meaning of human being and constant endeavour to find personal meaning in one’s existence. I conceptualised this as being closely aligned to the Heideggerian concept of Dasein.

Frankl claimed that making sacrifices reduces suffering. In the death camp he realised that survival and having a personal future could only represent hope if the death and suffering were regarded as meaningful. Accumulated life and practice experiences had produced in me a deep respect for the capacity of the ‘inner person’ to reconstitute wellbeing even in the face of apparent tragedy. This inner journey is never truly known to others but reveals itself in outcomes. Frankl’s assertions therefore ‘rang true’ for me during this re-visitation of them. They caused me to consider whether participants would say their acts of providing support now infused their lives with ongoing meaning. Additionally, Frankl had observed patterns of distinct staged psychological reactions as prisoners arrived in the death camp, were in the midst of imprisonment and ultimately gained freedom. I wondered about phenomenological temporality and whether participants in my study may describe such temporal points of demarcation. Would their experience of supporting their dying loved one have temporal compartments or perhaps the past may still be incorporated into the ‘emerging now’.

A powerful component of Frankl's writing is his representation of love:

Love is the only way to grasp another human being in the innermost core of his personality. No one can become fully aware of the very essence of another human being unless he loves him. ... he sees that which is potential in him, which is not yet actualized but yet should be actualized. ... the loving person enables the loved person to actualize these potentialities (Frankl, 1985, p. 134).

During the research interviews I expected to hear of determined efforts to help family members with intellectual disabilities to achieve their fullest potential in life and then to be given accounts of how they were assisted to cope with their terminal illness. It was highly likely that love, as portrayed by Frankl would be strongly in evidence.

“The Nursing Partnership”

This nursing theory models the interactive processes which occur between nurses and client. It was developed in 1992 by Judith Christensen, a New Zealand nursing academic, using a grounded theory approach. The research was conducted in a surgical setting. Christensen welcomed the prospect of further refinement of the model and intended that it form the basis for both clinical teaching and practice. On first encountering this nursing theory it immediately stood out to me as authentic and from that point on its precepts have resonated within my clinical practice. As a hospice nurse my reflections sometimes pivot out from “The Nursing Partnership” (Christensen, 1990). In this clinical environment I perceive it as multi-dimensional. For example for hospice patients ***Leaving the Partnership*** occurs through death and their families are strongly incorporated into this final stage of the nursing process. To demonstrate: ***Maximising Readiness*** is one of four concepts attached to this stage. Christensen wrote: “*Often patients would sense the confirmation within themselves that it was time to go. This seemed to come from a feeling within the person as well as from the cues given by others, especially nursing and medical staff*” (p. 145). This description is strongly representative of the intuitive responses, conversations and negotiations which occur between patients, family members and the hospice interdisciplinary team as death appears to be approaching.

Now entering a nursing researcher role I identified an expectation that participants would recount their own unique stories of multi-dimensional partnerships. A matrix of partnerships between professional and non-professional parties may be profiled as relieving or disturbing, transitory or enduring. It was fascinating to wonder how the

partnership between the dying person and family member would be recounted. Finally I felt Christensen's (1990) philosophical approach overlapped with the pretexts of hermeneutic phenomenology. For example the contextual determinants which influence outcomes equate with the phenomenological assumptions of inter-subjectivity and the co-constitutional power possessed by individuals.

Margaret Newman

In Newman's (1999) view disease emanates from disassociation between individuals and their own rhythmic form yet paradoxically it offers a unique pathway through which a higher level of consciousness and energy field can be attained. I identified strongly with these views and recognised an assumption within me that participants' accounts may encompass stories of intrepid journeys. I saw congruency between Newman's perspective and my research intent within her statement "*a liberated person transcends opposites, like good and evil and life and death, moving to unity consciousness*" (Newman, 2003, p. 241). I suspected that in having first faced the implications of a family member having an intellectual disability and then the sadness of them becoming terminally ill participants would have exceptionally well developed transcendental attitudes. Or would they simply have been crushed by these extreme circumstances beyond their control?

Newman's (1999) theorising was strongly influenced by her lived experience of supporting her mother who had motor neurone disease. This held tangible links to my proposed research topic and methodology. Newman specifically referred to mothers providing care for their children with intellectual disabilities as a demonstration of how facing severe difficulties can eventually become valued as a pathway to inner growth. Her theorising seemed to be infused with phenomenological perspectives so it was puzzling why no phenomenological texts were cited in her writing. I then discovered and was challenged by her stance that phenomenological interpretation must be supplemented by interactive dialectical engagement so nursing researchers and participants co-create valid knowledge forms. On reflection I hoped openly seeking participant feedback on transcript interpretation would permit such co-creation. I found Newman's proposition that "*the most authentic encounter one has with another person is when that person is encountering oneself*" (Newman, 1999, p. 85) to be highly inspirational in terms of my proposed research. It ignited images of 'the ultimate interview' where participants got lost in the recall of their own life world.

Jean Watson

Watson's philosophical positioning which dove-tails with Newman's (2003) also held connections with my anticipated research journey. I purposed to focus on people's feelings and the meanings they ascribed to the experience of providing support. Such questioning was seen by Watson (1999) as a hallmark of reintegration of sacred feminine principles into nursing practice. I considered the use of this explicit phenomenological terminology to be confirmatory that Watson's theories would influence my data analysis. Perhaps Watson's (2003) visions of transpersonal caring may materialise from participants' stories about supporting another who was so deeply vulnerable.

Watson (2002) believed caring involved the heart and soul and that loving intentionality allowed carers to touch another person at a deep spiritual level while providing practical assistance (1999). Watson (2003) spoke existentially of the circle of life, infinity, the mystery of humanity and how wounding invokes a capacity to heal. Several intellectual disability support professionals who I had spoken to, independently expressed the view that people with intellectual disabilities often possessed a very deep spirituality and an intuitive knowing of others. I now reflected that deep spiritual connectedness with their loved one may materialise from participants' accounts of providing support. Watson described inner connectedness with energy fields beyond the immediate which carers experience when they embrace the 'bigger plan'. This facilitates transcendence of dire circumstances including death. This view mirrored my expectation that participants may have found deep peace within their apparently tragic situations, such as evades those with an 'easier life'.

“Continuing Bonds”

'Ghostly type' encounters between living and deceased people are outside my personal experience. I am however very aware of how deceased people live on in the lives of surviving loved ones. I saw this concept of “Continuing Bonds” (Klass, Silverman, & Nickman, 1996) as being congruent with the phenomenological concepts of spatiality, temporality and inter-subjectivity. It was likely evidence would emerge from interview data of deceased loved ones, unbound by the here and now of time and space, exerting ongoing influence within the lives of their families. I mused over the possibility of this dynamic being profiled as functionally useful following bereavement and wondered if this inter-relationship may even be reframed by the interview itself.

Thomas Moore

In 2002 I was privileged to hear psychotherapist and best selling author Thomas Moore speak at the 14th International Congress on Care of the Dying in Montreal. The incantations of Moore echo on in my soul. Moore (1992) believes that deep mysteries of life can emerge from apparently irresolvable, chaotic circumstances. He upholds the unique essence and sanctity of every human life. Lindsay (2005) describes how contemporary society has assigned people with intellectual disabilities to an existence at its outer parameters. Moore's writings reinforced the intolerability of this situation. His conceptualisations indicate that even at the point of death people with intellectual disabilities deserve to be cherished and seen as central to life. I wondered if participants would speak about their experience of accompanying their dying family member as having a wondrous facet to it? Would the person with an intellectual disability have attained social centrality within their world as they themselves faded from it?

Conclusion

A range of theoretical and philosophical perspectives lying embedded within my psyche have been laid out in this chapter as pre-suppositions. Characteristics within them which overlap with phenomenological perspective have been identified. Instincts about how elements of these writings may evidence themselves in the analysis of research data have been voiced. This chapter has been written prior to gaining ethical approval and embarking on research recruitment so stands as a projection of imagined connections. The legitimacy of this representation of pre-suppositions will be revisited in Chapter Ten which will discuss research findings. Chapter Four has been the final one to profile the motivators, knowledge, theories, philosophies and research methodology under-girding this research project. The specific design of the research project will now be explained over the next two chapters.

Chapter Five

Research Methods: Data Collection

Transforming Research Ideas into Reality

The first four chapters of this thesis have shown how pre-existing knowledge and perceptions, new understandings and passion contributed to the implementation of this hermeneutic phenomenological research project. The research methodology has been detailed.

Research methods are the specific techniques and processes through which the research is conducted and must be congruent with the stated methodological approach. Collectively they comprise the research design (Crotty, 1998). The research design and methods used to implement this project are now outlined in Chapters Five and Six. This discussion is split to balance flow within the document. The main method of data collection proposed in the design was the facilitation of open ended interviews. The various sections in Chapter Five are directly or indirectly related to this. Considerations of the Treaty of Waitangi are placed at the forefront of the chapter in recognition of the Treaty's centrality within the life of our nation. Other aspects considered are: research ethics; the ethical approval process and related issues; participant recruitment; the interview process and the importance of field notes and reflexive journaling. The transcriber's role is also acknowledged.

Treaty of Waitangi: Considerations and Obligations

The Treaty of Waitangi is the founding document of New Zealand's bi-cultural society. Accordingly, consideration must be given to how any health research relates to Maori as the tangata whenua and to tauwi (Health Research Council of New Zealand, 1998, p. 35). Colonisation has disadvantaged Maori, leading to poor health outcomes (Durie, 1998) and Maori people with intellectual disabilities have experienced institutionally inflicted marginalisation (National Advisory Committee on Health and Disability, 2003). Terminally ill Maori have had poorer access to palliative services than Europeans (Minister of Health, 2001). Although this research was not Kaupapa Maori or Maori centred research it was focused on the convergence of these two areas of health care where Maori have been historically disadvantaged. This collectively represented a justification and need to explore the experiential perspective of Maori people who had supported a family member with an intellectual disability who was dying in a community setting.

Objective 1.3 in the Maori Health Strategy (King & Turia, 2002) states barriers to societal participation for Maori should be removed. Exclusion of Maori participants from a general population study on the basis of culture is regarded as unethical (Health Research Council of New Zealand, 1998). After reading and discussing the research proposal the whanau support worker from my employing organisation signed a document affirming it was acceptable to Maori (Appendix 10). She undertook to ensure adherence to Maori protocol, provide a culturally appropriate avenue for approaching Maori and personally support any Maori participants. I envisaged her mandate would engender the trust of any Maori participants but unfortunately this was not necessary. The whanau support worker shared about the project among whanau and iwi but failed to locate any Maori person who had lived the experience which was the focus of my research inquiry.

Ethical Implications for Recruitment

To be ethically defensible health research using personal information must offer sufficient potential benefits to society to outweigh the loss of participants' privacy (Health Research Council of New Zealand, 2002). Furthermore, recruiting bereaved people is only justifiable if the design is methodologically appropriate and sociological and theoretical benefits can be demonstrated (Stroebe, 2003). Reflecting on these factors I felt the existing dearth of knowledge did justify the research proceeding. Participants with a diminished capacity to comprehend information have traditionally been 'research fodder' and as 'special participants' require protection (Roberts & Taylor, 1998). The Australian Government National Health and Research Council (2005b) states that risks and undue burden must be evaluated when involving people with intellectual disabilities and also notes the ethical difficulties that a short life expectancy imposes on research involving terminally ill people (Australian Government National Health and Medical Research Council, 2005a). Although I perceived interviewing dying people with intellectual disabilities would offer rich data and therefore collective benefit, involving such vulnerable individuals as participants would have been unethical in view of my research inexperience. Finlay and Lyons (2001) confirm that researchers need highly developed skills to adequately interview people from among this population group. On balance it was very evident that interviewing bereaved family members who had supported a family member who was dying in a community setting was the most responsible way I could approach the larger phenomenon of dying in a community setting when one has an intellectual disability.

The Health Research Council of New Zealand (2002) requires health researchers conducting interviews to be trained and suitable. I had never conducted qualitative research interviews but had endeavoured to accrue extensive familiarity with phenomenological methodology through reading academic texts and close critique of existing phenomenological nursing research. Engaging in sensitive conversations was integral within my practice and I felt this offered further qualification as a suitable researcher. Another safeguard was that the interviewing process was to be overseen by my academic supervisor who had credibility as an established nurse researcher.

The inclusion criteria stipulated participants must be adults but did not specify an age range within which the family member had died. Because most dying individuals (even among this population group) are adults, and the scale of the project was small, I did not anticipate that two participants would be mothers who had lost young children. Purposively seeking to recruit among this group may have posed greater barriers to gaining ethical consent. It is recognised that conducting such interviews is opening up a highly sensitive topic and research into the respective harm and benefits is sparse (Burnell & O'Keefe, 2004). Burnell argues that with adequate researcher training and with safeguards in place, such parental interviews are justifiable, otherwise the voices of this parental group would remain muted. In hindsight, I believe these two mothers were afforded ample protection by features incorporated into the recruitment, interview and follow up methods of the project. The most significant of these were ongoing, voluntary consent, free access to bereavement counselling and the inclusion of post-interview discussions.

The Ethical Approval Process

The ethics application was submitted to the Central Regional Ethics Committee in late May and heard on June 13, 2006. A member of the committee had made prior contact to discuss the research proposal. The committee approved the research pending several alterations in design (Appendix One). These alterations were made and final approval was received on July 13, 2006 (Appendix Two). I found completing the ethics application was helpful in terms of understanding and clearly defining how I would conduct the research. A reconnection was made with the committee via email requesting permission to recruit Pam for the study. Frances's death was more historical than the specified timeframe of interviews occurring between 6 months and 8 years post-bereavement. Pam had originally been spoken to by a health professional known to her in the hope she could suggest possible participants and as a result strongly desired to contribute herself.

After reading the interview transcript Pam requested that the actual names and identifying features of herself and other family members be reinstated. This participant cited it feeling unnatural for her family to be separated from this aspect of their life story. An Informed Consent Form to Deviate from Confidentiality Agreement Form (Appendix Nine) was devised and emailed to the administrator of the Central Ethics Committee with a request for permission to comply with this participant's wishes. Revelation of this participant's identity was approved by the committee chairman (Appendix Three). This form was then signed by the participant and myself. Later on this process was replicated on behalf of the fifth participant.

Considering Emotional Issues

For multiple reasons participating in phenomenological interviews can be beneficial and emancipatory (Gillis & Jackson, 2002; Rosenblatt, 1996; Smith, 1999). I was also aware that raw emotions exposed during interviews could cause distress (Davidson & Tolich, 1999). If participants became upset during the interview an offer was made to pause or terminate the process, as suggested by Davidson and Tolich (1999). As bereaved people my study participants were emotionally vulnerable so free access to a bereavement counsellor was incorporated into the research design. Both participants and the transcriber were provided with contact details of the counsellor who in turn had been provided with written and verbal explanations of the project. She was advised of interview schedules ahead of time. As the researcher I attended clinical supervision regularly.

Issues of Consent

To ensure consent was informed recruiters gave participants an Invitation to Prospective Research Participants Sheet (Appendix Six) to inform their decision about returning an Expression of Interest Form (Appendix Seven). Participants were made aware that under the Code of Health and Disability Services Consumers' Rights (The Health and Disability Commissioner, 1996) Right 9 applies to participants in health research. A pre-interview meeting was offered but four participants declined, feeling our telephone conversation provided ample opportunity to ask questions, receive explanations and establish an elementary relationship. The Informed Consent to Participate in Research form (Appendix Eight) and sheet of interview questions were posted to these individuals. All participants signed the consent form following a further discussion immediately prior to the interview. Being mindful that consent to qualitative research involvement should be evolutionary, just

like the interview process, I reminded participants they had the right to withhold or retrospectively withdraw information.

Ensuring Confidentiality and Anonymity

The information disclosed during interviews was personally, socially and cultural important to participants so appropriate protection was required (Health Research Council of New Zealand, 2002). Recruiters did not name potential participants. Participants self-disclosed on the Expression of Interest Form. Partial anonymity describes how researchers alone know the exact data source. In my study my academic supervisor and the transcriber shared this knowledge but undertook to safeguard confidentiality (Appendix Four). Participants were invited to nominate a pseudonym for application to audio-tapes labels, research records, transcripts and subsequent written accounts of the interviews. I transported audio-tapes to and from the transcriber. Electronic data was secured through the use of a password known only to myself, my academic supervisor and the transcriber. The coding index, transcripts and audio-tapes have at all times been stored in a safe. No participants have requested the eventual return of audio-tapes but two have suggested they be archived as a sociological record of the lives of New Zealanders with intellectual disabilities. I am committed to electronically erasing the audio-tapes after five years but may consult the ethics committee at a later date about official archiving.

Avoiding Inducement

While it is unacceptable to coerce or induce participants, recognition of expenses and inconvenience is permissible (Health Research Council of New Zealand, 2002). In line with common courtesy and to express my gratitude a small individually selected 'keep sake' was posted to each participant at the conclusion of our personal involvement.

Defining an Ethical Approach to Interviewing

I sought information with particular regard to interviewing the bereaved because as an inexperienced researcher I felt very accountable. I looked strongly to Rosenblatt (1995) who advised goodness, rightness, morality, justice, propriety, virtue and legality should be exercised when interviewing this vulnerable group. He suggested the researcher and participant also embrace a mutually negotiated ethical framework in addition to externally imposed standards. I saw this concept to be congruent with the unique situatedness of phenomenological interviews and underlying philosophical assumptions of intersubjectivity and man's co-constitution of his life world. It also resonated with Tolich and

Davidson's (1999) assertion that interviewing involves reflexive questioning, listening and watching so quality is engendered by flexibility.

Recruitment

Who Were the Recruiters?

The recruiters were healthcare workers who had expressed a willingness to contact a person known to them who had experienced the phenomenon which I was proposing to research.

The Challenge of Recruitment

All participants were to be selected on the basis that they had supported a family member with an intellectual disability who had died in a community setting. Some professional caregivers who heard about the project expressed a desire to share their personal accounts of providing such support. I considered expanding the definition of 'family member' to accommodate this request. However, due to the small scale of the project, it was clear that focusing purely on actual relatives' experiences would produce thicker data in answer to the specific phenomenological question. This would subsequently produce more rigorous findings.

Purposive convenience sampling was applied by the health professionals who had volunteered to act as recruiters telephoning or visiting people known to them from within the small sample frame. A table was formulated to provide a recruitment trail.

Specific inclusion and exclusion criterion are presented in Box 1.

Box 1: Recruitment Criteria

Inclusion Criteria

The prospective participant:

- Had a family member with an intellectual disability anywhere on the continuum of severity
- Was at least 20 years old at the time they supported the family member
- Feels comfortable about taking part in an in-depth interview about their experience of supporting a family member with an intellectual disability who was dying
- Their family member has died between 6 months and 8 years ago
- Does not have any specific risk factors which increase the likelihood of them suffering psychological harm from the interview process
- Speaks fluent English and does not have a speech impediment

Exclusion Criterion

The prospective participant:

- Has been identified as having experiencing complicated grief

While ethical approval was being awaited potential recruiters seemed to be ‘champing at the bit’ but once ethical approval was gained some of this enthusiasm receded. Some individuals now declined to recruit and others were exhibiting strong underlying reticence. I empathised with their deep apprehension that they may cause a vulnerable person to be hurt and avoided coercing them into making the initial approach. Experienced researchers reassured me that recruiter ‘gate keeping’ was common and reportedly pronounced among palliative care health professionals (Hopkinson, Wright, & Corner, 2005). Ross and Cornbleet (2003) assert that clear articulation of methodological details and promotion of the research’s value can minimise this occurring but also stress the expert judgment and caring perspective of this professional group should be highly respected.

Todd (2004) also found recruiting bereaved parents of deceased people with intellectual disabilities challenging. I also discovered that despite earlier oral articulation of inclusion criteria several recruiters, after reading the Prospective Recruiters’ Information Sheet (Appendix Five) revealed that the individuals they planned to contact fell outside these as their family member had died suddenly.

I believed sequential recruitment would be the most effective method but after the first potential participant declined involvement due to personal circumstances I was advised to switch to simultaneous recruitment. Six participants were approached by four recruiters

who were health care workers and four interviews eventuated from these approaches. In a deviation from the research design the fifth person who participated did so as a result of snowball recruitment; a conversation with an early participant ascertained their interest and so the earlier participant provided them with the required paper work. Interviews occurred over a period of 13 weeks with the largest time lag being before interviewing the final participant. As will be seen in Chapter Six this led to the data from that interview being pasted directly into the rhetorical discussion of findings.

The recruitment steps applied in all but the snowballing instance are described in Box 2.

Box 2: Recruitment Process

1. Prospective recruiters (other health workers) who had identified potential participant(s) known to them were provided with a Prospective Recruiters' Information Sheet and an Invitation to Prospective Research Participants Sheet.
2. The recruiter approached the potential participant(s) in person or over the telephone.
3. If the potential participant(s) wished to know more about participation the recruiter provided them with an Expression of Interest Form and a stamped self-addressed envelope for return to the researcher.
4. Within three days of receipt of the Expression of Interest Form I telephoned the potential participant and offered a short meeting. Depending on whether a meeting occurred an Informed Consent to Participate in Research Form and a copy of the Proposed Interview Questions were given or posted to the person.
5. The research process was discussed immediately prior to conducting the initial interview. If the person desired to be interviewed they signed the Informed Consent to Participate in Research form.

Who Were the Participants?

The participants in four interviews were mothers who had supported their children with intellectual disabilities through the terminal phase of their lives. Two of these women had lost adult children; the other two pre-schoolers. The fourth interview deviated from the accepted phenomenological practice of hearing about the lived experience of a single individual. This occurred because a man requested his wife be a co-participant to reflect their collaborative provision of support to his dying sister. They felt the isolated account of one would be incomplete without the full contribution of the other. I decided there was

an ethical obligation to comply with their request. Amazingly I had imagined such a scenario a short time previously and written in my journal questioning whether it would be methodologically defensible to conduct an interview with multiple participants.

The participants other than Pam had been bereaved for 8 years, 6 years, 3 years and 6 months. The duration of interviews ranged between 55 minutes and 84 minutes. The one involving co-participants was the longest although I asked fewer questions than in any other interview. The couple's interaction directed the momentum and a sense of seamlessness prevailed.

Pam was the first person interviewed. She shared her story of supporting her daughter Frances who had Down syndrome. Frances died in hospital at the age of three in the late 1980s. She had acute myeloid leukaemia and spent most of the nine months between her diagnosis and death at home. Pam was the first participant to request that her identity and that of her family be revealed. As the initial participant she offered generous encouragement before and after our interview.

The second participant was Grace. Her son Matthew had a metabolically induced intellectual disability. Much of his earlier life had been spent living in an institution due to the lack of community support services and the prevailing social expectations when he was a child. During the decade before his death he had been happily resettled within the local community. He had shared several homes with other people who had also previously lived in the institution. Matthew survived for eight months following a sudden cancer diagnosis. He spent this time back in the family home where Grace and her frail husband supported him. Matthew was on a hospice programme and due to escalating symptoms was admitted there for his final days.

Simon's death was caused by overwhelming pneumonia secondary to influenza. He was a person with extensive physical and intellectual disabilities. The quest to identify the underlying syndrome involved international researchers but was unsuccessful. Simon's mother Sandra shared her story of accompanying him through the final five days of his life. Initially he was taken to the public hospital but then returned home to the house he shared with three flatmates who also had multiple disabilities. Simon's family, friends and staff from the house were present during this end stage of his life.

As already stated two people co-participated in the fourth interview. Dave and Alison offered their experiential perspective of responding to the deteriorating health of Dave's sister Maureen. Maureen was a person with Down syndrome who developed dementia during her middle years. Escalation of this coincided with her relocation from the institution where she had spent the majority of her life. At the time of her death Maureen was residing in a community based situation with other people also requiring intensive support.

Ethics committee approval was also obtained to waive the anonymity of the final participant and her family. Georgina told me about her daughter Endeavour, who like Frances, had died at the age of three from acute myeloid leukaemia. Endeavour was a child with Down syndrome whose warm personality and tenacity delighted her family. The course of Endeavour's illness had been 14 months. Despite spending considerable periods of time in hospital undergoing active treatment, she remained at home in the care of her family and the paediatric oncology nurses, once the terminal nature of her disease became apparent.

The Interviews

Anticipating the Interview Process

"Conceiving the (post-modern) interview as an interpersonal drama with a developing plot is part of a broader vision of reality ..." (Gubrium & Holstein, 2003, p. 73)

When embarking on the research project I viewed developing competency to facilitate open ended interviews as an ethical responsibility. I read widely to engender this capability, drawing particularly strongly on writing specifically about conducting research among bereaved people (Rosenblatt, 1995, 1996; Todd, 2004). I knew that narratives needed to offer me continuous dialogical engagement with the phenomenon so data collection and interpretation would be congruent with the hermeneutic circle concept (Baker, Norton, Young, & Ward, 1998). The key lay in enabling participants to freely reproduce their unique life worlds in authentic style (Davidson & Tolich, 1999). Empathy, intuitive understanding and personal warmth would be required to create a relaxed atmosphere; with minimal open ended questions providing prompting only. Continual reflective judgement would be required during interviews in order to identify topics to revisit and clarify (Osborne, 1994).

I felt enduring diffidence about interviewing people about such a powerful and deeply personal period of their lives. This was balanced by an awareness that hermeneutic phenomenology could inform social action and offer the participants personal benefits, even if recounting of a distressing situation was required (Gillis & Jackson, 2002). A secondary benefit would be potential illumination of my personal nursing practice engendered by self-reflection on the meaningfulness in the phenomenon (Drew, 2001). Davidson and Tolich (1999) confirmed the desirability of researchers personally conducting qualitative interviews in order to apprehend the social situatedness in which they occurred. They described participants' power to withhold, edit or retract information while researchers have power to facilitate disclosure which may cause participants to say more than intended. Rosenblatt (1995) confirmed that participants sometimes made revelations which even surprised themselves and that even experienced researchers may not always retrospectively know whether a question should have been posed. He advised the gradual introduction of potentially painful issues.

Tolich and Davidson (1999) described researchers' shaping of hermeneutic phenomenological interviews through their knowledge of the topic, consideration of relevant literature and awareness of emergent themes arising within preceding interviews. Gubrium and Holstein (2003) project an unlocking of knowledge; claiming that since World War Two people more willingly 'open up to strangers'. Realising the thematic guide would be governed by what emerged from previously gathered data, I pondered how the responses of one stranger would influence the questions posed to another – a perfect example of phenomenological inter-subjectivity.

I noted friendship should be avoided by the researcher providing only minimal personal information (Tolich & Davidson, 1999). Rosenblatt (1995) identified how active listening, impartiality, sensitivity in guiding discussion, clear communication and empathetic support could enhance interviews. I was reassured to recognise these skills were inherent within my practice. The advice of Smith (1999) that silence should be allowed to speak between words in order to provide space for connection with experiential meaning and that the initial question would forge the interview parameters was another source of practical guidance. Tolich and Davidson (1999) stated the initial question could only arise from the researcher's experientially informed, extrospectively based knowledge of the phenomenon and warned a need for substantial questioning may be indicative of fundamentally flawed questions or inaccurate thematic guides.

Assembling the Equipment

Analogue audio-taping equipment was used based on transcriber preference. Two audio-recorders were used to ensure capture. The audio-equipment, a notebook and tissues were taken to interviews in a small case. This systematic approach exhibited professionalism and respect and enhanced my sense of security. The tissues were used in almost all interviews by both the participants and myself. I suggest they inadvertently acted as an equaliser in the human to human context and signalled a hope of receiving a full and authentic account of each person's lived experience.

Strategic Preparation

I sought to engender competency by conducting two pilot interviews with friends who spoke about their experiences of living with a family member with an intellectual disability. This was confidence building, developed audio-recording and interviewing skills and provided partial orientation to the phenomenon of interest. A check list of practical tasks required before, during and after research interviews was compiled to ensure smooth facilitation and reduce researcher nervousness. Participants were offered a telephone call on the prior evening to confirm arrangements. Care was taken to ensure arrival was punctual and home baking was to taken share over coffee or leave for the family.

When conducting phenomenological interviews the research question must be kept within the gaze of researcher and interviewee. To achieve this, questions should be designed which assist the participant to locate and reveal the actuality of what their experience of the phenomenon of interest was like (van Manen, 1990). A sample of interview questions formulated are shown in Box 3. During the actual interviews I sought to be led by intuition, rather than by religious adherence to a prepared framework.

Box 3: Sample of Interview Questions

Openers

"Thank you for being willing to speak with me about your experience of supporting ...I wondered if you could briefly tell me about how life was for ... before he/she became unwell?"

"Can you tell me your story about how it felt to learn was terminally ill and describe the journey of supporting them during the final stage of their life?"

Prompts

"What way could I ask that question to help you talk more about that ...?"

"Can you describe how you felt about the world around you during this time?"

Specific Prompts if Participant Distressed

"What we are talking about appears to be distressing you ..."

"How do you feel about continuing the interview?"

Interview Environment

All the interviews occurred in participants' own homes although a mutually agreed location was offered. Several commented on the convenience and privacy being at home afforded. All situations met pre-set criteria of needing to:

- be private
- be comfortable
- have minimal intrusion from external noise

I had indicated to each participant the desirability of having freedom from interruptions during the interview. Participants nominated a time and chose a location within their house with this in mind. Sometimes family members were at home but exhibited unfailing consideration and actively 'created a space for us'. Some chose to join us for a cup of coffee and general conversation before or after the interview. They seemed to value sharing their own recollections of the person who had died. During interviews the participants and I sat informally with the audio-recorders positioned to clearly capture the conversation. An unanticipated advantage of being at home was participants' ability to spontaneously retrieve objects connected with their loved one. Photographs of the deceased loved one were shown at each interview. This generated a lovely sense that they were personally introduced and quietly present as the person at the core of the phenomenon.

Conducting the Interviews

“To truly question something is to interrogate something from the heart of our existence, from the centre of our being” (van Manen, 1990, p. 43).

While designing the research project I envisioned how interviews would proceed. It is not possible to report all the peripheral features which actually occurred and infused this phase of data collection with challenge and enrichment. However for reasons of rigour strands which were most consistently experienced and documented through field journaling are now presented. These considerations do not fit neatly together as various aspects arose before, during and after the data gathering process. This holds congruence with the nature of phenomenological temporality (lived time) which unlike chronological time is not always experienced as sequential (van Manen, 1990).

At the beginning of each interview the participant and I seemed to share nervousness and excitement. All participants had pre-read the research questions. Earlier I had questioned whether providing this list would undermine the participants’ intuitive recall and therefore the study’s methodological credibility. I subsequently concluded this action had been sound as it had offered a roadmap which reassured and empowered participants. Arguably being more relaxed had enhanced their access to the lived experience of supporting their family member. After re-listening to the first interview I wrote on my own question sheet **“pause and wait”**. As interviews accrued cohesion increased and I became less deliberate. For instance, it became second nature to explain that I would make a minimal contribution to dialogue but would indicate my engagement through body language such as nodding. I also became more acutely aware of my own physical and psychological reactions during interviews. Dana (1999) posits that such reflexive insight strengthens the authenticity of qualitative analysis. Despite exhibiting deep emotional distress at times participants were generally resolutely determined to continue without a break. In these moments I was deeply aware of being drawn into their experience. I later wrote how one participant was so strongly ‘wired’ in to me as she spoke. Some participants had doubted they had anything to offer. They were all ultimately surprised how much they did bring forward and referred to remembering previously forgotten details. Each interview concluded when the participant and I had developed a mutual perception that an end point had naturally been reached.

Once the audio-recorder was turned off participants often opened up further. The politics and sociological history surrounding the lives of people with intellectual disabilities arose intermittently throughout most interviews but at this point more candid revelations were made; deeply held beliefs and grievances were aired and stories with more specific details told. Some participants, obviously still reliving the life and death we had been sharing about, recounted particularly sacred or painful aspects of their experience. Others, apparently seeing me as a person holding considerable knowledge about palliative care, sought answers to questions they had ‘never liked to ask’. In these scenarios it was necessary to give well considered responses and to remain mindful that we were not in a therapeutic relationship.

Secrets were also revealed off tape. In some instances I inherently knew they should not be included as data and the participant confirmed this. More often clarification led to permission to refer to these supplementary statements and two people requested we resume audio-taping so they could have their points recorded. On two occasions I was privileged to hear how other family members had visions of the loved one who had died. This was spoken of in terms of being very pleasant, meaningful and providing comfort. I was struck by the total lack of bitterness exhibited despite all participants having been struck the double blow of a loved one having an intellectual disability and then suffering a premature death. Without exception gratitude was expressed for the enrichment their loved one had brought to their lives and some participants explicitly spoke of destiny.

More than one participant mentioned being sustained by coincidences during difficult times. This was fascinating as throughout the research project ‘things’ had occurred in my own life to an extent which seemed beyond being random. My family also became aware of this and I inwardly named these occurrences ‘food for the research journey.’ One episode occurred while I was stopped at traffic lights on the way to interview Georgina and feeling burdened with accountability. Suddenly a young man with Down syndrome extended his head out of the stationary taxi in front and stared intently back at me. Every such ‘coincidence’ was precious and built courage; saying “you are not misled – this person or these people will be dying one day and it is important that they receive optimal care”. Scholars rigorously debate the issue of ‘coincidences’, synchronicity and whether causality can originate in the paranormal sphere (Mansfield, Rhine-Feather, & Hall, 1998; Storm, 1999). Van Manen (1990) describes experiencing such a dynamic when he was researching the nature of secrets and offers the rationale that it arose from his intense focus on the topic.

“Whether we name divine presence synchronicity, serendipity, or graced moment matters little. What matters is the reality that our hearts have ... “ (Long, ND)

My initial intention was for participants to edit interview transcripts then later offer clarification, make additional disclosures, decide about retracting any prior statements and provide feedback on my interpretation during follow-up interviews. I imagined this would be an opportunity to check on participant wellbeing. Deciphering the presence or absence of the phenomenological nod through observing body language would enhance the credibility of findings. Rosenblatt (1995) considered the former function to be important because the reaction of bereaved participants to being interviewed was sometimes delayed. The planned second interviews were in fact switched to telephone contact as the ethics committee member spoken to felt re-interviewing represented an additional burden for participants. In actuality only one participant felt they wanted to read the interview transcript. This was delivered to them and they phoned a few days later citing minimal inaccuracies. Accordingly, all others were consulted on thematic identification only. Engaging with them over this seemed to be mutually revealing. More than one commented “I had not seen it like that before but yes that it **is** what it was like”. All participants offered to provide ongoing feedback if required and wanted to receive a summarised report of the research findings. Some also requested access to the entire thesis.

Writing Field Notes

I stopped on the way home from the first interview and scrawled thoughts and impressions about what had occurred. This was done promptly to capture the immediacy of the event; minimising overlay from subsequent stimuli. This set the pattern for the entire research project. Initially these records were transposed from paper into a specific electronic file but were later merged into the ‘Reflexive Journal’. This facilitated easy cross referencing of these two data sources during analysis. Field notes informed the research process through evidencing of the interaction between data collection and analysis. In several entries I referred to nearly ‘jumping out of my skin’ when a participant’s words were resounding loudly with the expressions of earlier interviews. I was left in no doubt about the meaning of the “phenomenological nod” (van Manen, 1990, p. 27).

The Reflexive Journal as Data

Hermeneutic phenomenological researchers are the primary instrument of data collection and analysis. Their relationship with participants is pivotal to the generation of quality findings. Therefore creating a reflexive journal is vital if rigour is to be ensured. Reflexivity refers to the “*there-for-me*” (van Manen, 1990, p. 35) quality through which a sense about an experience spontaneously comes out from within a person. I supposed this equated with the Husserlian concept of pure consciousness. Capturing this interchange in journal form would help decipher the synthesis of world view which reflexively occurred between myself and participants, and myself and the data. The reflexive journal increased awareness of how my cultural and experiential perspectives were impacting on my interpretive analysis of primary and secondary data. An audit trail was developed detailing my judgements, reasoning and emotional responses. The journal revealed the practical, emotional, academic and spiritual stories which lay alongside analysis as it progressed and evolved. The role played by the reflexive journal in the research has been reinforced by embedding selected extracts within the textual rhetoric which encases research findings.

The Transcriber Connection

When first informed about the research project the transcriber was enthusiastic about having professional involvement. She was advised whenever interviews were imminent and we physically exchanged audio-tapes before and after transcription. Secure electronic versions of transcripts were sent to me on completion. Sometimes we had brief confidential conversations about interviews which had occurred and I would ask about her emotional wellbeing. She chose not to access the counselling provided for within the research design and explained she coped with encountering emotionally challenging sections of interviews by taking longer breaks than usual. She described feeling humbled and enriched by the great love and strength permeating from these stories. I valued our encounters as the transcriber was the only other person who heard all the actual voices. Our brief words were like a touch stone for me. We never revisited these discussions again.

The Enmeshing of Data Collection and Analysis

As has already been stated discussions of research methods related to data collection and analysis are presented separately in this document. This is despite the fact they are operationally inseparable within phenomenological research. Chapter Five has addressed issues related to the Treaty of Waitangi, research ethics and the approval process,

emotional protection, consent, anonymity and confidentiality. The challenges of and strategies for recruitment have been delineated. The role of field notes, reflexive journaling and the contribution of the transcriber have all been explained and various facets of the interview process discussed. In Chapter Six the analytical pathways followed to produce research findings will be described along with the ways in which rigour was applied to the research process.

Chapter Six

Research Methods: Analysis and Rigour

Introduction

This chapter offers insight into the intriguing nature of hermenutic intuitive analysis while also providing an explicit decription of how it was enacted throughout this project. The opening section illuminates how I sought engagement within this process. The fascinating experience of reflexive data analysis is then focused on in depth. Finally, the rigour of the research is discussed against a framework suitable for assessing qualitative methodological studies.

Where it Began ...

Phenomenological abstraction and intuiting are closely aligned with art forms (van Manen, 1990). This corresponded with my own inner yearnings to write poetically. As a means of nurturing phenomenological capacity I began exploring poetry which reflected on contemporary New Zealand society (Isichei, 2005; Mila, 2005). I am indebted to my academic supervisor for sharing some of her own compositions at this stage and stating I should abandon constraining fear and start writing myself. This new venture produced creative satisfaction and offered a pathway for reframing challenging life encounters. One example of this was writing the following poem about the soulful experience of being with a person with an intellectual disability as their physical life slipped away.

The Passing

*I knew you were hovering on the edge of life
And was mindful
Of you and yours*

*What fear has death for one so pummelled by life
Yet your preciousness has been revealed
Your uniqueness celebrated by all around
You found a place
A home*

The cat found you and lived in your aura for days on end

*And as sweet comfortable sorrow flowed down our cheeks
We stood with unity
Separate hearts
Silently honouring your glorious afterglow*

Soon after beginning to write poetry I took tentative steps into phenomenological intuiting while replaying the audio-tapes from the pilot interviews several times, prior to electronically destroying them. The following journal extracts are representative of thematic possibilities I saw lying within my friends' recounted experiences.

Upside of Disability

Has a fast ticket to heaven when they die

She didn't really know us so that must have meant she didn't miss us when she was sent away

Surprise

When other kids suggested something was wrong with her

That puberty changed her

This limited trial did reassure me that I had potential to develop phenomenological tact (van Manen, 1990) and through this find meanings within, beneath and between the participants' words in my actual research. Most of all it showed me that I found such reflection interesting and fulfilling.

Reflexive Journaling and Transcript Analysis

"Meaningful reality is constituted at the nexus of the hows and the whats of experience by way of interpretive practice" (Gubrium & Holstein, 2003, p. 73)

I journaled reflexively whenever I had re-listened to audio-tapes, re-read transcripts or had been actively engaged in analysis. Spontaneous ideas or feelings were also journaled for further consideration. Writing reflexively provided insight into the interaction between research data and my own inner being. I wrote to capture the evolving analytical process, what meanings were elucidated, alignment with art forms including poetry and how this interacted with my psyche to mould subsequent data analysis. Although the reflexive journal needed to lay an audit trail for others I wrote the text 'to myself' as this style generated the most insight. The following excerpt typifies this style.

Am beginning to see some cross linking between the first three interviews - not so much as exact circumstances but in the underlying pretexts. It continues to strike me about the lack of bitterness, the resoluteness, the outward vision and acceptance, the joy from and ability to recall the disposition and responses and life events of the loved one. Also at points the poignancy of the pain. The perhaps holding 'props' for remembering but not accessing them. Feel some other thoughts re themes gathering - they are getting more focused on the inner world of participants than on actions as such????? Is the hermeneutic element kicking in?!

Streubert and Carpenter (1999) propose that in phenomenological research data analysis begins when the researcher hears the first participant speak their first word. This proved to be true during my project as analytical conceptualisation initiated during interviews flowed seamlessly on to illuminate systematic transcript analysis. I knew specialist software existed for assisting with the analysis of qualitative research data, but read that a systematic review of published nursing research had found its utilisation was limited (McLafferty & Farley, 2006). Additionally, Tolich and Davidson (1999) advised that novice researchers should avoid using such technology and focus purely on mastering the many other skills required to conduct fieldwork. Based on this information I decided not to explore use of this technology.

Formulating a plan to achieve hermeneutic phenomenological interpretation of data manually involved appraising a range of analytical frameworks, developed by several recognised phenomenologists. Some analytical systems seemed incompatible with hermeneutic phenomenological form and better suited to a Husserlian approach (Colaizzi, 1973). Reading van Manen's (1990) descriptions expanded my conceptualisation of how hermeneutic analysis occurs. I found Burnard (1991) had developed a system which supported the truthfulness of findings by maximising consumers' access to raw data. This model had clearly articulated steps and promoted close proximity to data which in turn enhanced interpretive integrity. Through delineation, personalisation and making other slight adaptations I devised a modified tool from this which I felt offered clear analytical guidance (see Box 4).

Box 4 Eighteen Step Analytical Tool: Adapted from Burnard (1991, pp. 461-464)

1. Complete field notes immediately following each interview to capture minor nuances (such as striking features of participants demeanour and body language), context, content and my immediate 'sense' about the interview
2. Compose self-memos when reflecting on possible data categorisation so thought trails are not 'lost'
3. Read transcripts and listen to audio- tapes to saturate myself with the data and ground myself in participants' lived experiences
4. Simultaneously make reflexive notes to capture initial impressions of patterns and ideas about emerging themes
5. Re-read transcripts to create and name as many sub-headings (sub-categories) as are required to capture even seemingly irrelevant aspects of the data content [Burnard cites Berg as calling this stage 'open coding'] This process which 'absorbs' most words contained within the transcripts involves reducing each sentence down to its core meaning then collating into groups
6. Organise sub-headings under larger categories headings- (collapse)
7. Review higher order headings and categories and sub-headings by removing any which are indistinct or merging those with strong similarities
8. Provide the academic supervisor with interview transcripts and request independent evaluation of thematic development [*N.B. This includes questioning confirmation of thematic fittingness to ensure agreement has not originated from: the researcher's designated categories being too broad and accomodatable or the reviewer unconsciously anticipating and unreflectively accepting the researcher's perspectives.*]
9. Make negotiated adjustments
10. Re-read transcripts and review again to ensure sub-headings and categories describe all aspects of pertinent data content
11. Produce a category list and highlight each one with a separate, distinctive colour. Make multiple photocopies of the transcripts then reread them while referring to the list of categories
12. Encode transcripts by highlighting sections of text with colours which denote the category to which it relates. Keep referring to a copy of the whole transcript so a sense of the entire context is maintained
13. Cut out, sort and paste all sections of text onto card in their designated groupings. (Include the statements surrounding the encoded section to maintain the completeness of the whole)
14. Consult with participants about how well a sample of their verbatim quotes correlates to the perceived meanings of the sub-heading and category in which they have been placed
15. Conduct a literature search to assemble evidence which may support or refute findings
16. Refer to the chart of sub-headings and categories and audio-tapes and intact transcripts as findings are written up. This maintains orientation towards the whole and to original meanings and transcripts
17. Write up categories sequentially, offering rationale for links between the various components of the category
18. Integrate a discussion which examines the relationship between the findings and relevant literature into the above process

Burnard had warned about the need to respect the complex and somewhat indefinable nature of qualitative analysis by avoiding robotic, unquestioning application of his system. As I engaged in the analytical process his wisdom proved to be more pertinent than I had envisaged.

At first I kept a print-out of the adapted framework beside me whenever I was working on analysis. Despite Burnard's earlier warnings I was surprised and felt incompetent when I began to feel a pulling away from faithful adherence to the process from step five onwards. Gradually I realised this arose from the data imposing itself powerfully on my psyche and exerting its own direction. Most strikingly I felt pressurised into colour coding transcript excerpts according to 'time zones' rather than thematic meanings. This was despite having noted down numerous thematic impressions as audio-tapes and transcripts had been repeatedly reviewed. I believe the varying degrees of 'chronological marbling' featuring throughout participant accounts contributed to this pressure. Sometimes this seemed to occur as a self-protective tactic as participants suddenly veered off into recalling a different temporal zone when approaching a painful point. Without fail they then returned to the apparently abandoned, very sensitive, aspect of their experience. The second reason I saw for 'temporal lurching' was that supporting a family member with an intellectual disability during their entire lifetime and the specific period of their dying is so melded together recollection is of one cohesive experience. I felt deviant embarking on this temporal, non-thematic coding while at the same time recognising the need to be carried by the data's powerful currents. The mixture of instability and adventure which marked this phase of the project is represented in the following quote.

"Phenomenological method ... constantly has to be invented anew and cannot be reduced to a general set of strategies or research techniques" (van Manen, 2006, p. 720).

These selected reflexive journal entries also reflect this mood:

Had not planned to deviate but it just sort of happened - SO - once I realised tried to capture on flow chart where it had come from and where it may now go.... but suspect it will shoot off again. I have ended up colour coding (by underlining) and sorting according to:

- 1) Pre illness (put these to one side - may smatter through like snow later)*
- 2) The terminal journey*
- 3) Reaching the final peak*
- 4) Living in the afterglow*

THEN really wacky - got this theme balancing which I put on a sheet - that has been strongly there for ages - HOW illogical 3 time zones on paper and 1 theme - sub themes posted over them all - thought 'stupid' but may as well see what happens - by the end of the day had transcript one fully pasted out - some sections on up to three sheets as multiple meanings - INTERESTING could see because of colours that the time zones had migrated into each other's patches and were dissolving so guess that is how the themes will show and gather strength. What is it - trust the process?

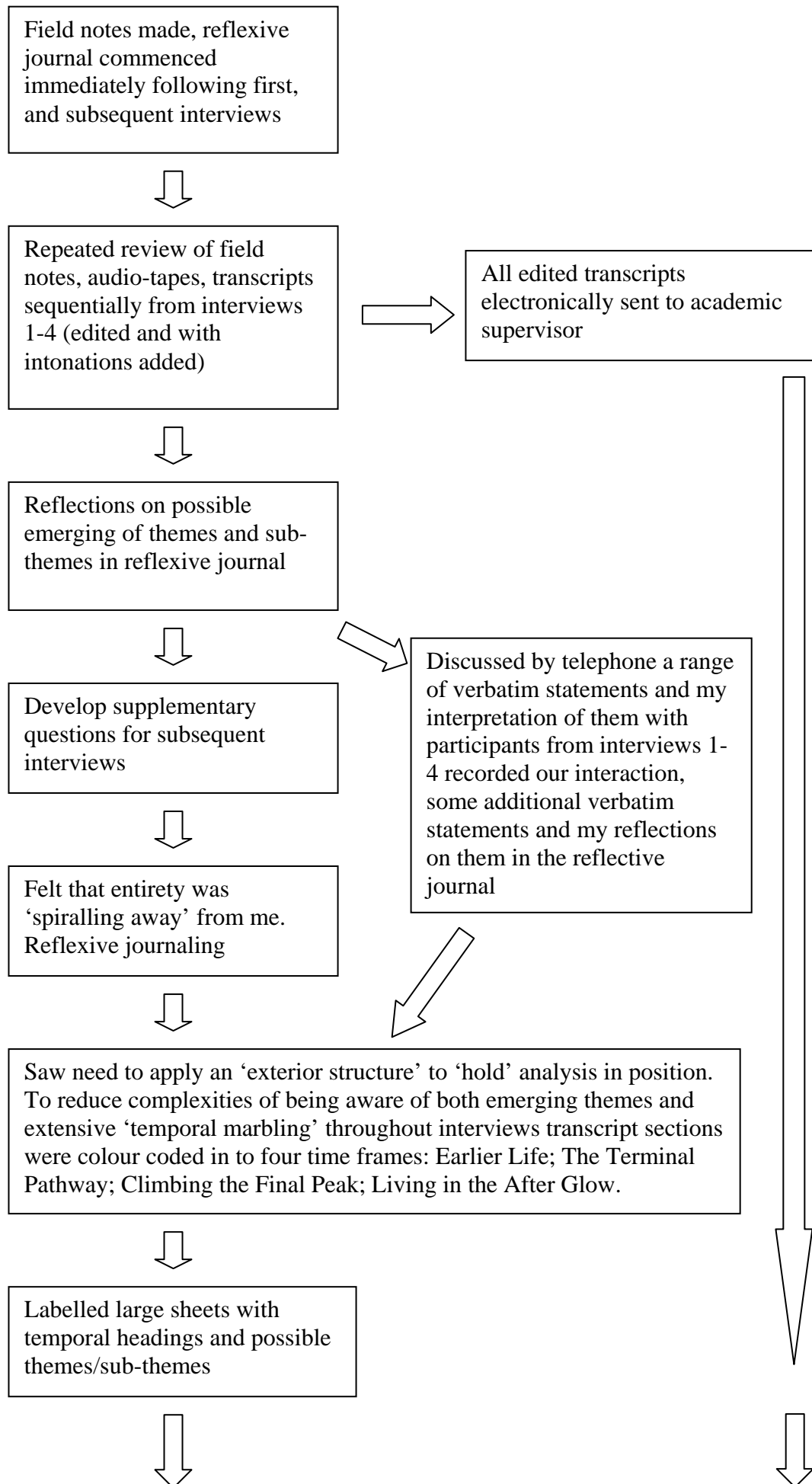
I can hear and feel the intonation not just of words but the whole inner being AND my reaction comes back to me too. Basically we had to allow ourselves to mutually go into a vulnerable state and in there was a depth of connection and openness.

The truths come like bubbles from my subconscious - which suddenly float up from underneath. It must be occurring deep within because it is quite common to wake up in the morning and be simultaneously engaging with the data - almost like audible words. At other times as I read the transcripts I begin to sense something - pan back - then let it swirl around until the

entire is revealed. This email received from Margi a while ago is now making total sense.

“... its organic the way that happens - it is so beautiful... very spiritual... as if the mind knew all along and was just waiting to show you... it has to keep some things hiddenis that the mystery speaking... anyhow how we visualise the world within which that occurs matters as the symbol becomes the reality - this is a careful word of advice.... the process is transformative and magical too.... so something that is already embodied I used was the walking on the beach.... so the perspective that you hold and know already is whole body rather than symbolic... does this make sense.... “(M. Martin, personal communication, June16, 2006).

The opinion of van Manen (1995) that it is impossible to train researchers to conduct phenomenological research offered further reassurance. The scope of this thesis limits description of rationale for, and descriptions of, the analytical process. However, a flow chart developed to capture the unfolding analytical process, as it appeared to be ‘spiralling away’, is presented in Figure 1. Its inclusion is intended to optimise the audit trail.



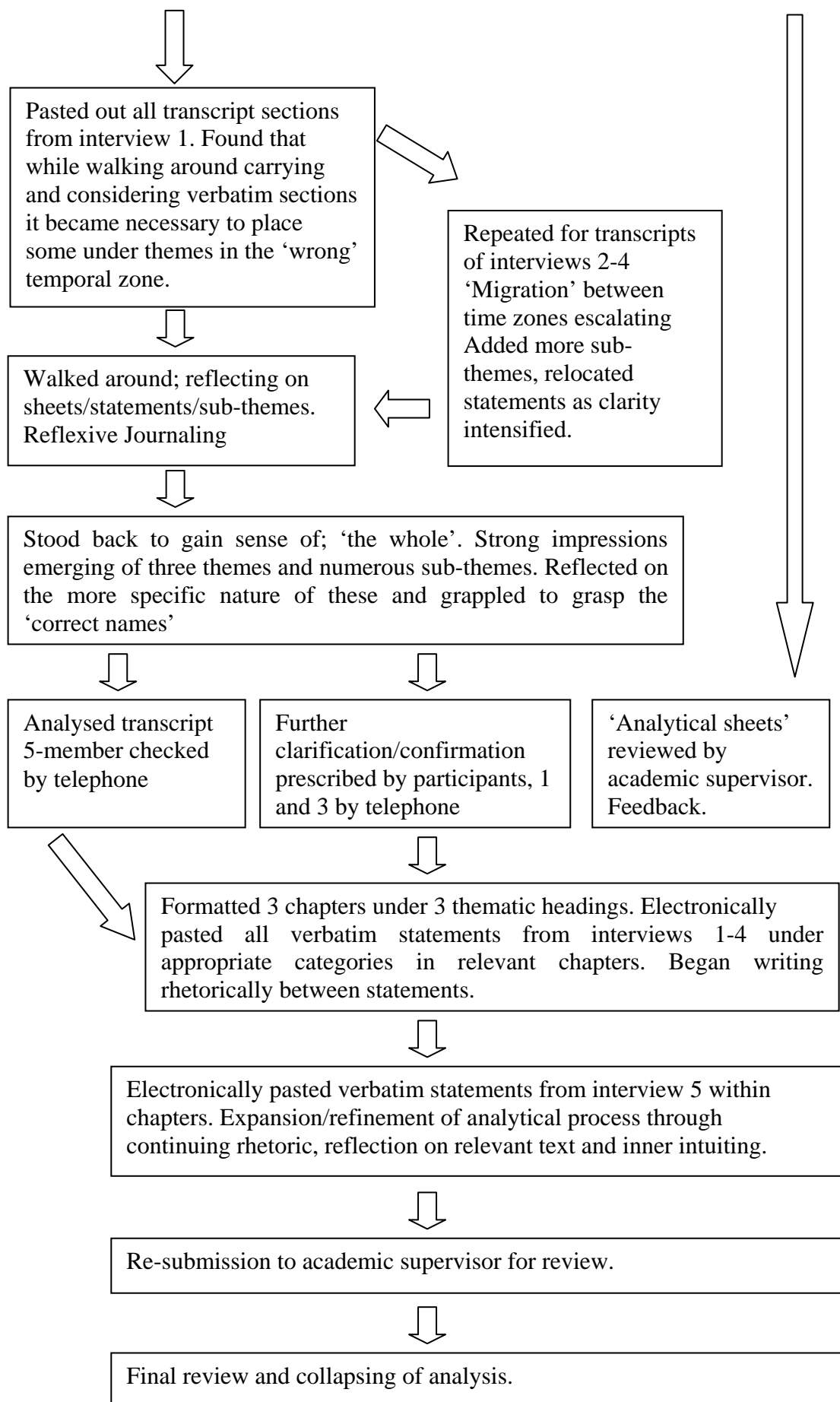


Figure 1: Analytical Flow Chart

Rigour and Trustworthiness

The degree of subjectivity inherent within qualitative research methodologies often leads to criticism of their scientific validity. Even exponents of qualitative approaches disagree about which criteria should be applied to demonstrate trustworthiness (Beanland, Schneider, LoBiondo-Wood, & Haber, 2000). Due to the underlying assumptions being divergent from those of quantitative inquiry a completely different assessment framework is also required to ascertain this (Tatano Beck, 1993). Beanland et al. (2000) assert that the methodological approach used should be the standard against which rigour is evaluated. They suggest considering rigour in terms of credibility, auditability, fittingness and confirmability. I accepted this framework while acknowledging academics proposed a range of other terminologies for benchmarking qualitative rigour.

Credibility

Credibility is dependent on the research process generating clear pictures (Tatano Beck, 1993). In phenomenological research declaration of pre-suppositions is also vital to credibility, as it promotes self-awareness and makes the researcher's interaction with data explicit (Drew, 2001; Osborne, 1994). In compliance with this my prior connections with people who had intellectual disabilities, the influence of literature related to the phenomenon and my close identification with phenomenology and other theories were disclosed at the outset. This was reinforced by incorporating reflexive journal excerpts into the textual rhetoric. If phenomenological researchers reflect on resources such as poetry, films and art works their awareness of human social situatedness heightens, thereby strengthening the analytical process (van Manen, 1990). I deliberately wrote poetry and watched DVDs (Farrelly & Farrelly, 1998; Marshall, 1999; Nelson, 2001) related to the research topic. Van Manen (2002b) suggests that looking to such outer spheres provokes thicker phenomenological description and I believe this was indeed an effective mechanism for enhancing the depth and credibility of findings.

Another test of the credibility of phenomenological research findings is their resonance with anyone who has lived the phenomenon being explored (Beanland, Schneider, LoBiondo-Wood, & Haber, 2000). This requires the production of interpretations with contextual depth (Gillis & Jackson, 2002). One way this occurs is by researchers providing opportunities for participants to express the negative 'under side' of their experiences

(Streubert & Carpenter, 1999). The spontaneity and minimal structure of phenomenological research is a methodological strength, allowing participants to subjectively locate and reveal awareness from their consciousness about 'life world' experiences. However, researchers must avoid manipulation and enhancement of accounts by participants seeking to 'please' the researcher (Osborne, 1994). To counter this possibility I sought to position myself as a neutral 'hearer' of the person's authentic truth. This was in line with Daly's recommendations (2005) that participants be permitted to lead interviews. Daly's other guideline that content accuracy be ensured by careful cross-checking of audio-tapes and transcripts was also followed. I knew phenomenological interviews should be recurrent until consistent patterns emerged across interviews. This revelation of trans-contextual structure is regarded as a hallmark of internal validity and supports credibility (Osborne, 1994). I am confident that sufficient interviews were conducted to achieve saturation. Sometimes participants' voices seemed so collective and strong it felt as if they were bound together. 'Insiders' who had collectively allowed me to step briefly into a world of which I am not a part. Having an inner conviction that the elucidated themes denoted "*elements without which the phenomenon could not be experienced*" (Mackey, 2005, p. 189) added a clear ring of truth to the credibility of findings. Comparing my research interviews with phenomenological bench marks I feel satisfied credible data collection occurred. Universal feedback that I was "good to talk to" suggests that participant disclosure was unimpeded and subsequent member checking confirmed recognition of truth within interpretation and the thematic categories created. As Streubert and Carpenter (1999) state, these elements support phenomenological credibility.

If a nursing researcher has a background familiarity with the phenomenon being researched this also supports the credibility of findings. However, insightful care must be taken to avoid imposing bias and engineering certain outcomes (Roberts & Taylor, 1998). As the researcher in this project I possessed extensive palliative care experience, had reflected deeply on palliative care provision for people with intellectual disabilities, read widely on the topic and built networks with people knowledgeable about the 'intellectual disability world'. These measures informed the rhetoric which was intertwined with literature throughout the research report. Initial thematic allocations were independently reviewed against transcripts by my academic supervisor. I was confident that her qualitative research experience enabled her to avoid pitfalls which can produce a false confirmation of the researcher's assertions (Burnard, 1991). The second literature review was performed after data analysis to avoid anticipation of findings, as recommended by Beanland et. al (2000).

Auditability

Phenomenological analysis is not definitive (Davidson & Tolich, 1999). Therefore each step of the research process must be recorded in a manner which would allow replication, beginning with an explanation of the origin of the research question (Baker, Norton, Young, & Ward, 1998). Care has been taken to clearly outline the research process in this document; for example an analytical flow chart has been presented. This was to render the study replicatable (Gillis & Jackson, 2002). Including statements from interview transcripts to illustrate thematic development and the synthesis of findings and rhetoric supports reliability (LoBiondo-Wood & Haber, 1998). I was constantly aware of this when writing the research report and sought to embed these components within it. In phenomenological research the researcher is the primary instrument of data collection and the researcher-participant relationship is crucial. Smith (1999) suggests that maintaining a reflexive journal provides an audit trail detailing researcher judgements, reasoning and emotional response to participants' stories. This helps decipher and make explicit the synthesis of world view which occurs between researcher and participant. On this basis the maintenance of a researcher's reflexive journal was incorporated into the proposed study design and segments presented within the final research report.

Fittingness

I believe evidence of fittingness will be strengthened over time if research consumers knowledgeable of the phenomenon affirm the reported findings (Gillis & Jackson, 2002). In order to project the fittingness of qualitative research, findings must be presented as compatible through comparing them with a range of literature on the topic (LoBiondo-Wood & Haber, 1998). Such comparisons are presented in Chapter Ten of this document. Robust descriptions of participants and the circumstances of their experience have also been provided so that the applicability of findings can be judged by others (Gillis & Jackson, 2002). The strong sense of themes and sub-themes within and running between transcripts from all the interviews corroborates the fit between the findings and the sub-phenomena they relate to. This is further reinforced by participants' decisive affirmations and reactions during member checking.

Confirmability

If the measures applied to enhance credibility, auditability and fittingness within the research process are successful the study will be regarded as possessing the quality of

confirmability (LoBiondo-Wood & Haber, 1998). This research project could have been strengthened through simultaneous or sequential methodological, researcher, theoretical or data triangulation (LoBiondo-Wood & Haber, 1998; Tolich & Davidson, 1999). I believe however that sufficient measures were taken to ensure the confirmability and sociological value of this research project within the context of its limited scope.

Conclusion

Chapter Two, pertaining to research methods, has described the analytical process utilised to produce the research findings. It discusses practical details and also portrays the underlying tenor of intuitive hermeneutic analysis. The rigour of the research project has also been evaluated.

Three major themes embedded within the phenomenon under investigation were explicated through hermeneutic analysis of the research data. The themes reveal different facets of what it is like to live the phenomenon supporting a family member with an intellectual disability who is dying in a community setting. The three themes are; **Interlocked Companionship**; **Search for New Balance** and **Permeable Interaction**. These research findings are profiled in Chapters Seven, Eight and Nine, where each theme is metaphorically portrayed as a group of boulders, submerged under ‘a unique river of lived experience’. The individual boulders comprising each group are a representation of the constituent sub-themes contained within each major theme. This section of the document exhibits a stylistic shift, as sub-themes are introduced and presented rhetorically, alongside the verbatim words of participants. This is done in order to release participants’ voices and so allow them to directly illuminate phenomenological truths. An informal font style is applied to the headings contained within these chapters, in keeping with the lyrical nature of the writing.

Chapter Seven

Interlocked Companionship

The Extraordinary Bond ...

As I gazed into the river of the lived experience of supporting a family member with an intellectual disability who is dying in a community setting there was a broad line of boulders near its point of origin. These boulders were readily apparent as they aerated the surface water with such force that this effect lasted the river's length. The collective name of these boulders was **Interlocked Companionship**.

These boulders symbolise an extraordinary bond between the research participants and their dying loved one. This came into my hermeneutic vision as a pressing awareness during interviews, when writing field notes, through repeated listening to audio-tapes and review of transcripts. I put this impression about **Interlocked Companionship** before participants during follow up telephone calls and they universally confirmed this to be their own personal reality. In a reflexive journal entry I wrote ...

I think the most striking thing was when I asked Sandra about whether she had perhaps experienced the death of her son as grief on grief, loss on loss and mentioned a possible relationship as companions. She said "it was terrible, absolutely terrible - it hit me so hard when he died. I never thought of it like that before - maybe - yes that was - that is what it was - must have been it - it was absolutely terrible. Simon was very special to me and so vulnerable - it was like you had more love and companionship than for a normal child. I could physically feel the pain in my heart - like a broken heart. It is alright now but it came and went for a long time. I didn't really talk much about it."

Georgina was the fifth person I interviewed and when we were off tape she asked me what sort of impressions I had gleaned from what others had already said. I related to her my idea about this incredible depth of connection. Her statement of recognition was rapid ...

Oh definitely. I wouldn't say that you love another child less but it's more intense - different- with your child with an intellectual disability. It is like you are right inside of them

While grappling with this concept I finally drifted into thoughts about the manner in which Samwise sacrificially accompanied Frodo in the Lord of the Rings trilogy. I purposefully viewed the scene which depicts both hobbits nearing the summit of Mount Doom (Jackson, 2003). They were all but totally consumed by the intensity of their epic journey and struggle to throw the ring into the lake. Watching as Samwise most soulfully said to Frodo "I can not carry it for you but I can carry you" I was hit by a deep knowing that this undeniably expressed the nature of the remarkable relationship as experienced by each participant.

In the remainder of this chapter I will present images of this group of boulders which impacted so markedly on each participant's voyage ...

Being Together ...

Being Together, either continually or episodically, was a vital component of each participant's relationship with their dying loved one. This desire to be present appeared to have several precipitating factors. The most powerful was simply to provide love and this was apparent in interviews through intonation and emotion. Another reason given for presence was to monitor the person's welfare in a manner which surpassed that which could ordinarily be offered by health and support workers.

Georgina described what occurred during Endeavour's times of hospitalisation ...

... the other time when the Down's syndrome probably made a difference was around her Hickman line. She might have tried to pull it out, , but maybe any two and a half year old you'd be nervous around, ... she wouldn't have been

alone in the room for, two minutes, we made sure there was always somebody there ... I wanted her to have company, which was an overriding factor.

When Grace realised Matthew had a terminal illness she almost instinctively decided to gather him in and provide direct care herself ...

But once he had the death sentence, there seemed no point in not having him home and keeping him for as long as he had. So I thought we could just have him and spoil him. So I just devoted the six months to doing the best I could for him. I thought I could watch him more closely than anybody else to see if he was in pain for instance. Because as soon as he was in pain, he got immediate relief provided. I don't know what would have happened if we hadn't been here ...

An account given by Alison and Dave expresses commitment to faithfully visit Dave's sister in her residential setting, even in the face of possible lack of recognition ...

Alison: She was often very drowsy, often probably not with us. The seizures and things sort of tended to continue. But you know, after a sort of a bad block, she'd be really...

Dave: Zonked, yeah.

Alison: ... uncommunicative for a couple of days. So when you visited then, you never quite knew whether...you'd get any sort of response out of her or not. But certainly on the days she *was* responsive - the old Maureen was there, behind the smile.

They also outlined the trust they placed in support staff to keep them informed in times of physical absence. It could be suggested that through this mechanism of delegated monitoring they were 'virtually present at all times' ...

Alison: If somebody rang me from the home and said something like that, I'd make sure I would be there within 24 hours or so. I left it up to them up to a point. But the last episode- we both went and saw her on - on the Sunday didn't we ...

A trend running through most participants' accounts was a strong desire to remain physically present with the family member until the point of death and beyond. Sandra spoke about the time after her son returned to the residential facility to die. Drawing on intuition she moved into a role I visualised as 'verbal cradling' ...

Well he's just lying in bed. He'd just come in and out of unconsciousness. I'd talk to him, and felt like he could hear me, because he couldn't talk. You know, normally he couldn't talk, ... , he used to make sounds and that, but I felt that he knew I was there, when I first went, ... , when he came back from hospital, so I talked to him.

Endeavour was encompassed within her home environment. As Georgina observed a changing pattern she drew comfort from offering presence ...

Monday morning she'd been sitting over there, with us over on the couch, very happily, I remember a Plunket nurse had come out to see William, and she just simply sort of lay down and lost all her energy really and we set up a little tea party and she managed to sit up for probably half an hour and then she just lay down again and really from then, until the Friday when she died, she was sleeping and I suppose going in and out of consciousness a bit. But she knew we were there...

Pam and Forde chose for Frances to remain in hospital for the final day of her life because they felt extremely secure surrounded by knowledgeable staff who cared deeply about them. Following her death it was suggested her body could be transferred to the hospital morgue for the night. Pam explained how they again knew clearly the right place for Frances to be ...

We decided that we would take her home and then contact the undertaker in the morning.

Empathetic Awareness and Advocacy ...

A large but flat boulder lying on its side was **Empathetic Awareness and Advocacy**. A sense of inner struggle was often inherent within participants' portrayal of themselves as advocates 'standing in the gap'. Despite their closeness to the family member, these key supporters realised they could imagine but not truly know the influence the person's intellectual disability had on their inner and outer world perspectives. Empathy and advocacy are perceivably integral to any caring relationship but I sensed that in this river they constituted a particularly large boulder. I reasoned this variation emanated from an expansion that had occurred within each participant's heart when they first became aware their loved one had an intellectual disability.

Feeling immediately the preciousness of her newborn daughter who had Down syndrome Pam instinctively summoned her self knowing and inner resources to give others permission to enter into this perspective. Expressions given in return, sustained her ...

So right from the start we accepted her. We had a lovely friend Jill who was looking after Isabella when Frances was born, and they came into the hospital, carrying a red rose and were very accepting, so it made it easier to accept and I think because of my personality in telling people, I tried to tell them in a way that - [*very animated*] I gabbled on so that they had time to draw breath before they had to say something. And right from the start, all our friends and family, neighbours, were very accepting of Frances and that was very important.

Endeavour's parents unreservedly loved her and the fact she had an intellectual disability actually brought a special kind of empathetic joy ...

Although it was an important part of her life, her Down syndrome, [*becomes very emotional throughout remainder of passage*] - it was a major part of her and a minor part of her at the same time. First and foremost, she was her own person. She had so much personality and brought such happiness to our lives. She was such a high functioning little girl that we had such a lot of pride in her achievements,

Georgina's instinctive understanding of Endeavour allowed her to acknowledge her daughter's expressions regarding her own situation and to promote her best interests during a time of great vulnerability ...

When she wasn't feeling well, she just lost her spark and she would just get a bit more lethargic and her skin would be not such a great pallor. If there was something coming that she really didn't want, she did this thing called the two handed wave. She would , gesticulate with her hands very very quickly and sort of pull quite a face, ... , she was very very clear when she didn't want something to be done. Often you could actually reason, to a certain extent with her, ... , she had the same comprehension really...

I saw a deeply empathetic heart underlying Grace's self- identification with Matthew's life threatening situation and sensed her continuing dilemma about whether palliative surgery should have occurred. It was patently still important for her to feel he had not been compromised because he had an intellectual disability. This was an example of how participants saw themselves as advocates 'standing in the gap'. Inner struggle was often inherent within these accounts. Despite their closeness to the family member supporters realised they could imagine, but not truly know, the influence the person's intellectual disability had on their outer world perspectives. Grace revealed ...

And if *I'd* been the patient, I would have wanted it myself; I would have had life at any cost. But I thought we were sort of treating him like a dog - just put him down rather than give him pain. So I don't know now whether that was the right thing or not. But I was persuaded that he wouldn't have the

operation. It'd be very expensive, but that was immaterial, we'd get money somehow...

Another participant who had to decide about what level of treatment her son would receive was Sandra. Her statement also portrays anguish, as she tried to stand in the space of her adult child and then grappled with her inner integrity over the influence she had exerted. A sense of shared burden and love exhibited by the young doctor appears to have eased the pain a little...

They said, we're going to put a tube down, well he's had that done lots of times. I couldn't see any point to it, ... , ... , with his lungs were shot, and why let him go through all that,... . But the woman doctor, she completely understood, but I felt terrible saying it. She did understand and she ended up in tears, and I ended up in tears ...

Having her hopes in a planned bone marrow transplant crushed was shocking for Georgina. Focusing on her empathetic love for Endeavour provided a new vision and creative way through her deep anguish. The precious side of tragedy was shared with those who mattered most ...

.... [*Very emotional in this section - breaking down at times*] and we got the results back that she wasn't in remission again, so there was no chance of the bone marrow transplant and really there was nothing more that could be done. So we felt **devastated**. I lay awake all night, thinking, what am I going to do? And then I thought, I'm going to have a party. So we had a party...rang up all the children who were Endeavour's friends, some of the ones through the hospital - a lot of her Down's syndrome friends, and some of our friends' kids who had really enjoyed her company and who had made Endeavour happy over the years. We got a bouncy castle and we had a petting zoo and I said to people it was not going to be a farewell. There was going to be a celebration of her life, it was going to be a happy occasion. It was one of our best days of

our lives.... that was probably about the three weeks before she died, and it was such a nice thing, ... , to be able to have her enjoying the celebration with us. , a really inspirational day. She loved other children and she loved animals, and so we thought well, that was probably the thing that was going to make her... the happiest.

In considering the decisions made by participants about where was the best place for their family member to die it seemed that empathy and advocacy acted as vital pieces of equipment. The next two quotes relate to formulating a knowing that for Maureen and Simon hospital was not that place ...

Alison: ... she was *acutely* uncomfortable in hospital -she didn't understand why she was there, why she felt so awful, that she didn't know anybody, that she had these whirling machines, I think partly she just shut down -it was just a little too much for her to cope with. I went and saw her within 24 hours of her being home, and she was lying in her room, very very weak, and not very well, but with this grin from ear to ear..., all the other residents in the home were sort of wandering in and out of the room, coming and checking on her, ... , sort of giving her a pat. And she was like the queen, holding court; she was, ... , I'm where I want to be now. So to me, I thought, yes, this is the right place, this is her home. This is where she really does feel is her place.

Dave: ,.... , that was very important for Maureen - being able to , stay in that environment, because if she'd been forced to move again, I think, as Alison said Maureen probably would have just curled her toes up.

And Sandra's story ...

He was in hospital five days. They did their best. The house asked us - would you like us to care for him? I said yes, that would be wonderful. ... because I'd had such a lot to do at the hospital - and I'd rather have him in his own environment. He'd be happier - mind you he wasn't really with it - but I felt it

would be nicer if he was in his own home. I'm sure he was happier because he was really sick, but he knew there was something different, and different people talking to him. It just seemed right for him to go back to his own home.

Later I sought clarification from Sandra about her allusion to her many experiences of Simon having been a hospital inpatient over the years influencing this particular decision. She cited a lack of personalised attention and claimed that especially in the early years it had been strongly inferred "you have to stay and care for him because we can't - he's not normal".

Disenfranchised Partnership ...

As has already been discussed an extremely strong bond existed between the participants and the dying person who had an intellectual disability. For any human connection to be perceived as threatened induces pain but participants' words and particularly their emotions indicated this trauma was experienced by them to an amplified extent.

Being aware of Grace's astute attunement to her son, I asked her during the follow up telephone call how she had felt when Matthew had required treatment. It was evident she had felt sidelined but this disenfranchisement had a positive intonation as it was potentially beneficial. Grace entered into collusion with the nurses as an indirect offering of comfort towards her son. This was despite the turmoil induced by physical distancing and emotional separation from Matthew as he entered into his private world of bewilderment ...

It was awful when Matthew needed an enema. I would tell him it would make him feel better. It was awful when he would trot off with the nurse into the bedroom - looking all shrunken and frightened.

Awareness of Matthew's perception of death induced a motherly desire in Grace that he be protected from the fear she believed knowledge of his imminent death would provoke. Grace was shattered when she found Matthew in distress and ascertained she had been overridden ...

I don't think they - the knowledge they're going to die should be forced on them. If they've got any sort of capability of making use of that time, I agree with it, but I **don't** think it should be a **blanket** rule that **everybody** is told that you're going to die. And they just have to lie there thinking well what comes next? Will I feel the earth coming in on top of me? Well the hospice didn't agree with me, they told him, and I went and complained about the **way** he was told - they just said, oh there there well he needed to know didn't he, ...And then of course he just got past knowing anything.

The perception that professional intrusion threatened to further disenfranchise Grace's unique partnership with Matthew continued to be exuded as she shared ...

I watched him die. [*Voice quivering*] ... I spent a lot of time during the day there with him, in fact they asked me not to, they said I was holding on to him [*cries*], they said, let him go.

The participant's demeanour at this point in the interview bore witness not only to this episode having provoked a sense of being pulled apart from her son but also an inner dislocation and anguished questioning, even now, of whether she had in fact 'harmed him' by remaining there ...

Grace was once again gripped with inner pain as her companionship with Matthew felt compromised when she was contacted by someone from a welfare organisation inquiring after Matthew's wellbeing two months after his death ...

I said well Matthew has died and I told you he was dead! I think you should have looked at the information before you rang me up. ... well I wasn't really nasty, but I was unkind. I think possibly she was a good woman trying to do something, but she just caught me on the raw.

Finally, during my telephone conversation with Pam she asked me ...

... you do know I was in a state of grief since the day Frances was born?

We spoke about this further and she explained that Frances's dying of leukaemia had occurred on top of the heartache that her daughter had been born with Down syndrome. This second layer of anguish was laid down as further suffering and physical death occurred, shaking the wondrous mother – daughter connection to its core.

Watching some of the things Endeavour encountered during her final days to some extent engendered a sense of chasm as trying to identify with what she was going through raised harrowing questions. Georgina's painful awareness of this was experienced alongside her husband's suffering ...

[Very emotional in this section] She had a bad night or two, which was upsetting. My husband found that very very hard, he kept those moments in his mind for a long time afterwards. Sort of focussing in on the distress she felt, the fright that she was probably experiencing. You know she was in quite a bit of pain, and I think she knew something was happening to her. And I think her sight might have been coming and going, *[breaks down]* and that was very distressing for her, because we couldn't really tell her then, I didn't know whether she could really understand then. But then she may not have understood anyway, even if she hadn't had her Down's syndrome - it's hard to say. I think that was, one time that was tough for her.

Meaningful Farewell ...

During four interviews participants expounded extensively about the bitter-sweet event - the funeral or **Meaningful Farewell**. Despite being partly constructed of grey sadness a warm comfort consistently broke through when this boulder was spoken about. At times it invoked outright laughter as humorous moments were relived.

Choices regarding the structure of the ceremony had been made with great care. The ongoing meaningfulness of this pivotal time, in terms of engendering a vehicle for reconnection was portrayed by Pam ...

And there were a couple of pieces of music that Judith suggested we might include at her funeral service, and even to this day a **tear escapes if I hear this music** they're not often played. But if they, do play it, it really brings it all back to me.

Participants described how they had referenced the choice of music to the person themselves. Maureen had derived much enjoyment from bright popular music and in this way she had guided selection ...

Dave: Her favourite song was Ba-ba-ba-ba-ba-Barbara-Ann. So we played that.

Such careful matching of music with Simon's persona induced a connection with the joy aspect of his life, while simultaneously creating for Sandra an atmosphere of transcending beyond all the grief and suffering which his funeral also represented ...

It was a lovely funeral and I made it light, you know, Simon's - he loved Rod Stewart, and We Are Sailing, so played that at the funeral. We had, cheerful sort of songs, made it really light, ..., everyone said what a lovely funeral it was, **it wasn't really like a funeral, it was celebrating his life,**

A desire to ensure their loved one was the central person at the funeral was consistently articulated by participants. That the nature of Matthew's farewell was inexorably linked to the life he had lived provided Grace with comfort. The honouring acknowledgement of Matthew's death by church officials of historical family importance also touched her deeply. These emotions, mixed with fresh sorrow, were conveyed as Grace said ...

... he had to go to church. And what he made of it I don't know - he used to stand in the back and he used to join in the hymns, ..., he used to wait until he heard the words, and then come in a little bit behind everybody else but they knew him for his singing, ... The priest who married my husband and me came

to see us in the hospice, and ... they all co-celebrated mass for him so that was rather impressive - having two monsignors and then the parish priest all... celebrating his funeral... . And the church was **crowded** but we got a little [whimpering] bit of comfort from the funeral service - you know the stone the builders rejected.

If Pam was to relive the experience of her daughter's funeral she believes she would seek to personally position Frances more strongly within its context ...

I really felt that I was going to be far too emotional to speak myself and in retrospect I rather regret that because the people that did speak spoke more about how well we had coped with Frances, than Frances herself, so I think if I had felt a bit stronger I would have talked about her life, ...

Although the involvement of members of the wider community who had been authentically connected to the loved one was patently appreciated. Even greater pleasure became visible during accounts of the presence at the funeral of people with intellectual disabilities and their supporters. Maureen had spent almost her entire life among this social group. They were her friends and comrades. It could be claimed that Dave and Alison saw them as the most important guests ...

Alison: It was a **really** nice service, the other four residents in the home, each had their caregiver with them, ... , they did specifically do a one to one for that occasion. ... towards the beginning of the service, they all went up to the front, where Maureen's coffin was. The team leader, ... , basically said these are the people that are important to Maureen. They looked a little bit kind of lost and they didn't really quite know what was going on, which was fair enough, but it was these were her friends.

Dave: ... they were very much acknowledged.

Of consolation to Sandra was the number of attendees at Simon's final farewell. Her interpretation of this as a signification that her son's life mattered was representative of others participants' sentiments also ...

I couldn't believe how many people were there. [*Eyes light up*] There was ... , all the young people that he lived with, they all came, and a lot of young people from the small villa where he lived earlier, they came as well, so there was a lot of wheelchairs at the funeral service. But I was **astounded how many people were there,**

Grace remembered ...

... , there was a **very large** representation ..., from the various houses he'd lived in and the workshops he'd worked in and the representation from his workplace. People from my parish, and I don't know where they all came from - there just seemed to be a big crowd of them there [*Fragile*]

Celebration of a precious life lived was an underlying meaning at all the funerals I was told about. It was also recognised that a sacred rite of passage was occurring. That details around the conveyance of Maureen's body out of the church assumed intense significance was typical ...

Alison: We didn't go up to the crematorium, ... , but we did take the coffin out of the chapel and there was a blessing and we stood and watched it go which **I think it's important** to sort of acknowledge that this, ... , your last goodbye

Dave: You need to go there.

Grasping the symbolic magnitude which the moment would hold Frances's parents were unified in their vision of how they desired this to be. Pam remains grateful that they held out for their specific wishes ...

At the beginning of the service, Forde and I took her coffin in, and at the end we arranged for everyone to put flowers on the coffin, and leave it there while we went and had afternoon tea. They tried desperately hard to counsel us out of it. They thought it was more closure if we took the coffin out of the church and put it into the hearse. But we had the afternoon tea and then Forde and I and a few others were with the undertaker, and took her coffin out of the church and put it in the hearse.

Unending Relationship ...

Another boulder within the grouping **Interlocked Companionship** is **Unending Relationship**. I saw the very fact that the interviews were occurring as evidential of participants still wanting to embrace and involve their family member within the 'now space' of their own lives. I derived this impression from such things as the emotional response engendered within me whenever I read Grace's answer to my question "do you think, that there's anything else that you'd like to tell me?" Her response ...

I can't think of anything I **haven't** told you.

It was as if these words were the thin crust covering a volcano. As our eyes met the painful fire within exuded from Grace's very soul. My soul knew she was emptied for now but that this was going to be an ongoing process for the remainder of her lifetime.

During a post-interview telephone conversation a statement made by Sandra articulated how others entering into dialogue about Simon delighted her. It summoned his presence and her ongoing relationship with him was felt to be acknowledged by others. Entering into the communion of sacred remembrance stokes the innermost fires, even in a supermarket aisle ...

I feel really happy bumping into people in the community who knew Simon and they mention him - even though he's been dead quite a few years. It's amazing really he pops up in all sorts of places. We have a little chat about him and

just remember. It is nice to be asked how I am. I have a friend at work. Sometimes we reminisce together about Simon. Nice people still mention him.

The ongoing place occupied by participants' loved ones was not only experienced as recall, but exhibited in descriptions of conjecture about how they may have experienced the 'present now'. Georgina portrays how this drawing of the person through to the present also rekindles the companionship enjoyed during their actual lifetime ...

We speak about her **very freely** and often say, Endeavour would have enjoyed this, or remember the time she did such and such?

The development of new relationship, even with others whom destiny had prevented from sharing significant lived time with the deceased person, was evident in several accounts. Pam spoke of this ...

So Frances died in May and Kirsty was born in September. It's quite interesting, because both the girls, whenever they got a new schoolteacher would mention Frances which was quite interesting. I think Kirsty rather regrets that she never met Frances.

Georgina seemed to experience Endeavour's continuing enrichment of her little brother's life as pleasant reassurance of family continuity ...

William knows, very much about her, ... , he was only 11 months when she died and I don't think he probably actually remembers her. I think probably a lot of it's ... the stories that we tell him about her. And...the photos that we've got up on the wall,... so that's nice... ,

Georgina expressed the versatility of Endeavour's influence, which was permanently ingrained within the life force of the family to which she will always belong ...

Birthdays and Christmas are always bittersweet. Something's missing, but in other ways, we think about her everyday anyway. She is still a part of our lives, and she really sort of made us who we are today.

A dynamic element which may contribute to **Unending Relationship** is the reclaiming, in death, of relationship lost in life. As a person with Down syndrome,. Maureen had been placed in an institution before her second birthday. Contact was portrayed as ill-advised so she was both geographically and emotionally distanced from her home and family of origin. With de-institutionalisation Dave and Alison did experience opportunity to embrace Maureen. For other family members this is yet to be realised. Dave and Alison expressed ambivalence about having discouraged another sister from establishing contact due to Maureen's emotional vulnerability at that time. They accept they were cast into a complex role as guardians of someone they hardly knew and look forward to what may still unfold between Maureen and the wider family ...

Alison: But she did come down and- unfortunately Maureen really wasn't very responsive but at least she did see Maureen and she did come to the funeral. It's kind of like as a family we're sort of reclaiming her, ...

Dave: Yeah.

Alison: Yes and I think that will continue to go on. I mean I know that sounds a bit strange. When I met Dave, I don't know how long I had known you before I knew you had another sister. It was quite a shock to me really your whole family, even your mother. Really for you, your family was you and Wendy and your Mum and Dad,

Dave: Right.

Reflecting on how their own children may later integrate their deceased aunty into their own lives the couple shared:

Dave: The children didn't really get involved with Maureen ...

Alison: The only one living at home now, she's actually the only one that had met Maureen. Rebecca came to the funeral, that was nice, ...

Dave: ... never been a part of their life.

Alison: And she hasn't been a big enough part of our lives that it's affected them - certainly in their growing up, years. They'll ask more questions as they get older.

Joy in the Recall ...

Each participant shared anecdotes and idiosyncrasies about their loved one with an intellectual disability and what shone through during these moments was **Joy in the Recall**. This boulder produced a glowing quality in the water above. As Grace drifted into her recollection of Matthew it was as if she had left me and gone off with him ...

In his funny way he could figure things out, **in a way that could sometimes surprise you**. Like knowing what day of the week it was on the 13th of January.

Meandering into reliving the time she spent with Simon was also enjoyed by Sandra ...

But we had a lot of happy times as well ,.... . It was lovely when he could run around. I think it was his best years, when he was a pre-schooler..., good times, even though he had his seizures, ... **yeah, he had happy times...**

At certain points the family member who had died seemed to become intimately present during interviews; providing fresh awareness for participants to locate memories. These delvings tended to be full bodied so the texture of personality and situation resurfaced ...

Alison: She had a beautiful smile. She could be quite stroppy at times. She definitely had, a lively personality. Physically she reminded me quite a lot of your Mum, and her, stubbornness reminded me an awful lot of your father. ... actually I'd forgotten this, it's funny it comes back - when I first started visiting in the home I'd sort of sit on a chair beside her, and she'd often just

push you out of the way, sort of, you're crowding me - I mean that really disappeared in the first six months or so

When Georgina shared the following memories with me it was as if she was back in the hospital with Endeavour and once again feeling touched by and proud of her daughter's personal qualities ...

The nurses seemed particularly *[emotional through next several sections of transcript]* fond of her , because she was a very affectionate wee girl. So she actually was a little draw card to the nurses who got very attached to her. I don't think she made the fuss that some of the other children perhaps made. She was a very accepting...little girl. And it wasn't just that she couldn't speak - because she certainly would have let us know if she wasn't happy about something but she -she, she was an obliging little girl and very keen to please.

Gratitude for Legacy ...

Feeling *Gratitude for Legacy* left as a gift by the loved family member with an intellectual disability was another universal component of *Interlocked Companionship* identified during transcript analysis.

For Pam a formal legacy has been co-created with Frances ...

... at the funeral people made donations, and the Wellington Down Association decided a very nice way of using that money was to set up awards - called the Frances Clarke Memorial awards which celebrate the achievements of people with Down's syndrome, and they're held annually at Government House... even though it's all this time later, I still feel very **moved** by it, ...

Other legacies have taken the form of ingrained strengths acquired through engagement in such special *Interlocked Companionship*. Pam has identified having an increased capacity to guide others as a positive outcome derived from weathered many intensely

difficult situations related to Frances's life and death. She spoke about the on-flow effect of insisting on carrying out Frances's coffin in a specific way in order to make this point ...

... one of the other mothers that I knew very well whose child had Down's syndrome, about the same age as Frances, later died of cancer, and that's how she arranged her funeral service as well.

Talking after our interview Georgina said she and her family may have been 'scene setters' when Endeavour entered the health system. She suspected the total love and respect which they had for their daughter and grand-daughter with Down syndrome offered a model and expectation for others to follow. Georgina also reflected on another legacy which has flowed out of her experience ...

...we've stayed in contact with the Child Cancer Foundation and that's been good because they said since we went through, a lot more bereaved families have stayed in contact and gone to events, , maybe we sort of said yes, ... , you can still enjoy life, and be part of the things your child would have done, even though she's not there anymore.

Sandra expressed an inner yearning to turn her experience into a legacy for others, through having opened out her deeply personal story. As she made this statement I had the impression that Simon was speaking also ...

It's good if you can help other people by what I tell you.

Sandra accredits her interlocked support of Simon with providing her with specific advantages - the gift of tenacity and also direction to work with children ...

Simon gave me a good understanding of children and coping. I can deal with a lot of problems, because I've been through Hell and back with Simon, ... , I can't understand people who go into the deep end over things, and I'm like,

goodness me, that's minor, that's really minor what you're going through.

... you know, he's taught me a lot, he really has,...

A concluding statement made by Georgina was indicative of her conviction that Endeavour's legacy would be an enriching and influential force in her life until she herself took her final breath ...

: you realise death is part of life. I'm not really afraid of death the same as I probably was.

Careful Positioning of the Body ...

Careful Positioning of the Body was a boulder which came into view during each interview. It lay alongside the other boulders depicting **Interlocked Companionship**. It was striking that no participant had laid their loved one's body in a certain place and felt a sense of peaceful completion. Seemingly, such finality of placement or acceptance of placement was so deeply significant that it needed to be a carefully staged process. Each next step needed to be awaited ...

Matthew's father was buried with him. Grace has not returned there, preferring to remember in other ways. Maureen's ashes are waiting at the funeral directors until she can be finally reunited with her loving mother ...

Alison: We have taken the opportunity to put a brick for Maureen in the garden of remembrance. It's just nice actually if both of us feel like popping by to say hello to Maureen, it's nice to have a physical place. There's a hill - that Dave's Mum asked her ashes to be spread from. Dave's decided he's going to put me to the test and make me climb the hill again with Maureen's ashes.

Dave: It could well be over Christmas or New Years we take them up...

Alison: ... Dave's mother....I think there was always a part of her that grieved for the fact that Maureen couldn't live with them.

Dave: Yeah.

Alison: She was always ... picking up, finding second hand clothes..., sending little parcels ...

Sandra was at pains to outline what had occurred following Simon's death. She detailed movement through her emergent feelings since Simon's ashes were placed in the garden at his house of residence...

The first few years we used to go every year, , where his ashes were out in the garden there, where the bush is, and just have a quiet moment there, and think about Simon. And they'd give us a cup of tea and it was quite nice. But we found as the years went on, there was hardly anyone we knew, and we didn't feel so comfortable. I wish I'd put them ... where my Mum and Dad are, there is no plaque there **to say who he is**. We thought about digging the ashes up, ... no, I don't think we should do that. I think we should just let Simon rest there ...

Pam told me that the family still has Frances's ashes and Georgina revealed this was the situation with Endeavour's ashes also. In relating this she illuminated the beauty of continuing **Interlocked Companionship** which extends into the immediate period of bereavement and beyond ...

After she died it felt the right thing, for her to be home. ... , we had her cremated, and always thought that we would scatter her ashes, but never have. ... , and I think one day - maybe when one of us goes *[breaks down]* we'll scatter her. At the moment, ... we like her being here ... That was nice having her here after she died ... And there was a nice peaceful feeling in the house.

Innate Managing of Reminders ...

A small boulder nestled at the edge of **Interlocked Companionship** was **Innate Managing of Reminders**. As each participant engaged in rich ongoing companionship with their deceased loved one there was an inherent aspect of vulnerability. This seemed to produce 'gate keeping with self' in the form of responding to one's inner knowing of what emotional keys certain objects possessed ...

Sandra spoke of her strategy of suppressing memories of some of the more heart rending events which she and Simon had shared ...

I get a bit muddled - they're the sort of things I push to the back of my mind. You want to get on with life; you don't want to dwell on things. And when you've pushed things to the back of your mind, ... , it's hard to remember. The details, you know.

In contrast to this guardedness each person also spoke of or produced 'props' which facilitated an ongoing sense of connectedness with the years shared as companions. Sandra had placed Simon's Plunket book beside her chair prior to my arrival for the interview and referred to it on numerous occasions. When asked if she generally read entries from it her reply seemed to indicate she had a deep awareness of the hierarchical relationship between objects and her own emotional state ...

I don't. I've got things put away, in a special chest. I've got his diary. The teachers did it at the secondary school in the special unit there, , but I've only read through it once. ..., I've got lots of things from way back when he was at preschool.... , I've also got a video, that I've never looked at, I've felt totally overwhelmed. I might one day, but I'm not strong enough yet to watch it but I love having the photos up in the hallway of him, so I see him every day, ...

Pam clarified how she co-existed with such objects of remembrance. She told me the little dress Frances had worn at the funeral, the coffin handles and the book, Sunday's Child,

which had so significantly provided comfort and guidance, had become treasured possessions but were rarely accessed. Another of Pam's reflections shows that sometimes lack of a certain reminder can also be a source of disappointment ...

I rather regret that we don't have more than a few seconds of video of her.

Grace struggled with the presence of some items which had been deeply significant to Matthew ...

... he developed into a very good swimmer, and he used to take part in the Olympics. He had swags and swags of medals and ribbons - he got some bronzes and gold and silver. I took them all recently and I gave them to my son and I told them he might like them, because I didn't want to look at them anymore. He loved his swimming.

I asked her if she had felt it was time to share them? Her answer was immediate and forceful ...

No, I didn't like having them because they meant so much to him - he'd be so proud of them.

So is Interlocked Companionship a Reality?

Based on the interviews undertaken during this research project, I posit the view that **Interlocked Companionship** creates an extremely forceful current. It permeates the lived experience of supporting a family member with an intellectual disability, while they are dying in a community setting. My conjecture is that this potent interlocking emanates from the special nature of the voyage which was being shared, prior to the family member receiving a terminal diagnosis. This deep connection endures beyond the family member's death, only possibly ending when both partners have reached the end of their life course. The evidence of this powerful bonding showed itself in each participant account. Although not uniformly expressed in an actual replication of specific words, it was a prominent strand running throughout participants' stories. It was also observable in their demeanours

as they gave voice to how their inner countenance had been during their lived experience as supporter.

In this chapter the various facets of **Interlocked Companionship** have been delineated and ‘fleshed out’ by the application of participants’ verbatim quotes. This exercise has demonstrated that it is imperative for health and support professionals, involved in the care of dying people who have intellectual disabilities, to insightfully acknowledge and support the unique inter- relationships which exist between the dying person and their closest family members. In Chapter Ten, specific issues pertaining to **Interlocked Companionship** will be further examined in the light of literature.

In the next chapter an image is generated of the second theme, or group of boulders, **Search for New Balance**.

Chapter Eight

Search for New Balance

A Constant Source of Activity ...

When seeking to intuit major meanings inherent within each participant's account of what it had been like to support their dying family member I saw evidence of experiencing turmoil, being spun, enduring crises and failure to find easy answers scattered throughout the interview transcripts. Pondering this I realised how each person had engaged in a continual pursuit for equilibrium through recurrently re-grouping themselves and others. As these nuances came repeatedly into my hermeneutic vision I realised there was a second group of submerged boulders creating a pattern within participants' lived experiences. It was **Search for New Balance**. I began to see this **Search for New Balance** as indicative of a deep-seated attitudinal adaptation having occurred. This, combined with highly developed inner agility, allowed the required maintenance of high functionality in the face of such intense turmoil and extreme demand.

Gauging the Changes ...

The most dominant boulder identified within this group exerted a major centralising force on the river's flow. As they described accompanying their loved one through a terminal illness each participant profiled watershed moments. They would detail observing change, either personal or environmental, and reveal how they had sought to allocate meaning to it. **Gauging the Changes** in this way often allowed a glimpse of the broader situation and led to reappraisal of the 'where from here' element.

Realism and common sense seemed to be highly developed attributes in the people interviewed. Even before terminal illness struck they had experienced going through the potentially challenging adaptation required to accept that a loved family member had an intellectual disability (Blair, ND). All the people spoken with had focused intensely on enriching that person's life through maximizing capability and choice. I suggest that the complexity of assisting their loved one with an intellectual disability to flourish in the world had engendered deep wisdom and intuitive awareness. In addition to utilising these

inner resources to assess new situations participants sought insight through reading or seeking information from experts.

These internalised and external components of *Gauging the Changes* were visible in Pam's account of Frances being diagnosed with leukaemia. Pam's astute ability to almost intuitively summarise the situation at the time and reflectiveness during the interview are also apparent ...

Frances had not been well for two or three weeks... , I took her to have a blood test, and they found it very difficult to get blood off her, I should have seen it as a warning sign. The same day, I got a call from my husband to say that Frances needed a blood transfusion straight away. And I'd **immediately** known - knew, from the reading that I'd done, that that was leukaemia. So I then had to drive to Wellington Hospital and they were very gentle there, but they didn't need to be gentle in a way, ..., because I just said, I know that she's probably got leukaemia and we took it from there.

On one level this description of such a momentous discovery seems rather bland. I believe this is because intuition had worked so powerfully underneath the surface as Pam gathered a sense that Frances was perhaps seriously ill. It was forceful enough to direct her to targeted research. In retrospect it could be claimed that her highly attuned motherly 'pick up' on the subtle shift in Frances's condition was as accurate as blood tests. This early **Gauging of the Changes** by Pam had also lead to her drawing her husband Forde into a shared awareness of the ominous possibility ...

As Frances was non-verbal Pam's motherly intuitive radar was the predominant tool utilised to assess the little girl's wellbeing during the course of her illness. The reliability of this is seen in the following interview extract when Pam stated ...

... the weekend before she died,..... - I could just tell that she was not feeling too good. She was a bit grizzly, so we went back into the hospital. And that's when they first started the morphine.

An underlying questioning within Georgina could not be extinguished and eventually time revealed this to be inner wisdom ...

... one day she bit her tongue - it bled an awful lot.... ,they put her under a general anaesthetic and they stitched it. I remember saying to the doctors *[sounding very reflective]* , they said, it just bled a lot because your mouth bleeds a lot. But I do actually remember thinking well it bled more than I would have thought. a short time later she scraped her mouth again it wouldn't stop bleeding, they said we're going to send her to have a bone marrow test.... , and it came back clear. I remember - I didn't feel that relieved, because it still seemed to me there was something funny about the bleeding. Then about eight months later - I noticed that she was bruising, - the doctor said take her in for a blood test on the Monday. Within about two hours they rang and said, there are blasts in her blood, we think she's got leukaemia - it was very sudden, but looking back, there were these unusual signs beforehand.

While reflecting back during the interview Georgina seemed to acknowledge that although guidance had been derived from understanding the science behind medical intervention there had also been an inner knowing simultaneously manifesting at a deeper level ...

... the main complication that we had, after the first round of chemo, was that she didn't go into remission. And looking back now - that wasn't a good sign.

Sandra saw *Gauging the Changes* during the last hours of Simon's life as having been so important to her that during the interview she supplemented her recollection of his last hours by referring to a written record in his Plunket Book ...

I've got here, renal failure and sight gone ..., he couldn't see anybody, ... signs of deterioration. I arrived there at 4 o'clock in the morning - Simon was still

deeply unconscious.... and I've got here, small seizures, which apparently he would not feel. Later more or less continuous fitting... just watching him die, and just watching him getting colder and starting from his toes, getting blue and um

I was intrigued as Sandra read this passage out. No voice alteration or explanation indicated the section “which apparently he could not feel” was not now within the totality of her own embraced narrative around Simon’s dying process. Yet it seemed to me this had been externally imparted information. It may be therefore proposed that offering external advice during times of **Search for New Balance** can become deeply integrated into the support person’s process. Other aspects needed no interpretive guide – Sandra was painfully aware of what the changes in Simon’s complexion were indicating.

Seizures had also been a feature of Maureen’s disability. They had potential to impact on her life with a terminal illness and her dying process. Dave’s insightful awareness of this profiles the manner in which those supporting family members became ‘their own experts’ and sought to use this knowledge to achieve pragmatism. I suggest those parts of the experience where they could reach this position became ‘pockets of still water’. Dave explained ...

The problem they had was of course, , cranking up the anti-seizure medicine tends to shut down all your responses, so you know, the, sort of balancing act about how much to control the seizures,

One aspect of the participants’ intimate connection with their loved one was possessing partial insight into how the person’s intellectual disability influenced their perceptions of and reactions to discomfort within their own bodies. Grace grappled for fuller understanding of Matthew’s responses and as she drifted back into the space of that most challenging night it was apparent by her far away expression as well as her words that these memories were being drawn close through the ‘lens of love’. She shared ...

...when he started to get in pain he was angry, and I remember one particular day I took him for a picnic, , he vomited, and he was so angry, he reckoned

he'd been given food that was off. And that was the first sign of... he was beginning to be unable to cope with it. Then he started to get a little bit of pain, and we started off with milder...pain relief. I'll never forget and it's been the worse night of my life. It seemed to get to his brain. And he went mad, and was throwing things around and smashing things, and he was a big big chap - not bad looking if you think of him like that...

Resetting the Compass ...

As has already been outlined the participants in this study had become adept at re-positioning their way of 'being in the world'. While focusing on data and the idea of balance and imbalance it was evident a **Resetting of the Compass** occurred over and over for each person I had spoken with. This could be gradual or as in this example lifted from Grace's interview it could have a more 'jumpy' quality to it ...

And then they thought they'd have a sort of checklist for patients, and said that everybody got health checks from time to time. And then they found that there's something wrong with his kidneys. At first they told me it'd be something like what Jonah Lomu had - it probably wasn't too bad and they could fix it up, they had a scan done to see how bad it was, and when they did the scan, they said it was definitely cancer, and it was quite far advanced. But we still thought - I was shocked when I heard he had cancer, because in my family there was no cancer at all. My mother and her side of the family wouldn't mention the word. In those days it was an unspeakable word, they used to say, you know, we don't mention, type of thing but it was in my husband's family.

Grace's thoughts indicate how finding a deeper meaning within the altered status conferred by Matthew's cancer diagnosis, was of vital importance to her. Relating this to her greater sense of orientation appeared to be a stepping stone on the way to assuming a new positioning within the world. For Grace this specifically involved her interpreting how Matthew developing cancer could fit into the framework of their shared historicity of

family and genetics. Finally Grace gained a deep acceptance and in an effort to hold her confused son close she chose to make major changes in her life direction ...

So he was bewildered - he didn't know why he was farewelled from work. They gave him a nice farewell, and he thought he'd been sacked or something. It was hard to explain to him, and then instead of being in their home, he **just came and lived at home** for a while ...

Over the whole course of Simon's life poor health and death had lurked at varying distances. When his final illness occurred Sandra viewed it in this light. She was somewhat used to a spinning compass and utilised insightful analysis of the situation and the revealing nature of time to bring clarity regarding which direction the needle would ultimately settle at ...

... he got the flu, you know, a residential centre, if someone gets the flu then everyone seems to get it. I was rung and told he had the flu, I didn't go to see him because I didn't want to get the flu, and you know, it wasn't wise to go anyhow. So he had the flu for -maybe six days, and I was sort of in touch,.... and I thought well with the flu you're not well anyway and then suddenly he took a turn for the worse, he became really ill one day, and he became unconscious turned to pneumonia. ..., he just got worse, and ended up with tubes, I didn't think he'd come out of that because he'd already had pneumonia twice,

Awareness of Timing ...

This leads into representation of the fifth boulder associated with **Search for New Balance - Awareness of Timing**. This boulder was identified through sensing how temporality, or lived time, impacted on participants' experiences of the phenomenon. It had the power to make the voyage easier or more difficult. Timing was expressed in many ways, including step by step, controlled and random and gratitude was offered regarding fortuitous timing on more than one occasion. Temporality also presented itself as a force shaping interviews through accurate reporting of chronological time assuming great

importance when participants laid out the course of their loved one's terminal illness and death before me.

Through caring for the terminally ill over a number of years I have developed a deep awareness of the alignment between birth and death. As a midwife translates observations during labour into predictions of when the child may be born, a palliative care nurse develops intuition around the correlations between the processes and timing of death. However due to the inexplicable uniqueness of each person this can never be an exact science. Grace may have found the outcome of this inability to predict exactly when her son would take his final breath distressing. Her demeanour while recounting his final day actually indicated acceptance that events unfolded as they did ...

And he started to change colour, and I called the nurse and she said he hasn't got long and we rang up to get my husband and my son and they came in but he'd gone by the time they came. So they were just there to carry him out.

I noticed chronological time, lived time and specifically 'time as a resource' were intertwined during the telling of stories. This ran on into all participants' articulations of what happened after their family member had died. Pam said ...

The next day around about eight or nine in the morning, we rang the undertaker and I did get the sense that he was actually ticking me off for not having rung him a bit earlier,... . and one of the things they had said at that grief seminar was that most people arrange funerals too quickly,... , that you don't arrange a wedding in two days - why do you arrange a funeral in two days? So they said, you really should try and leave it much longer than that. She died on the Wednesday, we had the funeral the following Tuesday. And that time just seemed to disappear so quickly. We had her at home, we had **lots of visitors**, and I found that **really helpful** to grieve, before the funeral.

The awareness participants had of time as a transformative agent was typified as Alison provided her perception of how her children's personal integration with their virtually unknown Aunt Maureen could influence the future ...

I think as time goes by you'll find our kids will ask I was never interested in the people in my family, with skeletons in the closet and things when I was 20, just had nothing to do with me, I was full of life, but as you get older.... - you start asking the questions about the family tree and who sits where and why ,

It appeared that most participants had also seen points in their experience where 'time was comfort'. During a post-interview telephone conversation with Grace she explained how she had been consumed by grief for a considerable length of time following Matthew's death and the death of her husband only two months later. Antidepressants did not ease her grief but the passage of time alone brought significant relief.

The events surrounding one's own chronological stage of life was seen to hold benefits by some as a source of maintaining equilibrium in bereavement ...

Alison: I suppose this sounds terrible -really in the last 10 years we've had fairly regular deaths. All our parents, brother of mine, a few aunties of yours. So it's, it's a time of the life,

Dave: It's very much like that. I suppose if you have a look over like you say, the last... five, seven years or something, we've had a few, so...

Alison: Pretty much one a year for a while.

Dave: I was just saying, we've got to the stage now where Alison, ... , she reads the death notices.

Alison: Oh. I'm not the only one that does that.

Dave: Yeah, I know, but it's a sign of age, isn't it, when you do...

Pam gave voice to the fluidity of lived time when it almost occupies two spaces simultaneously. She attributed the presence of time enough to grieve in the certainty that Frances would die with allowing a more even distribution of pain, thus softening the blow following her death ...

.... having nine months to grieve before she died, was a good thing, in some ways it was easier for us than some other families whose child had a potentially life threatening illness, but they never knew for years and years whether that child was going to survive or not. We knew that there was nothing that really could be done, and it was just going to be a gradual downhill, and although that sounds a bit morbid, it was actually quite helpful, because we weren't having hopes raised and then dashed, like a lot of the other parents who we were supporting, and they were supporting us. We were with somebody whose child had died suddenly - I think that would be much harder to take in than what we had to deal with. And I felt that at the time. And I still think that's true.

Although Sandra was sad that her time of having Simon in her life had ended the fact that he had survived for much longer than had been expected was an obvious source of comfort to her. She expressed her view and acceptance of this temporal finality and current spatial separation ...

I was really really close to Simon, ... , **I miss him**, but, I know he's in a better place and it would have been cruel to let him go on. When he was a pre-schooler, they thought he wouldn't live to become a teenager but he lived till he was 25! So he did really really well, ... , every Christmas, Geoff and I would talk ... , and think, oh I wonder if Simon's going to be with us next Christmas. So we were very lucky to have 25 years with him.

This stood in stark contrast to her experience of time as an adversary ...

I'd seen an auntie die, ... , and I got there just before she died, but with Simon, I was there a lot **longer**, it seemed to take a long. **I got there at four o'clock** and he died at nine o'clock, so it's five hours so it was really tough going.

Digging Deep to Cope ...

I observed that another boulder among this grouping was **Digging Deep to Cope**. It perforated participants' words as they recounted periods of extreme pressure and adjustment during the time of supporting the dying person. It appeared that drawing on their innermost strength was not new. They all chose to speak extensively about encountering and overcoming challenges which had been induced by their family member having an intellectual disability. One example of this was Sandra outlining her insider view of Simon suffering additional functional losses ...

... well the really tough part. Simon was about 15 ... his bones and everything would be stiffening up and causing him to fall.. sort of going more into a foetal position. The paediatrician said to me, one visit, you know, it will continue, it won't get better, and I said, oh do you think that he'll end up in a wheelchair? He said yes, and that **really hit me**. - that was **really hard**, really tough to take. And then you know I thought about it, and I thought well actually he'd be much safer in a wheelchair, because he's just too unsafe at the moment walking around.

It seemed that this boulder was partly composed of 're-positioning of self' and inherent within this there was a texture of 'sacrificing what has been intensely valued'. This is expressed through Sandra's traversing of immediate self interest and her compassionate willingness to surrender any possibility of her son's physical life being prolonged and therefore her own social role as his mother...

... a nurse had told me that they couldn't really do any more for him. I wasn't surprised. I said **I'd rather you didn't keep him alive artificially**, I said I don't think it's, kind, because he's been really sick so many times in his life...and with the pneumonia, and I said I feel it's going to happen again, and we're going to have to go through all this again, all the suffering, and the nurse agreed with me, so we agreed to just, you know, let it be, ...

Sometimes there were acutely sharp bends in the river of experience as participants supported their family member with whom they had such a depth of connection. This was illustrated in Georgina's account ...

... we'd had a blood test at 10 o'clock that morning, probably quarter to 12 we'd been sitting in the garden at my mother's place and by three o'clock she was in hospital hooked up to a drip, starting her chemo

It was as if Georgina had automatically steadied her inner being in order to streamline what was occurring in her outer world. In the same tenure, speaking about the painful post bereavement struggle Endeavour's father had endured after witnessing her in distress Georgina seemed to recognise her own restabilising process ...

... I found that really hard too, but I probably ... got to the point, much earlier than him where I was able to know that was only a short period of her life and, yeah I remember all the other stuff. But he found it very very hard ...

Descriptions of disorientation often featured within participants' accounts. However, it seemed to be inferred that *Digging Deep to Cope* permitted ongoing life navigation despite murky waters threatening inner equilibrium ...

As Pam recalled a now historical visit to the minister her intonation portrayed her reliving of its sad irony ...

And then we went along to visit her about ten days before Frances died, and it was a really weird feeling. We talked about it at the time, it was a really weird feeling for all three of us to have Frances lying there in her buggy while we discussed her funeral arrangements.

The individuals who spoke to me still had times when they felt the loss of their special family member quite intensely. No one had sought professional counselling since bereavement. They chose to trust in their own inner wisdom, the passage of time, contact

with nature and healing relationships. For some **Digging Deep to Cope** was a recurring theme as they were required to balance the experience they had lived within their current relationship to self and the world. Sandra shared ...

I still find that hard to deal with, that seeing Simon die. That's a part that I haven't really got over yet. And again, you get flashbacks, you know, seeing Simon die, but **I haven't come to terms with that- its just, really painful.**

Pam found the time of her child's death to be intensely challenging. I believe that the account she so generously shared of this sacred moment contained an inherent sense of 'struggling to keep her head above water' by desperately trying to grasp her inner self in order to maintain buoyancy ...

.... and it gave me a bit of a fright when she died, actually, because her nose bled, and just a second before she died she opened her eyes and looked all around which again freaked me out a bit,

I believed the boulder **Digging Deep to Cope** was coloured with specks of 'struggling with self acceptance'. One participant statement which revealed this was Grace's candid exposure of her inner reaction to Matthew's terminal diagnosis ...

.... I tried to persuade myself that - when I first thought he was going to die - maybe it was a good thing, because I didn't want him to be - not have anybody to... look out for him. I thought his life would only get more difficult. And then when he died I couldn't imagine I could ever have thought such a ...[break in tape]...it just seemed so awful that I could ever have thought it was a good thing.

Sometimes a participant's struggle to enter the peaceful waters of self acceptance was so intensified by external forces that the capacity for **Digging Deep to Cope** was almost extinguished. In Sandra's situation this came in the form of a visit by two policemen just after Simon had died ...

.... they explained why, because Simon hadn't seen the regular doctor, and because he died in a community setting, he had to have an autopsy, ... , two policemen came, ... they interviewed us but it really felt - we were the criminals. Then it went through my mind about that I'd said to leave him be and I didn't say that to the Policeman, because I thought oh goodness me, perhaps I am a criminal and that **made me feel terrible**. I felt really **really guilty**, ... , that was tough, I can tell you, really **tough**. And the police, they hung around for a long time as well,

Juggling Other Life Events ...

As a palliative care practitioner I am acutely aware that the presence of terminal illness in a family member does not remove other complexities of living from those connected to them. Interviewing supporters of family members with an intellectual disability reinforced this fact that life does not stand still around the person who is dying. The water directly above the boulder **Juggling Other Life Events** held the combined potential to suck participants down or to buoy them up. It was formed by the challenges and joys of living.

Georgina was in the position of supporting a child with a life threatening illness while giving birth to another. She was able to accommodate both roles and saw these divergent life events as naturally lying side by side ...

... she had her little brother, who was born about two months into her treatment. She just adored him. She was **so excited**, when he used to arrive *[giggles]* in the morning to see her,

During the precious final days of Simon's life Sandra had to juggle being present with him and being present with her elderly father. In what could be considered an understatement she said ...

I was actually caring for my father who wasn't well at the same time, so I had two sick people I was looking after, the same day I'd visit them both, so I was really busy.

Another dynamic example of needing to cope with simultaneous circumstantial onslaughts was Pam's portrayal of the week her young daughter with Down syndrome was diagnosed with leukaemia. The inclusion of her role as 'pregnant mother' and 'mother to Isabella' is indicative of the manner in which participants lived out their experiences against the backdrop of the demands and joys of their particular life stage ...

I was actually pregnant, and we had a rather harrowing week, my uncle, died, ... our boat came up off its mooring, I discovered that week that my amniotic fluid had disappeared and Frances had not been well for two or three weeks. ... I drove up to my mother, and we were going on up to the funeral of my uncle. I was phoned and told about the blood results ... and so I then had to drive back from Raumati to Wellington Hospital with Frances and Isabella ... They gave her a blood transfusion ... and we were there for a few days, came back home, and that night I miscarried, and had to ... have a D and C. So it was a very traumatic week.

Accommodating Personal Diversity ...

As I hovered in the vicinity of the grouping named **Search for New Balance** I became aware of one final boulder. It smoothed the water above. **Accommodating Personal Diversity** was held together by an astounding lack of bitterness and high level of pragmatic acceptance. Each of the people interviewed had been at the hub of the dying person's support network and so their role had partly involved holding the complete social situation together. I could observe that within this they overwhelmingly exhibited a flexible attitude towards and understanding of others.

Once again, this was a skill which had been honed through living among society with a family member who had an intellectual disability. Sandra displayed **Accommodating Personal Diversity** when she recounted ...

... but in later years Dad hardly saw him. I think it was too painful for him to see him like that. He was a bit like our daughter, ..., didn't want to see him when he, ... got worse like that, in the wheelchair. He had a lot to do with him when he was younger, but my father couldn't cope with anyone being sick, he was just like that.

The mutual ability Pam and her husband had to accommodate and even enjoy difference in each other was seen as playing a pivotal role in the experience of their daughter's death drawing them closer instead of driving them apart. To demonstrate this Pam recalled ...

... one of the books that we read, before Frances died, was a book that I couldn't read without lots of tears, and I wanted to zap through it, which I did in a couple of days, Forde found it so emotionally difficult that - you know, he's quite a slow reader anyway - but he took a month to read the book.

During the special time immediately after Frances's death Pam was able to reflectively accept that the reaction of her surviving pre-school child was radically different to her own when the paediatric oncology nurse asked who would like to help take physical care of Frances's body ...

... she involved Isabella in washing Frances and dressing her and I just found it a bit freaky. I couldn't do it so Isabella did it, and we were all there.

As a consequence of Sandra speaking about her encounter with the police I became aware of her deep conviction that difference should be respected ...

... then they asked about our family, ... , we said we had a son and a daughter, and they said, well where's your daughter? And we said, oh well she's at work,

and they said, why isn't she here? My husband said oh, well I rang her, , she chose not to be here, because she wanted to remember Simon how he was. she'd gone off to work. The policeman thought that was strange. But - it wasn't really, **you can choose, whether you want to see someone who's really sick or not, ...**

During the time of the funeral Alison and Dave had particular regard for Maureen's special friend James. One particular individualised decision struck them ...

Alison: yeah that's right, ... , I think we had a flower for him to put on the coffin at the end and I'm pretty sure the other residents with their caregivers went up and James wasn't... he ...

Dave: He didn't want to go anywhere near the coffin.

So Does Search for New Balance Lie Within the Lived Experience?

Living life is never a static exercise. I therefore evaluated whether **Search for New Balance**, as it existed within research data, deviated sufficiently from the norm to justify its proposition as a phenomenological truth lying within the answer to the research question: "What is it like to support a family member with an intellectual disability who is dying in a community setting?" I reached the view that the strength of participants' articulations depicting 'treading water' and 'regaining buoyancy' had indeed exposed a sentinel characteristic of the lived reality. A group of boulders, **Search for New Balance**, do underlie the voyage of this experience and collectively they protect against the currents which may otherwise suck a person inexorably downwards.

Prior to embarking on the interviews I had anticipated stories of receiving care from health professionals would feature strongly in participants' accounts. The circumstances of such input was detailed but I detected these and many other relationships engaged in by participants were portrayed as being very interactive and two-way. This dynamic gave rise to the third theme **Permeable Interaction** which is the focus of the next chapter.

Chapter Nine

Permeable Interaction

External Reciprocity ...

Inherent within my first intentions of conducting this research project was an assumption that its most central outcome would be to reveal how people supporting a dying family member with an intellectual disability experienced interaction with community based health and support services. This did emerge as one aspect within the third and final collection of boulders revealed through data analysis. One feature which struck me when participants spoke about these interactions was that influence was exerted in two directions. I also saw that participants' experiences were shaped by multiple external sources. This **Permeable Interaction** with individuals and societal groups, located at variable proximity to the participants and their family member, was profiled during each interview.

Inner Circle of Family Support ...

This boulder lay wedged in beneath others. It produced small slowly moving rings of calm on the river surface. Inter-relationships between the rings fluctuated but they were often observable as overlapping. As each participant gave voice to this dynamic they seemed to possess inner clarity about the structuring and roles which occurred within the **Inner Circle of Family Support** and how this impacted on their lived experience of providing support. A sense of security and warmth noticeably emanated during these sections of the interviews.

Endeavour's mother was her most constant support person during her terminal illness. As Georgina moved into this intensified role a simultaneous restructuring occurred within the immediate family in order to promote the wellbeing of Georgina and Endeavour. It also allowed key people to express their own love through contribution and presence ...

.... there was always somebody there either me - or my mother because Mike needed to keep working. He'd come in after work. - once William was born,

Mike and I would bring William home, and my mother would stay in there overnight, ...

I could hear that being surrounded by their extended family had produced a sort of 'nest' where Georgina and Mike could be with Endeavour until her life gently slipped away ...

The last week when Endeavour was sort of dying my mother came and stayed in the house and basically took over William's charge which meant that - Mike and I could just focus entirely on Endeavour, which made things so much easier. My sister did all the running around picking up prescriptions and making calls My husband's sister, was very helpful giving us support ...

Pam's description of positioning of the inner circle at the time of Frances's death was offered as a story of beauty ...

On the Wednesday afternoon they came in **quietly** and said that they thought she didn't have long to go, ... , and in the late afternoon my mother came down with Isabella who was five, and also Forde's two nieces. The younger niece had come up from Dunedin when I first brought Frances home. She was there shortly after she was born, and then she and her older sister were there when she died as well.

Sandra went to her dying son without hesitation. Although Geoff was Simon's step-father he had provided deeply loving support for many years. His offer to remain with Sandra and Simon was declined in what may be seen as indicative of the preference participants sometimes exhibited to 'take the brunt themselves' and thereby offer protection to others within the family circle ...

Geoff dropped me off at four o'clock in the morning and I was saying - no, don't stay, you know, there's just - no, it's not good, ... , he went back home. Geoff must have just got there after he died, I think he did , so he wasn't there in time, but , it was okay.

When Matthew was terminally ill his father was also in very poor health. Although this meant Grace needed to be the central support person she valued and validated her husband's contribution. She also received strength from the presence of her other son who could not be physically present so often due to professional commitments ...

George my husband used to come in to the hospice some of the time, but I don't think he could stand it as well as I could, so I did most of the time....he had a very weak heart.... I've always thought that George just made up his mind to keep going - while he was needed. Because after Matthew's death, he declined quite quickly, and he died two and a half months later.

... my other son was very good. For instance when Matthew had to have a scan he helped out there ...

Near the conclusion of my interview with Pam she touched on the way in which she had continued to experience the **Inner Circle of Family Support** after Frances had died ...

I think probably in general if any family loses a child that can sometimes put a huge strain on family relationships and other relationships. I was very lucky that it didn't. And I think possibly because of my personality and being able to talk things through quite openly with other people, and with my husband. That probably we grieved at the same pace, and I think couples that are not grieving at the same pace or in a different way, that can pose a lot of problems.

Watching Out for Others

This boulder was also present in the stories of all people interviewed. It caused bubbles of caring concern to intermittently rise to the surface. Sometimes it had a modifying influence as participants sought to shield another from a difficult impact. Georgina described reflexively 'softening the blow' in a time of immense pressure ...

.... my husband was at work, so I called him, and I said to him, look we've got these blood tests back and they're not good, I didn't tell him about the leukaemia, because I thought I'd rather tell him that when he got to the hospital

As will be discussed later, the local play centre community provided huge support during the course of Frances's lifetime and when Pam was recounting this I could see her reciprocal heart of care towards them ...

... when she did die, most of the play centre children came here and viewed her - we had her just lying in her cot [smiles] , and gave her flowers and cards and I think that that was a really good healing process for them too [*bright intonation*] ... in her funeral notice we said, children welcome. And the minister involved the children so that they drew butterflies during the service, [laughs] which was rather a long service.

Pam explained off tape her mindfulness towards her parents who had become estranged from each other. She strongly desired to assist them in navigating the inherent difficulties she anticipated because her mother had always been immensely supportive. Despite the pressure of having a dying child, she sought to ease their pain by deliberately bringing them together socially, prior to Frances's death and funeral.

Alison regarded the group of people living with Maureen as her friends and second family. As they had intellectual disabilities she was particularly concerned about them coping emotionally with the deterioration in Maureen's condition. She discovered their needs had been considered ...

They took the residents up the first day Maureen was there (in hospital). And we were a little aghast at that, it was a learning experience for us, ... but they said, in [large residential institution] people get sick and they just disappear... , it's really important for our clients to go to the hospital ... it's part of the process for them. So once they explained that to me I was quite happy ...

The support workers were highly valued and trusted by Alison but she worried about Maureen's terminal illness exposing them to unfair demands ...

I was really concerned that the caregivers at the home would get burnt out. That's a stressful job - for women who ..., their job entailed looking after intellectually impaired people - it wasn't really their job description to, give terminal care, and at that level ...

After Maureen returned home Alison and Dave were also aware of the impact on her fellow residents. They held a particular concern for Maureen's special friend James ...

Alison: And she lay in her room and the others - because that was the other thing that was of some concern to us really - how does it feel for the other people, her friends, people that she'd lived with for two and a half years, all with their own disabilities. the effect on them was, well, hard for us to understand how it affected them, but it certainly did.

Dave: they told us for instance that James, the special friend - when she was off at hospital, every night...

Alison: ... somebody'd go into Maureen's room to pull the curtains, and James would have got her pyjamas out and ...

Alison and Dave: ... laid them on the bed.

Alison: And several times when she was not well, James just went to bed for a day. I don't know what the long-term effects on James would be it was a very close relationship. I don't know how much we understand about, where do people go when they're dead, how do people with very limited understanding grasp even things that we think we understand.

This couple wanted Maureen's death to be managed in a way which assisted the residents in their grieving but recognised the limitations of their own knowledge ...

Alison: One of the other ladies had actually asked, where's Maureen? And they said, oh she's gone to be with her Mum, and I thought that that was a lovely way of putting it, but in some ways it didn't sort of - it's a tricky one. But it was nice that Maureen was at home for that first night, I think, that the others did have their time to have her still there.

Dave: ... there was like two families in this. ... , we're quite capable of understanding and rationalising it, but we didn't know how they would handle it, and, so very much we worked with (community care provider) about how they handle this process ..., right through that leaving the body there, the funeral ..., the degree of involvement that they wanted people from the house to have.

Although Grace was struggling with her own grief she had exhibited caring concern towards Matthew's girlfriend who had an intellectual disability ...

It was hard for his girlfriend. She was in tears over it. **I tried** to keep up some sort of contact with her afterwards. But it didn't work very well. And I had her out here once or twice, but she didn't seem very comfortable. Oh, she said, she had to get home because she had to, prepare the dinner or something, and she was very anxious to get away again. ... I made a few attempts but it didn't seem to me that I could get through to her, so it just lapsed.

Grace also cared about the welfare of a key community support worker ...

He was in a nice home before he left - and the woman there took it very hard, ... , she went for counselling. Because she said she was so affected by it, because she said he was a nice person to have in the house, he supported her, and she hated to see him suffering and dying. She was quite upset by it.

Perceiving Points of Difference ...

Although the interviews were not as dominated by participant accounts of interaction with health and support service providers as had been originally anticipated such descriptions did run throughout the collected data. What was particularly visible in these recollections was that as each individual was supporting their dying family member with an intellectual disability they became adept at **Perceiving Points of Difference** which, through their eyes, existed within services. And so another boulder contributing to the currents around **Permeable Interaction** was identified. As these perspectives were put before me it was predominantly in a spirit of pragmatic realism. The assessments offered had generally been reached while considering not just what had been experienced but the challenges the particular provider had faced in terms of the complexity of care and systemic constraints.

One area where differences were articulated was those that occurred between settings and this often continued into a deeper description of one or both. Alison told me that when Maureen returned home there was music playing quietly in her room. I asked if Maureen's radio had been used in hospital. This simple question led into Alison and Dave detailing a misfitting oxygen mask. Reviewing the interview I felt this expressed an even deeper sense they had – of incongruency between Maureen's way of being and the public hospital system ...

Alison: You couldn't really. She had this horrible oxygen in **those things make a din.** I think they had tried a radio, but I don't think it kind of penetrated all the other racket...

Dave: She was quite a small person, so she had this mask, it was miles too big - it sort of disappeared all over her face - but you could see when she was awake, she was trying to brush this thing off her face as well. They told me they tried one of those like in the tip of the nose, but you know, they couldn't get that to stay on.

Alison: It's tricky - the things you take for granted ...

Prior to bringing Matthew home Grace was concerned by the systemic inability of residential community support workers to provide him with non-regular medication for symptom relief in a timely manner ...

... he had morphine provided, they weren't allowed to administer it, I had to administer it to him. I don't know what would have happened if we hadn't been here ...

The relative positioning within services of the dying person and those supporting them could be experienced as hazy. This was particularly so during times of transition; when the roles and boundaries of the respective providers could become unclear and impose deficits in care. Maureen's discharge from hospital was one such time ...

Alison: ... it really just wasn't the right place for her to be. ... once we'd dealt with the immediate things ...

Dave: ... staff came back from the holiday period and suddenly the bed was wanted, ... , she was sort of thrown out with indecent haste. There was very little done to prepare the home. Friday night, she's got a catheter in nobody's experienced looking after a catheter , no supplies the home rang us to tell us that she was there.

Alison: ... it was a bit difficult to know sometimes what was our role and what was the home's role. it was the home that was expecting her back, so it was more important that the hospital liaised with them. But it certainly was done not very well.

Interviewer: Did the hospice doctors go and see her at the hospital before she was sent out?

Alison: No, no, no- it was about a week later I think it was they came and saw her.

An ongoing commitment by the community based intellectual disability support service to provide for Maureen's needs at a level above that which they were contracted to do was of immeasurable value to Alison ...

She came home from hospital with a catheter in... , somebody else in one of the other houses, had nursing experience , knew exactly how to deal with this, so she'd been seconded. they always seemed to find the right people, ...

Another way in which services were accredited with assisting the family member who was providing support was by providing decisive guidance, as in this instance where Alison's sense of direction had been uncertain ...

.... the [local hospice] medical staff assessed her and there didn't seem to be any doubt in their minds that she was an appropriate person for the hospice to be caring for. I relaxed because I wasn't standing there worrying about how the caregivers would, get enough fluids into her, because we had really acknowledged that this was now a terminal kind of pathway, it did take the stress of all of that away...

The couple went on to explain the sense of security they experienced as the hospice and residential support service moved into a partnership ...

Alison: ... (community care provider) was always totally supportive of looking after her. Our concerns were ... they did need nursing care support and so the relationship, when [local hospice] came on board and provided that nursing care and the medical support... , ... was, ... an absolutely ideal situation - it worked really well, ...

Dave: And there was also ... infrastructural support - whatever necessary to make the job easier.

Alison: ... mattresses, wheelchairs, whatever was required - it seemed to happen very very easily for everybody and I'm sure from certainly what (community care provider)'s people told me, they felt very comfortable about

just asking for gear, help, advice, whatever, it seemed to be a really good relationship.

And this trust in the combined expertise of those who knew about terminal care and those who intimately knew Maureen was seen to be of assistance as she entered into the dying process ...

Alison: Sharon [caregiver] actually contacted us towards the end and said - she's not so great. ...

Dave And somebody rang from the hospice as well to confirm that... the end was nigh, so to speak. It already confirmed what we thought within ourselves.

Alison: I had total faith really in the competence of the [community care provider] staff and the [local hospice] staff,... I didn't actually worry about the details. So maybe that sounds a bit callous, but it didn't seem to be my role. That was obviously being taken care of and nobody was stressing out about it. I sort of left that up to the professionals really I suppose.

Being provided with timely information was one of the ways in which Pam experienced benefit from her daughter dying in a ward environment ...

... the hospital staff were very helpful to us, ... saying what to expect and talking about the difference in breathing, and all that. So we knew what to expect - and that **knowing what to expect** and again **feeling** in control again helps you to get over it - to grieve properly.

Receiving truthful diagnostic and prognostic information at the time of Frances's diagnosis had also been appreciated by Pam. She simultaneously indicated how pleased she was that measures were not being limited due to Frances being a child with Down syndrome ...

I was really impressed with the hospital staff. They kept us informed all the way along, that's **really important**. If you have **full knowledge**, you feel

more in control ... , it's much easier to grieve ... A specialist haematologist, ... told us that her case was very rare and that they were consulting with overseas doctors. And I was very **impressed** on two counts. **One** that they were bothering to do that, and secondly that they kept us **fully informed** ...

These sentiments were also echoed by Georgina ...

So I went into the hospital with Endeavour. The doctors were very good - they were very upfront, ... , **which I appreciated, I wanted that.** ..., and they always treated her with great..., respect. I **never** felt for a minute that she was **in any** way compromised by - her Down's syndrome. I'm sure that she got exactly the same treatment that she **would've got**...otherwise.

Several participants accredited the presence of a key professional who traversed the interface between providers or institutional and home settings with offering added security. For Pam that person was the paediatric oncology nurse ...

... it was that feeling of being safe, and in control and I think if you've got somebody - that one person to liaise with, so you're not having to tell your story over and over again, ...

It appeared the opportunity to move between hospital and home with ease helped to integrate Endeavour's terminal illness as a natural part of her family's living ...

... sometimes the doctors would let us come home for even four hours in the middle of the day to cheer her up, or we spent a lot of time at Te Papa ...

That nursing and medical care gradually reached entirely beyond hospital walls empowered Endeavour's parents to fulfil their deepest desire. That she died in her own home seemed to be a source of ongoing comfort to Georgina ...

... the only time she went into hospital after that really were blood transfusions She'd go in with no energy and it would just perk her up ... Then there came the point where there were going to be no more transfusions, that was very close to when she died, The thought of that was quite upsetting, because then you were faced with it - she was on the decline. But then she died at home which was lovely. ... had we not been able to control her pain, then we were, going take her into the hospital again. We had some very good nurses who were coming you know several times a day,

The extent to which professionals allowed the dying person and family members to move alongside seemed to have a link to participants' emotional stability. Having an authentic relationship with hospital staff advanced both Pam's and Frances's wellbeing ...

... sometimes with blood transfusions - I knew what should be going in there, there was some drug that she also had to have. Once or twice the nurse forgot to give it so we had to remind them. So, ... , little things like that, because you're involved, I think, it really did help us ...

When Endeavour required treatment the impact on her mother was lessened considerably by the nurses 'going the extra mile' ...

... She had some words. She used to **sign** - and the nurses, some of them knew sign language too. She **understood everything that was going on**, if they came along to clean her Hickman line, they would bring along little gauze strips and give her some too and she'd be waiting there for it so she could be doing the same thing. I do think that the nurses made a special effort, and I do feel grateful [*breaks down*] to them for that.

Through acknowledging Matthew's girlfriend the hospice staff opened up a source of happiness for Grace and others ...

... he had a girlfriend, , and of course she was mentally handicapped too. ... She came to visit him in the hospice and they were very good - they let her stay overnight once or twice ... he was pleased to see her. He chirped up when he saw her, ...

A willingness by professional staff to demonstrate their own humanity and valuing of the dying person with an intellectual disability touched several participants deeply. This materialised during interviews not just as words but as emotion so deep it moved both the participant and myself to tearful silence.

In Pam's memory a positive aspect of Frances's need for intermittent hospitalisation was interpersonal connectedness ...

... we developed a **very strong** rapport with the, with half a dozen nurses in there that we got to know pretty well, ...

Pam told me how meaningful the responses of the nurses to Frances's death had been ...

The charge nurse had been having a dinner party. She left her dinner party and came in. Jenny was at the dinner party, and she came in as well. And I think that was **just so lovely** to have that continuity, to have them come in at that time.

It appeared to me the affection which Endeavour shared with the professionals involved in her care would be treasured by Georgina forever ...

Participant: ... it wasn't a terrible thing to be going into the hospital. She was very happy to go in there. We'd formed such *[becomes very emotional]* personal relationships with the nursing staff and, the doctors too. So it wasn't as if we were going into some impersonal place. She was quite excited at times when we walked in the door, because she knew she'd be seeing her friends again.

Interviewer: Feels like you've still got quite a strong emotional bond with those people who cared for her?

Participant: I do - it makes me feel very emotional when I think about them actually, because they really were such good friends to her. I do think - they made a difference to her life. And that meant such a lot. *[Remains very emotional to this point]*.

Grace articulated that unreserved acceptance of her son by hospice staff had brought great relief. The knowledge that he could safely transfer between home and the inpatient unit provided security also ...

How people manage without the hospice I don't know - it would have been really difficult taking him to a public hospital - being in a waiting room - having people stare at him and having him behave oddly would have just added to the difficulty of it all. So the hospice was very good in that we could go in and have no difficulty in just having him sympathetically looked after - no need to explain to anybody and, they, ... have him in for a while and settle him, and then I had one dreadful night ... The next morning I was wrecked and there was a hospice nurse came. I was so pleased to see her. And she said, let's take him away, pacify him, and adjust his medication, I think he pretty well stayed in the hospice after that. He used to come out and talk to the receptionist. He had a social tendency, ...

Simon returning home to die in his own familiar surroundings and being cared for by an experienced palliative care nurse and his own support staff with whom he had formed a deep relationship was seen as a natural choice by Sandra ...

... I'm sure he was happier because he was really sick, but he knew there was something different, and different people talking to him. You know the [house] staff were always at the hospital visiting and there was always, one

person at the hospital with him – no it just seemed right for him to go back to his own home.

... so he's put on morphine and he went back home, ... they just talked like he was well, just chat away to him and say what was happening, all that sort of thing. Much nicer for him, his own bed, ... they had music playing ... just like he was normally lying in bed and resting. They'd breeze in and out, really cheerful and different atmosphere to being in hospital.

Appreciating Pivotal People ...

Lying directly on top of the boulder **Perceiving Points of Difference** was a smaller one, **Appreciating Pivotal People**. This came into view when participants shared about key professionals who had exerted a disproportionately positive influence during their voyage of providing support to a dying family member with an intellectual disability. The people who made such a difference were not just limited to health professionals, although this group featured strongly.

Pam introduced me to this dynamic. As she spoke it seemed professional competence and the timing of first meetings seemed to assume high significance ...

..... the charge nurse was absolutely tremendous. We met her on **day 1** when Frances was first diagnosed. It was difficult to get bloods off her and she was the one that came in and was able to do that, ...

Pam repeatedly spoke of the immense contribution made by Jenny, the community paediatric oncology nurse. That Pam's sense of emotional connection with this nurse had not been diminished over the passage of many years was obvious. Some of the statements she made regarding Jenny's intuitive, compassionate actions aptly demonstrated reasons for this ...

... I could just marvel at her wisdom and maturity. She always went through the whole process with the family, the care, the death and the weeks

following. She did a lot of home visiting, she included Frances's older sister, ... She took the mystery out of it, for Isabella, and I thought that was so important. Jenny would ring to check ... and if I said, oh next time if you could bring such and such out an hour later she'd be out here with it, So she took care of the medical aspects. She took care of our emotional aspects as well. Towards the latter stages she was talking about the grief process, she recommended books to read. She talked through the funeral arrangements before Frances died ...

... we decided that we would take her home and ... I just had a **funny feeling**, and Jenny said, well would you like me to come home with you? But she sort of **sensed** how I was feeling and it really felt quite strange driving from Wellington Hospital all the way around to Eastbourne, holding a dead child in your hands.... , you sort of think about seat belts and things and what people would think it was really quite weird. And Jenny understood that perfectly. So she probably got home about 2 in the morning. But, you know, I was really grateful for that. ... always cheerful, always positive. That was our understanding of a wonderful, wonderful person.

Having access to a funeral director's knowledge also eased things for Pam when Frances died ...

The undertaker was quite interesting - I'd been to a grief seminar about two months earlier, and again I found that really helpful because they'd actually gone into the morgue and they explained what they did - so I knew what was going to happen, and I found that really helpful. Because I didn't know what they did. And that again was a sense of being in control and knowing what was happening.

Recalling the personal engagement of the local minister is also an ongoing joy to Pam ...

Participant: ... the minister took great care of us in the days leading to Frances's funeral. And the time afterwards. And she said that the day **following** Frances's funeral she just cried the whole day, ... , she was so moved by the whole thing, particularly as funerals were rather new to her, but she felt very much involved in it.

Interviewer: That must be precious to you.

Participant: Yes it is precious to me.

There was a special person, in the form of a support worker, who made such a difference for Sandra and Dave during the terminal phase of Maureen's life and after her death ...

Alison: Sharon was lovely. She used to go up to hospital and help with giving her washes ... it's a bit of a tricky one, because I suspect for the first day or two, it was part of her on-duty time. I think perhaps after that they said, no you've got to be at the house. And that's fair enough.

Alison:...the other lovely thing - Sharon was involved in dressing Maureen and doing her makeup.... , which was lovely they actually asked if they could go along, so they worked with, the undertakers. They had done **such a beautiful job** - she looked like **a lot of care and love** had gone into it. They had chosen her jewellery and beautiful makeup, ...

The parental trust running the facility where Simon lived contracted with an experienced palliative care nurse to provide additional care for him. As Sandra relived the contribution this professional had made it was obvious this had been experienced as holistic and multifaceted ...

I can't even remember her name now, but she was actually the parent of an intellectually handicapped young person. And she was such a big support to me. She understood how I felt, Simon was really really ill just before he went into

hospital , and I talked to her about ... I said ... if Simon gets really sick, I don't know if I should let him just linger on - and then she explained that it was up to me, to say, ... , let the doctor know,... so I did that, , through talking to her I felt confident to say something ,... and she was such a lovely, cheerful person, Really amazing.

And the thoughtfulness of another professional with whom Sandra had a pre-existing relationship was also pivotal ...

... the manager was really good times when I wasn't with Simon. I've actually got the note here -she tells me exactly who rang to ask about Simon.

The Contribution of Friends with Intellectual Disabilities ...

The Contribution of Friends with Intellectual Disabilities was a boulder which transfused a glowing quality into the water above. When speaking of this aspect of their experience participants exuded soft warmth. This seemed to be comprised of a mixture of deep humility and wonder at a mystery only half understood. Sometimes friends' families and support workers were integrated into this facet of participants' accounts.

Once Simon had returned to his home his friends were able to be with him. This was important to Sandra ...

Participant: ... they came and said hello to him - sort of- well they weren't speaking and things. They wheeled them in to see Simon, for a little while, **like a normal day, they come in and out.**

Interviewer: And do you feel they had a sense of what was happening?

Participant: Yes, they'd make noises and they'd go [*makes noise*] as though they're talking to Simon. [*smiles*] And yeah, yeah they did, yes. They tried to talk to him. ... through the grapevine other... , homes, found out, ... **some of the staff who had looked after him in the past came** to see him - that was nice. But ... he went into a coma later, , it just had to be family then. ... , the

parents were allowed to come and go, that was fine. ... because it was like ... ,
living in a big family, ...

Interviewer: And were those parents, ... involved in supporting their adult child who was, involved with Simon?

Participant: Yes, that's right, ... So we all felt like they were sort of our ... young people

Alison shared about some of the interactions she and Dave had with Maureen's friends and support workers following her death. It was evident that this whole hearted involvement provided some buoyancy for the couple ...

... we all went back to (community care provider) and there was flowers and - food to feed an army for a week ... some of their other clients and helpers from other homes... , I think they, were using it as a sense of this is a process, ... , to be involved. And that was actually quite nice, ...

One of Maureen's friends spontaneously expressed her positive view of the funeral 'after function'. This offering of her perspective was valued and experienced as therapeutic by Alison ...

... actually Glenys said to me, when I went back to the house after a few days - "good party" she said and I thought, oh cool, that's good.

Community Compassion ...

A feature which was common to all participants' narratives was the acknowledgment of being sustained by actions of the local community or sometimes 'communities within the community'. This trend revealed another boulder contributing to **Permeable Interaction, Community Compassion**. This could make a pivotal difference in 'finding a way through' their experience of supporting their family member with an intellectual disability who was dying. It was as if the compassion of others could 'calm the waters'.

This contrasts positively against historical societal attitudes. The births and deaths and lives of New Zealanders with intellectual disabilities were not always valued as they should have been. Although our primary purpose was to speak about the terminal phase of Maureen's life Dave and Alison told this story to demonstrate how her destiny had been shaped. Being born with Down syndrome seemed to have instantly defined her as 'other' to be excluded ...

Alison: ... that little country environment ... , it was pretty harsh for acceptance of somebody - ... I can remember your mother saying about your neighbour,

Dave: Yeah, Mrs ... , ... coming over ...

Alison: When Maureen was born.

Dave: ... when Maureen was a baby, and said, **came over to see the Mongol - I've never seen one of those before** And so that was the problem with support in the community - there was no such thing as support in the community. ... she was a lovely lady in her own way, it wasn't meant unkindly, but that's just the way she was, ...

Witnessing Pam's recall of the social context of Frances's life it was obvious she derived comfort from the significance this had held for Frances. Memories of engaging in advocacy during times of major social realignment left lingering fulfilment ...

I think in Frances's case, she was **born just at the beginning of the era** that was changing for people with intellectual disabilities. There was much more drive to **community living - mainstreaming in schools**. The sorts of things that you know, I [laughs] fought for a few years as well [laughs] and in our own particular case with Frances, certainly to comments made to us from friends, family and neighbours in the community were very positive and **I never ever got a sense** that she was any less worth as a person.

One participant who was required to straddle both eras was Grace. She had struggled with the expectation that she place her little child in an institution. Later, de-institutionalisation turned the tables on her ...

I was **horrified**, to think that he'd be put in the community, ... he was put in a home. He was very happy - and he developed skills that I'd never thought he would have had. And they got him a job ... He was in [large local manufacturer], you know ... And I still have fondness for them, because all the chaps there and the manager there were so good to him when he was in hospital they came to visit him and would send him things.

The society from which Matthew had been segregated now enjoyed his friendship and offered comradeship during his terminal illness. Grace continues to experience the gratitude and warmth this generated within her.

The thoughtfulness of Alison's boss evidenced the revolution in community attitudes which had occurred over Maureen's lifespan. Her death was validated as a personal loss of a loved family member. Through attending the funeral this woman acknowledged that Maureen's life had been precious to Alison ...

... my boss from work, she didn't even tell me she was coming, but she snuck in, which was really nice ...

Pam provided a picture of gaining morale and having 'domestic pressures' eased by a distinct sub-community of parents. Being soothed and enriched seemed to occur as a result of the empowerment these groups gave Pam to just 'be there' for Frances ...

So I had a lot of support ... from the play centre community. The parents there, right through Frances's life and illness were, absolutely tremendous in support and helping and having Isabella when Frances was in hospital - and all of those sorts of things.

The play centre community provided a safety net which was practical, long term and extended to care of the entire family. This portrayed the values shared by Pam and others within this self-help movement.

The strengthening and affirmation of friendship bonds secured Georgina. The caring touch of virtual strangers comforted her heart. She was bound into community as Endeavour's life was slipping away ...

.... there was our very strong group of friends, who we've known for years, and some of them were just fantastic at bringing us food. You knew they were thinking of you, ... We had only lived here for probably six months. ... but people were **very, very supportive**, ... we really felt that they cared ...

During the course of Frances's terminal illness she had intermittent admissions to hospital. The children's ward became a 'home away from home' and 'a second family' developed with parents who also knew the inner perils of supporting a seriously ill or dying child. In one way progress was experienced as a loss by Pam ...

We got to know a lot of the other families well. We actually got to know those families better, than we did when they had the new facilities and you had your own room ... , you felt a bit awkward to go knocking on somebody else's door.

The children who Endeavour befriended in hospital were recognised as giving her a precious social world. They became treasured and drawn into the centre of her family's ongoing life ...

... She couldn't go to kindy or anywhere like that. She missed out on that I suppose because her immunity wasn't good enough. She did have a very active little social life. ..., she really made friends with the other children who were up at the hospital, and we still see some of those children. They've become good friends of ours and of William's.

Tailoring Responses ...

A very small boulder, only glimpsed within some participants' stories, was **Tailoring Responses**. The waters above it became turbulent as Sandra went back to two such incidents. In acts of deference Sandra had become entrapped. She fought hard inside against the urge to free herself from the professional grip ...

... My minister he came and he was a bit of a pain too, he sort of wouldn't leave, and I didn't really know what was going on in the other part where Simon was lying,

Listening to Sandra's other account froze me. Her finely calculated behaviour was instantaneously tailored when she was told to identify her son. Against her social nature she entered into deception and a hollow act in order to deflect a shattering professional command. The screams from her inner being wanting to be cushioned from the visibility of death prevailed ...

I just took a quick look at him and then looked away and, was aware the policeman was watching my face very **closely** and it was just a **horrible feeling**, it **really was**. I thought maybe I'm not reacting well, **I looked quickly at him and I gave a little smile and quickly looked away**. But I didn't want to look anymore, any longer, because I didn't want to remember him like that,

Relationships in the Aftermath ...

Georgina's words, already shared, have painted a picture of her family's relationships with friends which traversed Endeavour's death. Enduring interconnections enliven and embody her memory. One could imagine the sight of William at play with special friends, cancer survivors, triggering sweet thoughts of Endeavour spending happy times with those same children. This story is about **Relationships in the Aftermath**, a chunky smooth boulder among the collection comprising **Permeable Interaction**.

Comfort and meaning were derived from Pam's ongoing personal connection with young people with Down syndrome and their families. She and her family were still 'counted among their number'. In this way Frances, who had allowed entry into that special world, still contributed to her family. Pam maintained access to her 'life with Frances' through her preserved bond with 'comrades outside mainstream motherhood' ...

... we've got another very close friend whose son was born just after Frances and, and **for many many years** she used to send a card on the day that Frances died, just saying she was thinking of us ... and I've still kept friends, the close people that I knew with children with Down syndrome.

For some participants this boulder was not constantly in place. Grace expressed the reality of the painful times after she lost both Matthew and her husband George. As the presence of others diminished she lost shelter and felt the full force of death's separating current ...

... at first lots of people supported me and I felt buoyed by that. After a few weeks I was much more alone and that was when it really hit.

Simon's death left Sandra in a gaping social void, compounded by the lack of extended family. The continuing care of people who had been involved in Simon's life was a buffering life line ...

... the staff rang and visited and the parents of other residents visited me - that **was my main support when Simon died**. Dad very shortly had to go into a home after that, so Dad couldn't really support me or anything. I had no other family in [local region] and Geoff hasn't either, it was [house], they were my main support. I wasn't working, so I didn't have the support of people I was working with.

Sandra's words capture the power generated when enduring connection with those close to the person with an intellectual disability who has died occurs. Validation is given to the deceased loved one and to the person who supported them in life.

Drifting Away from Services ...

At the time of our interview Sandra's earlier sense of being encompassed by residents, parents and professionals from Simon's home had largely evaporated. In a typical statement made by participants Sandra inferred that there had been a mutual loosening of the grip as the torrent of bereavement eased and ushered in freshness ...

So we hardly ever go to [house] now. Went recently, invited to a celebration and the new manager said, you're always welcome, but it's just not the same.

This gradual, peaceful floating apart of participants and support services was reflected in Grace's calm explanation also ...

It just naturally died. I did have a little contact with this particularly nice woman who was in his last home. No, it just lapsed I suppose ... I'm still a member I've been organising collectors around the area for years and years and years, and just a year ago, [location] decided to have it organised differently. I was no longer - they do their own organisation. So I'm not expected to do it anymore.

Unlike other participants Alison had only been involved in supporting her sister-in-law during the final few years of her life. They had never co-habited. Still she experienced her more rapid and total separation from Maureen's 'other family' as a loss ...

I used to enjoy going around there, I used to do some baking and go around. I liked the other guys in the house. They're **very loveable**. I sort of have this vague idea that I might continue doing that, I think I basically decided. I wouldn't know quite what my role would be and I think the other thing that possibly - the **staff turnover**

Frances had received valuable developmental support during her short life. After her death Pam continued to envelop her own sense of mission for providing ongoing advocacy and promoting advantage for young people with Down syndrome ...

We also set up a formal Wellington Down Association. Wellington Down Association and the national group are still going strong today. I was still involved in getting the early intervention centre going and was on the board of trustees of that for many years ... I organised the Frances Clarke Memorial Awards ... We were told once 7 o'clock came we should all scatter, but, one of the girls sang a waiata and I think Sir Paul [the Governor General] was just moved to tears at how beautiful it was and how talented these people were so that legacy has been great. ... it's a very positive thing that a lot of people have gained a lot of pleasure. It's also highlighted in the community - that people with a disability can achieve.

How Dynamic is the Influence of Permeable Interaction?

One of the immediate outcomes of having a family member with an intellectual disability is an explosion in the amount of **Permeable Interaction** which occurs between that person's family and outside agencies. The relationship to one's own community is often reframed and unexpected connections with sub-groups are made. A pervading sense running across all participant accounts, and gleaned from their demeanour when speaking about involvement with others, was that of expert management of complex interfacing. Everyone interviewed seemed to have a capacity to float to another level once the person with an intellectual disability became terminally ill and further layers were placed on top. They were analytical and deft at assessing what was helpful. They held views about encounters which they experienced as regrettable. Their focus was not just inward but expansive. They regarded others, took a broad view of services and most of all were immeasurably grateful for those things which made a positive difference as they supported their loved one to negotiate challenging waters. Many 'outsiders' were drawn into the story of each voyage as participants recognised individuals and groups who had influenced the prevailing currents.

The last three chapters have portrayed the three themes which were hermeneutically interpreted to be lying within the lived experience of supporting a dying family member with an intellectual disability who was dying in a community setting. This is now supplemented by a chapter discussing these elucidated truths against a background of related literature.

Chapter Ten

Glimpsing the Boulders as Embedded on the River Floor

Introduction

This research project has been based on six individuals' recollections of supporting their family member who had an intellectual disability and was dying in a community setting. Its purpose was to hermeneutically reveal embedded phenomenological truths so that others could better understand what this lived experience had been like. Through engaging in intuitive, interpretative analysis three major themes and numerous sub-themes came into view. I reflected deeply on how each of these findings related to the broader context of the phenomenon. Eventually a strong impression arose that they should be expressed metaphorically as three 'groups of boulders' submerged under the river of lived experience. The groups of boulders were: **Interlocked Companionship**; **Search for New Balance** and **Permeable Interaction**. Using this lens I saw the boulders which formed the three groups as factors that exerted an influence on the surface water during the river voyage which had been recalled by participants. Holding this image facilitated inner contemplation on and outward description of these revealed truths. An incidental realisation was that currents were also surging in from the larger river which participants had previously been negotiating as they had sought to maximise life opportunities for a child or sibling who had an intellectual disability.

In order to transpose these findings into a credible contribution to nursing practice (Girard, 2006) and in adherence with phenomenological tradition and research methodology (van Manen, 2002e) a range of theoretical texts with potential to challenge or enlighten these analytical findings is now interwoven with the elucidated truths. This rhetorical discussion is designed to create open spaces where my writing and reading as the researcher can enact deeper exposure of findings (van Manen, 2006).

The topics to be covered include: an overview of some of the terminal disease processes which affect people with intellectual disabilities; an outline of some of the psycho-social and spiritual issues which arise when supporting a dying family member with an intellectual disability; identification of specific sociological contexts of intellectual disability which may influence palliative care delivery; comments on pertinent issues generally and specifically related to palliative care; intellectual disability support and

hospital services; and the assessment and management of symptoms. This chapter concludes by drawing together the research findings and the philosophical and theoretical positions presented as pre-suppositions in Chapter Four.

Discussion of Literature and Research Findings

Common Causes of Death among People with Intellectual Disabilities

Acute Myeloid Leukaemia and Down Syndrome

Two research participants had supported their young child with Down syndrome who had developed acute myeloid leukaemia (AML). I knew that leukaemia causes the deaths of a disproportionately high number of people with Down syndrome and so considered this to be a phenomenon contained within the broader phenomenon being explored in this thesis. On this basis literature about the connection between leukaemia and intellectual disability was sourced in order to inform discussion of the research findings.

Awareness of increased leukaemia rates among people with Down syndrome occurred in the 1950s. Hasle, Haunstrup Clemmensen and Mikkelsen (2000) cross referenced the Danish Cytogenic and Cancer Registers and in doing so revealed an 18 fold risk, with most leukaemia diagnoses being made among children with Down syndrome who were 2 months or less or between 12 and 42 months old. Diagnoses fell away by 4 years of age and the development of solid tumours among children and adults with Down syndrome was significantly less common than in the general population. These researchers suggest the increased presence of tumour suppressor genes linked to chromosome 21 may explain this.

In children with Down syndrome the ratio of AML to acute lymphoid leukaemia (ALL) is 7:1. In the general population ALL predominates 6:5. The participants in my study had both understood an implication of having AML is that it requires more aggressive treatment. When leukaemia occurs in children with Down syndrome it is particularly complex to diagnose (Hasle, Haunstrup Clemmensen, & Mikkelsen, 2000). This was reflected in Georgina's experience. Transient abnormal myelopoiesis occurring in these neonates may resolve spontaneously or be precursory to leukaemia. Thrombocytopenia and anaemia can present for several months prior to leukaemia developing and an increased rate of co-morbidities, such as congenital heart disease, may mask symptoms and be perceived as barriers to offering aggressive treatment (Craze, Harrison, Wheatley, Hann, &

Chessells, 1999). These researchers found that treating AML with standardised chemotherapy protocols produced the same or slightly higher remission rates in children with Down syndrome, compared to other children, and that intensive supportive care minimised any additional risks. It was noted that medical options for treating children with Down syndrome and leukaemia changed markedly during the 1980s. This is embodied within the divergent stories of Pam and Georgina whose children became unwell over a decade apart. The authors assert that further gains will occur as scientific knowledge of the nature of leukaemia associated with Down syndrome increases.

Down Syndrome and Alzheimer's Disease

I felt pleased that Dave and Alison had been participants as this had profiled the increasingly common situation of a middle aged person with Down syndrome dying of Alzheimer's disease. Longevity has increased significantly for people with Down syndrome over the past 50 years but sadly neurological degeneration, aligned with Alzheimer's disease, invariably develops as these adults reach their 40's (Webb & Rogers, 2002). Initial presentation is memory loss and gradual functional deterioration ensues, in distinct phases (Krasuski, Alexander, Hortwitz, Rapoport, & Schapiro, 2002). I concluded these facts demonstrated that Maureen's need for palliative care reinforced that this was a scenario which palliative care providers should become increasingly familiar with.

Pneumonia as a Terminal Event

Simon's intellectual disability was caused by a non-specific syndrome and his death was from pneumonia. Maureen was admitted onto the hospice programme after hospitalisation for pneumonia and this recurred in the days just prior to her death. During research recruitment I became anecdotally aware of respiratory events not uncommonly causing sudden, traumatic deaths among very frail people with intellectual disabilities. I was told about families who had experienced memories of witnessing their loved one receiving unsuccessful resuscitation in an emergency department as being excruciatingly painful. These stories often encompassed survival of numerous 'near misses'. Registered nurses from support services recalled the deep soul searching and frustration invoked by such events. They reported having appealed for palliative care involvement to prevent possible hospitalisation as they had observed physical decline but that this was denied due to the absence of an explicit terminal illness or event. On this basis I thought it was important to source some research evidence about the relationship between pneumonia and intellectual disability.

I found one study in which large numbers of death certificates had been retrospectively reviewed and it was found 52% of certificates cited pneumonia as the primary cause of death of people with intellectual disabilities. This rate was 30% higher than the general population (Hollins, Attard, von Fraunhofer, McGuigan, & Sedgwick, 1998). A recent systematic review of literature also indicated pulmonary conditions took a far greater toll than cancer did among this population group (Hogg, Northfield, & Turnbull, 2001).

Researchers Yang, Rasmussen and Friedman (2002) concluded that as they age people with Down syndrome are at increasing risk of dying from pneumonia arising from an aspiration event or as a secondary effect of influenza. Rates of aspiration pneumonia among people with Alzheimer's disease are increased if they are on neuroleptics as these drugs impede the swallowing reflex (Wada et al., 2001). Silent aspiration and resultant chronic lung disease have been demonstrated to be prevalent among very frail people with intellectual disabilities (Rogers et al., 1994). Other risk factors include being fed orally by another person and gastrostomy feeding causing gastric over-distention. Literature also confirmed Sandra's assertion that pathogenic organisms causing respiratory infections spread rapidly within residential facilities for these vulnerable people (Lohiya, Tan-Figueroa, & Kuhler, 2000).

After considering this literature I believed it substantiated the impression I had formed; that pneumonia is a terminal event commonly experienced by frail people with intellectual disabilities. This evidence confirmed palliative care services should expect to provide support to people with intellectual disabilities dying of both acute and chronic pulmonary infections while living in community settings.

Epilepsy

Seizures were a significant feature of Maureen and Simon's lives and impacted quite markedly during their final illnesses. Morrison (as cited in Bray, 2003) found that 21% of people with intellectual disabilities were affected by epilepsy. This rate is even higher among some subgroups who have particular syndromes (Alpman et al., 2005; Yang, Rasmussen, & Friedman, 2002). These statistics indicate the need for people with intellectual disabilities and the services caring for them to receive input from palliative care services to manage seizures in the last stage of life, especially if taking oral medications has become impossible. Recalling the ongoing trauma Sandra experiences as an outcome of her son having recurrent seizures during his last hours I fervently hope both sectors will collaborate increasingly when this distressing symptom needs to be managed.

Palliative Care For People With Intellectual Disabilities

Participants in my research recalled the majority of interactions with health and support services in a positive light. I have described this in Chapter Nine where **Permeable Interaction** has been profiled. Literature about major aspects which were raised will be considered in this section. I do so against a personal awareness of deficits to be overcome, balanced by recognition of the potential to build on gains which have already been achieved.

Hospice and Palliative Care Services

It has been claimed that people with intellectual disabilities have been marginalised in their dying, even by the modern hospice movement (Brown, Burns, & Flynn, 2003; McEnhill, 2006; Read, 2005; Todd, 2005; Todd & Blackman, 2005; Tuffery-Wijne, 2002) and this is borne out by the New Zealand Palliative Care Strategy's description of disparities (Minister of Health, 2001). The involvement of hospice/palliative care services is represented as being pivotal to ensuring people with intellectual disabilities die with comfort and dignity. Collaboration, care coordination and specialist education are seen to be urgent requirements (Botsford, 2004; Lindsay, 2005; McEnhill, 2006; Persuad, 2006; Read, 2005, 2006; Todd, 2004; Todd & Blackman, 2005; Tuffery-Wijne, Hollins, & Curfs, 2005). Palliative care services offering emotional support to support workers who are often deeply attached to residents and bereaved family members is also seen as highly desirable.

It is known that support workers and family members may initially resist hospice input, especially inpatient care, equating it with re-institutionalisation and the medical model which previously dominated disability services (Brown, Burns, & Flynn, 2003; Todd, 2004). Intellectual disability support services frequently struggle to accept that residents are dying because they have focused so strongly on restoring the right to live a normal life (Todd & Blackman, 2005). Residential support services can not be expected to have the same knowledge about the legal formalities attached to dying as hospice services do. Brown, Burns and Flynn (2003) recount how a staff member who had cared for a terminally ill woman was distressed that police came to view her body due to the fact that her regular doctor had not seen her for two weeks. This example correlates with the chilling experience which Sandra spoke of when her son, Simon, died. These accounts demonstrate a vital area where the knowledge and guidance of hospices can prevent avoidable trauma from occurring.

Support to Die at Home

There is increasing agreement that people with intellectual disabilities should be offered uncompromised support to die in their own homes (Cavanaugh, 2004; Todd, 2004). Often 'home' is a suburban house where a small group of people reside together. Despite high motivation by staff to keep caring for the person, a lack of personal resources can result in relocation (Botsford, 2004; Lindsay, 2005; McEnhill, 2006; Read, 1998, 2005; Saunders, 2005; Todd, 2004, 2005; Tuffery-Wijne, 2003).

In my research Grace stated she could not have cared for Matthew at home without responsive hospice homecare services. She appreciated Matthew having the flexibility to move between his home and the hospice, according to need. By providing exemplary contact and expertise in a domiciliary environment the paediatric oncology service had allowed Pam and Georgina similar freedom to decide the best place for their children to be at any point in time. In Simon's case the trust which administered his residential care purposefully employed a registered nurse with palliative care experience to supplement the skills of support workers. Sandra was sure this had been pivotal to enabling him to die at home. Dave and Alison felt they, Maureen, fellow residents and the support workers had all benefited immensely once the hospice moved in to offer 24 hour access to specialist nursing and medical care, equipment, education and a range of other benefits.

Grace had expressed concern that Matthew's indications of pain may not have been recognised by support residential workers and that even if it had been there were systemic barriers to the timely administration of Morphine. These were major reasons why she had taken him back to the family home. Palliative care education programmes for support workers are being increasingly developed in response to such systemic weaknesses and the need for greater collaboration between hospice and intellectual disability support services has been widely identified internationally (King, Janicki, Kissinger, & Lash, 2005; McEnhill, 2006; Read, 2005; Regnard, Mathews, Gibson, & Clarke, 2003; Todd, 2005; Tuffery-Wijne, 1997, 2003). Negative attitudes and fear arising from lack of knowledge about intellectual disability can limit the contribution of palliative care and primary health care professionals and education is proposed to be the solution to this deficit also (Giannini, 2004; Lindop & Read, 2000; Todd, 2005; Tuffery-Wijne, 1997, 2002, 2003; Tuffery-Wijne, Hollins, & Curfs, 2005). During the era of institutionalisation only nurses working in such settings received education about intellectual disabilities exclusively (Brown, Burns, & Flynn, 2003). Ng and Li (2003) suggest that including this knowledge

within current undergraduate programmes would alleviate future nursing reticence about providing palliative care to this population group.

Grace's other motivation for taking Matthew home had been to provide nurturing, a sentiment mirrored in the actions of parents described by Cavanaugh (2004). It is known that terminal illness provokes intense emotional reactions within families as members with intellectual disabilities are deeply cherished. It is vital that all services acknowledge and honour the decisions and feelings of families (Jacquemin, 2005; Tuffery-Wijne, 2002).

Simon and Maureen had both left hospital and then remained in their supported care facility until they died. Participant accounts of this were permeated by relief that familiar surroundings and people seemed to ease the process of dying. In both instances supplementary palliative care input was required. In Maureen's case a time-lag had occurred between exiting the hospital service and entering a hospice programme. This highlighted the critical importance of meticulous discharge planning. Research shows the wellbeing of people with dementia and an intellectual disability is threatened if they move to mainstream services for older adults. Knowledge about intellectual disability within such facilities is scant and relocation can expedite decline (Thompson, 2002). In the light of this it is interesting that Maureen's family suspected her earlier resettlement from the large institution had accelerated symptoms of dementia.

Participants exhibited noticeable joy when sharing how, when their loved one returned from hospital, flatmates had drifted in and out offering love and care. They painted a picture of this interaction continuing into involvement with funerals. It was felt this had offered multiple benefits to all parties. These scenarios contrast with traditional practices of excluding and 'protecting' this population group from death, dying and the entitlement to grieve (Hollins, 1995; Todd, 2002, 2004). This open approach can impose its own burdens and insightful care needs to be taken of surviving residents (Jacquemin, 2005). Following parental estrangement and death people with intellectual disabilities often fear no-one will remember them (Blackman, 2003; Todd, 2004). For the friends of Matthew, Simon and Maureen a potential benefit from involvement in their funerals was gaining reassurance that a deceased person doesn't just disappear from the world of others. Maureen's family experienced personal growth through being part of such inclusive situations as friends visiting her in hospital. Dave, Alison and Sandra were very mindful of the 'second family' and cared about their wellbeing as their own family member died openly among them.

Hospital Services

“So even though the persons with developmental disabilities are not confined to the basements of hospitals as they were in the 1950’s – they still may not get past the doors of those they need to see the most” (Giannini, 2004, p. 48).

Several participants referred to the times when their family member had received hospital care. Unconditional acceptance of their loved one, special efforts and the receipt of uncompromised treatment were all referred to. Interestingly participants’ expressions of gratitude were so emotionally charged it stirred in me a sense these were rebounding off knowledge of historical deficits. This was reinforced when deficiencies which had occurred were rationalised away. Stories about adult hospitalisations were suggestive of a misfit between the person and the environment. This was not evident when Endeavour’s and Frances’s paediatric hospital stays were recalled. Congressi (2006) claims burgeoning quality control management systems do not ensure a smooth passage through public hospitals and that ethical constraints make accessing true patient voice about this almost impossible. He cites medical services as being more problematic than surgical ones. Maureen and Simon both suffered from seizures and pneumonia. Medically treated conditions are prevalent causes of death among people with intellectual disabilities (Yang, Rasmussen, & Friedman, 2002). This leads me to contend that Congressi’s warning holds ominous relevance for this group of health consumers.

Reduced language skills and prior inexperience contribute to the vulnerability and fear that individuals with intellectual disabilities feel if admitted to hospital (ADVOCACY Health Group, 2005). Tuffery-Wijne (2002) urges that the full extent of community based palliative care resources be explored before moving a person to a hospital or hospice. Relocation to hospital may offer medical benefits but these must be balanced against the burden of social dislocation (Jacquemin, 2005). Simon and Maureen’s residential support workers tried to be continuously present with them at the hospital as hospital staff lacked the time and interpersonal relationship to provide reassurance. This is congruent with the picture painted by Brown, Burns and Flynn (2003). Endeavour’s family never left her side. Georgina was particularly touched by the nurses who learnt to use sign language. Such efforts are not always typical. The National Advisory Committee on Health and Disability (2003) asserted some health practitioners were incapable of adapting their communication style to match the needs of people with intellectual disabilities. The committee found these deficits in knowledge and effective two way communication

frequently lead to inadequate monitoring and management of symptoms by New Zealand tertiary and primary health care providers.

Symptom Assessment and Management

Symptom assessment and management are key components of quality palliative care but are complex in some groups, such as those with altered consciousness and children. Another layer is added when supporting a person with an intellectual disability who has impaired verbal and non-verbal communication and understanding. Intuitive interpretation of each person's idiosyncratic behaviours, physiological indicators and unique vocalisation offers the only cues to underlying physical, emotional or spiritual distress. For this reason knowing a person intimately is a prerequisite to controlling suffering effectively. Increasingly modified assessment tools leading to individualised action plans have been developed. Health professionals are urged to involve families and support workers in their use. Recording of baseline behaviours when the person is comfortable is integral to assessment. The tools aim to transpose implicit awareness into shared, explicit information and to promote support workers' confidence in acting on their instincts (Astor, 2001; Harper & Bell, 2006; Read, 1998; Regnard, Clarke, Gibson, & Matthews, 2006; Regnard, Mathews, Gibson, & Clarke, 2003; Tuffery-Wijne, 1997, 2002; Tuffery-Wijne, Hollins, & Curfs, 2005). Another suggested approach is for palliative care professionals to prescribe medications based on experience and awareness of norms (Brown, Burns, & Flynn, 2003). Read (1998) warns reduced pain sensitivity may be a complicating factor.

Grace valued her ability to interpret changes in Matthew's disposition. For example she intuitively understood Matthew's fury at having been poisoned, after he vomited, as his typical response to the intrusion of illness. Incidentally, I linked this with the finding that people with intellectual disabilities often believe illness is located outside their bodies and that its effects are transferred by direct contact with objects or other people (March, 1991). When Grace related the episode she exhibited sadness but not surprise. Generally she understood her son's behavioural patterns, although she was still perplexed at times about how to reach him and relieve his bewilderment. For Endeavour's parents, grappling to find meaning in their daughter's pain had been heart rending. That this was resolved and her death was so peaceful brought immense comfort, although remembering the period of uncontrolled suffering cast a lingering shadow in bereavement. Sandra was traumatised watching as Simon had recurrent and finally almost continual seizures during his last hours. These experiences demonstrate that optimal symptom relief is not only vital for the dying person but for the family who live on.

Psychological Social and Spiritual Issues

Chronic Sorrow

Two participants in my research were mothers of dying preschool children with Down syndrome and another two had supported an adult child through the terminal phase of their life. One of the latter group, Grace, had also cared for a much loved baby who had died from the same metabolic disorder which had caused Matthew's intellectual disability. Each of these people framed their experiences as 'loss on loss'. Their unique words were variations on a verbatim quote cited by Todd. *"All that pain from the day she was born 'til the day she died. I wouldn't want to be without it. I still want her back"* (2004, p. 14).

Mallow and Bechtel (1999) assert that parents of children with intellectual disabilities overwhelmingly express sorrow when they become aware of the diagnosis but then seek to relieve the intensified family pressure and meet their child's special needs through identifying supportive services and gathering information. These researchers outline how mothers frequently re-experience the initial intensity of sorrow, as it radiates to become chronic grief. Occurrence of new health crises can reactivate mothers' grief. This validates the observation that mothers in my research projected 'grief on grief'. Such grief may evolve into situational depression (Hobdell, 2004). Hobdell characterises chronic sorrow as cyclical and asserts that professionals should expect individual parents to respond to their child's disability uniquely.

Tonkin (2006) interviewed several New Zealand parents about their experiences of losing a child to cancer. This revealed the complexity of grief when a child dies and that anticipatory grief is extensive. I believe verbatim quotes by participants in my research indicate this occurs just as powerfully when the dying child has an intellectual disability. Other commonalities between statements made by Tonkin's contributors and my research participant accounts were comments about the varying way couples grieve, that witnessing the child suffering can make it harder for parents to come to terms with the child's death and a description of parental concern for peripheral individuals and community groups who had become involved.

Despite the presence of double thicknesses of grief within participants' experiences they also gave voice to a co-existent awareness of beauty. Georgina was patently reliving searing brokenness as she recalled Endeavour's terminal illness but intermingled with this

were joyful emotions such as the recollection of the life celebration party and the overwhelming peace which filled the house following Endeavour's death. This trend was also observed by Donnelly, Michael, and Donnelly (2006) and articulated as "*a paradox between grief and an ability to see the "loveliness" of the dying process*" (2006, p. 365). While immersed in data analysis I was constantly grappling to discover the name of the research project. Eventually it became patently clear the answer lay in this exquisite blending of grief and beauty which so pervasively stood out from the account given by each participant of their extraordinary voyage.

Perpetual Parenthood

People with intellectual disabilities increasingly maintain close relationship with their parents (Blackman, 2003). When these adult children remain at home perpetual parenthood occurs (Todd & Shearn, 1997). Statistics show mothers predominately survive fathers as sole parents. Concerns may arise over providing ongoing support and the prospect of their own death, especially as the adult child will probably live to become elderly themselves and siblings peruse independent lives (Todd, Shearn, Beyer, & Felce, 1993). There is scant research into unrelenting care-giving by mothers of people with intellectual disabilities (Militades & Pruchno, 2002). Essex (2002) found mothers feel closer to such adult children than fathers and that the demands of caring were generally outweighed by the joys of the relationship.

Grace highlighted this issue by recalling her efforts to pragmatically accept that her much loved son would now be pre-deceasing her. She tried to reason that his early death would avoid burdening his siblings and inferred her own ultimate death would no longer become 'motherly desertion'. Grace's countenance and words projected such feelings of extraordinary love and tenderness I could see that no matter 'who left first' it would have been deeply problematic. The death of any adult child has a diverse, severe and permanent effect on elderly people, particularly mothers. It occurs out of sequence with the accepted pattern of life and engenders a pervading dislocation of self (Cacace & Williamson, 1996; Fitzpatrick, 1998).

Grace had experienced much beyond the predictable in her lifetime. As we concluded our interview she handed me some information on a 'scrap' of paper. I later saw a poem on the reverse side. Grace subsequently confirmed the poem she had inadvertently handed me was deeply meaningful to her and gave permission for this information to be included in my thesis. I do so in the belief that the 'soul of the poem' speaks for Grace. It offers

supplementary insights into what it is like for her to have survived her adult son with an intellectual disability who died of cancer, against a backdrop of previous grievous losses.

Candles

**The days of our future stand in front of us
like a row of little lit candles –
golden, warm, and lively little candles.**

**The days past remain behind us,
a mournful line of extinguished candles;
the ones nearest are still smoking,
cold candles, melted, and bent.**

**I do not want to look at them; their form saddens me,
and it saddens me to recall their first light.
I look ahead at my lit candles.**

**I do not want to turn back, lest I see and shudder
at how fast the dark line lengthens,
at how fast the extinguished candles multiply.**

http://www.poetryconnection.net/poets/Constantine_P._Cavafy/2162

Partnerships, Bioethics and an Evolving Sociological Paradigm

“The professional literature abounds with slogans that people with disabilities should be encouraged to lead as normal a life as possible as long as it relates to employment, housing and leisure time activities. However when it comes to sexuality there is a tendency to evade the issue” (Katz, Shemesh, & Bizman, 2000, p. 109).

The participants who had supported Maureen and Matthew presented an acute awareness of the needs and suffering of their special partners. During the interviews these relationships were respected as private and disclosure of intimate details was avoided. That the hospice depicted these close relationships on the genogram, invited Matthew’s girlfriend to stay overnight and entered into ongoing dialogue with support workers about how James was responding to Maureen’s declining condition was highly valued by participants.

After searching several databases I concluded most literature on the sexuality of people with intellectual disabilities focuses on deviant behaviour or sexual abuse, with little

written about consenting adult relationships. This substantiates Todd's (2004) claim that the sexuality of people with intellectual disabilities is deeply disturbing to and therefore historically denied by society. This may arise from the view that their childhood state is permanent and it can result in the assumption that any sexuality that is exhibited will be a danger to others (Cambridge & McCarthy, 1997). Blackman (2003) explains society's refusal to acknowledge people with intellectual disabilities as sexual beings arises from the eugenics movement's pervasive legacy of seeking to free society of 'defective' individuals by incarcerating them in large, segregated, institutions, where they could not reproduce. This brought to mind how Dave and Alison were continuing to "reclaim" Maureen, even after her physical death. Organisations and self help groups now promote understanding about sexuality and the right to enter into informed, consenting relationships (Foundation For People With Learning Disabilities, 2005; IHC, 2006b; Watson, 2006) but disapproval and misunderstanding of such relationships remains widespread.

Screening for foetal chromosomal abnormalities through amniocentesis began in the 1960s. Now expectation that 'at risk' women will undergo the procedure between 15 and 22 weeks gestation is virtually automatic (Kubas, 1999). Blackman (2003) argues this compromises free choice and cites knowledge of incidents where British parents who declined testing and/or abortion were framed as being irresponsible. The issue of genetic screening was spontaneously spoken of during my research interviews. I respect the personal intensity of such decision making and suggest only those who have faced this anguishing dilemma can truly know the intensity of soul searching it arouses.

A New Zealand self advocacy group of adults with intellectual disabilities defends the right to be born (Watson, 2006). International bioethical debate is fuelled by medical advances demanding new judgements about what level of disability contraindicates life saving interventions (Antommara, 2006). People with disabilities desiring to select 'imperfect' embryos for implantation in order to have children like themselves and whether they are qualified to redefine 'normal' from their 'disabled perspective' has invoked fierce debate ("The perfect disabled baby", 2006). I suggest these points profile how underlying professional and societal attitudes could impact on the terminal care offered to people with intellectual disabilities. Literature confirms such deaths can be viewed as release from tragedy and that being regarded as socially dead diminishes the significance of physical death (Tait, 2004; Todd, 2004; Todd & Blackman, 2005).

One outcome of institutionalisation was isolation from mainstream health services (Persuad, 2006). Accordingly health professionals viewed delivery of equitable health care to people with intellectual disabilities to be outside their mandate (Webb & Rogers, 2002). Sandra's account of feeling she and Simon were sidelined during his numerous childhood hospital admissions highlights the on-flow effects of history. Remembering earlier unsatisfactory encounters impacted on Sandra during Simon's final hospital admission. Todd (2004) identifies this as a common pattern. Theoretically, New Zealanders with intellectual disabilities can now freely access medical services. However, there are ongoing barriers, particularly for Maori. These include a lack of medical review, extensive over prescribing and acceptance that poor health is synonymous with intellectual disability (Bray, 2003; National Advisory Committee on Health and Disability, 2003; Webb & Rogers, 2002).

Spiritual Support and the Power of Love

It is argued that nursing especially is involved in helping the patient, the elderly, the disabled, or the person who for reasons of circumstance is out of step with the body to recover a livable relation with his or her psycho-physical being (van Manen, 1994, p. 7).

I see palliative care as philosophically positioned to support dying individuals as they discover their own unique place of holistic healing and hope. A significant component of palliative intervention therefore occurs in the spiritual realm. A recurrent feature of research interviews was the emotional intensity with which affirming responses exhibited by health and support workers were remembered. This recalls encompassed stories of intuitive response, spontaneity of presence, going beyond the call of duty and soul connectedness displayed through explicit emotion. Some may regard such acts as unprofessional. Arman and Rehnsfeldt (2006) claim love is fundamental to ethical caring. They suggest when health professionals offer exceptional humanitarian kindness, transcendancy and transformation of situations occurs. I would argue the consistency with which participants accredited such personal caring with having provided relief from turmoil demonstrates that such actions are both therapeutically potent and ethical. Tanyi, Werner, Recine and Sperstad (2006) researched how women receiving haemodialysis experienced nurses providing spiritual support. Attributes highly valued in nurses were authentic caring and the nurturing of interpersonal relationship; in co-existence with technical competence. This further supports my contention that encapsulating personal

engagement into health care delivered to dying people with intellectual disabilities is both justified and clinically effective.

“... consciousness of death or severe suffering makes us more open to the essence of love. ... love constitutes in existential and ontological terms an opposite to death” (Arman & Rehnsfeldt, 2006, p. 5).

In a statement resonant of the concept of **Permeable Interaction** Tanyi, Werner, Recine and Sperstad (2006) state that existential spiritual needs can only be met if two-directional trust exists between giver and recipients of care. Arman and Rehnsfeldt (2006) contend that the giving and receiving of love is integral to human wellbeing. They see this as embodied within empowered nursing practice when love is referenced to an ontology based on ethics of care. These authors exhort nurses to overcome external barriers, including nursing's cultural tradition, so that instinctive whole hearted responses are offered.

This dynamic is validated by participants in my study presenting such interpersonal encounters as watershed events. This eased their burden and brought comfort. The loving acts most emotively recalled were those which portrayed a spirit of total acceptance of and exemplary care towards their family member. Support workers told Todd (2004) about the important role love played when caring for dying residents. He was told management often disapproved of this, failed to offer debriefing or counselling to staff despite their long-term relationship with the deceased person and engaged in hurtful, economically driven actions like rapid bed filling. Arman and Rehnsfeldt (2006) remark on a trend to re-label love in academic writing. This resonated with my own application of terms, such as empathy, advocacy and being present, within data analysis. I reflected on how the fibre of love had permeated through each participant's account of their relationship with their endangered family member. Arman and Rehnsfeldt call such human acts of reaching out with holistic assistance to another person who is suffering, natural care. In my research participants also spoke about receiving affectionate support from members of parental sub-groups, people within the 'intellectual disability world' and members of the general community.

I observed that 'relativity to other' had assumed deep significance as each person supported their dying loved one. One example was Grace's sense of ongoing anguish over whether wanting to maintain a vigil at her son's bedside equated with 'holding on to him'. As her words re-birthed her lived experience the depth of her dilemma was obvious. It

evidenced the duplicity of meaning held within words (van Manen, 2002f) and the hermeneutic influence exerted through what is absent or hidden within discourse (Gadamer, 1975). Naturally she wanted to 'hold on to', in the way of providing the maternal comfort so ingrained from a lifetime shared. To feel forced by others to pull away in his final hours could imaginably be excruciating; perceivably the painful separation of a young child being institutionalised, re-scripted. On the other hand she was anguished that to 'hold on to him' might mean her deep desire for intimate proximity may have impeded her son's physical death and soul journey.

I believe my research analysis indicates the relativity between each participant and their dying family member and between each of them and 'other' was finely balanced. Insight into how this relates to delivery of professional care is held within the concept of 'nurse as guide'. This term describes how nurses may develop sensitivity to subtle nuances exuding from a patient's inner being. Such attunement invokes a skilful knowing of how to create and 'move' within 'space', so intuitive guidance can nurture unification of the body and soul (Martin, 1994). This concept is further reflected in the conclusions of Donnelly, Michael, and Donnelly (2006) regarding the unique spaciality maintained by nurses present at a home death. They represent the nurse as both standing back and moving forward. The nurse 'holds out' their deep understanding and experiences of the dying process as an offering used to coach family members, while also sensitively 'holding back' in honour of the centrality of 'other' during this intimate, sacred time.

Perception of Death

Another dramatic feature of Grace's experiential account was the controversy over Matthew being told that death was approaching. Much is believed, written and debated in palliative care literature about the role and degree of disclosure. I suggest that, just as the mantra that grief occurs in a discrete sequence has been subjected to the pendulum's swing, stances on unreserved disclosure may move in waves of professional fashion. Being truthful is also an underlying principle within contemporary intellectual disability support services. Debating all facets of this issue is impossible but some ways in which intellectual disability influences death perception will be outlined. This will not provide rote answers as each person with an intellectual disability is unique. For instance, I wondered on hearing of James's decision to refrain from going near Maureen's coffin if it was because he was scared he may also die if he came into direct contact with it.

All human beings have an innate fear of death which is gradually addressed through gaining understanding based on exposure to it. For people with intellectual disabilities a culture of secrecy about death frequently derails this fear-alleviating mechanism. Understanding that aging and becoming permanently dead is the ultimate fate of all living things may not occur until late into this group's adulthood (Blackman, 2003; Hollins, 1995). Significant debate endures about the respective influence age, life experience and intellectual capacity play in forming an image of death and dying (Blackman, 2003). The way people with intellectual disabilities conceptualise death, who should tell them if they are dying and how they are best informed have been largely unexplored issues (Brown, Burns, & Flynn, 2003; Saunders, 2005; Todd, 2004). This is due to both a lack of research and the reluctance by others to talk openly about the topic with these people (Todd & Blackman, 2005).

When a person who is significant to an individual with an intellectual disability is dying honesty, direct involvement in the dying process and provision of opportunities to engage in non-verbal rituals and to access appropriate bereavement resources are pivotal to ongoing wellbeing (Hollins, 1995). King, Janicki, Kissinger and Lash (2005) echo these views and suggest that familiar images from nature may be utilised to provide ongoing education about death and related issues. These authors regard being included in the funeral of significant others as a basic right and inner need if the potential death of self and others is to be comprehended. Denying individuals exposure and support to make sense of what is happening in or around them, renders resolution of overwhelming feelings impossible (Read, 2006). Todd (2004) profiles death as the most enduring taboo connected with intellectual disability.

Consideration of these dynamics reveals the complexity of judging whether it was 'correct' to disclose Matthew's imminent death to him. Presumably it was believed it was his adult entitlement to know he was beginning to 'enter the dying phase' and awareness would help him understand what was happening. On the other hand his mother and others had struggled to explain the impact of his cancer to him, such as when he thought he had been sacked. Matthew had spoken on occasions about death and Grace was acutely mindful of his perception. For this reason she asked he not be given explicit information. Matthew believed you were buried by soil but could not comprehend that an altered state of existence preceded this. Therefore Grace found him lying terrified, waiting for the earth to come down on him.

Read (2006) profiled this inherently problematic issue. She presented a case study of a woman who had a phobia about illness and was dying of cancer in her residential setting. Best practice strategies proposed by Read include consulting with a counsellor familiar with the person, only giving information in direct response to it being sought and rephrasing any words known to distress that individual (unless they introduce the word themselves). Read explains sensitive information should only be provided by people intimately connected with the dying person. Tuffery-Wijne (2002) suggests palliative care services consult with intellectual disability services before breaking difficult news and points out resources such as illustrations and role playing may be required to supplement mere words. She also notes people with intellectual disabilities have acute spiritual awareness and probably often have an inherent knowledge when death is imminent (1997). Jacquemin (2005) points out dying people with intellectual disabilities appreciate their own space. It should be acknowledged they alone can come to terms with their situation however they perceive that to be.

Advocacy and Self-Determination

I see the ethical expectation that people with intellectual disabilities be empowered to exercise autonomy over their own health care decisions as closely related to truthfulness and disclosure. Person centred planning reflects restoration of a previously denied human right (Kingsbury, 2004). There was an overwhelming appreciation expressed by participants to being given honest diagnostic and prognostic advice about their loved one's medical condition. That this was not given directly to the dying person was regarded to be reasonable. However, sometimes the participant had conveyed an interpretation of such information to their family member.

Brown, Burns and Flynn (2003) remarked on the unclear mechanisms through which family members were often forced to make hasty judgments. They cited potential alienation of support workers when this occurred. Tuffery-Wijne (2002) describes relatives' understanding of entitlement for proxy medical decision making as generally poor. All participants in my research found themselves forced to make such decisions on treatment. I noticed these followed deep consideration of up to four reference points: "what my dying loved one would want"; "what I would want if it was me"; "what they (health professionals/other family members) say would be best" and "what has happened before". Entering into this role was never easy. For example while Sandra had no inner doubts about avoiding prolongation of Simon's life the weight of decision making reinforced her sense the police were casting her as a criminal.

Kingsbury (2004) argues that end of life decisions for people with intellectual disabilities should be referenced to an established, ethically justifiable decision making pathway. Ryan and McQuillan (2006) also assert that following an ethical framework can enlighten such decision making. This should involve consulting with family members, professional caregivers and close friends of the person with an intellectual disability. They are the people who love and understand the person's desires and inner needs best. Multiple parties, including when possible the person with an intellectual disability, entering into recurrent, pre-emptive dialogue about end of life wishes is seen to be advisable. Recording the outcomes of these discussions is a pivotal component to the end of life being experienced as holistic, dignified and congruent with their unique personhood, by people with intellectual disabilities. Hospice nurses also have an important role in eliciting and supporting personal choice regarding end of life care (McEnhill, 2006).

My understanding from listening to recollections of encountering such crossroads was that participants sought advice and reflected with other family members and health professionals. I question, however, whether offering more structured support, such as having an ethical decision making tool on hand may have provided greater assurance and ability to live with the knowledge that the very best had been done for the deceased loved one. The young doctor's tears provided Sandra with empathetic validation, deeper than words, when she decided to stop all intervention. I wonder if an ethics committee had been readily accessible to share decision making, as suggested by Lohiya, Tan-Figueroa and Kuhler (2000) whether Sandra's burden would have been lightened even further.

Keepsakes and Memories

A strong element within **Interlocked Companionship** was the careful placement and valuing of objects connected to the deceased family member. Riches and Dawson (1998) report that being consistently shown photographs and other tangible reminders of children, including preserved bedrooms, contributed warmth during their research among bereaved parents. In another similarity to my research, these authors report the story of the artefacts was commonly expanded further during 'off tape' conversations. Observations reported by Riches and Dawson support my impression that these keepsakes were important to, and symbolically positioned by participants with great care, according to an instinctive and acute awareness of the objects' specific emotional linkages.

It seemed photographs and other possessions acted as ‘props’, not in the sense of ‘needing a prop to maintain the past’ but as vehicles for transformation. Riches and Dawson (1998) confirm these sacred objects draw the memory of the child into the present and in that space reinterpretation of their life and death occurs. They explain that as different family members regard and utilise articles in unique ways they provide a focus for not only recall but for collective imagination of how the deceased child may exist in the present. This was particularly strongly portrayed in the interview I had with Georgina. Sandra, on the other hand reflected on how the present may be for Simon and considering he would have ‘suffered more’ brought his ‘happiest years’ before me, as we stood in the hallway looking at his photo.

The most poignant indicator I found of ‘symbolic placement’ was the deep lack of inner resolution about the final placement of each loved one’s body. As a bereaved sibling Dave assigned equal importance to Maureen’s photographs and ashes as the participants who were mothers. It was not possible to locate research pertaining to this specific circumstance. However I would argue there is powerful substantiating evidence within Dave and Alison’s expressions of how they perceive the scattering of Maureen’s ashes, and the presence of her photo in their home, will fuel their family’s ongoing “reclaiming” of Maureen.

Modern society often judges the close retention of children’s memories and memorabilia as a “*failure to let go*” (Riches & Dawson, 1998, p. 137). These researchers argue such behaviour actually reincorporates the child into the fullness of personal and family life and the domination of the terminal event dissipates. Some of their research participants reported feeling like deviants. This resonates, in a slightly different context, with the intense emotion underlying Grace’s account of her inner struggle with being told “you are holding on to him” as Matthew lay dying. It also has relevance to the legacies which participants recognise and enjoy as part of their current lives. Pam was passionate when explaining to me how the creation of the formal legacy in memory of Frances benefited young people with Down syndrome, following Frances’s death. Another grieving parent also describes the deep meaningfulness of such a formal legacy (Roth, 2001).

As Maureen and Simon were dying their friends and flatmates connected with them, physically and emotionally. Blackman (2003) affirms the importance of ensuring that people with intellectual disabilities can embrace the memories of those they have loved and lost. She asserts that possessing such photos and other memorabilia is essential for

normal, individualised grieving and resolution to occur and advises that if possession is declined it should be re-offered periodically. Blackman also relates how on special occasions sensual triggers, such as aromas, can powerfully reinforce to people with intellectual disabilities that someone significant is missing.

James laid out Maureen's pyjamas each evening while she was in hospital. Once she returned he entered her room freely and frequently, making sure she was still there. He held tightly onto her relatives' hands when they came to visit. I suggest James's actions represented displays of love, the cry of his heart as he struggled to maintain contact with Maureen and his distressed efforts to make meaning out of the disturbed sense of continuity pressing in on him. He and Maureen had spent almost their entire lives in an institutional setting. They left their familiar friends and workers and were purposefully resettled together. Dave and Alison remarked on constant staff turnover which deterred them from returning to the house more than once or twice. Despite sensitive, insightful inclusion in Maureen's illness and receiving post bereavement support James's emotional positioning in the face of such recurrent losses must be precarious. His experience is undoubtedly replicated among many New Zealanders who are living and aging with an intellectual disability.

Drifting Away from Support Services

A recurrent pattern in my research was that participants' initial visions of maintaining long-term relationships with residents and staff at the home where their loved one had resided evaporated. Causes were uncertainty of one's reframed context and the disappearance of staff who had known their loved one. This seemed to be gradually regarded as 'one of life's changes' rather than a deep ongoing loss. Bereaved parents in Todd's (2004) study had overwhelmingly experienced dislocation from residential and non-residential intellectual disability services as immediate, total, abandonment. I suggest that however it happens the possible effect of these multiple 'vanishing acts' on the friends of deceased people should not be disregarded.

Several participants in my study maintained administrative links to non-residential services. Grace co-ordinated public collections and Pam had multifaceted involvement in building resources for and community appreciation of young people with Down syndrome. Georgina felt enriched by ongoing involvement with the Child Cancer Foundation. These mothers took the depths of experience held within them and offered it back to others as a

gift. Alison told me how she still reads the newsletters of an intellectual disability support service with great interest.

The Researcher's Theoretical Pre-suppositions Revisited

I will now share how pretexts named in Chapter Four as pre-suppositions began rising up within research findings. Due to space constraints within the context of this document limited examples will be offered, although numerous other links presented themselves during the project.

When considering Viktor Frankl's (1985) assertions prior to beginning the research project I had wondered whether participants may speak about deriving ongoing meaning from the experience of supporting their loved one through their life and death. All participants exhibited this characteristic. For instance Pam spoke of how she still found attending the Frances Clarke Memorial Awards and seeing the wonderful accomplishments of today's young people with Down syndrome deeply moving. From "The Nursing Partnership" I had formulated ideas that the nature of partnerships between participants and their loved one and others involved in the situation would materialise within data. That two of the major themes identified within the lived experience are **Interlocked Companionship** and **Permeable Interaction** gives credence to these anticipatory assertions.

Newman's (1999) theorising was focused on how inner growth and transcendence to higher levels of consciousness arise through suffering and adversity. These dynamics were visible in many participant statements. Sandra spoke about how she thought nothing of fresh life challenges which others encountered as being extreme. Georgina was grateful she has become the person she is today through being Endeavour's mother, despite the many sadnesses which this had entailed.

The involvement of the heart and soul when care is given to another is a perspective upheld by Watson (2003). This element was embedded as a strong strand throughout the experiential memories which participants recounted. One point where it surfaced was in Grace's revelation about how she brought Matthew back into the family home so she and her husband could surround him with special love and care until his life ended. Watson also referred to how embracing 'bigger plans' invokes an enhanced inner connectedness which then allows even the power of death to be transcended. This image became

enlivened for me as Georgina spoke of the beautiful peace which filled the house as others came to visit Endeavour following her death.

This leads into the concept of “Continuing Bonds” (Klass, Silverman, & Nickman, 1996). The concept permeated the data powerfully. Sandra spoke of how she still loved to sit with her friend at work and talk about Simon. The role keepsakes played in sustaining ongoing relationship is another example. An additional angle on the connection between this theoretical stance and the research was that there was always a sense during interviews that a special unseen guest was infusing the recall of participants with whispered impressions.

Finally, while keeping the research findings in view I revisited the justifiability of profiling the perspectives of Thomas Moore (1992). My conclusion was that this had been sound judgment as all participants alluded to discovering pockets of mystery and wonder in the midst of such potentially chaotic experiences. Based on a contention of Moore’s I had questioned whether participants would depict their loved one moving into a place of social centrality during the final phase of their lives. This suspicion was borne out. I demonstrate this by re-introducing Alison’s description of Maureen returning home from hospital: **“all the other residents in the home were sort of wandering in and out of the room, coming and checking on her, ... , sort of giving her a pat. And she was like the queen, holding court;”**

When considering whether it was indeed necessary to include the earlier chapter portraying theoretical pretext which stood as pre-suppositions a resounding “yes” rises up from inside of me. They have undoubtedly come into play by colouring my intuitive interpretation of data. I acknowledge however that the ultimate judgment lies with the reader and not the writer of the thesis.

What has this Underwater Scan Achieved?

In this chapter I have re-cast my eye over revealed phenomenological truths identified within the research data. These truths have been metaphorically represented as groups of boulders lying on the floor of the ‘river of lived experience’. Each boulder group has been seen to create distinct currents, influencing the voyage of the research participants, as they have navigated the phenomenon of interest. These insights have been used to guide the flow of writing as phenomenological impressions have been clarified through referencing

to related, evidence based, literature. The discussion has been framed under the major headings: Causes of Death Among People with Intellectual Disabilities, Palliative Care for People With Intellectual Disabilities and Psychological Social and Spiritual Issues. The pretexts presented as pre-suppositions in Chapter Four have also been revisited and explanations given of how each one showed itself through data.

The strengths and limitations of this research project will now be addressed in Chapter Eleven. This will be achieved by using a framework of three headings: researcher; methodology; methods and findings.

Chapter Eleven

Strengths and Limitations of the Research Project

Introduction

The scope and depth of this research project have largely been defined by the expectations and limitations associated with it being a three paper Masters thesis. Satisfying methodological demands and meeting the research aims has been achieved by continually focusing on the research question “what is it like to support a family member with an intellectual disability who is dying in a community setting?” The primary data sources were verbatim transcripts of five open ended interviews in which six people recalled their unique lived experience. A reflexive journal and field notes provided secondary data which contributed to the intuiting of deeper meanings swirling beneath participants’ words and demeanours. Interpretive hermeneutic analysis continued until I was satisfied the reflexive moving back and forth between emerging phenomenological truths and collective and individual data sources was not shedding any more light on the “bow wash” (M. Martin, personal communication, September 23, 2006) which was coming up towards me. This process generated a cohesive sense of the whole as strong voices came through calling out answers to the research question.

Three chapters were written in order to lead readers through the themes and sub-themes elucidated from the data in this way. These were presented in symbolic imagery as groups of boulders. Phenomenological rhetoric created openings where outsiders could gaze upon this specific experience as others had lived it. A fresh literature search was then undertaken to locate theoretical and poetic manuscripts capable of shedding additional light on research findings. The literature and findings were crafted to form a critical, rhetorical discussion in Chapter Ten.

Professionally I am a nurse. This has determined how I have stood within the context of this research project. Drawing on the patterns of my practice has been a key resource which has enriched and informed my research journey. This particularly applies to utilisation of my own ingrained reflective style. One manifestation of this is the interactive manner in which strengths and limitations of the research project are articulated in this chapter. This reflects my inherent approach to evaluating any process or outcome through

contrasting. It is also congruent with the phenomenological concepts of writing in tension where for instance logic is embedded in rhetoric (van Manen, 1997; 2006) and phenomenological belief that what is present may be seen through what is absent (Gadamer, 1975). A cross section of strengths and weakness identifiable within this research project are now discussed under the headings; **Researcher, Methodology, Methods and Findings.**

Researcher

I acknowledge my status as a neophyte researcher but suggest this limitation has been somewhat compensated for by my hunger for exploring phenomenological methodology and methods. This led to information being gleaned from established researchers and undertaking extensive reading and writing focused on the research approach. I have also drawn poetry into my thinking, writing and personal research journey. This was motivated by a contention of Heidegger's, that releasing poetic power into hermeneutic phenomenological methodology is essential to attaining the ontological aim of exposing the life world, because all people are inherently poetic (Crotty, 1998). I noted that there is ongoing debate about the extent to which phenomenology, as a vehicle for conducting human science research, should be linked to its philosophical roots and the poetic and literary realms (van Manen, 1997). A pre-existing yearning fuelled my inner desire to explore and include poetry. Accordingly I integrated poetic elements into this thesis. However a lack of poetic mastery, combined with the total avoidance of use of literary sources, brings into question how closely the Heideggerian model has been adhered to. If eloquent familiarity with these outer spheres is regarded to be precursory to researchers conducting quality phenomenological enquiries, then my lack of in-depth knowledge could represent a methodological limitation.

Roberts and Taylor (1998) assert that to be credible, phenomenological nursing researchers must focus on a defined practice facet about which they are deeply knowledgeable and strongly interested. I have ten years experience as a hospice palliative care nurse working in a community setting. I have no training or professional history of working within the intellectual disability sector. However in the two years prior to commencing this research I sought to address this deficit by reading and networking to acquire second hand knowledge from others immersed in the 'intellectual disability world'. This process has continued. I now feel I have been undertaking self directed learning towards an imaginary 'post graduate certificate in intellectual disability support'. Admittedly my insights are practice based only in relationship to the overlap with palliative care provision and there is still

much to be learned and discovered. On the issue of interest, as raised by Roberts and Taylor, I have been passionate about pursuing the research topic. I envision it as a series of human faces - numerous Daseins (Heidegger, 2004a) held embodied within my own inner being - those I have cared for in practice and now the six people who have so generously been participants in my research. And most of all those they have loved and lost.

I believe the over-riding strengths I have brought to this research include a pre-existing comfort and competence with having in-depth conversations, often with virtual strangers, about sensitive topics. Through my daily work I have learned to listen actively to both the words of a person and my inner intuition, in order to interactively get to the crux of an issue. These abilities have allowed me to engage with the research process confidently and insightfully. I suggest the most important implication arising from this was that participants sensed they were safe. This led to them revealing the depths of their experiences quite freely.

Methodology, Methods and Findings

Van Manen (2006) cites the view of Heidegger that it is ill-considered to claim adherence to one discrete phenomenological research methodology, as in actuality no such thing exists. It could be taken from this statement that phenomenology's 'looseness' translates into this being an undemanding approach which offers an 'easy road' for novice researchers. Yet van Manen presents the paradoxical fact that the lack of external frameworks demands high levels of astute interpretation and creativity if credible outcomes are to be achieved. I endeavoured to channel diverse inner and external resources into producing a tactful phenomenological answer to the research question "what is it like to support a family member with an intellectual disability who is dying in a community setting?" Admittedly the research must be viewed as inherently weakened by being a 'first attempt' but I think there is also an 'upside' to this. It is freedom from conforming to previously well trodden methodological pathways and the temptation to regurgitate a modified version of old work. I had to honestly assess whether the research design and methodology were leading to illumination of the phenomenon as each step was taken. In fact I was forced to deviate to a unique analytical pathway and this has been fully recorded. What has eventuated is not held up as a smart model to follow but it does hold authentic freshness.

American phenomenology deviates from pure and hermeneutic forms. Researchers using such an approach need to appreciate its newness and limitations, promote its nature and

originality and demonstrate its links to phenomenological philosophy to defend credibility (Crotty, as cited in Beanland, et al., 2000). I read published nursing research articles extensively in order to gain a mind map of how my finished project may look. I have also sought to follow Heidegger's hermeneutic pathway but admit I lack astute understanding of where the various phenomenological boundaries lie. As these are often not explicitly defined by nursing researchers it is possible I may have drifted into a hybrid form of American phenomenological analysis, somewhat blindly, and then failed to provide sufficient acknowledgement of this. This would not nullify findings though as Read (2006) rigorously defends the value of all qualitative methodologies as a means of exploring issues related to palliative care for people with intellectual disabilities.

Analysis first occurred during the interview process. This felt effortless, like second nature. Entering into formalised data analysis was more difficult as it was unfamiliar territory. Pervasive nervousness and self-consciousness imposed a sense of 'feeling like a pretender'. I felt this weakened the integrity of initial analytical consistency by constraining access to intuitive awareness and affecting a leaning towards cognitive understanding. It may be conversely argued that this dynamic rebounded to strengthen final analysis, as it drove me deeper into extensive and painstaking reflexivity, in an effort to ensure total data saturation and hermeneutic analysis had been faithfully achieved.

Furthermore, analytical findings were externally verified as recommended by Burnard (1991). My academic supervisor was supplied with transcripts of all interviews immediately after they occurred. This allowed her to draw on her extensive research experience and academic knowledge to form an independent view of what essences had been revealed through participants' words and intonations. Later she physically moved around reading and reviewing the numerous sheets on which sections of transcript had been thematically organised. I saw the fact that she was familiar with my world view and interpretive slant as a potential two edged sword. The fact we were 'on the same wave length' facilitated honest, interactive discourse about the research findings. Perhaps someone less understanding of my approach may have introduced a greater degree of challenge. On balance I think our compatibility and openness was valuable as it permitted a palpable sense of agreement about the trustworthiness of findings to be generated. Member checking of the thematic analysis also occurred through discussing examples of my intuitive interpretation linked to specific verbatim statements with participants during follow up phone calls. Invariably this fortified my understanding and participants appeared to be enlivened by the realisation they had been truly 'heard'.

Stroebe (2003) posits the view that methodological triangulation, where qualitative inquiry is precursory to quantitative would produce more robust research evidence, but as already discussed such triangulation was not possible within the confines of the project. Stroebe also suggests that qualitative research among the bereaved could be strengthened by inclusion in the design of a non-bereaved control. This reveals a further limitation in this study as it was not replicated in interviews with people who had supported a dying family member without an intellectual disability. Even if this research design had incorporated such participant triangulation, universality of findings could still not be claimed as Stroebe also notes that qualitative approaches ascertain “*personally constructed realities*” rather than “*incontestable facts*” (2003, p. 238). This research therefore stands simply to be judged as a representation of the encountered reality of six participants regarding what it was like supporting their dying family member with an intellectual disability.

In terms of recruitment, the lack of follow up for people who declined involvement was a weakness which disturbed me. I felt accountable for creating an intrusion into their lives through precipitating the recruiter’s approach. I suggest one strength of the design was the specification that recruiters have a background of working within the health or disability support sectors. This meant they perceivably possessed the professional and personal skills to approach individuals competently. It was emphasised their role was simply to offer the opportunity to participate, based on informed choice, and that I did not presume they ‘would deliver’.

Another factor worthy of consideration is the strengths and weaknesses participant characteristics introduced to the research. My epistemological approach was to seek knowledge from people who ‘**had** lived the experience’. Accordingly all individuals offered participation were bereaved. Stroebe (2003) describes how bias can be problematic when attempting to recruit bereaved people for qualitative research. She suggests the most traumatised bereaved persons, or those most critical of institutional encounters, will be least likely to participate. It was brought to my notice by a recruiter that one person who declined involvement in my study fell into the second category and so it is likely the bias Stroebe identified skewed my own data collection process. I believe this was further reflected in the statements of several potential recruiters that “I know someone who would be fantastic for your research but they are still so angry/upset I wouldn’t like to ask them”.

Todd (2004) comments that there are certain sub-groups of people with intellectual disabilities who are at risk of being particularly invisible. In keeping with this assertion, Bray (2003) warns that New Zealanders with mild disabilities, including some who have become parents, often remain unidentified. Perceivably if a young mother in this situation became terminally ill the issues confronting those people supporting her would have areas of overlap and difference from those ones faced by my research participants, who all supported a person with a moderate or severe level of disability. I believe the strongest value will be derived from this study when professionals and services meet people encountering circumstances most closely correlated to those presented within participants' stories. Conversely, less understanding will be offered regarding what it is like to support people belonging to other sub-groups within the spectrum of intellectual disability. An example of this would be someone with a minor, and possibly unacknowledged intellectual disability, who has become a parent and is now dying.

The project was limited to accessing the insider perspectives of six people, in five interviews. Like all phenomenological studies, the totality of truth lies exclusively within the meaning each participant attributed to their unique situation. I would argue though that there was valuable representation of some diverse phenomena which others are likely to experience within the phenomenon of supporting a family member with an intellectual disability who is dying within a community setting. Four participants were mothers of varying ages, one a sibling and one a sister-in-law of the deceased person. Three of the family members who died had Down syndrome. This is the most common intellectual disability of genetic etiological origin (Bray, 2003). Two of these were children who died from AML and the other was an adult who had developed Alzheimer's disease. It may be claimed that because these are not uncommon scenarios for people with Down syndrome representedness was a strength of the study. Loved ones received care and died in diverse settings and the time spans over which this occurred were variable.

I am a 'middle class' New Zealand European and all the participants also belonged to these ethnic and demographic categories. The insights offered by the research must therefore be most strongly applicable within this context. As a nurse I operate as a human being who is culturally orientated. This means pre-programmed attitudes, practices and power dynamics are constantly casting an influence within my practice (Ramsden, 2000). Transferring that principle to my role as a researcher, I acknowledge a degree of 'cultural colouring' will have 'rippled through' the project as my innate cultural positioning has influenced the inter-subjectivity which had been part of the research process. This is confirmed by the

assertion of van Manen (2002a) that cultural difference is integral to how daily life is experienced. Although this researcher-participant correlation was not purposively created several participants openly articulated their recognition of this dynamic and stated that it made them feel relaxed. I came to see this was in one sense a research strength. It promoted extensive and comfortable disclosure, within a framework of mutuality and minimisation of power dynamics.

A major limitation imposed by the lack of participant diversity is the total absence of the voice of Maori within the data. This disappointed me as it is known the health and wellbeing of these indigenous people is marginalised within New Zealand's health system (King & Turia, 2002) and that by failing to operate in culturally appropriate ways palliative care and intellectual disability services have historically imposed marginalisation of Maori (Minister of Health, 2001; National Advisory Committee on Health and Disability, 2003). Crotty states that *"peoples' perspectives, beliefs and values differ from age to age and culture to culture"* (1998, p. 95). Van Manen (2002a) comments on how almost unperceivable culturally imposed assumptions colour every person's experiencing of life. I present these phenomenological viewpoints as additional acknowledgement that research conducted by and among people of one culture has diminished value among other groups.

How relevant literature should be situated in relationship to research findings is open to debate. Presenting findings and literature in discrete sections holds a greater sense of conformity to research protocol, while producing a less formal, composite presentation of findings and literature is however potentially more user friendly for professional consumers of research (Burnard, 1991). I have sought to straddle both benefits by endeavouring to style the discussion chapter so the research analysis is pulled through and 'twirled around' pertinent literature.

I made a decision to predominately engage in my own data searching, especially during the second phase which followed analysis. I recognise my rudimentary ability has compromised the full retrieval of all pertinent sources. For example, I have failed to include references to any Australian research, where the strongest sociological and service correlation with New Zealand probably lies, because I failed to enter the term developmental disability when key word searching. Conversely, through independent searching I have been able to appraise a vast range of electronic information and have channelled my evolving awareness of the diverse elements emerging from the research

topic into a pursuit of particular ‘angles’. These would have been difficult to fully articulate to a librarian and undoubtedly some twists and turns would have been missed.

Conclusion

This research project has been based on a hermeneutic phenomenological methodology. It may be suggested that a limitation arising from the utilisation of a phenomenological approach is that each interview is only one person’s perspective regarding the experience of supporting a family member who has died. This is balanced however by the achievement of textually thick data collection which offers rich insights into the inner world of a unique other. I suggest the study’s inherent strengths, limitations and overall quality must be measured against Heidegger’s epistemological goal of bringing Being into view through revealing the surrounding existential structures (as cited in Crotty, 1998). The strength of the presentation of the actual thesis is also important. Van Manen states: *“Qualitative writing may be seen as an active struggle for understanding and recognition of the lived meanings of the life world ... These words need to touch us, guide us, stir us”* (2006, p. 713). In this regard only you the reader can judge how strongly this document has been crafted as a piece of phenomenological text.

In this chapter I have surmised what strengths and weaknesses are inherent within the execution and outcomes of this research project. In Chapter Twelve the relevance which research findings hold for individual nurses and palliative care and intellectual disability support services is considered. Recommendations are also made for future research which may profitably augment this study. Finally, the general importance of the research project is reflected upon.

Chapter Twelve

Thesis Conclusion

Introduction

I entered into the role of neophyte researcher as a New Zealand hospice homecare nurse with pre-existing knowledge about how community palliative care services sit within the health care system. This included impressions of how such services perform when various members of our society become terminally ill. I now stand back and review the significance of the research and its findings with an enhanced understanding of what it is like supporting a family member with an intellectual disability who is dying in a community setting. This is because an additional lens has been gifted to me through the varied stories and insights of the research participants. In this context I have come to see that the core function of this study is to share with other health and support professionals what has been revealed about the insider perspective of the phenomenon explored.

I believe what has been revealed through participants' accounts of their lived experience has potential to impact in several ways. Consumers may be inspired to reflect on the phenomenon, nursing practice could be strengthened, guidance obtained for policy development and recommendations used to shape future research direction. These specific aspects are addressed in this chapter where information and recommendations are presented as bulleted points under headings and subheadings.

Through networking and undertaking diverse reading about the palliative care needs of people with intellectual disabilities I have accrued an awareness of the many practice and research deficits which exist in relationship to the phenomenon under consideration. However this knowledge gleaned from these external sources has now been laid aside. This means that although the suggestions made may resonate with the writing of other authors they are all derived directly from elements of participants' stories which informed my own research findings.

Reflective Inspiration

In my view the least predictable and subtle impact this research report may have is the inspiration to reflect on the phenomenon. This reflection may arise as health and support

professionals assimilate the interpretive intuitive strand ingrained at the core of the analytical process and reinforced textually. I realised this would be one research outcome while reading the following opinion of distinguished phenomenologist Hans-Georg Gadamer.

“The reproductive arts have this special quality that the works with which they are concerned are explicitly left open to this kind of re-creation and thus have visibly opened the identity and the continuity of the work of art towards its future” (Gadamer, 1975, p. 107).

In this quote Gadamer expresses how the life of a created piece of work is presented and received in a certain way in a moment of time. The observer takes from it a unique meaningfulness. On reading this statement I was convinced the concept was applicable to the analyses derived from my phenomenological research, including the textorium (textual space) (van Manen, 2006) within the written rhetoric. Presenting verbatim excerpts from transcripts and outlining the unique analytical pathway which evolved has avoided research findings simply being displayed as a constructed whole. On one level this thesis is indeed an open art form. Its pieces have been left laid out and made available for repeated deconstruction and reconstruction by those research consumers who choose to carry them forward on their own waves of reflection.

Guidance for Clinical Practice

I have stood as a researcher gazing into a metaphorical river as others alongside spoke of what it had been like navigating the river’s course with their dying family member who had an intellectual disability. While doing this the question “what makes a difference?” continuously stirred around inside me until factors influencing the phenomenon and key suggestions for strengthening nursing practice and guiding policy development became clear. Participants’ actions and words have provided challenges and answers which I now share in the hope others will consider them useful building blocks for practice. Some suggestions are uniformly applicable while others have more specific relevance to context: hospital, hospice inpatient, community palliative care or intellectual disability support services.

These recommendations are wide ranging. This is because, just as I ‘mined’ the participants’ stories for meaning (van Manen, 1990), I have finely sifted through the findings and discussion of findings in order to leave no stone unturned. Participants often

articulated their belief that by contributing to the research project they would make a positive difference for others who later navigated the same waters. For this reason I felt obligated to present the full range of clinical implications I perceived to arise from the data. It is not envisaged every recommendation will be acted upon by every professional or service provider reading this report. They are offered as a spectrum of possibilities worthy of consideration.

Factors Influencing the Phenomenon of Supporting a Family Member with an Intellectual Disability who is Dying in a Community Setting

One outcome of the data analysis was identification of sub-phenomena lying within the wider phenomenon being researched. These ran within and across participant accounts. The following statements profile these factors which were found to exert an influence on the phenomenon of supporting a dying family member with an intellectual disability.

- Palliative care is being delivered to people with intellectual disabilities against a background of historical marginalisation within mainstream health systems and general societal discrimination.
- Many older New Zealanders with intellectual disabilities spent much of their lives in institutions. They have undergone major relocations, suffered multiple losses and experienced considerable life enrichment as a result of deinstitutionalisation. For some their relationship with their whanau/ family of origin has not been restored. For others a process of rebuilding is still occurring.
- The emotional and spiritual bonds between a dying person with an intellectual disability and their parents and siblings are usually exceedingly powerful. People with intellectual disabilities are deeply cherished. The occurrence of a terminal illness/event and the death of a person with an intellectual disability are experienced by families as extremely painful events. They do not represent release from an 'abnormal lifestyle' but as grief on top of chronic sorrow which was mixed with enrichment and gratitude for the presence of this special person within the family.
- As well as deep sorrow people supporting a dying family member with an intellectual disability experience a co-existent awareness of beauty, as joyful emotions and peace are intermingled with periods of turmoil. This reflects the cyclical nature of chronic

sorrow which becomes a way of being for mothers in particular following the birth of a child who has an intellectual disability.

- When people with intellectual disabilities are ‘actively dying’ optimal symptom control (including seizure management) protects the ongoing wellbeing of surviving family members. This is because the depth of soul connection means witnessing perceived suffering during the last days of a loved one’s life has strong potential to impede the process of family members coming to terms with the person’s death.
- Family members supporting a dying person with an intellectual disability have generally faced many preceding challenges. They have highly developed resourcefulness, judgment and inner strength. They commonly draw support from groups in the wider community and also assume informal responsibility for monitoring the impact of the situation on others beyond the family. They have a strong awareness of where ‘the right place is’ for their loved one to be at certain points of their terminal illness. Inclusiveness, empowered decision making, ease of transition between home and in patient services and receiving clinically competent input regardless of setting all contribute to a sense of wellbeing and the ability of the main support people to transcend the difficulty of the situation.
- There are no rote answers about how individuals with an intellectual disability perceive illness and death but compromised cognition and a previous culture of secrecy about death often impede understanding of aging and death. Having phobias about these issues is not uncommon and insightful individualised consideration is required when offering information.
- Family members of people with intellectual disabilities who are dying in supported living situations value the opportunity to work collaboratively with service providers and the involvement of people with intellectual disabilities who are friends of their loved one. Families can experience personal growth and comfort through being part of these inclusive situations.
- Blood relatives have concern for ‘the second family’ who their loved one has lived with and is dying among. They are deeply reassured if cohesive support is provided for the workers and residents who make up this sub-group. This includes resourcing with knowledge, equipment, nursing and medical oversight and emotional support.

- The continued existence of deceased people with intellectual disabilities is important to their families, friends with intellectual disabilities and professional carers. Involvement in funerals, the possession of objects of remembrance, the creation of formal legacies, rejoicing in personal legacies and the placement of the loved one's body are all of strong significance.
- People who have supported a family member with an intellectual disability in living and dying often desire to maintain a meaningful connection with the intellectual disability support sector.

Recommendations for Practice and Policy Development

Palliative Care and Hospital Services

- Community based palliative care services should provide exemplary contact and 24 hour access to clinical expertise to maximise the possibility of the person dying at home.
- Palliative care education programmes for support workers should reinforce information on the use of appropriate symptom assessment tools and be supplemented by incidental 'on the spot' training and explanation being given to support workers during visits by palliative care nurses.
- Palliative care services and hospitals should address any underlying negative attitudes and fear among health professionals through providing education about how to care for people with intellectual disabilities.
- Health care services should develop communication resources which accommodate the altered manner in which people with intellectual disabilities often perceive illness and death. For example a modified information pamphlet about the role of hospices could be designed collaboratively with staff from an intellectual disability support service. (NB: In mid 2006 practitioners in the UK indicated to me no such pamphlet has been developed there.)
- Those working in palliative care services and hospitals should document individualised care plans about how to best communicate with dying patients with

an intellectual disability. Families and support workers should be consulted about this.

- When a dying person with an intellectual disability is an inpatient there should be staff consistency, high staffing levels and a quiet environment. Genuine acceptance of the individual is imperative.
- Discharge planning and liaison between families, hospitals, community palliative care services and intellectual disability support services when a terminally ill person is discharged from hospital should be meticulous. Discharge back into the community should be offered as soon as possible.
- Palliative care and hospital clinicians should ascertain if person-centred planning and conversations have previously indicated what is/would be considered important by the person when faced with certain choices arising from the terminal illness, and that these matters have been recorded. When family members are required to make major proxy decisions about treatment options clear mechanisms should be offered along with ethical frameworks and the availability of an ethics committee.
- Health professionals should be aware that people with intellectual disabilities have acute spiritual awareness and often have inherent knowledge that death is imminent. They should therefore be allowed quietness and their own space to come to terms with their inner sensitivities.
- People with intellectual disabilities have the right to truthful information but disclosure should be well considered. Palliative care and hospital services should consult intellectual disability services and families before breaking difficult news. They should be willing to use strategies such as pictorial books and role playing to supplement mere words (Tuffery-Wijne, 2002). They should only give information in direct response to it being sought; rephrase any words known to distress that individual – unless they introduce the word themselves; and ensure sensitive information is only provided by people intimately connected with the dying person (Read, 2006).
- The desire of family members to remain in close proximity to their dying loved one should be supported. Informing them openly throughout their loved one's terminal

illness empowers them. They feel the death acutely. They particularly need to receive supportive guidance during the last hours. The loved one's terminal symptoms being well controlled helps them in the post-bereavement phase.

- All health and support services should utilise adapted symptom assessment and management tools which detect distress and indicate clear action pathways.
- Palliative care services should be prepared for increased participation in the care of people with non-malignant terminal conditions or events.

Intellectual Disability Support Services

- Policies and worker skills should be developed by intellectual disability support services to facilitate the timely administration of non-regular prescribed medications (including narcotics) in order to relieve symptoms.
- Debriefing and counselling should be offered to support workers and surviving friends with intellectual disabilities when a resident is dying or has died. The long-term nature of relationships with the deceased person should be acknowledged and the value of personal engagement validated.
- The impact of losing one's actual or potential lifetime role as a perpetual parent and the powerful effect which the death of a young or adult child has on parents should not be minimised. Access to counselling services should be offered while recognising this parental group will often choose to rely on friends, family, their own inner resources and the passage of time to mediate their feelings of loss.
- Friends of the dying person who have intellectual disabilities themselves should be informed and included during all stages of the illness and in bereavement. Any person who is a special partner of the dying person should be validated as such.
- Counselling, the possession of photos and keepsakes, the opportunity to take part in funerals and rituals marking the person's life and death should be offered in acknowledgement of the loss and grief which is being experienced by surviving friends who have intellectual disabilities.

Directions for Future Research

Facing up to the dying of people with intellectual disabilities has been rigorously evaded by society because it epitomises human vulnerability and suffering to a degree that makes others shudder. As a result there has been a historical absence of research into the circumstances surrounding such deaths (Todd & Blackman, 2005; Tuffery-Wijne, 2003). While performing literature searches I discovered this has begun to change during the last decade. This project represents a small offering made by a neophyte, non-professional researcher which should be considered in the context of this slowly growing body of international knowledge. Although the research represents a 'drop in the bucket' the bucket remains virtually empty so that one drop could be regarded as disproportionately significant. The small scale of this research project means it has left much to be discovered about the phenomenon of providing such support to a family member and about related phenomena. Accordingly I now suggest how the study could be expanded upon and tested through future research.

- Re-inaction of this study on a larger scale and including control groups would increase trustworthiness. For example having one group of participants whose deceased family member had an intellectual disability and another group whose family member did not. Any commonalities and differences revealed would illuminate how the dying person having an intellectual disability impacts on the lived experience. This would act to affirm, challenge and supplement the picture of the lived experience which it is claimed this study has revealed.
- Purposive recruitment of fathers or others who had been pivotal to but not the main family member supporting a dying person with an intellectual disability would allow comparative experiences to be exposed.
- Purposive recruitment of Maori participants would open up a window on how this phenomenon is experienced by the Tangata Whenua of New Zealand. People for whom English was a second language were excluded from this research due to my inexperience but uncovering the perspectives of ethnic minorities and immigrants would increase generalisability of findings.
- Another interesting comparison would be to involve a group of parents whose child with an intellectual disability was non-verbal and a similar group whose child had

near normal language skills. There are many more variations which could be based on the research design.

- Designing further qualitative projects to expand knowledge about (sub)phenomena identified by this research would be profitable. These thematically identified (sub)phenomena include: how decision making occurs; what is the experience of providing care and companionship like from the perspective of support workers and friends and partners of dying people who themselves have an intellectual disability. Read (2005) contends that collaborative research is needed to support and evaluate practice innovation. Inter-organisational collaboration and the application of innovative qualitative research approaches, such as utilising art work to allow wordless expression of metaphysical elements (Clark, 2003), should realistically allow achievement of such imperative insights.
- The sole male participant chose to be interviewed with his wife. (Based on the methodological understanding I had formed through reading texts I saw this as deviating from accepted phenomenological methods.) I now suggest further exploration could clarify if couples ‘pivoting off each other’ leads to thicker data generation and examine the methodological repercussions of conducting tandem interviews.

NB: I underscore that the insider view revealed through the research question was not the experience of the dying family member with an intellectual disability. This perspective continues to cry out for research. Addressing this holds unique challenges as palliative care research even among the general population has a pattern of seeking proxy viewpoints from professionals or family members (Hopkinson, Wright, & Corner, 2005).

Dissemination of Findings

From the inception of this research project, I felt a strong commitment to producing credible findings, and making these available to health care professionals. My sense that this was an ethical obligation and moral imperative was potentiated by the faith participants expressed regarding my capacity to achieve these outcomes. Each one clearly articulated their hope that by sharing their inner world stories, as primary research data, they could help other people who subsequently experienced the same phenomenon. Some participants spoke of imagining how pleased their deceased family member would be, that

their life being recalled and shared about during interviews, could ultimately assist other people with intellectual disabilities who were dying.

At the time of completing this thesis, several palliative care and intellectual disability support services have suggested an overview of the study could be profitably presented to their staff. Additionally, the steering committee of the 9th Australian Palliative Care Conference has accepted an abstract of a poster presentation of the research, to be given in Melbourne on August 29th, 2007. It is also the intention of myself and my academic supervisor, Dr Margi Martin, to co-write a research paper for publication in academic journal(s) subscribed to by health professionals from the palliative care and intellectual disability support sectors. A bound hard copy and an electronic version of the thesis will be deposited within the Graduate School of Nursing Midwifery and Health, and Victoria University of Wellington Library. Hard copies will also be deposited in:

- New Zealand Nurses Organisation Library
- Te Omanga Hospice Library
- IHC Library
- Donald Beasley Institute Library

The research findings and recommendations will also be disseminated to the whanau support worker aligned with the project.

Why This Research Project Matters: Final Words

There are more than 23,000 adults and 13,000 children with intellectual disabilities living in New Zealand. The last remaining residential institution for people with intellectual disabilities was closed as this research project was being implemented (IHC, 2006a). This means New Zealand is amongst the countries that are leading deinstitutionalisation (C. Johns, personal communication, September 28, 2006). I felt this event symbolically reinforced the strong importance of revealing how the dying process of New Zealanders with intellectual disabilities living in community settings is experienced by their families. This view resonated with a New Zealand researcher's recent claim that: "*There is very little research available where people with intellectual disabilities and their families have been able to talk about their experience*" (McKechnie, 2006, p. 4). I considered her summation to be pertinent in relationship to my own study where a space had been created for families to speak about the experience of providing support when the focus moved from striving for normal living to seeking a good and normal death.

The motivation for conducting this research project originated from a recognition that my personal knowledge and the professional body of knowledge about the phenomenon of supporting a family member with an intellectual disability who was dying in a community setting were both sadly lacking. Since completing the research I have concluded its true value will ultimately be judged through answers to three questions. The first one, to be answered by participants, is “what are you pleased other people now know about your experience of supporting your family member with an intellectual disability who was dying in a community?” Answers to a second question will be generated as professional research consumers reflect on “what do I now understand better about what it is like for families to support a loved one with an intellectual disability who is dying in a community environment?” The final question which must be posed at the ‘coal face’ will not be answerable for some time. It is “what difference has this research made?”

Conclusion

The research question under girding this research project, “What is it like to support a family member with an intellectual disability who is dying in a community setting?” was essentially generated by challenging practice experiences. This project has sought to provide an answer through exploring the ‘inner world’ experiences of five individuals who have lived the phenomenon, in accordance with the research purpose. The first research aim was to release the voices of families/whanau who have provided such support. During post-interview discussions, each research participant indicated that they felt their perspective of what it had been like living through this experience, had been truly heard. Every effort has been made in the writing of this thesis to reproduce their voices faithfully. Another aim was to support the clinical practice of palliative care or intellectual disability sector health professionals who may care for dying people with intellectual disabilities. The final research aim was to identify any palliative care service gaps existing for members of this population group. The intention of this was to contribute to enhanced outcomes for dying people with intellectual disabilities and their families/whanau. Evidence that the research aims have been achieved exists in the recommendations for practice, policy development and future research, and implementation of dissemination.

In compiling this final chapter of the thesis I have discussed the significance of the research findings and the project itself. This began by reflecting on why it was initiated and how insights into the phenomenon of supporting a family member with an intellectual

disability who is dying in a community setting have been expanded through the inquiry process. It has been shown how the research findings may trigger reflection, enhance nursing practice, drive policy development and indicate future research direction. In conclusion a statement has been made about the overall importance of this project. The sentiments expressed in this can now be heard to echo in an epilogue. It has been written as a 'stream of consciousness' by a neophyte researcher looking back on the rich journey of exploring a delicate and special phenomenon.

Epilogue

I am only able to reflect on what has occurred through returning to where first seeds arose - in my heart. A desperate cry of “what is this like for **you** experiencing your death when you have an intellectual disability? How do **you** see things? Sensing and shuddering at the potential tarring of the same existential brush. I grappled for an anchor in my discomfort about the human vulnerability before me. In truth there is self-preservation at the foundation of every act.

The project was gifted form and strength by many key individuals: academics, philosophers, researchers, phenomenologists, poets, film makers and clinicians. The project involved time, commitment, true grit and at times sheer terror. Shouting “why did I go out onto this cliff face called recruitment?”

Then they came. Words generously flowed from innermost reservoirs. Not done lightly but trust opening the door. A holding out intermingled with occasional instantaneous reclamation. Tops briefly lifted off finely covered truths. Data flickering and merging and congealing into currents and swirls and flows. Sameness and difference of the parts and the whole. Attunement and tossing around and bearing the weight of entrustment. Pondering and imagining. The voices of participants whispering. Gently prodding the psyche. Returning to clarify. Determined to be a vessel of truth so those who had allowed me to hold their golden batons could see them held high as the burning torches of advocacy and revelation. To say “SEE this is a mosaic of what it is like.” Authenticity carved out to reveal interlocked embodiment during the final voyage, the grappling for balance and astute interaction with outer resources. Now all the messages have been laid out on the dry ground beside the river where practitioners, service providers and researchers can feel their texture and evaluate what is their worth as stepping stones of progress.

Warm living breathing people
Relentless givers of
Over and over
On and on love
Bearing the etchings of sadness and grief and confusion and **PEACE**
JOY HAPPINESS AND GRATITUDE for the unique pathway

The echoes of breaking
Weeping wounds - colourless tears
Impassioned powerful words
Fuelled by the hand of destiny

Searing experience
Tamed and befriended
Welcomed now as overwhelming enrichment
And so they lived
To find the furthest reaches of sweetness
Accessible only through bitterness
So bitterness itself had become non-existent
In their equation of life

There were journey tales
So twisted tight and knotted over and over
You all carried this treasure so deep within
Your very beings
And yet your generosity and grace was such
That you humbly reached inside - risking reawakened rawness
And drew out from your very hearts
The trodden footsteps
Even to gaze afresh - so together we saw
From our separate angles
Sometimes clambering the same boulder
Focused on how you lived through the
Brilliance of those darkest days

And you spoke of being pulled deep deep deep into the raggedness of humanity
The searching of innermost self and others and that beyond
And most of all that merged becomingness
With the jewel of your souls
That cradled one who will shine forever
Enlightening and whispering
And simply be there

**To Each Person Who Shared Their Deeply Personal Story: My Gratitude and
Respect Will Be Unending**

Appendix One

21 June 2006

Ms Susan Marlow
Victoria University of Wellington
136 Woburn Road
Lower Hutt

Dear Susan

CEN/06/06/044

THE LIVED EXPERIENCE OF SUPPORTING A FAMILY MEMBER WITH AN INTELLECTUAL DISABILITY WHO IS DYING IN A COMMUNITY SETTING: AN INTERPRETIVE ANALYSIS OF FAMILY MEMBER'S ACCOUNTS

Thank you for the above application which was considered by the Central Regional Ethics Committee at its meeting on 13 June 2006.

The study was approved subject to the following issues being addressed:

1. Page 9, B16 change wording to "the study will be terminated if 4 suitable participants cannot be recruited".
2. **Information Sheet (OSEC 2.2, 30)**
 - Amend approval statement to read "this study has been approved by the Central Regional Ethics Committee".
 - Inclusion Criteria, bullet point 2, reword, "the participant.....of supporting a family member.....disability who was terminally ill".
 - Inclusion Criteria, bullet point 3, change "3" to "6 months".
 - Exclusion Criteria "People who have been identified *by the recruiters* as having experienced....".
 - Include information that quotations from interview material may be used in publication.
 - Include information on what will happen to the audio-tapes at the end of the study.
 - Include statement regarding access to grief counsellor as per page 9, B12 of application form.
3. **Consent Form (OSEC 2.2)**
 - Remove "but this will only occur if I give specific consent to do so".
4. **Suggestions/Comments**
 - You could consider combining "invitation to participate/research information/supplementary information into one form and using question and answer format.
 - Suggest consent form would be improved by bulleted list of things participants are agreeing to with yes/no tick boxes for responses.

Please forward your response in letter format with amended information sheet/consent form to the Committee administrator. Your response will be reviewed by two committee members and if the above points have been addressed to their satisfaction, final ethical approval will be given by the Chairperson under delegated authority.

If you have any queries, please contact me Claire Yendoll
Yours sincerely

Appendix Two

13 July 2006

Susan Marlow
Te Omanga Hospice
136 Woburn Road
Lower Hutt

Dear Susan

CEN/06/06/044 – THE LIVED EXPERIENCE OF SUPPORTING A FAMILY MEMBER WITH AN INTELLECTUAL DISABILITY WHO IS DYING IN A COMMUNITY SETTING: AN INTERPRETIVE ANALYSIS OF FAMILY MEMBER'S ACCOUNTS

The above study has been given ethical approval by the **Central Regional Ethics Committee**.

Accreditation

The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, March 2002.

Progress Report

The study is approved until July 2008. The Committee will review the approved application annually and notify the Primary Investigator if it withdraws approval. It is the Primary Investigator's responsibility to forward a progress report covering all sites prior to ethical review of the project in July 2007. You will be sent a form requesting this information. Please note that failure to complete and return this form may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.

Amendments

It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Yours sincerely

Claire Yendoll
Central Ethics Committee Administrator

Email: claire_yendoll@moh.govt.nz

Appendix Three

06 December 2006

**Ms Susan Marlow
Te Omanga Hospice
136 Woburn Road
Lower Hutt**

Att: Ms Susan Marlow

Dear Susan

CEN/06/06/044 - The lived experience of supporting a family member with an intellectual disability who is dying in a community setting: An interpretive analysis of family member's accounts

Thank you for your e-mail of 27 November 2006 seeking approval to reveal the identity of one of the participants in your research on their request.

This request has been noted and approved by the Chairperson under delegated authority from the Central Regional Ethics Committee.

Thank you for seeking ethical advice on this matter.

Yours sincerely

Claire Yendoll
Central Ethics Committee Administrator

Appendix Four

TRANSCRIBER CONFIDENTIALITY AGREEMENT

I am the transcriber employed by researcher Susan Marlow for her research project: **The lived experience of supporting a family member with an intellectual disability who is dying in a community setting.**

In order to protect research participants I undertake to maintain full confidentiality and non-disclosure of details regarding the content of the interviews which I transcribe.

Transcriber's Signature:

Date:

Researcher's Signature:

Date:

Appendix Five

PROSPECTIVE RECRUITERS' INFORMATION SHEET

Thank you for being willing to approach a potential participant for the research project:

The lived experience of supporting a family member with an intellectual disability who is dying in a community setting.

This research has been approved by the Central Ethics Committee.

The aim of this project is to provide a greater understanding of the topic, through revealing the meanings individuals attribute to the experience of having provided such support to a family member.

The main method of achieving this is through conducting a 60 – 90 minute interview with individuals who meet the inclusion criteria.

Inclusion criteria

- *The participant is an adult*
- *The participant feels comfortable about the concept of the researcher conducting an in-depth interview about their experience of supporting family member with an intellectual disability who was terminally ill*
- *The participant's family member with an intellectual disability died between 6 months and 8 years ago*
- *The participant's family member had a recognised intellectually disability, anywhere on the continuum of severity*
- *The participant does not have specific risk factors which would increase the likelihood of them suffering psychological harm from the interview process*
- *The participant speaks English fluently and has no speech impediment*

Exclusion criteria

- *People who have been identified by the recruiters as having experienced complicated grief*

These interviews will be audio-taped and typed up by a transcriber. Analysing the content of the data will then lead to research findings which will be written up in a thesis form. Direct quotes may be lifted from the interviews and placed in the research report to demonstrate why a certain finding has been made. Audio-tapes, transcripts and the researcher's field notes will be stored in a safe and destroyed five years after the project is completed (or returned to the participant if they indicate this preference)

Researchers using research methodologies involving interviews find participants generally experience benefits from contributing to research, even when the topic being discussed is a sensitive one. Participants in this study will be provided with details of how they can access the services of a grief counsellor free of charge if they feel this is necessary in order to debrief from the interview process.

If they identify as Maori they will be consulted about how any cultural needs should be met.

Once the thesis has undergone academic assessment a copy will be deposited in the Victoria University of Wellington library. Further outcomes of the research may be the publication of an article in a professional journal and the presentation of conference papers

Recruitment Process

1. The researcher provides you (the prospective recruiter/ health worker) with a ***Prospective Recruiters' Information Sheet*** and ascertains through discussion that you can identify potential participant(s).
2. You (the prospective recruiter) agree to act as a recruiter and approach the potential participant(s).
3. If the potential participant(s) wishes to know more about participation you will provide them with a ***stamped envelope addressed to the researcher*** and an ***Expression of Interest Form***. You will also provide them with an ***Invitation to Prospective Research Participants Sheet*** (which describes the research).
4. On receipt of the ***Expression of Interest Form*** the researcher will telephone the potential participant and arrange a short meeting with them. At the meeting the researcher will answer any questions and provide a copy of the ***Proposed Interview Questions*** and a copy of the ***Informed Consent to Participate in Research Form*** to the participant.
5. If the person would like to participate an initial interview time and venue would be arranged, with the understanding that the participant may freely cancel this without penalty.
6. The researcher would discuss the research again with the participant **immediately prior to conducting the initial interview**. If the person decides to participate in the interview process they would be requested to sign the ***Informed Consent to Participate in Research Form***.

Signed:

Sue Marlow

Date:

Appendix Six

INVITATION TO PROSPECTIVE RESEARCH PARTICIPANTS SHEET

Hello my name is Sue Marlow. I am a registered nurse (with specialist palliative care qualifications) employed by Te Omanga Hospice as a home care nurse. I am completing a MA (Applied) degree in clinical nursing and am a Teaching Associate at the Graduate School of Nursing and Midwifery, Victoria University of Wellington. As a post graduate student I have chosen to undertake a research project exploring the meaning people give to the experience of supporting a terminally ill family member with an intellectual disability. I am writing to you at this time as it has been suggested that you may consider participating in this research project through sharing your unique story of supporting your family member. The official research project title is:

The lived experience of supporting a family member with an intellectual disability who is dying in a community setting.

I realise the story of your experience will be very personal and so offer below answers to questions you may have about the research process as you consider whether or not you would like to be involved.

What ethical safe guards are in place?

This research has been approved by the Central Regional Ethics Committee. Methods have been included in the research design which will ensure ethical standards are upheld, ensuring confidentiality and privacy through protection of your identity and safe data storage. For example, if you participate in the research a pseudonym of your choice will be used so you will not be identifiable within the research report. Direct quotes from the interview may be included in the research report to demonstrate why a finding was made. However, all such statements will be presented in a manner which is devoid of identifying features. No other person besides myself (the researcher), the transcriber and my academic supervisor (Dr Margaret Martin) will have access to the records of interviews.

Why is the research being done?

Until now research into the experience of supporting a terminally ill family member with an intellectual disability has been absent or rare. My concern about this current lack of research on the topic motivated my decision to explore this phenomenon. The aim of this project is to provide greater insight and knowledge which will assist health professionals to care sensitively for people with intellectual disabilities who are dying and to provide optimal support to members of their families and whanau. It is also perceived that the research will provide further direction for future research into the palliative care needs of people with intellectual disabilities.

How will interviews be conducted?

Conversational interviewing has been selected as the most suitable method for revealing the 'insider voice' of those who have supported a family member in this way. Between four and six people who know about this experience would be interviewed individually. If you do decide to participate I would interview you for between 60 and 90 minutes. My questioning would be minimal and designed to help you say the things which are important to you. You would be invited to express your unique story. At a second informal meeting I would ask you to clarify and confirm my understandings of what you said during the interview.

Interviews would be conducted in your own home, unless you preferred another venue. Our conversation would be audio-taped and then a transcriber would produce a written record from the audio-tape. At all times audio-tapes, transcripts and my own notes about the interview will be securely stored and finally destroyed five years after the study ends (unless you specify that they be returned to you).

How can my story provide knowledge so health professionals can better understand what it is like to support a terminally ill family member with an intellectual disability?

Themes discovered within the data (your story and those of other participants) will be used to create a picture of what the experience of supporting a family member is like. I will write up the research findings in thesis form. After academic assessment a copy of the thesis will be deposited in the Victoria University of Wellington library. (You will be offered a full or summarised copy of the research report.) It is hoped to also publish the research in a professional journal and present it at conferences. The aim of these activities would be to share the findings with other health providers.

What are my rights?

As a voluntary participant you may request specific interview content be deleted. You also have freedom to withdraw from the project, without question, at any time until the data analysis process commences. As already stated full confidentiality and anonymity will be ensured.

How will I be protected emotionally if I take part in the research?

It is acknowledged strong emotions may arise from recounting the experience of supporting a terminally ill family member with an intellectual disability. The researcher will be sensitive to this and the interview may be paused or ceased at your request. You may choose to keep speaking but with the tape recorder off. Researchers using research methodologies involving interviews find participants generally benefit from contributing to research, even when the topic is a sensitive one. If the interview process brings any emotions or issues to the surface which you would like to speak with a grief counsellor about then you may access this service free of charge by contacting:

Bereavement Counsellor

Address

Phone:

Ask to speak to a message may be left on her answer phone. The counsellor is fully informed about and has approved this research project.

What if I have concerns about the research process?

Health research participants are entitled to be accorded the rights contained in the "Code of Health and Disability Services Consumers' Rights" Right 9 relates to how you can expect the researcher to treat you. You should feel free to communicate any concerns arising from the research process to my academic supervisor. Any such communication will only be disclosed to me (the researcher) with your consent.

Contact Details:

Dr Margaret Martin
Graduate School of Nursing and Midwifery
Victoria University of Wellington
PO Box 600
Wellington

Phone: 04 463 6140

Free phone: 0800 108-005 (dial 1 for the operator)

Email: Margaret.Martin@vuw.ac.nz

What will happen if I express dissatisfaction with health services my family member received to you (the researcher)?

It is not a researcher's role to respond to any dissatisfaction with health services which may be disclosed to them. If you express complaints about services your family member received you will be advised to contact the health service(s) concerned and follow the designated Complaints Procedure of the organisation(s) which provided health services.

Alternatively you could contact a local advocate from the Health and Disability Commissioner's office to discuss the matter

Phone: 04 494 7900 or 0800 11 22 33

(Refer to the "Code of Health and Disability Services Consumers' Rights" pamphlet you have been given by the researcher)

What do I do now if I would like to take part in the research?

- Complete the *Expression of Interest Form* and return it to me in the stamped self addressed envelope provided

Then what happens?

- I will contact you by telephone on receipt of the *Expression of Interest Form*
- A brief meeting will be arranged so I can answer any further questions. If you choose to proceed you would be provided with a list of possible questions
- We would arrange an interview time and venue, with the understanding that you can choose to cancel or postpone this without providing an explanation
- Immediately before the first interview I would answer any further questions
- You would then be invited to sign the *Informed Consent to Participate in Research Form*
- You may seek ongoing information throughout the interviewing process

Thank you for taking the time to read about my proposed research project.

Yours sincerely,
Sue Marlow

Date:

Appendix Seven

EXPRESSION OF INTEREST FORM

I would like to be contacted by nurse researcher Sue Marlow to discuss my possible involvement in the research project:

The lived experience of supporting a family member with an intellectual disability who is dying in a community setting.

Telephone Number:

(Or other contact details):

.....

Name:

Signed:

Date:

Appendix Eight

INFORMED CONSENT TO PARTICIPATE IN RESEARCH

Project Title

The lived experience of supporting a family member with an intellectual disability who is dying in a community setting

Check List

- This research project has been fully explained to me and I know I can ask further questions at any time
Yes ☐ No ☐
- I know I can withdraw from the study without penalty until analysis has commenced
Yes ☐ No ☐
- I know I can ask that the interview be terminated, the tape recorder be turned off or that specific statements I have made be deleted from the interview records
Yes ☐ No ☐
- I know all audio-taped and written records of the interview will be stored in a safe and confidential manner
Yes ☐ No ☐
- I know the research design incorporates measures to ensure confidentiality and to protect my anonymity
Yes ☐ No ☐
- I know that the data I provide will only be used for this research project and for papers or presentations arising directly from it – unless I give specific written consent for the data to be used for another purpose or to be released to another party
Yes ☐ No ☐
- I agree to be interviewed about my experience of supporting my terminally ill family member who had an intellectual disability
Yes ☐ No ☐
- I agree to the interview being audio taped
Yes ☐ No ☐
- I agree to a transcriber producing a written record of the interview
Yes ☐ No ☐
- I agree to the researcher analysing my personal story to generate research findings

Yes ☐ No ☐

- I agree to direct quotes made by me during the interview being included in the research report in order to demonstrate why a finding was made (NB: This would be in an altered form which prevented my identity being revealed)

Yes ☐ No ☐

- I agree to the research findings derived from the interview being included in a thesis, published research articles and conference presentations

Yes ☐ No ☐

Preferences

- I would like the audio-tapes and transcripts of the interview to be destroyed by the researcher

Yes ☐ No ☐

- I would like the audio-tapes and transcripts of the interview to be returned to me

Yes ☐ No ☐

- I would like to receive a summary of the results of this research

Yes ☐ No ☐

- I would like to receive a complete version of the results of this research

Yes ☐ No ☐

Consent

I agree to be a participant in this research project

Yes ☐ No ☐

Name of Participant:

Signature Date

Name of Researcher

Signature: Date

Appendix Nine

INFORMED CONSENT TO DEVIATION FROM CONFIDENTIALITY AGREEMENT

Project Title

The lived experience of supporting a family member with an intellectual disability who is dying in a community setting

I agree the design of this research has incorporated measures to ensure confidentiality and to protect my anonymity in compliance with the terms of approval by the Central Ethics Committee. These measures were taken during the process of transcribing the interview which occurred between myself and the researcher.

I have requested my actual name and the actual names of my family members be reinserted as my husband and I are comfortable with our identify being revealed and feel this would enhance the authenticity of my personal account.

I continue to agree to direct quotes made by me during the interview being included in the research report in order to demonstrate why a finding was made (Knowing this would be in an *unaltered* form which allowed my *identity to be revealed*).

I continue to agree to the research findings derived from the interview being included in a thesis, published research articles and conference presentations

Name of Participant:

Signature Date

Name of Researcher

Signature: Date

Appendix Ten

14th April, 2006

Sue Marlow
Registered Nurse

Dear Sue

I am writing to confirm that I have been provided with a copy of your research proposal titled: **The lived experience of supporting a family member with an intellectual disability who is dying in a community setting.** I have also been given a copy of the Cultural and Social Responsibility section of your national application form.

Opportunities have been provided to discuss the proposed research with you in person and to seek answers to any questions I may have about my possible role.

After due consideration I freely undertake to provide any of the following services in relation to the research should such services be required:

- Provision of consultancy regarding Maori protocol as it applies to specific facets of the research process
- Liaison support through communicating with Iwi, whanau or individuals, as necessary
- Advocacy and support for any Maori research participants who may desire this
- Advise regarding dissipation of the research findings in a manner which is culturally appropriate to Maori

I also understand that if there are no Maori recruited as participants you will personally inform me of this. Even in this eventuality I know I will be provided with a summary of the research findings. This is because the proposed research has relevance for Maori.

Yours sincerely

Gala August
Whanau Support Worker

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