**THROUGH MOTHERS' EYES: THE LIVED EXPERIENCE OF CARING
FOR A CHILD WHO HAS UNDERGONE AND RECOVERED FROM A
LIVER TRANSPLANTATION**

by

Sandra Elisabeth Ebbeling Murphy

A thesis submitted to Victoria University of Wellington

in fulfilment of the

requirements for the degree of

Master of Nursing

Victoria University of Wellington

2008

ABSTRACT

Paediatric liver transplantation is a complicated and costly procedure. It also has the potential to be life-changing for the child and family. Paediatric liver transplantation commenced in New Zealand in July 2001. Approximately six to eight New Zealand children require liver transplantation annually. International survival rates of children receiving a liver transplant have increased in association with effective drug therapy and technological advances, though the children experience varying levels of wellbeing.

Children are discharged relatively quickly following their major surgery. Upon discharge the child is assessed to be well, exhibits satisfactory liver function and the social situation at home is assessed to be conducive to their ongoing care. On discharge the child remains under the spotlight of health care workers. Monitoring reduces as the child's condition improves. The child is only seen by health professionals in outpatient appointments or if admitted back to the ward. The close engagement in the hospital setting is untangled. The child, mother and family regain their autonomy. The long term implications of caring for a child recovering from a life-threatening condition to relative normalcy are largely unobserved.

Mothers, whose children had undergone a liver transplant more than one year ago at time of interview and whose children were outpatients of Starship Children's Hospital, were invited to participate in this research. Mothers are generally the most common primary caregiver of children. In caring for their transplanted child following recovery, mothers are relied upon to provide information about their child's wellbeing and functioning.

A Heideggerian hermeneutic phenomenological approach, informed by the work of van Manen (1990) was used. Three mothers of children who had received a liver transplant were interviewed to reveal the meanings of the phenomenon - what is the meaning of lived experience of mothers in caring for their child who has undergone and recovered following liver transplantation? Little previous study regarding mothers' lived experience of caring for their child, who had recovered from a liver transplant, was found in the literature.

The emerging themes were punctuated with stress being a consistent feature. Utilising Ruddick's (1983) concepts of maternal thinking, the emerging themes were merged within the three interests governing maternal practice; preservation, growth and acceptability. The absolute capacity for attentive love draws the experience together. An essential theme identified out of the analysis was the concept of survival relating to the unique features of liver transplantation and the consequences of liver rejection and failure.

The findings contribute to the understanding of the phenomenon, emphasising the need for good support systems for families of children who have undergone transplantation; assistance in the establishment of maternal coping strategies and regular feedback on the children's progress acknowledging the role and care provided by mothers. Health professionals might develop new understandings of the dynamic and evolving issues arising out of the provision of care by mothers. There may be a greater empathy and understanding of the experiences of mothers in their roles of caring. The findings provide glimpses of the life of children who have undergone and recovered from a liver transplant.

Key words: Life experiences, Child health services, Liver transplantation, Phenomenological approach

ACKNOWLEDGMENTS

In fulfilling the requirements for this thesis acknowledgments and thanks must be given to the following people. I am grateful to the participants of this study for their overwhelming generosity and willingness to spare their precious time and to allow me to understand their lived experiences through their stories. This research would not have been possible without their contribution.

I wish to acknowledge my primary research supervisor, Rose McEldowney, and previously Joy Bickley Asher who both nourished and guided my research journey through a sustained process of encouragement and enrichment through to completion of this thesis. I also wish to thank Margi Martin for providing ideas and opportunities to contribute to the finished thesis.

My family provided encouragement to achieve my goal and I thank them for their patience when I tried to explain what I was doing and their understanding when I wished for solitude. I also acknowledge my Alaskan Malamute canine companions; Nushka and Yukon who provided me with excuses to take time out to think and contemplate my ideas in the fresh air, being dutifully towed around behind them.

I also wish to thank my colleagues, both lecturers and students at the Post Graduate School of Nursing and Midwifery, Victoria University of Wellington, New Zealand. They listened to my ideas and posed questions that assisted me to strengthen my thesis. Special thanks to the Faculty of Humanities and Social Sciences for their research grant that assisted in meeting some of the costs incurred in undertaking this research.

Special thanks must also go to the Auckland District Health Board and the Starship Foundation for the generous research scholarship that not only provided financial support, but also institutional endorsement of my research topic. My employers and colleagues have given me so much support and encouragement, this is especially appreciated.

TABLE OF CONTENTS

ABSTRACT.....	ii
ACKNOWLEDGEMENTS.....	iv
TABLE OF CONTENTS.....	v
LIST OF TABLES.....	x
TEXTUAL GUIDE.....	xi
CHAPTER ONE: Coming to understand the lived experiences of mothers’ caring.....	1
The evolution of the research interest.....	1
Overview of the thesis.....	5
Background - the philosophical underpinnings of this study.....	5
The purpose of the study.....	7
Selection of hermeneutic phenomenology.....	7
The research question and aims.....	9
Justification for the study.....	11
Outline of the thesis.....	11
Summary.....	14
CHAPTER TWO: Understanding the current knowledge to investigate the mothers’ experiences of caring.....	15
The background to the topic of this research inquiry.....	16
Key terms.....	17
A starting point; knowledge of the topic of liver transplantation.....	18
Liver transplant history.....	18
Statistics.....	20
Organ donation.....	21
Cultural Factors.....	24
Paediatric Liver Transplantation.....	25
Research undertaken in the area of liver transplantation.....	27
Quality of life following transplant.....	28
The Child.....	30
How children know about the world.....	30
Children experiencing a chronic illness.....	32

Mothers.....	33
How mothers know about the world.....	33
Mothers caring.....	35
Managing the child with health problems.....	37
The Nurse as researcher.....	38
My pre-understanding and background.....	38
Phenomenology - the study of lived experience.....	39
Heideggerian hermeneutic phenomenology.....	40
Summary.....	41
CHAPTER THREE: The methodological journey for a phenomenological research approach.....	43
Starting the journey, selecting the path and staying on track.....	44
Phenomenology as a research methodology.....	45
Husserlian Eidectic Phenomenology.....	46
Heideggerian Hermeneutic Phenomenology.....	47
Max van Manen's structural framework.....	52
Summary.....	56
CHAPTER FOUR: Research design to investigate the lived experience of mothers' caring.....	57
Focus of the research inquiry.....	57
Qualitative research methods.....	58
A belief in multiple realities.....	59
Sampling.....	59
Recruitment of participants.....	60
Inclusion and exclusion criteria.....	61
Approaching the participants.....	63
Introducing the participants.....	64
Cultural safety.....	66

A commitment to identifying an approach to understanding that will support the phenomenon being studied.....	68
Interview process and methods of data collection.....	68
A commitment to the participants' point of view.....	69
Transcription of the women's voices.....	69
Collecting the women's stories; the research interviews.....	70
Data management.....	72
That the inquiry is conducted in a way that does not disturb the natural context of the phenomenon of interest.....	73
Ethical considerations.....	73
Acknowledged participation of the researcher.....	77
Reflectivity and reflexivity.....	78
By reporting the phenomenon in a literary style rich with participant commentary.....	78
Writing.....	78
Trustworthiness, credibility and rigour.....	79
Working with the data.....	81
Summary.....	84
CHAPTER FIVE: Coming to understand the mothers' lived experiences of caring.....	85
Process for data analysis.....	85
Hermeneutic phenomenological reflection in action.....	86
Working with van Manen's procedural actions.....	89
Hermeneutic phenomenological writing.....	93
Summary.....	94
CHAPTER SIX: Interpretation and discussion of the emerging themes.....	95
Hermeneutic Phenomenological Reflection and Interpretation.....	96

Emergent themes.....	97
Being a stressed mother.....	98
Mothers knowing – “taking it all in”.....	100
Mothers caring for their “sick” children.....	105
Being vigilant	109
Holding on and letting go - Trusting others and sharing the care.....	111
Achieving normality and everydayness.....	115
Being part of a family.....	119
Being part of a wider community.....	122
Being the holder of memories.....	124
Being relieved and being able to plan for a future.....	125
Valuing the unique mother/child/liver identity.....	127
Maternal thinking – Emerging themes.....	128
The interest in preserving the life of the child.....	129
The interest in fostering the child’s growth.....	131
The interest in shaping an acceptable child.....	131
Linking maternal thinking to the emerging themes.....	133
Capacity for attentive love.....	133
Essential themes.....	134
Summary.....	135
CHAPTER 7: Discussion and conclusions arising from the inquiry.....	137
Revisiting the experience of engaging in the lifeworld of the mothers.....	138
Maternal thinking.....	139
Reflections	139
The participant perspectives.....	140
Insights into my experience.....	140

The limitations of the study.....	140
Opportunities for improvement.....	142
Review of the research aims.....	142
Recommendations for health service provision.....	144
Potential contributions of this research inquiry.....	146
Research opportunities.....	147
Concluding statement.....	148
 LIST OF APPENDICES:	 149
Appendix I Copy of Ethics Approval.....	150
Appendix II Participant Response Form.....	152
Appendix III Participant Consent Form.....	153
Appendix IV Information Sheet for Participants.....	155
Appendix V Sample questions.....	158
 REFERENCES	 159

LIST OF TABLES

	Title	Page
Table 1	Introducing the participants	65
Table 2	Example of a coded transcript	82
Table 3	Working with the emerging themes	129

TEXTUAL GUIDE

This textual guide has been developed to assist in the recognition of the voice used in the dialogue, unfolding as this research is read. This is consistent with hermeneutic writing.

The main body of the text and representing my words is presented in Times New Roman size 12 font.

The voices of authors of other published works are represented in the text in three different ways. A direct quote as several words within a sentence is presented in the “same font” surrounded by speech marks and is referenced accordingly. If the text quoted is more than a few words, it is:

Indented, single spaced and presented in italicised Times New Roman font (with the referenced in brackets).

Where I have outlined lists of characteristics, principles or an author’s framework, this is written in:

Arial bold italics font 12

This is accompanied by an explanation in relation to my inquiry.

The voices of the participants are presented throughout the text to support the inquiry.

The women’s voices are presented as narrative texts or interview transcripts

Malandra GD italics with font 10 and presented in one and a half spacing. Each of the participant voices is recorded with the pseudonym of each participant and an indication whether it is a narrative text or an interview transcript.

Entries from my personal journal are provided, these are presented in

Arial, italics, font 12

The purpose of the textual guide is like the holiday map with its symbols and signs that help to ensure that the holiday journey is smooth, uncomplicated and that the traveller does not get lost.

CHAPTER ONE – COMING TO UNDERSTANDING THE EXPERIENCES OF MOTHERS OF CARING

Liver transplantation is recognised in the health system as a standard treatment for liver failure in the western world of medicine; as it demonstrates a role in grasping back loved ones who face certain death. This is a thesis which positions the ability of the health system to save life which is a noble goal alongside the strong bonds that tie a mother and her child which are generally considered unbreakable and constant.

This chapter begins with a description of how the research interest evolved around the experience of paediatric liver transplantation and the links with the research philosophy. The statements of purpose of the study are outlined. The research question is stated with a discussion about how the question was formulated. Four research aims are presented for achievement in the course of the research process. The justification for the topic in the light of current knowledge in this area is included.

The chapter concludes with an overview of each chapter covered within this thesis. The contents of each chapter are summarised to highlight the progress of the thesis from beginning to conclusion.

The evolution of the research interest

The idea for this research has been developed through my professional experiences as a paediatric nurse for more than twenty-five years, providing and supervising nursing care to children with a wide variety of health problems. Understanding the complexity of caring for a sick child and the influences upon families and caregivers has been a particular personal interest. There have been many comings, goings and passing away of many children with various conditions. The care of children and their families experiencing liver failure and undergoing liver transplantation occurs in my work setting. Children experiencing transplantation surgery and their families are faced with a multitude of challenges that transcend across ethical, philosophical and social arenas.

Many new and inspiring interventions that save lives and reduce suffering have been developed.

Children with chronic liver failure are a particularly sick population with deranged liver function tests accompanied by yellow skin, yellow eyes, and malnourished bodies with swollen abdomens. One could be forgiven for thinking that they looked like starving Third World children. The following excerpt is transcribed from my personal journal that I kept during the course of my study. It highlights the fragility of the child in liver failure;

The child lay in her cot. Her abdomen was swollen and shiny. Blood vessels ran prominently across the wide divide of her girth. Her skin was yellow and even the whites of her eyes could not be described as such. She was listless and miserable. It took little to disturb her. Her breathing was shallow and quick as her diaphragm was pushed against by her swollen belly. Beside her bed sat her mother... watchful ... waiting. Life stood still. While every day life went on around her, life was on hold. A future was beyond contemplation, beyond imagination. She maintained a vigil. Every little change was noted and conscientiously reported to the nursing and medical staff. It would take so little to push this little child over the edge.

(Excerpt from researcher's personal journal, 2003)

Up until 2001, children with liver conditions were managed supportively by Starship Children's Hospital, in Auckland, New Zealand, or their local District Hospital. When the child reached a particular stage where the liver began to fail and it was apparent that survival depended on a liver transplant, transfer to the Queensland Liver Transplant Service in Brisbane, Australia was organised. Once officially accepted by the Queensland Paediatric Liver Transplant Service, the child and family were whisked across the Tasman Sea for assessment and work up for liver transplantation. Sometimes there was little time for families to sort out their affairs prior to departure. The sick child and their family literally disappeared. The long preoperative and postoperative periods went unseen by the paediatric team at Starship Children's Hospital (known as Starship hereafter). The child and family remained in Brisbane for a period ranging

from 14-71 weeks, a median of 24 weeks following transplantation depending on whether complications occurred (Wilde, Chin, Johnston, McCall, Munn, Nixon, Wesley, Young & Evans, 2007). Upon return to New Zealand, the children were generally well enough to be monitored and managed as outpatients. There was a perception that there was a potential to miss care requirements and a need to provide support in the transition to home for these families during this time.

When the contract for paediatric liver transplantation service in New Zealand was awarded to the New Zealand Liver Transplant Unit based at Starship in 2001 it was met with enthusiasm. In 2001, I travelled to Kings College Hospital in London, England to learn about paediatric liver transplantation and to assist in preparing the nursing team to commence the service at Starship. A large number of children were observed undergoing and recovering from transplantation. Issues arising were highlighted and the transplantation process was observed at first hand. The needs of these children and their families were uncovered. The importance of a high standard of care and support, both pre and post operatively and after discharge from hospital, were emphasised. The following excerpt is taken from my personal journal and highlights the magnitude of the liver transplantation process;

A whole ward is set aside at Kings College Hospital (London) to manage children with liver problems. The needs of this patient group are much more evident when they are all grouped together. There are children from all over the UK, Europe including Mediterranean and Middle Eastern countries. Liver transplantation is routine care. The staff's willingness to share their experiences and resources with our service is gratifying.
(Excerpt from researcher's personal journal, Sept 2001)

Between 1 January 2002 and 1 November 2006, twenty eight children have undergone liver transplantation at Starship (Wilde, et al, 2007). The shortage of donor organs and the subsequent lengthy waiting times has been a general source of anxiety, frustration and desperation. The level of anxiety experienced by families and caregivers is immense (Butler Simon & Smith, 1992; LoBiondo-Wood, Bernier-Henn, & Williams, 1992). The complexity and fragility of the children in advancing liver failure cannot be over emphasised. Their survival is a test for the skills of health care professionals.

It is disheartening to know that liver donors are scarce, especially when a partial liver transplantation from a live relative might not be an option.

There was a recent article in March 2008 in the New Zealand Herald. It concerns the dilemma faced by a young mother who wants to give her own daughter part of her own liver. The story continues that she couldn't donate as she was under the live donor age criteria. A subsequent decision has been reached that will allow her to be a donor for her daughter. This has been met with much relief by the mother and her family.

(Excerpt from researcher's personal journal, March 2008)

Occasionally families feel driven to talk to the media to highlight the problem. The stories open the doors to the public of the world of families' lives where they are caring for a sick child. The exposure can be incredibly stressful or empowering. Families state that they hope that through greater awareness, the issue of organ donation may be raised in everyday life, allowing the opportunity for a loved one to donate in accordance with their last wishes and benefit the waiting families. The public perception of organ donation undoubtedly benefits from the sharing of these stories. Through sharing the stories of the mothers of paediatric transplant recipients, there might be increased awareness. As Brenda (one of the participants shared),

*We just hoped and prayed that Betty would get a liver in time,
It was just so hard to know we were so close and yet so far away...
Brenda (interview transcript)*

In this study there were three participants who shared their stories. They are all mothers of children who have undergone and recovered from a liver transplant. I have given the participants pseudonyms; Anne, Brenda and Cara. Their children have also been given a pseudonym; Alex, Betty and Chloe. Further details of these participants are provided in Chapter 4.

By examining the phenomenon of the mother's caring for their child in a caring and attentive manner, an opportunity to increase understanding of life following a liver

transplant and generally raise awareness of the gift of liver donation and the opportunity for a second chance at life was visualised.

Overview of the thesis

This research inquiry was undertaken using a Heideggerian hermeneutic phenomenological methodology informed by van Manen's structural framework to guide the inquiry. Rather than undertaking the research in a regimented step by step manner, the researcher performed the inquiry using a circular process that occurs in relation to hermeneutic phenomenology. To capture and express this interpretive process the text at times seems to be slightly repetitive. Each time the data was engaged with there was an intense level of interaction. Then in stepping out of the hermeneutic circle there is movement in the overall analysis and interpretation. Although it would appear that the process is repetitive and that the same ground is covered, that back and forth movement occurs as more and more of the bigger picture is revealed. In the process, the circle begins to swing towards the world of the mothers and the reader is taken into the work world of transplanting children alongside their mothers, the main carers. The mothers experience then begins to be revealed as the layers are removed and their world is uncovered. Each time their world is entered the interpretation goes deeper. The full circle of the hermeneutic process demonstrates the classical approach of using hermeneutic phenomenology.

Background - the philosophical underpinnings of this study

Working in the field of paediatric nursing has contributed to my knowledge and skills in the provision of care to children with health needs. This provided the opportunity to observe the process of paediatric liver transplantation at the coal face. The role of mothers is also evident. The following excerpt from my personal journal provides a glimpse from within the hospital setting:

It is time for the clinical ward round; it is 6 days since the child received a liver transplant. A score of health professionals diligently enter the room to observe the progress of the child and to plan the way forward. It is as if the

court session has commenced – the mother stands at the head of the bed nearest to the child. Questions are directed towards the mum initially. The mother proceeds to interrogate the team for their perceptions, blood results and any other news that can be digested. It is her turn to ask the questions. Throughout this encounter, the mother is there.
(Excerpt from researchers personal journal, May 2004)

Working mainly within the hospital setting, provided me with a depth of understanding of the stressors and care processes surrounding care of the sick child in the inpatient setting. The experience of care in the community is less visible. The experience of health across the life course extends from diagnosis to treatment and eventual return to health and normalcy in children's lives.

Involvement in the lives of children and their families facing health challenges is valued. The physical, emotional and social effects of illness is observed and support measures and good communication are implemented to enhance care processes that lead to the child and family gaining well being. This research inquiry focused on the mothers of children who had undergone a liver transplant. A greater understanding of what life was like for mothers in caring for their children who had recovered from transplantation was desired.

Through hearing the stories of life and wellbeing away from the hospital, it was anticipated that a greater understanding of the phenomenon would emerge. It was this perspective that contributed to the selection of hermeneutic phenomenology as the research methodology, in coming to understand the meaning of the lived experience of mothers in caring for their children following recovery from liver transplantation. In using an ontological focus – that is, a focus on the meaning of the lived experience - it was apparent that hermeneutic or interpretive phenomenology would facilitate the inquiry. This intention is discussed in more detail in Chapter Three.

The purpose of the study

There is little research into the lived experiences of children and their families following recovery from liver transplantation in New Zealand. The purpose of this study was to explore the lived experiences of mothers in caring for their children following recovery. It was proposed that the insights gained would provide meanings that highlight the mothers' experiences and call attention to the child's re-engagement with activities of every day life. An excerpt from my personal journal highlights an early observation of a mother following her child's liver transplant;

I recently observed the behaviour of one of the mothers whose child who had recovered from transplantation. Prior to and during the transplant process the mother has been preoccupied and withdrawn. She had been completely focussed on her child. When I next met her after her child had recovered from the liver transplant, she was a changed person. It was hard to believe that it was the same person. The change had resulted in an altered outlook and attitude. Her reactions had changed dramatically. She was now animated and interested in those around her and their plight. It was as if she had benefited through her plight, and now had the strength to share and be compassionate outside of her previous circle.

(Excerpt from researcher's personal journal, April 2005)

A desirable outcome of the research was envisaged that through illumination of the meanings of the lived experiences the study might also uncover differences related to the New Zealand perspective of paediatric liver transplantation. Revealing insights and meanings in the New Zealand environment might be an opportunity to improve patient outcomes for children and families and support the New Zealand Liver Transplant paediatric programme.

Selection of hermeneutic phenomenology

Heidegger's (1927/1962) hermeneutic phenomenology informed by van Manen's (1990) phenomenological approach, was selected as the most appropriate methodology to investigate the lived experiences of mothers in caring and mothering their children

who had recovered from liver transplantation. A hermeneutic (interpretive) phenomenological approach fits the holistic view, considering the whole person and their perception of the health-illness experience. This aligned with the researcher's personal and professional philosophy

The inquiry sought to reveal the nature and meaning of being a mother caring for a transplanted child, making their lived experience understandable. One approach might have been to interview the children who had experienced liver transplantation and seek their descriptions and narratives to explore the meaning of their lived experience (Wise, 2002). A different perspective might have been taken by interviewing the siblings or families of children who had received a liver transplantation (LoBiondo-Wood, Williams, Wood, & Shaw, 1997).

Hermeneutic understanding is gained through seeking to understand other ways of being in the world. The researcher gains understanding through in-depth dialogue from the participant as well as contextual images that might be relevant such as published literature, art, films and works of fiction that might be available. The phenomena are the focus of inquiry. In this research, the phenomenon is the mother's experience of caring for a child who has undergone and recovered from a liver transplantation. In sharing the experiences of mothers as they care and nurture their child, their stories tell a journey of living with chronic illness to a life perceived as relatively normal and happy life.

The Heideggerian hermeneutic phenomenological approach has been widely utilised as a research method to gain understanding of the lived experience of undergoing procedures, coping with illness and life-changing events (Draucker, 1999). There is a paucity of published research that examines the lived experience of children following liver transplantation. Phenomenological research has been performed in the area of adult liver transplantation, studying adult recipients or spouses (Forsberg, Backman & Moller, 2000; Robertson, 1999; Thomas, 1995; Wainwright, 1995).

In selecting Heideggerian hermeneutic phenomenology as the research approach, clarification of the use of language, and attention to rigour were required. The research was based on fundamental assumptions and a general orientation to life that guides inquiry (van Manen, 1990). In order to ensure a ground of understanding of phenomenology it is necessary to explain some of the tenets of phenomenology as a philosophy and as a research methodology.

The research was approached in a manner that was cognisant of personal knowledge, attitudes and understandings of the researcher. In the seminal article by Carper (1978) nurses' ways of knowing are described as empirical, personal, aesthetic and moral ways of knowing. White (1995) contributed socio-political knowing as an additional way of knowing for nursing. Having a close association with the liver transplantation programme and working with children and families in this service, allowed me to contribute to the data collection, analysis and interpretation. My role as researcher is deeply entwined in the research process in accordance with the Heideggerian hermeneutic phenomenological tradition.

The two-way dialogue between the researcher and the participant facilitates the sharing of experiences and stories, facilitating interpretation. This fits well with the open unstructured interviewing technique used to collect the data in my research. Interviewing processes and data collection are discussed in Chapter 4. In accordance with the Heideggerian tradition this research utilised participants' narratives to contribute to the generated understanding.

The research question and aims

In developing a research question, a careful refining and thoughtful consideration of the idea was required. For the purposes of this research a research question that supported the purpose and significance of my topic was refined and stated. In the process of developing and writing up the proposal for this research inquiry, I benefited from the challenges and suggestions of colleagues, university staff and fellow students, strengthening my confidence and resolve to pose the following research question:

<p>What are the meanings of a mother's lived experience of caring for her</p> <p>child who has recovered from a liver transplantation?</p>
--

Through the inquiry it was proposed that the meanings of the lived experience of mothers in caring for their children, who had undergone liver transplantation, survived, recovered and were now living at home and experiencing good health would be uncovered. The research aims for this thesis arose from my quest to undertake this research in a robust manner and make a contribution to existing knowledge around paediatric liver transplantation. Four aims were developed for this research;

- 1.a). To uncover the essential themes of the meanings of the lived experience of mothers as carers of children who have undergone and recovered from liver transplantation.
1. b). To analyse the data collected and present the findings. Rich descriptions and hermeneutic phenomenological reflective writing will capture the essences of the lived experiences of mothers caring for their child in the realm of home.
2. To highlight the contribution of phenomenology as a valid research methodology, by providing rigorous and balanced research conclusions that provide new knowledge and stimulate the “phenomenological nod” (Sandelowski, 1986).
3. To present the significance of the success of paediatric liver transplantation as a valuable health care service in New Zealand to health care planners, providers, funders and the wider community.
4. To provide glimpses and insights into the life of the child who has recovered from a liver transplant as seen through the mothers' eyes.

Justification for the study

Up until the end of 2006 there were 28 children living in New Zealand who have undergone liver transplantation (Wilde et al., (2007). Following a successful liver transplant, a transplanted child does not stand out in a crowd. Their presence is largely invisible, unless they are seriously unwell and or suffering from complications. One

might wonder what life is really like for a child who has survived and is apparently thriving following a liver transplant. What care do they need? The longer term effects on family wellbeing and functioning of a child receiving a liver transplant are little known. This study provides insights into the outcomes for not only mothers and children, but also for the family experience.

Paediatric liver transplantation is expensive. The estimated cost of a child undergoing liver transplantation is NZ\$ 224,745. The ongoing funding is provided to the Auckland District Health Board by the New Zealand Ministry of Health. Some people suggest the cost is high and that the cost of one child receiving a transplant prevents other children with more day-to-day health needs benefiting from the health funding. The value of paediatric liver transplantation needs to be considered in wider terms than only the value in dollars. Statistics related to incidence, morbidity, mortality and waiting times for transplants and length of stay are explored more fully in Chapter Two.

Outline of the Thesis

The progression of the research thesis is portrayed throughout this manuscript. The actual research process and the development of my thinking around the topic are described. The research journey is shared with the reader, illuminating the meanings of mothers' experiences and providing glimpses of the children's lives with a successful liver transplant.

In Chapter Two the background information to support the research is provided. This chapter explains some of the key terms used throughout the thesis. Some historical information provides insights for the reader of the enormity of the progress made by advances in medical sciences. The processes surrounding paediatric liver transplantation are outlined. The current status and efforts towards increasing life expectancy, improved quality of life and patient outcomes are discussed. Relevant statistics and an overview of current policy applicable to liver transplantation are outlined. A review of the published literature is provided. This includes; previous studies relating to transplantation, mothering with a particular relevance to the experience of mothers in caring for children with health care issues, and coping

strategies and understandings. The issue of chronic conditions in childhood and adaptation to illness and recovery are also discussed. Personal experience and background form the basis of preunderstandings in the hermeneutic phenomenological approach. Relevant phenomenological studies are explored, informing knowledge of the lived experience method.

In Chapter Three the theoretical influences on this research and the chosen methodology are discussed. This methodology chapter indicates the stance taken in undertaking this study. The chapter explains the phenomenological perspectives in relation to other methodologies and the choice for data collection and analysis. Phenomenology as a philosophy and a research methodology is compared in relation to the two major phenomenological schools of thought. Justification for selection of a qualitative framework for the research and hermeneutic phenomenology as the research methodology is included. The work of Max van Manen is presented, including a description of the procedural framework proposed by van Manen (1990) and used for this research. This leads to the next chapter where the method and design arising from the chosen methodology are covered.

In Chapter Four, the method and design of the inquiry into the lived experience of mothers caring for their transplanted child is described, using the framework described by Streubert and Carpenter (1999). Support for the selection of and justification for the number of participants is provided. The processes used to invite participants to take part in the study are presented. The particular methods used to facilitate phenomenological reflection and hermeneutic understanding while analysing narratives are identified and discussed. Issues of rigour and trustworthiness are discussed. Ethical considerations as well as the methods and processes used to obtain ethical approval are relayed. Finally the processes that are used for phenomenological reflection and writing are outlined.

The process of the analysis of this research is covered in Chapter Five. The thematic analysis and the emergence of common meanings through the development of narratives are described. The methods used to analyse the data are provided to provide the reader with an appreciation for the hermeneutic phenomenological approach. The writing and rewriting that was undertaken is demonstrated. A description of the participants follows

and the data are presented utilising the hermeneutic tradition of writing. The process of phenomenological reflection is revisited and Heideggerian philosophical underpinnings are outlined specifically in relation to the analysis and interpretation.

Chapter Six presents the interpretations of the research findings as they developed from the analysis of the data, utilising the interpretive phenomenological approach. The emerging themes are discussed and examples of hermeneutic reflective writing are used to support the interpretations that arise in accordance with the process described by van Manen (1990). The evolving themes emerging from the analysis are considered against the knowledge found in the published literature, as well as other sources of knowledge, such as; current events, media, films, and entries from the personal journal. The themes are merged and using Ruddick's (1983) thoughts on maternal thinking draw them together.

Chapter Seven concludes the study. A brief overview of the themes is provided and the manner in which the themes merged using Ruddick's (1983) concepts of maternal thinking to enhance the meanings arising out of the interpretation. The essential themes are revealed and discussed. The experience of undertaking the inquiry is reflected upon. Limitations of the study are provided and this is followed by a discussion of the opportunities for improving the research. The achievement of the research aims is discussed in order to demonstrate how each aim was achieved. The overall significance of the research is discussed. The recommendations emerging out of the findings for health service provision are made, including how the recommendations might be implemented. Potential contributions of this research are discussed in relation to the various audiences, i.e. nurses and other health professionals, families, health administrators. In conclusion possible future research opportunities are suggested.

Summary

The process of liver transplantation is complex, costly and lifesaving. Liver transplantation is now standard treatment for the management of liver failure in children. The Starship service is performing an average of 6 – 8 liver transplants per

year. The experiences of mothers provide a different way in which to evaluate successes of liver transplantation in New Zealand. Mothers play a vital role in caring and mothering a child who is recovering from transplantation. Mothers as major caregivers give insights into the mothers' lived experiences of caring and the lives of their child who have undergone liver transplantation, as well as other family members.

Using the hermeneutic phenomenological research approach of Heidegger (1927-1964) and van Manen (1990), an enriching trip of discovery and increased awareness of the multiplicity and complexity of the meanings arising out of life and lived experiences of mothers caring for their transplanted child are provided. The understanding and portrayals provide descriptions that will change the way in which we view the world in all its richness. Justification for using hermeneutic (interpretive) phenomenology as distinct from descriptive phenomenology is related to the importance of context of the social world, time, language and the necessity of shared understanding. A Heideggerian hermeneutic phenomenological approach has numerous benefits for this study. The findings have the potential to contribute to shared meanings and strengthen knowledge through enhanced understanding. The findings also illustrate the uniqueness and diversity of human experience. It uncovers previously hidden and unknown phenomena and ways of Being. Through evocative and interesting narratives, the readers of research are privy to the voices of participants and their lifeworld.

CHAPTER TWO - UNDERSTANDING THE CURRENT KNOWLEDGE TO INVESTIGATE THE EXPERIENCES OF MOTHERS OF CARING

This chapter provides the background to the topic of this research inquiry and orientates the reader to the context of this research. The phenomenon of interest is divided into more manageable pieces to assist in understanding the topic, allowing the reader to approach the findings with a starting knowledge of the topic of paediatric liver transplantation.

A brief description of the history of liver transplantation is given. Key terms are presented to clarify understandings of meaning. Research undertaken in the area of liver transplantation is vast and covers a multitude of issues and experiences. This provides a platform for my research question. The current status of paediatric liver transplantation is examined both internationally and nationally. A brief review of the history of liver transplantation is provided. The beliefs pertinent to New Zealand society and culture are covered in relation to transplantation.

Progress within transplantation surgery has made significant strides. The liver transplantation process for children is described to inform the reader of the current status of knowledge. I provide an overview of the current status of liver transplantation. Current policies are covered and the ways they affect the current practices related to liver transplantation and organ donation. The processes involved in liver transplantation are discussed. I provide an overview of the experience of the child undergoing liver transplantation including pre-operative, post-operative and upon discharge particularly in relation to the New Zealand experience. The benefits and possible implications for the children and families are discussed. The challenges faced by children and their families are discussed with regard to knowledge of adjustment to illness, transplant and life changing events.

Children and families' experiences of long term chronic illness are reviewed to provide a sense of the magnitude of problems, worries and concerns. The role of parents and more specifically mothers in the provision of care is reviewed. I have explored the ways in which mothers manage when their child has health problems, including chronic and life-threatening conditions, as there is not a vast amount of published research on the mother's experience of caring for a sick child. The published research is examined to identify maternal coping strategies. Mothers understand the reality of their lives through a complex system of life experiences, knowledge and understanding. How do mothers make sense of their own reality, particularly when emerging from the acute sickness/illness/hospitalised arena and returning to the safety of home? I provide an overview of the ways of knowing for women and particularly mothers.

In participating in this research, I have presented my own pre-understanding and background to state the influences of my knowing upon the analysis and interpretation of the findings. I have reviewed and critiqued sources of knowledge around the topic, to bring a greater understanding of the phenomenon being investigated. I reviewed other published research, particularly hermeneutic phenomenological research and explored the relevance to my inquiry. The philosophical underpinnings of hermeneutic phenomenology act as a guide to the research process.

The background to this research inquiry

The literature review was undertaken to provide a knowledge platform upon which to base this research. Having a good basic knowledge and awareness of the pre-existing knowledge around the research question facilitated a familiarity with the vast amount of information surrounding liver transplantation. Liver transplantation is widely documented both in textbooks, literary sources and in the published health literature.

Key terms

A basic explanation of some of the key terms used in the text will be useful in understanding this research.

1. *Liver transplantation* is the transplantation of a whole or part of a liver, either from a cadaveric or live-related donor.

2. *Cadaveric donors* are organ donors who are certified as deceased but on life support. They are confirmed brain dead following testing confirmed by two medical consultants who undertake the assessment separately and agree on the findings. Consent for removal of organs or tissue is approved by the next of kin and then the donor is taken to operating rooms for organ and tissue removal before having life-support withdrawn.

3. *Live-related liver transplant* is the removal of part of the liver of a living and sometimes related donor. The donor undergoes a partial removal of their liver. Following recovery the donor is able to continue a normal life and the remaining liver increases in size to compensate.

4. *Extra hepatic biliary atresia* is a congenital malformation. The flow of bile from the liver to the gastrointestinal tract is interrupted. The bile builds up in the liver causing progressive liver failure. Despite attempts to surgically correct the obstruction, recovery of normal liver function is not always achieved (Chardot, Carton, Spire-Bendelac, Le Pommelet et al. 2001). It is the most common condition for which liver transplantation is currently performed in childhood.

5. *Portoenterostomy* is otherwise known as the Kasai procedure. A piece of small bowel is taken and joined between the bile ducts in the liver and the small intestine to bypass the blockage of bile between the liver and the small bowel. The operation is most successful when undertaken before three months of age (Chardon, et al., 2001).

6. *Immunosuppressive medication* is medication that reduces the body's response to transplanted foreign tissue to reduce the risk transplantation rejection.

7. *Hermeneutic phenomenology* is a qualitative research methodology that was described by Martin Heidegger (1927-1962), a German philosopher and phenomenologist. It is a descriptive (phenomenological) and interpretive (hermeneutic) methodology. The facts of the lived experience are captured into language (the human science text) in an interpretive process.

8. *Hermeneutics* is derived from the Greek word *hermeneuein* - 'bringing to understanding particulars where the process involves language' (Leonard, 1989). A more simplified definition of hermeneutics is textual interpretation, or finding meaning in written word.

9. *Lifeworld existentials* is "the lived world as experienced in everyday situations and relations" (van Manen, 1990, p. 101). Van Manen describes four fundamental lifeworld themes that assist in the reflection; lived time (temporality), lived human relation (relationality), lived body (corporeality) and lived space (spatiality). These are fundamental to the lived world of experience.

A starting point; knowledge of the topic of liver transplantation

Liver transplantation history

Until the 1960s people with end-stage liver disease had no treatment options. Liver failure was a fatal disease. The first attempted liver transplantation was performed in 1963 by Thomas Starzl (Starzl, Iwatsuki, van Thiel et al., 1982; Starzl, 1992), and though unsuccessful, was the beginning of the reality of potential survival. Past survival rates were slim and treatment was seen as largely experimental. It was not until the 1980s, that real advances in survival were achieved with the introduction of Cyclosporin, a powerful immunosuppressive agent (Sheets, 1989; Trzepacz, Brenner & van Thiel, 1989). New drugs and regimes continue to be discovered and implemented to improve graft survival, with reduced serious side effects and improved quality of life.

There have been dramatic changes in knowledge within the field of surgical, anaesthetic, medical and nursing profession, including other members of the multidisciplinary team such as dieticians and pharmacists. I recall twenty five years ago, how small the multi-disciplinary team actually was. There has been massive changes in technology including; organ preservation, surgical techniques, monitoring capabilities and drug management. This has all contributed to the continued improvement of survival and long-term outcomes (Atkison, Ross, Williams, Howard, Sommerauer, Quan & Wall, 2002).

Paediatric liver transplantation has become an accepted treatment when the liver fails. Survival rates of children have increased over recent years in association with effective drug therapy and technological advances (LoBiondo-Wood, Bernier-Henn & Williams, 1992; Sokol, 2002; Whittington, Alonso, Superina & Freese, 2002). The challenges faced are immense. As knowledge and technology have advanced, life expectancy has increased; and the issues of quality of life of the survivors have become more evident.

A magazine article featuring the story of a girl called Stormie Jones (Rubin, 1991) had a significant influence in developing the idea for this research. Stormie had a rare genetic disease called hypercholesterolaemia. The story of her transplantation arose at the time when paediatric liver transplantation was emerging as a treatment option. The story covered the tumultuous years of a young girl's life following ground-breaking heart and liver transplantation in the United States in 1984 at the age of seven years. The story of her life and her mother's experience were extremely moving. The following is an excerpt from an article in the Texas Monthly.

No-one would hesitate to say that as a medical experiment, Stormie Jones was a dazzling success. Starzl's groundbreaking surgery validated laboratory theories about cholesterol metabolism and doubled Stormie's life span, giving her more than six years in which she lived a reasonably active life and reached the threshold of adulthood. In assessing what had been accomplished and what had failed, the doctors more often note as a point of pride that Stormie died not from the cholesterol imbalance that threatened to kill her at age six, but from the complications arising from her transplants... For even though Stormie can be considered a success,

the moment she died she also became something else. She became a symbol of the limitations of medical science.
(Rubin, 1991, p. 177)

The challenges Stormie and her mother faced were enormous. Stormie faced death, overcame it, rose above it and then died leaving her anguished mother to live on. Transplantation surgery has come a long way since 1983 and children now face a more certain future (Wang & Saab, 2004). The implications of undergoing and emerging from such a stressful situation, has huge implications upon the child, mother and family.

Statistics

Pertinent statistics and data available are incorporated for the reader to gain a sense of the current status of paediatric liver transplantation in New Zealand. Current policies in place guide the practices related to liver transplantation. This ensures consistency and allows for accurate data to be extracted for analysis. The data also assists in analysis of the possible benefits and implications for the adults and children and families both waiting and receiving a liver transplant. The data is collected by the New Zealand Liver Transplant Unit, and the findings are fed back to the Ministry of Health to assist in funding and policy decision making.

The following statistics are based on the report by Wilde, et al. (2007) on the first five years of paediatric liver transplantation in New Zealand between January 2002 and November 2006. Twenty-eight children have undergone twenty-nine transplants (one child was re-transplanted). The median waiting time was one hundred and twenty-two days and the median age at transplantation was two and the half years. The most common diagnosis was extra-hepatic biliary atresia (59%). The children spend an average of two days and the median stay in hospital following the operation is twenty-five days. Families from outside of Auckland spent fourteen weeks in Auckland from immediately prior to transplant till discharge back to their home. Survival in this period was 100%

The success of the transplantation programme is highly dependent upon the donation of organs. Many people wait a long time for a transplant and sometimes die while waiting. It is vital that children are assessed for consideration for liver transplantation early to speed up the search for a donor liver (Kelly, 2002). The possible reasons for failure to obtain organs are discussed.

Organ Donation

A critical requirement for the process of transplantation surgery is the donation of healthy and viable tissue and organs. Organs may be donated by a living person or donors who are declared brain dead in accordance with legislated criteria. In the case of a live related liver transplantation, part of the donor's liver is removed (Fung, 2002). An organ can be sourced from a suitable living relative or friend in an effort to save the life or improve the quality of life of another human being, without causing permanent harm to the donor. In the case of cadaveric donors (heart beating-deceased) the organs may be donated by relatives on behalf of their deceased or nearly deceased relative. This occurs where the donors will not survive. Life-support is withdrawn after the removal of donated organs. Sometimes the donated liver is able to be split successfully and this expands the pool of liver donors (Fung, 2002).

Varying beliefs around the topic of organ donation and transplantation are held in societies and these impact on the acceptance of transplantation as a feasible and accepted treatment. In New Zealand there are generally lower levels of organ donation per head of the population. The reasons for this are controversial and varied and not the specific focus of this study, except to identify that there are conflicting views as to how organ donation should be managed in New Zealand. The debate centres on whether it should become law that people with healthy organs donate unless they specify that they don't wish to donate. This system is practised in Sweden and donor rates are correspondingly much higher. The shortage of human donors is a major problem (Whittington, Alonso, Superina & Freese, 2002).

Donation is exploited in some countries, where people are prepared to donate an organ or partial organ for money. This is often done in the face of poverty. There may be intense coercion or family pressure. Occasionally stories emerge through the news of kidnapping and even murder to harvest donor organs. There have also been a number of forensic television series lately that have used this topic to inspire the storyline. Strong leadership is required to ensure impartiality, confidentiality and compliance with legislative requirements and health policies.

In New Zealand there are also financial implications upon families choosing to undertake live related liver transplantation.

Donating a piece of your liver for your child or loved one is a noble gesture. It provides an excellent chance at survival; however it comes at a cost. A live donor undergoes a huge operation and this is not without risks. The donor can expect to be off work for up to three months. The problem lies with paying the bills. The donor and family must survive on what is often a much reduced financial income. Who has sufficient resources in this day and age to support themselves and their families with only a minimum amount of financial support? It explains why there might be a reluctance of family putting their hands up to be donors.

(Excerpt from researcher's personal journal, December 2007)

In New Zealand, holders of a driver licence are invited to indicate upon application whether they wish to be an organ donor. In the event of the individual becoming severely ill or injured it is an indication to the family of the individual's desire to donate. The family or next of kin is not compelled to consent to the donation. There are differing views regarding whether the donors indication should be seen as consent. In New Zealand it is current practice that health professionals approach for consent for organ donation from the families of relatives in life-threatening conditions, where recovery is not possible and the patient has suffered "brain death" for consent purposes.

Sometimes families will offer to donate organs when the possibility for non-recovery of their loved is given.

In Australasia, there is an agreement between Australia and New Zealand to manage the allocation of donor organs. This means that the organs can be matched more carefully to recipients in tissue typing as well as size. Most children will receive a reduced or split liver graft (Kelly, 2002). In the event of a patient suffering fulminant liver failure, the first available and most suitable donor liver can be transplanted into that patient. This increases the donor pool especially where unusual tissue typing requirements are required. It also ensures that the most effective use of donor organs.

There is often a perception that many organs are wasted as they are not requested by health professionals. Not all organs are suitable for transplantation and the inappropriate use of poor quality organs may jeopardise success for the recipient. The right time to ask and the right set of circumstances need to be present for the request to be made of families experiencing the grief of losing a loved one.

In New Zealand society, there are growing concerns about the level of well-being of the population. With increasing levels of morbidity in the population, there is a concern that the quality of organs may also be affected and therefore be unsuitable for donation. With increasing rates of drug and alcohol abuse, infectious diseases including Hepatitis B and C and the increasing levels of obesity in the population, it can be anticipated that the donor pool will continue to contract. Obesity is a major health concern in society. Obesity is associated with “fatty liver” (a liver that has a higher ratio of lipid than normal). The fatty changes may exclude obese individuals from donating (Fung, 2002). Cultural factors are an important component in organ donation as the intrinsic beliefs that govern thinking affect the manner in which the body is viewed.

Cultural factors

Maori respect of the body is an important concept to be considered in terms of health, life and death. The body is sacred and seen as a taonga (something to be treasured). There has been reluctance to donate organs as Maori believe that the body must be treated with mana (respect) and to damage a body is culturally inappropriate and disrespectful. With education and support, Maori are beginning to recognise the benefits of transplantation for their whanau (family members) and are increasingly willing to come forward with appropriate support and respect. Some cultures consider that the body is sacred and that for the soul to settle, that the body must be whole. The body must be treated with the utmost respect in order for the person's spirit to move into the after world. This can cause extreme distress if the family/whanau observes that their beliefs are not being followed.

Alternatively some cultures don't believe in having an active part in the death of another human being, even if the person is found to be brain dead person and an attitude that whilst there is life there is hope. This means that whilst a person might be deemed brain dead, that while the heart is still beating that the person is still alive. Japan supports this through legislation and organs can only be taken when the donor is dead (no heart beat). This puts precious organs at risk as the perfusion of donor organs is compromised. Robust live related transplantation techniques were developed largely in response to this (Todo, 2002).

During the surgery for liver transplantation, there may be a need to replace lost blood volume with blood transfusion. Some cultures and religions have strict restrictions on the receiving of blood products. When members of the United Church of Jehovah Witness identify their membership, careful negotiation and discussion is undertaken to clarify informed consent issues. In the case of children requiring blood products there are policies and procedures available to guide health professionals on the correct action to undertake that the rights of children and their families are upheld. Legal

representation is often sought. As a result of advances in surgical techniques and the use of blood volume expander products, the effects of blood loss can be minimised or reduced.

Cultural beliefs must be considered on a person by person basis. It would be inappropriate to assume that everybody with a certain ethnicity or religious belief would have the same wishes or requirements. It is essential if cultural safety is to be practised, that there is clear two way discussion with sound rationale and an opportunity to participate fully in decision-making. In the current era of health, there is a requirement that appropriate support be provided to enhance informed consent. The presence and active involvement of Maori Health support workers, Pacific Island Health support workers as well as advocates and interpreters are available assist in the care negotiation.

Issues around the process of organ donation are contentious. There is also a sensitive and highly emotive aspect around organ donation that centres on death and dying and living and surviving. This research inquiry focused on the caring of a child who survived liver transplantation. The experience has a profound effect on individuals and the acknowledgement and gratitude towards donors was evident throughout this inquiry.

Paediatric Liver Transplantation

Paediatric liver transplantation is leading edge care with a multidisciplinary focus to ensure that the child and family achieve optimal outcomes. The following discussion describes the process of liver transplantation.

Liver failure is a serious and life threatening condition. In New Zealand the most common cause of paediatric liver failure is extra-hepatic biliary atresia (known as biliary atresia). Biliary atresia is a congenital malformation that prevents bile from leaving the liver and reaching the small bowel. The Kasai procedure – a Portoenterostomy is performed if the condition is diagnosed soon enough, though a percentage of these children proceed to liver failure (Hadzic, Davenport, Tizzard,

Singer, Howard & Mieli-Vergani, 2003). Other causes of liver failure may include cellular, vascular, anatomical, metabolic or oncological abnormalities (Kelly, 2002).

Children who require a liver transplant may present acutely or chronically. If acute liver failure is unable to be averted or reversed, the child may need an urgent liver transplant. It is not unknown for patients in acute fulminant liver failure to die before liver transplantation is able to be organised. Some children's liver failure may progress more slowly, and this is more common course of liver failure in childhood. The slower onset of liver failure has the effect of causing chronic illness in the child. The child's deterioration is usually gradual and can range from months to years; however the level of wellness may diminish to the extent that the child requires constant hospitalisation.

The diagnostic and assessment process prior to listing for paediatric liver transplantation is extensive. This is undertaken to ensure that the child is correctly diagnosed and that they will actually benefit from a liver transplant. The assessment also ensures that the child is in the best possible physical condition, under the circumstances, prior to this major surgery. The child and family undergo a pre-transplant assessment and selection that includes physical, emotional, mental and social factors. The assessment is undertaken by a large multidisciplinary team. The child's case is presented to the Liver Transplantation Selection Committee at Auckland City Hospital to gain agreement and consensus to proceed to listing. Once there is agreement, the child must wait for a suitable liver to become available. It is important to maintain the best possible level of health while waiting. Some children are able to wait at home, while others will need to remain in hospital until a liver becomes available. The children waiting in hospital are usually more fragile and require a high level of care to maintain their condition until a donor becomes available.

The surgery involves highly technical and skilled care. The average surgery is six and a half hours (Wilde, et al., 2007), and the child is admitted to the Starship Paediatric Intensive Care Unit following surgery. Complications are not uncommon, due to the fragility of the children and the level of technical complexity. Once haemodynamically stable and breathing spontaneously, usually 24-48 hours post transplant, the child is transferred to the Medical Specialties Ward at Starship for their ongoing care. Once the child's new liver begins to work, the child begins to recover. The dark yellow colour of

their skin and urine diminishes. They improve steadily and are usually ready for discharge within two to three weeks if their recovery is uncomplicated. The child is discharged to the care of the family if they live within easy distance to Starship in Auckland or to the Ronald MacDonald Family House (a home away from home for families from out of town which is supported by the Ronald McDonald Charity) if they are from out of town.

Following a successful liver transplant, there is a return to relative normality as the child regains their strength and improved liver function (Bucuvalas & Ryckman, 2002). The child remains under close surveillance with daily blood tests and reviews. There is a low threshold to admit the child for investigation if blood results change or if infection or bile blockage is detected (Orie, Ohkohchi, & Satomi, 2004). For the first three months, the child must remain near to the hospital, especially if they live outside of Auckland. This can be disruptive for family functioning, but is considered necessary to ensure that their liver function remains stable. The child is slowly able to resume some activities, including the return to school. The child is monitored through regular blood tests and outpatient reviews. The family is responsible to monitor the child for subtle signs of ill health and seek advice in a timely manner. This responsibility largely falls upon the major caregiver; more often the mother.

Research undertaken in the area of liver transplantation

A search of published research commentary was undertaken to gain an appreciation of the existing knowledge. My search began as a key word search in the Cinahl and Medline databases. The initial key words (underlined) searched for were; liver and transplantation. There was a large amount of data that included; medical, nursing and allied health research and management protocols. The search was then combined with child to allow a paediatric perspective to emerge out of the search. The results were, then combined one by one with family, maternal, mother. I also searched the words caring, thinking and knowing, combining it with the words qualitative, hermeneutic, interpretive and phenomenology to identify works that had utilised this methodology

previously in relation to the topic. Quality of life was also searched in relation to the other sources to gain a perspective regarding outcomes.

Further searches were undertaken arising from the references quoted in articles that might provide further knowledge or new perspectives around the topic. The references were sorted according to the knowledge revealed to aid in developing consistent findings. I also searched the databases at the local library to get a perspective around the topic at a more general level. This included finding other works such as fictional sources, magazines, newspapers and other media e.g. films.

A wealth of knowledge was uncovered surrounding a wide range of topics related to liver transplantation. These included knowledge about quality of life, coping mechanisms, returning to work, risk of dying, psychological functioning, stressors of family members as well as a variety of other topics. In the next section the information is grouped into topics. An overview of the relevant published research is provided to support my assumptions.

Quality of life following transplant

The challenges faced by children and their families following transplantation are immense. Quality of life issues vary according to the stage of recovery that the child and family are experiencing. Eiser (2001) undertook a systematic review of measures of quality of life for children with chronic illness and concluded that there are a number of problems identified in measuring quality of life for children. These included; “confusion about the definition and measurement of quality of life, limited availability of disease specific measures, discrepancies between child and parent ratings, limited availability of measures for self completion by children, lack of precision regarding the content of domains of quality of life and cultural appropriateness of measures of use in the United Kingdom” (Eiser, 2001, p. 205).

Kelly (1998) recognised that nutritional rehabilitation following a child’s successful liver transplant had a significant influence on the quality of life in the longer term. Pubertal development and growth spurt were reported by Codoner-Franch, Bernard and

Alvarez (1994) as a positive indicator of future quality of life. Laifer and Guido (1995) and Poole (1998) reported successful pregnancies in transplanted women, both of which are vital to longer term quality of life. Early studies indicated less favourable psychosocial development of children, significant motor delay and subsequent educational difficulties (Windsorova, Stewart, Lovitt, Waller & Andrews, 1991), however more recent studies indicate that if children undergo transplant early, normal psychosocial development may be expected after transplant (Beath, Cash, Brook, Mayer, Buckels & Kelly, 1997). All these issues have relevance to measuring the quality of life for children who have undergone liver transplantation and for their families. A key component of the liver transplantation process is the genuine desire to increase the life expectancy and quality of life (Sokol, Cleghorn, Goulet, da Silveria, McDiarmid & Whittington, 2002).

The majority of studies of recovery from liver transplantation in the literature have largely focused on the effect on adult recipients. Quality of life has been measured in conjunction with outcomes such as physical and functional recovery (Gelling, 1998; Wainwright, 1995; Robinson, Switala, Tarter & Nicholas, 1990; Forsberg, Backman & Moller, 2000; Robertson, 1999; Thomas, 1995; Wainwright, 1995). The findings suggest that the quality of life for adult recipients and their families is enhanced by transplantation. A return to activities enjoyed prior to experiencing liver failure is observed upon recovery. A study of the subjectively experienced meaning of health and quality of life among liver transplant recipients one year after transplantation was undertaken by Forsberg (2002). This phenomenological study uncovered the main theme of having the freedom to choose what ever you want to do and being able to do it. A return of a quality of life in adults includes such aspects as returning to work, maintain intimate relationships independence and ability to earn an income. These are focused on adult life goals.

The impact of the transplant upon quality of life on the child and family focuses on different aspects. The pre-transplant situation and the family's ability to resume normal life are influenced by coping skills; social situations and psychological recovery (LoBiondo-Wood, Bernier-Henn & Williams, 1992). The quality of life is not only measured in terms of the child's quality of life but must also consider the family's quality of life as well (Wise, 2002). Bradford, (1991) reviewed the existing literature in

relation to psychosocial impact of liver transplantation on children and their families. The conclusions drawn were that psychological functioning was not assessed consistently throughout the transplantation process to allow comparison of findings. The review also highlighted that there was a lack of assessment of the reactions of siblings to the upheaval of transplantation. Overall the review found that in the longer term that the children experienced less hospital admissions and that psychological difficulties diminished. Bradford (1991) stated that many families continued to have problems in normalising their responses both in and out of the family unit.

The success of liver transplantation is dependent upon improving the quality of life of the child; by allowing the child to live a relatively normal life where activities of daily living appropriate to the child's level of growth and development can be achieved. The functioning of the child in the context of the family and the functioning of that family, now and in the future is a definitive measure of success (Wise, 2002). The care that the child receives in the home environment is pivotal to their adjustment to their new life and wellbeing. All these issues have relevance to measuring the quality of life for children who have undergone a liver transplant and their families.

THE CHILD

How children know about their world

Children experience their world through their family, culture, environment, and their experiences over time and this is dependent upon their level of development. Children at different levels of age and development express themselves utilising various levels of language. I have observed that children may often express themselves more clearly through play, singing, writing, artwork or drama. Play is the work of children and it is the way children learn to understand their experiences in the world.

In children's bedtime tales and nursery rhymes the mother is illustrated as caring and kind. In the tale of Peter Pan, Peter's mother is described as "caring and kind". Painting motherhood in this manner is often comforting and familiar to children. I have noted that when a story is linked to loving mothers, children are often able to settle more quickly. Mothers are synonymous with everything good and caring.

Children who have had a liver transplant with the Paediatric Liver Transplant Service at Starship currently range in ages seven months to fifteen years. The children are at different stages of cognitive, linguistic, emotional and social development. The methods of communication and the quality of dialogue vary. The voices of children often go unheard and it is their mothers and families who are there to interpret and facilitate their knowledge and adjustment to the experiences.

Wise (2002) used the hermeneutic phenomenological approach to come to understand the experience of children who had undergone a liver transplant. She interviewed school age children and looked at the child's own experience of transplantation, surgery, hospitalisation and recovery. The predominant theme arising from her research was striving for normalcy. This hermeneutic phenomenological inquiry utilised in-depth interviews for data collection. These older children were interviewed successfully in an independent manner. The child's stage of development is a challenge to researchers undertaking a hermeneutic phenomenological study. Though obtaining data from older children is possible, there are distinct difficulties in eliciting data from younger children. We can rely upon the insights of a key caregiver to describe the child's responses to situations, and this is where the value of interviewing the mothers is recognised.

It is important that the data collected reflects the experience, allowing for analysis that will provide meaningful interpretation. Children desire to please adults (Broome, 2003). Children may offer information that they perceive the researcher wants to know or thinks is the right answer (Knafl, Cavallari & Dixon, 1988). This may also occur when interviewing parents, as they may wish to portray their child more favourably. Parents are emotionally attached and may find it difficult to be objective. In delving

into the experience during the interview, data must be obtained that allow for validation of the findings.

Children are an important component of most family units. In society today there are a multitude of combinations of what constitutes a family; single parent families, nuclear families, with grandparents; reconstituted families; same sex marriages and even foster families. Children are viewed within the family and the context of family. Children are not considered in isolation. The family is the structure in which the lives and actions of children and their families are accomplished. The concept of family centred care is a fundamental principle of paediatric care (Burns, 1994; Casey, 1995; Coyne, 1995). This concept stresses the importance of family centredness, negotiation, trust and partnership in care. Children are affected by the events, practices and beliefs held by the family.

Children experiencing chronic illness

The experiences of children and families with long term chronic illness were reviewed to provide a sense of the magnitude of problems, worries and concerns. Chronic illness has a profound influence on the child and family. Advances in chronic illness management have led to an increasingly dependent population of children, whose life expectancy and quality of life is largely unknown (Cohen, 1995). The long term experience emerges as their survival rates extend. Unpredictable long term outcomes lead to parental uncertainty. Ahmann (1994) found in her literature review that by exploring the family strengths and needs in caring for a child with a chronic illness that family centred care is enhanced and that this provides an excellent platform from which to strive for optimal care. Children learn and behave according to experiential learning as well as through knowledge of their disease and treatment (Eiser, 1993).

In relation to paediatric transplantation, patients and their families face many human challenges. Bradford (1991) found that following transplantation, children and their families often experienced an exacerbation of pre-existing emotional problems. Families continued to experience problems in normalising interactions in and out of the family (Windsorova, Stewart, Lovitt, Waller & Andrews, 1991). The child and family

must adapt to a changed lifestyle. Weichler (1993) identified a trend of decreasing support for the child and family in the post transplant period and emphasised maintaining support to assist family coping skills.

Forsberg, Backman and Moller (2000) found that health professionals often failed to appreciate the degree of uncertainty and fear about the future, lying just beneath the parent's consciousness. From my own experience, I have found that mothers often appeared to be coping well. However in developing a therapeutic relationship between the nurse and mother, the worries, uncertainties and stress of caring for a chronically sick child emerged. This insight became central in my practice and I developed a capacity to engage sensitively to enhance the long term well being of the mother and child as the focus of care. The study has enabled me to articulate this capacity.

LoBiondo-Wood, Bernier-Henn and Williams (1992) utilised the maternal perspective to examine the impact of a child's transplant on post hospitalisation family adaptation using the Family Adaptation Model. Social support was the only variable that significantly correlated with family adaptation. The multidisciplinary team's approach in assisting families may optimise well being for the child. Ullrich, Meyke, Haase, Erzfeld, Becknam, Schmidt-Scheller et al. (1997) supported a team approach in providing emotional support during the transplantation process.

MOTHERS

How mothers know about their world

This study focused on mothers' lived experiences of caring. Since biblical times, images have been presented that portray mothers caring for their children. Mothers are revered for their role. Religious icons and statues depict the Virgin Mary in deep devotion to Christ as a baby. One only has to look at the array of Mothers' Day cards and the marketing publicity associated with Mother's day to acknowledge mothers. Motherhood is valued in our society.

The ways of knowing for women and more particularly women as mothers has a particular relevance to my research. Belenky, Clinchy, Goldberger and Tarule (1986) examined ways of knowing in which women view reality and draw conclusions about truth, knowledge and authority. For women, knowledge development is not necessarily developed out of academic work. Women develop ways of knowing through a multitude of roles (Munhall, 1994), experiences and relationships with family and friends. Women's knowledge is further founded from various sources that might include; what they read through media such as women's magazines, see on television, through engagement at coffee groups and get-togethers, and through community involvement such as Plunket groups, school committees. The women's existence and involvement in the world is described by a Heideggerian phrase as their way of being-in-the-world (van Manen, 1990).

Ruddick (1983) describes maternal thought, as the unity of reflection, judgement and emotion - the intellectual work of mothering. Generally speaking, mothers share similar behaviours related to their particular situations and the demands placed upon them. She states that a mother's knowledge is normally protective, nurturing, fostering and shaping a child's growth and development into a person who is socially acceptable. I have observed the shared lifeworld of the mother and child; the close relationship mothers have with their children. Where the relationship is strained between the mother and child; the knowledge that the mother holds is affected by the events around her and her intimate knowledge of the child may be affected. The mothers' authenticity within their lifeworld relates to the way in which they are aware and their ability to make choices that have a direct bearing on the child. The overall wellbeing of the child is largely dependent on the mother, and where the child is jeopardised society may step in.

Mothers continue to develop expertise in knowing their child. I have observed mothers discussing their child's complex condition and care at a high level of knowledge relating to their child. This is knowledge borne out of a close and intimate relationship (Thorne & Robinson, 1988; Perkins, 1993; Thorne, 1993; Dixon, 1996; Kirschbaum & Knafl, 1996). Both Ruddick (1983) and Gibson (1999) describe a process of critical reflection in relation to maternal thinking; mothers examine their beliefs, values,

feelings, attitudes and experiences to reflect critically. Through critical reflection mothers learn to use knowledge that is cognitive and rational, as well as emotional, intuitive, experiential and contextual (Henderson, 1997). These ways of knowing assisted me to know that mothers could know and convey pertinent data in the course of the research.

Mothers caring

Mothers are generally perceived as the major caregivers in the lives of children. In the past, before the emancipation of New Zealand women, it was the traditional and expected role of women to actively raise the children. Women performed the major childrearing role, whilst the men worked and provided for the family. As women sought more equality in their roles, some men have taken a larger role with childrearing. Women have returned to the workforce, though invariably a larger percentage still do the larger amount of cooking, house work and caring for the children.

In order to provide insights into the mothers' caring, it is vital that we are clear what caring means. Caring is a quality that is commonly attributed to mothers. Care or caring has a wide dimension of meaning and van Manen (2002) discussed the topic of care-as-worry. The implication is that care is about fretting and worrying. If the word "care" is looked at more closely, the word is translated in German and Dutch to "zorg" and in Danish and Swedish to "sorge". Van Manen (2002, p.6) defines the meaning of *zorgen* as "*zorgen* for someone is to care". To understand the earliest meaning of care is to understand the association with sorrow and anxiety. The word sorrow derives from the words "zorg" and "sorge" that means anxiety and worry. In turn the expression of sorry has the meaning of "it causes me pain and regret. What is actually being said is "I care" van Manen (2002, p.6).

Caring occurs in the everydayness of everyday life. Caring infers a sense of alleviation of worry, of taking away the worries of one and taking on the worry for another. In the case of mothers, this is seen as a part of a mother's role (van Manen, 2002). Other meanings of care may be the caring of a nurse or other health professional. In this context, caring is also a professional responsibility Taking care of one's own wellbeing

or safety to avoid injury or poor choices is also care. Taking care of oneself is a personal responsibility that can be supported and encouraged by others who in turn also care to ensure that the person makes the best choices and maintains the best health and wellbeing. Society purports to care for members of the community; however individual needs are often invisible in the greater picture of the community.

In the bittersweet movie *Steel Magnolias*, the mother, McLynn, played by Sally Field supported her daughter through a serious illness. Her daughter eventually suffered renal failure. Eventually her daughter received a kidney transplant which gave her a second chance at life. Her daughter's compliance with her therapy was poor and despite the mothers caring attention and help, her worries are revealed when her daughter becomes critically unwell and finally succumbs to her illness. The mother cared deeply, but at the end of the day that care was not enough.

My research was focused to understanding the meanings of the lived experiences of mothers in caring for and nurturing their children following recovery from a liver transplant. Mothers are able to provide information about their child's well-being, demonstrating that the mothers' experience of caring for their transplanted child would provide insights into their child's lived experience as well. Previous research undertaken has looked at experience of mothers caring for children with special health needs. The themes that arose were varied depending on the level of chronicity and specialised health care needs.

Elliott and Luker (1997) found that mothers caring for their child with severe atopic eczema identified the burden of normal child care. Garcia (1996) identified themes of uncertainty as a core category, covering vigilance, searching for answers, taking charge and finding a balance by mothers in caring for their children with asthma. Glasscock (2000) described the experience of mothering a child with cerebral palsy and identified the themes of caregiver burden, increased family/social support requirements, learning about their child's care requirements, multiplicity of mothering roles and socio economic implications. Hodgkinson and Lester (2002) suggested that the lived experiences of mothers caring for their children with cystic fibrosis were decision-making with regards to genetic implications, burden of care, coming to terms with a personal change in identity.

Caregiver burden is a commonly recurring theme emerging out of studies of the lived experience of mothers in caring for their child with special health needs. This had relevance for the study as the manner in which the research is undertaken, as the wellness of the child, the presence of sleep deprivation or pressures might have added to the perceived burden of care on the mothers. This research inquiry needed to ensure that the process was not time consuming or onerous in any manner. When there is a chronically ill child in the family, mothers assume the burden of responsibility for care and develop expertise in knowing their child (Thorne & Robinson, 1988; Kirschbaum & Knafl, 1996; Robinson, 1996).

Managing the child with health problems

The role of parents and more specifically mothers in the provision of care was reviewed. How do mothers manage when their child has health problems that include chronic as well as life-threatening conditions? The published research was examined to identify maternal coping strategies.

Mothers play an important role in the care of the chronically ill child (Gravelle, 1997; Miles, Holditch-Davis, Burchinal & Davis, 1999). Mothers support and empower their families to meet their child's needs. Family members are increasingly becoming the primary caregivers in chronic childhood illness, though in practice, mothers provide most of that care (Stewart, Ritchie, McGrath, Thompson & Bruce, 1994; Eiser, 1994). The shifting roles can produce a dilemma for the mothers when parenting becomes care giving (Turner-Henson & Holaday, 1992); however the reality in our society is that the mother is expected to take both roles. Mothers are the most common key caregiver of children experiencing chronic illness (Gravelle, 1997; Miles, Holditch-Davis, Burchinal & Nelson, 1999). Mothers are relied upon to provide information about their child's level of well-being and adaptation during clinic reviews and on admission to hospitalisation. The use of mothers as participants in this study supported my belief that mothers would allow the research questions to be answered in relation to their role as

mothers and carers. Caring is a concept that spans the everyday phenomenon of being-in-the-world.

THE NURSE RESEARCHER

My pre-understanding and background

How do we know what we know? What shapes our knowledge? Do the roles we hold influence the ways of knowing and understandings held? In coming to understand the lived experiences of mothers, in keeping with the selection of Heideggerian hermeneutic phenomenology, I have described my own ways of knowing in relation to being a woman and a nurse to ensure that my own preunderstandings and conceptions are explicit. There is a sense of positioning myself as the researcher to ensure a balanced view that opens the field to exploration. In addition to the empirical, personal, aesthetic, moral and socio-political ways of knowing (Carper, 1978; White, 1995), Berragon (1998, p. 211) acknowledges that the nurses knowledge is also “influenced by other disciplines such as psychology, sociology, physiology and anatomy”. These ways of knowing for nursing also contribute to interpretation and analysis in research. As a nurse researcher, I bring my own ways of knowing based on my knowledge as a woman and a nurse to this research.

As a woman, I have experienced cultural and social conditioning that prepares one for the role of mothering. I played with dolls as a child and played “mother” with my wee friends. I undertook roles particularly important in the era in which I was reared and schooled in. I helped to look after my younger brother and when the neighbour has twin girls I practically spent every free moment helping her out. I cooked and sewed, went to Brownies and then Girl Guides and developed home craft skills. I am not a mother personally, however I have “mothered”. I have cared for children, from infancy to adolescence; I have been present for many young mothers, assisted in establishing breastfeeding, teaching infant care and basic childcare; both in my role as a nurse as

well as having been a sister and friend to many mothers. I am still contacted to provide advice and support in the mothering role.

In caring there is an engagement with children and families. Paterson and Zderad (1988, p.21) describe engagement as “a commitment to reach out to understand the person in a nurturing manner that directs the person towards their human potential and with a will or concern to understand and help the person”. Watson (1985) describes nursing as the art and science of human caring. From these definitions it is clear that caring is fundamental to the role of nursing. Burns (1994) supports the role of nurses in caring to extend to encompassing the child and family.

Family centred care is a key principle of care that is practiced in paediatric settings (Coyne, 2005b). As a paediatric nurse, I have worked in partnership to support and nurture the child and family unit. I appreciate the opportunity to be involved in the lives of children and their families facing health challenges, observing the physical, emotional and social effects of illness and recognising the need for effective support measures including good communication to enhance care processes. As my knowledge and experience has developed, I have been drawn to become more interested in the experience of health for children and their families across the care continuum. This interest extends from diagnosis to treatment and the eventual return to health and normalcy in children’s lives. In order to gain a personal understanding of the meaning of lived experiences, phenomenology has something to offer as a methodology.

Phenomenology – the study of lived experiences

Phenomenology is an effective methodology to discover the meaning of lived experiences (Spiegelberg & Schuhman, 1982). Phenomenology is suitable for researching nursing questions about nursing phenomena. So it is no surprise that phenomenology is “probably the most common methodology in nursing and midwifery in Aotearoa/New Zealand” (Giddings & Wood, 2001, p. 15). Phenomenology is a research method that can provide understanding of the person’s reality and experience, valuing individuals and the nurse-patient relationship, embracing a holistic approach to the person (Benner, 1985; Holmes, 1996). Phenomenology has been influenced by two

major philosophical perspectives; Husserlian transcendental phenomenology and Heideggerian hermeneutic phenomenology.

Linking the philosophical assumptions of Heideggerian hermeneutic phenomenology to the purposes of research would appear to be a logical step. Draucker (1999) suggests that partnerships with philosophers and other scholars should be strengthened allowing ideas from Heideggerian interpretive phenomenology to not only guide their methods, but also enrich their findings creating new narrative literature that allows for flexible and creative presentations of interpretive findings, while demanding adherence to sound interpretive scholarship.

Heideggerian hermeneutic phenomenology

The Heideggerian approach to the phenomenological methodology supports the notion that data is generated by the knowledge of the participant as well as the researcher (Walters, 1995). The preunderstandings of the mothers as well as my own preunderstandings must be considered. In utilising a qualitative research methodology, the narrative stories and experiences of mothers talking about their children are balanced against the knowledge and preunderstandings of the participants and my own preunderstandings. The aim is for clearer insights and understanding that will contribute to the overall thematic analysis.

I acknowledged my own background and preunderstandings and I immersed myself into the subject through a number of medium as suggested by van Manen (1990). A process of review and critique of the classical and current published literature both on the topic of paediatric liver transplantation and other aspects related to understanding the research topic was completed. I explored other ways of knowing that contributed to my understanding such as literature, short stories, poetry and fiction as well as other sources such as media and audiovisual collections. The role of the background to the research inquiry is an important distinction of the Heideggerian hermeneutic phenomenological approach (Draucker, 1999).

The Heideggerian hermeneutic phenomenological research method has been widely utilised to gain understanding of the lived experience of undergoing procedures, coping with illness and life-changing events (Draucker, 1999). Heideggerian hermeneutic phenomenological research methods have also been used to enhance understanding of transplant experiences. Liver transplantation has been studied in this manner to understand the meaning of life following recovery from liver transplantation (Gubby, 1998; Robertson, 1999; Wainwright, 1995; Thomas, 1995), though these inquiries are focused on adult liver transplant experiences. The hermeneutic reflection in these research articles provides insights into the real meanings of the participants' lived experiences.

Wise (2002) examined the lived experience of children who had undergone a liver transplant. This hermeneutic phenomenological study aimed to uncover the experiences of paediatric liver transplant recipients from the period prior to transplantation, through surgery and beyond. This study was carried out in the United States. It relates to a different health system, culture of child rearing and focuses on a wider experience of liver transplantation from the pre-transplant to post-transplant period. Despite this, there are some similarities to the New Zealand child's experience. Replication of the study in New Zealand study might show whether New Zealand children experience similar lived experiences. It would also be enlightening to see whether the experiences of the children, had any relevance to the meanings of the lived experiences of the mothers in caring for their transplanted child. As I made my way through the published literature to find background to support my research question, I found that there was little hermeneutic phenomenological nursing research to be found around my research question.

Summary

In presenting the background of this research inquiry, you have been introduced to liver transplantation in all its complexity. In coming to develop an understanding of the background to the topic, this literature review has considered the ways of knowing and the influence of their lived experiences as children, mothers and nurses. The concept of family in relation to child rearing and care of the child who has undergone a liver

transplantation is discussed. Maternal thinking has been discussed and the three main interests identified by Ruddick have been explained. The concept of family centred care has been explored through the literature review to develop an understanding of what caring in a paediatric service entails. Some key terms have been defined to clarify meanings. An overview of the history of liver transplantation has been provided. I then provided an update of liver transplantation today, covering statistics, organ donation and cultural influences. The process of paediatric liver transplantation in New Zealand is provided.

In coming to develop an understanding of the background to the topic, this literature review has considered the ways of knowing and the influence of their lived experiences as children, families, mothers and nurses. The concept of care has been explored throughout the literature review to develop an understanding of what caring is in relation to my own understanding of care. The concept of family centred care was discussed and the involvement of mothers as key caregivers was supported. Mothers are intensely involved in caring for their child. Mothers' experiences of caring for children with high health needs were sought. Maternal thinking has been discussed and the key goals of mothers have been identified. Various definitions of caring have also been provided.

In accordance with Heidegger's philosophical framework, the importance of the researcher's background is acknowledged in order to provide information that also impacts on the final interpretation of the data. Phenomenology as a method of uncovering the lived experiences has been discussed. Examples of other studies that have also utilised hermeneutic phenomenology in caring were presented. Hermeneutic phenomenology is supported as a reliable source of knowledge and a reliable method. There is growing amount of research into the experience of liver transplantation. The majority of literature was found to examine the adult experience.

Little research has looked at the lived experience of the child and even less using the maternal perspective. Mothers have traditionally taken on the majority of the caregiver role, and they are well placed to describe their child's wellbeing. The long-term effect of liver transplantation on children needs to be researched, so that issues relating to quality of life and well being can be more fully addressed.

CHAPTER THREE - THE METHODOLOGICAL JOURNEY FOR A PHENOMENOLOGICAL RESEARCH APPROACH

In planning a journey, a starting and finishing point is visualised, a route is planned and the mode of travel chosen. Similarly, in undertaking a research project, a starting begins with an interest and formulation of research questions or hypotheses. The destination of the research journey is the final interpretation and statement of recommendations, contributing to the overall significance and value of the research and new knowledge uncovered. The actual journey is a voyage of discovery of knowledge. In this chapter I discuss the methodological decisions that were intrinsic to my research journey.

In this chapter, I discuss the theoretical framework that justified the qualitative approach in contrast to a quantitative approach. In supporting my decision to select hermeneutic phenomenology to answer the research question, I have returned to the process I used when I explored the most appropriate way to answer my research question. The philosophical underpinnings of phenomenology are summarised, emphasising the key differences between the philosophies of Husserl (1913/1970) and Heidegger (1927/1962). I then summarise some of the distinctions between Husserlian phenomenology and Heideggerian phenomenology.

Assumptions and principles underlying hermeneutic phenomenology are discussed. I present the selection of van Manen's (1990) structural framework of hermeneutic phenomenology to provide a way forward in ensuring that the methodology can be worked through in a compassionate manner that is true to the chosen methodology. In the early stages of planning this research, there were several considerations I needed to confront in regards to methodological selection. Hermeneutic (interpretive) phenomenology is an effective method of gaining an understanding of the meaning of life following recovery from liver transplantation. The method has been widely used to capture the lived experience of individuals. The published literature has many examples

of patients sharing their lived experiences, as well as exploring the meaning of the lived experience of being a parent or caregiver and their own lived experience.

Hermeneutic phenomenology, as a research methodology, allows a thoughtful reflection of my research questions to gain a deep understanding of the meaning of caring for the child who has recovered from transplantation. The understandings may contribute to the planning and implementation of nursing care, as well as enhancing the perceptions of the experiences and outcomes of the child. In delving into the shared world of the mother and child it is anticipated that the child's lived experience and being-in-the-world will be revealed. The use of Heideggerian hermeneutic phenomenology values the understandings and meanings of the children and families and this may enhance nursing care delivery

Starting the journey, selecting the path and staying on track

Following an exploration of the field of paediatric liver transplantation, a research question emerged that formed the basis for this thesis. This research journey began with a research question. The question developed guided the selection and justification of hermeneutic phenomenology as the methodology for my research.

<p>What are the meanings of a mother's lived experience of caring for her child who has recovered from a liver transplantation?</p>
--

In my research, I wanted to elicit understandings; insights and perceptions from exploring the mothers' lived experiences' of caring for their children who had been faced with liver failure, undergone and survived a life-saving liver transplant and had now recovered.

Phenomenology as a research methodology

Polit and Hungler (1993) define phenomenology as “an approach to human inquiry that emphasises the complexity of human experience and the need to study that experience holistically as it is actually lived” Phenomenological enquiry focuses on the intersubjective or universal experiences of individuals (Walters, 1994).

The phenomenological approach is congruent with the philosophical orientation to holism of nursing (Oiler, 1982). Holism is defined as the consideration of the complete person in the treatment of disease. The phenomenological approach has a high degree of applicability for nursing research (Walters, 1994). The phenomenon of interest to nursing is the everyday lives of people being-in-the-world, usually coping with health, some form of illness or procedure. Phenomenology is suitable for researching nursing questions about nursing phenomena (Taylor, 1994). Phenomenology has the potential to create a reflective and considerate approach to nursing care by revealing the true nature of the lived experience. Phenomenological research contributes to valuing individuals and the nurse-patient relationship (Benner, 1985), and though not the primary aim of the research, can have positive outcomes for participants.

Phenomenology originates from the domain of philosophy. Phenomenology as a branch of philosophy has been influenced by a number of philosophers including great names such as; Husserl, Heidegger, Gadamer, Marcel, Sartre, Merleau-Ponty and Ricouer. The phenomenology of Husserl and Heidegger will be outlined to provide an overview of their works and the associate notions and assumptions.

Phenomenological study requires a close observation and scrutiny of human experience as lived by the participants. Phenomenologists believe that knowledge and understanding are in our background and that these cannot be made completely explicit (Koch, 1995). People and the contexts in which they live are interdependent. Knowledge and understanding of life may emerge from people’s life experiences. In the next section I summarise the key differences between Husserlian and Heideggerian

phenomenology. The reasons for choosing to take the path of Heideggerian phenomenology and focus further into the work of van Manen became clearer.

Husserlian eidetic phenomenology

Edmund Husserl lived from 1859-1939. Husserl, a German philosopher and a mathematician, is often considered the founder of phenomenology. His ideas developed in the late 1800's. Husserl's philosophy was the close of the Cartesian tradition, and came to mean the study of phenomena as they present themselves through the consciousness (Koch, 1995). Husserl aimed to establish a science of phenomena, as a science of cognition of essences rather than matters of fact (Annells, 1996). Mathematics influenced Husserl's thinking and he sought a logical method to gain understanding of human consciousness (Byrne, 2001a). Husserlian phenomenology is considered the grand finale of the Cartesian tradition; thinking of a human's relationship to the world in terms of subjects knowing objects (Dreyfus, 1988). Husserl considered that his method was the only way to advance philosophy to the status of a rigorous science. Early nursing phenomenological researchers utilised Husserlian phenomenology. This may have been driven by a need to gain recognition, funding and acceptance by scholarly institutions who valued the quantitative research paradigm (Allen, Benner & Diekelmann, 1986).

Husserl's basis of knowledge or epistemology was realised by reduction (also called bracketing (Byrne, 2002). Husserl contended that bracketing (setting aside preconceived notions), enabled phenomenologists to describe the phenomena under study in an objective manner (van Manen, 1997a). Husserl maintained that by suspending commonly held beliefs or presuppositions, that this would assist phenomenologists to describe the fundamental structures in our life-world, the world of lived experience (Cohen & Omery, 1994).

In utilising the Husserlian approach to a research inquiry, the researcher needs to clearly state their assumptions prior to data collection and analysis. The researcher does not

undertake extensive literature review until data collection is completed, thus preventing the effect of preconceptions and prior knowledge. In this method, the researcher remains detached from the participants. In utilising these strategies, Husserl proposed that the research would demonstrate the ideals of science including rigour and objective ways of knowing in reducing human experience into descriptive essences. This challenges my own philosophy; I oppose the concept that one can set aside one's own beliefs and knowledge based on personal experience and knowledge in a completely objective manner.

Heideggerian phenomenology

Martin Heidegger (1889-1976) was a student of Husserl. Heidegger reconceived many phenomenological perspectives. Heidegger moved from the epistemological emphasis of Husserl to an emphasis on the ontological foundations of understanding, which is reached through 'being-in-the-world' (Annells, 1996; Dreyfus, 1991; Gelven, 1989).

Plager (1994) outlined five main assumptions of hermeneutic phenomenology described by Heidegger in "Being and Time". I have utilised the concepts to allow me to position Heideggerian hermeneutic as a methodology for research. The assumptions are written in Times New Roman bold italics font and this is followed by commentary to clarify the assumptions and relate it to my research inquiry;

Human beings are social, dialogical beings (Heidegger, 1927/1962; Taylor as cited in Plager, 1994; Ten Have & Kimsma, as cited in Plager, 1994).

Heidegger called everyday existence 'Dasein'; this can be literally translated to mean "being there" (Dreyfus, 1991), or what it means 'to be' (Gelven, 1989). In coming to understand ourselves as human beings, we need to discover how we exist in our everyday lives; Heidegger (1927/1964) called this "average-everydayness". This notion

is central to this research inquiry as it is the mothers' every day lived experiences of caring that I intended to encourage the mothers to talk about.

Heidegger claimed that we are culturally and socially embedded in familiarity with our practices and skills, developing common meanings and understandings and that these experiences are bound by time. Heidegger emphasised the importance of 'temporality' or time so that people might better understand the dimension of time in history to comprehend what it means for Dasein, to "be".

Heidegger stated that people are as much part of the world as the world is part of them (Lemay, 1994). A person's reality or world involved a set of meaningful relationships, practices and language by being born into a culture and each person's reality is qualitatively different (Heidegger, 1927-1964; van Manen, 1997a). This co-constitutionality is the philosophical assumption that the person and world are one (Koch, 1995).

Heidegger's notion of "thrown-ness" also had a high degree of applicability to my research. Heidegger (1927/1964) stated that every human being is completely shaped by the "world" into which they are thrown. Heidegger defined the "world" as the culture/social environment in which a person finds themselves. He went on to describe that at birth, a baby is "thrown" into a culture, however the does not become Dasein until their thinking and behaviour is shaped by their environment (Gelven, 1989). This has implications for my research through the shaping of human beliefs, values and behaviour is shaped by norms, standards and regulations. The impact of the environment and "thrown-ness" shapes the Dasein of the participants and shapes their understanding. Mothers have a huge part to play in providing the care for their child as to what the environment for the child will be. This has a direct affect on the way in which the child's understanding is shaped.

2. Understanding is always before us in the shared background practices; it is in the human community of societies and cultures, in the language, in our skills and activities, and in our intersubjective and common meanings (ibid).

The ideas of background, preunderstanding, co-constitution and interpretation arise out of the two notions. The notion of background is the knowledge that the person is handed down and is a way of understanding the world. It is what is “real” for the person. Heidegger’s position assumes that it is not possible for a person to completely clear about background meanings, skills and practices (Koch, 1995).

In contrast to Husserl’s assumptions, Heidegger proposed that there was no place for the techniques of bracketing and phenomenological reduction (Koch, 1995). The gender, culture, history, and related life experiences prevents us from maintaining an objective viewpoint.

Being-in-the-world is communicated through language. Language is the form of our communication and understanding. Language is a product of the human culture in to which we are ‘thrown’, it is not a tool, and it is a way of ‘being-in-the-world’, it is how we relate, come to understanding and share our reality and interpretations (Allen, Benner and Diekelmann, 1986) . The “collectivity of language” described by van Manen (1997a) has the capacity to limit or enhance a person’s ability to share their experience of phenomena. Heidegger emphasised that “language is as Dasein is” (as cited in Dreyfus, 1991). Hermeneutic phenomenology requires a sustained engagement with the voices, the text and associated works to gain understanding from the inquiry.

The concept of time was also a pivotal concept for Heidegger. “Time” is the key to understanding our being-in-the-world (Heidegger, 1927-1964). Time and being cannot be separated in trying to understand lived experience. Humans are bound by our culture and therefore shaped by the era in which we live and experience life (Koch, 1995). In the experience of liver transplantation, there have been phenomenal advances over time and liver failure has gone from certain death to survival and a return to health. Time is

a great healer. Time has witnessed great changes in the technological knowledge relating to human health and treatment. Time spans our being in the world in everything we do.

According to Heidegger's philosophy, a person's way of being-in-the-world occurs in three different modes; undifferentiated, inauthentic or authentic (Heidegger, 1927-1964). If a person was in an undifferentiated mode it implies that the person never questions their place in life. I understand this to be the non questioning acceptance of one's place in the world. Inauthenticity relates to a person's thrown-ness into the world. In this case the person takes charge of their own destiny by exchanging one world for another. This means living a life that they don't necessarily embrace, though nonetheless live in. In an inauthentic mode of Dasein a woman may rear and care for her children to bring them up in the culture in which they live even knowing that it is harsh or punitive. The last mode of a person's being-in the world is authenticity. This may be explained as a person living with the acceptance of the inevitability of death, and so living in harmony and exhibiting care towards their world and being (Heidegger, 1927-1964). He describes the authentic mode as a thrust towards synchrony. The person embraces their world and they in turn are embraced by their world. In an authentic mode understanding flows more freely. A participant's mode of being-in-the-world affects their ability to experience being-in-the-world and the phenomena of study.

3. We are always already in a hermeneutic circle of understanding (ibid).

Heidegger (1962) described the hermeneutic circle as the "circle of understanding". He stated that being in the circle is not a matter of choice, as we are always in the circle. Understanding relies on the shared understandings and practices of humans. Involvement in daily activities constantly enriches our understanding in a circular manner. We take into account all that has gone before, so our understanding exists or is "to hand" (Heidegger, 1927-1964). The process of understanding is ongoing and not static. Understanding is constantly built upon past experiences. This has implications for the children and families who have survived and recovered from transplantation.

The experiences they have had along the way have a direct impact on their current and future understandings and the meanings constructed.

4. Interpretation presupposes a shared understanding and therefore has a three-fold forestructure of understanding (ibid).

The notion of a three-fold forestructure links understanding with interpretation (Koch, 1995). Heidegger (1927/1962, p.192) described a three-fold structure consisting of forehaving, foresight and fore-conception. He called it “that which is taken for granted”. “Forehaving” is the arrival at an experience where a person uses their present skills and knowledge to interpret the experience. “Foresight” is the point of view that a person has because of their background and helps them make an interpretation. Finally “fore-conception” relates to the expectations related to the person’s background that helps them to anticipate when interpreting an experience (Koch, 1995). This is an explanation of why Heidegger did not believe it was possible for a researcher to put aside assumptions, preconceptions or beliefs about a phenomenon. My lived experience as the researcher has a direct bearing on the way in which the phenomenon is interpreted. If another researcher was to undertake the same research as I have undertaken, their interpretation would be different from this one.

5. Interpretation involves the interpreter and the interpreted in a dialogical relationship (ibid)

Heideggerian phenomenological research is more concerned with understanding and interpreting human experience than describing it. The researcher or interpreter and the participants engage in a dialogical relationship that allows the researcher to delve into the data and drawing out essences and interpretations, In turn the participants verify the stories and through a process of teasing out and dwelling in the data, meanings are able to be drawn out. In the process of collecting the data, the comments were related back and confirmation was sought that the meanings were congruent with the meanings they had for the participant.

Max van Manen's structural framework for hermeneutic phenomenology

Max van Manen is a Professor of Education at the University of Alberta in Canada. His research endeavours have included education, health sciences including psychology and nursing. Van Manen was influenced with “the hermeneutic phenomenological traditions arising out of Germany (from about 1900 to 1965) and the Netherlands (from about 1945 to 1970)” (van Manen, 1990, p. 2). In these schools of phenomenology there was no marked concern with a prescribed method or epistemology, rather the student learnt about phenomenology by doing phenomenology, with the good texts arising from the talented scholars. Van Manen was influenced by the works of Husserl, Heidegger, Langeveld, Beets, Bollnow, Gadamer, Dilthey and, Merleau-Ponty. Van Manen (1990) acknowledges the contribution of the philosopher Gadamer. He supported the suggestion that an obsession with method went against the intent of human science study. He goes on to describe the contribution of William Dilthey, developing the distinction between the natural sciences and the human sciences and that Dilthey proposed that the subject matter of the human science method is characterised by; focusing on persons or beings, having a consciousness or awareness; acting in a purposeful manner both in and on the world and creating meanings that express the experience of being-in the-world. Van Manen (1997) supports dialoguing with participants through in-depth interviews as well as utilising other texts such as publications, artworks, films, novels and the researcher's journal to facilitate understanding.

Van Manen (1990) proposes a methodological structure for performing hermeneutic phenomenology consisting of six procedural actions. The method extends Husserl's philosophy of the “lifeworld” and Heidegger's hermeneutic interpretation. I utilised this framework to guide the interpretation of the findings and enhance my analysis. The framework allows the analysis to be worked through in a sympathetic and mindful manner, discovering the essences of phenomena to develop deeper understandings of the meanings that phenomena have for people. There is no single standardised method for hermeneutic phenomenological inquiry. In fact it is argued that there is no method

(Gadamer (1975). By using thematic analysis the researcher identifies essential themes of the phenomenon, as described by van Manen (1990) and Byrne (2001c). In this inquiry I observed the structural framework, however I moved in and out and round the data to ensure that I did not make conclusions too readily and therefore risk stifling the interpretation.

Van Manen (1990) does not support a step-by-step set of procedures in performing phenomenological research. He argues that interpretation is supported through the depth of description of the phenomenon. Skilful writing techniques convey the findings, the researcher uses narratives, stories and paradigm cases to support the analysis. Van Manen's (1990) six procedural actions have been used to describe how the methodology fitted with my intention of answering the research question.

(1) Turning to a phenomenon which seriously interests us and commits us to the world (van Manen, 1990, p. 30-31).

In order to really delve into the phenomenon and obtain rich and detailed descriptions, the researcher should not only know their topic but should be interested in the topic to the extent that they really want to know the answer to the research question. Paediatric liver transplantation is an important feature of my occupation and the challenges of providing optimal care to children and families is a major interest to me. The importance of the maternal voice in providing insights into their child's wellbeing is extremely important. This is a tribute to the mothers/caregivers who provide care to their child once recovered sufficiently from a paediatric liver transplant to be cared for at home and protect/safeguard the liver function of this special gift of a donated organ.

(2) Investigating experience as we live it rather than as we conceptualise it (ibid).

In exploring the experiences of the mothers, it is important to investigate the experience as it is lived. The notion of 'being-in-the-world' enables researchers to bring their experiences and understanding to the research. Heideggerian phenomenology necessitates a closer researcher involvement than the more detached standpoint of

Husserlian phenomenology (Koch, 1995). We learn about our world from being in our world; reading widely, talking and listening to people; including colleagues and families, and watching people's behaviours. People must be viewed and understood in the context in which they were living and experiencing their daily reality.

(3) *Reflecting on the essential themes which characterise the phenomenon (ibid).*

In utilising a qualitative research methodology, the narrative stories and experiences of mothers talking about their lived experiences and of caring for their children emerge. The knowledge and preunderstandings of the participants and my own preunderstandings, provide clearer insights and understanding that will contribute to the overall thematic analysis and the identification essential themes. Through this reflection on the essential themes, a greater understanding of the lived experiences of mothers caring for their children who have had liver transplants will be achieved.

(4) *Describing the phenomenon through the art of writing and rewriting (ibid).*

Writing.... rewriting... rewriting..... Writing is the process of putting the voice onto paper. The writing is reflected upon continuously, until the characterisation is completed (van Manen, 1990). In transcribing the interviews, the words are captured allowing the researcher to review and dwell upon the words. In the process of the interviews, field notes are taken during and immediately after each of the interviews, to capture expression, emotions and other data that would be lost in transcription process. Each draft of writing unfolds more meaning and exposes more of the phenomenon to the outside world. The written word captures the experience and gives a further level of understanding.

(5) *Maintaining a strong and oriented pedagogical relation to the phenomenon (ibid).*

A clear and disciplined orientation to the research question must be adhered to ensure that the description captures the essences of the inquiry. Van Manen recommends a “strong and oriented pedagogical relation” to the phenomenon in order to avoid loose

descriptions and early conclusions (van Manen, 1990). The researcher must keep an open mind in order to capture the true meaning of the phenomenon.

(6) *Balancing the research context by considering parts and the whole (ibid).*

The research inquiry is a circular process; in fact the circle continues to rotate although for the purpose of submission of the theses the process ends. Despite this the end is never absolute. During the undertaking of this research, research diaries, reflexive journals and personal journals were useful to record thoughts, ideas and reflections to maintain a balance and ensuring that the context was considered in the parts as well as in the whole. The breaking down of the data to its smallest unit allows us to see it at its most basic unit of understanding and this allows us to see how they make up meaning between the parts and the whole. It may permit the researcher to detect very subtle meanings that would be lost within the vastness of the data.

I have utilised the structural framework of Van Manen (1990) to guide my interpretation of the data. The framework makes a useful contribution to the methodological ground for contemporary human science researchers by progressing hermeneutic phenomenology for nursing research.

Summary

In undertaking a research inquiry a statement of the selected methodology which will facilitate the seeking of an answer to the research question was made. The philosophical framework that forms the basis of the selection of a qualitative approach is outlined. An overview of Husserlian and Heideggerian phenomenology is provided. Further exploration of the assumptions made by Plager (1994) in relation to Heidegger's hermeneutic phenomenology allowed for positioning of Heideggerian phenomenology as a methodology for this research. Heideggerian hermeneutical phenomenology, as a research methodology, allows a thoughtful reflection of my research question to gain a

deep understanding of the meaning of the lived experience of mothers caring for their children who have recovered from a liver transplant.

Van Manen's (1990) approach to hermeneutic (interpretive) phenomenology informed by Heidegger's concepts was used to undertake the inquiry. Van Manen's methodological structure for performing hermeneutic phenomenology using the proposed six procedural actions was used. The key processes were upheld without placing need for an ordered approach.

The well-used phrase "there are many means to an end", is applicable to the many methodological approaches that could be taken to answer a research question. The researcher selects the most appropriate methodological approach to answer the research question. To answer my research question, I have used van Manen's hermeneutic phenomenological approach informed by Heidegger's philosophical assumptions. In applying the methodological decision the next chapter describes the methods and design process.

CHAPTER FOUR - METHOD AND DESIGN OF THE RESEARCH TO INVESTIGATE THE LIVED EXPERIENCES OF MOTHERS

The focus of my research inquiry was to investigate the lived experiences of mothers, whose children have undergone and recovered from a liver transplant. In using hermeneutic phenomenology, this chapter describes the method and design I employed to answer my research question. The decisions around method and design of the research needed to be congruent with the hermeneutic phenomenology of van Manen informed by philosophical notions of Heidegger.

The six important characteristics of a qualitative research approach described by Streubert and Carpenter (1995) have provided a manner in which to discuss the method and design features in an organised manner. Using their characteristics I cover the particular steps and rationale for the design features. This covers all aspects relating to the manner in which the research was undertaken and included; sampling; recruitment; cultural considerations; interviewing; transcription; data collection; data management; analysis; ethics; reflectivity; reflexivity; writing and issues of rigour.

In working with the data I describe the processes used to move towards an assembly of the analysis, beginning at the commencement of the research and moving forward towards interpretation of the meanings of the lived experience. I describe the process of hermeneutic phenomenological reflection used for analysing the data to draw out the essences of the lived experience. Writing in the hermeneutic phenomenological tradition is discussed as an integral part of the research process.

Focus of the research inquiry

The focus of this research inquiry was to explore the meanings of the lived experiences of mothers in caring for their children who have undergone and recovered from a liver transplant. The research highlighted the depth of knowledge held by mothers about their children and the shared lifeworld of the mother and child. Interviewing mothers

provided an opportunity to gain reflections upon the meaning of the lived experience of caring. My research question was congruent with utilisation of the hermeneutic phenomenological approach proposed by van Manen and informed by the philosophy of Heidegger.

Qualitative research methods

Quantitative and qualitative approaches are employed to answer all manner of research questions. Nurse researchers are increasingly utilising qualitative research approaches to study problems of interest to nursing (Bailey, 1997). There is a growing inclination to utilise a variety of methodological approaches in the search for new knowledge and understanding in nursing (Reeder, 1985; Sarter, 1988).

Qualitative research examines phenomena as they occur in their natural settings to interpret the meanings that the phenomena have for people. A qualitative approach involves the collection and analysis of subjective narrative materials, and a minimum of control is imposed by the researcher (Burns, 1994). Qualitative research explores lived experience to understand and extract meaning. It involves the systematic collection and analysis of narrative materials in a manner ensuring credibility of the data and results (Byrne, 2001b).

Streubert and Carpenter (1995) identified six important characteristics of a qualitative research approach, and this lent support for utilisation of the framework to support the method and design of this research inquiry. Each of the six features is written in Arial bold italics font. I have then gone on to explain the relevance of each characteristic to the research method and design.

A belief in multiple realities (Streubert & Carpenter, 1995, p. 10).

Each of the participants in this research had varying experiences around caring for their transplanted child. Their children were at different ages and stages of development both at the time of transplant and at the time of the mothers' interviews. Each child's degree of incapacity prior to and recovery following transplant was unique. The social, cultural emotional and physical characteristics are examples of the differences; these in turn create different individual realities for the participants.

Sampling

Sampling is defined as "the utilisation of a proportion of individuals or cases from a larger population, with a view to those participants being representative of that population as a whole" (Minichiello, Aroni, Timewell and Alexander, 1995, p.). The population is defined as the entire set of individuals who could be studied (Polit & Hungler 1993). Sample size is decided in accordance with the chosen research methodology.

In undertaking a hermeneutic phenomenological research inquiry, the need to explore the meaning of the lived experience in an in-depth manner was positively linked to a smaller sample size. For the purposes of this study, it was felt at the outset of the research design, that a sample size of four to six participants would be sufficient to be applicable to the existing paediatric liver transplant recipients.

Minichiello, Aroni, Timewell and Alexander (1995, p.) define reliability as "the extent to which a method of data collection gives consistent and reproducible results when used in similar circumstances by different researchers and/or undertaken at different times". I found that after interviewing three mothers that similar themes were arising out the interviews. When recurring themes arise out of the interviews of participants it is a good indication that sample size was satisfactory to inform the findings. A smaller sample size fits well with the hermeneutic phenomenological approach, as the method allows the researcher to concentrate on extracting more detailed data.

Purposive sampling is defined by Polit and Hungler (1993) as a sampling method in which the researcher selects the subjects on the basis of personal judgement. The participants are selected on the basis that they will be the most representative or productive. This method of sampling is appropriate for an in-depth study where the results are not to be generalised (Guba & Lincoln, 1994). In developing the sampling process, inclusion and exclusion criteria were developed in order to ensure that the participants would be able to provide the data that would answer the research question. The number of New Zealand children who have undergone liver transplantation is small and this meant that the sample for this research would be small. Once sampling decisions were made, recruitment of participants proceeded.

Recruitment of participants

The selection of participants was an important feature of the design. The selected participants needed to be able to provide data that would successfully answer the research question. The participants for this study were mothers of paediatric liver transplant recipients. I have only provided a brief general outline of the participants with a view to ensuring anonymity, to the best possible standards.

In selecting mothers as participants, sampling criteria were developed to ensure that the participants would be able to provide data that would provide insights into the issue. Robertson (1999) utilised a hermeneutic phenomenological study to portray the lived experience of adults in the post-liver transplant period and this study had described clear criteria that in turn supported the sampling criteria for my research. These were considered and adapted in developing sampling criteria for my study.

The process of recruitment of participant for any research depends largely on the goodwill and willingness of participants. There was no pecuniary reward for participation. This research project could not have proceeded without the successful recruitment of mothers as participants. The recruitment process was tailored to gain participation of mothers who could provide in-depth dialogue, to provide insights into revealing answers to the research question. The recruitment of mothers did not commence until ethical approval had been obtained. The inclusion and exclusion

criteria were designed to assist in recruitment of participants that would most likely be able to provide accurate insights into the research question (Cohen, Kahn & Steeves, 2000).

Inclusion and exclusion criteria

In discussing the inclusion and exclusion criteria, I have provided the reasoning for the sampling criteria for my study is provided. Inclusion criteria are the features that allow inclusion and participation in the study. Exclusion criteria are the criteria used to exclude participants from participation in the study.

As discussed in Chapter 2, mothers were selected as fairly consistent primary caregivers of chronically ill children (Gravelle, 1997). I decided that mothers of children did not need to be in a traditional nuclear family structure. Families are no longer confined to the traditional nuclear family structure. Inclusion of the children's mothers as participants was preferred, though other caregivers undertaking a 'mothering role' were also considered. Where a different primary caregiver such as an "adoptive" mother, was responsible for the everyday love, care and attention of the transplanted child, that person would not have been excluded from participation. This was made in respect to the cultural differences of Maori and Pacific Island participants, where interfamily adoption or whangai adoption is a fairly common practice. The manager of Maori Health services at Starship Children's Health, (August 2002), supported this stance. Both Maori and Pacific Island groups might otherwise have been excluded from the research due to the family custom.

It was a basic assumption that the majority of the participants would be able to speak fluent English. From my dealings in the clinical practice setting, I had observed that most parents were able to speak English to a level that allowed them to convey their perspectives about their child's well being. The waiting period for liver transplantation is lengthy, accompanied by prolonged periods of hospitalisation. I also observed that parents' fluency and comprehension of the English language improved with the need to communicate with health care team members regarding their child. Selection for liver transplantation in New Zealand is usually based on the individual being a permanent

New Zealand resident. The majority of transplant recipients speak English or are demonstrating an improving fluency in English. Where fluency of English of a participant was an issue, and I perceived lack of competency in communication, the participant was excluded from the research.

Criteria were also applied in regard to the transplanted child's condition and circumstances in selection for suitable participants. The circumstances included the length of time since transplantation and the child's well being at the time of the mother's interview. The child needed to be at least one-year post transplant at the time of the mother's interview. This allowed for the child to recover from the surgery, overcome possible complications and adjust back to home life. The second requirement was that the child was followed up as an outpatient by Paediatric Liver Transplant Service, Starship. This would allow me to ensure that identified needs could be relayed to the most appropriate service, e.g. support services at Starship

A further requirement was that the child recipient must not have been an inpatient in hospital for at least three months prior to the interview. The child was required to be relatively well when their mother was interviewed. The child's current level of well being was considered relevant to recent hospitalisation. Recent hospitalisation was defined as within the previous three months at time of the interview. This criterion was developed to accurately portray the mothers' lived experiences of caring and nurturing their now well child in as normal home setting as possible. Recent hospitalisation had the potential to affect the mother's perceptions and experiences related to the child's lifestyle. A shorter time of non-hospitalisation was chosen than Robertson (1999). I made this criteria based on my knowledge that Starship clinicians have a lower threshold for readmission to hospital and that it was not uncommon for the children to be readmitted. This would have limited my overall possible number of participants.

Children not living locally in the Auckland region, have a higher incidence for precautionary hospital admission to their local base Hospital or to Starship Children's Hospital. Abnormal blood results or fever are rigorously investigated to exclude the diagnosis of a serious illness or graft rejection. Where access to Starship is difficult, e.g. due to distance from hospital, measures are implemented to ensure that the child

with a liver transplant has easy access to early treatment in the event of rejection or sepsis.

Recruitment of participants was based on the total number of possible participants after the application of the inclusion and exclusion criteria. Participants were recruited from the current outpatient lists of paediatric liver transplant clinic at the Starship Children's Hospital. Potential participants were selected in conjunction with the paediatric liver transplant and gastroenterology nurse specialist. A list of the total sample population was formulated and then utilising the sampling criteria, inclusion and exclusion criteria were applied. A list of possible participants for recruitment resulted.

Participants' children were not required to have had their liver transplant in New Zealand, though they needed to be residing in New Zealand at the time of the interview. Using a sample of mothers who were living in New Zealand assisted the researcher to generalise the findings to a New Zealand perspective.

Approaching the participants

The paediatric liver transplant and gastroenterology nurse specialist made the initial approach to potential participants using the list of possible participants. The potential participants were approached when they came to an outpatient clinic, or alternatively, the nurse specialist phoned the participants. Agreement for the nurse specialist to take this role was confirmed with the clinical director of the service. Owing to the small number of participants required, it was felt that this would have minimal impact on the nurse specialist's current workload. When the nurse specialist confirmed that she had contacted five potential participants and sent the necessary documentation to them, further recruitment was suspended to avoid unnecessary disturbance of mothers.

The Information Sheet (see Appendix Two) and Participant Response Sheet (see Appendix Three) were designed in the development of the project and approved by the Ethics Committee. The Information Sheet described the intended research in general terms and provided potential participants with information to assist them in reaching a decision as to whether or not they wished to participate in the research. The nurse specialist either gave or sent an Information Sheet and Participant Response Sheet to

each potential participant. Where face to face contact was not made with the potential participant, the nurse specialist followed up with a phone call. Reply paid envelopes were provided. The telephone contact numbers were included so that the participant could choose to contact the researcher or researcher's supervisor at the Graduate School of Nursing, Midwifery and Health at Victoria University of Wellington.

I did not make the initial approach to potential participants. This was designed to ensure that participants would not feel coerced or pressured to participate. The potential participants were advised that I would not contact them directly unless they indicated a willingness to participate or requested additional information. It was stressed that it was their choice whether they wished to participate.

Introducing the participants

Five mothers indicated an initial interest in participation in the research. The Information Sheet and the Participant Response Sheet were then sent out. In the interests of maintaining participant confidentiality and privacy details of the participants I have only utilised non-identifying data.

Each of the participants had a child who had a functioning liver transplant at the time of interview. Information was obtained about the age of children, time since transplant, current level of well-being, family structure and where they lived. For the purposes of the analysis and ease of writing I limited the information to prevent identifiability. I gave each of the mothers a pseudonym (fictitious name). A pseudonym was also given to their child.

In allocating pseudonyms, I gave the mothers a name corresponding to the alphabet to denote the order in which they were interviewed. I allocated each mother's child with a pseudonym starting with the same letter of the alphabet. This allowed me to think about the order in which I had interviewed the participants and also helped me to link the mother and child pseudonyms to each other when I was analysing the texts.

Table 1: Introducing the participants

Participant Number	Order of interview	Pseudonym of mother	Pseudonym of child	Age of child at time of proposed interview (years)	Comment Ethnicity
1	1	Anne	Alex	4	NZ European
2	2	Brenda	Betty	12	NZ European
3	3	Cara	Chloe	8	NZ European
4	n/a	Dora	David	13	Withdrawn due to child's deterioration -Pacific Island
5	n/a	Edna	Eve	3	Withdrawn due to inability to contact -Maori

Initially the sample consisted of three New Zealand European mothers, one Maori mother (Edna) and one Pacific Island mother (Dora) and they all lived in New Zealand at the time of recruitment. One of the five was subsequently unable to be contacted, leaving four mothers. Finally, only three mothers participated in the research, as the circumstances around the wellbeing of the child of one of the four changed prior to the interview and therefore did not meet the inclusion criteria. As the first three interviews had already been undertaken and strong congruent, consistent themes were arising, I was confident that I had sufficient data to undertake an analysis that would inform me of the lived experiences of caring for a child. After the withdrawal and exclusion of two participants, all the participants were New Zealand Europeans. The mothers were not necessarily living in Auckland. The reasons for the lack of representation of Maori and Pacific Island participants are discussed next.

Five prospective participants were approached and they all indicated their initial interest by returning the Participant Response Sheet (see Appendix Two). I then phoned each participant who had expressed an interest in participating at a time that was indicated to

be a suitable time in the Participant Response Sheet. Potential participants were fully briefed when contact was made. It was at this stage that I explained that I really wanted to get the maternal perspective of the lived experience. I discussed that the information sheet had not been really clear and that I needed to be sure that I was collecting the data accurately. It was agreed prior to proceeding that they understood the research question and were in agreement. Only four participants were able to be contacted.

Edna was unable to be contacted on the listed phone number and despite leaving several detailed messages on the answering system, no contact could be made using the contact information I had been provided with. I wrote a letter to Edna giving my contact details and suggesting that if I didn't receive a response I would accept that as her decision not to participate. I heard no more.

I commenced with interviewing the four participants and decided to assess the need for further participants at the completion of the four interviews. Unfortunately before I could commence the interview of Dora, her son fell very ill and no longer met the criteria for inclusion. I was unable to proceed with the interview, as her child experienced deterioration in his condition and hospitalisation as this would have altered her experiences of caring for her child following transplantation. I informed Dora of my decision and reasoning and thanked her for her interest.

Cultural safety

Maori and Pacific Island children with liver failure are over represented in the incidence statistics (Starship Liver Transplantation Business Plan, 2000). Biliary atresia, a major reason for requiring a liver transplant in childhood (Hadzic, Davenport, Tizzard, Singer, et al. 2003), is known to occur more frequently in Maori and Pacific Island children. All the Maori children who underwent liver transplantation between January 2002 and November 2006 had a diagnosis of extra-hepatic biliary atresia as the reason for their liver failure (Wilde, et al., 2007).

Researchers have an obligation to ensure that research undertaken in New Zealand is carried out in a manner that recognises their obligation to the Treaty of Waitangi. The implications of the Treaty of Waitangi for this research were addressed.

Acknowledgement, involvement and consideration of Maori issues were required. The New Zealand Health Research Council website has a specific section pertaining to research that involves Maori participants (<http://www.hrc.govt.nz/Maoguide.htm>). Two key areas in research relate to lack of consultation with Maori and not reporting findings of the research to Maori. This was acknowledged and incorporated into this research.

I consulted with the Ward Kaitiaki and the manager of Maori Health Services at Starship Children's Health. Their responses for my research were supportive and encouraging. This research was viewed as an opportunity to consider the implications and benefits of paediatric liver transplantation for their people. During the initial business case development for paediatric liver transplantation in 2000, Maori input was sought. Further contribution of advice and support was extended in the planning of this research. I met with the manager of Maori Health Services to obtain advice and critique of the planned interview process, to optimise data collection taking into account a Maori perspective. An offer was made to discuss specific findings relating to Maori to further enhance my own interpretation and analysis of aspects relating to cultural background.

Maori participants were offered Kaitiaki support or another nominated support person. I considered that the Kaitiaki would promote a sense of comfort and confidence to the participant, whilst being mindful of participant confidentiality. Kaitiaki also offered support to help with child minding support, as the family chose. There was one Maori mother (Edna), one Pacific Island mother (Dora) and three New Zealand European mothers (Anne, Brenda and Cara). Edna was withdrawn in response to being unable to contact her. It was felt that this may have been related to a change of mind and not wanting to lose face, or possibly a change of contact details that had not filtered through at the time of contact.

Pacific Island considerations

Similarly the researcher utilised the Pacific Island services in a similar manner to the Maori participant. Once again, prior to interviewing the participants I approached the Pacific Island Health Services Manager at Starship Children's Hospital. Suggestions were sought to optimise data collection, as well as to put participants at ease and

optimise the data collection during in-depth interviewing. During the analysis of data, subtle insights were to be discussed with the Pacific Island Health Service to optimise my interpretation.

Participant support

I explained to the participants that it was possible to have a support person present during the interview if they chose. Although the offer of a support person of their own choice or a mutually agreed, culturally appropriate support person was made, none of the participants wanted to have a support person present for the interview. This may have been due to the participants knowing me and feeling comfortable to talk on a one-to-one basis.

Childcare arrangements were discussed at the first telephone discussion to assess requirements for childcare. I explained that I had received funding that would pay for childcare during the interview if that was required. The funding also allowed for the reimbursement of any travel costs associated in attending the interview for the participant and a support person. The costs associated with childcare and support persons were budgeted for in the proposal. None of the participants identified or requested any needs for assistance with childcare or travel reimbursement.

A commitment to identifying an approach to understanding that will support the phenomenon being studied (ibid).

My research question sought meaning of the lived experience of mothers. The study of lived experience is supported by phenomenological research. The development of understanding and description of meanings emerged from in-depth interviews of the participants. In engaging in a one-to-one interview, there was the potential for the interview process to be therapeutic and have healing properties through the intensive level of communication. Aiming to understand lived experiences is about supporting and nurturing the phenomena and utilising phenomenology supported this.

Interview process and methods of data collection

The interview process is described with an explanation of the actions I took to adhere to the hermeneutic phenomenological research approach and maximise the data collection. The actions taken are discussed in relation to the published literature and best practice.

The interviews were audio-taped. I anticipated that I would have large amounts of data arising from the interview process. Audiotaping enabled me to obtain rich and detailed data, whilst simultaneously observing and recording data relating to body language, posture and other subtle cues in communication. Mothers gave consent to the audiotaping of interviews. An affirmative response to the request to audiotape was one of the inclusion criteria. Factors such as mothers' age, mothers' wellbeing and mothers' financial situation were not exclusion criteria. I observed that within a few minutes of commencing the interviews that the participants had relaxed and appeared largely oblivious to the audio taping and were able to share their experiences in an open manner.

I explained that the interview audiotapes would be transcribed by a transcriptionist. Participants were fully briefed regarding audiotaping.

Commitment to the participants' point of view (ibid.)

The interviews for this research were in-depth and unstructured. Open ended questions were utilised to encourage the participants to express their ideas and tell their stories. The interviews were audio taped and transcribed to capture the voices of the participants into written text. The writing of field notes during and immediately following the research to back up the transcripts with additional unseen data was also completed. Throughout the analysis, the voices of the participants were transferred into the body of work to demonstrate participant involvement, through direct quotes and the retelling of stories. The themes emerging were checked with the participants to ensure that their stories were heard, this contributed to ensuring issues of rigour.

I was confident that interviewing the mothers would reveal the meanings of the mothers' lived experience and that in addition, insights and glimpses of the child's wellbeing and life might be uncovered. Mothers are relied upon to provide information about their children at follow up appointments. Many people were sure I would want to know the child's experiences. They questioned why I was not interviewing children as participants in this research. Although any snapshots about the children's lives would be enlightening; I actually wanted to find the meaning of the lived experience of mothers' caring. I envisaged rich and detailed stories would be shared which would facilitate my analysis and interpretation. In the paediatric setting the contribution of mothers as highly credible informants is valued, as they are the primary carers and they know their children best. In the initial stages of this research, I did not really clarify my positioning in interviewing mothers to gain insights of their lived experience. As a result the initial forms were open to interpretation. In discussion with my research supervisor, I clarified my positioning, discussed my intentions with the mothers and ensured that they were in agreement. I notified the Ethics Committee of my progress and it was felt that my presentation and initial application had reflected my current goals

Transcription

Mothers consented for a third person, the transcriptionist, to hear the tapes. I explained to the participants that the transcriptionist had signed a confidentiality agreement. I chose to utilise a professional transcriptionist to transcribe the audiotapes. Byrne (2001b) recommends that the transcriptionist be familiar with medical technology and use of dictation machines. Pseudonyms were developed and some personal details changed to reduce identification. The transcriptions were coded to prevent divulgence of participant identity and stored in a secure locked cabinet that only the transcriptionist and myself would have access to. The participants were informed that the transcript and audiotapes would be held securely for ten years following the completion of the study. The participant was advised that they would then be either returned to the participant or destroyed according to their wishes.

Collecting the women's stories; the research interviews

Data collection was performed utilising unstructured in-depth interviewing. Polit and Hungler (1993) describe in-depth interviewing as a method of data collection in which an interviewer asks open ended questions of a respondent. The interviews were unstructured, allowing the interview to proceed in a manner that facilitated rich portrayals and stories by the participant. I developed a schedule of questions, though these were only used to help steer the conversation in the direction of meaningful data disclosure and collection where the discussion faltered. The interview data was added to the data already collected from other sources such as the media, journals, women's magazines, television and movies.

The participants were given a choice of venue for the interview. These were the Starship Children's Hospital, their home or another mutually agreed setting. The venue needed to be located where the participant and I would not be interrupted and that audio taping would proceed effectively. I explained that the research project had received some funding that would enable me to travel to their region if required. Where a room was required, it was planned to book the room for two hours, based on the assumption that the interviews would be of around sixty to ninety minutes duration. Byrne (2000) recommends a quiet environment with no distractions to facilitate data collection.

The appointment was set at a mutually agreeable time to both parties. The interviews were scheduled for one and half-hours, with some extra time allocated for social update, gaining consent and debriefing. The planned time required was outlined to participants to ensure they had a realistic perception of their participation commitment.

I undertook a pilot interview to polish up my interview skills. The pilot interview assisted me in conducting the interviews in a manner that encouraged rich and detailed dialogue and data.

In the interview I was positioned across from the participant in order to capture both our voices on the audiotape. This facilitated my observation of non-verbal communication that might otherwise have been missed on transcription. Through audiotaping interviews

and immediate accurate transcribing of the data, a degree of verbal accuracy was guaranteed (Byrne, 2001b).

The research interviews had three stages. The introduction covered an overview of the process and aimed to build trust between the participant and myself. Consent was obtained at this stage. Warm up questions included demographic information and general progress of the child. The planned process of the interview and the management of the data and its analysis were explained.

Most of the useful data was obtained in middle stage of the interview. I used open-ended questions from my question schedule see Appendix Six. Prior to the interviews, I developed a list of open-ended questions to stimulate discussion and to build rapport and modified questions to probe the line of conversation, ensuring that the topic remained the focus. Listening, paraphrasing, probing and summarising were utilised to ensure the accuracy of my understanding. The questions used referred to the actual name of their child so that the participant could think directly about their own situation and associate easily to themselves and their child.

Throughout the interview, I questioned and checked with the participant to ensure that my understandings and perceptions were accurate and depicted correctly. The final stage involved summarising the participant responses, allowing opportunity for confirmation and ensuring information saturation. Each participant was scheduled to have one interview. A time was arranged ranging from one to one and half-hours, and this coincided well with the actual length that the interviews took. I explained that a further interview or phone call may be required if further clarification or explanation was necessary during the analysis. Permission for this to occur was sought prior to commencement of the interviews and then revisited with the participant at the completion of the interview. Participants were thanked for their participation. I ensured that the participants were aware of the research process leading on from the interviews and answered any questions.

Data management

Data management practices were commenced early in the research process. This ensured that the anticipated immense amount of transcribed material, field notes and other material would be managed in a manner that facilitated the analytic process. For ease of understanding and the purposes of this thesis I utilised the descriptions of some of the terms related to data management described by Cohen, Kahn and Steeves (2000);

interview transcripts – the audio taped and transcribed interviews of the participants by the researcher

field notes – ‘the written accounts of observing and participating in social interaction’ (ibid. p. 58), prior to, during and after the interviews, this includes environmental, interactions, non-verbal communication, ideas, insights

field documents – documents collected that illustrate symbolic aspects of the participants experience e.g. photos, poems, newsletters, newspaper articles

field text – the construction of a multilayered, symbolic and distanced text constructed by data collection that facilitates hermeneutic interpretation (ibid. p. 59)

narrative text – conveys the present understanding and interpretation of the data to other readers and stands alone as the findings of a hermeneutic phenomenological study (ibid. p.71)

Data analysis began with data collection and this is supported by Cohen, Kahn and Steeves (2004). The analysis involved moving from interview to a narrative text that can stand alone for other readers to hear and understand the phenomenon (Ricoeur, 1981).

The believability or plausibility of the text is often reflected by the phenomenological nod and this contributes to dependability and credibility of the research (Koch, 1995). How many times have we read or heard some idea and found that it resonates and we

find ourselves nodding? This research is a snapshot of time. Future phenomenological descriptions may challenge this work. The nature of Heideggerian hermeneutic phenomenology does not lend itself to transferability (Koch, 1995). It is a unique encounter and influenced by events and human thinking that is unique to this encounter. Another researcher who undertakes similar research may give a different account and have different interpretations.

Koch (1996) suggests returning data to research participants to improve the validity through confirmability. The return of the data presents ethical and practical problems. In the case of my research the participant's child may have deteriorated or died. There may have been a change in family circumstances since the interview and the interpretation may be different due to changed experiences. This eventuated as one of the children went on to suffer complications requiring treatment.

That the inquiry is conducted in a way that does not disturb the natural context of the phenomenon

Undertaking this study to gain an appreciation and understanding of the participants' lives, took into account that their everyday lives would not be disturbed through their involvement. The interviews were organised in a setting chosen by the participant. There was no attempt to alter the participants lived experience or manipulate or modify the participants in any manner.

Ethical considerations

This research aims to contribute to the scholarly knowledge of nursing, both nationally and internationally, enhancing the understanding of the mothers' lived experiences of caring for their children following liver transplantation. It may contribute to increasing the health and wellbeing of New Zealand children and their families. As the researcher I was obligated to maintain the highest ethical conduct in performing this research, ensuring the protection of the participants. I worked up the proposal in preparation for submission to the Victoria University of Wellington at the beginning of the academic year in February 2003.

An ethics application was submitted to the Ministry of Health Auckland Ethics Committee in accordance with the stated requirements. The committee considered the application in February 2004. I attended the meeting and was able to address the committee and approval was given subject to a few minor alterations. Once approval for the research proposal was obtained, the ethics application was submitted for ethical approval. Methodological support was developed and worked on simultaneously. Data collection by interview did not proceed until ethical approval was obtained. Ethical approval was obtained in early 2004 following adjustments required by the Ethics Committee (Appendix One). A pilot interview was undertaken in March 2004, with the rest of the interviews being scheduled to commence after March 2004.

Ethical principles for research are present to protect the participants. The research proposal met the requirements of the relevant Ethic Committee and was given approval to proceed. The participants were fully informed of the research process. Consent was obtained from participants through a process of informed decision-making. Participants were informed of the purpose and procedures involved, as well as any risks or benefits, before the study was initiated. The participants were advised of their rights to choose to participate or withdraw from the study at any point, knowing that this would in no way affect the care they received from health care services. A written consent (see Appendix Four) was developed and this was signed by the participant to indicate their willingness to participate. A verbal consent was obtained at the commencement of the interview onto the tape. Participants were not coerced or subjected to any undue pressure during recruitment. The participants were keen to participate and contribute.

A particular concern for me was that participants must be protected from psychological harm. The interview largely discussed their now “well” child. There was a potential for distress to arise out of the dialogue. Prevention or minimisation of psychological harm to participants was ensured. The research was conducted ensuring that the benefits of the research outweighed any potential risks or actual discomfort to the participants. The steps taken to ensure the protection of the participants will now be discussed. This group of children have been through a gruelling health experience. Involving children in research is contentious and needs to be done in a manner that reduces unnecessary harm or trauma (Glantz, 1996).

I have observed that the age and associated level of comprehension plays a large part in the understanding and coping of a child following liver transplantation. If the participants had been the children, there was a high probability that issues may have forgotten or not understood the events that had occurred and discussing the events might have had a detrimental effect on the child, depending on the child's level of understanding.

As charge nurse of the medical specialties ward, I held a position of perceived authority. It was essential that participants did not feel coerced to participate. It was agreed that I would not make the initial contact with participants. The paediatric liver transplant and gastroenterology nurse specialist went through the inclusion and exclusion criteria against a list of potential participants. From the names remaining on the list following adherence to the criteria, the nurse commenced seeking interest in participation. The postal packages were sent out to the potential participants who had indicated an interest. I gave an information sheet to the potential participants, reinforcing they were under no obligation to participate. The nurse specialist was not informed of who finally consented to participate in the research.

Depending on the wellbeing and medical status of the child, there was high likelihood that I would have future contact with the participant in my role as charge nurse. The parent was reassured that the information shared would remain confidential and that treatment would not be affected by their participation. In reality, the sharing and insights that the researcher gained as a result of the research contributed to the therapeutic relationship of caring for the child and family. I was concerned that there might be the potential for maternal distress arising out of the interviewing process.

During the planning of this research I set up a contingency plan to deal with distress arising out of the interviews. I planned to utilise my knowledge and communication skills to be diligent in detecting and dealing with parental distress. If distress occurred during the interview, participants would be offered the opportunity to suspend the interview briefly or to terminate the interview. The participant's permission to refer them to the Consult Psychiatric Liaison service at Starship Children's Hospital would be sought where indicated.

All parents are routinely referred to The Consult Psychiatric Liaison service when it becomes apparent that liver transplantation is a possibility. The Consult Psychiatric Liaison Service provides ongoing support and counselling to all families along the liver transplantation journey. This research was discussed with a senior child psychiatrist involved in the Starship Consult Liaison Team service. The availability of psychological assessment and support/counselling was offered by the service in the event of extra support being required if I was not able to resolve the issues utilising my own skills in therapeutic communication. It was anticipated that the participants would feel comfortable to use this publicly funded service. It was planned that if participants specifically requested to make contact or meet again with me in my capacity as a researcher– a further meeting would be arranged at a mutually agreed time and venue. However this was not requested.

For the purposes of my research, participants were not involved in discussion arising out of the data. It was envisaged that it may have been difficult for the participants to be involved in validating the analysis and discussion as their identity within the researcher's analysis was hidden. A summary of the research findings will be given to the participants on completion. However copies of the transcripts were not requested. The audiotapes of the data collection are being held and they will be returned or destroyed after ten years in accordance with the wishes of the participant. This met the requirements set by the Ministry of Health Ethics Committee.

An agreement to participate in the research was obtained, and arrangements were made to set up an interview. I explained that informed consent was required and that this would be in the form of written and verbal consent. Both written (see Appendix Four) and verbal consent was obtained. Verbal consent was obtained at the beginning of the taped interview and recorded for future reference within the transcripts. Written consent was obtained prior to commencing the audiotaping and this was retained in my research records.

The participants were required to consent to the interview, knowing that they would be expected to express inner feelings and describe their lived experiences. As their child was indirectly involved in the research, it was preferable that the child was agreeable for their mother to talk about their level of well being and lived experience where

appropriate to the level of the child's comprehension. Where the child's age, level of development and comprehension was at a level where they understood what was happening, the mother was asked to confirm that she had told the child about the interview and confirm that the child held no objection.

The information obtained about the interviewees was kept confidential and secure. Transcripts are kept in a locked cabinet. The conversations were not shared outside the purpose of the research. The privacy of the research subjects was maintained and efforts to ensure anonymity were taken. Pseudonyms were used and changing facts or descriptors as suggested by Byrne (2001b). It was important that the participants understood that there was a possibility of identification due to the small number of children who have undergone liver transplantation in New Zealand. Every effort was made to reduce identifiability and protect the privacy of participants. Demographic information was not provided in the report to reduce identification of the participants relating to their geographical location and other details e.g. age of child at transplant were also not stated to avoid this. The transcriptionist maintained confidentiality and gave a written assurance of this. A professional transcription service was utilised with this in mind.

Acknowledged participation of the researcher in the research (ibid).

In investigating the lived experiences of mothers whose child had undergone and survived liver transplantation, it was important that I appreciated their experience and had immersed myself in the relevant literature. This allowed me to gather the breadth of data required to gain understanding of the lived experiences. As the researcher, I immersed myself in the area of research. This allowed me to be viewed by the participants as interested and committed to telling their stories in a sympathetic and understanding manner. If I had utilised a quantitative approach I would have had to take an objective stance and put my ideas, understandings and personal views to one side to allow a pursuit of objective truth. This would be insensitive to the participants' experiences and limited depth of inquiry required to understand the participant's lived experiences.

Reflectivity and reflexivity

Reflectivity and reflexivity were both addressed in this inquiry. Reflectivity is the process of considering the findings, while reflexivity is the conscious action to respond to or make decision based on the findings. In the course of inquiry I kept a personal journal. Entries were made based on reflections and insights were recorded, as were the decisions made in the undertaking the research on the basis of the findings and insights gained. This was undertaken to address rigour and to provide links to the decision trail (Smith, 1999) as the assumptions and ideas developed. I found that in keeping the personal journal, I was able to track my thinking and the evolving understandings and meanings as they emerged in the process of this hermeneutic phenomenological inquiry. I also collected newspaper clippings, book reviews, poetry and spontaneous ideas and in turn these influenced the analytical process. I did not write into the personal journal on a daily basis, rather I kept it on hand to put in ideas, decisions and insights as they occurred. The use of a research diary, or in this case a personal journal, has been described by some critics as self indulgent according to reports described by Koch and Harrington (1998).

Reporting the phenomenon in a literary style rich with participants' commentary (ibid).

Using a qualitative approach required that I honour the voice of the participants. Direct quotes are included from the transcriptions to ensure that participants' voices were heard. By utilising a phenomenological approach the experiences were not categorised in a quantitative manner. The phenomenon was allowed to emerge reflecting the rich descriptions and stories. The analysis and interpretation illustrates the phenomena revealing the depth of the inquiry and extent of the participants' experiences of the phenomenon.

Writing

Skilful writing techniques within the narrative text convey the findings to the reader. Narratives, stories and paradigm cases were used to support the analysis. The method undertaken for the analysis is outlined in this chapter and the data analysis is shared in Chapter Five. The language of the phenomenological text has the power to reveal the

world as we live in it. The world of life is not static, but is constantly changing and evolving as new realities are exposed (Heidegger, 1962).

The primary objective of my research was the direct investigation and description of phenomenon as experienced in life. Through a process of reflection and writing I sought to reveal new understandings of the lived experiences within the current level of understanding as described by van Manen (1990). Jardine (1990) describes phenomenology as the giving of voice to human experience. Through the process of writing, I have allowed the reader to hear the voice of mothers, as they described their lived experiences of caring for their children who have undergone and recovered from liver transplantation.

The process of phenomenological writing requires writing, writing and writing with a lot of thinking in between. The text was worked in a descriptive and detailed manner that allows the readers of the research to make their own interpretations and judgements. Other sources, insights and media were also accessed to strengthen the data and support understanding. The next section explains how rigour was incorporated into my research inquiry.

Trustworthiness, credibility and rigour

In my role as a researcher, I needed to build the confidence of readers of this research, that the resulting text is authentic and credible. In accordance with the hermeneutic tradition, the final interpretation is considered credible, rather than absolute or true (Koch & Harrington, 1998). I have provided the narrative text to the readers of the research where appropriate to make their own interpretations and judgements. When the text resonates with the reader, one often finds oneself nodding. The “phenomenological nod” (Koch, 1995), is the physical acknowledgement of the reader of being able to imagine a similar experience or association with the findings. The phenomenological nod is considered confirmation. This is further endorsed by Heidegger who stated that validity was contained within the phenomenological nod (van der Zalm and Bergum, 2000; van Manen, 1990).

The dependability of this research may be scrutinised in relation to the smaller number of participants and the difficulty in generalising with the wider population from the findings (Guba and Lincoln, 1994). Qualitative researchers must demonstrate dependability and gain the readers' confidence in the truth within the findings and analysis. The need to develop a rich and textured understanding of the experience as described by Sandelowski (1995) is inherent to qualitative research approaches. It is appropriate to work with a smaller number of participants. This allows the researcher to devote the time and energy to ensuring that the data is worked with in a manner that brings forth new and credible understandings on the issue. The population of paediatric liver transplants in New Zealand is small. The small sample size would have been a challenge for quantitative methods; however it fitted with a qualitative approach.

The hermeneutic phenomenological approach to research is not grounded in 'an epistemology of facts and objective reality' (Cohen, Kahn & Steeves, 2000), consequently qualitative research is often criticised as 'anecdotal, impressionistic and subject to researcher bias' (Allen, Benner & Diekelmann, 1986). In attending to issues of rigour, this research inquiry aims to achieve a greater appreciation of the findings by the wider health care team. Phenomenological researchers need to ensure that issues around trustworthiness, credibility and rigour are addressed. In attending to these issues methodological rigour is fostered.

Credibility is promoted within hermeneutic phenomenological research inquiries through detailed and contextual writing, and a reflexive account of the research process. The incorporation of an audit trail or decision trail and reflective diary may assist in ensuring credibility by guiding the readers of research through the world of the participants and the researcher by being transparent about the decisions made in the course of the research (Koch, 1994).

Working with the data

At the beginning of this research inquiry I immersed myself in the existing research around liver transplantation and text books. I also ensured that I read media stories in

the newspapers, and magazines and fictional pieces of work. I also watched television and DVDs with transplantation themes. Van Manen (1997) supports the concept that the researcher needs to immerse themselves to fully explore the phenomenon. This process assisted me in coming to understand the existing knowledge, possible biases and misconceptions and to guide my analysis from the outset. I also commenced my personal journal at this point to map out my thinking as well as provide a basis for decisions and turning points in my analysis.

Heidegger's (1927/1962) hermeneutic circle guided the process of the research inquiry. The analysis involved working with all aspects of the data. I immersed myself in the data. I listened to the tapes over and over to strengthen my familiarity with the mothers' voices and made notes as ideas jumped out. Once the transcripts were typed, the interview transcripts were read and reread to decide what was relevant and what could be put aside. The words that had been transcribed that did not contribute to the text and any mistyped words were removed including unnecessary words such as "ums" and "ahs" from the data without altering the original meanings of the experience.

The interview transcripts and field notes were checked for accuracy of transcription and then formatted with large margins. The interview transcripts were coded according to participants with individual unique coloured pages. Participant one was coded as blue and so the transcripts were printed onto blue paper. The same applied to the other two participants who were also coded and printed on different coloured paper. This allowed me to cut up the text into its smallest unit and still know which participant had said it at a glance. Each speaker on the transcripts was coded as either the participant or the researcher. I was then able to recognise who had spoken each sentence. Each line was given the page number and the line number. This contributed to efficient handling of the data. It allowed me to cross reference and return to the original quote efficiently and accurately.

Table Two: Example of a coded transcript

Speaker P= Participant R= Researcher	Transcription	Page	Line
P	There were many times when I despaired.	12	1
R	So you felt in despair?	12	2
P	Yes, very frightened actually. I didn't know if she would	12	3
P	make it. It was like we were playing a waiting game... I'm	12	4
P	not very good at waiting!	12	5
R	That's understandable under the circumstances!	12	6

Essential characteristics or ideas were identified in the in the interview transcript margins to enhance the analysis of the evolving field text.

I continued to read and reflect. I made multiple copies of the transcripts in the coded colours. I cut up the first set of transcriptions, analysing the individual words. I put the words all over the floor in a room that wouldn't be disturbed. Words the same essentially were initially placed in the same piles. Then the words were grouped together to the same or very similar meanings. In using the transcriptions in the three colours, I was also able to identify, if one participant repeated the same word over and over – suggesting possible emphasis.

Another copy of the transcriptions was cut up into sentences, phrases, ideas and themes. It was like having a large jigsaw puzzle all over the floor. Once again they were sorted into piles and then grouped together. Though they were on the colour code paper, this time I could see at a glance in what order the comment had been made and also see whether it was the participant or myself who had spoken the sentence.

Slowly the ideas began to flow out. Similarities and common themes were emerging out of the data. The piles were placed into labelled envelopes to aid in revision or revisiting the findings. This also helped maintain some control over the data and allow for a quick review of findings during the analysis and interpretation.

The groupings were compared to the field text again looking for meanings arising from the working of written text. Each part of the data was worked with in relation to the whole of the data and conversely the whole text was worked with in relation to each part of the data. Cohen, Kahn & Steeves (2000) describes this as the dialectic process of analysis. As the data developed into a rich description, early initial notions of the meaning arose out of the whole text. The evolving reflexive awareness of the texts developed into meaning in a continuous cycle throughout the analysis.

The field text was worked with through; rereading, rewriting and thinking using Cohen, Kahn and Steeves' (2000) process to develop the narrative text. Throughout the analysis I remained close to the data which aided in drawing out initial interpretations. Once I had an understanding of the text, I undertook line-by-line coding, applications of tentative theme labels and passages were documented in the margins. This process was done in accordance with van Manen (1990) descriptions of thematic analysis. Ideas arising from the field notes were annotated next to the comments to give context and additional insight into the meanings.

Passages of field text that illustrated essential meanings within themes were given labels and they were compared to other passages that conveyed similar meanings and these were grouped together identified as sub themes within themes, capturing the essential meanings of each theme.

The course of action of writing and rewriting is fundamental to interpretive phenomenology of van Manen (1990). The writing progressed from recognition of themes to an association of themes. Documentation of the hermeneutic process drove the transformation of the field text to a coherent narrative text. A narrative text that captures the essences of the lived experience is the objective of the research inquiry. Interpretation of the findings is contained within the understandings revealed within the narrative text. The presentation of the findings was based on the data present within the narrative text.

Heideggerian hermeneutic phenomenology requires that the researcher remain true to the data and orientated to interpretation and understanding, mindful that there is no uninterpreted fact (Heidegger, 1962). The final interpretation of the analysis is

considered as tentative, rather than absolute or true. It is hoped that readers of this research are able to acknowledge that the description is an experience they can associate with. The ongoing literature review was worked on in conjunction with the analysis.

Summary

In this chapter the method and design employed to undertake this research inquiry has been discussed. Congruence to the philosophical underpinnings of the hermeneutic phenomenological approach has been made. Decisions made relating to sampling size, recruitment of participants, the interview process and data collection methods have been outlined. Ethical considerations relating to informed consent, privacy and confidentiality as well as cultural safety were outlined. The process of obtaining ethical approval is discussed in the context of this research. The management of the large amounts of data is complex and the methods used to analyse the data have been outlined. Having described the method and design, Chapter Five, serves to further discuss the analysis of the data and prepare to unlock the interpretations in Chapter Six.

CHAPTER FIVE - COMING TO UNDERSTAND THE LIVED EXPERIENCE OF MOTHERS CARING FOR THEIR CHILDREN WHO HAVE SURVIVED LIVER TRANSPLANTATION

The focus of this chapter is to present more detail of the process used in the analysis of my research data. The analysis is described in detail as a researcher narrative to highlight the process along the research journey towards revealing the meanings of the lived experiences of mothers of caring for their children who have survived and recovered from liver transplantation. The challenges faced in undertaking the analysis are described. The insights of the participants, my own contributions as a researcher and the influences of a wide variety of mediums that included literature, media, cinematic and fiction have been reflected upon. The processes I used in undertaking and presenting my analysis are presented using van Manen's structural framework for analysis and the benefits and challenges faced are discussed in accordance with the Heideggerian hermeneutic phenomenology.

The focus of this research inquiry was to explore the meanings of the lived experiences of mothers in caring for their children who have undergone and recovered from a liver transplant. In accordance with the six procedural actions recommended by Van Manen (1990), the knowledge held by mothers about their children and the shared lifeworld of the mother and child were analysed. In utilising a Heideggerian hermeneutic phenomenological research inquiry, the analysis was closely linked to the philosophical assumptions of the Heidegger's hermeneutic phenomenology, in contrast to other philosophical frameworks. In utilising hermeneutic phenomenology there was a need to immerse oneself and consider the whole.

Process for data analysis

In exploring the meaning of the lived experiences of mothers in caring for their child I used van Manen's (1990) procedural actions. My chosen methodology influenced

decisions relating to the analytical approach and the interpretation, and this is discussed in more detail to assist the reader to understand the reasons for the particular actions taken. In phenomenological research there is no prescribed order or set of directions for undertaking the analysis. This can be daunting for novice researchers like myself, feeling overwhelmed by the amount of data presenting itself and needing to work through the vast amount to bring out the key themes and expose the meanings of the lived experience.

Data management practices

Data management practices were commenced early in the research process. This ensured that the anticipated immense amount of transcribed material, field notes and other material would be managed in a manner that facilitated the analytic process. For ease of understanding and the purposes of this thesis I utilised the descriptions of some of the terms related to data of Cohen, Kahn and Steeves (2000) as discussed in Chapter Four.

Within the hermeneutic phenomenological method, the data is not restricted to the interview contents. It was possible to include the abundance of data that the researcher is continuously exposed to arising from preunderstandings, reflections and understandings developing through the research process, as well as the abundance of other sources including fiction, poetry, magazine articles, and cinematic sources.

Hermeneutic phenomenological reflection in action

The key work of hermeneutic analysis is the writing and rewriting (van Manen (1990). I worked with the transcripts as well as the word and sentence analyses. An example of the hermeneutic phenomenological reflection is provided below as an example of the process used to write hermeneutically. This is an example of how I wrote and rewrote the text arising from the interview transcripts to achieve a narrative text.

Interview One

Anne – Mother

Alex - Child

Transcript : Page 4 line 13 – page 5 line 1

The transcript was read and I listened to the voices on the taped interviews. The unnecessary text was removed for ease of understanding. As stories appeared, I identified the lines of the corresponding text and recorded it so that it could be rechecked for consistency. The transcript was then examined on a word by word basis. In this way I was working with the huge transcript, with multiple ideas and stories and in turn drilling down to its smallest unit – each word. The coding done prior to the textual analysis assisted in providing clarity during the analysis, allowing me to cross reference and return to the data in its smallest unit.

Example of edited transcript:

Day to day his sleeping isn't good, so we don't get a lot of sleep... other than that he is quite normal now, he seems to me to be quite a normal little three year old, though... but always at the back of your mind, thinking, is he well or is he just being naughty... at night when he is getting up and awake in case he is feeling unwell... or whether he's just being a horrible toddler.
(Anne)

The edited transcript was read and reread and pondered upon. At the same time I consulted my field notes corresponding to the interview and the notes that I had made as Anne had talked about the issues. I noted that Anne had developed a tired look and rubbed her face as she spoke about sleep. It seemed that sleep was an issue in the family. The observations I became aware of were noted as the things that jump out and needed to be recorded.

Example of analysis of the edited text

Sleep is an issue -He sleeps poorly and the parents sleep poorly as a result

What is quite normal? Not quite up to normal? - He is quite normal. He seems to me to be quite normal.

There is an ongoing dilemma in being able to identify what action to take when he gets up.

The mother is concerned that he may be unwell and she will miss it.

It is always a thought at the back of your mind.

When your child has a transplant you're always watchful for subtle signs

I went through the edited text pulling out phrases, comments and initial ideas that were emerging. Some of the words or ideas that were apparent were; sleep, normal, ongoing, dilemma, action, concern for, unwell, miss it, thoughts, watchful, subtle signs.

Following an intensive period of thinking and reflecting on the ideas leaping out of the edited transcript, a first rewrite was commenced.

First Rewrite

Alex doesn't sleep well and this has an effect on both his parents. He appears to be quite a normal three year old. When he gets up at night, Anne doesn't know what the reason is. She worries that he may be wakeful because he is unwell, but at the same time she realises that he may be being naughty or it may be related to his level of development.

The text was reworked to preserve the integrity, but also to present the ideas that had arisen in the edited transcript. This had the effect of bringing in the thoughts and reflections that presented as the writing proceeded. I wrote the first rewrite as I heard the interview, bringing in the identified themes and ideas.

Second Rewrite

Alex has disrupted sleep patterns. Alex's poor sleeping habits have a negative effect on his parents' own sleeping plans. Anne is unable to differentiate the reasons behind his poor sleeping. Anne worries that she may misdiagnose his sleeplessness.

Following a series of rewrites the interpretations of the text needed to be developed towards the final narrative text. This required reflection and consideration to extract the meanings. I focused on the themes emerging and how they related to the story that was being developed.

Interpreting

Alex's parents sometimes find it difficult to differentiate between normal and bad behaviour for a toddler. Anne is aware that sleeplessness can be caused by a number of causes and they worry that they will misdiagnose a health problem. Anne describes Alex as "quite normal", though there is a pervasive sense that may she is worried about whether Alex is developing normally.

The next stage of writing was to consider the text and to further extract the philosophical notions that emerged from the analysis of the text. The notions included; normal everydayness, temporality in terms of it being night 'time', sleep time and bed time. Corporality was recognised by search for bodily clues of illness. The text below demonstrates the linking of philosophical notions to the narrative text. What is present

is the text that will provide the insights and understandings of the phenomenon of inquiry?

Narrative text

When Alex gets up out of his bed at night and toddles down the hall toward his parents' bedroom – he's looking for comfort. Anne awakens from a light sleep. She sleeps poorly because of the broken sleep. Alex stands at the door. He wonders what to do? Anne sits up and looks at her little son. Should she send him back to bed or does he need her. Although there is an urge to put him back to bed there is a prickle of fear... what if he is unwell. If he's unwell, she needs to detect it early so that he can receive the correct medical treatment. Anne knows that other mothers have similar problems with poor sleeping with their toddlers, but Alex is special. That's why it's worrying, because he's gone through a lot, but is he being naughty or does he need me as a keeper of his liver. Am I being a good mother?

As the process of hermeneutic reflection progressed, I began to feel attuned to the data. I started to uncover the hidden meanings and discreet inferences made within the conversations, working towards the textual analysis and resulting interpretation. The finished narrative text is the product of hermeneutic phenomenological reflection. The narrative text allows the reader to really appreciate the story to its full potential, as the voice in word.

This form of writing is not undertaken quickly or effortlessly. It requires a real commitment to drawing the voices into text, providing a clear manuscript that describes the experience and promotes meaning. The field notes and the personal journal were referred to in order to provide insights into the possible notions and arising assumptions.

Working with van Manen's procedural actions

In introducing and describing the analysis of my data I have used van Manen's (1990) methodological structure for performing hermeneutic phenomenology consisting of six procedural actions. I described the analysis in accordance with the six actions. There is no particular order in the six procedural actions though they provide a clear structure to

allow me to cover the topic comprehensively and to maximise the analysis that arose out of the data.

1. *Turning to a phenomenon that seriously interests us and commits us to the world (van Manen, 1990, p. 30);*

The topic of paediatric liver transplantation was one in which I had experienced intense and sustained interest. I began the analysis from the very outset of the research process, as I undertook the literature review and prepared for the data collection. At the beginning of this research inquiry I immersed myself in the extant research around liver transplantation. I also ensured that I exposed myself to media stories in the newspapers, and magazines, videos and fictional pieces of work.

2. *Investigating experience as we live it rather than as we conceptualise it (ibid).*

In exploring the experiences of the mothers, I was able to observe life as it was being lived. I was able to see it first hand. I gained insights through investigating the experience as it was lived through the contact I had with the mothers over a sustained period. The notion of ‘being-in-the-world’ enabled me to bring my experience and understanding to the research. Heideggerian phenomenology necessitates a closer researcher involvement than the more detached standpoint of Husserlian phenomenology (Koch, 1995). Throughout the research process, I read widely, talked and listened to people; including colleagues and families, and watched people’s behaviours knowing that this was contributing to my analysis as well as providing insights that would guide my interpretation.

3. *Reflecting on essential themes that characterise the phenomenon (ibid).*

In the process of reflecting on the essential themes which characterise the phenomenon, I developed a narrative text that reflected the stories and insights arising out of the participant interviews. This occurred in conjunction with the knowledge and

preunderstandings of the participants, my own preunderstandings, data contributing to the overall thematic analysis and the identification of essential themes. As the themes emerged from the analysis they were corroborated with examples of the text as they had emerged and possible commonalities/similar attributes were incorporated to characterise the phenomenon. Through this ongoing circular method of reflection on the essential themes, a greater understanding of the lived experiences of mothers caring for their children who have had liver transplants was achieved.

4. *Describing the phenomenon by writing and rewriting (ibid).*

Writing.... rewriting... and rewriting..... Writing was integral to developing and drawing the understandings out of the texts. The process allowed me to move the data from the voice and my mind to words on paper. I used several approaches to the text to facilitate the ongoing nature of the analysis and the surfacing of the interpretation. From the outset of the research inquiry I kept a personal journal, collecting articles, thoughts, insights and personal reflections.

The data had to be brought down to its most basic and simple before being brought together again to reflect the multiplicity and complexity of the emerging commonalities and themes, as described on p. 82. I then returned to the original transcripts to check that the themes emerging matched the context and original intention of the participant content. The next step was to work through the transcripts in systematic manner pulling out sets of text which seemed to reflect an idea and then rewriting them several times. As they were rewritten and reflected upon a list of spontaneous ideas that emerged out of the writing were recorded as these captured ideas that might have otherwise been lost. The texts were then developed trying to illuminate understandings out of the reflections. Through working consistently on the field texts and utilising the information and ideas from the field documents I worked to develop a narrative text that would capture the essence of the lived experience and allow the reader to understand more fully the meanings arising out of the mothers' lived experiences.

5. *Maintaining a strong/oriented pedagogical relation to the phenomenon (ibid).*

A clear and disciplined orientation to the research question was maintained, ensuring that the textual description captured the essences of the inquiry. Van Manen (1990) recommends a strong and oriented enquiring relation to the phenomenon, in order to avoid loose descriptions and early conclusions. In order to maintain a focus, I had written up my research question and had it constantly displayed, so that it was highly visible and that it would be captured and processed through internal intellectual processing systems and thus help me to remain oriented to the research question.

In addition to this I kept the data sorted into piles and labelled into envelopes so that I could go back and re-evaluate the groupings and reflect on the sorted data. The groupings were sorted and comparisons made. Where consistencies emerged, these were reread in the body of the transcript to ensure that the real meaning was extracted. As there was an extended period of analysis, I felt it contributed to my opportunity to dwell in the data and consider it fully. There are real benefits in taking one's time and being in the right state of mind to undertake the analysis and interpretation.

6. *Balance the research context by considering the parts of the whole (ibid).*

Through out this research process, a personal journal was kept to record thoughts, ideas and reflections to maintain a balance and ensuring that the context was considered in the parts as well as in the whole. The research data was considered in parts through breaking down the data in the transcripts in the smallest possible portion – words and sentences and then considering the smallest parts back against and with the whole of the data including the field text, field documents and personal journal.

Hermeneutic phenomenological writing

The process of hermeneutic phenomenological reflection for analysing the data to draw out the essences of the lived experience is discussed. Writing the narrative in

accordance with the hermeneutic phenomenological tradition was undertaken, and the reasons for decisions taken during the analysis to ensure trustworthiness, credibility and rigour of the research findings were discussed.

Skilful writing techniques within the narrative text convey the findings to the reader. Narratives, stories and paradigm cases were used to support the analysis. The language of the phenomenological text has the power to reveal the world as we live in it. The world of life is not static, but is constantly changing and evolving as new realities are exposed (Heidegger, 1962).

Through a process of phenomenological reflection and writing I revealed my understandings of the lived experiences as described by van Manen (1990) and Jardine (1990), giving of voice to human experience. Through the process of writing, I have allowed you to hear the voice of mothers, as they described their lived experiences of caring for their children who have undergone and recovered from liver transplantation.

In reality, the sharing and insights that the researcher gained as a result of the research contributed to the therapeutic relationship and had the effect of illustrating the caring bond between mother and child. I found that after interviewing the three mothers that similar themes were arising out the interviews. It was interesting to consider if this was a factor of the experiences being so similar amongst the majority of mothers, or if in fact it was a coincidence in this study. As the themes seemed to be recurring, I took this as good indication that sample size was satisfactory to inform the findings. I had initially aimed for four to six participants, but owing to the nature of recruitment process, I had to be flexible and work with the mothers I engaged as participants for the study. Corroboration from mothers reading the study and/or further research with a bigger group of mothers would be needed to make a claim that common themes were emerging out of the three interviews were reflective of the possible samples. I felt that in actual reality there was unlikely to be any other or different themes immersing.

Heideggerian hermeneutic phenomenology requires that the researcher remain true to the data and orientated to interpretation and understanding, mindful that there is no

uninterpreted fact Heidegger (1962). The final interpretation of the analysis is considered as tentative, rather than absolute or true.

Summary

The knowledge that mothers have of their children is extensive and mothers insights into their child impressive (Calvacca, 1990; Cohen, 1988). How is this knowledge developed? Is it related to their close relationship to the child they have conceived, and borne? Or is it the result of the close and intense relationship that mothers and children develop due to need? Is the love borne out of the intimacy and primacy of care that a child requires until they are at a level where they can assume control of themselves in their lives? Utilising the maternal perspective provided rich and detailed descriptions of text for analysis (van Manen, 1990).

In accordance with the Heideggerian hermeneutic phenomenological approach, I have had to recognise my own ways of knowing. I have explored and critiqued the many sources of knowledge around the topic in an effort to bring the whole to the fore. I also explored other sources of knowledge that informed my understandings and preconceptions to develop a wide sense of understanding of the current knowledge.

CHAPTER SIX - INTERPRETATION AND DISCUSSION OF THE EMERGING THEMES ARISING FROM THE ANALYSIS

As the analysis progressed from the initial phases of sorting, rearranging and reflecting on the data, as described in Chapter Five, clearer themes began to emerge. The interpretation of the findings presents the understandings arising from the exploration of the phenomenon and reveals the lived experiences of mothers of caring for their children who have survived and recovered from liver transplantation.

The interpretation draws together the findings of the inquiry to a greater understanding of the phenomenon. In phenomenological studies the interpretation stage has the potential to be ongoing and evolving. For the purposes of this study, there was a sense of completion as the meaning arose out of the texts. My understandings continued to be shaped and refined as a result of my interest in the phenomenon that had continued over the course of my study.

I trust that the insights and understandings that are revealed will leave you, the reader, with a greater understanding of the phenomena and an invigoration for the human science method. My findings are presented in a truthful and meaningful manner, acknowledging my reasoning behind the interpretations that I have formed. Recommendations arising out of the interpretation are drawn in the conclusion in Chapter Seven.

There is no surprise that maternal stress featured highly in each of the emerging themes throughout the interpretation. Maternal stress was recognised by the mothers. This was apparent in the role of mothers, and the ways in they mothers cared for their children, developing coping strategies along the way. The burden of care experienced by the mothers was compared and contrasted to the experiences of mothers whose children had different conditions or health needs.

Knowing your child and developing the knowledge to care for them was empowering for mothers and this was strengthened through the caring experience. Examples that highlight this theme are provided and interpreted utilising hermeneutic phenomenological reflection. Through knowledge comes a sense of control. There was a need to be in control. Vigilance is a form of control that forces the person to be attuned to changes in an ongoing manner and reduce the effects of outside influences. Gaining control resulted in a sense of achievability and relief. Mothers were gradually more willing to trust others in the caring role of their child once they felt in control themselves. Achieving normality and everydayness emerged as confidence grew. Mothers gradually returned to more normal patterns of daily living and caring. Linked to this theme was a sense of relief and being able to plan for the future.

An interesting aspect was the concept of being part of a larger, wider family. The mother's focus gradually shifted from the sick child and transformed into a concern and awareness of those around her. There appeared to be a greater sense of compassion for others and a greater awareness of being-in-the-world.

Leading from the interpretation, the incidental and essential themes are discussed. I discuss the emergent themes and the interpretations drawn from my research. The themes are considered and examined in terms of being incidental and essential to the phenomenon.

Hermeneutic Phenomenological reflection and interpretation

In the interpretive stage of the research, I drew upon the hermeneutic phenomenological writing techniques developed in the analysis, as described by van Manen (1990). I sought to capture the nature of the phenomenon and to provide examples that demonstrated the meanings from the narrative texts. The resulting narrative texts reflect the stories, knowledge and insights arising out of the participant interviews. Some of the interview transcripts have been used verbatim, as they clearly describe the participant's experience. Greater understanding is achieved in conjunction with the knowledge and preunderstandings of the participants, myself as a woman and a nurse, and the world of knowledge in which we live.

Through an ongoing circular method of reflection on the themes, a greater understanding of the lived experiences of mothers caring for their children who have had liver transplants was achieved. In hearing about life as a mother caring first hand, I gained insights into the experience as it was lived. The notion of ‘being-in-the-world’ (Heidegger, 1927-1964) enabled me to bring my experience and understanding to the research. Ongoing contacts with mothers in my work and conversations regarding day-to-day experiences have contributed to my understanding of the phenomenon.

My understanding and interpretation was further influenced by reading widely, talking and listening to people; including colleagues and families. I became a watcher of human behaviour. This assisted me to develop insights that have contributed to my interpretation. In linking my findings back to the published literature, I have backed up my assumptions in a manner that demonstrates rigor.

EMERGENT THEMES

My interpretations surfaced out of the analytical process. As the reflective process proceeded, spontaneous themes that emerged out of the writing were recorded. As described in Chapter Five, the data was worked with in a number of ways that included word analysis, phrase/section analysis, reading analysis and hermeneutic phenomenological reflection of ideas. The drawing on external sources contributed to this interpretation. The initial themes that surfaced out of the analysis were not surprising. The emergent themes that interpreted the experiences of mothers caring for their child following a liver transplant have been listed;

- Being a stressed mother
- Mothers knowing – “taking it all in”
- Mothers caring for their “sick” children
- Achieving normality and everydayness
- Being vigilant
- Holding on and letting go
 - trusting others and sharing the care
- Being part of a family

- Being part of a wider community
- Being relieved and being able to plan for a future
- Being the holder of the memories
- Valuing the unique mother/child/liver identity

Being a stressed mother

When I spoke to a mother in the course of my clinical practice about the lived experience of mothers caring for their transplanted child, she summarised the concept of the experience as “terrifying”. Stress is a normal physiological and emotional response to situations experienced by humans. The impact of varying levels of stress can be beneficial or detrimental for individuals. A level of stress was a factor emerging out of most of the themes. I have woven the theme of stressfulness throughout the following emerging themes. This allows the themes to be more easily revealed. Alonso et al (2003) describe the most striking findings of their research into functional outcomes of paediatric liver transplantation was the impact of stress on parents and families.

There is an overwhelming responsibility on parents caring for a recovering child. More often the greater responsibility for the caring is placed on the mother. Smith (2000) revealed the isolation experienced following discharge to home, the need for information, reassurance and specific advice and support. It is little wonder that the early period following discharge is identified as stressful.

Each of the mothers interviewed identified that caring for their child was moderately stressful. The levels of stress changed depending on progress, perceived problems and fatigue. As time passed after transplant, the levels of stress became more manageable. In a study undertaken by Rodrigue, MacNaughton, Hoffman, Graham-Pole, Andres, Novak and Fennell (1997), stress of caring was identified as a consistent theme in the transplantation of children. A longitudinal assessment was undertaken examining parenting stress, coping resources and family functioning among twenty seven mothers of children undergoing various organ transplantation surgeries. The stress of caring was broken down to parenting stress, financial strain, caregiver burden and family stress.

Time is a commonly identified dimension in relation to stress. A commonly spoken phrase is that “time is a great healer”. Indeed the mothers reported that their stress levels had lessened with time. Time was also a trigger for the stress in terms of the pressures of time relating to the administration of medication and the withholding of food to ensure a steady absorption of the immunosuppressant medications. A steady absorption of the immunosuppressive therapy lessens the risks of side effects and liver rejection.

Medication times are a challenge for Anne and her family. There are certain requirements that they have been taught and always comply with. Alex just rolls over for his morning medication and Anne puts it into his mouth. He swallows and just goes off to sleep again; it's no problem at all. It is the evening dose that is the issue. Anne is the middle of dinner preparation and Alex is getting hungry. He can't eat anything for the time around his medication. He gets understandably whiney and Anne finds herself watching the clock and wishing that time would pass more quickly. She feels a sense of relief when he can have his medication and he can start to eat again. He always takes his medications like a dream.

Anne (Narrative Text)

The mothers developed an acute sense of time and the medication regimes began to be programmed to a daily pattern. The first dose of the day is often early and this would have been extremely disruptive to most families. However it was a daily regime that was kept. At the same time the children accepted the medication as part of their usual routine and so there was no fuss or refusal encountered by the mothers.

The child experiences time as a means to an end, moving to the next activity; eating or drinking or doing something. Alternatively the mother experiences this lifeworld as another important task to be ticked off, a necessary requirement of life of which she is the major monitor. It has the potential to be stressful for her or just another routine occurrence. It reflects on the lived human relation – relationality in that it has the capacity to draw the mother and child close or drive them apart. ‘Most families’ would have found this time schedule stressful. However the family experienced it as a matter of normal routine and the pressure had been absorbed with time. The mother pulled together to make a potentially stressful situation, a standard, routine operation. It was not possible to extrapolate that the mother had headed this attitude, though as the key caregiver, the mother took it in her stride and so had the rest of the family.

The mothers were confident, being-at-home in the home environment; setting the tone and routine. The lived environment of home is the mother's castle, it is the safe haven in the battle raging. An aspect to be considered is whether the theme of 'parenting in public', identified by Darbyshire (1994) experienced in the hospital setting was resolved, or whether despite being home that they felt they were being closely monitored by the hospital system and watched by the wider outside community who take an interest in such things.

Anne finds that Alex is very easy to manage in relation to taking his medications. Ever since his feeding tube was removed when Alex first got home from hospital, it is just 'down the hatch' without any protest. Anne is happy with Alex's compliance in taking the medication. It makes this aspect of his care so much easier for her. She hopes that if she can instil a sense of 'everydayness' into his medication regime now, that when he eventually assumes self responsibility he will see it as a daily routine, like brushing his teeth!

Anne (narrative text)

This period in time is relatively easy, but will it always be so? What must Anne do to ensure that he remains compliant when in the future he assumes self-responsibility? This maternal coping strategy was identified by Rodrigue, et al. (1997). Attempts to maintain family integration and understanding the child's medical situation suggests that "knowing" is a coping strategy in caring, this leads into the next emerging theme of mothers knowing.

Mothers knowing – "taking it all in"

The mother's caring role was integral to this research inquiry. The mother's experience of caring and the knowledge she held of her child was examined within the realm of normal maternal expectations and experience. The role of the mother in this situation is shaped by the intensity of the experience as well as the extra levels of surveillance and care requirements. A person's knowledge is in direct relationship with the world. What we know is a direct response to what we experience in the world.

*Brenda finds herself constantly noticing changes or differences in Betty's eyes. She notices how Betty is looking, scanning for any changes. Brenda never **knows** whether Betty is going to be*

*well or unwell, from one day to the next. As Brenda never **knows** for sure, she finds herself constantly watching. If Betty does become unwell, Brenda will be the first to **know**.*
Brenda (narrative text)

In this narrative text the mother has an intense need to know if there are changes. Knowing was emphasised during the participant interview and there was a real sense of intensity in Brenda's face. Brenda had seen Betty unwell prior to the liver transplant and was aware of Betty's signs and symptoms. She focused on Betty's corporeality – lived body as an important way of knowing what is happening to her daughter. In the home, the lived space - spatiality, there is no thorough physical assessment by the hospital health professionals on a daily basis. Brenda had assumed this role to an extent in Betty's life. Nobody knows Betty like Brenda does. This added another dimension to the relationality that Betty and Brenda experience. Over time, Brenda may begin to relax a little more, but in terms of temporality, its early days for Betty. Brenda says she knows how quickly things can change.

Motherhood is a developmental step that creates an immense change in the roles of women. This impacts on the lived human relation – relationality as described by van Manen (1990) and is experienced within the realm of being a mother and having a mother's knowledge and wisdom to apply to this potentially complex little being – her child. Barclay, Everitt, Rogan, Schmied and Wylie (1997) undertook an analysis of women, becoming mothers. They suggest that new mothers undergo a profound reconstruction of self. The magnitude of change that many women face in new motherhood must be further intensified by discovering that your new child is experiencing a life-threatening condition.

Ruddick (1983) describes maternal thinking as the evolution of thinking that occurs through being a women and becoming a mother and nurturer. This supports the observation of a higher level of thinking and knowledge noted by the mothers in caring for their children. Over time they had developed confidence in their knowledge and ability to take care of their child, gained through increasing familiarity and involvement in caring for their child (Gibson, 1999).

The mothers I interviewed knew their own child better than anyone else. This was apparent by mothers being able to easily recall and reflect on stories, demonstrating the depth of their knowledge and experience.

Anne knows Alex best... Anne values the partnership that she shares with her husband. She tries to give him a slice of the decision-making responsibilities, but she sees her husband looking to her for support whenever he is unsure. On the one hand she wishes that he could know Alex and his cares as well as she does, however she would rather be consulted than allow Alex's care be compromised.

Anne (narrative text)

This is not surprising when one considers the immense growth of knowledge that a new mother develops from conception of the baby, through pregnancy, birth and through to infancy, childhood and adolescence. The knowledge never stops developing. Ruddick (1983) summarises the interests of mothers that govern maternal practices as preservation, growth and acceptability of the child. These are major concerns for mothers. A mother will generally go on to become an advisor to her own children as they in turn experience parenthood.

Hagedorn (2003) describes the family experience of childhood chronic illness as experiencing a new way of life. They were “travelling a different road” (Hagedorn, 2003, p. 1). I support the suggestion that the participating mothers were travelling a different road in caring for their child. They developed new knowledge, lived with uncertainty, experienced different interactions and relationships, as well as coming to experience caring in illness, confronting mortality and experiencing faith, hope and love. The mother of a transplanted child requires additional knowledge to care for her child.

There was no doubt that mothers learn a lot from their education in preparation for discharge from hospital following their child's successful liver transplant (Smith, 2000). This learning continues over the phone or at outpatient follow up appointments. The learning does not stop and is strengthened by a need to know the rationale and importance behind the cares provided. The implications of not complying with the care

were clearly understood. The participating mothers felt that they had been well prepared for discharge, even if the reality had come as a bit of a shock.

One day the transplant team said to us did we want to go home? We did, but we didn't! It was really scary as we packed up the car. As we drove away from our second home in Auckland, we had lovely weather and we were going to make our journey home a bit of a holiday. We were excited and felt prepared to resume our life; it was the beginning of our new way of life.

Brenda (Narrative text)

Having the three month stand down waiting period in Auckland prior to discharge had assisted Brenda the mother to develop her skills and develop confidence in her level of knowledge and decision-making. How did Brenda the mother feel about the decision to go home? Her experience of the child's corporeality would suggest that she knew the child was well enough to be discharged. The pull of home – the lived relationship to the environment, (spatiality), is a strong pull. One can imagine the dichotomy between wanting to go home versus staying in Auckland. Brenda knew that Betty was well enough to go. The medical staff posed the question to Brenda, about whether she wanted to go home. This had the effect of giving her confidence in making the decision. However, the team would not have suggested discharge unless Betty was ready to go. The team has been within the existential of relationality of Brenda for some months and they knew her well.

There was a time after Betty was transplanted and they had been home for a while. Day to day life rolled along, with very few "bumps". Then Brenda came down with an illness. She was really sick. She couldn't talk; she was all stuffed up and felt really miserable. At the same time, Brenda was so worried about Betty receiving the care she needed, that she was beside herself. Brenda felt panicky. Who could care for Betty? However Brenda was so sick, that she left the care of Betty in the hands of her husband, with the assurance from her husband that the medications would be sorted. She went to bed. Having taken some strong medication, Brenda fell into a deep sleep. The following morning Brenda awoke and to her shock discovered that the night time medications had been forgotten. Brenda really beat herself up about that. So it made her more aware that she needed to share the care, the information and decision-making more with her husband.

Brenda (Narrative Text)

Mothers described learning through their experiences and successes, as well as their mistakes. They learnt to move on and not dwell on them. It went without saying that the mothers took their role and the knowledge they possessed very seriously. As a result gaining further resolve and strength, and moving onwards and upwards in their confidence and competence both individually but also as a couple. With time mothers began to change the orientation of authority. The changing relationality between external sources to internal sources was apparent as the mothers learnt to listen and trust their own voice, as suggested by Belenky, Clinchy, Goldberger and Tarule (1986).

There was a real sense of growing confidence in the decision-making process and this had been a source of individual growth for the mothers. All the mothers used medical terminology with confidence and apparent understanding. The learning was out of necessity, and practicality, born from a mother's love that extends between them and their children. The existential of corporeality was experienced through the view that the mother held of the child. Under the mother's critical gaze, there were test results, symptoms and signs to be observed for, however the caring mode of the mother was very strong and remained in balance within the mother-child relationship.

Being home was a chance for mothers to begin to care for their child in that environment. The existential of lived space – spatiality as described by van Manen (1990) supports the lived experience in the environment. "Home is where the heart is" brings to reality that being home is a special place, where you feel comfortable, you feel you know the nooks and crannies and it's where you are known by family, friends and the wider community. The reconnectedness of the relationships that one had before the "world went mad" is associated with our relationality - lived relation, as the mother reengaged with the family, friends and neighbours of home. The places and faces of the people she knows so well. The mothers began to develop routines for daily activities, settling into constructive problem-solving and developing strategies for issues that arise. The confidence in their knowledge was bolstered by being in one's home. "My home - my castle" is a saying that supports women's decisions in the home. At home she is the queen of the castle and her decisions reign. Although mothers assert that they make

decisions together with their partner, the day-to-day decisions of the minute are made by the attending caregiver who most often is the mother.

Mothers caring for their “sick” children

Caring for a child with a chronic or life threatening illness places a mother under stress. This was a feature identified by the mothers both within this research and in the published literature. The mothers’ knowledge was informed by the experience of caring for a child with a chronic or life threatening condition.

Alex is well, at the moment and he does have a functioning liver, it’s different than before his transplant when he was so ill. Now Anne thinks... he may get ill, but she doesn’t think that maybe ... he may pass away...

The “illness thing” is a big thing, but Anne finds the day to day worrying about being sick is not as huge as losing your child altogether

Anne (Narrative text)

The mothers’ role had an influence on the relationality between the mother and child namely; mother as nurse as opposed to mother as caring maternal mother. The mother acknowledges that the ‘illness thing’ is a concern, but she is prepared to face whatever she has to in caring for her child, if the alternative is that her child might die.

“When they told me that there was a possibility that Chloe might die, I was just shaking. I started ringing everybody to tell them. It was really horrific. It’s times like this that you consider how dependent and vulnerable you are. I couldn’t have made it through without the support of my family and close friends. They were there for us and I appreciate it so much. The experience has made me a stronger person. I will fight to save the life of my child and I will do what I’m directed to ensure she stays well. You see other families whose children are dying and it just changes you. It has made me so much more determined to be the best mother for my child.”

Cara (interview transcript)

As the mothers emerged out of the other side of their child’s successful liver transplant, the need for ongoing care was apparent. Although the children of the participants were largely well at the time of the mothers’ interviews, there were other children who had

not fared so well or had gone on to develop complications. It is little wonder that having undergone a state in which the mothers had so little control, characterised by worry, anxiety and hopelessness, that a loss of control had been encountered. A mother's personal experience of illness and the manner in which that was experienced - corporeality (Van Manen, 1990) has an influence upon how she now experiences her child's illness.

Neither Anne nor her husband was sick as children, Anne recounts how she never spent time in hospital herself. When Alex was so sick, they spent a lot of time in the hospital and at Ronald MacDonald House. There always seemed to be someone worse off than then, and so it really opened her eyes, as well as all the family's eyes. Anne feels that they can cope with a lot now.
Anne (Narrative text)

As the mothers emerged from the chronically sick caring mode to the acute surgical caring mode in the hospital setting, they experienced times when there was nothing they could **do** for their child, apart from being there, in the child's presence, lived environment. There were feelings of losing control. As the child recovered, the mothers regained a sense of control and order, providing the care, re-establishing roles and a return to the family relationality. The mother experienced growing confidence in her role and relationships, both within the family as well as the extended family and friends.

"Preparing to come home was a big step. When the liver transplant team told us that we could go home, it was a feeling that I will never forget. Leaving the security of the hospital and the surroundings at Ronald McDonald House' where we had made so many new friendships was so scary, but it was also kind of liberating. It was a sign that Chloe had made it through. It meant that I now had to take full responsibility for Chloe and continue to provide the care to keep her well. That was a big responsibility. In retrospect I feel that I have managed well with all the care requirements and the mothering as well."
Cara (Interview transcript)

The mothers dealt with their mothering role, as well as coming to grips with medication regimes and monitoring strategies. They were prepared for this aspect of the caring role through teaching, checklists and discharge planning. Although the teaching is directed toward the parenting couple, the emphasis of the education is directed to the mother, as

described by Gibson (1995). More often at Starship both parents are trained in the hospital setting. By the time discharge to home occurs, the father has usually already returned to work to support the family and so the mother is the key person present. She is there to take on the information and to gain experience in decision-making and providing the care.

The mother-child relationship has been challenged through chronic illness, hospitalisation and life-saving surgery. Often there had been little time available to spend alone together. The child regained trust and security. Support and counselling is provided by the Child Psychiatric Liaison Service at Starship. The work of readjustment to health concerns and re-establishing a normal mother-child relationship is developed over time. One mother said that once she was home and providing all the care, that she finally felt that she had her little girl again. One of the mothers expressed the re-establishment of her role as mother as a little daunting. There was a real awareness that the siblings had missed out and it was now important to be present for all her children.

It was evident that the prevailing concern and anxiety continues. The mothers assumed responsibility and accountability for the daily care and monitoring. The mother undertook the role of observing for subtle changes and abnormal signs or symptoms. Fisher (2001) identified the themes of mothers needing to retain order to minimise uncertainty. The mothers developed strategies to cope with concerns about the care of their child. Each mother was readily able to take prompt action if concerns arose. By being prepared for any complications there was a sense of control, minimising the chance of anything going wrong. The mothers learnt to listen to their own voice as described by Belenky, Clinchy, Goldberger and Tarule (1989).

"When Alex got sick, I really wasn't sure who to contact, should I ring the General Practitioner or the Paediatrician at our local hospital or the Nurse Specialist or the Specialty Consultant at Starship Children's Hospital. Following that I developed a plan so that I know who to contact straight away next time."

Anne (interview transcript)

Having a plan to help deal with complications or concerns is an efficient way of ensuring that the correct actions are taken. Having a plan provided a level of

reassurance to the mothers and their families. This had the effect of lessening caregiver stress levels. Having mastered control over their child's care requirements, mothers developed increased confidence. There was a sense of vulnerability in regard to corporeality, that despite all contingencies and specialty knowledge that there would be other occasion of ill health to cope with. Despite all the best care in the world, you were walking a tightrope.

The mother in her role as caregiver also undertook the role of being the key person to communicate through to the health professionals involved in their child's care after discharge. The mothers monitored their child for signs and symptoms of possible health concerns, as well as administering a strict schedule of medication. The mothers could be described as the navigators for their child's journey through the health illness continuum of care. The mothers ensured that their children attended clinics that included follow-up clinics and laboratory blood testing. The mothers negotiated the care pathway, and relayed the information back to the rest of the family.

Cara was a little concerned about Chloe. Chloe had been having some diarrhoea. It hadn't really stopped, and so Cara had taken the normal steps to ensure that it was treated accordingly. A trip to her general practitioner had been made and faecal samples had been taken. This had been the normal course of action. But...Cara felt it had now been going on for a while, in fact too long. She felt she should have heard from someone as to what to do. Cara thought that perhaps she should ring the nurse specialist... she asked the researcher "what do you think?"
Cara (narrative text)

If things went wrong, such as; suspicions of illness, changes in signs and symptoms or changes in blood results, there was a definite sense by the mother that it was their responsibility to co-ordinate and communicate with the health professionals. When a mother had a concern, she felt she should be listened to, so that the correct action could then be implemented. One mother described the situation where her child had been unwell. As much as she was worried, once she had followed the correct course of action her child was admitted and was receiving appropriate treatment, the mother felt overwhelming relief once someone else was taking responsibility.

Brenda says she had good advice from a friend... her friend had seen how scared Brenda was in the beginning, all the time, in case Betty got sick. Brenda wasn't sure how badly illness might

affect Betty. She didn't really know when to call the doctor. Maybe she might 'jump the gun' and panic. Her friend suggested that if the illness went for more than 24 hours, then perhaps contact someone... so now Brenda maintains that thought. If Betty gets a tummy bug, I give her twenty four hours... generally she's ok the next day.

Brenda (Narrative text).

For Brenda having a magic number - twenty-four hours- gave her the confidence to trust her judgement. This in turn increased her confidence in decision-making in how to deal with her sick child. In turning to her relationality of lived experience, Brenda was able to make clear decision on how she was going to deal with illness and having this endorsed by her friend increased her confidence and shared her load of worry.

Being vigilant

The theme of being in control was a strong and consistent theme. Being in control was associated with symptom management, maintaining a high level of vigilance.

Vigilance and heightened awareness were consistent features that came through in all the interviews. The mothers described a changed level of vigilance from the pre-transplantation period when their children were chronically sick. The emphasis changed and this may have been related to the growing level of individual concern experienced;

"I feel I have to be attentive all the time",

Anne (interview transcript)

"I was living worried and couldn't sleep, just trying to keep my child alive",

Cara (interview transcript)

This was replaced by the vigilance experienced by the mothers whose children had received transplanted livers, which were functioning well and had largely recovered from the surgery. The following story is an example of hermeneutic writing that illustrates the fears expressed regarding Anne's child, Alex;

When Alex gets up out of his bed at night and toddles down the hall toward his parents' bedroom – he's looking for comfort. Anne awakens from a light sleep. She sleeps poorly because of the broken sleep. Alex stands at the door. He wonders what to do? Anne sits up and looks at her little son. Should she send him back to bed or does he need her. Although there is an urge to put him back to bed there is a prickle of fear... what if he is unwell. If he's unwell, she needs to detect it early so that he can receive the correct medical treatment. Anne knows that other mothers have similar problems with poor sleeping of their toddlers, but Alex is special. That's why it's worrying, because he's gone through a lot, but is he being naughty or does he need me as a keeper of his liver. Anne wonders whether she is being a good mother.

Anne (Narrative text)

Alex's mother Anne was worrying about the cause of not sleeping. Although the "not sleeping" was the initial cause for concern, Anne indicates that there are deeper issues that surface through the experience that includes fearing for the future and needing herself to be personally vigilant in order to safeguard her child's future wellbeing.

Time was an important dimension in terms of vigilance. The concept of time and the relevance to being vigilant was evident. Every day was another milestone. The further the child got from the transplant the better the child and the liver were faring, there was a sense that a mother could begin to live again. Time was also considered vital around medications. All the mothers maintained a very strict schedule that they adhered to. This ensured that medications were not missed, and that drug levels were maintained at optimum levels. The mothers felt that they needed to maintain the vigilance for the medication schedule. If the child was going into the care of others, their sense of vigilance increased. The mother needed to ensure that the child would continue to receive medications. The mothers needed to be assured that the medication schedule and blood testing regime would be followed religiously.

Being close and being vigilant was also a feature in the relationality between Alex and Anne. It was Anne that woke at night, and it was Anne that Alex came to seek reassurance from. Perhaps Anne sensed that her husband may not completely understand their need for each other. Her husband had to work the next day and might have had his sleep disturbed. The house was quiet. Was it too quiet? Was there something to fear? On the one hand, Alex might have been lonely in his quiet little room. The inviting comfort of his parent's room with company was what he might have

been searching for. But what if there was something wrong? In my experience with young children this is quite normal. It is a developmental and behavioural hurdle that needs to be covered by children and mothers. Deciding when action was required and when normal parenting skills were called for was a challenge. This leads into mothers trusting others and being able to share the responsibility of care.

Holding on and letting go – trusting others and sharing the care

As the mothers mastered control over their child's care and gained confidence in the care requirements, it became evident that mothers were reluctant about handing over the day-to-day management of their children's care. The reluctance also extended in varying degrees to their husbands or partners, and especially to strangers. There was a sense that no-one was able to care and observe the child as well as they could. This self imposed criterion increased the stress levels for the mothers. Although the mothers provided opportunities for their husbands or partners to take increased responsibility, the vigilance remained and stress levels were not initially diminished.

*Anne feels that the responsibility for Alex's care fall **largely** upon her, as her husband works. Sometimes she feels like she would like to share it a little more. Her husband does do it ... However her husband always turns to her when medications are due... Yes... it **mostly** falls back onto mums and that ensures the routine is followed... but her husband **always** asks her and sometimes it gets a bit frustrating... it really is a big responsibility and it is **always** on Anne.*

Anne (Narrative text)

Anne voices a sense of frustration at the pressure of wanting to let go and share the care, but “always”, “mostly” and “largely” having to shoulder the load. Through the repetition of these words there is an emphasis on the role not being shared fairly and a sense of wanting to be able to let go.

Strategies were developed to cope with letting go. Mothers spoke highly of the general understanding of family and friends in making the transition to being able to share the care. The confidence of the mothers grew over time with successful relinquishment.

There were some friends who were not prepared to take the added responsibility and the mothers could understand the reasons for this. I have found that mothers often find it

difficult to allow others to undertake parts of their role. A key component of paediatric nursing is the focus on facilitating shared responsibility for the provision of care and decision making. Coyne (1995a) found in a critical review of the literature around parental participation in the hospital setting, that the principle is often complex and that it is often affected by attitudes and expectations. If it is difficult to fully implement in a controlled setting, one can easily imagine the difficulties in the smaller family unit.

There were significant delays in time in actually letting go and trusting others. The mothers perceived a high level of responsibility in placing the care of their transplanted child into the arms of others. The relationality of the situation was raised. The relationship between the mother and child and with others was teased out and there was a period of vetting before the child could be cared for by another and there was no hesitation in snatching back the care, if things didn't appear to go well.

"Chloe had been to stay at one friend's house for an overnight stay. She came back vomiting... The next time she went to stay at the same friend's home again, she came back she was vomiting again. I said 'right, you are not going to stay at that friend's place again'... She convinced me to let her go again... The following morning, the next time she stayed there she had dark circles under her eyes and she slept in until very late... I couldn't wake her, she was just exhausted... I won't let her go there again."

Cara (interview transcript)

"The first time Betty went to a wee friend's place, it was just down the road. I took her down with all her medication... The mother at whose place she was going to stay with was just so good... She knew that I was concerned. She said to me 'Look if it makes you feel better you can just come down and give Betty her medications', I said 'No' but I asked if I could ring her... I set my alarms as usual to remind me of her medication times and so I rang. It was perfect, I was relieved, the medications were given on time and Betty was happy... I now leave Betty with that mother and I don't ring any more... It was an independence thing for me and now I can go out for an evening and not think about it. That's really nice."

Brenda (Interview transcript)

The mothers all reported reluctance to "let go" and then "letting go". This was accompanied by 'being worried' or 'being there in mind' even when they weren't physically there. They were mentally on standby. The mothers phoned, popped in or left detailed instructions to allay both their own anxiety and that of the temporary carer.

When problems arose, or the child became unwell during initial separations, the period of adaptation and transitioning process was modified again. There was a real fear within the lived relations between the child, carer and the mother. Another difficult transition was that of allowing the child to return to institutions such as kindergarten and school. The mothers used the word “allow” in talking about this transition, this may signify that it was a conscious carefully chosen decision rather than a foregone conclusion.

Allowing others to have responsibility for Alex was a big step. Anne and her husband decided that Alex would go to preschool. Despite this they were more than a little worried. It's important to Alex's parents that Alex has the same opportunities as other children his age and has an opportunity to live his life as normally as possible, but it comes with risk. There is so much already happening in the morning with his medications and the daily routines, that it really is an effort to fit in preschool. They have the perception that they are always rushing. Anne was worried about Alex's susceptibility to infection. Anne had been educated about the risks at Starship. Anne had been advised to discuss their concerns at the preschool in order to safeguard him. Anne thought she had made it all very clear, so she was more than upset when we found out that Alex had been exposed to chicken pox. The preschool didn't appear to appreciate how important it was. It is difficult when parents are just beginning to trust someone else to care of their child and then something like this happens. There is a fine balance between keeping Alex safe and keeping him happy as well. Maybe Anne wouldn't take him if he didn't like it, but he loves it.

Anne (Narrative text)

In managing the situation that had the potential to be disempowering, the transition back to school was done carefully and methodically. There was a sense of needing to be in control and to have input into ensuring that the transition would be successful. Over time, and with successful ventures away from the child, there was a real sense of relief at being able to find time for one self. Mothers were able to consider a return to relative normality; finding work or time to relax, though this was not always the case. The return to normal activities and relationships was promoted, however contingencies were appreciated. Being away from home was a big step. Associated with the return to normal activities was the factor of time and rushing around.

"It has been very difficult, as I haven't been able to go out to work... I did try because we needed the money... I went out and got a job... but it just didn't work out. Chloe just kept getting little sicknesses and I constantly needed to take time off work, I was worried that in the stress of it all that I might forget to give her medication... I tried part-time work, but Chloe just got more and more tired and run down and that wasn't working either... So now I work from home. I can drop everything at any time and attend to her... If she needs me I am here."

Cara (Interview transcript)

In making the transition to returning to work, there were difficulties in getting time out of the work environment to care for Chloe when she was unwell. This placed a stress between Cara and her employer. Cara perceived a changed relationality between her employers, the other employees and herself. She had a responsibility to her employer and Cara felt guilty that it was effecting her capacity to do her job as well as possible. As time passed there was even the planning and undertaking of time out for a few days with minimal or only mild anxiety. Over time, the temporality of allowing oneself to extend one's life outside the home and doing things for themselves was considered.

"To be able to get away and forget about all the hard times is great! Nothing seems to be a problem and you aren't constantly reminded of the transplant thing... We go on holidays twice a year now... It is just so special!"

Brenda (interview transcript)

The sensation of time passing sometimes moves slowly and at other times rapidly. The events being experienced at a particular time, affects recognition of the experience. Maintaining the child's routines to ensure compliance with medications was highlighted as an important aspect of care. In ensuring that routines and regimes were followed, a sense of control was developed and this had a positive effect in reducing stress (Zamberlan, 1992). These processes extended to medication and hygiene aspects as well as other aspects routines of daily life.

As discussed under the section about motherhood in the literature review it was revealed that mothers generally undertook the primary caring role, and in the process they often carried the burden (Glasscock, 2000; Gravelle, 1997). Generally in society, mothers are adding other commitments to their already busy schedules. It is clear that that mothering is stressful even when you don't have a child with special health

requirements. Societal expectations play a large part. Caring for a sick child adds to the burden of care and the associated stress experienced. Rodrique, et al. (1997) reported increased parenting stress, financial strain, caregiver burden and family stress following a child's liver transplant. The mothers interviewed shouldered the majority of the mothering role. This included taking responsibility for the co-ordination of care. Efforts were made to share the care, though mothers were hesitant to trust others without clarity of care requirements.

The mothers strived to maintain normality not only for their transplanted child, but also the family. There was a high level of appreciation for partnership and co-operation in caring for their child. The role of extended family and friends was valued. The roles of close others was an important provider of support. The importance of a focus on siblings was also uncovered. The mothers were aware of the effects of the transplant process upon the siblings. There were clear perceptions that despite their best intentions that the siblings had or could miss out.

Having survived the uncertainties and fears surrounding the transplantation surgery, mothers expressed relief at having made good progress. The mothers were surprised at their own strength, demonstrating a sense of relief, came the need to hold the memories for future reference and even future generations. As fear receded mothers were more able to contemplate their own futures and anticipated relative normality for their child and family.

Achieving normality and everydayness

Achieving normality and everydayness was an important concept. In contrast to maintaining a constant vigilance for possible complications or danger, there was a sense of developing a knowing for what was considered "normal" (Zitelli, Miller, Gartner, Malatack, Urbach, Belle, et al., 1988).

"I am a little bit more lenient (now), you have to sort of let go..."

Cara (interview transcript)

Brenda knows that Betty knows what she needs to do to keep herself well and safe. Brenda has instilled it into her because she knows that in the future Betty will need to assume normality and self-responsibility. However Brenda is not ready to let go yet... she still keeps a look out for her. She tries to instil a level of independence into Betty's self care activities
Brenda (narrative text)

An improved level of well-being as has been described by Alonso, et al (2003); the child who has undergone a transplant goes from being extremely sick to a well-looking child. The child often only has a large fading abdominal scar and a daily regime of medications. The intensity of care, balanced against the need for normality was a real dilemma. They all wanted to get on with life, but there was also a sense that the child was travelling along a slightly different highway of life. In the transplantation journey all the mothers had confronted morbidity and mortality.

Anne says although she knows that Alex may get ill, she doesn't like to think about him dying. The thought of Alex dying was always at the back of her mind before transplant. The illness thing is a big thing, and she worries on a day to day basis about it, but it's not as huge as the thought of losing Alex altogether.
Anne (narrative text)

Temporality features in the movement of time, as the child experiences improved health, the memories faded and life moved on. Planning ahead for the future was a reality. Holidays could begin to be planned, goals set and growing up and becoming independent. Challenges were faced as they arose rather than been constantly anticipated. As milestones were achieved and progress noted there was a real sense of wanting to celebrate and be appreciative of the normal everydayness of life.

*"In the beginning, when Alex was small and so sick... we didn't really celebrate birthdays and Christmas... It was a quiet reflective time. Now we really have very big family Christmases... It is much more of a **normal** life..., as **normal** as it can be under the circumstances."*
Anne (interview transcript)

"Alex is so well at the moment... That is a celebration in itself – we have come such a long way... There was a time when I didn't dare to plan a future and I just concentrated on getting us through it... it was no easy trek. The memories linger to this day... Alex was so weak and every day was such a struggle. I knew that Alex needed a transplant to survive, but in my heart I

knew that a liver may not come in time... It was always at the back of my mind that he might die, but I tried not to dwell on it... I lived day by day, hour by hour, minute by minute... Today, I can't imagine how life might have been if Alex hadn't got a liver in time...

Since Alex has recovered from his liver transplant, the illness thing is still a big concern. I worry about that on a day to day basis... I know he might get ill. The worry of Alex dying has subsided from my day to day thinking and has been replaced with the daily concerns for his wellbeing."

Anne (Interview transcript)

The negative aspects remain, but are pushed to the back of the mind while the everyday positive experiences are the focus. This indicated a growing level of confidence and a return to a relative normality. Home was described as a space for comfort and security. There was a general milestone achieved in having returned to home following transplantation. Moving from the security, safety and familiarity of the hospital setting to home was described as a major hurdle. The lived environment was altogether much more normal. Once the adjustment was made, routines were developed and the mothers developed a sense of being in control in their own homes.

In her own environment the mother can attend to the child, as well as the rest of the family. She generally becomes more accessible to the extended family. Being at home – in their lived space - was a big step. Spatiality is described by van Manen (1990) as the environment that impacts the concept of “being-in-the-world”. Being at home allows the mothers to develop their routines and begin incorporating their child's routines as well. Medication regimes became very much part of the daily routines. Taking medication was likened to being as normal as brushing one's teeth and no fuss was experienced, apart from juggling meal times around pill times. The safety of the home was established with regards to hygiene and environmental safety.

In the event of planning on being away from home, planning and decision-making was required. Going on a holiday was a previously unattainable concept with their sick child, waiting on a transplant call. Now holidays could be contemplated, planned and realised.

"We can actually plan holidays now... I am actually owed a lot of holidays!"

Anne (interview transcript)

Starting preschool or school and returning to school was a particular concern. Holding off in starting the child in preschool or school was an option that had been toyed with. All the mothers expressed that despite initial misgivings, that the benefits had been realised in seeing their child re-entering into normal life. The return to normal life had overriding benefits despite minor set backs. Controls had been set in place by all three mothers to ensure that their child's reintegration was safe. These involved discussions with the teaching staff, education by health services and setting in place rules that the staff and child were familiar with. There had been disappointments, and I sensed that these had led to the mothers being increasingly stressed and increased levels of vigilance. Maintaining strategies that had been designed to lessen the risk of exposure to infectious diseases was one example

*Sending Betty to school was quite scary. Brenda worried that Betty would pick up infections; Brenda was not sure how Betty would react to illness. Brenda says she felt a bit isolated at that time and so got some support from the nurse specialist at Starship regarding what to do. We talked to every one involved at the school and they really responded well. It put my mind at ease. Betty really loves school and Brenda is getting better at **knowing** when to worry and when to relax. It's just a matter of **knowing** how to let go a little.*

Brenda (Narrative text)

Access to hospital services was an issue in relation to locality and accessibility. Having a health professional to consult with, put issues into perspective and mothers appreciated being able to pick up the phone and ring. Often they already knew the answers but just required validation. The lived space relationship between home and hospital was a concern and the time required to travel back to hospital was also considered. Coping with health requirements depended on how far the family lived from their base hospital and the distance from the Liver Transplant Unit at Starship Children's Hospital. In managing their children's wellbeing, the further they lived away from the hospital, the more important it became that strategies had been thought through and developed.

"We were awake all night when Alex got sick... We just kept checking his temperature every hour... We weren't really sure what to do or who to contact. We weren't sure whether to call the GP, or the paediatrician, or the transplant team... I have just got that sorted for next time..."

We didn't have a very clear plan of what we should do in the event of illness. We didn't know what was wrong with Alex and we were worried that it might be chickenpox... He was diagnosed with pneumonia... The illness was very worrying for us and there was no sleep at all... I called the GP and went to her and she referred us straight to the hospital, so it was all fine in the end... The paediatrician saw us and admitted us because his temperature was very high... Alex spent a week in hospital on IV antibiotics... Once I was within the hospital system I was fine – I felt safe and that everything would be OK... The paediatrician was very thorough and I felt confident that he knew what he was doing, I felt a bit less threatened in staying in hospital. It was probably better for me because it takes the stress away... The nurses looked after the temperature and made sure he was alright... At last I started to relax a little bit.”

Anne (Interview transcript)

The mothers developed a reportedly good rapport with their local doctor or paediatricians as a first line step in managing their children's health. If there was any doubt about their children's wellbeing or management there was no hesitation in contacting the Starship Liver Transplant Team members for reassurance, confirmation or referral. Starship was always there. The relationality between the mother and the hospital were strong. This provided reassurance and support to families in the adjustment to home and re-entering normal life.

When Betty was sick we were all sick... it affected us all as a family

Brenda (Narrative text)

Being part of a family

A child's transplant has a major impact on family relationships. Some mothers reported that their family had grown closer through the shared experiences. Although the transplant had been an extremely stressful time for the mother, it had also given an opportunity to reflect on the experience and to recognise that they had grown personally during the experience.

“In a funny kind of way I am pleased it happened, as I don't know what would have happened to our family otherwise... It really changed us and made us really appreciate friends and family”

Brenda (Interview transcript)

"The responsibility for caring falls largely on me because my husband works... Even so, my husband always seems to turn to me as to whether we are giving his medication... but he does do it... but it mostly falls on the mums I think... to make sure the routine is followed. If there is ever an issue, my husband asks me first... and I feel like Ohhh! It really is a big responsibility".
Anne (Interview transcript)

Trusting their spouse or partner was an evolving experience. There was a genuine willingness on behalf of the mothers to share the load more fully, though at the same time there was a strong pull to retain control and ensure the same level of vigilance. The mothers recounted experiences where their spouses had either let them down or got things wrong. Trusting their spouse to assist in managing the medication regime had been an area for concern and strategies had been developed to streamline the processes and to minimise errors or misunderstanding. Medication regimes were documented as were plans and telephone numbers to ring in the event of needing to call for help.

Siblings of the transplanted child were an existing area of concern for mothers. The mothers all recognised that despite their best efforts that they felt that the siblings of the transplanted children had missed out. The nursery rhyme about 'Jack and Jill' provides a metaphorical dimension to the understanding of the issues that arise out of sibling experiences of a child's illness (Fleitas, 2000). In trying to attend to all the children's needs there was a risk that the siblings may be suffering and strategies were described.

The transplant has had an enormous effect on Chloe's brother. Cara is sure he felt abandoned because of all the time she had to spend with Chloe. Cara knows that he still experiences the effects of that abandonment now. He doesn't like it when Cara goes places. It is as if he has a fear that she will disappear when he is not looking. He often comes down to her bedroom in the night, just to check that she is still there. Cara really wishes she could reassure him
Cara (Narrative text)

Normal sibling relationships were encouraged and mother recognised a need for fairness. Efforts were identified as ways to involve siblings and provide some special time as well e.g. separate outings, special time set aside. It was time to make it up to the other family members.

"The other child has missed out" Cara (interview transcript)

All of the mothers expressed concern for the experience endured by the siblings. Mothers made an effort to spend special time with the siblings and also to be honest with them regarding the sibling's experience. This was helped by the recordkeeping. Mothers appeared to appreciate the achievements of all their children and memoirs of the siblings were also included in the record keeping activities.

In acknowledging the contribution and experiences of siblings, there was also an identified need to share some quality time between partners. This links closely to trusting others and allowing others to share the care to enable the parents to have some time out for each other. This in turn had the effect of strengthening the relationships with friends and extended family as well as re-establishing the family, family values and roles.

Anne is aware of the effects that Alex's illness and transplant has had on the family. Anne's other child gets lots of love and hugs from the extended family. He has grown very close to his grandparents. She tries to have special time with both the kids. Sometimes she takes him out for a morning and has some time together; one on one. Anne plans take him away with me for a night when he is older, so that he doesn't feel left out. Anne really wants her other child to feel special too!

Anne (Narrative text)

The mothers described a willingness to focus on their families initially. Through bringing about a sense of control in their family life, and then extended family relationships, there was the increased willingness to reengage back into friendships. There was an intense focus on relationality. The mothers appreciated the support afforded upon them by friends and extended family. This led to a return to normality, though there was a sense that the mothers felt that they were no longer the same individuals they had been prior to transplantation of their child. Time and experience had changed them. LoBiondo-Wood, et al, (1992) found a strong consistency with their research in relation to previous research showing that social support is one of the factors necessary for family adaptation. McCubbin and Patterson (1983) identified social support as an important factor, stating that families who have support are more resistant

to major crisis. Re-engagement with family and friends was valued by all the mothers who participated in the research.

I am not the same person anymore. The transplant has changed me. I value my friends and family so much more.

Brenda (Interview transcripts)

Being part of a wider community

The process of transplantation and recovery allowed the mother the opportunity to shift her focus from her own situation and more closely consider and appreciate the experiences of others. This extended not only to family and friends, but also to the lives of others that the mother had chanced upon during the transplantation and hospitalisation process.

Brenda met so many other parents and children during the transplant process. It really opened her eyes. Brenda was amazed at the strength and love experienced during this time between the families. She really benefited from their support at the time. Brenda has maintained contact with some of the people she met. Some of the children have since died and it makes Brenda even more thankful for Betty's recovery. She will never forget or take for granted what she has gained.

Brenda (narrative text)

The mothers spoke of other families they had met and got to know, including families who had children with a wide variety of illnesses and some of whose children had died. There were some relationships that had continued following discharge from transplantation admissions and they would continue to be close in the future. There had been a real sense of community – relationality- in the home away from home – spatiality. Although the mothers had been thrown into the world of chaos in facing and undergoing a very stressful experience, the mothers in turn could now view it as an enlightening and transformative journey.

There was also a greater sense of compassion for other mothers in the community whose children were also experiencing ill health. Although there was acknowledgement, that perhaps some of these mothers had not experienced anything on

the same scale as they had, there was empathy for their concerns. This is highlighted from an experience I have taken from my personal journal;

Today I watched a mother of a transplanted child being on the ward. I couldn't believe the metamorphosis that this mother had undergone. Prior to, during and after the transplant I had observed an uptight singly focussed mother. There had been a lack of compassion and understanding towards the other mothers and children on the ward. This mother had regularly complained about other mothers, other children and their families. I had never seen her take an interest in any other child on the ward. Today was different; the mother had come for a routine admission and was only to be in hospital for an overnight stay. I saw her smiling and chatting to other mothers. She got down and talked to some of the children in their pushchairs and chatted in a friendly manner to their mothers. She was exceedingly patient and understanding. It appeared that she now had the time and interest to devote to others...

(Excerpt from researcher's personal journal, May 2005)

The sense of care and compassion was also seen to extend to others as well.

Cara described a situation in her community where she had been approached by the mother of an otherwise well child. The mother was anticipating a brief encounter in the hospital setting for the first time ever was concerned and stressed. The mother had told Cara about her child needing to have very minor ear surgery - grommets. The mother was exceedingly worried and fearful about her child having to undergo a general anaesthetic. Cara recounted how she had listened and reassured the mother. She said that she had been much more understanding of the other mother's plight and worry than she would have been previously. She surprised herself!

Cara (narrative text)

We are much closer as a family now.

Brenda (interview transcript)

Relationality also determined that the extended family now took a higher priority in family life. The mothers were able to recognise the impact that their child's liver transplant had upon the extended family and the long term changes that the family had undergone.

Being the holder of memories

Women are often the storytellers for families both officially and unofficially. This is common in a wide number of cultures where the women share the verbal history within the families. As the mothers re-engaged with life, there was a need to reflect upon the experience that they had experienced and its immensity for all.

I have a special big box and we actually went through it the other day... It's like a diary in a different form... We sat down and looked through it, and it was such a good thing to do, we will keep it forever... We put all the cards, well wishes, drawings and that sort of thing into the box... I haven't got round to putting anything into a book... I also have a folder where I keep all Betty's records, results and letters... It is an important document and it makes me feel confident that in the case that something happened to one of us that the family could get the necessary information.

Brenda (interview transcript)

A strong theme that emerged was the sense that this was history-in-the-making. During the period when the child is often very sick, hospital staff often encouraged the mothers to keep a diary as a reminder of the events and to log milestones in the waiting period prior to transplantation and during the transplantation process and recovery. The recording of events is seen as a way in which histories could be shared in the future with siblings and even with the transplanted child. It may assist in informing the transplanted child about this important event in their life and to stress the importance with regards to understanding their own body and mastering commitment and compliance with their health requirements in the future. There was an urge for the mothers to emphasise what had happened and how far they had come on their transplant journey together. It had brought the families closer together.

The mothers were able to recall very detailed information regarding their child's transplant and its effect on the family. Time is a great healer, but it also steals away our most precious memories. The maintenance and retention of memories was a high priority for all the mothers. The mothers were all at varying stages of organising their memoirs together. The memories varied but included; photographs, video recordings, newspaper and magazine articles, poems, diaries, patient information and results,

greeting cards and letter as well as mementos such as a curl of hair, or a picture done by the child or siblings. Combining histories into a variety mediums is a common industry used by women whereby experiences are expressed through scrap booking, needlework or writing.

It was envisaged that by keeping the memories together that the memories would remain strong and the significance would remain high. While the family was involved in the assimilation of memories, it was apparent that the mothers drove the process.

"We keep the stuff together", Brenda (interview transcript)

"I have kept a record so that we can look back", Brenda (interview transcript)

"I have kept an album of photos right from the start", Anne (interview transcript)

"Complete strangers sent us letters and cards and I have kept them all", Brenda (interview transcript)

"One day he and his siblings may wish to look back to appreciate what happened", Anne (interview transcript)

"I might want to write a book in the future", Cara (interview transcript)

By holding the memories, mothers were able to relate to family, extended family and friends in a more creative manner, allowing for expression of the experience in a manner that they felt confident to share. In preparing the memories, it allowed mothers to take an objective look at their own subjective experience and consider the experience for what it meant to them. This processing allowed them to appreciate the path and to look forward to a future with their child.

Being relieved and being able to plan for a future

By coming out the other side of transplant with a return to relative normality, there was a sense of relief and the opportunity to imagine a future life. Being more than a year post liver transplantation had been a milestone of achievement. There was a sense of

appreciation for the gift of life and the opportunity to experience a second chance of life for their child. Mothers described the changed relationships.

“The liver transplant has changed our lives and our whole family has a greater appreciation of life”.

Anne (interview transcript)

Mothers began to talk about how their child might cope in adolescence or adulthood. There was a sense of permission in being able to imagine a future not only for the transplanted child, but also the rest of the family

*“It feels so natural to say **when** he grows up. I never afforded myself the luxury prior to his transplant, but now I feel **we can** live again. He **may** have some restrictions on his life, but **he will** make the most of it and all we **can** do is helping to prepare him and assist him to understand the importance of being compliant... **when** he grows up”.*

Anne (Interview transcript)

There is a real emphasis in this interview transcript upon an anticipated future. There was a real confidence in the voice and nonverbal communication of this mother when she spoke about the future. The words that I have put in bold support this notion.

“I have changed I find myself letting go and not fretting the small stuff”. Cara (interview transcript)

There was also a concept of taking each day as it came. Becoming less focussed on the day to day events and looking forward. Mothers expressed a commitment to the transplantation process through a willingness to share their story and inspire others in contributing to the donation of organs. I have known many mothers to go forward to tell their stories to the media, not only to support the cause of transplantation, but also to celebrate their achievement.

“Other family members have signed up as donors”. Anne (interview transcript)

There was a sense that it was now time to nurture the family as a whole. In this way there was commitment to sharing the love out more fairly. Mothers experience a deeply transformative journey similar to the experience described by Clarke (2006) about

mothers caring for their children with cancer. With the passage of time there was a transition from the way of living one's life in limbo and finally returning to a kind of normality.

Valuing the unique mother/child /liver identity

In re-establishing relative normality there was also the opportunity to look at the special bond and sense of identity that arose from the experience of caring for their child. Mothers identified that they were changed as a result of the experience.

*Alex and Anne are a unit, practically a single entity. They have been through a lot together and Anne recognises and values the special closeness of the relationship. The relationship feels indivisible. Through this close relationship, she is able to detect very subtle changes that may otherwise go undetected. In being transplanted with a new liver, Alex has also been transplanted into a closer relationship with his mother. It is a relationship of devotion and necessity. Anne recognises the importance of trusting others and taking time out to nurture herself and the husband-wife relationship, though this is challenging. When leaving Alex, strategic planning is undertaken with military precision. Despite this, Anne feels compelled to check on Alex repetitively to ensure that he is safe, happy and well. Deep down, Anne would rather “be” with him. Anne would have a low threshold for a speedy return and reunion. When she returns, Anne expresses a sense of relief. It is a stressful time for Anne and she realises that the anxiety that she experiences is out of the realm of normality. There is a dilemma between **being there and being away** in body but not in mind.*

Anne (Narrative text)

In developing such a close bond as a result of the intense caring process, there was the potential for separation anxiety to be apparent. This was masked by the high level of vigilance and concern expressed. However the process of separating from their child was difficult. The intensity of caring had a direct bearing on the depth of care and love in the relationship.

The language used by the mothers was often focussed on ‘the liver’. The mothers related to their child, but also to “the new liver” as a distinct from the child’s liver. Sometimes the mother would refer to the liver as “his liver” and sometimes calling it “our liver”. The way in which the mother related to the child and his liver was an interesting aspect of

maternal thinking, self-identity and the notion of bearing a child who in turn has a defect in the case of congenital causes of liver failure – a less than perfect baby and the implications on them as mothers.

A possible explanation of the identity issues may relate to the intense feelings that surround the donation of the liver. There may be shared sorrow for the mother who now has only a memory of her child, as distinct to this mother who holds the life of her transplanted child so close to her. In not knowing who the donor is or was and the impact of his/her death, there is the potential for the identity of that individual to remain as part of their child's identity in "the liver". Perhaps this is an unconscious tribute to the donor.

In considering how the emergent themes could be dealt with in a way that brought about some further closure and meaning in this research enquiry, I once again returned to the published literature.

MATERNAL THINKING - EMERGING THEMES

In the course of my enquiry I read Sarah Ruddick's essay about maternal thinking again (Ruddick, 1983). When I had earlier reviewed her essay, parts of the writing had resonated with my own thinking, whilst others seemed wholly philosophical and I could not grasp the meaning or intention clearly. The article had also been written originally in 1980, and I needed to take into account the era in which it was written.

On this occasion when I picked up the article, I was astounded at how much more her work resonated with my emerging themes. Taking into account that the original essay had been written in 1980, and that the emancipation of women had continued to emerge, I felt that her writings still had something special to offer this interpretation. I felt that I could utilise her ideas around maternal thinking to guide the interpretation.

Ruddick (1983) proposed that maternal practice is generally governed by three interests; satisfying the child's demands for preservation, growth and acceptability. In considering the three interests I was surprised to find that each of the emerging themes

was able to fit into at least one of the interests. The table below show I lined up the emerging themes under the three interests.

Table 3; Working with the emerging themes

The capacity for attentive love		
Preservation	Growth	Acceptability
<ul style="list-style-type: none"> • Being a stressed mother • Mothers' caring for their "sick" children • Being vigilant • Holding on and letting go - trusting others and sharing the care • Mothers knowing – "taking it all in" • Being relieved and being able to plan for a future • Being the holder of the memories 	<ul style="list-style-type: none"> • Being a stressed mother • Mothers knowing – taking it all in • Achieving normality and everydayness • Being vigilant • Holding on and letting go - trusting others and sharing the care • Being part of a family • Being relieved and being able to plan for a future • Being the holder of the memories • Valuing the unique mother/child/liver identity 	<ul style="list-style-type: none"> • Being a stressed mother • Achieving normality and everydayness • Being vigilant • Holding on and letting go - trusting others and sharing the care • Mothers knowing – "taking it all in" • Being part of a family • Being part of a wider community • Being relieved and being able to plan for a future • Being the holder of the memories

The interest in preserving the life of the child

In working to preserve the life of her child, mothers are working in a peculiar relation to "nature" (Ruddick 1983). As the child who has a devastating diagnosis undergoes life-threatening surgery- the mother is working to preserve her child at all costs. Natural outcome diminishes in the context of specialty care and attention.

Today one of the children on the ward was notified that a donor liver had become available – they were going for "their" liver transplant. At that point we had several sick children on the ward awaiting a cadaveric donor as well. I remember consoling the crying mother of one of the other children still waiting.

She wanted to know why her child wasn't selected. Her child had the same blood type. Once a brief explanation had been given without breaching confidentiality,, she was happy for them, but so sad for her child and herself...She cried...

(Excerpt from researcher's personal journal)

The mother perceives that nature in it's unpredictability of germs and diseases, poses a threat to her child who has had a liver transplant. How does this affect her experience of caring for her child to minimise risk and optimise survival? This can be extremely stressful for the mothers.

I am always worried about her

Cara (interview transcript)

You wonder if it (disease) is going to creep back... it is always there in the background

Cara (interview transcript)

As mothers, they feel a duty to know what is going on at all times and thus maintain control. In knowledge comes the a measure of comfort and reassurance that she will be able to detect changes early, as well as take whatever necessary actions are required to minimise risk to her child. In engaging in the act of preservation the mothers express fearfulness and a high level of vigilance. Although the mothers identified that they appeared more concerned than their spouses, they felt compelled to comply. Faced with the fragility of the life she seeks to preserve, Ruddick (1983) states that maternal thinking recognises humility and resilient authentic cheerfulness. Indeed while interviewing the mothers, I was struck by their nonverbal cues and body language that supported their voices. Though the mothers do their best, they are aware that despite all they do that things can go wrong and that their child's life can be threatened through no omission or fault of their doing.

When you have been forced to have to face the reality that you maybe could have lost your child, it brings things home...

Brenda (interview transcript)

The interest in fostering the child's growth

In addition to preservation, Ruddick (1983) states that mothers must also foster growth and welcome change. As the mother experiences change, she must internalise and accept that change too. As her child's condition or medication regime changes, the mother familiarises herself with the change and then implements the change in the mindset that she is doing the best possible for her child. She is building resilience both personally and for her child as supported by Brooks and Goldstein (2001).

It took Brenda a year to settle once they all returned home. Brenda felt she needed to 'catch my breath' and feel alright about breathing normally. It meant not being on the edge of her chair all the time. Being in hospital had been a real adrenaline rush. In the beginning it was very scary to be finally making the decisions that decided how Betty would progress and ensuring that all the right steps were taken to ensure that she continued to develop and grow.

Brenda (narrative text)

In being open to change, the mother is always looking out for better ways of doing things, of performing, of being committed to the best opportunities for her child. Baker Miller (1973, p. 56) states "in a very immediate and day to day way, women live for change". The mother takes on the role of communicator between the multidisciplinary team and family.

In fostering the growth of the child the mothers are also preparing them for a future. Part of growth is accepting and implementing change to be resilient and competent humans. They are "their children" now and always will be, but they will eventually fly from the nest and when they do, the mothers want them to have grown physically, emotionally, socially, culturally, psychologically and spiritually so that they have the best possible chance at life with a transplanted liver.

The interest in shaping an acceptable child

The third interest stated by Ruddick (1983) is the requirement upon the mother to shape the child's growth to be acceptable to the social group from which the family arises. So

in addition to the values she has bestowed upon the child, the child must be in the process of becoming an adult acceptable to the next generation.

Ruddick (1983) states at some point the mother's desires and dreams for her child will be contradicted by the society in which women live in accordance with maternal powerlessness in a society she does not determine. She ascribes this kind of mothering as inauthentic as the maintaining a blindness or subordination in a dominant society. In the late 1970's the emancipation of women was still developing and progressing. I feel that the role of women is on a much more equal standing in this age, that the influence of feminism has brought women's rights to the fore. One might argue that perhaps they have not come far enough, if the mothers of these transplanted children identify themselves as the key caregivers of the child and the roles they hold. In the case of each mother who participated in this study, the choice to be the primary caregiver had been a role they had decided upon and taken on in partnership with their partners. There was a real expectation that the fathers would play an active role in the care and rearing. This would have the effect of the child's development of values being more authentic and reflecting the caregivers and societies values and norms of the subcultures they belong to.

The social group the children were reared in must correlate to the relationships the children will relate to in the future. I have observed that it is very important for the transplanted children to be accepted back into their peer group. The lived human relation is described by van Manen (1990) as one of the fundamental lifeworld themes. The emergent themes of 'being part of a family' and 'being part of a wider community', fit into the interest of acceptability. In order to be accepted into these social groups, a degree of acceptability and perceived normality is helpful.

As the mother cares for her transplanted child, there is a sense of relief at the child's life progress and survival. Mothers begin to feel confident in being able to plan for their children and the future of their families. The child begins to undertake roles and activities similar to other children their age and the children make friends and fit into these social groups as well.

It is through reviewing, remembering and appreciating the journey through life, the mother, child and family have the opportunity to review events, and recall people they have met and places they have been. In addition having memoirs allows children who may not have been at an age where they were able to comprehend what had happened to them and their family, to be informed and to assist in acceptance of their condition and the life they live.

Linking maternal thinking concepts to the emerging themes

Ruddick's (1983) essay suggested that there were three interests that governed maternal thinking. The emergent themes that arose out of the analysis and interpretation were able to be nestled within each of the interests. One might consider that this suggests that the interests of all mothers are closely shared; I propose that though the interests are similar, the journeys travelled are remarkably different. The journey travelled by each mother whose child has special health needs, and in the case of this thesis, the journey travelled by the mother in caring for her child who has recovered from liver transplantation is a different journey, a similar journey albeit different. That is what makes us all human, all the same and all different at the same time.

Capacity for Attentive Love

What runs clearly through as a theme is the "capacity for attentive love" described by Ruddick (1983) and in her essay, she describes how Simone Weil developed the notion of "attention" and Iris Murdoch the related notion of "love". Attention and love are crucial to the construction of "objective reality" and the cumulative effect is the movement of the mothers' thinking through the three interests of preserving, growth and acceptability and their cumulative effects (Ruddick, 1983).

I believe that the application of attentive love permeates all aspects of a mother's care. It was openly apparent through out the interviews and in hearing the stories and writing and rewriting the texts. This may explain the depths of grief the mothers emerged from, the happy enthusiasm mothers demonstrated despite the hard road travelled, the

optimism shared even when life is hard, the patience extended to their child even when sleep is poor and days start early and fast.

ESSENTIAL THEMES

One essential theme that was identified was that of the consequences of the child's liver transplant failing. When your liver fails death becomes a reality without transplant. Although measures are taken to slow the process, there is a point at which life is no longer sustainable and that without transplant the child will die. The only way to manage a failed liver transplant is to receive another liver transplant. This means starting at square one, being assessed, worked up, accepted for further liver transplant and then going onto the waiting list for a donor liver. Having been through this experience once, one can only imagine the anguish. It would be harrowing a second time for mothers and their children and families. Would the mothers wonder whether there was anything more they could have done? Families go in without any real expectations when their child's liver fails in the first instance. I have observed in the clinical setting that the second time around is all the more stressful related to the technical difficulty and risk of complications. The experience is intensified by their background and previous experience.

Other solid organ transplantations display a different course in the case of failure. In the event of a failed heart transplant, the damage done to the other organs and the fragility of the vessels following a heart operation mean that the failure can be rapid and chances of a paediatric heart transplantation are rare. There is a sense in having received the heart that the best chance has been given. Nature takes its natural course and death is more rapid. A second heart transplant is extremely rare.

In the case of kidney transplantation failure, parents have usually already experienced kidney failure prior to the kidney transplant. The mother of a child who has failing renal function will be familiar with the artificial means of filtering the wastes from the body using either peritoneal dialysis or haemodialysis. Dialysis is a therapy that can save a child's life, usually for a fairly long time, until a renal transplant can be

performed again. There is a sense that there is a stopgap measure that can be fallen upon to save the child's life in the event of failure.

For this reason, I identified that a major essential theme arising out of all the emerging themes was ensuring the ongoing survival of the child. Survival may be considered in terms experiencing of "a long life" or a "good life". The child has already previously faced liver failure, then transplantation. The drive to avoid failure of the transplanted liver is a major difference experienced by the mothers. It is the maternal interests in preservation, growth and acceptability in the realm of attentive love that support the drive for survival.

Summary

There is no doubt that the mothers caring for their children who have undergone and recovered from a liver transplant, experience a deeply transformative journey. Mothers value all their children, though it is apparent that there are many additional features that influence the lived experience of caring for the transplanted child.

Hermeneutic phenomenological reflection has enhanced the manner in which the themes have emerged. The narrative texts as well as the actual interview transcripts have been used throughout the chapter to highlight and support the interpretation. In the nature of hermeneutic phenomenology one must acknowledge that the interpretation is also based on the researcher's historicity and background and that the interviews were a mere moment in time. If the phenomenological nod can be achieved it will be an indication of the rigour infused into my work.

A common thread woven throughout all the emerging themes was that the lived experience of caring for a transplanted child was stressful. However that stress had not been necessarily considered detrimental. It meant walking the journey of life differently with one's eyes open wide. Mothers need additional knowledge to provide the specialised level of care to their child and this develops through a wide variety of means.

Mothers caring for their child who has undergone and recovered from a liver transplant have usually experienced chronic illness in their child first hand. In receiving a liver transplant, the child trades one chronic illness for a different chronic illness. Caring requires a high level of vigilance and this is sometimes at the expense of letting the child go and entrusting others with the child's care.

In an effort to achieve normality and everydayness, a return to more normal patterns of daily life are pursued. The importance of family and friends and their contribution and presence is honoured. A wider appreciation of the community is attained. In some cases a drive for media attention for the cause of liver transplantation and organ donation is undertaken. The mother has a role in ensuring that the memories and events are held and not forgotten. There is a definite sense of being relieved and being able to move forward and plan a future.

The identity of the mother, child and liver are closely entwined and the mother identifies with the child and the liver. This leads to the concept of maternal thinking proposed by Ruddick (1983) and the three interests that govern maternal practice; preservation, growth and acceptability. Encompassing these interests is the capacity for attentive love that filters all through the nature of mothers caring.

The final theme identified was the drive for survival of a liver transplant. In comparing liver transplantation to heart and kidney transplant, there are unique aspects and themes that emerge out of the inquiry. As this chapter concludes, the finding within the interpretation and indeed arising from the understandings achieved, provide a way forward in utilising the data for some purpose.

CHAPTER 7 - DISCUSSION & CONCLUSIONS ARISING FROM THE LIVED EXPERIENCE OF MOTHERS IN CARING FOR THEIR CHILD WHO HAS SURVIVED LIVER TRANSPLANTATION

As the final chapter unfolds, the opportunity arises to look back over the writing up of this research inquiry. In this final chapter I revisit the experience of engaging in the lifeworld of the mother in caring for her child who has undergone and recovered from a liver transplant. I have reflected on my experience of having shared the participant narratives and the writing and rewriting of the transcripts and other media to produce hermeneutic phenomenological texts both from the participant perspective and from insights into my own experience.

The limitations of the study are discussed to illustrate where aspects of the research inquiry might have been improved, to position the study and to identify opportunities for further research. The research aims are reviewed to measure accomplishment of the aims set at the outset of the research.

The implications and contributions that this study can make at a personal, theoretical, health policy and health service provision level are discussed. Recommendations arising out of the interpretation of the data are proposed for health service provision. Opportunities for future research arising from the recommendations of this research inquiry are stated.

It is without a doubt that in coming to understand the lived experiences of mothers in caring for their children, that valuable insights into the understandings we have about paediatric liver transplantation have been uncovered. Mothers have a valuable voice, to contribute to the understandings we derive in the provision of health care across the continuum of care.

Revisiting the experience of engaging in the lifeworld

In the course of interviewing the three mothers, rich and detailed data was obtained. Utilising the structural framework proposed by van Manen (1990) the following themes emerged. Each of the emerging themes was examined closely and interpreted utilising the rich text to develop narrative texts that strengthen the evidence and rigor through a process of writing and rewriting.

Being a stressed mother was a theme that reverberated throughout the interpretation. The knowledge that mothers have and develop in the course of caring for their transplanted child is tremendous. They continue to grow in their knowledge and this is evident in the skilled care provided to their child. Mothers had a high level of vigilance as they sustained the care and attention. There was very little that they missed. They reacted in a responsive manner to unanticipated change. In caring for their transplanted child, there was a drive to encourage and embrace normality and everydayness in their lives.

In the course of a return to normality there was a need to allow others to share in the care. Going to preschool or school was a big achievement in releasing the child into care where the child was not necessarily the school's chief concern. Integration of the child also meant allowing the child to experience activities undertaken by their "normal" peers, including sleepovers which came with their own stressors.

In renegotiating normality there was a greater appreciation of family and friends, including recognition of being part of a wider community. In looking more externally, the mothers experienced a sense of relief and with that came the ability to contemplate a future for themselves, the child and the family as a whole. In recognition of the enormity of the experience the mothers had all collected an assortment of memoirs including photographs and cards. The memories were kept together, to be pulled out from time to time to remind everyone of what they had experienced.

In overcoming such an intense experience it is little wonder that a close bond developed between the mother and child and to some extent the liver. This unique identity may relate to the donated liver causing a third level of identity between the mother and child.

Maternal Thinking

Ruddick's (1983) essay on maternal thought contributed to the final interpretation of the findings. She proposed three interests that generally govern maternal practice are preservation, growth and acceptability of the child. On further consideration, each of the emergent themes was able to be sorted under at least one of the interests and this had the result of further clarifying the meanings. In addition to the three interests described by Ruddick (1983), an overarching capacity for attentive love was also described. This capacity had the effect of drawing together all the meanings. The inspired meaning revealed in the course of investigating the experience of a mother caring for a child who has undergone and recovered from a liver transplant is the capacity for attentive love.

Reflections

As I shared the conversations with the participants, I was in a unique position in which to hear their stories first hand. In progressing to the analysis and interpretation, I was suspended within a prolonged period of "dwelling in the data", which extended out my enrolment in the thesis. The benefit of this enforced immersion provided me with the space to think. Our minds are not computers forming concrete tasks in the minimum of time. This methodology cannot be rushed. I had the luxury of walking and thinking, and keeping a personal journal over a long period in the course of this thesis.

I lived with the data and found myself talking out loud and then scribbling my ideas down on paper. The process of dwelling allowed me to think about our experiences of being-in-the-world. This promoted an authentic mode of thinking that facilitated in me the opportunity to imagine and strive to produce a text that really told the story.

Phenomenological inquiry is a circular process and the end point was in working towards the submission of this thesis. The end is never absolute. The meanings

continue to emerge and evolve. Throughout this research process, I kept a personal journal to record thoughts, ideas and reflections to maintain a balance and ensuring that the context was considered in the parts as well as in the whole. In addition I pasted in newspaper clippings, magazine articles and quotes that had a bearing on my own understandings. There was a great deal of insights and understandings that emerged from studying in an in-depth manner.

The participant perspectives

The participants shared their stories in the course of the unstructured interviews. Their contribution was made willingly and with a real commitment to the research question. The participants were not coerced to participate and gave freely of their time. The interview was an opportunity to share their voice and to contribute to the understandings of health care professionals. At the conclusion of the interview there was a general feeling that the process had been therapeutic. In talking about their experiences and memories, feelings were aroused. None of the participants required additional counselling or referral to the Starship Consult Liaison Service.

Insights into my experience

I have benefited greatly from the opportunity to undertake this research inquiry, utilising hermeneutic phenomenology as my methodology. When one sets out on a research journey you have an inkling of what you might reveal, based on what you have experienced and read. It is exciting. It would be easy to race ahead once you have Ethics approval without really preparing the way forward. It is an extremely humbling experience to hear the stories and then to take them and work on them in a manner that both honours the voices and reveals the underlying meanings.

The limitations of the study

There are always limitations on the outcomes of research. There are overt and hidden causes that need to be considered. The researcher needs to be aware that what is revealed is not always what is actually happening. There are multiple realities,

explanations and interpretations which must be uncovered if the full picture is to be revealed. In selecting participants there are risks of some of the people may have hidden agendas for sharing the knowledge. I was not aware of any overt reasons for the participation of the mothers.

This research looked to reveal the meaning of the lived experience of caring for their child who had undergone and recovered from liver transplantation. The research inquiry was directed towards answering that research question. If other data was sought from this research it may not be able to be extracted accurately as the data was selected for the specific reason of answering the research question.

At the outset of this research I had intended to interview four to six mothers. For reasons, out of my control, I eventually interviewed three women about their experience. There will no doubt be criticism about how one can interpret the findings when the sample size was small. In phenomenological research it is not uncommon for the sample size to be restricted to a single participant. In undertaking the interviews, I was impressed by the consistency of the themes that emerged from the stories. I decided that three good participants would be sufficient for the purposes of this research.

In the selection of the participants there were unforeseen issues with the recruitment of Maori and Pacific Island mothers. I had hoped that through the contribution of diversity in cultures, that I would enrich the findings to reflect the New Zealand experience. For reasons I have explained earlier, I did not manage to recruit Maori and Pacific Island mothers who fitted the sampling criteria. Some children experienced more hospitalisation and this may have been due to a number of factors including unforeseen complications, socio-economic reasons and exposure to illness. Another issue may have been an unwillingness to be interviewed and fear of identification. As the mothers were not coerced, these reasons were not revealed. Edna had initially agreed to participate and then was unable to be contacted without accessing confidential patient information, and was therefore not pursued. Dora had also agreed to participate, however in the time between showing interest and giving consent her child became unwell and required a series of hospitalisations that excluded that mother from participation.

Opportunities for improvement

In any research project there are always ways in which the research inquiry could be improved. One opportunity for improvement I can make is the reduction in length of time it has taken for this research to be completed. Ethics approval was obtained at the end of 2003. There were delays in confirming participant agreement to participate, as I had delegated the selection to another person to avoid coercion. I should have started the process of undertaking the participant interviews, while I waited for further participants. As a novice researcher, I was concerned that I needed to have my complement of four to six participants. In the end I had three participants and they provided a wealth of consistent data.

Orii, Ohkohchi and Satomi (2004) undertook a study of the rehospitalisation after transplant. They found that there is a frequent rate of readmission for cholangitis, viral infections, portal stenosis and liver rejection. This report provided insight into the possible reasons why recruitment was difficult as there is a low threshold for admission and high admission rate with complications.

A further opportunity for improvement is adjustment of the sampling criteria. In retrospect I might have been able to include more cultural diversity if my sampling criteria had been more accommodating for these groups. On further consideration, there may be benefits in having undertaken and refined the process of interviewing the mothers. In a further research inquiry I might be able to focus on other cultural groups and this would give interesting similarities and contrasts.

Review of the research aims

The research aims that were developed at the beginning of this inquiry arose from my desire to undertake this research in a rigorous manner, making a contribution to existing knowledge around paediatric liver transplantation. Four aims were put forward for this research inquiry.

The first aim (a & b) was to uncover the essential meanings of the lived experience of mothers utilising rich descriptions in accordance with the hermeneutic phenomenological reflection, capturing the essences of the lived experiences of mothers caring for their transplanted child in the realm of home. I achieved this aim as is evident in the interpretations of this research inquiry.

The second research aim was to highlight phenomenology as a valid research methodology, by providing new understandings of the value of the data provided by the participants and the new knowledge revealed in the course of this research inquiry. The interpretations and conclusions reached in the research study demonstrate the validity of phenomenology as a research approach. In interpreting the data, new ways of considering and understanding the data have been presented. Though the overall findings may not reveal new knowledge, the way in which it has been presented and shared is new and it will contribute to future understanding.

The third aim was to support a growing appreciation of the significance of the success of paediatric liver transplantation as a valuable health care service in New Zealand to health care planners, providers, funders and the wider community. In hearing the stories of the mothers of caring for their transplanted children, it is evident the liver transplantation has a remarkable effect on the child, family and wider community as they pitch together to provide for the needs of members of society in need. In some of the cases, whole communities band together to raise money to support a child and family during the transplantation process – this can only promote charity and a sense of goodwill in the community. In funding the liver transplantation of children to have their liver transplant in New Zealand there are obvious economic bonuses.

Providing a paediatric liver transplantation service in Auckland attracts health professionals of a high level of expertise that has side benefits for other children using the hospital service. There are also obvious advantages to caring for children of New Zealand in New Zealand where they have access to culturally appropriate care and access to family and extended family who play a large role in the care and treatment of children and particularly children of Maori descent and Pacific Island descent. Keeping

the family together also allows life to continue in as normal way as possible, reducing the effects of separation, allowing for early return to work and being able to retain family homes and jobs.

The fourth aim was to provide glimpses and insights into the life of the child who has recovered from a liver transplant based on the mothers' experience and as seen through mothers' eyes. Through out the analysis and interpretation of the data, insights into the lives of the transplanted children have been exposed. One has a real sense of their experience arising from the lived experiences of the mothers in caring for their transplanted child.

Recommendations for health service provision

I have developed some recommendations based on the interpretation arising from this research for health service provision.

1. Foster effective relationships between caregivers and their local health care providers to build trust and confidence and promote open communication.

Communication is the key to strengthening the relationships that the families have with their local health providers. Ensuring that regular updates are sent to their general practitioners, paediatric home care nurses and local paediatricians at their local district health board will keep them updated and connected. Families should be encouraged to develop good relationships with their general practitioner so that day-to-day health needs can be dealt with in a confident manner. The families need to be involved in the sharing of the information so that they can feel that the health care providers at their home base will understand the magnitude of their experience.

2. The development of closely negotiated care plans to guide care requirements and to assist in obtaining correct level of action in the event of health concerns.

Discharge care planning should be started in a timely manner alongside the discharge education. The individualised care plan will take into account the local resources and services in the region that the child and family will be returning to. The plan will have the clear parameters and instructions that the family can follow. The plan will also detail the expected action that might be expected by their local health providers. This will ensure that there is clarity about the correct action to be taken in the event of health concerns.

3. Increase the awareness and support for siblings of children undergoing liver transplant to ensure that their needs for support are met.

In providing care for the child there also needs to be an increased focus on the siblings to ensure that their emotional wellbeing is preserved. Greater support for families while living away from home would mean that all children would get the care and attention they need including schooling and health care. Where concerns are raised about the coping mechanisms of siblings these could be raised with the team to identify the best action to alleviate symptoms and provide support.

6. Advocate for the continuing awareness of the benefits of organ transplantation to the general public and health professionals and health funders.

In undertaking this research and publishing an article it may be possible to increase the awareness to my colleagues, the wider health profession as well as the public. In sharing the mothers stories there may be a greater appreciation of the experience and the benefits enjoyed not only by the recipient but also the family. Awareness of organ donation will be raised within the wider community and the benefits will be translated into a greater appreciation of the benefits. The potential to raise the profile to politicians may lend support important aspects of liver transplantation,

Potential contributions of the research inquiry

This research inquiry has the potential to assist mothers experiencing caring for their transplanted child to understand some of the feelings they may be experiencing. It may also allow others closely associated with these mothers to more fully appreciate the meaning of the experience. In doing so it may provide additional support for the families caring for sick children. By hearing about the experience, parents and caregivers caring for their child and facing the prospect of liver transplantation may have a greater understanding and be in a better position to provide a balanced informed consent.

There is also the potential for a wider understanding by the media and general public of the caring experience of mother in caring for a child who has undergone liver transplantation. There may be a greater appreciation in general for the role of all mothers caring for children both well and with special health requirements.

The understanding and empathy of health professionals and healthcare team workers may be enhanced by the stories of caring that are often assumed but not necessarily known. It is also hoped that the awareness of the benefits of organ donation will be enhanced.

When one is not consistently exposed to a situation, it can lead to the nature of an issue being oblivious and hidden. When you are faced with sick children on a daily basis it can cloud your judgement and understanding. In the process of this research, the curtains have been drawn and a fuller picture has been exposed. Through an examination of the issue and resulting different perspectives my own personal understanding has been enhanced.

The current economic climate emphasises judicious spending of the health dollar. There is debate regarding the allocation of health funding to quaternary health services, which benefit only a very small proportion of the population. Public opinion and input into decision-making is required to determine and ensure the funding of tertiary and quaternary health services. This research has the potential to provide support for

ongoing funding of paediatric liver transplantation and clarity around donor organ policy in New Zealand.

Research opportunities

Possible opportunities for research are numerous. Interpretive and descriptive research has the effect of stimulating an interest in new research questions. As stated earlier, owing to the lack of cultural diversity of the participants, it would compliment this research if it was undertaken using culturally diverse participants. It would be interesting to compare the emerging themes of this research with the emerging themes obtained with Maori and Pacific Island participants.

In utilising hermeneutic phenomenological inquiry, it would be challenging to apply a similar methodology, method and design to the lived experience of other mothers whose children have undergone other solid organ transplantation, e.g. heart, lung, kidney, to actually validate the emergent themes, identifying the incidental and essential themes of the phenomenon undertaken in this thesis. This might also be applied to the experience of fathers and siblings.

A further research idea might be to repeat the interviews when the children become adolescents to see whether the mothers have similar experiences spanning over time or whether there is a lessening of the high level of concern.

From an organisational perspective, it might be advantageous to undertake a questionnaire to see whether particular concerns that arose in the context of this interpretation, can be drilled down further and clarified to support organisational changes.

A longitudinal study might also assist in capturing whether the experiences of caring for mothers changes in response to new initiatives or changes in resources. It may even capture the changes in responses over time as the mothers adjust or receive more or less support.

Conclusion

The voice of mothers is regularly sought and valued, but is it always heard? This hermeneutic phenomenological research inquiry was undertaken to investigate the phenomenon of mothers caring for their transplanted child. The emerging themes were discussed and the relevance of Ruddick's (1983) writing around maternal thinking was used to demonstrate the drawing together of the ideas and so highlighting the mothers' capacity for attentive love.

The perspectives of the participants were described in relation to their participation in the research inquiry. My own insights into my experience were also outlined. The limitations of this research have been outlined from my critique of my interpretation and findings. Opportunities to improve the quality of this research were discussed. The research aims stated in Chapter One were reviewed. Each aim was discussed to demonstrate achievement in the course of the research inquiry

Four recommendations were developed for health service provision. The potential contributions and research opportunities arising out of this research inquiry are proposed. The way in which this might be achieved was discussed broadly as a starting point to move forward from this inquiry

Mothers have a valuable voice to contribute to the understanding we derive from their interactions in the pursuit of caring. In the process of this research I have seen hope restored, where hope faltered. In the process of receiving a donated liver for their dying child, the mothers' sense of gratitude for fellow man has been enhanced. Clutching your child back from the grip of death is a valiant feat. The wonders of science continue to exceed our expectations, the technological advances, the growth of knowledge continues. May it continue to do so?

LIST OF APPENDICES

	Title of document	Page Number
Appendix I	Copy of Ethics Approval.....	150
Appendix II	Participant Response Form.....	152
Appendix III	Participant Consent Form.....	153
Appendix IV	Information Sheet for Participants....	154
Appendix V	Sample questions.....	158

APPENDIX I

APPENDIX II

Participant Response Form

Through mothers' eyes: The lived experience of 4-6 children after liver transplantation

Dear Sandra Murphy

I have had an opportunity to read your information sheet regarding your research project. This is **not** a formal consent to participate but will allow you, the researcher, to make contact with me and answer any questions or concerns I may have.

1. I would like further information about this research

Yes No Unsure

2. I would like to participate in the interview

Yes No Unsure

My name is(Full name please)

My address is..... My phone number
is.....

.....

The time of day it is convenient for phone contact.....

—

Please fold and place into the postage paid envelope, if you wish you may contact the researcher directly. Phone: Work (09) 3074949 Extn. 6366 or Mobile 021 2518352

APPENDIX III

Participant Consent Form

Through mothers' eyes: The lived experience of children after liver transplantation.

- I have received an explanation of the research project and had an opportunity to ask questions and have them answered to my satisfaction.
- I know that my participation is voluntary and that my choice will not affect any health care treatment my family requires in the future.
- I understand that my child is not required to participate in the interview. However I have spoken about my participation in this interview with my child and there is no apparent opposition.
- I understand that I may choose not to answer questions during the interview and I can stop the interview at any time.
- I may withdraw or withdraw any information I have provided for the project before data collection is completed, without penalty or giving any reason.
- My information will remain non-identifiable and my name will not appear in any presentation or the report of the research findings.
- If during the process I become upset, the interviewer will provide support and may offer to refer me to the Starship Children's Hospital support services.
- I consent to the interview being audio taped. At the end of the project - the transcriptions of the interviews will be kept securely for ten years. The tapes will be offered back to me or destroyed if they are unable to be returned. A summary of the research findings will be given to me.

Continued over page.

- I know that the Human Ethics Committee at Victoria University of Wellington and the Auckland Ethics Committee have approved this research project.
- If I have any concerns about the research, I can contact the appointed supervisors. They are Dr Joy Bickley Asher, or Dr Rose McEldowney, Senior Lecturers at the Graduate School of Nursing and Midwifery at Victoria University of Wellington. Phone (04) 463 5410. Alternatively I can contact an independent Health and Disability Advocate. This is a free service.
 - Health Advocates Trust (Upper North Island) Freephone: 0800 205 555
 - Advocacy Network Services (Lower North Island) Freephone: 0800 423 638
 - Advocacy Services South Island Trust (South Island) Freephone: 0800 377 766
- If I require the presence of a support worker, a mutually acceptable person will be made available for the interview at no expense to me.
- I have read and understood the above information and agree to participate in this research project

Signed.....Dated.....

Name of the participant.....

Statement by the researcher

- I have discussed the aims and process of this research project

with(Name of the participant)

Signed.....Dated.....

Researcher's name.....

APPENDIX IV

Through mothers' eyes: The lived experience of children after liver transplantation.

Information Sheet for Participants

Version 1.

1.11.03

Hello,

My name is Sandra Murphy. I am a nurse with extensive experience in paediatric nursing. I am studying for the award of Master of Arts (Nursing). I am seeking to find out what life is like for children following recovery from a liver transplant and about their well being. As a member of the team involved in the paediatric liver transplantation service, I have become increasingly aware of the changed lifestyle and long term effects of liver transplantation on children and their families.

You are invited to take part in this research project. I wish to individually interview some mothers of children who have undergone liver transplantation at least one year ago. The interview would take around an hour. I would be happy to come to talk with you in your home or we could meet in a private room at the Starship Children's Hospital as mutually convenient. There would be no cost to you associated with your involvement. Your participation is entirely your own choice. You do not have to take part in this study, and if you choose not to take part your child will continue to receive their usual care.

During the interview I would like to hear about your perceptions of your child's experiences and their level of wellbeing and participation in everyday life since their transplant. The questions seek detailed descriptions of your child's wellbeing and adjustments.

For example the questions may cover:

What is life like for your child following their liver transplant?
Can you tell me about your child's current level of wellness?
How do you compare your child's progress in comparison to others
their age?

Our conversation would be audio taped so that I can recall all that was said. At the end of the study, the findings may be published or used to give a teaching session.

Confidentiality would be maintained and your name would not be revealed. Every effort to maintain anonymity would be taken, though as a result of the small number of liver recipients this may be difficult to achieve. Any tapes or notes used in the conversations would be kept locked away safely and securely at all times. The tapes would be either returned to you or destroyed depending on your wishes. No material that could personally identify you or your child will be used in any reports on this study. At the end of the study, you would receive a summary of the findings of the research. The information would benefit nurses and other health care team workers.

If you would like further information or have any questions, I can be contacted by phone. My work phone number is: (09) 307 4949 Extension 6366, at home (09) 416 5502 . Alternatively my supervisors Dr Joy Bickley Asher or Rose McEldowney can be phoned on Ph. (04) 463 5410. If you have any concerns regarding your rights as a participant in this study you may wish to contact a Health and Disability Advocate, telephone 0800 555 050.

This study has received ethical approval from Auckland Ethics Committee as well as the Victoria University of Wellington Human Ethics Committee.

If you would like to be involved in my project, please sign the enclosed participant response form and mail it back to me in the prepaid envelope attached. Once I receive your form, I will telephone you to discuss this further with you.

Please feel free to contact the researcher if you have any questions about this study.

Thanks very much

Yours sincerely
Sandra Murphy

Post Graduate Student	Charge Nurse Ward 26B
Graduate School of Nursing and Midwifery	Level 6
University of Wellington	Starship Children's Hospital
Te Whare Wananga o te Upoko o te Ika a Maui	Private Bag 92-204
	Auckland

APPENDIX V

Sample questions: Through mothers' eyes: The lived experience of caring for a child after liver transplantation.

1. What do you think having a liver transplant has meant for you and (name of child)?
2. What has it meant for you in your every day life?
3. What has it meant for you in regards to coming home from hospital and life at home?
4. What about the family and child?
5. Can you tell me about a situation that you found challenging/sad/happy/worried and tell me the story around that?
6. How has your child's development made you feel?
7. What effect does your child have upon yourself and others?
8. How does your child's health impact on your lifestyle?
9. What has it meant for her/his overall wellness and you and the family?
10. How has your child's place in the family been influenced?
11. Can you recall a time where your child was really unwell and how you coped with the challenge?
12. Can you recall a discussion you have had with your child regarding their current level of health in relation to their transplant? Can you tell me about the incident and the outcome of the discussion?
13. I wonder if you could tell me about a normal day for yourself and then we can focus on any areas that arise from there?

PROBES

Can you give me an example of that?

Can you remember a specific incident that illustrates this?

Can you tell me more about that experience?

How does that feel when it happens?

You just said something that I want to go back to... repeat... I wonder if we could spend a bit of time talking about that?

What effect does that have on you?

REFERENCES

Ahmann, E. (1994). Family-centered care: Shifting the orientation. *Pediatric Nursing*, 20(2), 113-117.

Allen, D., Benner, P., & Diekelmann, N. L. (1986). Three paradigms for nursing research: Methodological implications. In P. L. Chinn (Ed.), *Nursing research methodology*. (pp. 23-38). Rockville, Maryland: Aspen.

Alonso, E. M., Neighbors, K., Mattson, C., Sweet, E., Ruch-Ross, H., Berry, C., et al. (2003). Functional outcomes of pediatric liver transplantation. *Journal of Pediatric Gastroenterology and Nutrition*, 37(2), 155-160.

Annells, M. (1996). Hermeneutic phenomenology: philosophical perspectives and current use in nursing research. *Journal of Advanced Nursing*, 23(4), 705-713.

Atkison, P. R., Ross, C., Williams, S., Howard, J., Sommerauer, J., Quan, D., et al. (2002). Long-term results of pediatric liver transplantation in a combined pediatric and adult transplant program. *Canadian Medical Association Journal*, 166(13), 1663-1671.

Bailey, P. (1997). Finding your way around qualitative methods in nursing research. *Journal of Advanced Nursing*, 25(1), 18-22.

Baker Miller, J. (1973). *Toward a New Psychology for Women*. Boston: Beacon Press.

Barclay, L., Everitt, L., Rogan, F., Schmied, V., & Wylie, A. Becoming a mother – an analysis of women's experience of early motherhood. (1997) *Journal of Advanced Nursing*, 25(4), 719-728.

Bartlett, W. R. J. (1996). *A cost-effectiveness analysis of liver transplantation*. Unpublished PH.D., University of Tennessee, Tennessee.

Beath, S. V., Cash, A. J., Brook, G. A., Mayer, A. D., Buckels, J. A. A., & Kelly, D. A. (1997). Long term outcome of liver transplantation (LTx) in babies less than 12 months. *Journal of Pediatric Gastroenterology and Nutrition*, 24, 485.

Belenky, M. F., Clinchy, B. H., Goldberger, N. R., & Tarule, J. M. (1986). *Women's Ways of Knowing. The Development of Self, Voice, and Mind*. New York: Basic Books Inc.

Benner, P. (1985). Quality of life: A phenomenological perspective on explanation, prediction and understanding in nursing science. 8, 1(1-14).

Berragan, L. (1998). Nursing practice draws upon several different ways of knowing. *Journal of Clinical Nursing*, 7(3), 209-217.

Bradford, R. (1991). Children's psychological health status- The impact of liver transplantation: A review. *The Royal Society of Medicine*, 84, 550-554.

Brooks, R. & Goldstein, S. (2001). *Raising resilient children – Fostering strength, hope, and optimism in your child*. Chicago, Contemporary Books.

Broome, M. (2003). The influence of relationships on children's and adolescents' participation in research. *Nursing Research*, 52(3), 191-197.

Bucuvalas, J. C. & Ryckman, F. C. (2002) Long-term outcomes after liver transplantation in children. *Pediatric Transplantation*, 6, 30-36.

Burns, M. (1994). Creating a safe passage: The meaning of engagement for nurses caring for children and their families. *Issues in Comprehensive Pediatric Nursing*, 17, 211-221.

Butler Simon, N., & Smith, D. (1992). Living with chronic pediatric liver disease; The parents' experience. *Pediatric Nursing*, 18, 455-458.

Byrne, M. (2001a). Critical incident technique as a qualitative research method. *AORN Journal*, 74(4), 538-539.

Byrne, M. (2001b). Interviewing as a data collection method. *AORN Journal*, 74(2), 233-235.

Byrne, M. (2002). Hermeneutics as a methodology for textual analysis. *AORN Journal*, 73(5), 968-970.

Calvacca, L. T. (1990). *An investigation of the relationship of mothers' flexibility and accuracy of mothers' perception of their children's fears to the ego development of ten to twelve-year-old children*. New York: New York University.

Carper, B. A. (1978). Fundamental patterns of knowing in nursing. *Advances in Nursing Science*, 1, 13-23.

Casey, A. (1995). Partnership nursing: Influences of informal carers. *Journal of Advanced Nursing*, 22(6), 1058-1062.

Chardot, C., Carton, M., Spiore-Bendelac, N., Le Pommelet, C., Golmard, J., Reding, R., et al. (2001). Is the Kasai operation still indicated in children older than 3 months? diagnosed with biliary atresia? *The Journal of Pediatrics*, 138(2), 224-228.

Codoner-Franch, P., Bernard, O., & Alvarez, F. (1994). Long-term follow-up of growth in height after successful liver transplantation. *Journal of Pediatrics*, 124, 368-373.

Cohen, M. H., & Omery, A. (1994). Schools of phenomenology: Implications for research. In J. M. Morse (Ed.), *Critical Issues in Qualitative Research* (pp. 136-156). Thousand Oaks, CA: Sage Publishing.

- Cohen, M. Z., Kahn, D. L., & Steeves, R. H. (2000). *Hermeneutic Phenomenological Research - A practical guide for nurse researchers* (Vol. 2). Thousand Oaks: Sage Publications.
- Coyne, I. T. (1995a). Parental participation in care: a critical review of the literature. *Journal of Advanced Nursing*, 21, 716-722.
- Coyne, I. T. (1995b). Partnership in care: parents' views of participation in their hospitalized child's care. *Journal of Clinical Nursing*, 4(2), 71-79.
- Darbyshire, P. (1994). *Living with a sick child in hospital*. London: Chapman and Hall.
- Dixon, D. M. (1996). Unifying concepts in parents' experiences with health care providers. *Journal of Family Nursing*, 2(2), 111-132.
- Draucker, C. B. (1999). The critique of Heideggerian hermeneutical nursing research. *Journal of Advanced Nursing*, 30(2), 36-373.
- Dreyfus, H. L. (1988). Husserl, Heidegger and modern existentialism. In B. Magee (Ed.), *The Great Philosophers: An introduction to Western Philosophy*. New York: Oxford University Press.
- Dreyfus, H. L. (1991). *Being-in-the-world: A commentary on Heidegger's Being and Time*. Cambridge: MIT Press.
- Eiser, C. (1993). *Growing up with a chronic disease: The impact on children and families*. London, Jessica Kingsley.
- Eiser, C. (1994). Making sense of chronic disease. The 11th Tizard Jack Memorial Lecture. *Journal of Child Psychology, Psychiatry and Allied Disciplines*, 35, 1373-1389.
- Eiser, C. (2001). A review of measures of quality of life for children with chronic illness. *Archives of Disease in Childhood*, 84(3), 205-211.

Elliott, B. E., & Luker, K. (1997). The experiences of mothers caring for a child with severe atopic eczema. *Journal of Clinical Nursing*, 6(3), 241-247.

Fisher, H. R. (2001). The needs of parents with chronically sick children; a literature review. *Journal of Advanced Nursing*, 36(4), 600-607.

Fleitas, J. (2000). When Jack fell down... Jill came tumbling after: Siblings in the web of illness and disability. *MCN, The American Journal of Maternal/Child Nursing*, 25(5), 267-273.

Forsberg, A. (2002). Liver transplant recipient's experienced meaning of health and quality of life one year after transplantation. *Theoria Journal of Nursing Theory*, 11(3), 4-14.

Forsberg, A., Backman, L., & Moller, A. (2000). Experiencing liver transplantation: A phenomenological approach. *Journal of Advanced Nursing*, 32(2), 327-334.

Fung, J. J. (2002). Highlights of the Eighth Congress of the International Liver Transplantation Society. 3(2). Posted 07/04/2002.

<http://www.medscape.com/viewarticle/438900>

Gadamer, H. G. (1975). *Truth and Method*. New York: Seabury.

Garcia, M. K. (1996). *The lived experience of mothers of children with asthma*. Unpublished PH.D., Texas Woman's University.

Gelling, L. (1998). Quality of life following liver transplantation: Physical and functional recovery. *Journal of Advanced nursing*, 28(4), 779-785.

Gelven, M. (1989). *A commentary on Heidegger's being and time* (Revised Ed.). DeKalb, Illinois: Northern Illinois University Press.

- Gibson, C. H. (1995). The process of empowerment in mothers of chronically ill children. *Journal of Advanced Nursing*, 21(6), 1201-1210.
- Gibson, C. H. (1999). Facilitating critical reflection in mothers of chronically ill children. *Journal of Clinical Nursing*, 8(3), 305-312.
- Giddings, L. S., & Wood, P. J. (2001). Phenomenology - telling a story: an interview with Liz Smythe. *Nursing Praxis in New Zealand*, 17(3), 15-26.
- Glantz, L. H. (1996). Conducting research with children: legal and ethical issues. *Journal of the American Academy of Child & Adolescent Psychiatry*, 35(10), 1283-1291.
- Glasscock, R. (2000). A phenomenological study of the experience of being a mother of a child with cerebral palsy. *Pediatric Nursing*, 26(4), 407-410.
- Gravelle. (1997). Caring for a child with a progressive illness during the complex chronic phase: Parents' experience of facing adversity. *Journal of Advanced Nursing*, 25(4), 738-745.
- Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin, & Lincoln, Y. S. (Ed.), *Handbook of Qualitative Research* (pp. 105-117). Thousand Oaks: Sage Publications.
- Gubby, L. (1998). Assessment of quality of life and related stressors following liver transplantation. *Journal of Transplant Coordination*, 8(2), 113-118.
- Hadzic, N., Davenport, M., Tizzard, S., Singer, J., Howard, E., & Mieli-Vergani, G. (2003). Long-term survival following Kasai Portoenterostomy: Is chronic liver disease inevitable? *Journal of Pediatric Gastroenterology and Nutrition*, 37(4), 430-433.

Hagedorn, M. I. E. (1993). *A way of life: a new beginning each day. The family's lived experience of childhood chronic illness*. Retrieved 04/07/, 2003, from <http://www.phenomenologyonline.com/articles/hagedorn.html>

Heidegger, M. (1927-1964). *Basic Writings from Being and Time (1927) to the Task of Thinking (1964)*. San Francisco: Harper.

Heidegger, M. (1962). *Being and Time* (J. Macquarrie & E Robinson, Trans.). Oxford: Blackwell Publishers (Original work published 1927).

Henderson, D. (1997). Consciousness-raising a feminist nursing action. In S. Thorne & V. E. Hayes (Eds.), *Nursing Praxis: Knowledge and Action*. London: Sage.

Hodgkinson, R., & Lester, H. (2002). Stresses and coping strategies of mothers living with a child with cystic fibrosis: implications. *Journal of Advanced Nursing*, 39(4), 377-383.

Holmes, C. (1996). The politics of phenomenological concepts in nursing. *Journal of Advanced Nursing*, 24(3), 579-587.

Jardine, D. (1990). Awakening from Descartes' nightmare: On the love of ambiguity in phenomenological approaches to education. *Studies in Philosophy and Education*, 10, 211-232.

Kelly, D. A. (2002). Managing liver failure. *Postgraduate Medical Journal*, 78(925), 660-667.

Kelly, D. A. (1998). Current results and evolving indications for liver transplantation in children. *Journal of Pediatric Gastroenterology and Nutrition*, 27(2), 214-221.

Kirschbaum, M., & Knafl, K. (1996). Major themes in parent-provider relationships: a comparison of life threatening and chronic illness experiences. *Journal of Family Nursing*, 2(2), 195-216.

Knafl, K. A., Cavallari, K. A., & Dixon, D. M. (1988). *Pediatric Hospitalization: Family and Nurse Perspectives*. Illinois: Glenview.

Koch, T. (1994). Establishing rigour in qualitative research: The decision trail. *Journal of Advanced Nursing*, 19, 976-986.

Koch, T. (1995). Interpretive approaches in nursing research; the influence of Husserl and Heidegger. *Journal of Advanced Nursing*, 21(5), 827-836.

Koch, T. (1996). Implementation of a hermeneutic inquiry in nursing: philosophy, rigour and representation. *Journal of Advanced Nursing*, 24(1), 174-184.

Koch, T., & Harrington, A. (1998). Reconceptualizing rigour. The case for reflexivity. *Journal of Advanced Nursing*, 28(4), 882-890.

Laifer, S. A., & Guido, R. S. (1995). Reproductive function and outcome of pregnancy after liver transplantation in women. *Mayo Clinical Proceedings*, 70, 388-394.

Leonard, V. (1989). A Heideggerian phenomenologic perspective on the concept of the person. *Advances in Nursing Science*, 11, 40-55.

LoBiondo-Wood, G., Bernier-Henn, M., & Williams, L. (1992). Impact of the child's liver transplant on the family: Maternal perspective. *Pediatric Nursing*, 18(5), 461-471.

LoBiondo-Wood, G., Williams, L., Wood, R. P., & Shaw, B. W. J. (1997). Impact of liver transplantation on quality of life: a longitudinal perspective. *Applied Nursing Research*, 10(1), 27-32.

McCance, T. V., McKenna, H. P., & Boore, J. R. P. (2001). Exploring caring using narrative methodology: an analysis of the approach. *Journal of Advanced Nursing*, 33(3), 350-356.

McCubbin, H. I., & Patterson, J. (1983) The family stress process ; the Double ABCX model of adjustment and adaptation. In *Social Stress and the Family: Advances and Developments in family stress, theory and research*. (Eds M. Sussman, H. McCubbin & J. Patterson) pp. 7-37, Haworth Press, New York.

Miles, M. S., Holditch-Davis, D., Burchinal, P., & Nelson, D. (1999). Distress and growth outcomes in mothers of medically fragile infants. *Nursing Research*, 48(3), 129-140.

Minichiello, V., Aroni, R., Timewell, E., & Alexander, L. (1995). *In-depth Interviewing - Principles, Techniques, Analysis* (2nd ed.). Sydney: Wesley Longman.

Munhall, P. L. (1994a). *Revisioning Phenomenology: Nursing and Health Science Research*. New York: National League.

Munhall, P. L. (Ed.). (1994b). *In Women's Experience*. New York: National League for Nursing Press.

Orii, T., Ohkohchi, N., & Satomi, S. (2004). Rehospitalization after pediatric living-donor liver transplantation. *Clinical Transplantation*, 77(6), 880-885.

Paterson, J., & Zderad, L. (1988). *Humanistic nursing*. New York: National League for Nursing.

Perkins, M. (1993). Parent-nurse collaboration using the caregiver identity emergence phases to assist parents of hospitalized children with disabilities. *Journal of Pediatric Nursing*, 8(1), 2-9.

Plager, K. A. (1994). Hermeneutic Phenomenology. A Methodology for Family Health and Health Promotion Study in Nursing. In P. Benner (Ed.), *Interpretive Phenomenology. Embodiment, Caring and Ethics in Health and Illness*. (pp. 65-83). Thousand Oaks: Sage.

Polit, D. F., & Hungler, B. P. (1993). *Essentials of nursing research: Methods, Appraisal and Utilization*. Philadelphia: Lippincott.

Poole, J. H. (1998). Liver transplant and pregnancy. *Journal of Perinatal & Neonatal Nursing*, 11(4), 25-35.

Reeder, F. (1992). Response to: Being there: who do you bring to practice. In D. A. Gaut (Ed.), *The Presence of Caring in Nursing* (pp. 18-23): National League for Nursing.

Robertson, G. (1999). Individuals' perceptions of their quality of life following a liver transplant: An exploratory study. *Journal of Advanced Nursing*, 30(2), 497-505.

Robinson, L. R., Switala, J., Tarter, R. E., & Nicholas, J. J. (1990). Functional outcome after liver transplantation: A preliminary report. *Archives of Physical Medicine & Rehabilitation*, 71(6), 426-427.

Rodrigue, J. R., MacNaughton, K., Hoffmann, R. G., Graham-Pole, J., Andres, J. M., Novak, D. A., et al. (1997). Transplantation in children. A longitudinal assessment of mothers' stress, coping, and perceptions of family functioning. *Psychosomatics*, 38(5), 478-486.

Rubin, D. (1991, April 1991). Calm after the storm. *Texas Monthly*, 142-178.

Ruddick, S. (1983). Maternal Thinking. In J. Trebilcot (Ed.), *Mothering. Essays in Feminist Theory* (pp. 213-230). Maryland: Rowman & Littlefield Publishers.

Sandelowski, M. (1986). The problem of rigour in qualitative research. *Advances in Nursing science*, 8(3), 27-37.

Sandelowski, M. (1995). On the aesthetics of qualitative research. *Image - the Journal of Nursing Scholarship*, 27(3), 205-209.

Sarter, B. (1988). Philosophical sources of nursing theory. *Nursing Science Quarterly*, 52-59.

Schulz, K., Hofman, C., Sander, K., Edsen, S., & Burdelski, X. (2001). Comparison of quality of life and family stress in families of children with living -related liver transplants versus families of children who received a cadaveric liver. *Transplantation Proceedings*, 33(1-2), 1496-1497.

Sheets, L. (1989). Liver transplantation. *Nursing Clinics of North America*, 24, 191-199.

Smith, B. A. (1999). Ethical and methodologic benefits of using a reflexive journal in hermeneutic-phenomenologic research. *Image - Journal of Nursing Scholarship*, 31(4), 359-363.

Smith, T. (2000). Making family-centered care a reality. *Seminars for Nurse Managers*, 8(3), 136-142.

Sokol, E. M., Cleghorn, G., Goulet, O., da Silveria, T. R., McDiarmid, S., & Whittington, P. (2002). Liver and intestinal transplantation in children: Working group report of the first World Congress of Pediatric Gastroenterology, Hepatology, and Nutrition. *Journal of Pediatric Gastroenterology and Nutrition*, 35(2 Supplement), S159-S172.

Sokol, R. J. (2002). Introduction to the pediatric liver research agenda: A blueprint for the future. *Journal of Pediatric Gastroenterology and Nutrition*, 35(1 Supplement), S2-S3.

Spiegelberg, H., & Schuhmann, K. (1982). *The phenomenological movement: A historical introduction*. (3rd ed.). Hague: Martinus Nijhoff Publishers.

Starzl, T. E., Iwatsuki, S., Van Thiel, D., & al., e. (1982). Evolution of Liver Transplantation. *Hepatology*, 2, 614-636.

- Stewart, M. J., Ritchie, J. A., McGrath, P., Thompson, D. R., & Bruce, B. (1994). Mothers of children with chronic conditions: Supportive and stressful interactions with partners and professionals regarding care-giving burdens. *Canadian Journal of Nursing Research*, 26, 61-82.
- Streubert, H. J., & Carpenter, D. R. (1999). *Qualitative research in nursing: Advancing the humanistic imperative*. (2nd ed.). Lippincott Williams & Wilkins, Philadelphia.
- Taylor, B. (1994). *Being Human: Ordinarieness in Nursing*. Melbourne: Churchill Livingstone.
- Thomas, D. J. (1995). The lived experience of people with liver transplants. *Journal of Transplant Coordination*, 5(2), 65-71.
- Thorne, S. (1993). *Negotiating Health Care: The social context of chronic illness*. Newbury Park: Sage.
- Thorne, S., & Robinson, C. (1988). Health care relationships: the chronic illness perspective. *Research in Nursing and Health*, 11(5), 293-300.
- Todo, S. (2002). Use of the marginal/expanded donor in liver transplantation. Non-heart-beating donor. *Program and abstracts of Eighth Congress of the International Liver Transplantation Society*, Jun 12-15, Chicago, Illinois.
- Trzepacz, P., Brenner, R., & Van Thiel, D. (1989). A psychiatric study of 247 liver transplant candidates. *Psychosomatics*, 30, 147-153.
- Turner-Henson, A., Holaday, B., & Swan, J. H. (1992). When parenting becomes caregiving: caring for the chronically ill child. *Family Community Health*, 15(2), 19-30.
- Ullrich, G., Meyke, A., Haase, H., Erzfeld, C., Beckman, S., Schmidt-Schaller, S., et al. (1997). Psychological support of children undergoing liver transplantation and their parents: A single centre experience. *Pediatric Rehabilitation*, 1(1), 19-24.

Van der Zalm, J. E., & Bergum, V. (2000). Hermeneutic-phenomenology: providing living knowledge for nursing practice. *Journal of Advanced Nursing*, 31(1), 211-218.

Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. Ontario: Althouse Press.

Van Manen, M. (1997). From Meaning to Method. In *Qualitative Health Research* (Vol. 7, pp. 345-369). New York: Sage Publications.

Van Manen, M. (2002). Care-as-worry, or "Don't worry be happy". *Qualitative Health Research : An International Interdisciplinary Journal*, 12(2), 264-280.

Wainwright, S. P. (1995). The transformational experience of liver transplantation. *Journal of Advanced Nursing*, 22(6), 1068-1076.

Walters, A. J. (1994). Phenomenology as a way of understanding in nursing. *Contemporary Nurse*, 3(3), 134-141.

Walters, A. J. (1995). The phenomenological movement: Implications for nursing research. *Journal of Advanced Nursing*, 22(4), 791-799.

Wang, V. S., & Saab, S. (2004). *Liver transplantation in the era of model for end-stage liver disease*. Retrieved 02/04/2004, 2004

Watson, J. (1985). *Nursing: Human science and human care: A theory of nursing*. Norwalk, CT: Appleton-Century-Crofts.

Weichler, N. (1993). Caretakers' informational needs after their children's renal or liver transplant... including commentary by Pittaway ED with author response. *Anna Journal*, 20(2), 135-140.

White, J. (1995). Patterns of knowing; Review, critique, and update. *Advances in Nursing Science*, 17(4), 73-86.

Whittington, P. F., Alonso, E. M., Superina, R. A., & Freese, D. K. (2002). Liver transplantation in children. *Journal of Pediatric Gastroenterology and Nutrition*, 35(1 Supplement), S44-S50.

Wilde, J., Chin, S., Johnston, P., McCall, J., Munn, S., Nixon, C., Wesley, A., Young, Y., & Evans, H. M., (2007). Paediatric liver transplantation in New Zealand: the first 5 years. *The New Zealand Medical Journal*, 120(1260), ISSN 1175 8716, from <http://www.nzma.org.nz/journal/120-1260/2679>.

Windsorova, D., Stewart, S. M., Lovitt, R., Waller, D. A., & Andrews, W. S. (1991). Emotional adaptation in children after liver transplantation. *Journal of Pediatrics*, 119(6), 880-887.

Wise, B. V. (2002). In their own words: the lived experience of pediatric liver transplantation. *Qualitative Health Research*, 12(1), 74-90.

Zamberlan, K. E. W. (1992). Quality of life in school-age children following liver transplantation. *Maternal-Child Nursing Journal*, 20(3-4), 167-229.

Zitelli, B. J., Miller, J. W., Gartner, J. C., Malatack, J. J., Urbach, A. H., Belle, S. H., et al. (1988). Changes in life-style after liver transplantation. *Pediatrics*, 82(2), 173-180.

Participant Consent Form

Through mothers' eyes: The lived experience of children after liver transplantation.

- I have received an explanation of the research project and had an opportunity to ask questions and have them answered to my satisfaction.
- I know that my participation is voluntary and that my choice will not affect any health care treatment my family requires in the future.
- I understand that my child is not required to participate in the interview. However I have spoken about my participation in this interview with my child and there is no apparent opposition.
- I understand that I may choose not to answer questions during the interview and I can stop the interview at any time.
- I may withdraw or withdraw any information I have provided for the project before data collection is completed, without penalty or giving any reason.
- My information will remain non-identifiable and my name will not appear in any presentation or the report of the research findings.
- If during the process I become upset, the interviewer will provide support and may offer to refer me to the Starship Children's Hospital support services.
- I consent to the interview being audiotaped. At the end of the project - the transcriptions of the interviews will be kept securely for ten years. The tapes will be offered back to me or destroyed if they are unable to be returned. A summary of the research findings will be given to me.

Continued over page.

- I know that the Human Ethics Committee at Victoria University of Wellington and the Auckland Ethics Committee have approved this research project.
- If I have any concerns about the research, I can contact the appointed supervisors. They are Dr Joy Bickley Asher, or Dr Rose McEldowney, Senior Lecturers at the Graduate School of Nursing and Midwifery at Victoria University of Wellington. Phone (04) 463 5410. Alternatively I can contact an independent Health and Disability Advocate. This is a free service.
 - Health Advocates Trust (Upper North Island) Freephone: 0800 205 555
 - Advocacy Network Services (Lower North Island) Freephone: 0800 423 638
 - Advocacy Services South Island Trust (South Island) Freephone: 0800 377 766
- If I require the presence of a support worker, a mutually acceptable person will be made available for the interview at no expense to me.
- I have read and understood the above information and agree to participate in this research project

Signed.....Dated.....

Name of the participant.....

Statement by the researcher

- I have discussed the aims and process of this research project

with(Name of the participant)

Signed.....Dated.....

Researcher's name.....

Participant Response Form

Through mothers' eyes: The lived experience of 4-6 children after liver transplantation

Dear Sandra Murphy

I have had an opportunity to read your information sheet regarding your research project. This is **not** a formal consent to participate but will allow you, the researcher, to make contact with me and answer any questions or concerns I may have.

1. I would like further information about this research

Yes No Unsure

2. I would like to participate in the interview

Yes No Unsure

My name is(Full name please)

My address is..... My phone number is.....

.....

The time of day it is convenient for phone contact.....

Please fold and place into the postage paid envelope, if you wish you may contact the researcher directly. Phone: Work (09) 3074949 Extn. 6366 or Mobile 021 2518352

Auckland Ethics Committees

Private Bag 92522
Wellesley Street
Auckland
Delivery Address:
C/O Ministry of Health
3rd Floor, Unisys Building
650 Great South Road, Penrose
Fax (09) 580 9001

June 2004

Sandra Murphy
11 Tornado Place
West Harbour
Auckland.

Dear Sandra

AKY/04/02/011 Through mothers' eyes: The lived experience of 4-6 children one year after liver transplantation using an in-depth interview of the mothers, PIS/Cons V#2 12/03/04

Thank you for your amendments, received 2 June 2004.

The above study has been given ethical approval by Auckland Ethics Committee Y.

Certification

It is certified as not being conducted principally for the benefit of the manufacturer or distributor and may be considered for coverage under ACC.

Accreditation

This Committee is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, March 2002.

Documents Approved:

- Information Sheet/Consent Form V#2 12/03/04

Progress Reports

The study is approved until 2 June 2005. The Committee will review the approved application annually. A progress report is required for this study on 2 June 2004. A form should come off our database requesting this information prior to the review date. Please note that failure to complete and return this form may result in the withdrawal of ethical approval.

Please advise the Committee when the study is completed and a final report is also required at the conclusion of the study.

Requirements for SAE Reporting

Please advise the Committee as soon as possible if there are any serious adverse events which relate to this study.

.../2

General:

All amendments to the study must be advised to the Committee prior to their implementation, except in the case where immediate implementation is required for reasons of safety. In such cases the Committee must be notified as soon as possible of the change.

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,

Sandra Sparks
Administrator, Committee Y

Cc: Auckland Research Office