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LIVING A DIVERGENT EXPERIENCE: THE MATERNAL PERCEPTION OF CRITICAL ILLNESS

A thesis presented in partial fulfillment of the requirements

for the degree of

Master of Philosophy in Midwifery at

Massey University

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ABSTRACT

The aim of this grounded theory study was to describe and generate a conceptual explanation of the experience of maternal critical illness. Sixteen participants provided the data which was collected over nine months. The primary data collection methods used in this study were unstructured interviews, and participant observation. Data was also obtained from three published autobiographical accounts.

Constant comparative analysis of the data eventuated in the identification of four linear stages, from the first symptoms of illness to a subsequent pregnancy, which were conceptual categories. These categories were named 'identifying a problem', 'being overwhelmed', absorbing' and 'getting on'. These conceptual categories were drawn together in the core category, a basic social process 'Living a divergent experience of childbearing'.

The experience of childbearing for the women in this study diverged from the sociocultural expectations of childbearing in New Zealand and from their personal expectations. Their divergent experience of childbearing informed their continuing perception of childbearing as an illness which risked maternal life. These findings have implications for midwifery practice, education and research.

ACKNOWLEDGEMENTS

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Firstly, my sincere appreciation is extended to the women who took the time to share their stories with me. I was privileged to have met and spent some time with them. This study would not have been possible without them. Their honesty and enthusiasm was a powerful incentive for me to finish this study.

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Finally, my love and heartfelt thanks go to my family. To my father who has long believed that not only *could* I complete a master's degree but that I *should*. His pride and belief in my endeavors kept me going. To Lawrence who tolerated my disappearing for hours on end to work on this study and, as always, considered my needs before his own.

PROLOGUE

There are no Honest Poems

About Dead Women

What do we want from each other after we have told our stories do we want to be healed do we want mossy quiet stealing over our scars do we want the powerful unfrightening sister who will make the pain go away

(Lorde, 1986, p.61)

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CHAPTER ONE: INTRODUCTION AND OVERVIEW OF THE THESIS

Introduction

Childbearing¹ and critical illness are topics rarely connected in popular thought. One event centres on bringing new life to the world, the other threatens life. However, for some women, their experience of childbearing is also the experience of critical illness. Theirs is the maternal experience of critical illness.

At first glance there appears to be dissonance between the needs of a healthy childbearing woman and the needs of a critically ill woman. This study looks at the occasion when the two become one. Grounded theory methodology is used to analyse maternal critical illness from the woman's viewpoint and the relevance of this research data for New Zealand midwifery practice is examined.

This chapter introduces an historical perspective of midwifery in New Zealand. Statistical evidence of the type and prevalence of maternal critical illness as far as it can be determined is presented. This is followed by a discussion on the place of midwifery care for critically ill childbearing women. Events which led to interest in the research topic are explained, and the aims and layout of the study are presented.

An historical perspective on midwifery

The physiology of childbearing is similar for women regardless of their culture or the society in which they live. However, societal attitudes toward women and children may change over time and influence women's experiences of

¹ Childbearing here refers to the period from conception to six weeks postpartum

childbearing.

Changes in political, professional and consumer attitudes toward childbearing in New Zealand are reflected in the renaissance of midwifery practice which focuses on childbirth as a normal, natural event in a woman's life. An investigation of sociocultural factors reveals the path which led to these attitudinal and practice changes.

Early references to the practice of midwifery, as a formal office or lay status in western history, date back to the books of Genesis and Exodus in the Old Testament, and the writings of the ancient Greeks and Romans (Donnison, 1988; Murphy-Black, 1995).

As far as literature suggests, the business of childbirth was women's work and left in women's hands. Surviving Greek and Roman texts written by men who attended births indicate they did so mainly in the role of scientific observer or surgeon called on to use instruments when natural childbirth was not possible (Donnison, 1988).

By the middle ages, Catholicism dominated most of Western Europe. As the watch-dog of sexual morality, the Catholic church exerted a powerful influence on midwifery practice. Midwives were required to be women of good character and religious orthodoxy. Their practice, influenced by the misogyny and superstitions of the time, was clearly prescribed. The birth of other than a whole, healthy baby left midwives open to the charges of witchcraft, an offence punishable by execution (Donnison, 1988; McCool & McCool, 1989).

The 18th century was an age enlightened by reason and science. The use of reason and science was thought to promise unending progress. The Enlightenment Project changed the place of women in society. Its legacy was an ideological rift between masculine and feminine orientations to the world.

Reason was thought to be a masculine trait while women, being closer to nature by virtue of being able to bear and suckle children, were seen as irrational and inferior to men (Bradley, 1989). Men's control of politics ensured their social, economic, political and educational dominance over women (Bradley, 1989; Van Vucht Tijssen, 1990). These attitudes became entrenched during the industrial revolution.

Following the industrial revolution, the 'body as machine' metaphor built on Descartes' (1637) theory of mind-body dualism. The 'body as machine' view dominated scientific thinking for the next three hundred years (Nisbet, 1966). The end result of this thinking, a woman's body as a machine untrustworthy in childbearing, was the medicalisation of childbirth. The predominant goal of medicine was to reduce maternal and fetal morbidity and mortality.

As early as the 1760s the medical profession argued that birth held inherent risks for mother and baby; midwives were ignorant and unsafe in their practice while they, with their scientific knowledge, approach, and medical technology, could lessen the risks. Methods to hasten labour and delivery were promoted as enhancing safety in childbirth although statistics indicate that the reverse is true (Donnison, 1988; Tew, 1995).

The prospect of freedom from the dangers associated with childbirth led to an increasing number of hospital-based births. A compelling incentive to birth in hospital was pain-free labour. Women "... equated pain with danger and freedom from pain with safety" (Simkin, 1996, p.249). Another incentive to birth in hospital was the availability of free medical services in New Zealand as a result of the 1936 Social Security Act and in Britain with the 1946 British National Health Service Act. Canada, Australia, and the United States of America introduced insurance cover for childbirth under medical supervision while free hospital care was offered to those who could not afford insurance.

By 1951 95% of all births in New Zealand took place in hospital (Encyclopaedia of New Zealand, 1989). In Britain the number of hospital births rose from 79% in 1968 to 98% in 1994 (Bryar, 1995).

Medicine's aim to reduce maternal and fetal morbidity and mortality was laudable. However, the impact of this was to put doctors at the centre of the pregnancy and birth experience. The psychosocial and emotional aspects of pregnancy and birth were largely ignored. Emphasis was placed on the abnormal while overlooking the fact that for most women, pregnancy and birth, although a major physiological event, is a normal and straightforward process. The focus for women and midwives was the woman in her total childbearing experience, while for doctors it was the product, a safe delivery of a healthy baby and a healthy mother. Women wanted safe and pain-free childbirth. Hospital birth under a doctor's care held that promise. As demand for homebirths fell larger numbers of midwives began working in hospitals.

Working in a hospital the midwife, as a hospital employee, was constrained by bureaucratic regulations and management strategies. Midwives vied with doctors and students for their chance to deliver babies, while the use of technologies available in hospitals "... reduce[s] dependence on the skills of midwives" (De Vries, 1995, cited in Bryar, 1995, p.52). Correspondingly it may be argued that reliance on technology also reduced the skills of midwives.

In the United States of America midwifery training was abolished in 1935 (Roberts, 1995). With the decline of direct entry midwifery, trainee midwives in Scotland, England and Northern Ireland (Donnison, 1988), Australia (Lecky-Thompson,1996), and New Zealand had first to be registered nurses. These midwives were already familiar with the medical model of health and illness and came under the control and supervision of the medical profession until they acted as little more than obstetric nurses. It has been said that nurses carried

their pathological outlook with them into the field of midwifery (Donley, 1986). The influence on midwives to practice in the medical model was strong and strengthened during their midwifery education. Midwives were inducted into the medical paradigm during their education.

An example of the indoctrination of midwives into the medical model of practice may be found in midwives' textbooks. A statement found in the second edition of Myles' Textbook for Midwives, a standard textbook for midwifery training, states, 'Both doctor and midwife are essential, even for normal cases, if the woman is to receive the maximum benefit of all modern investigations and treatment during pregnancy and labourThe midwife must co-operate as one of a team ...' (Original emphasis), (Myles, 1953, p.628).

Thirty two years later in the tenth edition of Myles' textbook she states her opinion on natural childbirth,

Childbirth has been made safer, shorter and easier by the very scientific procedures some misinformed women object to. Reverting to primitive methods is a retrograde step which has no justification and should not be condoned If she knew more she would realise the wisdom of having faith in professional experts, and allowing them to make decisions regarding her own and her baby's wellbeing and safety throughout labour (Original emphasis), (Myles, 1985, p.99).

A generation of midwives were co-opted to perform the shroud-waving for the medical establishment placing the institutional rules above the needs of individual women in the name of safety. Murphy-Black describes this as a female conspiracy, women controlling other women by colluding with men. Women betray mothers "... in the name of 'being a good midwife'." (Murphy-Black, 1995, p.283).

The late 1960s brought a rise in both the consumer movement and the womens' movement. As a result, women began to regain control over their bodies. This was taking place in all health spheres including pregnancy and childbirth. New Zealand midwives however, were caught napping. The opportunity to unite with consumers from a political strength to refocus childbearing on women was missed. After successful lobbying from the New Zealand Obstetrical and Gynaecological Society, under section 54 of the 1977 Nurses Act, midwives lost their autonomy. The responsibility for birth, delivery and postpartum care was legally restricted to medical practitioners. Midwives could practice only under the supervision of qualified medical personnel.

It was not until 1983, that due to increasing dissatisfaction amongst women of childbearing age and some midwives about the growing medicalisation of childbirth, consumers and midwives formed the 'Save the Midwives Association'. This association fought against proposed moves to further control midwives who practiced home births in New Zealand. The medical profession's response to home birth was to once again raise the issues of safety. Women were accused of being dangerous, selfish, and risking their own and their infants' safety. The answer was to educate women "... on the reasons for current practice, which has a 'scientific rationale'." (Donnison, 1988, p.199).

Medicine's arguments for hospitalised, interventionist birth were being rebutted. Midwives and nurse-midwives using the scientific method to their own ends, began to keep their own statistics (Anderson & Greener, 1991; Bortin, Alzugaray, Dowd & Kalman, 1994; Cavero, Fullerton & Bartlome, 1991; Declercq, 1995). Not only was the safety of a noninterventionist approach to childbirth supported by their statistics but also the cost efficiency of midwifery care was stressed. The comparative cost efficiency of midwifery care to medical care has appealed to service funders in many nations.

Unique to the New Zealand situation was the Cartwright inquiry of 1987-1989 in which the denial of women's rights to information and informed consent in certain gynaecological services at National Women's Hospital, Auckland, was investigated. This inquiry helped to fuel the growing disillusionment with the medical profession and to hasten the changes which followed.

As a result of combined consumer/midwife lobbying, section 54 of the 1977 Nurses Act was amended in August 1990 by the New Zealand Government. This amendment gives New Zealand midwives the legal status of autonomous practitioners. Midwives may take responsibility for the care of women through pregnancy, delivery, and postpartum.

The disparity between the medical model of childbirth and the perspectives of consumers and midwives was clear. In the medical model, birth is normal only in retrospect; a positive outcome is measured by having a live, healthy mother and baby. The consumer/midwifery perspectives are that birth is a normal life event; that information and decision making needs to be shared and women's satisfaction with the birth experience is integral to a positive outcome (Flint & Poulengeris, 1987; Gaskin, 1977; Guilliland & Pairman, 1994).

In 1988 the New Zealand College of Midwives (NZCOM) was established. The philosophy and code of ethics for NZCOM was formed with consumer consultation. NZCOM believes continuity of care enhances the woman's childbearing experience. It also meets consumer demands of the childbirth experience by recognising the partnership between the woman and the midwife, making this a cornerstone of their standard for practice (New Zealand College of Midwives, 1992).

A current perspective of midwifery in New Zealand

Changes in midwifery education followed these legislative amendments to the status of midwifery. A three year Bachelor Degree programme for direct entry midwifery training was reintroduced in Auckland in 1992 and is currently operating in four New Zealand centres. Midwives are no longer required to be registered nurses. Nurses who later wish to become midwives enter the same programme with a shortened course for recognition of prior learning as a nurse. This programme highlights the fact that midwifery is a profession separate from nursing.

In New Zealand there remains some debate among the midwifery and the nursing professions on midwifery's professional autonomy from nursing. This debate was highlighted in a discussion on the proposed changes to the 1977 Nurses Act. In the October 1996 issue of the New Zealand Nursing Journal, Sherrard, Head of a school of nursing, calls for support for the continuation of "...one piece of legislation for the two professions: a Nurses and Midwives Act" (Sherrard, 1996, p.2). In the same publication, Guilliland, National Director of the New Zealand College of Midwives states, "...midwifery must have its own Act and regulations, to retain its autonomy" (Guilliland, 1996, p.23).

Midwifery's autonomy of practice was hard won and would not have been possible without unfailing consumer support. This was epitomised by the slogan 'women need midwives need women' adopted by the midwifery/consumer lobby group in the 1980s. Today in New Zealand women are able to choose from a range of options for maternity care. They may choose a private obstetrician or an independent midwife or general practitioner as the lead maternity care provider (LMC) and the place of birth may be a hospital or at home.

Under section 51 of the Health and Disability Services Act (1993), an authorised practitioner appointed by the woman is the Lead Maternity Carer (LMC). An LMC may be a doctor, midwife or hospital and is funded through the maternity services budget. The LMC has the legal, practical and professional responsibility for ensuring the care provided to the woman throughout her entire childbearing experience is safe and clinically appropriate.

Clinical appropriateness may lead a midwife to decline a client or direct her to 'share care' with a physician if the woman has a condition which may require specialist medical input during her childbearing experience. If there is an unexpected complication during childbearing, under section 51 of the 1993 Health and Disability Services Act, LMC's are expected to know the limitations of their practice and to consult or hand over the woman's care to a specialist medical practitioner or specialist medical team when appropriate.

The situations when this may occur vary depending on the practice ability of the LMC or the health of the woman. Limits to the ability of an LMC to manage complications during childbearing are revealed with startling clarity in the instance of maternal critical illness.

An international perspective of maternal critical illness

In the past few decades maternal mortality has declined. This is attributable in part to improved medical and surgical interventions, advances in critical care, improved hygiene, lifestyle and nutrition, and the discovery of antibacterials to treat infection (Simpson, 1995). However the worldwide maternal mortality rate remains at an estimated 500,000 per annum with the main causes of maternal death being haemorrhage, sepsis, hypertensive disorders, obstructed labour and illegal abortions (Kwast, 1991, p.155).

Maternal critical illness is not widespread. However, a small but significant number of women do become critically ill during childbearing. For most women the cause of critical illness is from classical risks of pregnancy and childbirth such as hypertensive disorders and haemorrhage which remain the leading causes of maternal death. For some women critical illness is caused by preexisting health conditions exacerbated by pregnancy, and for a small number the cause is iatrogenic. However, the rate of maternal morbidity is difficult to assess.

Many statistics collated do not differentiate between mild and severe forms of maternal illness but merely acknowledge them as complicating the pregnancy or the puerperium (Simpson, 1995). Statistical information is complicated further for disorders such as preeclampsia for which there is no international consensus regarding definition and classification (Kwast, 1991). Some causes of maternal morbidity are not differentiated and are classified either as 'other' or under general statistics only. In spite of the difficulties in classifying the type and degree of maternal critical illness it has been suggested that the incidence of maternal critical illness is on the rise (Fleshler & Sala, 1995; Harvey, 1992; Macdonald, 1994)

Harvey (1992) cites the advent of paediatric intensive care units 25-30 years ago as contributing to the numbers of women needing obstetrical critical care. Female babies and children who would have died without specialist care have now reached child-bearing age. Some of these women, despite health handicaps which may profoundly affect their pregnancies, are choosing to become pregnant.

Women with certain underlying disease processes in the past would have either been unable to achieve pregnancy or been warned to avoid pregnancy. As a result of improved technological advances, refined organ transplant techniques, and new immunosuppressive agents these women live longer and choose to become pregnant (Fleshler & Sala, 1995; Macdonald, 1994).

The epidemiology of disease is changing. The incidence of ischaemic heart disease is increasing (Macdonald, 1994). A growing number of women of childbearing age are diagnosed with human immunodeficiency virus (HIV) or acquired immune deficiency syndrome (AIDS). Pregnancy appears to hasten the course of HIV and AIDS and predispose pregnant women to complications seldom seen before in that population (Rodrigues & Niederman, 1993).

Advances in modern medicine may not only enhance the outcome of a pregnancy deemed to be at risk but may also contribute to maternal critical illness. Iatrogenic causes of maternal critical illness include tocolytic therapy (drugs that inhibit preterm labour) which has been implicated in contributing to maternal morbidity and mortality from pulmonary oedema (Dabbs, Kraemer & Hoops, 1996). Vigorous stimulation of labour has been linked to maternal deaths secondary to amniotic fluid embolism (Aickin, 1996).

A clearer picture of the incidence of maternal critical illness may be gained by looking at maternal admissions to intensive care units. Mabie and Sibai (1990) published statistics from a Memphis Tennessee maternal intensive care unit for a three year period from January 1, 1986 to January 1, 1989 (Figure 1). Of the 200 admissions over this period by far the largest group was for hypertensive disorders (46%). Medical problems complicating pregnancy (44%) included cardiac, pulmonary, renal, septic, and gastrointestinal problems.

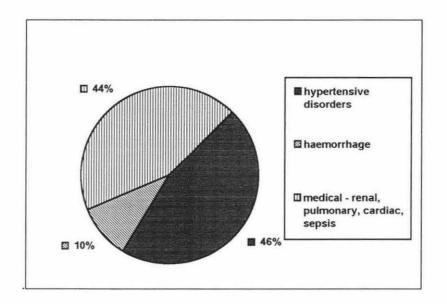


Figure 1. Memphis maternal ICU Admissions 1986-1989 (n=200). (Mabie & Sibai, 1990).

Statistics from an obstetric intensive care unit in Cape Town, South Africa (Figure 2) show a similar distribution (Smith, 1996). For a three year period

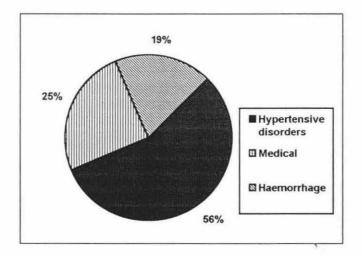


Figure 2. Cape Town maternal ICU Admissions 1992-1994 (n=529). (Smith, 1996).

from January 1992 to December 1994, 56 percent of the 529 admissions were for hypertensive disorders in pregnancy and postpartum. Medical disorders included cardiac, renal, and septic problems, and anaesthetic complications.

A New Zealand perspective of maternal critical illness

In New Zealand the rate of direct maternal deaths from complications of pregnancy, childbirth, and the puerperium has decreased steadily over the years. In 1968 the number of maternal deaths per 10,000 live births stood at 2.4, by 1980 this had fallen to 1.4 and by 1990 the rate had dropped to 0.6 maternal deaths per 10,000 live births (Ministry of Women's Affairs, 1993).

The leading causes of maternal deaths from 1986 - 1991 were amniotic fluid embolism, pulmonary embolism and sepsis (Aickin, 1996). Pre-existing cardiac valve disease is the most frequent cause of maternal death not directly associated with pregnancy (Aickin, 1996).

The New Zealand Ministry of Health collates and publishes statistics under the three digit International Classification of Diseases codes. In the *Hospital and selected morbidity data* (1993) some diagnoses have their own code. For example, '642' is the code for 'Hypertension complicating pregnancy, childbirth and the puerperium'. Here the diagnosis is explicit but the severity of the illness is not indicated. Other diagnoses share codes, for example '646' indicates 'Other complications of pregnancy not elsewhere classified' and code '648' allows for a broad range of 'Other current conditions in mother complicating pregnancy, childbirth and the puerperium' (New Zealand Ministry of Health, 1993, p.89).

In 1992 there were 30,836 deliveries classified as normal in New Zealand public hospitals. A further 17,394 or 36 percent were classified as having pregnancy complications. Of the latter group, hypertension complicated the

pregnancy, childbirth or puerperium of 2259 women (7.3%) (New Zealand Ministry of Health, 1993).

In an effort to gain some insight into the number of women who become critically ill during pregnancy, childbirth or during the puerperium I wrote to the managers of five intensive care units nationwide asking for maternal admission statistics for 1994 and 1995. Replies were received from three of the managers. Figure 3 provides a summary of the number of women with childbearing complications and reasons for their admission to intensive care units in three New Zealand cities in those years.

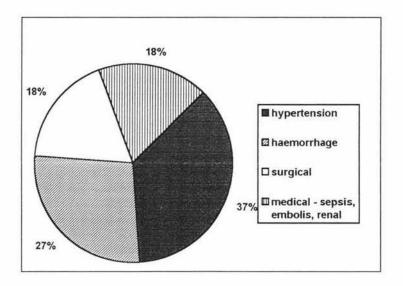


Figure 3. New Zealand maternal ICU admissions in three centres 1994-1995 (n=33).

Sixteen women were admitted to the three units in 1994, and seventeen women in 1995. Paralleling overseas findings the main reason for admission was hypertensive disorders (37%). The reason for surgical admission was not explicated in the admission data.

Midwifery and the critically ill woman

In midwifery the woman is the central focus during her childbearing experience. The midwife supports the woman in her innate ability to carry and give birth to an infant, and in the informed choices she makes during this process. If the woman becomes critically ill, her options for choice and control are circumscribed. Is she then to be the recipient of only medical and nursing care or does midwifery have a place?

It has been argued that in this situation the midwife, if she continues to participate in the woman's care, ceases to practice midwifery. "Midwives who share care with practitioners from another discipline, in such a way that they do not have responsibility for the total service, remain responsible for their midwifery decisions and actions but ... are not practising midwifery" (Guilliland & Pairman, 1994, p.5). On the other hand, the New Zealand College of Midwives handbook for practice (1992) states that midwifery is "...collaborative with other health professionals" (p.7).

Some authors insist on the importance of midwifery care to enhance the peripartal experience for women at risk of developing or experiencing health complications in pregnancy. According to Myles (1985) and Avery and DelGiudice (1993) the safest and most appropriate form of care for high-risk women is collaborative care between the woman, a physician and a midwife or nurse-midwife as this enhances the woman's education and support.

Silverton (1993) believes the presence of a maternal medical disorder in pregnancy may create a medicalised and pathological approach to care. The role of a midwife in the care of such women is to provide education and psychological support, and to "... seek to emphasise those aspects of the pregnancy, labour and puerperium which are normal ... having a baby could be

the first time that the woman has felt any similarity with other healthy women" (p.187).

Lewis (1995) asserts that having midwives capable of caring for women who become ill during pregnancy is necessary. Women's need for information, support, advice, and continuity of care from a midwife is greatly increased at this time. Midwives with "...additional expertise and experience, together with their traditional role, are well-placed to provide the best care and support to those women whose pregnancies become complicated" (p.354).

The above authors agree that midwifery care enhances the childbearing experience of women who are experiencing or who have experienced critical illness during childbearing. Empirical support for this belief is needed. This topic merits study because women can and do become critically ill during the childbearing experience.

Aim of this study

The aim of this study is to explore women's experiences of maternal critical illness. It is hoped this study will inform the practice of health professionals involved in the care of women who become critically ill during their childbearing experience and thereby to enhance the experience of these women.

The research question

As a hospital based midwife with intensive care nursing experience I am often asked to care for women who become very ill during pregnancy, labour or the immediate postpartum period.

My midwifery education and subsequent early experience was focused on normal pregnancy. I began to ask: Does critical illness alter a woman's experience of childbearing and if so, how? Are there fundamental differences which I as a midwife should be aware of to optimise the childbearing experience of this woman?

My search for the answers was twofold. I asked the women about their experiences and I searched the literature for information. My first approach drew a wealth of information while the second drew a blank; I found no published research on women's experience of maternal critical illness.

Using grounded theory method, I conducted a constant comparative analysis of data collected on women's experiences of critical illness during childbearing. I asked each woman who participated in this study "What has this experience been like for you?"

Chapter content and overview

This study is presented under nine chapter headings. A brief outline of the content is given to guide the reader through the research progress leading to the conclusions which have been drawn.

Chapter one: Introduction and overview of the topic

Chapter one introduces the topic in the context of midwifery and maternal critical illness. The reader has been introduced to the topic with a discussion of the midwifery context and maternal critical illness. Events which stimulated the research question, the research question itself and the aims of the study have been stated.

Chapter two: The use of literature in grounded theory

Chapter two provides the reader with background information about the use of literature in grounded theory. A review of nursing and midwifery research on

maternal critical illness is given as a means of situating this research in the context of research already undertaken.

Chapter three: The research methodology

This chapter discusses grounded theory methodology and its link with symbolic interactionism. A detailed description of the research method for this particular study is given. This includes ethical issues, participant selection, and the method of data analysis.

Chapters four to seven are the four data chapters:

Chapter four: Identifying a problem

In this chapter the first category is discussed. This follows a process from the women's first suspicion that something may be wrong with their health to seeking help from a professional health care provider.

Chapter five: Being overwhelmed

The physiological and psychological effect of illness and its diagnosis are discussed in this second of the data chapters. This chapter begins when the women are sent to hospital and ends with admission to an intensive care or high dependency unit.

Chapter six: Absorbing

Following transfer from an intensive care or high dependency unit to a general ward the women in this study utilised a range of cognitive mechanisms to take in the event, incorporate its meaning into their broader biographical profile and reduce the intensity of the event.

Chapter seven: Getting on

After critical illness in childbearing, the women in this study wished to get on with life. The decision- making process about whether or not to have another child subsequent to maternal critical illness is explored. The challenge to get on is described in this final data chapter and factors which assist or hinder this process are presented.

Chapter eight: Living a divergent experience of childbearing

The basic social process which emerged from this study is presented. This chapter integrates the constructs presented in chapters four to seven.

Chapter nine: Standards of rigor, limitations and implications

Chapter nine provides the reader with a basis on which a grounded theory study may be evaluated. Implications for midwifery education and practice are discussed. The strengths and limitations of the study are explored and recommendations for further research are suggested. A concluding statement about the research is made.

Referencing technique

The referencing technique used throughout this study is the American Psychological Association (APA) style modified by British usage for quotations.

Summary

The focus of midwifery practice is on the well-woman normal childbearing experience. Midwifery care in New Zealand involves continuity of care with a partnership approach between the woman and her midwife. Professional health care of the critically ill woman involves a specialist team approach with a medical model focus.

For a small but significant number of women, the childbearing experience is complicated by critical illness. Paradoxically, it has been suggested that women who become or are at risk of critical illness may benefit greatly from midwifery care to enhance their childbearing experience.

Professionally in New Zealand, nursing and midwifery are taking increasingly separate paths. Midwifery is being recognised as a profession separate from nursing; midwives are not required to have a nursing background. The following literature review highlights the contrast between nursing and midwifery focus on the topic of maternal critical illness.

CHAPTER TWO: LITERATURE REVIEW

Introduction

Most research methods begin with a critical review of the literature. The greater part of reading comes early in the investigation to formulate a research question or hypothesis based on previous studies. This is not so in grounded theory studies. This chapter explains the use of literature in grounded theory method.

As a hospital-based midwife who sometimes cares for critically ill women I could not begin this study as a *tabula rasa*. Indeed, prior to undertaking this study, I actively searched for literature on this topic to enhance my midwifery practice. Had I found literature on the topic this study may never have been undertaken, certainly not as a grounded theory study. The following review demonstrates the lack of midwifery focused literature on maternal critical illness.

Use of literature in grounded theory studies

Researchers using the grounded theory process are enjoined not to read in their chosen field before generating theory from their field research. Prereading may skew the findings by biasing the researcher and may lead to forcing data in an expected direction rather than trusting the findings to emerge (Glaser & Strauss, 1978). For the same reason the would-be researcher is advised to stay clear of an overworked field of research (Glaser & Strauss, 1978). These are two reasons why the grounded theory method works well in areas where there has been little previously published research.

Glaser and Strauss (1978) do however recommend early and wide reading "...in a substantive field different from the research" (original emphasis), (p.31). This type of

reading, while avoiding preconceived concepts, assists researchers in finding a style for writing up their own findings.

Once constant comparative analysis of the data has begun 'selective sampling' of literature, driven by the emerging categories, may commence. Literature is treated as a data source and may be integrated into the data chapters. Both academic and popular literature earn their place as sources of data by virtue of their relevance.

After saturation of categories has been reached and the theory emerges, Glaser and Strauss (1978) believe literature in the same field may be covered, if it exists. At this stage the researcher cannot be shaken from original ideas and categories but will permeate the work with comparisons. This final review of literature places the theory or model in context with existing theories and literature.

The review of literature which follows underscores the greater emphasis of nursing on the pathology of pregnancy-related illness contrasted with the psychosocial aspect, and the more muted research response of midwifery on topics beyond the scope of the normal pregnancy experience. The outcome of this review gave impetus to the decision to study the topic of maternal critical illness from a midwifery perspective.

Literature on maternal critical illness

The initial search for literature on women's experience of critical illness in pregnancy or postpartum was approached using the Cumulative Index for Nursing and Allied Health Literature (CINAHL). This was productive.

Topics covered included pre-eclampsia in pregnancy (Kelly & Mongiello, 1982; Macdonald, 1994, Petrone & Mandel, 1994; Roberts, 1994; Surratt, 1993), sepsis

in pregnancy (Fein & Duvivier, 1993; Simpson, 1995), respiratory complications in pregnancy including pneumonia (Rodrigues & Niederman, 1993) and adult respiratory distress (Dabbs, Kraemer & Hoops, 1996; Roth, Riley & Cohen, 1992; Suratt & Troiano, 1994).

As I read these articles, I found with increasing disappointment that they were presented with a pathophysiological focus. They outlined the cause of each disorder (if known), aetiology, physiological principles of nursing management, laboratory values and use of technology for monitoring. Although invaluable for hands-on nursing care, I was searching for midwifery-orientated articles and articles which described or researched women's experiences of critical illness in pregnancy.

Harvey (1992), in her article on haemodynamic changes in pregnancy and use of cardiopulmonary monitoring, was the only author to specifically remind readers that a critically ill pregnant woman has emotional and social needs as well as the physiological. Harvey provided a care plan which included maternal-infant attachment, breastfeeding, perinatal grief support, and methods to assist birthing while the patient is ventilated. She also reminds the reader that childbirth is a family experience and care should be family-centred.

Articles on the psychosocial impact of general admission to intensive care units were found (Stanton, 1991; Wood, 1993). They discussed nursing measures to reduce detrimental psychological effects of the intensive care unit environment on the patient.

Psychological and physiological effects of admission to intensive care units were found to have long term detrimental consequences (Campbell, 1995; Daffurn, Bishop, Hillman & Bauman, 1994; Sawdon, Woods & Proctor, 1995). An appreciable number of patients had no recollection of their stay in an intensive care unit, while some reported vivid nightmares and hallucinations.

Most had minor to moderate physical and psychological sequelae including sleep disturbance, depression and weight loss. Authors advised changes in clinical practice to reduce distressing psychological effects of an intensive care stay and recommend improved education and social support following discharge. The importance of the role nurses play in supporting family members while the patent is in intensive care was also discussed (Johnson, 1986; Murphy, Forrester, Price & Monaghan, 1992; Johnson et al, 1995).

Saarmann (1993) and Jones and O'Donnell (1994) investigated the effect on a patient of transfer from an intensive care unit to a ward. They agree transfer to a general ward where the area is unknown and monitoring is less intensive may be anxiety-provoking. Strategies suggested to reduce anxiety include giving clear, concise information on what to expect when transferred to the ward, weaning the patient from monitoring equipment before the move to a ward and transferring during daytime hours only.

No articles which discussed the psychological impact of admission to an intensive care unit on pregnant or postnatal women were found. Broadening the literature search to include the psychological impact of high-risk pregnancies brought inconclusive results.

Some studies defined high-risk pregnancy when the fetus was at risk. This included situations such as preterm labour, intrauterine fetal growth retardation and multiple pregnancy. Other studies discussed the psychological impact of maternal disorders such as drug addiction (Kearney, Murphy, Irwin & Rosenbaum, 1995) and diabetes (Persily, 1995). As I was interested only in the impact of maternal critical illness I selected only those studies which included risk to the women's physical health status.

Illness often confines the sufferer to bed. The effects of bedrest during pregnancy have been discussed. Maloni (1993) found evidence of three major

physiological changes secondary to bedrest. These were: muscle atrophy, cardiovascular deconditioning and weight loss. These changes impacted negatively on postpartum recovery although "... women previously on bedrest are expected[by family and nurses] to recover at the same rate as postpartum women whose activity was not restricted" (p.426).

Women's views of antenatal hospitalisation have been elicited and published. Loos and Julius (1989) found women experienced loneliness, boredom and feelings of powerlessness. White and Ritchie (1984) reported most stress in relation to "... separation from home and family, disturbing emotions, changes in family circumstances, health concerns, and changing self-image, in that order" (p.54).

Ford and Hodnett (1990) used a descriptive correlational design method to examine the effects of stress and social support on adaptation in hospitalised antenatal women. They found social support was predictive of adaptation but adaptation decreased as hospitalisation progressed. Another descriptive correlational study compared childbirth expectations of 'high-risk' and 'low-risk' women (Heaman, Beaton, Gupton & Sloan, 1992). The authors found high-risk women had less positive expectations for childbirth, expected more medical intervention and had more difficulty coping with pain than low-risk women. The authors suggest women faced with a threatening situation, test reality by obtaining information and mentally rehearsing the event. Implications for nursing practice include education and promoting realistic goals and expectations.

A grounded theory study of 21 parents who experienced high-risk pregnancy and the birth of a preterm infant was conducted by McCain and Deatrick (1994). Women in this study were hospitalised for either fetal-risk diagnoses such as pre-eclampsia and

eclampsia. Participants identified the basic psychosociological problem of emotional response to events leading to the birth. Three transitional stages which emerged from the data were: a sense of vulnerability related to problems identified with the pregnancy, heightened anxiety related to symptoms; and treatment. The stage of heightened anxiety evolved into working to accept the inevitability of a premature birth.

High-risk pregnancy was found to have a deleterious effect on family functioning (Mercer, Ferketich, DeJoseph, May & Sollid, 1988; Stainton, 1994; Kemp & Page, 1986). Stainton believes family focused nursing can assist the family to achieve higher levels of functioning while Kemp and Page (1986) advise utilising the family's existing coping methods and support systems.

The aforementioned studies reflect a review of literature which emphasises the nursing focus on the disease process and nursing treatment in an acute situation of maternal critical illness. It also highlights the lack of a midwifery perspective on maternal critical illness although women's experiences of pregnancy deemed to be at risk from a maternal perspective have been addressed. Significantly, women's experiences in the postpartum period following maternal critical illness has been underdeveloped in the literature.

Some literature does have merit when considered in the framework of developing theory as discovered by this study. The literature search was broadened to include MEDLINE for medical literature and PSYCHLIT for psychology literature The literature which was theoretically sampled will be presented in an integrated analysis with the data.

Summary

The use of literature in grounded theory method has been explicated and a review of literature on maternal critical illness has been given. Further literature searches were undertaken during theoretical sampling and are integrated in the data analysis chapters.

CHAPTER THREE: METHODOLOGY

Introduction

This chapter sets the context and background for the present study. Symbolic interactionism as the philosophical and theoretical underpinnings of grounded theory method is outlined. An argument for the applicability of grounded theory method for midwifery research is made and the suitability of the method for this particular topic is addressed.

An explanation of the method used in this study follows. The process of participant selection using the grounded theory method of theoretical sampling is discussed and a profile of the study participants is presented. An explanation of the constant comparative method of data analysis combining both inductive and deductive methods is given.

Symbolic Interactionism

Symbolic interactionism is a specific approach to the study of human life and behaviour. George Herbert Mead, a professor of philosophy at Chicago University (1894 - 1931) and one of the founders of symbolic interactionism had a profound effect on its development. Mead identified two forms of social interaction; nonsymbolic, where an individual responds to another's gestures and actions without interpretation, and symbolic interaction, where individuals interpret each other's gestures and actions and jointly act on their interpretation. Mead was primarily concerned with symbolic interaction (Mead, 1934).

Mead was particularly interested in the concept of self. In Mead's philosophy self emerges through the process of social experience and activity. Based on previous experiences, human beings constantly interpret the world through verbal and nonverbal symbols. This interpretation influences the way they act toward each other and toward themselves (Mead, 1934). In this way the individual can act on the world and is not constrained to a reactive role. As self is developed over time the key to understanding actions of individuals is to understand their history and desires.

Herbert Blumer, influenced by Mead, developed a methodological position of symbolic interactionism. According to Blumer (1969) the three fundamental premises on which symbolic interactionism rests are:

- The meanings human beings have towards things dictate how they act toward them
- The meaning comes out of social interaction with other human beings
- During the encounter individuals modify the meaning of the thing and handle such meanings through a process of interpretation

Grounded theory

Blumer was a tutor of Anselm Strauss when Strauss undertook his sociology doctorate at the University of Chicago. Blumer introduced Strauss to the ideas of George Herbert Mead (Strauss, 1970).

Strauss became a colleague of Barney Glaser when both were employed as sociologists on the faculty of the University of California School of Nursing, San Francisco. In 1965 they published a conjoint study on dying patients; it was while undertaking this study that the grounded theory method was born.

Glaser and Strauss' methodology was influenced by Strauss' background in symbolic interactionism while Glaser, who gained his doctorate from Columbia University, believes his academic background influenced him in multivariate analysis and the notion of basic social process (Glaser, 1978).

The acceptance of symbolic interactionism as an underlying philosophy means that grounded theory is more than a method of data analysis, it is "... an entire philosophy about how to conduct field research" (Polit & Hungler, 1991, p.324).

Grounded theory is a systematic, inductive, qualitative research method for generating and verifying theory from empirical data. The researcher does not begin with a preconceived hypothesis or research question; the theory is generated after data analysis has begun. The key to the grounded theory method is simultaneous data collection, coding and constant comparative data analysis. This method of data analysis combines both inductive and deductive research methods; the induced codes guide where to go next for deductive comparison. The name for this method arises because the theory is empirically grounded in the data from which it is generated. In this way the theory will fit and work.

By "fit" we mean that the categories must be readily (not forcibly) applicable to and indicated by the data under study; by "work" we mean that they must be meaningfully relevant to and able to explain the behaviour under study (Glaser & Strauss, 1967, p.3).

The theory which emerges is forever developing and cumulative as no single theory can ever be entirely germaine to every situation (Glaser & Strauss, 1967). The steps which were followed to arrive at the basic social process as it relates to the maternal experience of critical illness will be more fully covered later in this chapter.

Authors claim that grounded theory itself is evolving in its method (Annells, 1996; Chenitz & Swanson, 1986; Keddy, Simms & Stern, 1995). Glaser and Strauss later differed in principles of data analysis. Glaser (1992) wrote Emergence vs Forcing Basics of Grounded Theory Analysis to refute the stance Strauss and Corbin (1990) had taken in Basics of Qualitative Research: Grounded Theory Procedures and Techniques. Glaser castigated them for "...writing a whole different method so why call it 'grounded theory'?" (p.2).

Glaser's major objections to Strauss and Corbin's (1990) work centre around the nature of the research question, coding, and saturation of categories including finding the core category. Strauss and Corbin's method, according to Glaser is overformulaic, full of fractured, forcing rules producing a "...full conceptual description by a preconceived model..." (Glaser, 1992, p.101).

At first reading, Strauss and Corbin's (1990) method appealed to me as a first-time user of grounded theory. It appeared to lay clearer guidelines to follow. However, after rereading Glaser's (1992) *Emergence vs Forcing Basics of Grounded Theory Analysis* I felt comfortable following Glaser's method to allow the data to emerge. Therefore, for the purposes of this study, I have adhered to Glaser's method of analysis (Glaser & Strauss, 1967; Glaser & Strauss, 1978; Glaser, 1992).

The applicability of grounded theory to midwifery research

Grounded theory was first developed by and for sociologists. However researchers in many other fields now use this method to accomplish the purpose of their studies. Glaser & Strauss (1978) believe grounded theory method is of practical help in discovering and applying fundamental processes in everyday programmes and problems.

Grounded theory has gained popularity as a qualitative research method in nursing (Benoliel, 1996; Chenitz & Swanson, 1986; Streubert & Carpenter, 1995). Midwifery, like nursing, is a practice-oriented profession and like nursing can benefit from a systematic method of empirical data collection and analysis to add to knowledge. Grounded theory is one such systematic method of inquiry. Some of the methods of data collection, for example unstructured indepth interviewing, participant observation, and note taking, are used in daily midwifery practice.

Midwifery is "...based upon an integration of knowledge that is derived from the arts and sciences; tempered by experience and research..." (New Zealand College of Midwives, 1992, p.7). Grounded theory method has been found in midwifery literature to provide either a descriptive or theoretical model for midwifery care.

Bassett-Smith (1988) produced a grounded conceptual framework for midwifery practice based on the midwife's role in authenticating the childbirth experience. Beck (1993) developed a substantive theory based on women's experience of postpartum depression. Jackson's (1996) study on the experience of women who had unplanned caesarian sections led her to advance a conceptual model for women whose experience is lost within the focus of normal birth. In Kearney, Murphy, Irwin and Rosenbaum's (1995) grounded theory description of pregnant crack cocaine users, the basic social psychological process of 'salvaging self' was identified. An exploratory grounded theory study on how women utilise health care during pregnancy by Patterson, Freese and Goldenberg (1990) found the goal of safe passage through pregnancy and childbirth to be the driving force behind seeking prenatal care. While there have been many studies on the clinical implications of critical illness in pregnancy, grounded theory method offers the opportunity to understand how critical illness impacts on the woman's childbearing

experience. Grounded theory methodology was particularly appropriate for the topic as this approach does not start with a research question or hypothesis but rather an area of interest for study (Glaser & Strauss, 1967). This approach enabled an indepth examination of women's experience of critical illness during childbearing and led to an inductively derived basic social process.

Recruitment and ethical concerns

In accordance with the sampling strategies of grounded theory, the population chosen was that most likely to demonstrate the area under study. The sample population consisted of women who had been critically ill around the time of the birth of their baby.

- Critical illness was defined as a childbearing-related illness which
 necessitated admission to an intensive care² or high dependency³ unit and
 precipitated delivery of a healthy infant or occurred not greater than seven
 days after the birth of a live healthy infant.
- A healthy infant was defined as a baby who did not require neonatal intensive care at the time the woman agreed to be in the study. This criterion was included as I did not wish to be too intrusive and overburden a mother who was also concerned for her baby's survival.

For the purposes of this study the women had to be fluent in English. This was due to my own shortcoming as an interviewer in speaking only English myself and the unavailability of funds to hire an interpreter. Ultimately all respondents spoke English as their first language.

² An intensive care unit allows 1:1 nursing care, invasive monitoring and mechanical ventilation of a dangerously ill person

³ A high dependency unit allows 1:1 nursing or midwifery care and invasive monitoring of a dangerously ill person

Women who had been transferred from the intensive care or high dependency unit to a ward and were considered well enough by their nurse or midwife to receive an information sheet about the study were invited to participate. These participants were interviewed in a postnatal or general ward prior to discharge home and again at between six to eight weeks postpartum⁴. Eight women responded to an invitation to participate in this phase of the study, seven were primiparas⁵ and one had given birth to her second child.

The nurse or midwife in charge of the woman's care was given an information sheet about the study (see Appendix A) and a notification of interest form (see Appendix B). The nurse or midwife was asked to hand these personally to the woman saying "I have been asked to give you this". If the woman was interested in hearing more about the study she signed and returned the notification of interest. On receipt of this form I then went to the ward to see the woman, answer any questions she might have, obtain her written consent, (see Appendix C) and arrange a time suitable for the first interview.

During data analysis, as substantive codes began to emerge, it became apparent that a sample of women who had longer than two months to reflect on their experience of critical illness around the time of the birth of the baby was needed. This was to compare and saturate emerging codes. Data collection guided by this sampling strategy is representative of sampling in grounded theory and is called theoretical sampling.

In order to access this sample approval was sought from the Ethics Committees to place an advertisement in the New Zealand Action on Preeclampsia (NZApec) newsletter (see Appendix D). Four primiparous women and one who had recently experienced a pregnancy subsequent to

⁴ Postpartum means after the birth

⁵ Primipara is a woman giving birth to her first child

maternal critical illness responded to my advertisement and agreed to participate in the study. I answered any immediate queries at the time and sent an information sheet (see Appendix E) and consent form by post at each woman's request. After reading the information sheet the women then rang me back to arrange a time and place to meet for the first interview. It was then that written consent was obtained. One woman who lived in another city was interviewed by telephone; written consent from this participant was obtained by post.

As data analysis continued, women who had experienced pregnancy after their experience of maternal critical illness were sought to provide a full range of, and to saturate, emergent categories. A third source of data was obtained. This consisted of three personal accounts of critical illness in pregnancy followed by a subsequent pregnancy published in the United Kingdom Action on Preeclampsia (UKApec) newsletter. One woman who answered the advertisement in the NZApec newsletter also met this criterion.

Prior to commencement of this study the research proposal was sent to hospital management to gain approval to conduct research. Hospital management approval was provisionally granted on condition of gaining approval from the relevant Ethics Committees. The research proposal was then sent to Massey University Human Ethics Committee, and the appropriate Crown Health Enterprise Ethics Committee and was approved.

To obtain a second data source I telephoned the secretary of the New Zealand Action on Preeclampsia support group and asked if it would be possible to place an advertisement in the newsletter, and gained permission to do so. I then wrote to the appropriate Crown Health Enterprise and Massey University Ethics Committees explaining why it was necessary to seek a second theoretically driven sample. I enclosed a copy of the proposed advertisement

and information sheet. As soon as approval from both Ethics Committees had been granted the advertisement was placed in the newsletter.

Ethical requirements

Ethics committees have stringent policies to ensure the rights and safety of participants are upheld. The following outlines the procedure undertaken to ensure ethical requirements were met.

Informed consent

The information sheet sent to participants outlined the purpose of the study, the manner in which data were to be collected, and procedures in which the participants would be involved including an estimated time frame. Participants were invited to take part in the study, and to consent to have the interviews audiotaped. Participants' rights to decline to answer questions, to request the audiotape to be turned off, and to withdraw from the study at any time were made explicit (see Appendix C). Informed consent was confirmed by a witness who had a concern for the woman's welfare. A copy of the signed consent form was made and returned to the participant.

The women providing the third source of data through published material were not contacted as their stories were published in a public forum and as such their consent was thereby deemed to have been given.

Confidentiality and anonymity

Confidentiality and anonymity were assured. The tapes were transcribed by myself. Tapes and transcripts were kept in a secure place and coded to avoid naming the participants. Consent forms were kept in a secure place separate from the tapes and transcripts. Any identifying place or person was edited out of the transcripts at the time of transcribing to ensure no details which could

identify the participant, her place of care or her carers could be identified. The names given to the women in the study are pseudonyms.

Prevention of harm

The potential for harm to the participants seemed minimal. The most likely source of harm was psychological distress experienced by telling their stories. The name and contact number of a free counselling service was included in the information sheet.

All women who were sent an information sheet about the study agreed to participate. From the first moment of contact each participant began to tell her story. Heiney (1995) asserts story telling is beneficial to people facing a life crisis or major life transition by enabling them to find meaning in overwhelming events. Most women expressed the hope that by participating in this study they may help others in the future who undergo a similar experience. Others participated as a way of saying "thank you" to the unknown staff who cared for them during their illness.

Participants' right to information

Participants were free to ask anything about the study at any time during the course of the study. At the completion of the study each woman's own tapes were returned to her with a summary of the study results if she wished.

Legal Issues

The copyright of the thesis is my own. The tapes and the stories contained on the tapes belong to the women who shared their experiences with me. The right to use these stories in my study was given to me by each woman with signed consent. To comply with requirements of the Ethics Committees all data will be securely and confidentially retained in written form for ten years.

Data Collection

Data collection took place over seven months and all interviews were unstructured. Hospitalised participants were interviewed in a quiet, private room in the hospital. All other interviews were conducted in the women's homes at their request. Each interview took between one and two hours.

After confirming consent on tape I asked the women to describe their experience from the time they began to suspect all was not well. The question was phrased as "What has this experience been like for you?" The question which initiated the second interview was 'What has it been like for you since the last time we spoke?'

During interviews, participant observation was employed as a data source. Participant observation meant that while in conversation with the woman, I was also observing and interpreting her actions in the context in which she was directly situated in order to understand more fully her own unique experience as it had meaning for her. Participant observation involved note taking with the woman's permission and also enabled direct clarification of meaning at the time, especially if oral cues did not match nonverbal cues. Participant observation notes were recorded in the transcripts.

Field notes were made as soon as possible after the interview ended. Field notes contained demographic data on the participant, the geographical area, and records of observed social support systems such as family members and friends who may have been present.

Profile of study participants

Of the thirteen women interviewed, eleven were New Zealand born of European descent. One woman was British born and had been a permanent New Zealand resident for many years. One woman identified herself as a New Zealand born Maori. The age range was from 24 to 41 years, the median age being 30 years. All were married. Eleven women were primiparous, the twelfth woman had experienced critical illness during her second pregnancy. The last woman interviewed had experienced a normal pregnancy and delivery after critical illness during her first pregnancy. All the women in this sample had completed secondary education, four had completed tertiary education, five had qualified for a trade. Eight women were employed in paid work at the time of admission to hospital and five were on maternity leave.

The reasons for admission to an Intensive Care or High Dependency Unit varied as did the stage of pregnancy or postpartum period at which this occurred. Six women were admitted antenatally with preeclampsia, and one following a myocardial infarction. Six were admitted in the immediate postnatal period, four with preeclampsia or HELLP Syndrome, one woman was diagnosed with Haemolytic Uraemic Syndrome and one with coagulation problems. One woman was admitted five days postpartum with toxic shock syndrome. Ten of the women in the sample had caesarian sections while three had vaginal deliveries.

Published reports

The three women in this population were British, all were married and one woman had a previous pregnancy before experiencing critical illness. Each woman had a subsequent pregnancy 10 months to two years after experiencing critical illness caused by preeclampsia in her first pregnancy.

⁶ Antenatal means before the birth

⁷ Postnatal means after the birth

⁸ HELLP Syndrome is an acronym for Hypertension, Elevated Liver enzymes and Low Platelets

Data Analysis

Simultaneous data collection and constant comparative analysis with coding of data are the key analytical processes used in the grounded theory method to generate theory; in this way grounded theory is both an inductive and deductive process. All transcripts, memos, published autobiographical accounts of critical illness in pregnancy, participant observation notes, and field notes were analysed and coded line by line as they became available. Analysis began as soon as the first tape had been transcribed.

Open coding

The first basic analytical step is 'open coding'. The researcher performs a line by line analysis of the data, constantly comparing incident with incident looking for similarities and differences. During open coding I asked myself three questions as recommended by Glaser and Strauss (1978) "What is this data a study of? What category does this incident indicate? What is actually happening in the data?" (p.57). The purposes of repetitively asking these questions while analysing the data is to keep the researcher theoretically sensitive and to generate a core category.

During open coding the data is 'fractured' and coded in every way possible to form different concepts which are then clustered into categories (Glaser, 1992). Categories are named using 'in vivo' codes; these are derived from words used by participants in the study. When all data have been open coded, selective coding begins.

Selective coding

'Selective coding' focuses on a 'core category' and may guide the researcher to further theoretical sampling. Only codes which relate to the core category and are mutually exclusive of each other are used. Codes which do not relate to the core category cannot be forced to fit. Codes that have been generated are 'substantive codes', arising from the empirical substance of the data. During substantive coding the analyst also asks theoretical questions of the data to begin theoretical coding.

Theoretical codes

'Theoretical coding' is a second level of analysis. Theoretical codes emerge from the data and form links between substantive categories showing how each relates to the other leading to the generation of theory. 'Theoretical sampling' and substantive coding comes to an end when the categories are 'saturated' and a core category emerges.

Core category

Core categories are often the last category to be saturated as they absorb so many codes. They account for variations in patterns of behaviour and have explanatory power. Grounded theory generated around a core category "...accounts for a pattern of behaviour which is relevant and problematic for those involved" (Glaser, 1978, p.93). There may be more than one core category emerging from data analysis but the analyst focuses on only one core category, the other may be demoted and filtered into the theory as far as it effects the core category or it may be omitted and become the focus of another study (Glaser, 1978).

Basic social process

A grounded theory study always has a core category. A core category may be a basic social process (BSP). A BSP is identified by a gerund ending, which confers the impression of its occurrence and change over time, it also accounts for change over time. To demonstrate and account for change over time a BSP must have "...at minimum, two clear emergent stages [that]... differentiate and account for variations in the problematic pattern of behaviour' (Original emphasis), (Glaser, 1978, p.97).

Memos

Memos are analytic ideas which occur to the researcher while analysing the data. They are separate from the data but theorise and abstract the researcher's thoughts, questions and ideas emerging from the data clearly showing gaps in the emerging theory and pointing out potential directions to take. As ideas emerged during coding, I stopped and memoed these as recommended by Glaser and Strauss (1967).

Memos are for the researcher's own use and may therefore be sketchy and brief or long and detailed as long as they are primarily focused on analysis and theory construction. An example of how memoing leads to abstraction and assists theory construction is the following memo which I wrote when analysing data and formulating codes from descriptions of how the women said they felt on admission to hospital:

Pain, anxiety, fear - once admitted no panic? Acceptance? Once disaster has occurred too late for emotional arousal? Resignation? Events moving too quickly to take in. No knowledge of what to expect = no cognitive control - give oneself up to the hands of others, the experts. (Personal memo, 1996, p.10, lines 1 - 5).

This line of thought which occurred to me while analysing data involving women's descriptions of events as they happened on admission to hospital led me to review literature on natural disasters and traumatic incidents. This in turn led to the level two category 'being overwhelmed' presented in Chapter Five.

Summary

This chapter has introduced grounded theory methodology and explored its appropriateness for this study. As a form of field research which requires a particular form of systematic, indepth, data collection and analysis of experience in the everyday world, it is suited to this type of study which began with no research question or hypothesis but an interest in women's experiences of maternal critical illness.

The research process has been outlined including information on participants, ethical principles adhered to, data collection and analysis. The data will be presented in the following chapters.

INTRODUCTION TO THE DATA

The results of the study are presented in Chapters Four to Seven. Verbatim data obtained from participants is contained in these chapters. The following conventions have been used and are presented here to assist the reader's interpretation.

Key to abbreviations

... material edited

Proper noun pseudonym for each participant

1: the first or second of the participant's interview

1 - 10 line number from the verbatim transcript

Roman font speech of the participants

Italics the interviewers comment or question

[] word replaced to protect anonymity

UKApec United Kingdom Action on Preeclampsia

Newsletter

CHAPTER FOUR: IDENTIFYING A PROBLEM

Introduction

While pregnancy itself is not an illness it does produce symptoms and discomforts such as amenorrhoea, nausea, and constipation which are explained by normal hormonal changes and the growth of the fetus. The postpartum period may bring abdominal pain ascribed to normal involution of the uterus, or hard breasts and low grade fever which is taken as a sign of lactation being established. At any other time in a woman's life these discomforts may be investigated for a sinister cause but during pregnancy and postpartum are expected and described as normal by health care professionals, lay persons and literature.

Expecting physiological changes, women in this study attributed many of the prodromal symptoms of maternal critical illness to more benign manifestations of pregnancy and the postpartum period. Failing this, to some benign illness such as "a tummy bug".

In this study the decision to get assistance was made after careful weighing up of potential physical and psychosocial outcomes and took place in three stages. Stage one 'is something wrong?' is a period of appraisal and initial management; stage two 'something is wrong' is a period of reappraisal; the final stage, stage three 'seeking help' is the time the women sought professional medical help. The following discussion expands on each of these stages.

Is something wrong?

Everyday body sensations are interpreted and given meaning within the context of everyday experiences and expectations (Alonzo, 1979; Cowie, 1976). When awareness of some physiological discomfort, pain or change arose, each

woman assessed her health status in terms of what was familiar or in terms of what she expected from normal pregnancy. The initial appraisal took place within the terms of her knowledge about pregnancy and illness, her stage of pregnancy, her own salient biographical features such as her health history, the general context, her recent activities and her whereabouts. Each woman, in a real sense, asked herself "is something wrong?" and made a diagnosis based on the answer to these questions.

I thought I had indigestion. On the Tuesday I had the same pain but it went away and on Wednesday -most of Wednesday but it wasn't so bad. I was at work and being active kept my mind off it (Gemma 1:181-185).

I just felt dizzy and vomiting and diarrhoea at the same time, I had a hot sweat at the same time. I thought it was heartburn (Tessa 1:11-16).

Anyway, that day I got a really bad pain in the middle of my abdomen up under my ribs and I thought it must be indigestion because I'd never had indigestion so I thought it must be like that. It went away (Frances 1: 12-13).

I felt distracted, I had to keep getting up. I felt very unsettled. I didn't know if it was heartburn, I almost wondered if I was in labour because I'd been so well (Ruth 1: 142-144).

I had this swelling in my feet and I felt quite strange. But it was hot so I put the swelling down to that and with a first child you think it's normal to feel a bit odd (Elspeth 1:1-3).

If initial sensations or symptoms were mild, vague or short lived they were ignored, an 'avoidant strategy' (Folkman & Lazarus, 1991) or treated conservatively, a 'containment strategy' (Alonzo, 1979). The types of treatment or action to take in response to the symptoms was based on what the woman

suspected the cause to be and what had worked before. This meets Alonzo's (1979) Type II situation where an anticipated impact on one's body state leads to prior garnering of resources to prevent or contain the full impact. Rubin (1984) places this firmly in the context of pregnancy, describing one of the maternal tasks of pregnancy as "... loading of knowledge of what to expect, the probable and the possible, and of how to cope with the manifest phenomena" (p.55). The women acted on their initial diagnoses with knowledge from various sources.

I bought a drink and an iceblock. I thought it might make it go away if I have something cold and something to drink but that didn't work (Tessa: 1:16-17).

That night I stopped in to buy Quickeze [an antacid] ... I thought, 'Well with pregnancy you get indigestion so I'd better have something that works.' (Frances 1: 18-19)

So I went home, I went to bed. I said 'Just give me a cuddle and a hot water bottle and I'll be all right.'... I thought it was just indigestion or something, a tummy bug or something like that (Barbara 1: 52-71).

Heartburn is common in pregnancy; the signs of gastroenteritis are known to most people first or second hand. The women normalised their symptoms according to expectations. This pattern of assessment of health deviation in pregnancy has been studied in premature labour by Patterson, Douglas, Patterson and Bradle (1992). Assessment of premature labour was found to cause 'diagnostic confusion' because symptoms were ambiguous, and women expected normal pregnancy-related body changes.

This behaviour has been demonstrated in past studies on illness. Davis (cited in Locker, 1981) found parents of children who contracted poliomyelitis diagnosed the initial symptoms as a common childhood ailment or resulting

from the children's previous activity. Studies on heart attacks (Cowie, 1976; Hackett & Cassem, 1969; Johnson, 1991) discovered patients initially normalised the symptoms in a variety of ways. They interpreted signs of a cardiac infarction as nerves, gas, or indigestion and acted according to this interpretation. Initially the women in this study felt that nothing too unusual was happening to them.

Emerson (1970) believes a 'nothing unusual' stance prevails in an ambiguous situation. Behaving as though nothing unusual is happening sanctions the individual to follow a more comfortable pattern of behaviour. The individual who takes a 'something unusual' is happening stance with no visible proof may be labeled a hypochondriac or emotionally disturbed resulting in discomfort and embarrassment. The 'nothing unusual' viewpoint is usually held until it becomes untenable or other participants corroborate the 'something unusual' stance.

Seeking medical advice as a first line of action was often discounted, if it was considered, for two reasons. The first was a disinclination to 'bother' anyone which Albert (1980) suggests may be due to consumer belief that professional health care providers are busy people whose services are already misused.

I'm not one to ring up if I don't have to, and first time pregnancy I thought 'I don't want to ring them up if it's nothing.' (Ruth 1: 145-146).

The second reason was a fear of 'loss of face' which supports Emerson's (1970) view of resultant discomfort or embarrassment.

It made me feel like I was a hypochondriac first time mum... I just thought they'd think I was a hypochondriac because honestly I thought it was just indigestion (Barbara 1: 66-71).

Seeking professional medical help with a poor history of illness or with no unusual symptoms to present did expose two women in this study to discomfort and embarrassment.

By the time I got to [hospital] the driver said 'You seem fine but we will get a doctor to check you out anyway.' So I felt like a git, a real idiot calling the ambulance for heartburn (Tessa 1: 115-118).

When I broached the subject [of an elective caesarian section] to my consultant's team I was treated with bemusement and made to feel neurotic (Clarke, UKApec, No, 7, 1994, p.15).

One woman in this study was subjected to delay as her primary health care provider normalised the symptom and advised her to act accordingly.

I just started feeling um, cramping in the stomach and I just lay there with a hottie. And I rang the midwife and she said 'Take some paracetamol'.

And what happened after that?

I just kept taking paracetamol and paracetamol. She said to me perhaps I'm just trying to pass a small clot and she actually did come around but she didn't take my temperature (Kate 1:14-19).

Alonzo (1979) asserts that illness "... results from a cumulative process in which an individual and/or others evaluate the degree of containment over the range of situations associated with his [sic] containment set" (p.400). In this study women 'contained' the symptoms by normalising them, and treating them conservatively with proprietal indigestion remedies, hot packs or comforting food.

The route from perceiving oneself as well to perceiving oneself as ill is not always direct, especially when symptoms are vague and ambiguous. When the symptom did not respond to first line management, persisted or prevented the

women from continuing their daily activities the women in this study then defined the symptom as a problem.

Something is wrong

Reappraisal took place when symptoms reappeared or became worse and the woman's tolerance declined. The women in this study then decided that something was wrong. Zola (1973) points out that factors which constitute sickness differ between individuals. A general definition posited by Cowie (1976) is a deviation from normal or expected experience and an inability to rationalise this incongruity.

About twenty minutes later I couldn't stand the pain (Barbara 1:53).

And then I sort of felt flushed and wanted to go to the toilet and felt very sick and felt something was definitely wrong. More wrong than having just heartburn because it didn't go away. I'm in trouble here (Tessa 1:18-19).

...I began to vomit continually. The pain was unbelievable - a ripping, stabbing, burning sensation I shall never forget (Clarke, UKApec, No. 7, 1994, p.15).

Women in this study waited until symptoms were obvious or severe before seeking help corroborating that Emerson's (1970) 'nothing unusual' stance is held until a 'something unusual' stance can be corroborated by others. However, Rubin (1984) asserts that pregnant women expect to cope with anxiety and pain without assistance.

When the situation becomes too painful to cope with... she avoids asking for help as long as possible. When she has to request or to demand that "somebody do something" or "give me something" she finds this demeaning, a source of shame later (Rubin, 1984, p.68).

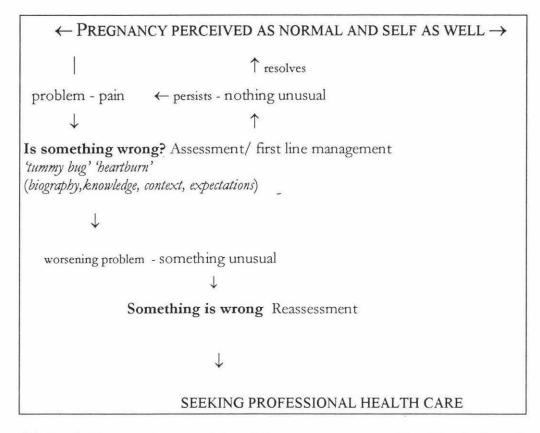


Figure 4. Diagrammatic representation of diagnostic assessment, problem identification and management, and route to professional health care provider

As the subjective severity of symptoms mounted, time delay in getting assistance diminished. One woman, finding herself ill in a public place and unable to drive, telephoned a relative.

I rang my uncle and I said, 'Something's wrong, I'm in trouble.' And I said, 'I'm breathing funny.' And he said to ring an ambulance because he said, 'By the time we get to you-' You know, I could be really crook or I could be - who knows (Tessa 1:145-147).

Hackett and Cassem (1969) and Zola (1973) suggest the role of a second person is significant in encouraging help seeking. For those persons for whom denial is a major cause of delay, a second person may be successful in goading them to seek help. Calnan (1983) agrees, suggesting others have a lower

perception of the threshold of need when seeing another person suffer. He also offers a more pragmatic reason. Others, when put in the position of adviser "...may tend to be more cautious because of the moral responsibility when taking risks with other people's health..." (p.27). It is wiser, if in doubt, to err on the side of caution. Encouraging the seeking of help also frees the advice giver from a time and emotional commitment which will dig into their busy lifestyle and disrupt plans.

Lay consultation, as a method of coping, has featured in previous studies (Calnan, 1983; Hackett & Cassem, 1969; Johnson, 1991) but did not feature prominently in this current study. Only three of the thirteen women interviewed reported that they discussed feeling unwell with a lay person before seeking medical help. Each lay person was a family member. Lack of consultation has been identified as characteristic during pregnancy. "A woman expects to muddle through or cope with painful situations or conditions on her own" (Rubin, 1984, p.68). Demographic detail revealed eleven of the thirteen women interviewed in this study were either at home alone or at work when they first identified a symptom such as 'heartburn'.

McKinlay (1973) found women who were independent financially and socially made lay consultations less often than women who lived with relatives or were dependent on them economically and in other ways. It may be suggested that the women in this current study were familiar with independent problemsolving in this situation. They had knowledge of expected sensations in pregnancy or relied on methods which had worked or were known to have worked previously. It may also be argued that there was simply no one with whom to consult. Women were either alone, or for those in the workplace, coworkers may have been viewed as unsuitable lay consultants; the workplace may be regarded as an unsuitable venue to discuss health concerns. As one woman said,

My school regarded pregnant teachers as an unwelcome disruption to the timetable, and there was considerable pressure to ensure that such inconveniences as antenatal appointments were kept to a minimum (Turner, UKApec, No. 10, 1995, p. 13).

These varying situations support the assertion that appraisal and lay consultation is context bound.

Seeking help

While not believing the symptoms of heartburn or gastroenteritis to be life threatening, the women were compelled by unrelieved pain to seek help from a professional healthcare provider. Many factors influenced whom she contacted: her relationship with her primary healthcare provider, her knowledge of where to seek help, the time of day, where she was at the time, and whether she thought the problem was pregnancy related or not. If the problem happened during the day, women who had a good relationship with their doctors found it convenient to consult them and the fear of looking foolish was not as constraining.

I was going to go out with my husband and I thought 'Before I go I'll get this checked. Fortunately my doctor could see me straight away, he took my blood pressure and said 'Go straight in to [hospital]' (Nancy 1:20-24).

The stuff I'd got didn't work so I stopped off at the doctor again the next day. My blood pressure was up and I'd put on another kilo so she sent me to [hospital] (Frances 1:19-21).

I rang the doctor and she said 'Come in for an appointment' and I did. And she looked at me straight away and said 'To hospital' (Karen 1:24-5).

Two other women felt they had been given permission to call the hospital directly. This expedited matters and minimised the risk of loss of face. Zola (1973) recognised this as 'sanctioning'.

I'd just been to my first antenatal class and they said 'At any time of the day or night if you're uncertain about anything you can ring the hospital.'

Would you have done that if you hadn't been told in antenatal class?

I don't think I would've. I had an appointment at the specialist again on Monday and I would've waited until then and if it hadn't gone away I would've called a doctor or something but because I'd gone to antenatal class and they said it doesn't matter what time it is, there are people there day and night. And they said 'Come in, we'll check you out.' So we did (Gemma 1:190-205).

I rang [the hospital] and they said 'You'd better come in if the doctor told you that.' Because [the doctor] said if I had any more pain I was to come straight in (Barbara 1:54-57).

Not all critical illness during pregnancy or postpartum begins in the community. Becky had a normal delivery in hospital then went on to develop clotting problems after a postpartum bleed.

It must have been an hour and the afterbirth didn't come out properly. Everyone was waiting. I saw the doctor's face. He was frowning, he looked worried.

And what were you doing, were you bleeding? Were you in any pain?

The pain! It was just like contractions in labour. I thought with the birth it would all be over but the pain was so painful - so intense (Becky 1:32-44).

The pain following birth was unexpected but Becky took her cue from her health care provider. Becky's appraisal of her health condition was confirmed by the look on her doctor's face. There was no ambiguity about her situation therefore help was given within an hour.

It has been described in the literature that people provide themselves with a clear indicator that something is out of the ordinary to influence the doctor's reaction when they present for help (Albert, 1980; Locker, 1981; Patterson, Douglas, Patterson & Bradle, 1992). Sometimes the indicator that something is wrong such as continuous vomiting or bleeding is obvious to all parties. Sometimes symptoms, such as pain, are obvious only to the experiencing woman. Indicators such as hypertension or abnormal laboratory results are obvious only to the professional. Women in this study provided themselves with a good history of illness before seeking professional health care. They "... create[d] the appearance of a valid treatment claim" (Albert, 1980, p.245).

Locker (1981) believes that when deciding to consult a doctor people provide some justification for the delay in seeking professional help. Cowie (1976) in his study on perception of heart attack concurs. The route from wondering if something was wrong to seeking professional health care may be protracted. The delay is caused by ambiguous symptoms that lead to the self-diagnosis of a normal body response to pregnancy or some other benign illness such as a "tummy bug". It was only after home remedies had failed to work and symptoms worsened that the women sought professional advice.

Summary

When pregnancy has been trouble-free it is difficult to adjust to the notion that a serious threat to health is present. Following a problem such as heartburn, behaviour is initiated in one of two ways; firstly there is an attempt to bring the stimulus into line with the current image of pregnancy such as taking proprietal remedies. When stimulation such as pain fails to respond to first line treatment, a reappraisal of the situation is undertaken to adjust the image of pregnancy in line with the sensory data, that is, recognising the state of unwellness as being unusual and seeking help.

The process from asking oneself "is something wrong?" to seeking help can take place almost instantaneously or appraisal may be revisited over several days. Appraisal is a cyclical process until the stimulus is raised or level of tolerance is lowered to such a degree that professional health assistance is sought.

Following diagnosis, each woman in this study was admitted to a high dependency or intensive care unit. This admission introduced the stage 'being absent' which is presented in the following chapter.

CHAPTER FIVE: BEING OVERWHELMED

Introduction

'Identifying a problem' to 'seeking help' proceeded in a loosely linear sequence which culminated in admission to a hospital. By the time women were diagnosed as having a potentially critical illness the stress response had already been excited by two mechanisms: the physiological response to illness and pain, and the psychological response to anxiety. Both are strongly implicated in the category 'being overwhelmed'.

The psychological response to stress depends very much on the magnitude and force of the stressor, on the coping methods available for the individual to use, and on the individual's previous methods of coping. Denial, regression, distancing, and dissociation, to complete unresponsiveness to the environment, the 'conservation-withdrawal response' (Engle & Schmale, 1972, cited in Luckmann & Sorensen, 1980) are possible responses to stress. Authors assert that in the short term these methods of coping are healthy and positive (Folkman, 1984; Lazarus & Folkman, 1991; McManus, 1940; Moos & Schaefer, 1987).

This chapter discusses the physiological and psychological processes which grouped around 'being overwhelmed'. The benefits and consequences these processes had for the women during the crisis of critical illness is also discussed.

Holding on

In this study five of the sixteen women either sought help directly at a hospital, two by ambulance, or were in hospital when they became critically ill. The remaining eleven women were sent to hospital from their doctor's surgery. Data from this study reveal that women with a clear indicator that something was wrong such as vomiting or severe pain reported directly to the hospital from the doctor's surgery. Other women in the study performed additional tasks before going on to hospital; they remained 'holding on' to self through independent thought and action.

I stopped and bought a nightie at [department store] on the way to hospital (Jenny 1: 18).

I went home, packed a bag, read up my pregnancy books on toxaemia. (Nancy 1: 37-38).

It has been indicated that this behaviour could be a form of 'denial' (Hackett and Cassem, 1969; Johnson, 1991). It has also been suggested (Cameron, 1996; Mechanic, 1977; Mishel & Braden, 1988) that other social factors influence what happens between the doctor's surgery and the hospital.

Wiener and Dodd (1993) submit that ill people juggle three types of work: biographical work (see Chapter Six), work related to the illness, and work related to everyday life. The balance, they believe, is one of 'relative equilibrium'. For the women in this study, while the illness did not appear life-threatening and was not incapacitating, activities relating to everyday life took priority. Christensen (1995) suggests people expect to prepare for hospitalisation: "There is a general preparation for a temporary withdrawal from the usual pattern of daily living" (p.57). It may also be said that by following a prescribed behaviour or ritual act such as buying new night wear and packing a bag for hospital helps to regulate threat-related emotions and preserve a comfortable emotional equilibrium (Cohen, 1993; Emerson, 1970; Folkman, 1984).

According to Cameron (1996) people are more likely to comply with medical advice if they believe the doctor and are able to perceive the serious implications of the symptoms.

I was told to go to[hospital]. I had a G.P⁹ until I was twenty weeks [gestation] and then I was sent to someone else. He didn't really know me. He said 'I think you've got this toxaemia¹⁰ thing'. We didn't know how serious it was. I went home to pack a bag and the doctor phoned at home to find out where I was. He said to my husband 'Is she fitting [convulsing] yet?'. I just about spun out (Elspeth 1: 5-9).

Through a mutual unfamiliarity between Elspeth and her doctor, compounded by the language in which the doctor couched his diagnosis, the physician lacked 'credible authority' which Mishel (1988) postulates helps an individual "... adopt the physicians view" (p.99). It was not until the shocking realisation that she could have a convulsion that the urgency to go straight to hospital hit Elspeth.

Admission to hospital did not negate 'holding on'. As long as there was work related to every-day living to do, the women in this study 'held on' to do it.

All I was thinking was 'Oh my gosh, has anyone contacted my husband or my uncle?' So I gave them the numbers and they said they rang [my uncle]. I said to them to ring [my husband] at work then, I want to know why he's not here (Tessa 1: 195-197).

I insisted on an epidural. They weren't too happy about that! With all the pain I was in I remember insisting I wanted to see my baby when he was born (Ruth 1: 178-179).

⁹ General Practitioner

¹⁰ Toxaemia is an alternative term for preeclampsia

'Holding on', while demanding effort from the women, was not always visible. When first admitted to hospital, Frances' condition was unstable but not yet critical. She and her husband hoped the next set of tests would show an improvement in her condition. Quietly waiting and hoping enabled Frances to hold on.

Um, I remember watching the clock. We just watched that clock, the hands of the clock going 'round (Frances 1: 12-14).

The possession of hope, it has been suggested, is an important determinant in being able to endure the present (Christensen, 1995; Morse & Carter, 1996).

Letting go

If not already overwhelmed by critical illness the women in this study began to 'let go' as soon as help in the form of medical intervention had been procured and essential work outstanding in every-day life had been completed. In this study 'letting go' followed the women's perceived downward trajectory in their physical status.

Like it just went straight down. Like your whole body just went straight down (Barbara 1:169-170).

It was later that morning I went down hill. Everything went down hill from bad to worse (Ruth 1: 181-182).

Up until that time the women had to make decisions about their health and health care; now they could give themselves into the hands of the experts. Women in this study became passive participants in their health care.

They took me up to intensive care and they hooked me up (Tessa 1: 171).

They were giving me blood and more blood (Barbara 1: 148).

They took me in and stabilised me, then they put me in an ambulance to [base hospital] (Elspeth 1: 10).

The process of 'letting go' was enhanced by the speed at which things happened.

It was like one big whirlwind ... it was just like a big rush. Like I was there one minute and they were talking about it ... then the monitor just gone [sic] crazy or something and they decided they had to do it there and then so it was still moving at amazing speed (Barbara 1:125-155).

They were rushing for a reason and they tried to explain what it was and I thought I took it in but obviously I didn't, um, I was a bit confused ... So we were down in recovery room and everyone was milling around and there were lots of faces then we were in theatre and it was over (Gemma 1:39-42).

In the days that followed I was wheeled about at lightening speed from one dark room to another (Clarke, UKApec, No. 7, 1994).

When events happen unexpectedly and quickly there is a mismatch between one's internal model of reality and the sensory input. Cognitive ability to keep pace with events is lost. From considering oneself a healthy woman with a probable disorder to becoming a critically ill patient in hospital happens quickly and thoroughly. Unable to care for themselves the women in this study had no option but to let others care for them.

Trust in a caregiver has been posited as a method of reducing uncertainty (Mishel, 1995) and allows a person to relinquish self care (Morse & Carter, 1996). This feeling is not limited to admission to hospital. Oliver Sacks described his feeling when rescued off a mountain in Norway following the

rupture of a tendon in his leg. "From the moment of my rescue my memories became less vivid, less charged. I was in others' hands now and had no more responsibility to act, or feel" (Sacks, 1984, p.18). The women had little choice but to trust their caregivers when they did not know what was happening or why. 'Letting go' was compounded by lack of knowledge.

I just knew that I had to do what they said and I did. I wasn't going to argue because it was a real unknown. First time round, nobody telling you anything. I was told I had to have an emergency caesarian section and that's all I knew (Ruth 1: 175-177).

Because I didn't honestly know what was happening so that was a horrible thing for me. Like, I didn't really know (Barbara 1: 123-124).

I thought 'Oh my god what the hang is going on?' Because nobody actually told me what was going on. They were all too busy trying to find out results from two days ago and then they were running around giving me steroids, giving me a chest x-ray ... and you know, no one had actually physically said 'Well, *this* is what's happening to you'. They were all busy running around (Tessa 1:168-176).

As their physical deterioration increased and medical management became more urgent, women in this study 'let go' completely. Placing absolute trust in their caregivers the women signed consent for the surgical birth of their baby and other surgical interventions without being fully aware of the consequences of their actions.

They gave me a consent form and I just went [waves hand uselessly in the air]. The doctor said to [husband] later 'It's supposed to be informed consent but I don't think she was really informed.' And I wasn't (Becky 1: 50-53).

I was signing this form not conscious of what was happening. I knew I had to sign the form otherwise I was going to die.

Did you feel it wasn't really happening to you?

Oh I'm too young for this. This is unreal. This is a nightmare. By that time the bed was just covered in a whole circle of people. There were just so many people it was unreal (Tessa 1: 220-228).

For the women in this study 'letting go' was not done of their own volition although the *wish* to let go may be conscious. Two women in the study described how they wished to 'let go'-and distance themselves from events which were surrounding them.

In some ways, with our jobs we were disadvantaged ... I knew what was going on at a cellular level and I thought 'I've got to stop thinking of this' (Nancy 1:66-67).

I just wanted it to stop and when they said they'd take me to theatre and give me a general I thought 'Oh good, I'll be out of it, I won't feel the pain' (Becky 1:43-4).

Norbeck and Tilden (1983) assert that a stressful event results in a 'call to action'. However, too many calls to action result in overload and impairs effective problem-solving methods. For the women in this study physiological and psychological overload led to 'shutting off'.

Shutting off

The form the medical assistance ultimately took such as surgical delivery of the baby by caesarian section, mechanical ventilation, and invasive monitoring, was far beyond most women's experience and control and in themselves precipitated crisis. Caplan (1961) defines crisis as the time the individual has failed to problem-solve by utilising intrapersonal and interpersonal resources and anxiety reaches an intolerable level. This level of arousal cannot be sustained for a prolonged period (Moos & Schaefer, 1987). Data from the

current study suggests this leads to a temporary 'shutting off' The phrase which marks this stage for the women in this study is "I don't remember".

'Shutting off' is a method of coping with an overwhelming and frightening situation. This term describes a defense mechanism employed when threats to self cannot be avoided and over which an individual has no control. The benefit of 'shutting off', it may be argued, is to protect psychological survival.

I was numb, I don't remember very much. It's the shock mechanism, it's like a dream, like this isn't happening to me (Elspeth 1: 17-18).

I think I remember getting out of the ambulance and coming through but I don't remember anything from there. I don't remember the operating room, I don't remember anything (Barbara 1: 43-46).

I was in so much pain.

Did they give you anything for the pain?

I don't know, I can't remember. These are the things I've missed out on (Ruth 1: 169-170).

According to Mead it is possible to distinguish between self and the body. "The body can be there and can operate in a very intelligent fashion without there being a self involved in the experience" (Mead 1934, p.136). The example Mead gives is running away from danger. It was not possible for the women in this study to run away in the physical sense although the body was in a state of preparedness for a fight or flight response. It was however, possible to remove the self.

It seems almost unreal because I wasn't really there for a lot of it (Kate 1: 77).

I felt my body was here and I was sort of away from it almost (Barbara 1: 251-2).

I was out of it (Becky 1: 54).

While the three women above describe 'shutting off' as a feeling of being external to themselves, Ruth 'shut off' by turning inward.

I was so in to myself they could have done anything and I wouldn't have known (Ruth 1: 171-172).

There are numerous biological and structural changes which take place in the body as a result of stress and illness. Physiologically 'shutting off' may be a response to the worsening of the disease state, continuation of extreme pain, hyperventilation, and the result of a prolonged stress response upsetting the body's biochemical balance leading to ischaemia and hypoxia. The whole process is further affected in critical illness by drug administration such as opioid analgesics, anaesthesia and anticonvulsants. Physiological effects secondary to the illness process and drugs have psychological consequences.

I thought it was just like a dream sort of thing and I'd wake up and I'd be all right (Barbara 1: 256-257).

Well I had sort of vague memories, I kept thinking I was in a nightmare (Kate 1: 61).

In my mind I knew [the baby] was being looked after but I used to have horrific nightmares constantly. Everytime I fell asleep I'd see hands in my sleep saying 'Where's your baby' and I'd wake up... but then they told me it was probably one of the drugs doing it (Greta 1: 45-48).

A mixture of being on a drug induced coma, periods of semi consciousness and hallucinations (Ruth1: 1-2).

My husband said I was delirious because at one stage I passed the hottie back to him and said 'This isn't my baby' which I can't remember saying (Kate 1: 33-34).

In acute critical illness there is little time to ease in to the knowledge of the situation. There is no time to prepare for the events which follow, and unfamiliarity restricts ability to mentally prepare. 'Shutting off' enables the woman to bear the unbearable for a little while. The inability of the women to remember their admission to an intensive care or high dependency unit is not exceptional. Many patients have no recollection of their time in an intensive care unit (Daffurn, Bishop, Hillman & Bauman, 1994; Jones & O'Donnell, 1994).

Sleep, although it brought nightmares, was another method of 'shutting off'. Most women in this study commented on increased sleepiness immediately following the critical period of the illness while still in the intensive care or high dependency unit.

I just wanted to sleep (Becky 1: 79).

I just dozed and doctors were coming around all the time and blood was being taken. Obviously something was wrong but it didn't really click it was that drastic (Gemma 1: 54-59).

I slept half the time like I couldn't keep awake. I'd be talking to [visitors] and I'd just fall asleep. I just couldn't take it. I think your body knows and you just shut off (Barbara 1: 310-312).

Many factors are implicated in the increased sleepiness of individuals who have critical illness. Illness itself generates feelings of fatigue. The atmosphere in an intensive care or high dependency unit is rarely sleep-promoting, lights, noise, and twenty-four hour monitoring lead to sleep deprivation (Wood, 1993).

Medications such as opioid anaglesics produce somnolence. Physiologically, sleep enhances tissue repair by conserving physiological resources by lowering the basal metabolic rate thereby decreasing the need for energy expenditure (Borbley, 1987; Hartmann, 1973; Moorcroft, 1993).

However, it is also argued that sleep may be a protective mechanism allowing periods of escape from the situation and as such is employed as a means of being overwhelmed. Borbely (1987) suggests sleep exerts a beneficial effect on mental health. Moorcroft (1993) speculates sleep is a recreational activity promoting peace of mind; it is also an adaptive response providing protection from danger during times of vulnerability. Hartmann (1973) maintains sleep is restorative following psychic strain such as anxiety and hypervigilance and is necessary to regulate emotion and restore a sense of self.

The psychological benefit of 'shutting off' may be noted by the experience of three women who relapsed during their recovery. During readmission the protective mechanisms which result in 'shutting off' did not reoccur. Although the women in this study had little or no memory of the first admission, when fully aware of events, each woman found the time of readmission to be more stressful than the first.

When they took me back to theatre I thought I should pay attention because I'd missed it the first time. I had a good look around and I was even more nervous then because I wasn't out of it (Becky 1: 87-90).

That's probably worse the second time in ... especially being so aware this time.

You weren't as sick as you were the first time?

No that's right... really frightening, really frightening (Kate 1: 112-115).

I was so frightened, luckily my midwife was with me and she rang the ambulance. But it was horrible, horrible (Jenny 1:186-187).

Many reasons may be implicated in this response: the threat to self was not perceived to be as great, the process and surroundings were familiar, events did not move as quickly as in the previous instance, and the illness process was not as severe as the first time. Mead (1934) suggests that in some situations events are entirely cut off from the self and do not cross the threshold of self-consciousness. Nevertheless these experiences remain as sensuous or sensible experiences ready to appear under specific conditions. It may be suggested that on readmission the body's memory responded to the cues although the intellect failed to record it as an experience of the self.

Summary

This chapter introduced the category 'being overwhelmed'. The processes involved: 'holding on', letting go' 'shutting off' provided the women in this study a way of coping with overwhelming stress. This stage has an observable breaking point from the previous stage of 'identifying a problem' beginning with the diagnosis of a potentially critical illness and ensuing treatment. The consequences of this stage are important and problematic for the women involved during stage 'absorbing' which is discussed in the next chapter.

CHAPTER SIX: ABSORBING

Introduction

The third stage, 'absorbing' incorporates forms of cognitive adaptation following the critical juncture of maternal critical illness. 'Absorb' is a verb which meanings include "incorporate as_part of oneself... take in... reduce the effect or intensity of..." (Reader's Digest Oxford Wordfinder, 1993, p.7). This chapter discusses the mechanisms by which the women seek to take in what has happened, to incorporate these events into the narrative of their own lives by finding meaning, and to reduce the intensity of the impact of the illness on their childbearing experience.

Taking in

'Shutting off' offers psychological protection by preventing too much overwhelming and unwelcome information being taken in during the acute crisis period. A crisis, according to Moos and Schaefer (1987), is followed by "...a slow dawning awareness of the reality of the event" (p.10). When transferred from the intensive care or high dependency unit to a postnatal or general ward physiological recovery had begun. Medications had been lessened and reality filtered into consciousness. The full impact of what happened began to sink in.

Yeah, it didn't really sink in until I got up to the general ward (Kate 1: 69).

It wasn't really until Monday when I actually got out of bed and felt sick then and the nurses were saying you've had HELLP syndrome or disease and gave me something to read about it that I realised it was quite, serious...That was a bit of a shock when it hit home, I got a

little emotional and sort of looked at the babies and thought 'Oh my god' (Gemma 1: 69-88).

It wasn't until the Saturday, three days later that it hit me (Frances 1: 50).

The women wished to know more as they physically recovered. Immediately after the critical illness their concerns were for concrete knowledge about what happened during the period of critical illness. There were many memory gaps to be filled as a consequence of 'shutting off'.

There's lots of gaps, for a while I kept thinking, 'What happened on the Saturday, was I expressing to keep my milk going?' and 'Where was [baby] on the Sunday?' I don't remember a thing (Kate 1: 6-9).

Gaps in memory were filled by asking staff and family members to describe what had happened. These gaps continued to be filled weeks later.

There were little gaps everywhere. They [doctors] came back up and told me a lot of things which I'd forgotten (Barbara 1: 346-347).

When I came back to consciousness [husband] would say to me 'Do you want to know what's happened?' and I'd say 'Yes' and he'd say 'Oh well, your kidney's failed and you've had a dialysis system going,' and I'd say 'OK that's enough' (Ruth 1: 48-50).

I said to [husband] the other day, 'Where was baby when I was in [unit] and he said 'She was with you.' And I don't remember. My sister put together this very nice little thing here just to start on. [Pulls out a book. Begins reading] 'When baby came to stay... Today baby went to visit her mummy in [unit] and had a cuddle and a feed (Kate 1: 181-192).

The need for knowledge about the illness began in a small, tightly focused manner. Women could only absorb a limited amount of information at one time.

I sometimes felt I was bombarded with people all talking at me, things to be done, things to be tested. Sometimes I couldn't take it all in because I was tired, ill, and stressed myself (Greta 1:109-110).

I didn't ask for any information on the disease because I just didn't have the energy.

Did you think about asking for information?

No I didn't, I had to concern - my main concern was to get well (Ruth 1: 21-25).

I could just take in little bits... he'd run through it all but I could only take in so much at a time (Ruth 1: 50-51).

At first I didn't really want to know and then I got curious.... and then I actually got my summary back from [the hospital] yesterday I think it was and it was actually very interesting and I thought, 'Oh, that's what my haemoglobin was, and that's what that was', you know. Everything sort of put into place (Barbara 2: 134-148).

As they improved physically and their knowledge base widened the women's quest for broader based, more abstract knowledge grew. The need for knowledge had a resurgence at the time women considered a second pregnancy; this will be addressed in the following chapter.

The better I got the more I wanted to know about what I had and what happened to me and what it all meant (Kate 1: 267-268).

Studies on the effects of illness support the assertion that patients can only absorb so much information at one time (Luker, Beaver, Leinster & Owens, 1996; McKim et al, 1995; Thompson, Ersser, & Webster, 1995).

Finding meaning

A major adaptive task following a life crisis posited by Moos and Schaefer (1987) is to establish meaning and understand the personal significance of the situation. Women with known preexisting medical complications in pregnancy are often monitored closely and critical illness may be averted. However, it is difficult to predict who will become critically ill during the childbearing experience. For most women who become critically ill in childbearing the illness appears to strike 'out of the blue'. When an event occurs which challenges the belief that the world is a predictable, controllable place persons involved ask "why me?"

That's your main question, 'Why me?' And no one can answer it. That's the hard part because there's no answer to it (Barbara 1: 357-359).

I don't know why it chose to pick on me for, I was fit and young and healthy...especially when it's so rare (Kate 1: 151-154).

When I came to consciousness one of the first things I said to [my husband] was 'Why me?' And he said 'Well, is there anyone else you would wish it on?' (Ruth 1: 218-220).

This question is asked in situations other than illness experiences. In an account of a skiing incident when he was swept into a deep crevasse Sedon (1996, p.51) wrote, "My mind raced. I was angry with myself. I should have known. Why? Why me! I thought I was going to die, and I said sorry to my family and goodbye".

A review of the literature on illness by Locker (1981) found the question "why me" was rarely asked in the event of trivial illness. He also found it was not consistently asked in the event of catastrophic illness. Locker concludes "The

extent to which phenomena can and therefore need to be explained is influenced by the assumptions one makes about those phenomena in the first place" (p.63). In the case of critical illness in childbearing there are the dual phenomena of illness and childbearing.

Women sought to find meaning in the experience and incorporate it into the narrative of their own lives. This task is modulated by reconstructing events leading to the illness. Cowie (1976) found a retrospective reconstruction of events leading to a heart attack "...always placed it in a historical context of anything from a few hours to one year" (p.87).

Caplan (1961) proposes that crisis draws attention to previous conflicts, particularly those symbolically linked with the present problem. There is an attempt to integrate the past with present experiencing. Rosenwald (1992) asserts, "We stop to take stock of our past development before we move on. Seen in this light, 'consequences' do not only follow stories but precede them as well" (p.273).

Personal stories are the means by which identity is established. The investigation into events, often apparently unconnected, led to a certain point where meaning was found and this exerted an emotional impact. Freeman (1993) believes that in reconstructing events,

All available facts are not put together because what to count as a fact derives from the questions and hypotheses one brings to the task of inquiring. By selecting some and rejecting others he[sic] has already determined what type of story he wants to tell (p.118).

Christensen (1995) in a study of 21 surgical patients found participants selected what they believed to be the critical issues when constructing a story. Attaching

meaning to an event and integrating it into the person's life story is a "... constant process of analysis and synthesis" (p.60).

I actually had an accident outside here and I slipped and twisted my side and fell on my stomach and grazed my leg and I also wondered if that had contributed to the heart attack (Tessa 1: 556-558).

You ask yourself all sorts of questions. Painting the baby's room, was it paint fumes? Maybe I did try and do too much. I don't know, who knows? No one. That's what's frightening (Ruth 1: 197-199).

And I do feel guilty, like what I might have done in the past to cause this. That caused [my baby] now problems that I didn't even worry about ten years ago (Becky 1:169-172).

I had this real guilt trip that I had done it to him... and I said, 'It was something I did.' [The doctor] said 'No.' But I believed it, I thought I tried to kill him (Greta 1: 89-91).

Some women reviewed their past to find meaning in the present. They recounted a litany of 'like: not like' to explain how this experience of critical illness fitted their life pattern.

I've had a lot of things happen to me in my past (Tessa 1: 276).

Tessa then went on to recount the story of her parent's divorce and the consequences of that on her childhood; her parent's deaths and deaths of close family members; a broken engagement and the attempts of two ardent suitors to woo her. She described her lucky escape from an accident and recounted holidays she had enjoyed.

So I've had some really good times and some really bad times (Tessa 1: 318).

For Tessa the experience of maternal critical illness fits the pattern of her biographical history of good and bad times. For Barbara the illness experience doesn't fit, it's not like anything in her past:

I've always been independent and done everything. In my family I'm the only one who's never had stitches, um... I've never done anything drastic and that's the real hard part. Like my brothers have all had car accidents... and I've never even had a stitch in my life, so it was a really foreign thing to me. Mum's been sick, and dad's been sick, gran, and everyone. And I've always been there, you know? (Barbara 1: 227-239).

In an analysis of the role of attribution in major illness Turnquist, Harvey and Anderson (1988) found patients do attribute their illness to something. The more severe the disease the less likelihood of a dominant causal explanation being given. Illness is easier to accept if risk factors were already present.

I always thought it mightn't be straightforward with my age and my history, we both did so we weren't too taken by surprise (Nancy 1:26-29).

But I was reading in a book, I'm nearly 35, I've got short stature and it was a multiple birth and they are three of the five common reasons why people get it (Gemma 1:152-155).

Although the illness experience may be attributable to causes outside the woman's control the loss of the expected birth experience cut deeply.

Reducing intensity

During pregnancy women imagine the birth experience. They fantasise about what it will be like, how they will cope and begin making informed choices about positions for labour and pain relief (Oakley 1979; Rubin, 1984). Only one woman in this study had a normal birth and immediate postpartum period.

For all the other women the birth or immediate postpartum period was a time of crisis. The women expressed a deep sadness that birth plans had been upset.

I thought the delivery would be the worst but it was the easiest. I thought I'd have a caesarian but no matter what happened in the delivery I always thought I'd go to the ward and be a mother with my baby beside me, even if I couldn't do things for her because I'd had surgery I'd have her there. It wasn't like that (Becky 1: 99-107).

We'd thought about it and how things should go, yeah, and I said to [husband] 'Well you can cut the umbilical cord.' and all this sort of stuff. And I wanted to have a drug free labour if I could and yeah,... you feel cheated, the moment's been stolen (Barbara 1: 447-452)

I guess I feel we have been cheated of a normal childbirth and the joy that goes with it (Ruth 1: 194-195).

Well I really wanted to have a normal delivery, just to have that feeling cause I never had that feeling with [toddler]. They were going to opt out and do a caesarian but at least I tried for a normal delivery sort of thing... I wasn't sure if it was going to be done Tuesday afternoon. They said I could be on a shortlist and go through the night, so I wasn't going to sleep very well that night. I went up to the ward then cried (Tessa 1: 34-39).

The intensity of the loss of an expected, planned birth experience could be eased by viewing it in a more positive light. Moos and Schaeffer (1987) refers to this as 'cognitive redefinition'; accepting the basic reality but restructuring it to find something favourable. The women were emphatic that an emergency caesarian section and subsequent treatment were life saving measures undertaken by the hospital team.

A 1988 study by Green, Coupland and Kitzinger (cited in Niven, 1992) found the psychological well-being of women after birth did not rely on the number or type of interventions during childbirth "... but rather to their belief that the 'right thing happened' " (p.134). For women in this study who experienced maternal critical illness there was no question that the 'right thing happened'.

You can't thank people enough for saving your life, how can you? And to them they're just doing their job (Ruth 1: 59).

I think, 'She shouldn't even be in this world', you know? She should still be safe in my tummy. But she wouldn't have been safe, she could not have lived (Barbara 1: 458-460).

...And the only way to stop it was to have the babies. I - we, thought I'd come back out. An hour later he's got two, well I suppose they were sick because they were premmies - two sick babies and a partner that could die. He told me yesterday he's glad I didn't die. That sort of statement you think 'Whoa!' (Gemma 1: 342-351).

You grieve for the trauma and what might have been but when something does go wrong - fifty years ago I most probably would have died and so would [baby] (Elspeth 1: 66-67).

A strong element in reconstructing events for many of the women in this study was luck. Even the most apparently unlucky events and situations could be viewed as serendipitous when seen in a fresh light.

Luckily I couldn't go to sleep, I couldn't have taken two panadol and it would've gone away. So it was just lucky that the pain was so extreme that I took notice of them (Barbara1:463-466).

It was just so lucky really, just on the off chance. [Husband] was going out and I said 'Hang on, I'll go with you but I'll just phone my doctor and see if I can schedule an extra visit' (Nancy 1: 1-5).

I'm lucky my body didn't get right to the fitting [seizure]. It's very scary because when it's started there's no cure, no stopping it. I'm just lucky it didn't progress that far (Elspeth 1: 67-68).

For all but one woman, who became critically ill five days postpartum, there was a gap of some hours before the women could see their babies. Most women had an emergency caesarian section under general anaesthetic. This prevented them from seeing the baby at birth. Although the babies in this study met the criterion of 'healthy baby' at the time each woman was invited to participate, they were often premature or distressed so were taken to a newborn nursery for close observation after the birth. Initially the women in this study did not express concern for their newborn infant.

I didn't worry about the baby, I was still feeling - I was too sick, too tired, I just wanted to sleep. I knew I had a daughter and I knew she'd be safe but I didn't care. I was getting myself better first (Becky 1: 76-82).

I was stuffed and I honestly don't even remember thinking - I mean, it's a horrible thing to say - 'What's happened to the baby?' (Barbara 1:190-191).

It has been suggested by Benner and Wrubel (1989) that "When an illness is extreme, it temporarily becomes the whole situation, and the other aspects of the person's life may fade into the background" (p.80). Knowing the baby was safe, well, and taken care of freed the women in the early hours of their illness to work on their own recovery.

In this study, lack of early contact did not decrease the women's affection for their babies when they were finally united. The women expressed no concerns about maternal-infant attachment. This finding supports Eyer's (1993) refutation of 'bonding theory' first popularised by Kennell and Klaus in the 1970's. Bonding theory stipulates that if a mother and her baby do not have

early contact after birth then bonding, a particular strong maternal attachment, will not occur.

It took a few days. Like, I didn't think she was mine but that didn't worry me. They said in antenatal class 'Don't worry if you don't feel bonded straight away, for some people it takes a few days.' So I thought it would because I didn't have her with me to bond with. When I felt better I could think of her. At first I didn't even worry about her so it was probably better she wasn't with me (Becky 1: 157-166).

I had no fear of bonding with him. It just didn't enter my head because I was just glad to be alive and glad to have this baby we planned (Ruth 1: 17-18).

I didn't have any of this bonding thing because I felt I'd known him all my life. I didn't feel I can't bond with him, that he's not mine. I knew him (Greta 1: 53-54).

For some women, knowing they had a baby waiting for them helped to stimulate their recovery.

I just felt if [baby] was doing well I could take the rest of it, as long as she's doing well I could handle it. If it was her or me I'd rather it was me (Nancy 1: 73-76).

At least I could smell him and feel him against my body and my face our pride and joy. Knowing that we had a baby at last, really gave me the spirit to fight (Ruth 1: 140-141).

It took two weeks for my blood pressure to settle, but I fought back to health so that I could be with my baby (Clarke, UKApec, No. 7, 1994).

Wanting and needing to mother the baby within the confines of their physical ability was important to the women to help reinforce their role as a mother.

Breastfeeding or expressing colostrum¹¹ was an important sign to the women that they could take on a vital mothering function which could be done by no one else.

It was amazing [looking down at her bust] oh there's something there, I could do something for her as well, not just the nurses (Nancy 1:118-120).

It was so good when they brought her down [to the unit], it was great! And expressing some colostrum for her - it was something I could do for her (Becky 1: 111-114).

However, one woman described feeling pushed beyond her physical ability to cope with her newborn which had a deleterious effect on her recovery.

I could barely walk and I could barely feed him a bottle and I usually had to give him to [husband] to wind because I'd be breaking out into a sweat, that's how weak I was. Um, then he was left in my room during the days and I had to cope with changing the nappies and I could barely get the safety pin through the nappy and things like that. And they'd say at night time 'Just ring the bell and we'll come in and feed him.' And I'd ring the bell and they wouldn't come and I'd have to end up shuffling down the ward to say, 'Hey, can you come and feed [baby] his bottle?' and they wouldn't have the bottle ready. So he'd be getting really stressed.

Which stresses you more

Yeah and I did. I felt probably worse on [the ward] than I did in [the unit] when I was ill (Ruth 1: 8-16).

Taylor (1983) in an article on cognitive adaptation to critical events avers that measures taken to promote readjustment functionally overlap That a measure undertaken to promote readjustment in one area may facilitate readjustment in other areas thereby serving several needs simultaneously. It may therefore be

¹¹ Colostrum: the first fluid from a woman's breast after childbirth

argued that 'taking in' assists in 'finding meaning' and the meaning given to the event may help to 'reduce the intensity' of the experience.

Summary

The stage of 'absorbing' is one of cognitive adaptation to critical illness and the unexpected trajectory of the childbearing experience. 'Absorbing' began slowly. Women in this study initially focused on 'taking in' concrete information and gradually sought to 'take in' more abstract information This assisted them to incorporate the event into their lives by 'finding meaning' and 'reducing intensity' of the illness experience. They positively recognitising the events by focusing on the outcome believing they were "lucky" to be alive.

The process of physical and psychological recovery continued after discharge from hospital. This process is discussed in the following chapter 'getting on'.

CHAPTER SEVEN: GETTING ON

Introduction

'Getting on' builds on the previous stage of 'absorbing'. Some situations can never be mastered or forgotten; they must be controlled, accepted or redefined to achieve an optimal quality of life. Women who experienced maternal critical illness never stated that they could close the door on the experience and put it behind them. However, they realised the need to get on with their lives.

I mean, it's happened. I can't dwell on it. Just move on (Tessa 2: 78).

Just get up and get over it. Otherwise you end up dwelling on it and that's not a good thing to do (Gemma 2: 57).

I don't dwell on it too much. This situation will never go away (Ruth 1: 212).

'Getting on' required a combination of physiological and psychological recovery and a new way of regarding childbirth with which they could live comfortably. This chapter discusses the process of 'getting on' under the headings 'recovery', 'facing misgivings', 'minimising risk', and 'reaching out'.

Recovery

Physical recovery is required after any birth experience as women recover from giving birth, and adjust to the demands of a new family. It has been suggested recovery from normal childbirth may take at least six months (Tulman & Fawcett, 1991).

One of the major complaints in the postpartum period following normal delivery is fatigue (Flagler, 1990; Ruchala & Halstead, 1994; Tulman & Fawcett,

1991). Hillan (1992) found almost twice the number of women who had caesarian section deliveries compared to vaginal deliveries, complained of fatigue which was compounded by insufficient physical care and lack of support. Gardner and Campbell (1991) suggest fatigue is related to a combination of many factors; psychosocial demands of adjusting to a new role, stress, fluid and hormonal shifts, lack of sleep, low haemoglobin levels, suboptimal maternal health, and wound healing. Impediments to full recovery are magnified for women who have experienced maternal critical illness. The road to wellness was long and not entirely smooth.

Some women in this study retained residual physiological problems secondary to their critical illness such as renal, and sight impairment, and ongoing hypertension. Three women required readmission to hospital because of a recurrence of illness. For these women the psychological set back was as great as the physical set back.

I thought, 'Finally home, I can work on recovery.' And then I go backwards, it was a huge set back (Kate 1: 112-113).

It wasn't the pain of the surgery, my body wasn't well. I knew it shouldn't have been an ongoing problem although they told me I'd feel worse before I felt better but they kept saying I'd get better really fast and I wasn't (Nancy 1: 60-65).

Even without a major physical set back recovery was slow.

I was feeling like I wasn't recovering. I was so tired and depressed. Just feeling sick and tired. All I wanted to do was stay in bed. I didn't really enjoy her, I was just too tired and I'd just feed her and pass her to someone to burp and change so I could go back to sleep... I couldn't enjoy her and I thought 'What a shame' because she's new born (Kate 1: 230-248).

Mum took me up to [shopping complex] for a coffee and we were hardly in there and I said 'Mum, I've got to get out.' It was overwhelming, all the noise, the crowd and that muzak that they play over the sound system. It was just too much (Jenny 1: 18 - 21).

And I was getting so tired. I went up to [supermarket] and tried to do some shopping. And I was so, after the first two aisles I said to [husband] 'I want to go.' I just couldn't handle the atmosphere. I just couldn't. I felt claustrophobic and really knackered and couldn't be bothered (Tessa 2: 594-601).

I didn't have any energy. Couldn't do - couldn't even brush my teeth and no one understood, it was a frightening exhaustion. I kept all my blinds shut after I got out of hospital, I wanted to be left. I needed that space to come to terms with what had happened.

How long did it take to really begin to recover?

It took six months. I used to hate the sunlight, I wanted quietness and dullness. I saw a lady on T.V. when her kiddie died and she said she wanted to wear a veil over her face and I could understand that. I thought, 'I'd have been into that' (Greta 1: 77-85).

The word convalesce comes from the Latin 'con' meaning together and 'valere' to be well. The women in this study expressed a strong association between social support and recovery. Many felt they would not have made such a full recovery without the aid of supportive partners, family, and friends working together with them to help them get well.

Social support has been defined as "...the emotional, instrumental and financial aid that is obtained from one's social network" (Berkman, 1984, p.415). Many studies report a positive correlation between social support and health or a buffering effect on stress (Cobb, 1976; Harlow & Cantor, 1995; House, Landis & Umberson, 1988). Weiss (1969, cited in Berkman, 1984) suggests social relationships have six major functions: to provide a climate where individuals can freely express their emotions; to provide a sense of

belonging; to nurture; to reassure; to provide tangible assistance; to provide guidance and advice. These functions were served for most of the women in this study.

Then my friend - that friend I told you about - she came up from [city]. It helped that she was a nurse, she works in neonates, she understands things and explained things. She drove me round. It was easier on [husband]... If she hadn't been there I'd have stayed [in hospital] (Nancy 2: 8-21).

At the moment I've got my sister and my mother. If I want to go somewhere they'll pick me up, take the car seat in the car. They were great for the first two or three weeks, working shifts. I got a nanny in as well... I mean it does make a huge difference having a very supportive husband... He comes home, baths [baby], cooks dinner... He's prepared to accept the fact that it's going to be hard the next few months and we'll muddle through it (Kate 1: 237-365).

Mum and dad did everything to get ready. [Husband's] mum and dad and their family did it all so when I came home the bassinet was there, and all her clothes, and everything was done. I just walked in to her room, opened her drawers, got out her clothes and put them on her.

You've got a close family.

Definitely. And living close. Like, mum lives close, and my sister-inlaw. She comes over and like she just takes over and she does things. Her and mum fluff around... I think oh yeah, O.K. that'll be great. Thanks mum. I think you just get too tired and you think 'Oh well, too bad. Either it doesn't get done or somebody else does it for you so just be grateful' (Barbara 2: 27-43).

Women with little social support from family or friends found there was little support offered by community services.

... there was no home help offered, there was nothing ever suggested, at all. I mean, we just came home and we were forgotten about, I guess (Ruth 1: 27-28).

I had a week at [small maternity hospital] and it just made all the difference. They knew my situation, they were expecting me and they pampered me like you wouldn't believe... they allowed me to keep [baby] in the nursery at night and looked after him so I could get my sleep and rest which is the most important thing. So I didn't have any worries, it was great. Used to bring my meals in on a tray.

So you were a very special pampered person.

Yeah. And I really think it was that week that um, got me on the mend (Ruth 1: 93-100).

I was just so tired, and [toddler] came home when I came home. I had the cleaning lady for four hours that week because that's all that they'd give me. My auntie cooked a couple of meals and brought them over.

Doesn't sound like a lot of help

No, it wasn't really a lot of help. My sister never came round. I just went back to bed and slept. And [toddler], I put videos on for [her] one after the other and made sure she had some lunch and breakfast and food to keep her going and keep herself occupied... (Tessa 2: 585-593).

The women in this study who were interviewed in a period longer than six months after their experience of maternal critical illness said it took at least six months to feel they had recovered. During and after recovery each woman faced the prospect of a future pregnancy with some misgivings.

Facing misgivings

Most women at some stage after a first pregnancy face the decision of whether or not to have another child. Women who have experienced critical illness because of pregnancy related complications must also make the decision. That decision is coloured by the very real possibility that a future pregnancy may jeopardise their life and the life of the fetus. The ramifications are potentially great. They must weigh up their desire for more children with the risk of

leaving motherless the dependent and loved child they already have or having to terminate a wanted pregnancy to save their own life.

Of the thirteen women interviewed for this present study, four stated they would not consider a subsequent pregnancy. One woman felt her age precluded another pregnancy. The two women who had limited social support during the convalescent phase after maternal critical illness also stated they would not consider another pregnancy. Should the illness reoccur in a subsequent pregnancy these women believed there would be no one to mind the child they had, no one to help support their husbands, and it would cause undue strain on the marriage.

Lately I've been toying. We could try again ... Then I think do I want to put myself through all that? Who'll look after [child] if I spend weeks in hospital? [Husband] doesn't need the stress, let's just forget it (Ruth 1: 199-203).

One woman believed her marriage had been jeopardised by the experience of maternal critical illness and was encouraging her husband to go to a counseling service with her.

Yeah, for the pair of us because our marriage isn't working out as well as it could be... but if we could see a counselor and he could change and be more open and realise what has happened to me - there has been so much (Tessa 2: 284-290).

However, "The decision to become a mother is more complex than the rational decision-making process can encompass" (Bergum, 1989, p.154).

After all we'd been through Mike and I felt thrilled and tremendously lucky to have James. But we were both adamant that we wouldn't risk any further pregnancies. However in time I gradually changed my mind and eventually managed to talk Mike into trying just once more (Webster, UKApec, 1996, No. 11, p.14).

I really want another child but I'm quite nervous. If I wasn't so nervous I'd be pregnant by now but lately it's really been on my mind, when I go to bed and when I wake up it's baby, baby, baby (Frances 1: 79-81).

Despite the nervousness expressed about becoming pregnant again, many women in this study found comfort in talking to other women about their childbearing experience. Talking to others and comparing experiences helped to form an acceptance of less ideal expectations of the pregnancy and birth experience.

It's quite good to compare, no one seems to have this normal pregnancy that's all hunky-dory (Becky 2: 364-365).

I think how lovely she is and how lucky we were, especially in comparison...comparing ourselves to someone we knew who had similar complications (Nancy 2: 217-221).

Out of all my friends and people I know only one has had a normal birth as the book says. Everyone else has had a dilemma of some nature (Elspeth 1: 49-50).

During her study of 78 women with breast cancer, Taylor (1983) noted virtually all women in the study thought they were doing as well or better than other women. Taylor suggests that making comparisons with others less fortunate is a self-enhancing comparison, boosts self-esteem and is a method of self-protection against threat. Taylor (1983) concludes, "The point, of course, is that everyone is better off than someone as long as one picks the right dimension" (p.1166). For one woman in this study, information sharing and comparison caused further alarm.

You hear all the dreadful things that have happened to people, none of them has a happy story about pregnancy. You get a distorted view perhaps, I know it's a minority but it's a large minority - it's everyone I know (Frances 1: 90-92).

Uncertainty of maternal health during a subsequent pregnancy is impossible to deny because causes are for the most part unknown, cannot be prevented and the outcome is unpredictable. Women in this study adopted a view of childbearing that corresponded to the medical model of childbearing; that childbearing is only normal and safe in retrospect. The crucial issue for the women in this study when considering a future pregnancy was the misgivings they faced surrounding their own health.

Two choices of action in an uncertain situation are mooted by Maslow (1962), the choice between safety or daring. Either choice may be wise depending on the particular person, their status and the situation in which they must choose. Safety avoids more pain than the person is able to bear at the moment. If basic safety needs are met the person may choose to be more daring. Women in the present study faced their misgivings by seeking to reduce uncertainty and increase safety when considering a future pregnancy.

Women who chose not to have a future pregnancy carefully considered effective methods of contraception. One woman consulted her doctor less than eight weeks after the birth to inquire about a tubal ligation¹².

He said, 'It's not the sort of thing you do on the spur of the moment'. And I said, 'Well, we have discussed it and we don't want any more children.' But he said, 'The girls are only young and if anything happens to them -' I said, 'We are not going to have any more children just because something happens to them' (Gemma 2: 176-180).

¹² Tubal ligation: Tying off the Fallopian tubes to effect a permanent means of contraception

Other women in the study sought to ensure their health needs would be met during a subsequent pregnancy.

I'd be closely monitored, they wouldn't let me get as sick again (Ruth 1: 200).

We paid to see an obstetrician to get it from the horse's mouth. This was a year later. You can start going forward with the information I have now, I know exactly what to do if I ever get pregnant again. Go to see that obstetrician, have a scan at eight weeks to see if the capillaries are embedding properly, a quarter of a disprin a day, I don't know if that's proven yet. You get watched very closely (Elspeth 1: 55-58).

It just means next time I'll be under a high risk category.

Are you thinking about a next time?

Well I wasn't. I mean, that was the last thing on my mind and, um, I was petrified of falling pregnant again, well I will be of course.

Mm

They'll be very supportive, I'll be under a specialist. Probably stick me on IV antibiotics straight away (Kate 1: 122-128).

I read anything I can get my hands on about preeclampsia. I joined Apec and I try to learn more (Frances 1: 26-27).

The problem is, when I get pregnant I won't be able to just go to my GP, I'll have to come to the hospital for my checkups and with the hospital system it means I can't choose the time and there's always the waiting so I'll have to take more time off work so I need to work all I can now ... It's no longer pregnancy is a natural thing, when you're pregnant you're sick as far as I'm concerned. I'll be sick. Not sick but I'll take extra care of myself, it won't be like before ... but the doctors are optimistic, it might happen again but they'll keep a closer eye on me, on my blood pressure (Frances 1: 83-94).

Ideally I'd like to have another one [baby] and when I went back to [the doctors] they were actually a lot more positive about your body, that it would never let you get to that critical stage again because it knows what it's been through and it would sort of block off, um. So they gave me a better chance of having a normal pregnancy and I'd be under a specialist and watched and everything like that. There's always a risk (Barbara 2: 391-395).

There are two predominant models of professional care in childbearing in New Zealand, the midwifery model and the medical model. The midwifery model anticipates childbearing to be normal and asks women to trust their bodies to a natural process. The medical model aims to prevent complications believing pregnancy to be normal only in retrospect. While unquestioning acceptance of the medical model is gradually being challenged, following maternal critical illness the participants in this study made a clear deliberate choice to seek care under the medical model of childbearing. Bursztajn, Feinbloom, Hamm and Brodsky (1990) refer to this as a 'paradigm shift' which follows a crisis of confidence.

Benner and Wrubel (1989) believe it is not uncommon after medical treatment to think of the body as a faulty, vulnerable machine and object. Mead (1934) suggests individuals become objects to themselves or enter their own experience as an object "... only by social means - only by taking the attitudes of others toward himself [sic] - is he able to become an object to himself" (p.226). In this way the effect of a model of healthcare may be seen. There is consonance between the model of care offered by medicine and the type of care sought by women in this study in a pregnancy subsequent to maternal critical illness.

The women in this study realised they could not categorically avoid illness in a subsequent pregnancy. An event which generates uncertainty is considered to be highly stressful (Folkman & Lazarus, 1991; Mast, 1995; Mishel, Padilla,

Grant & Sorenson, 1991). However, uncertainty was decreased by gaining a feeling of control over the potential health consequences of a subsequent pregnancy. This was accomplished by building on their knowledge of the pregnancy disorder, and by forming certain expectations and assurances of specialist medical care.

In health, mastery may be defined as "... an effortless ability to complete tasks without consideration..." (Johnson, 1991, p.83). In illness mastery is "... the ability to behave in a way that can mitigate the aversiveness of an event" (Mishel & Sorenson, 1991, p.167). The women in this study considered a future pregnancy as they would an illness and sought to minimise risk.

Minimising risk

Women mentally prepare for a future pregnancy following maternal critical illness by acknowledging the risks and planning to accommodate them by early detection and control mechanisms. For pregnancy following a critical illness, the maternal task of seeking safe passage (Rubin, 1984) does not appear to apply. To seek safe passage may assume the belief that a safe passage is to be found. Women in the present study preparing for pregnancy following maternal critical illness, hoped for safe passage but were knowledgeable about the perilous course they charted.

Patterson, Freese and Goldenberg's (1990) grounded theory study on how women utilise health care during pregnancy found a similar response. Family and personal medical history, and personal experience shaped the focus and level of affect in seeking safe passage during pregnancy. Women did not necessarily choose the most convenient health professional in pregnancy. The study found women were prepared to travel further, pay extra or bear the inconvenience of public clinics to receive better pregnancy care as judged by their individual criteria.

To put oneself in a situation which has been emotionally upsetting or traumatic raises old feelings and fears. Memories and feelings associated with any traumatic experience may resurface for a long time afterward (Smith, 1986). This has been found in studies on childbirth following incest (Rhodes & Hutchinson, 1994) and revisiting the scene of rape (Frazier & Schauben, 1994). A pregnancy subsequent to maternal critical illness caused unpleasant memories to resurface.

Just talking about it has made it all come back (Elspeth 1: 69).

I was absolutely terrified when I got pregnant [again]. The upset - it all came back and I thought 'I can't face being sick again' (Greta 1: 26-28).

Of the four women who experienced childbearing after maternal critical illness, two had unplanned pregnancies and, committed to the pregnancy, elected to continue it. For two of the women the subsequent pregnancy was planned. To live comfortably through a following pregnancy women put measures in place to enable them to cope.

Women who had been critically ill in their previous pregnancy ensured first that risks were minimised or able to be controlled. This was done by gaining knowledge through literature, by fostering a working, trusting relationship with medical personnel; questioning the physician on statistical probabilities of the problem recurring. They also ensured vigilant health monitoring would be available throughout the pregnancy and also discussed fears with health workers and supportive others. This process expands 'taking in' during the previous stage of 'absorbing'. Trust in the potential health care provider was predominant requirement.

Honesty from the primary health caregiver helped build trust. Women in this study accepted that although the possibility of risk remained, should complications reoccur, the women would be treated with regard to her wishes and in her own best interest.

One doctor towards the end was very blunt with me and I was very pleased. He said to me 'You're not going to have a birth how you want it. It's not going to be how you think. They're not going to take any risks with you.' I wish I'd known a bit earlier (Greta 1: 18-21).

If honesty and joint consultation was lacking, trust was diminished and stress rose.

My consultant was wonderful and reassured me that I would not be allowed to go past 38 weeks ... However, I was dismayed to discover once I passed 32 weeks his attitude changed ...he wanted to push my pregnancy as far as it would go. Suffice to say, I became quite twitchy. I felt like a guinea pig in some mad experiment (Clarke, UKApec, No. 7, 1994).

Folkman and Lazarus (1991) refer to these forms of coping as emotion-focused and problem-focused coping. Emotion-focused coping directs attention to the problem in an effort to control it, such as gaining information on the topic. Emotion-focused coping also includes wishful thinking and maintaining hope (Mishel, Padilla, Grant & Sorenson, 1991). Problem-focused coping describes taking direct action on the environment to bring about a desired outcome. Although arguably one may wish to control one's health during pregnancy and remain completely well, Thompson et al (1993) assert that it is more important to believe one can control and influence some consequences of the event both emotional and symptomatic.

An internal locus of control and commitment accomplish reciprocal roles. (Florian, Mikulincer and Taubman, 1995; Kobasa, 1979). Commitment allows

people to remain in the situation. In this study commitment to the pregnancy appeared to enable the women to remain in the pregnancy despite the probable risk to their health. The search for control leads people to engage in problem-solving actions including finding outside sources of support.

Walker, MacBride and Vachon (1977, cited in Berkman, 1984) suggest social networks may function to provide access to new contacts and diverse information in certain circumstances. Accessing new contacts and diverse information was emphasised for the women in this study when they contemplated and carried another pregnancy. Harlow and Cantor (1995) found "...outcome-focused individuals sought the company of others who... could provide emotional support [and]... increased time spent with others who could best provide them with information about how to attain the ideals toward which they strive" (p.337). The ideal in a pregnancy following maternal critical illness was, for the women in this study, their own continuing good health which would lead to the birth of a healthy baby.

This time I took low-dose aspirin and was closely monitored throughout... Because I started to get uptight around Christmas time, when it had all gone wrong the previous year, they admitted me to hospital as a precaution (Webster, UKApec, 1996, No.11, p.13).

My second pregnancy was difficult for me emotionally, but I had read and continued to hunt out any information I could lay my hands on about pre-eclampsia. I had consultant care and additional antenatal checks and was prepared to be put on low-dose aspirin... The pregnancy reached its 37th week and I was extremely stressed out. I was fearful my placenta would pack up or that I would fall victim to another fit and die... I felt the situation was slipping out of my control and begged to be induced but was firmly told 'no'. I knew I had only one choice left and I decided to use it - I insisted on an elective caesarian section (Clarke, UKApec, 1994, No 7, p.15).

The consultant put me on low-dose aspirin from 12 weeks and my GP was wonderful, seeing me every week... Weeks 20 to 30 were full of anxiety. I felt like a timebomb waiting to go off. During this period the APEC Helpline operators were wonderful and reassuring (Turner, UKApec, 1995, No10, p.13).

However, all women considering or experiencing a subsequent pregnancy after maternal critical illness approached it with less serenity than they approached their first.

The thing on my mind when I got pregnant was that my sister was almost due with her first baby then. And she used to say 'I'm not sick, I'm pregnant. This is a natural thing, not a sickness.' So that was my mindset when I got pregnant ... It's no longer pregnancy is a natural thing. When you're pregnant you're sick as far as I'm concerned (Frances 1: 1-37).

You can never be blasé again. You're aware of all the other things that can happen (Elspeth 1: 69-70).

According to Benner and Wrubel (1989), after illness the individual involved "... may cease to perceive the body as a reliable dwelling place and set of capacities and come to see it as an alien source of disease and danger" (p.293). The perception of the body as an unreliable dwelling place, it may be argued, has great significance for the woman who relies on her own physical ability to nurture her unborn and newborn child.

Reaching out

It is said that life after crisis will never be the same (Benner & Wrubel, 1989; Norris, 1990). The effects of illness are not all negative. Mast (1995) suggests illness may result in "... increased tolerance and appreciation for others, greater self-acceptance, and increased optimism and joy in life" (p.19).

The women in the present study stated that they had a renewed appreciation of life and would never take life for granted again. One woman confided that she "kicked herself" if she realised she was forgetting how precious life is. A number of the women described how they felt compelled to reach out and help others who were facing an experience similar to one they had been through. Four women in this study had accepted invitations to speak to medical, nursing or midwifery students about their experience to express 'the patient's' view of maternal critical illness.

Moos and Schaeffer (1987) believe "One effective way to come to terms with an unalterable situation is to assist other individuals to negotiate a similar crisis or transition. In this way, individuals who have experienced an event leave a legacy of knowledge and bolster their self-esteem" (p17).

I knew I had to do something to help others who have also suffered that's why I got [support group] up and running (Ruth 1: 105).

I gave my name to Plunket, I can go around and talk to people who have been through it (Elspeth1: 35).

Throughout the pregnancy I held onto... the thought that soon our story would be giving hope to other parents... (Turner, UKApec, No. 10, 1995, p.13).

The message we would like to pass on to other couples embarking on a second pregnancy is this: be assertive, learn everything you can about the disease and never let doctors treat you as guinea pigs for their theories (Clarke, UKApec, No.7, 1994, p.15).

Campbell (1986) in a study on the experience of mastectomy discovered that the postmastectomy woman "... reaches out for a new and broader context, where her experience will be of use. She becomes aware of herself as a model

for others, who see her as a strong survivor, a teacher/advisor, a provider of encouragement, inspiration and hope" (p.93). For the women in the present study this was also a continuation of 'finding meaning'; being able to reach out and assist others helped to create a personal meaning and expand purposefulness in their lives.

The women in this study felt they had a vested interest in participating in research; this gave an altruistic meaning to the event. Many women who participated in this study stated one reason as the "wish to help others". While valuing social research some women also felt they played a role in finding a cause and cure.

That's why I'm doing the selenium testing and all that. I just do everything we can to help find a reason why (Barbara 1: 368-370).

That's what I'd like to see in New Zealand, more medical research. I'm taking part in the study [researcher] is doing at [hospital] (Ruth 1: 189-190).

Summary

The stage 'getting on' is the last of the data chapters. In order to get on with life following maternal critical illness, women had to recover physically and psychologically and adapt to residual physiological problems and an altered way of thinking about childbirth. 'Getting on' was enhanced by good social support and if a subsequent pregnancy was considered, by minimising risk and maximising safety which helped reduce uncertainty.

Glaser (1978) recognises that codes are inter-related and codes pertaining to each stage may relate to one or more stages further on in the process. When the choice was made to become pregnant or pregnancy was discovered, there was a resurgence of knowledge-seeking about the type of illness which built on

'taking in' (Chapter Six). 'Reaching out' (Chapter Seven) expanded on 'finding meaning' (Chapter Six). From searching to find meaning in the experience in the biographical history of their own lives, some of the women in this study enlarged meaning of the experience by reaching out to help others. The following chapter discusses the basic social process and presents a conceptual model which emerged from this study.

Table 1. Code levels of the basic social process 'Living a divergent experience of childbearing'

Level one codes	Level two codes	Basic social process	
Is something wrong?	Identifying a problem	LIVING A DIVERGENT	
Something is wrong		EXPERIENCE OF	
Seeking help		CHILDBEARING	
Holding on	Being overwhelmed		
Letting go			
Shutting off			
Taking in	Absorbing		
Finding meaning			
Reducing intensity			
Recovery	Getting on		
Facing misgivings			
Minimising risk			
Reaching out			

CHAPTER EIGHT: THE PROCESS OF LIVING A DIVERGENT EXPERIENCE OF CHILDBEARING

Introduction

Most women have a notion of what their childbearing experience will be like. The notion may not be fully formed and it may not encompass the ideal. It is based on personal knowledge, learned knowledge and socialised expectations. When the biographical reality and sociocultural norms diverge, as they do in the event of maternal critical illness, there is a rupture in the taken-for-granted view of life. When nothing was as it had seemed and the future was uncertain, the women in this study found their experience of childbearing diverged from the perception they previously held and those perceptions that were socially constructed.

Chapters Four to Seven presented the conceptual categories which emerged from the data on the maternal experience of critical illness. In this chapter the basic social process is presented and a concluding statement is made.

Expectations of childbearing

Social interactionism, on which grounded theory method is founded, is based on the premise that meaning dictates human behaviour, arises out of social interaction and is modified through a process of interpretation. Symbolic interactionism takes place within a framework of past experiences, future consequences and environmental situations (Mead, 1934). Cohen (1993) asserts "We are born into a sociocultural reality - a prestructured set of shared beliefs, values and customs that characterize a distinct world view" (p.79).

With each passing decade maternal risks in childbearing in New Zealand decline (see Chapter One). The medical model goal of a healthy mother and baby tends to be already assumed by many women entering the childbearing experience. Therefore, the personal and social expectation of childbearing is increasingly that of a 'well woman' experience.

Prior to the experience of maternal critical illness, the women in this study had formed and recounted the expectations they held for their childbearing experience (Chapter Six). Although not fixed, these expectations were formed by sociocultural norms, and knowledge garnered from literature, other people, and past experience. For all but one woman who, because of her age and medical history, thought her childbearing experience might not be completely "straightforward" the women in this study thought of themselves as healthy during childbearing and expected to remain so. Each had some expectation of a 'normal' childbirth, of shared information and decision making, and of control. They expected to be able to manage self-care and look after the baby postpartum. The actual experience of childbearing for these women diverged markedly from their expectations.

The divergent experience

Childbearing for the women in this study was characterised by the loss of an expected 'normal' and healthy childbearing experience. The experience began to diverge with 'identifying a problem' (Chapter Four) and escalated as illness took over.

The women experienced loss of control; people were "rushing" it was like a "whirlwind". Decisions regarding their health care were made by the medical team, and information was not shared as the women had little knowledge about what was happening to them and what to expect. The women in this study found they were 'being overwhelmed' by both the urgency of medical

treatment and the relentless disease process (Chapter Five). Nearly all the women in this study had the most interventionist of deliveries, a caesarian section. All the women in this study experienced maximal technological intervention for their own health care. The women's main concern was for their own survival.

Over the weeks following the critical illness the women in this study began 'absorbing' what had happened to them (Chapter Six). They incorporated the events into the narrative of their own lives and slowly regained the ability to take care of themselves and of their babies.

Following recovery from the critical illness the women in this study were 'getting on' with their lives (Chapter Seven). However, their lives had been changed by their experience of childbearing and expectations for future childbearing never matched previously held expectations. Benner and Wrubel (1989) suggest that "... there is no way to step outside one's own history. The person both constitutes and is constituted by his or her experience" (p.61). Although physically recovered the women in this study continued to 'live' their experience of childbearing.

Living

'Living' involves such concepts as sustaining oneself, surviving, pulling through, and continuing on. 'Living' pervades each of the four conceptual categories introduced in this study. The process of 'living' a divergent experience changed over time and applied equally to the women's psychological and physiological state.

In this study the women's health was threatened before symptoms became apparent. As the illness and the experience began to overwhelm them they sustained themselves, 'holding on' (Chapter Five, p. 58) until finally they shut

off and survived with artificial life support. The aspect of survival was paramount when considering a subsequent pregnancy; they could never be "blasé" about health in childbearing again (Chapter Seven).

When the illness was past, the experience of illness associated with childbearing lived on. Although 'getting on' with life (Chapter Seven) the illness experience continued to inform the women's perception of childbearing both for themselves and for other women who entered the childbearing experience.

Living a divergent experience of childbearing

'Living a divergent experience of childbearing' is the basic social process which emerged from this study on the maternal experience of critical illness. The concepts, 'living' and 'divergent experience' are present at each stage of the childbearing experience for the women in this study.

'Living a divergent experience of childbearing' meets the requirements of a basic social process. It is a core category which emerged from and is central to the four stages in this study: 'identifying a problem', 'being overwhelmed', 'absorbing' and 'getting on'. 'Living a divergent experience of childbearing' is a process which occurs and changes over time yet is a complete process within itself.

Basic social processes must also be fully variable to other social units (Glaser, 1978). Analysis of the data revealed that the experience of maternal critical illness follows a pattern similar to general illness experiences. In all four stages of this study the illness experience followed an illness process described in nursing and sociological literature. This can be related to a general model of illness (Morse & Johnson, 1991) or specific experiences such as a heart attack (Cowie, 1976; Johnson, 1991). Principles that relate to uncertainty (Mishel, 1988; Mishel, 1995), crisis (Caplan, 1961; Moos & Schaefer, 1987), stress

(Folkman & Lazarus, 1991), and social support (Cobb, 1976; Harlow & Cantor, 1995) were found to be relevant to the childbearing experience of the women in this study.

Summary

It has been proposed in this study that the basic social process 'Living a divergent experience of childbearing'-pervades all stages of a woman's childbearing experience and informs her continuing perception of childbearing. 'Living a divergent experience of childbearing' is able to be related to other theories such as crisis theory, stress and coping theory, uncertainty theory, and theory of social support.

The following chapter addresses standards of rigor in a qualitative study and the limitations and implications of this study on midwifery education, and midwifery practice. Suggestions for further research are made.

CHAPTER NINE: STANDARDS OF RIGOR, IMPLICATIONS AND LIMITATIONS

Introduction

This chapter discusses the standards of rigor for evaluating a qualitative study as suggested by Guba and Lincoln (1981). A number of implications for midwifery education and practice arose from the findings of this study and are addressed. Limitations of the study are discussed and suggestions for further research are considered. A concluding statement about this study is made.

Standards of rigor

Guidelines for establishing trustworthiness of results in qualitative research have been explored by several authors; most make reference to the work of Guba and Lincoln. I have therefore used Guba and Lincoln's (1981) criteria of credibility, fittingness, auditability and confirmability for evaluating rigor in this study.

Credibility

Credibility, according to Guba and Lincoln (1981), may be determined when participants, a population equivalent to the sample, and others within the discipline being studied recognise the experience as their own. During the year I gave midwifery care to a population of high-risk women who were not participants in this present study. Findings were able to be confirmed during therapeutic conversation. When appropriate, for example, the statement "Some women say it takes weeks before they can take it all in and the better they get physically the more they are able to" was met with "Yes, I'm finding that". I was also able to discuss the study at two midwifery research seminars. The

response I received from midwives attending the seminars confirmed credibility related to their practice experience.

Guba and Lincoln (1981) believe "No one can reasonably expect a *full* corroboration.... [But] data and interpretations will be at least minimally credible to the audiences that are in a position to judge them" (original emphasis), (p.112-113). Participants in this study will have a further opportunity to judge the credibility of the findings when they receive the summary of findings at the conclusion of this study.

Fittingness

This refers to the ability to transfer the findings from one study to another context or situation. Guba and Lincoln (1989) suggest the ability to do this is dependent on the degree of similarity between the two contexts and can be assessed by the inclusion of 'thick description' which involves a full description of the context in which the study took place. Throughout this study I have provided thick rich slices of data from this present study. I have also referred to academic and literary works on illness, crisis, and childbearing to demonstrate the transferability of the findings.

Auditability

Lincoln and Guba (1981) believe auditability of the data is the criterion for judging consistency of a qualitative study. A qualitative study can never be replicated by an independent researcher, however it can pass the criterion for consistency when an independent evaluator is able to say "Yes, given that perspective and those data, I would probably have reached the same conclusion" (Guba & Lincoln, 1981, p.124).

My supervisor and co-supervisor carefully followed the process as I analysed the data, challenging my thoughts and biases. Throughout this study I have clearly stated my decision trail that the reader may follow my analysis and understand how the conclusions were reached. Thick, rich slices of verbatim data have been included that the reader may have access to the data to follow my discussion.

Confirmability

Although no researcher can be completely objective, the data itself must be factual and confirmable. In this way it "... shifts the burden of proof from the investigator to the information itself" (Guba & Lincoln, 1981, p.126).

As the researcher I have stated my [known] biases before beginning; my type of work, professional qualifications and professional interest in the topic under study. To audit this study my supervisor requested at random, tapes and associated transcripts to confirm their accuracy. The findings have been confirmed by a population similar to that in the study and findings from other academic studies have been demonstrated to 'fit'.

Implications for midwifery education

Since 1962 midwifery education objectives have included a focus on the normality of childbirth (Hill, 1982). With the 1992 reintroduction of direct entry midwifery in New Zealand, midwives do not necessarily have a nursing background or qualification. Specialist skills and knowledge are needed to enable midwives to care for critically ill women during the childbearing experience. If these skills are lacking, the care of women who do not fit the scope of midwifery practice may be left in the hands of specialist nurses. While appropriate postgraduate education enables nurses to acquire the skills and knowledge to care for critically ill women, nurses do not have midwifery

knowledge and skills to enhance the childbearing experience for the woman and her family. The possibility of a postgraduate education course for midwives to acquire skills and knowledge to care for critically ill women while retaining a midwifery focus could be investigated by midwife educators or by a hospital inservice education co-ordinator.

Implications for midwifery practice

Women in this study mistook the early symptoms of critical illness for the normal discomforts of pregnancy or some other benign condition. There is a need to educate women early in their pregnancy about symptoms which indicate they should see a health professional without delay. However, there may be a fine line between scare mongering and informing. Clear verbal or written permission to contact the midwife, doctor or hospital may overcome initial hesitation to seek advice about ambiguous symptoms.

The need for knowledge grows, changes and is manifest in many ways. The importance of having a family member present and fully appraised of the situation at all times cannot be over estimated. It is the family member, usually the woman's partner, who is the prime source of information during the stage of 'absorbing', a stage which continues long after discharge. Midwives can also assist by visiting on the postnatal ward and talking to the woman about what happened. In the early stages of recovery, care should be taken not to overwhelm the woman with information. Allowing the woman to lead the questioning about her illness will ensure she receives only as much as she is able to take in at the time.

One method by which the women can control the amount of information they receive is by being provided with printed information given to them early in the recovery period before discharge home. Clear information sheets on the disorder available for the women to keep will enable them to take in more at

each reading. Women in this study who belonged to NZApec spoke highly of the information leaflets they were given by this group.

During the 'absorbing' stage the women in this study were ill and weak. The expectation of some midwives that the women fully care for their newborn baby at this time pushed the women beyond their physical ability to manage. The illness experience was reinforced and heightened. This came at a time when the women were employing cognitive avoidance mechanisms by concentrating on their motherhood role within the confines of their physical ability. Midwifery care reinforces the motherhood role. The results of this study indicate that it is necessary for midwifery staff in the postnatal period to give as much practical support as possible. This allows the mother to simply enjoy her baby without taxing her physical reserves. If possible, family members should be encouraged to live-in to assist.

The loss of a longed for birth experience is permanent. Women need to understand what happened and why. Results of this study suggest that it is important to help the women to understand and accept that events leading up to the illness were beyond their control. Internalising attributions of success such as timely seeking of help, and the coming in of breast milk may be beneficial. By creating every opportunity to breastfeed and assisting the woman to breastfeed, if this is the desired method of feeding, midwives might promote women's positive feelings about motherhood and enhance their feelings of competence and control.

Convalescence is a slow and lengthy process. Women who have experienced critical illness during childbearing report that recovery stretches a long way beyond the immediate postnatal period. Social support appears to have significant impact on the perceived quality of convalescence. Some women have little or no social support. Policy makers and social services must be aware

that following maternal critical illness women have special needs. They require follow-up clinic visits, trips to a laboratory for ongoing screening, simultaneously attempting to care for a new baby, a family, and recuperate from critical illness. Midwives are well placed to ascertain the levels of support available at home for women following maternal critical illness and can make initial contact with the appropriate social services. Midwives must bear in mind that family members are not always a source of social support. Tessa's husband coped with the issue of her illness by avoidance and her sister "... never came round." (Tessa 2: 585).

Women who have experienced critical illness in pregnancy or postpartum have special needs in a subsequent pregnancy. Health professionals need to understand women's fears and anxiety when contemplating and carrying the next pregnancy. They need to be prepared to offer pre-pregnancy counseling, to monitor the woman closely throughout the pregnancy and to keep her fully informed. By catering to an increased need for information health professionals enable the woman to maintain vigilance.

Few may disagree that in a health crisis such as a postpartum haemorrhage or pulmonary embolus, life saving measures take primacy. It must be remembered by all involved that before, during and after the critical illness the central figure is a woman becoming a mother with all that means to her. Although technology at such times is needed, care of the woman cannot be reduced to just that. Midwifery care is intimate and guided by the individual woman's own unique history, knowledge, expectations and skills.

In the stage of 'being overwhelmed', even if the woman has 'shut off', a midwifery history will indicate the woman's hopes for her childbearing experience and method of infant feeding she wishes to adopt. Midwifery care can facilitate the woman's wishes. During maternal critical illness the baby can

be put to the breast, colostrum can be expressed. Midwives, attuned to the normal, can observe the normal physiological postpartum process, can assess if this deviates, and take appropriate measures to maintain and enhance the normal.

Pregnancy subsequent to maternal critical illness places a woman outside the scope of midwifery only care. However, midwifery care has a valid place in the care of such women. Data from this study suggests women 'living a divergent experience of childbearing' maximise safety in two ways. They pursue scientific knowledge support from medicine and literature, they also solicit social support.

While doctors may only see the women at booked appointment times, continuity of midwifery care enables the midwife to truly be 'with woman'. As Frances said, "... it might happen again but they'll [the doctors] keep a closer eye on me, on my blood pressure" (Frances 1: 94). While the doctor tends to the illness the midwife is there for the woman. Midwifery skills enable a midwife to care about the potential health problems while caring for the woman. The midwife is there to listen, to reassure, and to validate the woman's experience and remind her of her own skills and expertise. Midwives are the guardians of normal childbearing and midwifery care enhances the normal aspects of the childbearing experience.

Limitations of the study

As this study is at Master's level, by far the greatest limitation was the lack of time. In a grounded theory study the researcher must wait for the core category to emerge from the data. In this study the core category 'Living a divergent experience of childbearing' emerged very late in the process. Time constraints precluded a deeper analysis of secondary sources which may have given this study more depth and broader application.

Due to time constraints this study only examined the women's experience of critical illness. The women's partners and other family members go through the experience too. Many women stated they could not have coped without a supportive partner and they believed their partners had the worst of it.

The sample size of sixteen participants was small; women who experience maternal critical illness are not a homogenous group. This study is located in New Zealand and all women in this study spoke English as their first language. There is strong indication that methods utilised by the women in this study in 'living a divergent experience of childbearing' are culturally based (Wright & Phillips, 1980). Without further research the results of this study cannot be said to be generalisable to other countries and cultures.

Recommendations for future research

This study looked at the experience of maternal critical illness when the baby was healthy. Many women who become critically ill during pregnancy either have the pregnancy terminated to save the mother's life or have babies which have a very fragile hold on life because of prematurity or secondary to the maternal illness. A study on the experiences of these women may be beneficial to health care providers as not every experience of maternal critical illness ends with a healthy outcome for both mother and baby. The needs and forms of support women with a different outcome in maternal critical illness may differ.

The topic of maternal critical illness is broad. This study focused on one aspect - albeit a most significant one, the maternal experience. The use of different methodologies and different populations such as the family, the professional health care provider, in a situation where the baby is also at risk, and the experience in different countries would add to the body of knowledge on this topic.

Grounded theory study is not the only possible approach to this topic. Data collection with different tools such as the 1988 Mishel 32-item Uncertainty in Illness Scale (MUIS) during the acute phase of illness, the 1990 Mishel Uncertainty in Chronic Illness Scale, or the 67-item Ways of Coping Questionnaire (Folkman & Lazarus, 1991) would help verify the findings and giver broader application to them.

Maternal critical illness is not the only divergent experience women may encounter in childbearing. Situations such as the premature birth of a baby or an acute caesarian section also diverge from the 'normal' childbearing experience. Application of the basic social process 'Living a divergent experience of childbearing' to these situations is required to test the validity of, and further develop the process.

CONCLUDING STATEMENT

In this study a grounded theory approach has been used to explore women's experiences of critical illness during childbearing. Four conceptual categories emerged from the study: 'identifying a problem', 'being overwhelmed', 'absorbing', and 'getting on'. These categories followed the process of the experience of maternal critical illness from identifying a possible health problem in childbearing to considering a pregnancy subsequent to maternal critical illness. The core category 'Living a divergent experience of childbearing' which emerged from this study meets the requirements of a basic social process.

Findings of this study suggest that expectations of childbearing are socially, culturally and personally constructed. Maternal critical illness in childbearing diverges from the personally held and sociocultural expectations of

childbearing. This experience continues to inform expectations of childbearing for the women who have survived maternal critical illness. The contribution of midwifery care for women who become critically ill during their childbearing experience and for women who have a pregnancy subsequent to a maternal critical illness has been explored.

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APPENDICES



ALBANY

FACULTY OF SOCIAL SCIENCES DEPARTMENT OF NURSING AND MIDWIFERY

APPENDIX A

Researcher: Elizabeth Reid ph [...]
Supervisor: Dr Cheryl Benn ph [...]
Co-Supervisor: Denise Dignam ph [...]

The maternal perception of critical illness during pregnancy and postpartum in women whose first language is English

Information Sheet

My name is Elizabeth Reid. I am a Registered Nurse and Midwife currently doing my Masters Degree at Massey University. The topic of my Masters thesis is 'The maternal perception of critical illness during pregnancy and postpartum in women whose first language is English'. This research is in no way connected to the hospital, it is undertaken soley through Massey University.

I have asked the staff to make available this information sheet to women who meet the criteria for this study. As you were in [...] unit after the birth of your baby I invite you to participate in this study.

Your participation at a mutually agreed venue would mean that at a time convenient to you within the next two days I will interview you. I will interview you a second time around six weeks after the birth of your baby. Each interview could take from 30 minutes to 2 hours. You will have the opportunity to discuss what being ill after the birth of your baby was like for you. With your permission these interviews will be tape recorded.

The audiotapes will be transcribed by myself; transcripts and tapes will be stored in a secure place. Apart from myself the only other people who may hear the tapes are my thesis supervisors Dr Cheryl Benn and Denise Dignam from Massey University. You may read and comment on the transcript of your own tape should you wish to.

Your identity will be kept confidential, your name will not be used and no staff member at [the hospital] will have access to the information you give me.

At the end of the study a summary of the study results will be sent to you along with the audiotapes of your conversation should you wish them. In the long-term your participation may help to improve care given to women who are ill after the birth of their babies.

If you have any queries or concerns regarding your rights as a participant in this research you may contact the Health Advocates Trust, phone [...].

You have the right to decline to take part or withdraw from this study at any time, you have the right to refuse to answer any questions,. You have the right to request the audiotape turned off at any time.

Please take time to discuss this with whoever you wish. If you have any queries I am pleased to answer them at your convenience. Please feel free to contact me about this study at any time on the above telephone number.

If you would like more information with a view to participating in this project please complete the reply form, fold and place it in the secure box marked 'Liz Reid'

APPENDIX B

· · · · · · · · · · · · · · · · · · ·
NAME:
WARD:
I wish to be contacted with a view to taking part in the study 'The maternal
perception of critical illness during pregnancy and postpartum'
Please place this form in the marked box outside the ward office



ALBANY

FACULTY OF SOCIAL SCIENCES DEPARTMENT OF NURSING AND MIDWIFERY

APPENDIX C

The maternal perception of critical illness during pregnancy and postpartum in women whose first language is English

Consent Form

articipant:		

Investigator: Flizabeth Reid

I have heard and understood an explanation of the research project I have been invited to take part in. I have been given and I have read a written explanation of what is asked of me. I have had an opportunity to ask questions and have had them answered to my satisfaction, and I understand that I may ask further questions at any time.

I understand that I may withdraw from the study at any time and to decline to answer any particular questions.

I agree to provide information to the researcher on the understanding that my name will not be used without my permission. The information will be used only for this research and for publications arising from this research project.

I agree/do not agree to the interview being audiotaped.

I also understand that I have the right to request the audiotape to be turned off at any time during the interview.

I consent to take part Information Sheet.	in this research und	der the condition	s set out in the
Signed:			_ Participant
In my opinion consent was	given freely and with unde	erstanding	
signature	_ witness name _		witness
			date
Consent obtained by signature		name	

APPENDIX D

ADVERTISEMENT

I am seeking women who were in an Intensive care Unit or a High Dependency Unit around the time of the birth of their baby who would be interested in participating in a study I am undertaking for my Masters thesis through Massey University.

My name is Elizabeth Reid, I am a Registered Nurse and Midwife, the topic of my Masters thesis is 'The maternal perception of critical illness during pregnancy and postpartum in women whose first language is English'.

If you might be interested in participating please phone [...] or write to [...] for a full information sheet.



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APPENDIX E

Researcher: Elizabeth Reid ph [...] Supervisor: Dr Cheryl Benn ph [...] Co-Supervisor: Denise Dignam ph [...]

The maternal perception of critical illness during pregnancy and postpartum in women whose first language is English

Information Sheet

My name is Elizabeth Reid. I am a Registered Nurse and Midwife currently doing my Masters Degree at Massey University. The topic of my Masters thesis is 'The maternal perception of critical illness during pregnancy and postpartum in women whose first language is English'. This research is undertaken soley through Massey University.

As the result of an advertisement in the NZApec Newsletter you have requested further information about the study. After reading this information sheet I invite you to participate in this study.

Your participation at a mutually agreed venue would mean that at a time convenient to you before the 31st of November I will interview you. The interview could take from 30 minutes to 2 hours. You will have the opportunity to discuss what recovering from illness after the birth of your baby was like for you. With your permission these interviews will be tape recorded. A follow-up interview to clarify points you have made may be required.

The audiotapes will be transcribed by myself; transcripts and tapes will be stored in a secure place. Apart from myself the only other people who may

hear the tapes are my thesis supervisors Dr Cheryl Benn and Denise Dignam from Massey University. Your identity will be kept confidential and your name will not be used. You may read and comment on the transcript of your own tape should you wish to.

At the end of the study a summary of the study results will be sent to you along with the audiotapes of your conversation should you wish them. In the long-term your participation may help to improve care given to women who are ill after the birth of their babies.

If you have any queries or concerns regarding your rights as a participant in this research you may contact the Health Advocates Trust, phone [...].

You have the right to decline to take part or withdraw from this study at any time, you have the right to refuse to answer any questions,. You have the right to request the audiotape turned off at any time.

Please take time to discuss this with whoever you wish. If you have any queries or wish to discuss participating in this project please feel free to contact me at any time on the above telephone number.