

**WOMEN'S EXPERIENCE OF SEVERE  
EARLY ONSET PREECLAMPSIA:  
A HERMENEUTIC ANALYSIS**

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## **Attestation of Authorship**

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person nor material which to a substantial extent has been accepted for the qualification of any other degree or diploma of a university or other institution of higher learning, except where due acknowledgement is made in the acknowledgements.

## **Dedication**

This study is dedicated to Wendy and Evan Roberts and their son Finn. Their experience with severe preeclampsia has inspired my thesis journey.

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## Abstract

Preeclampsia is a complex, baffling and unpredictable syndrome. The condition affects the lives of approximately one in every twenty pregnant women. Most cases are mild but some are serious enough to threaten the life of mother and baby. Medical research has yet to identify a cause, and the search for a cure continues. Delivery remains the only method of resolving this dangerous complication of pregnancy and may need to be effected before the fetus has become mature enough to avoid the risks associated with preterm birth. Women's experience of preeclampsia has received little attention in midwifery and obstetric literature.

This hermeneutic phenomenological study has been designed to answer the question "What is women's experience with preeclampsia before 34 weeks of gestation?" Eight women who had experienced severe preeclampsia were interviewed. Their narratives are analyzed to uncover the meaning of the lived experience of preeclampsia from diagnosis to postpartum recovery. Three data chapters reveal some of the ways that preeclampsia reveals itself as the disease progresses. The findings of this study indicate that there are many atypical presentations of preeclampsia and that sometimes early "showing" goes unrecognized. The woman may in fact feel better as the disease progresses. Late diagnosis leaves the woman and her family shocked and may compromise fetal and maternal safety. Having preeclampsia changes the reality of pregnancy and early parenting for a woman. Emotional consequences are significant and include an increased risk of post-traumatic stress disorder. The unpredictable manner in which preeclampsia first "shows itself" is analyzed in the first data chapter and the following two chapters explore the way in which a woman's life may be thrown out of control by diagnosis and management of the disease.

Paradoxically, women with severe preeclampsia often lose continuity of care with their midwife at a time when they most need the support of a familiar and trusted professional. Provision of continuity creates a challenge for the midwife when the woman's care is taken over by secondary services. Innovative ideas to enhance the safety and holistic quality of care for women with preeclampsia are discussed.

# Chapter One

## Orientation to the Study

### Introduction

Until the late nineteenth century practitioners had little understanding of preeclampsia and the associated mortality was considerable, even with the attendance of experienced obstetricians. For Evalina, one of the daughters of the renowned nineteenth century London banker Lionel Rothschild, preeclampsia could neither be anticipated nor treated as this tragic account by Weintraub (2003) recounts:

*In the first stages of labour on Tuesday, December 4, 1866, Evelina was seized with convulsions. Arthur Farre, also obstetrician to the Princess of Wales, summoned two additional physicians, who could only assist in delivering a stillborn son. Minutes later Evelina was dead. (p.207)*

Family correspondence records that Evelina had apparently been well until the day before when her mother spent time with her as she was a little uncomfortable. Almost 150 years later, the threat of maternal and perinatal mortality associated with preeclampsia still remains. New Zealand statistics show that maternal mortality from preeclampsia and eclampsia was high in the decade between 1927 and 1936, ranging from 23 (0.92/1000 live births) deaths in 1932 to 40 (1.47/1000 live births) in 1928 (Mein Smith, 1986). Whilst deaths from preeclampsia have declined dramatically since the provision of universal antenatal care in the early 1920s the World Health Organization estimates that over 160,000 women still die from preeclampsia each year and the condition has remained a leading cause of maternal death for several decades (Myers & Brockelsby, 2004).

The latest available New Zealand statistics show that there were no maternal deaths associated with preeclampsia or eclampsia between 1999 and 2002 (R.Kay, NZ Govt. Statistician, personal communication, January 27, 2005). The current New Zealand incidence of preeclampsia is difficult to extract from statistics because of the way in

which hypertension of pregnancy is recorded. Globally it is also difficult to estimate the incidence of preeclampsia accurately due to the number of definitions and classification systems utilized and the wide variation in case reporting. There are disparate incidence rates reported between countries with rates as low as 2.5% and as high as 9.7% (Myers & Brockelsby, 2004). However, Shennan and Chappel (2001) estimate that the incidence of preeclampsia is probably less than 5% in an average antenatal population. The cause of preeclampsia is not yet fully understood and there is no cure except delivery of the baby but the midwife and doctor now have infinitely more knowledge to enable them to reduce this risk for the women in their care.

This study explores the experience of women who are diagnosed with severe early onset preeclampsia. I chose to limit the inclusion criteria to those women who had developed the disease at a gestation where delivery involved a balance between induction of labour or cesarean section for the mother's safety and a need to minimize the risks of prematurity for the baby. Seven women who had experienced the diagnosis of preeclampsia between 24 and 34 weeks and one who was diagnosed at 37 weeks (but was included as she had been ill for some time prior to diagnosis) were interviewed during a 12 month period between 2003 and 2004. I used hermeneutic phenomenology as my methodology to explore the way in which the experience of preeclampsia affected the lives of these women. Van Manen's (1990) thematic analysis has been used to uncover the meaning within the stories each told of their experience.

## **What is preeclampsia?**

Preeclampsia is a condition that occurs in pregnancy. The etiology remains poorly understood although there are several theories including genetic predisposition and defective trophoblast invasion resulting in reduced placental perfusion which leads to multiple maternal physiological disturbances (Baker & Kingdom, 2004). The underlying pathology is complex and clinical presentation varies extremely widely. Preeclampsia is largely a silent disease (Redman & Walker, 1992) and in many cases causes no symptoms until the mother or baby are very ill. Most cases are mild and occur close to full term with minimal maternal and perinatal risk but in severe preeclampsia women are at risk of multi-organ failure and death, and their babies are at risk of intrauterine growth

restriction, intrauterine death and complications of prematurity. In most cases the interests of mother and baby coincide when delivery is indicated but tragically it is sometimes necessary to deliver a woman for her own safety at the expense of a baby who is too premature to survive delivery (Serenius et al., 2004).

Ideally, women would be diagnosed with the disease at a point when they can be delivered in time to prevent serious complications but the reality is that the disease can fulminate with little warning. Preeclampsia may also be diagnosed for the first time after delivery (Matthys, Coppage, Lambers, Barton & Sibai, 2004). The variability of preeclampsia makes diagnosis challenging and women are often shocked and ill prepared for diagnosis.

## **Research Question and Aims of the Study**

The research question asks: “What is women’s experience with severe preeclampsia occurring before 34 weeks of pregnancy?” I invited women to talk about their experience from the point of realizing that something was wrong with their pregnancies to their recovery and reflection after they had given birth.

The aims of the study are:

- To describe the experiences of women who were diagnosed with preeclampsia early in pregnancy
- To uncover factors in women’s experience of the development of preeclampsia that may warn caregivers of the need for more intensive surveillance
- To identify ways in which midwives and other maternity caregivers may provide safer and more sensitive care for women who develop preeclampsia

## **What prompted my study/personal context**

As a midwife I have been intrigued by the pathophysiology of preeclampsia for many years but my commitment to the study of preeclampsia stems from my involvement with Wendy Roberts, a client who developed a fulminating form of HELLP syndrome in her first pregnancy. HELLP syndrome is a severe form of preeclampsia. The acronym represents **H**aemolysis, **E**levated **L**iver Enzymes and **L**owered **P**latelets (Curtin &

Weinstein, 1999). Wendy developed fulminating HELLP syndrome at 34 weeks in her first pregnancy (Cowan, 1997). Following emergency caesarean section Wendy was expected to recover over a few days but her condition deteriorated the next morning as she haemorrhaged due to DIC (Disseminated Intravascular Coagulation). DIC is a serious complication of preeclampsia characterized by coagulopathy and widespread bleeding (Norwitz, Chaur-Dong & Repke, 2002). Wendy developed multisystem failure but eventually recovered thanks to the skill of many skilled specialists and intensive care nurses, her determination to live, her awareness of her baby's dependence on her, and the presence and strength of her husband and family.

As Wendy's midwife I have relived the days preceding her diagnosis of HELLP many times. Did I respond quickly enough? Was I mindful of the early signs? As I journeyed with her through the times of crisis I traveled an emotional roller coaster moving from the dreadful realization that she may not survive as yet another body system shut down to a commitment to battle this dreadful condition which can devastate lives within hours.

Following this experience, in 1995 Wendy and I co-founded the charity "New Zealand Action on Preeclampsia" (NZAPEC) a group closely aligned with the group UK Action on Preeclampsia co-founded by journalist Isobel Walker and obstetrician Chris Redman. Isobel's first child Benji was born prematurely because of preeclampsia, prompting her interest in this area. (Redman & Walker, 1992). One of the aims of NZAPEC is to raise awareness of the condition and as the current director of the organization I am frequently immersed in reading about or discussion on preeclampsia. It has become a passion.

## **Justification for the Study**

At the commencement of this research there were no studies identified in the literature that explored the experience of women who suffer preeclampsia although research about the disease itself is well represented in medical and midwifery literature. Through my involvement with NZAPEC I have been approached by many women who have experienced the disease. I have become aware of a need for these women to have a voice. Their case studies appear in the literature and their physiological responses to

disease become part of the growing body of scientific research into preeclampsia but their lived experience is seldom spoken or heard, apart from the stories they tell for the NZAPEC newsletter and in consumer literature. I have heard many such stories over the years of my involvement and was keen to take the opportunity to listen to such stories, ask more questions and engage in a phenomenological analysis. This is my justification for the study.

## **My Pre-understandings and Biases**

I came to this study with knowledge of the condition of preeclampsia and experience in caring for women with the disease at varying levels of severity in my midwifery practice. My work experience includes 10 years in a tertiary hospital delivery unit and for the past 15 years I have worked as a case-loading independent midwife providing home and hospital birthing care. The New Zealand maternity system enables the midwife to work as an autonomous “Lead Maternity Carer” (LMC) and receive reimbursement for services through a Government agency. It is the responsibility of the LMC to detect preeclampsia and organize appropriate investigations and referral to specialist obstetric services.

Prior to conducting this study I believed that I had considerable knowledge about my research question from my experience as a midwife. In addition, through my involvement with women who had contacted NZAPEC for support or to offer their stories for publication in the newsletters I had some insight into the lived experience of preeclampsia. The pre-assumptions I bring to this study are that women are usually quite shocked to hear the diagnosis of preeclampsia, that hospital admission is traumatic, advice is often conflicting and that many women are afraid to consider another pregnancy following an experience with severe disease.

It is impossible for me to “bracket” my knowledge of women’s experience of preeclampsia in a Husserlian manner (Crotty, 1998). Because I have been closely involved with women who have developed preeclampsia my pre-understandings frequently come back to mind as I reflect on the data provided by participants’ transcripts. However I have since discovered that my pre-understandings offered me a

comparatively superficial understanding of the lived experience of preeclampsia. Through this study I have gained a deeper insight into women's experience of the disease. There have been no contradictions but rather more questions to direct my thinking towards seeing the meaning that lies behind. Gadamer's (1976) notion of the researcher bringing their own horizon or prejudice to a study, and the belief that this pre-understanding enables the researcher to interpret data and constitute understanding has guided my study.

## **Methodology**

I have taken a hermeneutic phenomenological approach and have been informed by the German philosopher Martin Heidegger [1899-1976] and van Manen (1990). The term "hermeneutic" originally referred to the interpretation of biblical text and came into use in the seventeenth century (Crotty, 1998). Since then the term has been applied more broadly to include interpretation of other texts and human activity to attempt to interpret and understand. Heidegger (1927/1962) spent his life searching for and writing about the meaning of being or the term used by him, Dasein. According to Crotty this more enlightened understanding of being enriches our existence. Phenomenology is described by Heidegger as our way of access to ontology, the study of being, or more particularly, 'being-there'.

Preeclampsia is a serious disease and caregivers must focus on timely diagnosis and delivery for the safety of mother and baby. The experience may be acknowledged as difficult for the woman but caregivers' focus is necessarily on safety rather than on the emotional impact on the woman and her family. In this study I have focused on the interpretation of the experience of preeclampsia and aimed to see beneath the obvious to gain a deeper understanding of what it is like to be diagnosed with preeclampsia at a gestation remote from full term of pregnancy.

Heidegger's (1927/1962) notion of a phenomenon as "what lies in the light of day or can be brought to light" (p.51) seems to fit perfectly with my research topic. Preeclampsia may begin very early in pregnancy but may not be diagnosed until weeks or months later. The disease may show itself or may appear as a semblance of "something which it

is not” (p.52). The difficulties experienced with timely diagnosis are illustrated in the participants’ stories. The phenomenon of preeclampsia may exist but may not be recognized when it “shows itself as itself” or as “a semblance of itself” thus presenting a challenge to caregivers. Using Heideggerian philosophical notions I will discuss how women experienced the revealing of the phenomenon of preeclampsia and then how they experienced the reality of living with the disease.

## **Relevance to midwives**

Midwives provide seventy percent of the primary maternity care for New Zealand women (New Zealand College of Midwives, 2005). They are the practitioners who are likely to work most closely with women during the time that they are starting to become symptomatic with preeclampsia. When a woman is admitted to hospital with the condition, it is the midwife who will be alongside her, although responsibility for care becomes a secondary medical concern. Even in hospital women with preeclampsia may deteriorate rapidly and close vigilance is important. Following discharge from hospital, it is the midwife who provides care for four to six weeks. For maternity care to be holistic and effective, insightful understanding of women’s experience of preeclampsia is necessary.

There is currently no effective screening test to ensure that all women are diagnosed with preeclampsia early enough to prevent serious complications, although current international research (the SCOPE study) is underway to identify molecular and clinical markers that differentiate early in pregnancy women who will subsequently develop preeclampsia. It is hoped that the study will lead to the development of predictive algorithms that offer first time mothers an accurate risk rating for the disease as well as for preterm birth and intrauterine growth restriction (NZAPEC, Spring, 2004).

In the mean time, practitioners must remain vigilant for signs of the disease, which presents with a wide diversity of signs and symptoms. This study seeks to reveal some of the complexity of vigilance as revealed through the women’s accounts.



## **Structure of Thesis**

### **Chapter 2: Literature Review**

This chapter explores the literature in order to provide context for the research study

### **Chapter 3: Research Design and Method**

This chapter includes a description of the research study using Van Manen's (1990) method of hermeneutic analysis. Study design and conduct are discussed, including ethics, data collection, data analysis and rigour.

### **Chapter 4: The Showing of Preeclampsia**

In this chapter data relating to women's experience of becoming unwell with preeclampsia is analyzed.

### **Chapter 5: The Thrownness of Preeclampsia**

Diagnosis of preeclampsia involves significant change in the life of the woman and her family. The experience of sudden change is explored in this chapter.

### **Chapter 6: Loss, Guilt and towards Recovery**

Serious preeclampsia can involve a sense of loss and guilt and recovery from preeclampsia may be protracted. Emotional and physical factors pertaining to loss, guilt and grief during pregnancy and the postnatal period are explored here.

### **Chapter 7: Discussion**

This chapter examines the meaning from the three data chapters and explores the research question in the light of the research findings. Implications for midwifery practice are discussed.

## **Summary**

Preeclampsia can strike a healthy woman at the time when she anticipates the birth of her baby. For most women, the disease is mild and resolves quickly following delivery. For some, it seems to come from 'nowhere' and dramatically take charge, threatening the life of both mother and baby. There is much not yet understood about the nature of the disease. This study recognizes that there is also much not yet understood about what the experience of having pre-eclampsia is like for the woman. The following chapters pursue a journey towards new understanding of the woman's experience.

## **Chapter Two**

### **Literature Review**

#### **Introduction**

This chapter provides a background context in order to relate to the narratives of the participants in my study. I will provide an historical perspective of preeclampsia, a brief summary of the current theories concerning etiology and an overview of pathophysiology. Symptoms of preeclampsia are often vague and misleading (Baxter and Weinstein, 2004) and in view of this a discussion on classic and less common presentations will be included. As management has a significant impact on women's experience of preeclampsia, current trends in management of severe preeclampsia will be outlined. Implications for the woman's future health following preeclampsia will be discussed. The intention of this chapter is not to provide a comprehensive text on the pathophysiology and management of preeclampsia, rather to provide a summary of knowledge from existing literature on which the reader may relate to women's experience of the disease.

The relationship of the midwife and the woman with preeclampsia in the framework of the New Zealand partnership model and statutory referral guidelines will be explored and the issue of continuity of care in this context will be discussed. Women with severe preeclampsia often require early delivery and the implication of this for the mother and baby will be addressed. Finally, I explore the topic of emotional distress following experience of preeclampsia.

The majority of the literature is from overseas sources, but some key New Zealand references are included in regard to midwifery care. Most of the professional literature associated with preeclampsia is clinical and relates to advances in knowledge concerning pathophysiology and management rather than women's experience. Consumer literature contains a wealth of women's accounts of the disease and excerpts from some of these have been included.

## Definition of Preeclampsia

Preeclampsia is a syndrome with extremely variable clinical presentations reflecting the complex underlying pathology, and is unique to human pregnancy (Hayman & Myers, 2004a). In clinical practice it appears that there is little uniformity in the way preeclampsia is diagnosed (Harlow & Brown, 2001). This lack of consensus was highlighted in an editorial describing over 1000 women with hypertension in pregnancy (Brown & Buddle, 1997). In New Zealand the classification accepted is according to the Australasian Society for the Study of Hypertension in Pregnancy (ASSHP) Brown et al., (2000). Hypertension in pregnancy is diagnosed when the systolic blood pressure is  $\geq 140$  mmHg and /or the diastolic blood pressure is  $\geq 90$  mmHg. According to the ASSHP classification, a clinical diagnosis of preeclampsia can be made when hypertension arises after twenty weeks gestation with the addition of one or more of the following:

- Proteinuria:  $\geq 300\text{mg}/24\text{hr}$  or spot urine protein / creatinine ratio  $\geq 30\text{mg}/\text{mmol}$
- Renal insufficiency: serum/plasma creatinine  $\geq 0.09\text{mmol}/\text{L}$  or oliguria
- Liver disease: raised serum transaminases and /or severe epigastric/right upper quadrant pain
- Neurological problems: convulsions (eclampsia); hyperreflexia with clonus; severe headaches with hyperreflexia; persistent visual disturbances (scotoma)
- Haematological disturbances: thrombocytopenia; disseminated intravascular coagulation; haemolysis
- Fetal growth restriction  
(Brown et al., 2000, p.134).

Preeclampsia has been variably called PET (preeclamptic toxemia), GPH (gestational proteinuric hypertension), toxemia, hypertension gestosis, and HOP (hypertension, oedema and proteinuria). Pre-eclampsia more correctly names the condition as it is a disorder which can lead to eclampsia (convulsions) and may not necessarily involve proteinuria or oedema (Stone et al., 1995) as implied by some of the other names.

## Historical Perspective

The earliest reference to eclampsia is in the Kahun papyrus from Egypt over 3000 years ago (Stevens, 1975). Hippocrates recognized the seriousness of symptoms of the disease, writing in the *Coan Prognosis* XXX1, no. 507 “In pregnancy, drowsiness with headache accompanied by heaviness and convulsions is generally bad; such cases are generally liable to some sort of fits at the same time” (Chadwick & Mann, 1950). Over the centuries eclampsia was considered to be some form of epilepsy. The first appearance of the word eclampsia was in 1619 in Varandeu’s treatise on gynaecology (Ong, 2004). The Frisian midwife Catharina Schrader whose memoirs record vivid accounts of obstetric emergencies between 1693 and 1740, attended a woman who appears to have suffered an eclamptic fit. The following account appears in her journal (Marland, 1987):

*...fetched to Driesum to a weaver’s wife, after a previous midwife had delivered a baby the day before: (The other midwife) Found that there was still another child, but could not help the woman with all her torturing... Then I was fetched. Found that the child lay with his stomach first. Turned it quickly. A living child and the woman was completely well. But on the second day the woman was alone in the house; the people were milking. Then a strange man came in, who asked the woman in the child bed if he could light a tobacco pipe, which he did. After that the woman got such an attack of fits, that three men could not hold her. Together with periods without speech. Died the same day. One questioned if the person who had come in there had committed murder. (Case 671)*

It seems clear this renowned midwife did not recognize this tragic death as a complication of childbirth. Another renowned midwife, Madame le Bousier du Coudray, the chief midwife in Paris wrote in 1773 about convulsions in labour. She related the condition to pregnancy as she recognized that delivery of the baby was the only way to save a woman who became unconscious following convulsions (Ong, 2004). However, according to Chesley (1974) it was possibly the early nineteenth century before eclampsia was distinguished from epilepsy.

Early treatments of preeclampsia were aggressive and practices such as phlebotomy and purgation persisted from the time of Hippocrates to the nineteenth century. When physicians regarded eclampsia as toxæmia these forms of treatment seemed logical

ways to remove the toxins (Ong, 2004). As it was recognized by practitioners such as Mauriceau and Madame le Bousier du Coudray that delivery seemed to resolve the threat of convulsions, gradually termination of pregnancy was seen as the “cure” to the terrible disease (Ong). However, the associated mortality was high and by the end of the nineteenth century more conservative treatment in the form of sedation with morphine and chloral hydrate was adopted by leading obstetricians.

Unfortunately the swing to conservative management came at a cost for the baby and stillbirth rates soared in the early twentieth century (Chesley, 1984). The risk of fetal compromise remains significant with expectant management (Sibai, 1994) although advances in fetal surveillance have reduced the risk of fetal death (Hall, Odendaal, Steyn & Grove, 2001; McCowan et al., 2000). If delivery is indicated, medical advances have made induction of labour and caesarean section a less risky option for the woman (Mashiloane & Moodley, 2002). However, despite significant advances in management and improved neonatal and maternal outcomes, prediction and timely diagnosis of the disease can be challenging and the decision between expectant management and delivery remains problematic particularly for women with severe preeclampsia remote from term.

## **Pathophysiology**

The pathophysiology of preeclampsia is complex; involving the interplay of abnormal genetic, immunological and placental factors (Duckett, Kenny & Baker, 2001).

### **Genetic factors**

Epidemiological studies suggest that there are inherited components in the pathogenesis of preeclampsia. In 1961 the first systematic, prospective familial study on preeclampsia was conducted. Pregnancies of 115 daughters and 147 sisters of women who had suffered pre-eclampsia were analyzed. 37% of sisters and 27% of daughters had developed pre-eclampsia (Chesley, Cosgrove & Annitto, 1968). Subsequent work has suggested that there is a three to four-fold increase in recurrence risk for first degree relatives of an affected individual (Duckett et al., 2001; Morley, 2004). A large Norwegian study found that men who had fathered one preeclamptic pregnancy had an

almost two-fold risk of fathering another preeclamptic pregnancy with a different partner. This suggests a role for inherited components from both parents (Astin, Scott & Worley, 1981; Lie et. al., 1998).

### **Immunological factors**

The immunological theory is supported by the hypothesis that in a normal pregnancy a state of tolerance to paternal antigens exists (Morley, 2004). This tolerance appears to be impaired in pregnancies affected by pre-eclampsia, and studies have hypothesized that increased risk of pre-eclampsia correlates with shorter duration of sperm exposure. The incidence of pre-eclampsia is increased for women who use contraceptive methods that prevent exposure to sperm indicating that tolerance builds up over time (Duckett et al., 2001). In-vitro fertilization and intracytoplasmic sperm injection may be associated with a three fold risk of pre-eclampsia compared to the risk to women who have been exposed to their partner's sperm naturally (Wang, Knotterus, Scuit, Chan & Dekker, 2002).

### **Placental factors**

Placental development and the maintenance of a successful pregnancy are dependent on trophoblast invasion into the maternal decidua and myometrium leading to spiral artery transformation early in pregnancy (Kenny, 2004). Abnormal placental implantation and shallow invasion of the trophoblast resulting in diminished uteroplacental circulation is common to women with pre-eclampsia. However, inadequate trophoblast invasion is also seen in pregnancies complicated by intrauterine growth restriction in the absence of preeclampsia suggesting that the maternal condition of preeclampsia must involve other factors (Shennan & Chappel, 2001).

### **Endothelial and circulating factors**

The vascular endothelium forms a continuous layer lining the blood vessels of the entire vascular system and is not an inert barrier between the intra- and extra- vascular compartments; it allows the transfer of nutrients, waste products, regulatory molecules and phagocytic cells across the basement membrane and has metabolic and secretory functions important in pregnancy homeostasis (Waring, 2004). In preeclampsia,

circulating factors (yet to be identified) from the placenta lead to oxidative stress triggering changes which lead to maternal endothelial cell dysfunction and as the vascular endothelium is present in all organ systems endothelial dysfunction may account for the multi system presentations of the disease.

Many markers of endothelial damage are raised in preeclampsia (Duckett et al., 2001). Alteration of normal endothelial function in pre-eclampsia includes increased sensitivity to pressor agents with decreased production of the vasodilator prostacyclin and increased production of the vasoconstrictor thromboxaneA<sub>2</sub>. Platelet aggregation is also increased (Pipkin, 1995). Imbalance between vasoactive agents leads to generalized vasoconstriction and reduced tissue perfusion contributing to multiple organ damage. Loss of endothelial cell integrity leads to an increase in vascular permeability, reduced circulating plasma volume and haemoconcentration (Morley, 2004). Blood pressure becomes raised in preeclampsia because of arteriolar vasospasm which increases resistance to blood flow. In compensation for increased resistance, cardiac output is increased so that blood is forced through the constricted arteries at a higher pressure (Redman & Walker, 1992).

## **Progression of disease**

Hypertensive diseases of pregnancy are the second leading cause of maternal death in the UK, with an estimated 10 women per year dying from complications of the condition. NZ statistics are difficult to interpret but at the country's largest tertiary obstetric centre there were no maternal deaths from preeclampsia over the two years covered by the latest annual report (Auckland District Health Board, 2004).

## **Maternal complications**

### **Renal**

Normal renal function is generally maintained in pre-eclampsia until the disease is advanced but the kidney is more susceptible to damage by preeclampsia if there is pre-pregnancy chronic hypertension (Gillham & Hayman, 2004). During the course of a normal pregnancy protein excretion may increase and up to 0.3g of protein per 24 hours



is within the normal range (Duckett et al., 2001). In preeclampsia the initial renal change is defective tubular functioning leading to a reduction in clearance of uric acid and creatinine (end products of metabolism). Consequently serum uric acid and creatinine levels rise. The characteristic kidney lesion seen in pre-eclampsia is glomerular endotheliosis due to swelling of the endothelium and fibrin deposition causing reduction in the capillary lumen (Duckett et al.). Rarely, acute renal failure may follow but this is usually associated with sepsis or haemorrhage (Gilham & Hayman). Drakeley, Le Roux, Anthony and Penny (2002) reviewed renal complications in pregnancy including 1433 women with pre-eclampsia and 251 with eclampsia. Only 31 of these women developed renal failure, all in the postpartum period, with fifty percent needing dialysis and two deaths. All women with severe renal impairment had either placental abruption or HELLP syndrome. Pathological renal changes due to pre-eclampsia usually resolve postpartum (Gilham & Hayman).

### **Hepatic**

Changes in liver function secondary to preeclampsia are thought to result from vasoconstriction of the hepatic vascular bed. Periportal fibrin deposition, haemorrhage and hepato-cellular necrosis have been observed and in severe cases necrosis and rupture can occur (Duckett et al., 2001). Liver rupture is rare and has a mortality rate of over 30% (Gilham & Hayman, 2004).

### **Cardiopulmonary**

Women with preeclampsia are hypovolaemic due to increased capillary permeability reflecting endothelial disease, with resultant fluid overload in the tissues. Pulmonary oedema (excessive accumulation of fluid within the interstitial and alveolar spaces) occurs in 2.9% of pregnancies affected by pre-eclampsia (Gilham & Hayman, 2004). The reduction in intravascular volume is reflected in a raised haemoglobin and haematocrit (Morley, 2004). A raised haematocrit places women at increased risk of thromboembolic disease which is a leading cause of maternal mortality (Hibbard, 1996).

### **Cerebrovascular**

The commonest cause of death seen in eclampsia is intracerebral haemorrhage (Duckett et al., 2001). This is a consequence of uncontrolled hypertension, and may reflect

inadequate or delayed antihypertensive treatment (Gilham & Hayman, 2004). Hypertensive encephalopathy is a sub acute neurological syndrome characterized by visual symptoms, headache, seizures and other disturbances such as altered mental status and focal neurological signs in the presence of hypertension (Norwitz, Hsu, & Repke, 2002). The condition may be manifest as retinal detachment, retinal arteriolar vasospasm and thrombosis of the central retinal arteries resulting in cortical blindness in severe cases (Kesler, Kaneti, & Kidron, 1998).

### **Neurological**

A history of headache is significant in a woman with preeclampsia. Two theories have been proposed to explain this. Firstly, it has been proposed that cerebral vasospasm leads to reduced perfusion and abnormal cerebral activity (Morley, 2004). Zatik et al. (2001) provided supporting evidence for this theory in their study comparing cerebral haemodynamic changes in healthy and preeclamptic women. Secondly it has been proposed that the headache is caused by cerebral oedema (Douglas & Redman, 1994). Brisk reflexes are seen in pre-eclampsia and are associated with cerebral oedema which can affect the function of sensory pathways and motor centres throughout the brain and spinal cord (Morley, 2004).

### **Eclampsia**

Eclampsia literally means “flashing lights” and is the occurrence of convulsions in association with signs and symptoms of preeclampsia in the absence of other neurological conditions such as epilepsy, subarachnoid haemorrhage and meningitis (Gilham & Hayman, 2004). There are few systematically collected population based data that allow the assessment of accurate incidence of eclampsia and the associated mortality but it is estimated that there are 50,000 maternal deaths per year worldwide as a result of eclampsia (Duley, 1992). The incidence of 4.9/10000 maternities in the UK in 1992 (Douglas & Redman, 1994) contrasts with an incidence of 6-100/10000 in developing countries (Norwitz et al., 2002). Douglas and Redman noted that most cases of eclampsia occurred despite normal frequency of antenatal assessments and that the complication could be unheralded by hypertension or proteinuria. These authors estimated a maternal case fatality of 1.8% from their data.

Eclamptic seizures are clinically indistinguishable from other generalized tonic-clonic seizures and seldom last longer than 3-4 minutes. Cerebral oedema is associated with convulsions but the cause remains unknown. However, hypertensive encephalopathy, ischaemia, vasospasm and haemorrhage may all be involved in the pathogenesis (Gilham & Hayman, 2004). Almost half of all cases of eclampsia occur antenatally and 75% of the remaining cases occur intrapartum or within the first 48 hours of delivery. Late postpartum eclampsia can occur up to 4 weeks after the birth. Megan Gollings (2001) described her experience of eclampsia at 31 weeks:

*Until twenty nine weeks all was well. My blood pressure was found to be slightly higher than usual but blood and urine tests all came back normal. The only hint of what was to come was my ever expanding ankles which I blamed on the heat and humidity and being on my feet all day. A few days later I developed a bad pain in my right side. When I could stand it no more I spoke with the midwife who referred me straight to the specialist and I was sent directly to the hospital for a review. When the pain suddenly subsided all was deemed well and it was back home for the night. The next morning I returned for monitoring of the baby and an ultrasound revealed a kidney stone which by then had finished its little journey. Three nights later I went to bed with what I thought was indigestion caused by my ever expanding belly. By one in the morning the pain under my rib cage was so unbearable I just paced the room trying to get through it. I was extremely frightened and anxious and was vomiting. At 3am I woke Andy and told him to take me to hospital because I thought I was going to die. Within minutes I was diagnosed with HELLP. By then my head felt like it was going to explode (my blood pressure reached 210/100) and I remember asking if I was having a stroke. That's the last I remember. I'm told I had an eclamptic seizure lasting 30 seconds and the obstetric team had the paddles out ready to "jumpstart" me when I finally came round on my own. After a general anesthetic and emergency caesarean section our little 1335gm baby boy Sam was born. Not quite like I planned it!*

Megan's story illustrates the difficulty often associated with diagnosis of preeclampsia which can be misdiagnosed or even masked by another condition.

### **Placental abruption**

Placental abruption is partial or complete separation of the placenta from the uterus during pregnancy, with increased perinatal morbidity and mortality. Maternal morbidity is associated with haemorrhage, either directly and indirectly from the effect of hypovolaemia on major body organs (Gilham & Hayman, 2004).

### **Disseminated intravascular coagulation (D.I.C.)**

D.I.C. is a disorder which may cause massive uncontrollable haemorrhage. The endothelial damage in preeclampsia stimulates laying down of fibrin (Duckett et al., 2001). Fibrin formation and fibrinolysis are increased which may lead to excessive consumption of clotting factors (Gilham & Hayman, 2004) with consequent massive uncontrollable bleeding.

### **Fetal complications**

Placental abruption is a serious risk for the fetus of a preeclamptic pregnancy and the underlying placental pathology in preeclampsia may also lead to considerable fetal compromise. However recent research has indicated that there may be a pathophysiological difference between late onset and early onset pre-eclampsia (Kingdom, Geary & Hindmarsh, 2000). In the late gestation form of the disease, it appears that the placenta adapts to a limited degree of utero-placental ischaemia. Kingdom et al. found that in late onset disease the placenta was 15% heavier than normal at delivery. The majority of previously healthy women who develop pre-eclampsia do so at term and have normal or even heavier babies compared to normotensive women. This group accounts for 80% of preeclampsia.

It is the early onset preeclampsia (i.e. before 34 weeks) that involves the greatest risk for the fetus. Iatrogenic prematurity as a result of emergency delivery for worsening maternal condition may further compromise a neonate that has become growth restricted and possibly hypoxic secondary to placental pathology or abruption. According to Simchen and Kingdom (2004) placentas from these pregnancies have patchy areas of placental thrombosis and infarction, maldeveloped villi, and uteroplacental ischaemia, whereas in late gestation disease the placenta has adapted to a limited degree of uteroplacental ischaemia and has not become damaged by thrombosis.

The fetus in early onset disease is at greater risk of neurological injury (Bernstein, Horbar, Badger, Ohlsson, & Golan, 2000). Cheng, Chou, Tsou, Fang and Tsao (2004) found that delivery before 32 weeks because of preeclampsia was associated with an increased risk of poor cognitive outcome at two years of age. They note that fetal growth

restriction in their study sample would have occurred in the first two trimesters and suggest that clinical manifestation of growth restriction will depend on the stage of brain development at the time of exposure to disease.

## **Symptoms of preeclampsia**

The classic symptoms are a frontal headache, visual disturbance and epigastric pain (Duckett et al., 2001). Most women are asymptomatic until pre-eclampsia is severe. With the onset of severe disease headache, dizziness, tinnitus, drowsiness, general malaise and altered consciousness are commonly reported. Frequently, these symptoms precede eclampsia and reflect poor cerebral perfusion, probably as a result of arterial spasm (Hayman & Myers, 2004b). Visual disturbances from blurred vision to blindness may result from spasmodic changes within the retinal arterioles, and ischaemia and haemorrhage within the occipital cortex. Hayman and Myers list epigastric tenderness and upper abdominal pain as vague symptoms. However, due to the unpredictable nature of the presentation of preeclampsia, a low level of suspicion should be maintained (Duckett et al., 2001). Barry, Fox and Stirrat (1994) reported three cases of upper abdominal pain which was incorrectly diagnosed in women who were later found to have severe preeclampsia. These authors assert that epigastric pain is often a grave symptom in pregnant women and discuss the importance of timely diagnosis as the disease may progress rapidly. Moore et al. (2003) reviewed data from all patients with HELLP syndrome at a tertiary centre between 1985 and 2000. They found that HELLP syndrome patients with epigastric pain had worse laboratory parameters and longer periods of hospitalization than patients without epigastric pain.

## **Management- The paradox of safety and risk for the mother and baby**

Management decisions involve consideration of the stage of gestation, the mortality and morbidity involved with prematurity, and the results of investigations indicating maternal organ damage and fetal compromise (Morley, 2004). Sibai et al. (1994) recommend delivery for severe preeclampsia although some authors such as Hall et al. (2001) have proposed a more conservative approach, excluding cases of HELLP syndrome and maternal or fetal instability. Their conservative (expectant) management

involves administration of glucocorticosteroids to enhance fetal pulmonary maturity, antihypertensive treatment, close clinical assessment in hospital and administration of magnesium sulfate if eclampsia develops. Their expectant management gained a mean of 11 days. For the preterm fetus, these days can represent a significant reduction in morbidity. The commonest indication for delivery was fetal distress and the most common maternal complication was placental abruption, with an incidence of 69 out of 340 women (Hall et al., 2001). The approach to practice in New Zealand and many other centres is expectant management as long as maternal and fetal safety is not compromised. Obviously in some cases this is not appropriate and urgent delivery is needed.

When delivery is indicated in preeclampsia remote from full term there is a high caesarean section rate, possibly related to a high incidence of intrauterine growth restriction and unfavourable Bishop's score. Induction of labour is associated with an increased risk of perinatal mortality (Mashiloane & Moodley, 2002). However, emergency caesarean section is associated with increased maternal morbidity and vaginal delivery is preferred by some obstetricians although success for this mode of delivery is not more than 50% (Mashiloane & Moodley, 2002). On the other hand, when the fetus is very small delivery by caesarean section may be the method of choice (Murphy & Stirrat, 1999). According to current ASHHP guidelines (Brown et al., 2000), delivery is indicated if preeclampsia occurs at term or at gestations remote from full term (> 37 weeks) for the following complications:

- Deteriorating liver function
- Inability to control blood pressure despite adequate anti-hypertensive therapy
- Deteriorating renal function
- Progressive renal function
- Progressive thrombocytopenia
- Neurological complications or imminent eclampsia
- Placental abruption
- Concern regarding fetal welfare

When delivery is indicated preterm because of severe preeclampsia, particularly if the indication for delivery is fetal, delivery by Caesarean section will usually be in the best interests of both fetus and mother.

This study has focused on the experience of women with severe preeclampsia but most cases of preeclampsia are not associated with serious maternal or fetal complications and present at term.

## **HELLP Syndrome**

Several participants experienced the severe form of preeclampsia involving haemolysis, thrombocytopenia and liver dysfunction which was first described by Pritchard, Weisman & Ratnoff (1954). However, the first published article naming the syndrome as HELLP appeared in the literature almost thirty years later. Weinstein (1982) reported his findings in a unique group of preeclamptic/eclamptic women who had a severe form of preeclampsia characterized by haemolysis, elevated liver enzymes, and a low platelet count. Weinstein devised the acronym HELLP to name the syndrome. HELLP syndrome occurs in 4-12% of women with severe preeclampsia and can manifest at any stage during pregnancy, but 30% of cases occur postpartum. Of these cases, only 80% will have been diagnosed as preeclampsia antenatally (Hayman & Myers, 2004b).

## **Symptoms of HELLP syndrome**

The presentation of HELLP syndrome may be non-specific and misdiagnosis is more likely when the condition develops before term. Diagnosis may be delayed with consequent risk for mother and fetus (Sibai, 1990). The symptoms of HELLP syndrome include epigastric pain, nausea and/or vomiting, non specific viral illness type symptoms, visual disturbances, headache, bleeding from the gums, jaundice, and neck or shoulder pain (Cowan, 1996). Sibai lists further presentations such as significant weight gain and oedema, convulsions, gastrointestinal bleeding, haematuria, and flank pain. As the classic symptoms of pre-eclampsia such as hypertension and proteinuria are not always present in women with HELLP syndrome, a non-obstetric diagnosis such as gall bladder disease, viral hepatitis, gastroenteritis, kidney stones, peptic ulcer, acute fatty liver of pregnancy, idiopathic thrombocytopenia purpura, thrombotic thrombocytopenia purpura, pyelonephritis and hemolytic uremic syndrome may be made. However,

disseminated intravascular coagulopathy (DIC), placental abruption and fetal death contribute to the significant maternal and fetal morbidity and mortality involved with the condition (Hayman & Myers, 2004b).

## **Diagnosis of HELLP syndrome**

The laboratory criteria for the diagnosis of HELLP syndrome most commonly used in clinical practice were defined by Sibai (1990). However there remains confusion regarding terminology and diagnosis and a lack of consensus regarding which tests and levels should be used to diagnose the syndrome. The following presents an overview of laboratory investigations most commonly used in the diagnosis of HELLP syndrome.

### **Haemolysis**

Haemolysis, defined as the presence of microangiopathic hemolytic anaemia, is a hallmark of HELLP (Baxter & Weinstein, 2004). Haemolysis is confirmed by an abnormal peripheral blood smear with the presence of burr cells (crenated, contracted, distorted red blood cells with spiny projections along the periphery), shistocytes (small, irregularly shaped red blood cell fragments), and polychromasia. Red blood cells become damaged by passage through small blood vessels with damaged endothelial lining and fibrin mesh deposits (Baxter & Weinstein, 2004; Sibai, 1990).

### **Elevated liver enzymes and liver damage**

Elevated levels of liver enzymes reflect damage within the liver. Hepatic damage results from micro-emboli in the hepatic vasculature. Jaundice may be present; serum bilirubin levels rise as a result of haemolysis (normal range 5-20  $\mu\text{mol/L}$ ). High levels of the enzyme Alanine transaminase (ALT) are specific for hepatic damage (normal range 35-40 U/L). Aspartate transaminase (AST) levels increase with liver damage but the enzyme is also found in other organs (heart, kidney, pancreas and red blood cells) so elevated levels of AST are not specific for hepatic damage (normal range 5-60 U/L). Gamma glutamyl transpeptidase (GGT) is found almost entirely in the liver and levels of this enzyme are elevated in HELLP syndrome (normal range 0-50 U/L). Lactate dehydrogenase (LDH) is another liver enzyme which is found in other parts of the body (heart, skeletal muscle and red blood cells) but may also be elevated in HELLP



syndrome (normal range 120-250 U/L). Tissue damage and ischaemia within the liver leads to obstruction of blood flow and distension which potentiates liver rupture (Weinstein, 1982). The classic hepatic lesion associated with HELLP syndrome is periportal or focal parenchymal necrosis. Pain is usually localized to the right upper quadrant or mid-epigastric region and is caused by distension.

### **Low platelets**

Platelet consumption occurs in preeclampsia as arteriolar vasospasm damages the endothelial layer of small vasculature, forming lesions. The lesions allow platelet aggregation and the formation of a fibrin network. In HELLP syndrome the circulating volume of platelets reduces as consumption increases, resulting in thrombocytopenia (normal level  $150-450 \times 10^9/L$ ). A level of  $<100 \times 10^9/L$  is significant in diagnosis of HELLP syndrome.

### **Partial HELLP Syndrome**

Women who manifest 1 or 2 but not all 3 of the components of HELLP syndrome have a better prognosis than women with complete HELLP syndrome (Audibert, Friedman, Frangieh & Sibai, 1996). However it must be realized that as with preeclampsia, the natural course of the disease is to worsen over time (Baxter & Weinstein, 2004).

### **Management of HELLP syndrome**

The only definitive treatment for women who have HELLP syndrome is delivery. The condition is potentially fatal for mother and fetus with the most common cause of maternal death being liver rupture (Poole, 1998). Deteriorating liver function and/or progressive thrombocytopenia is an indication for delivery regardless of gestation. It is important to be vigilant as HELLP may develop postpartum. In an analysis of 304 cases by Sibai (1990) 69% of women had evidence of the condition antenatally while in 31% the disease was manifest postpartum. Of those women in the postpartum group, the onset of manifestation ranged from a few hours to 6 days, with most developing within 48 hours of delivery. 21% of women had no evidence of preeclampsia prior to delivery.

## **Maternal and perinatal outcome of HELLP Syndrome**

HELLP syndrome can be associated with poor maternal and perinatal outcome. Sibai (1990) reported a maternal mortality range of 0-24% and a perinatal mortality range of 7.7-60%. Maternal morbidity is mostly associated with disseminated intravascular coagulation (DIC), placental abruption, acute renal failure and ruptured liver haematoma. Most perinatal deaths are associated with placental abruption, intrauterine asphyxia and prematurity. The North American context of Sibai's work may have affected the statistics as adverse outcomes such as abruption are more common in black American women. Issues such as late attendance could also have influenced results. New Zealand statistics are difficult to obtain but the fact that there have been no reported maternal deaths from preeclampsia in the latest available statistics reflects a different picture in this country.

## **Long Term Implications of Preeclampsia**

There is now considerable epidemiological evidence to demonstrate a relationship between pregnancy complicated by pre-eclampsia and an increased risk of maternal coronary heart disease in later life (Hannaford, Ferry & Hirsch, 1997; Jonsdottir, Arngrimsson, Geirsson, Sattar & Greer, 2002). There may be a similar disease mechanism underlying pre-eclampsia and coronary heart disease. Underlying cardiovascular disease (particularly coronary heart disease) is the metabolic syndrome, involving a range of metabolic abnormalities including insulin resistance, hyperglycaemia, hyperlipidaemia and coagulation disturbance. In normal pregnancy physiological changes lead to relative insulin resistance, hyperlipidaemia and an increase in coagulation factors. These metabolic changes could be seen as "stress" tests of maternal carbohydrate, lipid and vascular function and consequently adverse pregnancy outcome such as preeclampsia may indicate increased future risk of metabolic and vascular disease (Sattar & Greer). This lays open the possibility of opportunities for timely education and screening of at risk women.

## **Prevention of Preeclampsia**

The identification of effective strategies to prevent preeclampsia is clearly a priority for research. Currently there is insufficient evidence to suggest that dietary advice or medication is effective in the prevention of pre-eclampsia (Takser & Fraser, 2004). However several trials have demonstrated that nutritional supplements and medications may have some benefits in the reduction of risk of preeclampsia.

### **Vitamins C and E**

As oxidative stress has been proposed as a factor in the endothelial cell dysfunction of preeclampsia, trials using antioxidant vitamins C and E have been conducted. The first study to report a clinical benefit involved administration of 1000mg Vitamin C and 400IU Vitamin E daily to a group of 283 women at high risk for preeclampsia, defined by abnormal Doppler results or a past history of the disease (Chappell et al., 1999). Preeclampsia occurred in 17% of the women in the placebo group compared with 8% of the women in the treated group (adjusted odds ratio 0.39). High risk women in the placebo group who developed preeclampsia had lower plasma Vitamin C concentrations than women in a normal pregnancy control group. These preliminary results have been promising but clinical use cannot yet be recommended. Further studies are needed to confirm preliminary results and it is not known if results from a high risk population can be extrapolated to a low risk population. Neonatal safety has also to be evaluated (Takser & Frazer, 2004).

### **Calcium**

Calcium supplementation has been shown to have a beneficial effect in the reduction of preeclampsia in a meta-analysis of 11 trials involving 7000 women, comparing at least one gram of calcium daily during pregnancy with a placebo (Attallah, Hofmeyer & Duley, 2003). The overall effect was that the group receiving calcium supplementation was over a third less likely to develop preeclampsia than the group receiving a placebo. The greatest benefit was seen in women with inadequate dietary intake of calcium and high risk of hypertension. Further studies are currently in progress.

## Aspirin

Antiplatelet agents may reduce the risk of pre-eclampsia as shown in a recent meta-analysis involving over 30000 women (Duley, Henderson-Smart, Knight & King, 2003). The reduction of risk was found to be greatest at aspirin doses of > 75mg. Overall analysis of the data showed that antiplatelet therapy was associated with a 15% reduction in the risk of pre-eclampsia, a 14% reduction in the risk of perinatal death and an 8% reduction in the risk of preterm birth.

## Other trials

Sodium restriction and supplementation with fish oil, zinc and magnesium have been trialed but it is unlikely that these will prove beneficial in reduction in risk of the disease (Takser & Fraser, 2004). Pre-eclampsia has complex aetiology; therefore it is unlikely that simple nutritional therapy will have a significant prophylactic effect. Further studies aimed at an understanding of the complex biochemical pathways may eventually lead to the development of more effective preventative strategies.

## The midwife and preeclampsia

In New Zealand pregnant women are required to choose a Lead Maternity Carer (LMC) who coordinates their care from early pregnancy through to between four and six weeks after the baby's birth. The LMC may be a general practitioner, a private obstetrician, a hospital team midwife or consultant or a self employed midwife. According to the New Zealand College of Midwives website (2005):

*New Zealand midwives work in a partnership model of care with women. In this model each woman and her midwife are partners, working together to ensure that the woman has care that best meets her individual needs. The woman and the midwife get to know each other well over the whole maternity experience, building a relationship of trust with each other, sharing information and decision-making and recognising the active role that both play in the woman's maternity care.*

The partnership model of care was first introduced as a model for midwifery practice by Guilliland and Pairman (1994). Legislative changes enabled midwives in New Zealand to practise autonomously through the 1990 Amendment to the Nurses' Act 1977

(Burgess, 1996). If a woman has risk factors or her pregnancy becomes complicated the midwife is required to discuss with the woman the need for consultation with an obstetrician and to implement referral under the guidelines documented in the Ministry of Health Maternity Services document (Ministry of Health, 2002). When a woman develops severe preeclampsia she must be referred to an obstetrician, and under the above referral guidelines responsibility for care must be transferred to the secondary service, either a private specialist or the hospital team headed by an obstetrician. At this point the midwife may retain a role in the woman's care, either in a shared care capacity where she retains midwifery responsibility or in a support role. She may also choose to hand over care and opt out of involvement completely or become involved again during the postnatal period when it is possible that she may once again assume the role of LMC.

A recent study evaluated continuity of midwifery carer for women of mixed obstetric status (Homer, Davis, Cooke & Barclay, 2002). The researchers concluded that women were more likely to feel in control during birth and to subsequently regard their experience positively when intrapartum care was provided by a midwife known to them antenatally. A difficult birth can impact significantly on the emotional and physical health of a woman. According to Hendricks (1999), "Continuity of midwifery care can be particularly important for women who are trying to come to terms with the circumstances surrounding their baby's birth, if it has not gone according to plan"(p. 15). Hendricks interviewed a woman who articulated the value of continuity to her:

*...She ... was there to talk about the whole events of the labour and the whole experience. She had the time to sit and listen, and because at the time of the labour there was so much intervention...it was a bit vague in my mind and a bit clouded. She was there to go over it which was good. (p.16)*

It is clear that a woman who develops severe preeclampsia needs the skill and knowledge of a specialist obstetrician. Once preeclampsia is diagnosed, responsibility for the woman's care should be taken over by an obstetrician but this does not negate the need for continuity of midwifery care in a partnership relationship that is flexible and able to continue throughout a complicated pregnancy. Effective shared care between a midwife and specialist is possible with good communication. Guilliland and Pairman (1995) stress that continuity of caregiver is essential, providing opportunities to develop

a relationship based on trust. When midwifery care is fragmented, the partnership is compromised: “Fragmentation of the woman’s experience into discreet components of care means that the midwife is more likely to lose sight of the whole woman-person with whom the partnership is formed.” (p. 38). While others such as Freeman, Timperly & Adair (2004) have questioned practicality of the partnership model as proposed by Guilliland and Pairman the woman who suffers from preeclampsia may be most in need of continuity of care at a time when her care is most likely to become fragmented.

However, for the LMC midwife who retains responsibility for midwifery care of the woman with preeclampsia, the challenges of providing frequent extra visits to monitor maternal and fetal wellbeing involve time and financial considerations. The current funding system does not adequately recompense a midwife to provide the number of visits that may be involved and for an LMC working with a focus on primary care it will probably not be within her scope of practice to provide midwifery care for the woman who needs specialized emergency care such as management of a Magnesium Sulphate infusion.

### **Post-traumatic stress disorder (PTSD) and preeclampsia**

Post-traumatic stress disorder was first recognized as a psychiatric syndrome in 1980 and originally described among American servicemen who had served in the Vietnam War (Reynolds, 1997). Following exposure to a traumatic event almost all people experience problems such as sadness, distressing memories, emotional instability, feelings of vulnerability and sleeplessness. Usually these symptoms begin to diminish after a few weeks but if emotional symptoms persist for longer than four weeks they may indicate PTSD. These symptoms include:

- Re-experiencing the event: recurrent bad memories of the event or nightmares about what happened.
  - Avoidance: avoiding situations which cause recollections of the event for example the hospital or certain people and places.
  - Increased arousal: irritability, sleeplessness and exaggerated startle responses.
- (van Pampus et al., 2004, p. 183).

The prevalence of PTSD in the general population is estimated to be between 1 and 8 percent and women are twice as likely as men to suffer from the disorder (Wijma, Soderquist & Wijma, 1997). PTSD was specifically related to pregnancy in the 1990's. (van Pampus et al.). De Mier et al. (2000) identified a link between perinatal medical risk and maternal distress in the postpartum period. The first study to investigate the link between PTSD and preeclampsia was conducted by Engelhard et al. (2002). The study explored whether preeclampsia predisposes to PTSD in patients and their partners. The study sample of 113 women and 102 partners included primiparas with recent (<2years) experience of hospitalization for preterm preeclampsia, preterm birth, full term preeclampsia or uneventful pregnancy. Approximately one fourth of women met criteria for PTSD in response to both preterm birth and preeclampsia suggesting that preeclampsia predisposes to PTSD, primarily but not exclusively resulting from the associated preterm birth. The incidence of PTSD in the term preeclampsia group was not significantly lower than that of the preterm group but was substantially higher than the control group, suggesting that preeclampsia as such may contribute to psychological stress.

According to van Pampus et al. (2004) PTSD develops in between five and ten percent of people who experience a traumatic event. The relationship between exposure to the traumatic experience and development of the disorder is complex and only partially understood. Swedish researchers (Wijma, Soderquist & Wijma, 1997) have estimated that between 1.5 and 3 percent of all women have PTSD six months after having a baby. There are clear differences between postnatal depression and PTSD but there are a number of symptoms common to both disorders, for example problems with sleeping and concentration but there are clear differences in risk factors and progression of each condition (Wijma et al., 1997).

According to Quinnet and Hynan (1999) and De Mier (2000) mothers of high risk infants report more symptoms of PTSD than mothers of full term healthy infants. These authors found a small but significant correlation between infant's birth weight and prediction of PTSD. Callahan and Hynan (2002) used a questionnaire to identify symptoms of PTSD related to childbirth and the postnatal period and found that the

severity of postnatal medical complications in the infant is the primary predictor of PTSD in mothers.

It is unclear how to prevent such psychological problems but important to recognize and treat the disorders in a timely and effective manner (Callaghan & Hynan, 2002). Effective treatment for PTSD in the form of cognitive behavioural therapy involves exercises and cognitive restructuring. Psychiatric referral is indicated in serious cases (van Pampus et al., 2004).

### **Implications for the mother-baby dyad**

Psychological disturbances such as postnatal depression and PTSD may have a significant impact on the mother and baby during the important early months following delivery. Recent studies investigated the link between postnatal depression and child development (Hay, Pawlby, Angold, Harod & Sharp, 2003; Kuurstjens & Wolke, 2001). Kuurstjens and Wolke studied the effects of postnatal depression on cognitive scores at 20 months, 4 and 8 years. They concluded that long term effects may be found when maternal depression is chronic, the child is male, had neonatal risks, or the family suffered other social risks. Hay et al. examined the link between postnatal depression and violent child behaviour at age 11 years. They found that in both boys and girls, violence associated with symptoms of attention deficit hyperactivity disorder and problems with anger management were predicted by postnatal depression in the mother. Galler et al. (2004) examined the relationship between maternal mood, infant size, feeding practices and scores in a national high school examination at age 11-12 years. Postpartum maternal moods, including reports of despair and anxiety were found to be significant predictors of lower scores. It is clear that many other variables such as mothers' mental health prior to pregnancy and difficult infant behaviour which could contribute to maternal stress need to be addressed. However these studies point to the probability that the mother's mental state after childbirth is an easily identifiable factor in the child's intellectual and social development. The effect of postnatal depression, posttraumatic stress and PTSD on women's future health and the impact that this has on her child merits further research.



## **Women's experience of Emergency Caesarean Section**

All the participants in my study were delivered by emergency caesarean section, for sudden deterioration in either their own condition or that of their baby. Birth can be traumatic, even an apparently normal birth can be traumatic for some women. The psychological consequences of emergency operative delivery are not well researched. However, certain types of birth such as emergency caesarean section can be psychologically more difficult (Reynolds, 1997). Reynolds cites loss of control and extreme pain during the birth process as one of the two features of childbirth that make it potentially traumatizing. Ryding, Wijma and Wijma (1997) conducted a study aimed at investigating whether women experienced emergency caesarean section as traumatic and whether they experienced post-traumatic stress reactions or post traumatic stress disorder (PTSD) one or two months post partum. They interviewed 25 women a few days and between one and two months following emergency caesarean section. The occurrence of a traumatic delivery experience and post-traumatic intrusive stress reactions such as nightmares, images and intrusive thoughts was assessed. One third of the women had serious post-traumatic intrusive stress reactions although none suffered PTSD. Individual vulnerability was a factor in subsequent development of psychological trauma. Further analysis of the data (Ryding, Wijma & Wijma, 2000) showed that occurrence of a traumatic delivery experience and traumatic stress reactions were related to the woman's ability to feel confident during the delivery and on the relation between expectations and birth experience. The results of this study may be limited by the small sample and comparison of these results with results of research into women's experience of other types of emergency birth would be informative. Boyce and Todd (1992) found that women who had experienced emergency caesarean section, when interviewed at 3 months postpartum, had a six times greater risk of developing postpartum depression than those who had a spontaneous vaginal or forceps delivery.

Post-traumatic stress disorder has been described in relation to pregnancy and birth since the 1990s. Menage (1993) reported post-traumatic stress disorder in women who had undergone obstetric and /or gynaecological procedures.

## **When Preeclampsia leads to loss of a baby**

Studies over the past 25 years have made it clear that the grief involved with loss of a baby does not differ greatly from the grief involved in other bereavement situations (Chambers & Chan, 2004). The Cochrane Review of studies involved with support for women after perinatal death revealed that, based on descriptive studies, one in five mothers or family members will suffer some form of psychological abnormality after perinatal death. They listed pathological grief reactions as abnormally intense, prolonged, delayed, inhibited or distorted. According to Janssen, Cuisinier, Hoogduin & Grauw (1996), grief intensity tends to increase in relation to the gestational age at which loss occurs, but by one year after the birth the mental health of women who had experienced a fetal or neonatal loss was no different than that of a control group, whereas at six months the difference was still substantial. Hughes and Riches (2003) claim that around a fifth of women have disabling grief symptoms at one year following loss and these authors suggest that parents who suffer perinatal loss are likely to experience grief lasting up to two years. Grief is said to be prolonged if there is no improvement by 6 months after the loss (Hughes & Riches).

Capitulo (2004) conducted a study involving online communication between bereaved mothers and one grandmother who had experienced a perinatal loss through miscarriage, stillbirth or neonatal death. For all of the participants their loss had been a life changing event. The online perinatal loss group enabled mothers to express their grief and support one another. Grieving was able to become visible beyond the time when society expects mothers to show their grief following the loss of a baby. According to Capitulo time may help many mothers to recover from their grief but some might not ever heal completely, or wish to do so. Grief was exacerbated by holidays and anniversaries which brought profound sadness. Many women recounted stories online about family and friends who were unsupportive and refused to listen, precipitating more pain for the bereaved. Partners often grieved differently and women told of relationship problems associated with their grief. Chambers and Chan (2004) highlighted the difficulty and inadequacy of research in the area of grief support following perinatal death. Little is

known about factors predictive for perinatal grief or the most effective means to prevent or reduce the severity of distress. There is no information available from randomized trials to indicate whether or not there is a benefit from providing specific counseling or support following perinatal death (Chambers and Chan).

## **A mother's experience with early onset preeclampsia**

Susie (Anderson, 2002) contacted NZAPEC for support following the death of her baby after her traumatic experience with very early onset preeclampsia. She subsequently wrote her story for the newsletter. Selected excerpts from her story highlight the trauma of losing a baby who has to be born too early because of severe preeclampsia:

*It's a week since my baby boy, Benjamin, passed away. He'd been delivered at 25 weeks, as a result of my pre-eclampsia. He was with us for 19 very precious days. 19 days of a bigger roller coaster than I could ever possibly hope to describe. I know we're a lot luckier than some people are, because at least we got to know him. Nevertheless, I am still very hurt and very angry with myself, God and all those well meaning people who say hurtful, well-meaning things.*

*I felt guilty. I still feel guilty. A health professional telling me that "there's no need to feel guilty - it's not your fault" just doesn't cut it when you are well aware that your health is the reason that your baby is being delivered so quickly. I hope one day to have a happier story to share with you all. We had the most beautiful little boy. He had a lovely room to come home to, a beautiful big garden to play in and a huge family and lots of friends who were looking forward to his arrival with great anticipation. It seems so cruel and unjust that that mean monster, pre-eclampsia snatched our baby, who had nothing wrong with him bar his prematurity.*

Susie's story illustrates the heartbreak that can be associated with severe preeclampsia and grief deepened by guilt over maternal illness resulting in a birth of a baby too premature to survive is poignantly conveyed. The literature does not represent women such as Susie well. It is appropriate that my study focuses on women's experience of preeclampsia as there is a clear need for this type of research to be conducted.

## **Summary**

In this chapter I have presented some historical aspects of preeclampsia and outlined the current theories concerning etiology of the disease. Current understanding of

pathophysiology is summarized, including a section on HELLP syndrome. The wide range of symptoms experienced by women presents a diagnostic challenge and experts continue to debate optimum management. Severe preeclampsia frequently involves emergency caesarean and women's experience of this procedure is explored. Implications for the future health of the woman who has preeclampsia are introduced and prevention is briefly covered.

The New Zealand Lead Maternity Carer concept is explained and the challenge of providing continuity of care for a woman who develops preeclampsia is introduced. While much is now understood about the nature of preeclampsia it still remains a challenge. Early diagnosis is not always easy. The speed at which it can develop into severe disease such as HELLP syndrome is rapid. Women and babies' lives are at risk and the aftermath of such a childbirth experience can lead to PTSD. Finally I have introduced the voice of a preeclampsia sufferer to bring the focus back to the research question "What is the experience of women who develop severe early onset preeclampsia?"

## Chapter Three

### Research Design and Method

#### Introduction

In this chapter I will set out my reasons for choosing interpretive phenomenology as a means to address my research question “What is women’s’ experience of severe early onset preeclampsia?” I will discuss the philosophical underpinnings, which have guided and illumined my work and show how the research question and the method used are appropriate. In particular the philosophy of Heidegger, van Manen and Gadamer has seemed to “fit” my study, and examples will be used to illustrate this claim.

The structure of the study will be set out, including recruitment of participants, interviewing, data analysis and ethical considerations. Rigor and trustworthiness will be addressed.

#### Philosophical Approach

##### Phenomenology

The roots of phenomenology originate in the “preparatory phase” influenced by the work of Franz Brentano [1838-1917] and his student Carl Stumpf [1848-1936]. It was through the work of Stumpf that the scientific rigour of phenomenology was demonstrated (Madjar & Walton, 1999). The philosophy was further developed by Edmund Husserl [1859-1938] in Germany before the beginning of the First World War. Since then this method of inquiry has come to occupy a prominent place in modern philosophy. Phenomenological research is an interpretive methodology that is concerned with understanding phenomena that are part of human experience. As such it is well suited as a methodology with which to address my research question. Phenomenology is a method for investigating and describing a phenomenon precisely as it is experienced, in terms of what it means for the person who experiences it. Husserl coined the precept *zu den sachen selbst* (towards the things themselves) to emphasize the focus of his philosophy.

Three schools of phenomenological inquiry have developed according to Cohen and Omery (1994). The first, guided by Husserl has been termed descriptive or eidetic, and shows evidence of association with the positivist (empirically verifiable) paradigm. This was probably a reaction to critics who regarded qualitative research to be “soft” and unscientific (Denzin & Lincoln, 1998). Koch (1995) agrees that the Cartesian tradition, in which all beliefs must submit to proof beyond doubt, is evident in Husserl’s phenomenology. Husserl’s focus was the nature of knowledge (epistemology) while his pupil Martin Heidegger (1889-1976) focused on the nature of existence (ontology) (Cohen & Omery). Heidegger regarded hermeneutics as a philosophical, rather than a scientific method of inquiry.

The second school of phenomenological philosophy is guided by the work of Heidegger whose philosophy aims to interpret phenomena and uncover hidden meanings. Hermeneutic inquiry guided by Heidegger is commonly referred to as hermeneutics. Other terms include interpretive phenomenology and existential phenomenology (Koch, 1995). The term existential is likely to relate to the influence of Gadamer (1989) who was mentored by and continued the work of Heidegger. Gadamer’s form of inquiry is known as hermeneutic phenomenology.

The third school has been guided by the Dutch school (including van Manen) and represents a combination of descriptive and interpretive phenomenology. (Cohen & Omery, 1994). I have found the work of Heidegger, Gadamer and van Manen to be particularly helpful in my interpretation of women’s experiences of preeclampsia.

### **Heideggerian Hermeneutic Phenomenology**

Heidegger (1927/1962) focused much of his lifetime work on ontology, the study of being. He believed that phenomenology was the access to ontology: “Only as phenomenology is ontology possible” (p.60). Heidegger was concerned with the phenomenology of human being, or Dasein. This state of “being-in-the –world” is a position through which we make sense of our existence. He stated, “Phenomenological description, as a method, lies in interpretation” (p.61). A Heideggerian notion which

leaped out and caught my attention as being perfectly suited to the study of women's experience of phenomenology was Heidegger's (1927/1962) notion of phenomenon as "What lies in the light of day or can be brought to the light" (p.51). Preeclampsia may be present as a disease affecting a pregnant woman or her unborn baby for some time before diagnosis. The challenge lies in seeing and recognizing what must eventually be brought to light.

Fundamental to interpretive phenomenology as described by van Manen (1990) is the notion of "existentials" or "life world themes". He describes "lifeworld" as the lived world as experienced in everyday situations and relations. Apart from the different lifeworlds experienced by different people and by individuals in various situations, there are four existentials that are used for guidance in the research process; "lived space (spaciality), lived body (corporeality), lived time (temporality), and lived human relation or other (relationality or communality) (p.101).

Lived space is concerned with the way a person experiences the space they inhabit physically such as their home or hospital room but in a more general sense may refer to the context of a person's being such as background and profession. Lived body relates to the fact that we encounter another person firstly through their bodily presence. The bodily presence both reveals and conceals (van Manen, 1990) and may be affected by the presence of another, for example, under the gaze of another the body may lose its naturalness (Linschoten, 1953; Sartre, 1956 cited in van Manen, 1990). Evelyn felt self conscious and shy as midwives provided postnatal care for her following her caesarean section:

*...you become such public property as well .The midwife had to help me with expressing and you know, every part of your body's being looked at, examined and so that was quite overwhelming.*

Lived time is subjective and is about a person's way of being in the world in a temporal sense. What has happened in the past travels with a person to shape their present time and the present experiences may modify the influence of the past. Perspective on the future may be coloured by past and present experiences. For example, a woman who has been critically ill during childbirth may have an altered awareness of the fragility of life

as she embarks on parenting. Lived other is the lived relation with another person either in a physical sense as people meet in a corporeal way or indirectly e.g. through written or electronic communication. For example Lynda felt the presence of her obstetrician in a therapeutic way following the very preterm birth of her baby at 25 weeks:

*Later in the ward I was sitting in the bed facing the window and Natalie came in and she said a little prayer, put her hands on our shoulders and then she kind of stopped and Dave and I were kind of just sitting there, and we turned around and she'd gone. Like a little angel. We didn't even hear her leave the room. She has such a nice manner, she's so gentle you know. It's so nice to have somebody calm like that in the middle of all the stuff that's going on*

These notions have helped shape my understanding of the nature of the ontological world at the focus of this inquiry.

## **Gadamer**

Hans-Georg Gadamer [1900-2002], like Heidegger, claimed that philosophical hermeneutics does not involve a rigid system of collection and analysis of data. Gadamer (1989) says, "A person who seeks to understand must question what lies behind what is said. If we go back behind what is said then we inevitably ask questions beyond what is said" (p. 333). His focus was the illumination of the ordinary process of understanding (Habermas, 1990), claiming that understanding gained would not necessarily be superior, rather that it would be different. Being mindful of this I am aware that interpretation of data in my study is my own interpretation and as such can contribute just *some* further understanding of women's experience of preeclampsia. According to Gadamer "Discovery of true meaning is never finished, it is an infinite process". (p. 265).

Gadamer introduced the two central ideas of pre-judgement and universality to phenomenological thought (Ray, 1994). According to Gadamer, pre-judgments, or prejudices are part of a researcher's linguistic experience and horizon of meaning and therefore make understanding and interpretation possible. As such they should not be put aside. He maintained that in the process of coming to understand, fruitful prejudice is separated from that which obstructs understanding (Dowling, 2004). Universality



refers to the common human consciousness shared by researcher and subject, which makes understanding possible.

### **The Hermeneutic Circle**

The hermeneutic circle (Gadamer, 1989) is a concept basic to hermeneutic interpretation. The interpreter needs to have some ideas and a beginning understanding of the “text” that is being interpreted. From this starting point, understanding is developed from what is already understood and consequently the enhanced understanding illuminates a fresh starting point. Another way of looking at the hermeneutic circle is to see that the “whole” can only be understood through “grasping” its parts and parts can only be comprehended through an understanding of the “whole”(Crotty, 1998). Therefore hermeneutic interpretation becomes a cycle of understanding, which is constantly expanding.

Gadamer (1989) describes the hermeneutic circle as the fusing of horizons, which is a circular process. Horizon is a metaphor for range of vision (Walsh, 1996). In order to understand the meaning of something for another person, the researcher must not stay rigidly attached to their own fore-meaning, but needs to remain open to embrace the meaning held by the other person (or text). According to Gadamer, the researcher who is aware of his or her own biases is able to recognize the uniqueness of meaning held by another. Heidegger and Gadamer shared the belief that it is through language and speech that our “Being-in-the-world” is both manifest and understood (Maggs-Rapport (2001). The words of the participants have been interpreted by me and are now offered in yet another layer of interpretation. Such is the interpretive nature of ‘meaning’.

### **Hermeneutic interpretation**

Hermeneutic interpretation of text can be traced back to ancient Greek study of literature and Biblical exegesis (explanation of Biblical text) in the Judeo-Christian tradition (Crotty, 1998). However the term “hermeneutics” has been used in the context of Biblical studies from the seventeenth century and since that time has been applied to interpretation of non-Biblical texts as well as human situations and behavior in order to gain deep understanding.

Language is fundamental to human reality and written language (text) can transmit meaning between people. According to Crotty (1998) “Hermeneutics assumes a link between text and reader that provides a basis for the interpretation that is to emerge” (p.91). Through interpretation of text it is possible that the interpreter may gain an awareness of meanings that the author of the text may have been unaware of or unable to articulate.

### **Pre-understandings**

Researchers may have a great deal of knowledge about their chosen area of study prior to commencing interpretive research. Husserl believed that prior knowledge would influence interpretation and urged the researcher to aim to put this knowledge aside.

The process of suspending the researcher’s beliefs in order to study a phenomenon is termed “bracketing”. Husserl borrowed the term from mathematics. However phenomenology is not empirical or theoretical but rather, according to van Manen (1990); phenomenological study “aims at gaining a deeper understanding of the nature of our everyday experiences” (p.9). The same author questions whether it is possible for a researcher of human science to put aside their own knowledge and suggests that presuppositions will constantly come back to mind during reflection. According to van Manen:

*The problem of phenomenological inquiry is not always that we know too little about the phenomenon that we wish to investigate but that we know too much. Or, more accurately, the problem is that our “common sense” pre-understandings, our suppositions, assumptions and the existing bodies of knowledge predispose us to interpret the nature of the phenomenon before we have even come to grips with the significance of the phenomenological question. (p.46)*

I came to the study with knowledge of the condition of preeclampsia and experience in caring for women with the disease at varying levels of severity over many years of midwifery practice. I believed that I had considerable knowledge about my research question from my experience. The experience of caring for one particular woman has

stayed vividly in my memory because of the seriousness of her condition and the concern I felt as her Lead Maternity Carer. Subsequently through my involvement with women who had contacted NZAPEC for support or to offer their stories for publication in the newsletters I had gained further insight into the lived experience of preeclampsia as I stated in Chapter One. My experience prior to conducting my study was that women were usually quite shocked to hear the diagnosis of preeclampsia, that hospital admission was traumatic, advice was often conflicting and that many women were afraid to consider another pregnancy following an experience with severe disease. In my research I aimed to clear my mind (to the best of my ability) of my own experience of caring for clients with preeclampsia as I listened to participants' stories.

According to Crotty (1996) cited in Crotty (1998) "Phenomenology suggests that, if we lay aside, as best we can, the prevailing understandings of those phenomena and revisit our immediate experience of them, possibilities for new meaning emerge for us or we witness at least an authentication and enhancement of former meaning"(p.78).

However, it would have been impossible for me to "bracket" my knowledge of women's experience of preeclampsia in a Husserlian manner as I believe that my background travels with me in my research journey. In line with the thinking of van Manen I considered my pre-understandings at the commencement of my research. I have aimed to approach data openly without prejudicing the material. Because of my close and ongoing involvement with women who have developed preeclampsia my pre-understandings frequently came back to my mind as I reflected on the data provided by participants' transcripts. However my pre-understandings offered me a comparatively superficial and "taken for granted" understanding of the lived experience of preeclampsia and through my study I have gained a deeper insight into women's experience of the disease. Gadamer's (1976) notion of the researcher bringing their own horizon or prejudice to a study, and the belief that this pre-understanding enables the researcher to interpret data and constitute understanding has guided my study.

## **Study design**

### **The research question**

My research question was “What is women’s experience of severe early onset preeclampsia?”

### **Ethical approval**

Ethical approval was obtained from the Auckland Ethics committee in March 2003 (Appendix A). Throughout my study I was aware of the need to protect the rights of participants, particularly as there was a potential for distressing memories to be triggered during interviews. My ethics application included a personal commitment to provide for the cost of counseling for participants should the need become apparent during the research process.

Although participants experienced some distress while talking about their experiences, the need for counseling did not arise. In each case women were very willing to talk about their experiences and when given the opportunity to discontinue the interview if painful memories were triggered, all opted to continue after a short break as they wanted to share what had happened to them.

### **Recruitment of participants**

Inclusion criteria for this study were that women had experienced severe preeclampsia at less than 34 weeks of pregnancy and that they were fluent in English. Sampling involved both purposive and snowballing methods. Purposive sampling resulted in three women expressing interest in being interviewed in response to an advertisement in the NZAPEC newsletter. Two women approached me after being told of the study by Sue Watson, convenor of the Trauma after Birth Support group, TABS. The sixth woman contacted me after one of the participants told her about the study. Following the initial recruitment another two participants became involved after they had provided their stories for the NZAPEC newsletter. It was apparent that their experiences offered rich data and they willingly agreed to be involved. The latter of these participants was

diagnosed with preeclampsia at 37 weeks, which was much later than stipulated in my inclusion criteria but because she had been unwell from 30 weeks and as her experience was significant for my study I elected to include her. I had anticipated that between 5 and 9 women would be interviewed. The sample of eight women provided a level of information that seemed sufficient as similar themes were repeated (Kleiman, 2004). In phenomenological inquiry the number of participants usually ranges from one to a maximum of 10 (Giorgi, 2003).

In phenomenological research the emphasis is on interviewing small numbers of participants in order to obtain in depth data concerning a phenomenon, rather than the utilization of larger samples to provide information that may be generalized to a large population as in quantitative research. The study aims to research the meaning of what it was like for these women to experience preeclampsia at a gestation where delivery for their own safety involved some compromise of safety for their babies.

## **Study Participants**

All women were European and with two exceptions had experienced severe early onset preeclampsia in their first pregnancies. Two women had experienced severe preeclampsia in their third pregnancies. All but one have had pseudonyms allocated to themselves and their babies. One preferred to use her own name. I will list the participants with a brief summary of their experiences as follows:

**Evelyn and baby Grace** Admitted to hospital at 32 weeks and induced at 34 weeks. Baby Grace delivered by emergency caesarean section for fetal distress. Progressed well.

**Victoria and baby Amy** Admitted to hospital at 30 weeks. Very urgent emergency (crash) caesarean section the following day for fetal compromise diagnosed during ultrasound scan. Progressed steadily through challenges of prematurity.

**Nadia and baby Thomas** Diagnosed with HELLP syndrome at 33 weeks 5 days. Emergency caesarean section. Nadia's condition critical at time of delivery but both recovered well.

- Kate and baby Lilly** Admitted to hospital with severe preeclampsia at 29 weeks. Condition suddenly deteriorated (fulminated) over several hours and Kate delivered by emergency caesarean section. Baby Lilly in poor condition but recovered steadily despite several complications of prematurity.
- Lorena and baby Brent** Lorena developed preeclampsia in her 34<sup>th</sup> week and was admitted to hospital at 34 weeks. Initially was to be induced but as condition was deteriorating rapidly, delivered by emergency caesarean section. Lorena critically ill postoperatively. Experienced post traumatic stress disorder (PTSD) but not diagnosed until subsequent pregnancy.
- Lynda and baby Sean** Lynda had experienced preeclampsia with two previous pregnancies. Babies born at 31 and 32 weeks and progressed well. In third pregnancy Lynda developed severe preeclampsia at 24 weeks. On admission to hospital initially stable but deteriorated after several days and delivered by emergency caesarean section. Baby Sean died aged 5 days from complications of prematurity.
- Sarah and twins James and Tim** Sarah was admitted to hospital for fetal monitoring and doppler studies due to suspected poor growth of one twin. She was diagnosed with severe preeclampsia in hospital and delivered by emergency cesarean section.
- Deb and baby Johanna** Deb's first two pregnancies had progressed well. Her third "did not feel right" from the start and she developed symptoms of headache and slightly raised blood pressure from 30 weeks. Deb was admitted to hospital at 37 weeks in a critical condition. Baby Johanna was delivered by caesarean section. Johanna has slight developmental problems

Participants were initially provided with an information sheet about the study (Appendix B) and after reading this agreed to participate by signing a consent form (Appendix C). I contacted them occasionally regarding progress of the study and offered them all a copy of the completed thesis.

## **Protection of participants**

Anonymity and consent have been mentioned above. Tapes and transcripts were kept without identifiable names in a private home office. The typist responsible for transcription of tapes signed a confidentiality agreement (Appendix D). Any detail concerning the participant, her midwife, doctor or hospital, which may have lead to identification, has been removed or altered.

At the commencement of each interview I explained that I was very aware of the potential for distress through the sharing of the woman's experience and offered to discontinue the interview should it prove to be upsetting for the participant. Most women became tearful as they recalled their illness, and recording was stopped when this happened. However no participants opted to discontinue the session as they were keen to share their stories, often beyond the time of the interview. As I left each participant I ensured that they were feeling emotionally safe and found that most women felt that the opportunity to talk about their experiences had been helpful.

Occasionally a woman would express negative feelings about her caregiver (s) and I was very aware of my professional responsibility to avoid commenting on the practice of another midwife or doctor.

## **Interviewing**

### **Venue**

Interviews were all conducted in the participants' homes with the exception of one, which was conducted by phone and letter because of distance. Following the receipt of a letter from this woman I phoned her and asked her to clarify some of the things she had written. After the phone conversation, during which I wrote notes, I crafted a story which I then emailed to the woman. I then received back an amended version, which I have used for analysis.

### **Interview process**

The interviews were unstructured and lasted from one to two hours. I requested a second interview with one woman as she had a lot of painful experiences to share and I felt that

prolonging the initial session would have been too hard for her. She was very positive about being available for a second interview some weeks later.

Staying mindful of the need to remain close to my research question, I commenced each interview with an open-ended question such as ‘Please tell me about your experience with preeclampsia starting from when you were first aware that you were unwell’. From there participants would talk quite freely. I occasionally asked for clarification with a question such as “Could you please explain what that felt like to you?” It was rarely necessary to bring the woman back to the topic, as invariably the research question was the focus of her recalled story.

One of the purposes of the interview in hermeneutic human science according to van Manen (1990) is “...exploring and gathering experiential narrative material that may serve as a resource for developing a richer and deeper understanding of a human phenomenon” (p. 66). From the first interview I was aware that the women were sharing with me insights that I would have not had without being involved in this study and I felt very grateful for the commitment that they showed to my study by being so willing to share their experiences in an open and in depth manner. Kleiman (2004) discusses a relationship of dialogical openness between researcher and participant with the researcher ready to allow the participant to speak and ready to listen. “It is in fact this proffered readiness to listen that inspires participants to relate what presents itself to their consciousness in the immediate situation.” (p.5). As interviews surprised me with new insights I made entries into a reflective journal.

## **Transcription**

Most tapes were transcribed by the typist who asked for clarification from me when taped details were unclear. I personally transcribed the last two interviews. I spent time reading and re-reading transcripts to “dwell with” the data long enough to ensure that I had captured a pure and accurate description of the phenomenon as advocated by Madjar and Walton (1999). Early in the research process the transcripts were returned to participants in order for them to amend any part. One woman returned the transcript to me without reading it as she was too busy but said she had felt very happy with the



interview and was confident that the transcript would be satisfactory. Others made minor changes. It was encouraging to become aware of how committed the participants had become to the study. This awareness deepened my commitment to the study and the participants being mindful as van Manen (1990) noted "...participants of the study often invest more than a passing interest in the research project in which they have willingly involved themselves...And accordingly, the researcher develops a certain moral obligation to his or her participants that should prevent a mere exploitive situation." (p.98). My commitment to use participant stories to shed further light on womens' experience of preeclampsia was strengthened.

## **Reflection and Analysis**

Ultimately the project of phenomenological reflection and explication is to effect a more direct contact with the experience as lived (van Manen, 1990, p.78). This has been both challenging and exiting as I have struggled to move from description to reflection and in the process come to a deeper understanding of my research question. However, interpretation was not necessarily the final step in the research process as I found that insights occurred at each stage from data collection to the final stages of analysis. Gadamer (1960/1982) said, "Discovery of true meaning is never finished, it is an infinite process" (p. 265). I do not claim to have answered my research question, I am merely on the way to discovering the answer.

Human science research involves the crafting of text (van Manen, 1990). Following transcription of interviews, I read through transcripts several times before crafting each transcript into a story. Keeping in mind my research question, I reluctantly discarded any material that did not apply directly to this. The process of deriving a story from the interview transcripts has been described by Caelli (2001) and serves to reconstruct the narrative in a chronological and logical order. The crafted stories retained large sections of authentic quotes from participants but flowed more naturally than the transcripts without the inclusion of repetition or irrelevant material. From these narrative stories, it became apparent that key ideas were emerging and on these I based my preliminary interpretation. This method is in keeping with van Manen's thematic analysis in which "grasping and formulating a thematic understanding" refers to "a means to get at the

notion we are addressing” (p.79) rather than a rigid process. Themes, or “essential meanings” (Kleiman, 2004, p.7) help the researcher to see and focus on an aspect of a phenomenon, and are a means of providing shape to the writing of the research project but as van Manen (1990) has pointed out “Theme *is always a reduction of a notion*. No thematic formulation can completely unlock the deep meaning, the full mystery, and the enigmatic aspects of the experiential meaning of a notion.” (p.88). I was aware, as stated by Kleiman, that while one essential meaning may have a foreground presence, one or more others may also be present and that “individual essential meanings are not distinct elements as they appear in varying relationship to each other” (p.7). Certain texts were so rich that it was difficult to confine them to only one section of analysis as they related to various themes.

Working with parts of the copious collection of data at times clouded the picture of the whole. The global sense is important for determining how the parts might be constituted (Kleiman, 2004). Through a cycle of writing and re-writing, reflecting, discussion with supervisors, re-writing and reduction, three chapters were formulated. Philosophical ideas such as Heidegger’s (1927/1962) phenomenological notions of “showing and semblance” (p.51) guided and illuminated my analysis.

These notions in particular seemed to shed light on the phenomenon of preeclampsia particularly well. It is often difficult for midwives and doctors to diagnose preeclampsia in a timely manner and the confusing ways in which preeclampsia “showed itself” to women and caregivers highlighted the challenge encountered with recognition of this confusing disease.

Kleiman (2004) reminds researchers that accuracy of interpretive findings must be substantiated in the raw data. I frequently returned to the transcripts to ensure that I had remained true to the context of the data. My interpretation was presented to other midwives for feedback and critique. Several presentations were made to colleagues with similar professional backgrounds. Ideas were discussed at group supervision meetings with students at similar stages in their own research. My supervisors who are both experienced midwives challenged and affirmed my developing thesis and therefore I

acknowledge the input of many others as well as the participants who so willingly shared their stories.

## **Rigour**

The concept of rigour in qualitative (naturalistic) inquiry has been debated over more than 20 years. Aroni et al. (1999) suggested that concern about rigour may stem from the fact that researchers working in the qualitative paradigm have been drawn into positivist thinking and risk losing integrity in their own methodological positions. In the words of Mays and Pope (2000) many who do not embrace the qualitative paradigm remain skeptical. Tobin and Begley (2004) suggest that following a long history of important scientific findings, the language of quantitative research has become the universal language of research rather than that of a particular paradigm. Hamburg and Johansson (1999) argue that transference of terms across research paradigms is inappropriate but Morse (1999) cautions against outright rejection of terms from the quantitative paradigm in case this leads to rejection of qualitative research as a science.

Tobin and Begley (2004) postulate that qualitative researchers should not reject the concept of rigour but place it in the context of their work. Thus the debate continues. Tobin and Begley consider that rigour should apply to both positivist and interpretive paradigms but suggest that the language relating to rigour in qualitative work is expanding to include terms such as goodness (Arminio & Hultgren 2002; Denzin & Lincoln; 2000, & Smith, 1993). The concept of goodness should be reflected in the entire study through at least six elements according to Arminio & Hultgren. These elements are epistemology and theory, methodology, method, researcher and participant as multicultural subjects, interpretation and presentation and recommendations. This chapter contains evidence of my journey through five of these elements of research. Recommendations for practice will follow in the discussion chapter.

The work of Guba and Lincoln (1989) was important in proposing three major criteria of “credibility”, “transferability” and “dependability” for evaluation of qualitative research. Credibility has been demonstrated by the response I have received when discussing my interpretation with midwifery colleagues, undergraduate students, and

supervisors. I have also discussed some of my findings with participants and all have agreed with my interpretation. Maggs-Rapport (2001) regards a 'dependable' study as one which employs a methodology appropriate to the research question and suggests that "as an integral element of 'good evidence', the dependability of a study in displaying the appropriateness of the science behind the method, and the effective transference of that knowledge to others, should be of paramount concern." (p.12). I have argued the case for the appropriateness of the science and the method and by presentation of this thesis I hope to add to the knowledge about women's lived experience of severe preeclampsia.

Koch and Harrington (1998) suggest that a research project is plausible when the work is engaging, has an internal logic achieved by detailing each interpretive, reflective turn. These authors argue that 'reflexivity' enhances the credibility of qualitative research.

Reflexivity involves ongoing self-critique and self-appraisal and a recognition that research is shaped by its context. Throughout my study I have monitored my journey of collection and interpretation of data through self-reflection and feedback from academics, clinical midwives and participants. I have explained my personal context and that of the participants. I have aimed to write in an engaging manner and keep the thread of logic as I have linked narrative and interpretation with philosophical notions. I have found the participants' stories moving and challenging. My goal has been to ensure that their voices are heard, some new understanding of their experience will be revealed to you, the reader, and that you travel easily through the worlds of my participants as I have interpreted them.

## Summary

In this chapter I have explained the philosophical influences that have underpinned my study. I have briefly discussed the history and meaning of phenomenology and hermeneutic enquiry and stated the reason I feel these methodologies fit my research question. I have outlined the methods used in this research including gaining of ethical approval, recruitment and protection of participants, and collection of data. Analysis and interpretation of narrative using van Manen's method has been described and this is set within the context of the hermeneutic circle and lifeworld existentials.

The importance of acknowledging pre-understandings and prejudices has been explained and set in a personal context as my pre-understandings have traveled with me. The chapter concludes with a discussion on the debate concerning methodological rigour in qualitative research and the ways in which this study meets with acceptable standards. The following three chapters contain verbatim excerpts from participants' stories and my analysis of the themes, which have emerged from a study of the narratives. My interpretation of the phenomenon of women's experience of preeclampsia is presented:

***Zu den sachen selbst!***

***(To the things themselves!)***

***Husserl 1859-1938***

## Chapter Four

### The Showing of Preeclampsia

Diagnosis of preeclampsia at a time which is optimal in terms of maternal and fetal wellbeing is a challenge for the midwife or doctor. The disease may “show” itself in many ways, some obvious, some atypical and confusing. Symptoms may hint that something is wrong, they may come and go, they may be confusing or they may suddenly announce the disease with frightening urgency. Heidegger (1927) defines “appearances or symptoms of an illness” as occurrences in the body that show themselves and in the self-showing “indicate” something that does *not* show itself. (p.25). The possibility of this self-showing looking like something else as a “semblance” of another disease process is always a danger (Heidegger). This is a great challenge for pregnant women and their caregivers.

The experience of pregnancy is unique for each woman. As a pregnant woman anticipates her advancing pregnancy and approaching birth she expects certain things to happen depending on the knowledge she has gained from her previous experiences, other women, her own research and from her maternity caregivers. When her experience differs from her expectation of what she understands to be normal, it is likely that a woman will be concerned. It may be very difficult for a primigravid woman in particular to recognize the boundaries of normal in pregnancy. Often the variation will be minor and no cause for alarm but when preeclampsia is developing the variation may be a warning that heralds serious complications and the need for prompt intervention. It is this realization that **something is different, something is wrong, the “showing” of preeclampsia** that will be explored in this chapter.

#### **Hinting, hiding, confusing**

Evelyn was the one participant whose “hinting” of preeclampsia was typical in that her blood pressure started to increase several weeks before she was diagnosed with the disease. She recalled the first time she became aware of the possibility of preeclampsia:

*It was around about my 28th week and my midwife had been checking my blood pressure regularly. She picked up that my blood pressure had risen slightly and just sort of made mention of it and referred me to an obstetrician. He just went over what preeclampsia is, and didn't necessarily say that was what it was going to be. So it was just kept an eye on basically, and then, a month later I was referred back to him around about 31 weeks and my blood pressure had gone up further, I also had 1+ of protein in my urine...*

This example illustrates a type of “self showing” indicating that preeclampsia may be developing. The first symptom appeared before the woman was really unwell and there was then an indication to watch vigilantly for further signs and symptoms. This type of “showing” makes diagnosis and management of preeclampsia relatively straightforward for the maternity caregiver. Progress is reasonably predictable and there is time to watch and wait with the awareness that intervention will be likely at some stage in the future.

Other examples suggest that preeclampsia may be considerably less predictable and may initially confuse both woman and caregivers, sometimes leading to potentially dangerous delays in diagnosis. Kate felt that something was wrong for several weeks before she was diagnosed with severe preeclampsia at 29 weeks:

*At about 20 weeks I started getting some oedema. By about 25 weeks my mother was getting quite concerned about how much oedema I had and how I was feeling. By about 26, 27 weeks I could leave really deep thumbprints of oedema all the way up to mid calf. I didn't feel great, I was really tired, and I just felt really gungy. It's hard to describe, but I guess that kind of fluey feeling-I don't know if that's how I would describe it but I generally didn't feel well. With the oedema I was finding mobility difficult as well. I had so much oedema. Mum was worried about that as well. My face had suddenly ballooned since the previous time she saw me. That really triggered her concern and John's as well, me just feeling unwell, and just looking unwell. I think I looked really sick. I was very tired and run down for about four weeks before Lilly was delivered.*

Kate experienced the general malaise common to women who are becoming sick with severe preeclampsia. Her oedema was severe, especially so early in pregnancy and she was finding it hard to walk and function generally. Family members are more likely than the midwife to be aware of “the showing” of preeclampsia in the middle trimester because antenatal visits are still monthly at this stage. This highlights the need to educate women early in pregnancy about the symptoms which indicate the need for

urgent assessment. Women with severe preeclampsia frequently describe a feeling of “unwellness” which may be attributed to a viral infection or physiological changes in pregnancy. Such a showing is a “semblance”. It may seem that a woman “just feeling unwell” has a condition such as the “flu”. Consequently the preeclampsia remains hidden and unrecognized until another time.

Lynda, who had experienced preeclampsia in two previous pregnancies, was 24 weeks pregnant when she started to feel unwell with flu-like symptoms:

*It all went well until about twenty four weeks, then I started getting backaches, quite high between my shoulder blades. I was just feeling like crap, having a bad day for a day, and then it would go away for two or three days and then come back. I had headaches, no energy whatsoever, just like I had been knocked about really badly. The pain came on at night and I felt my bed was really, really uncomfortable. I could not lie on anything and be comfortable. It was like something suddenly changed. In hindsight I remember I felt quite bad with my first baby Scott but I didn't connect it, because I had no problems with blood pressure or protein or anything. With him I remember feeling really in pain, like there was no relief. I got in and out of the bath twice trying to relieve the pain. It was just like a bad flu you know.*

When Lynda started to experience symptoms of preeclampsia she did not connect her pain with her symptoms which heralded the onset of the disease in a previous pregnancy. Perhaps she did not want to acknowledge to herself that her pregnancy was becoming complicated. Perhaps the pain was so strong and she felt so unwell that rational thought was precluded. She may also have discounted the possibility of preeclampsia occurring at such an early gestation. After several episodes of intense pain Lynda rang her midwife for advice:

*I got these wicked backaches, but I didn't know what it was. I rang my midwife, and she said it was just a virus, so I went back to bed, and the next day I felt OK. Four days later it came back again. It was only in hindsight that I realized that it was a similar thing to with Scott but it wasn't obvious because I had no problems with blood pressure or protein or anything. I think the third time it happened I went to the doctor crying, thinking it must be a kidney infection after I looked through the books that I had- which wasn't much, - but I thought it's got to be something, you can't just tell me it's a virus, you know-recurring at intervals like that. The doctor took my blood pressure and told me it was high.*



When Lynda experienced the pain for a second time she didn't seek advice from her midwife. How are midwives to "know" when something is wrong when the woman doesn't report back with continuing symptoms? Lynda had been told four days previously that her symptoms were probably due to a virus and therefore she might have been reluctant to re-contact her midwife. How can midwives ensure that their clients feel free to contact them if concerned, without risk of feeling that they are over-reacting?

It is interesting to consider what might be happening to a woman and her baby in the times when the symptoms disappear, even when they have been severe. The disease itself does not disappear in those times but appears to hide in the absence of symptoms, potentially confusing both the woman and her caregivers.

By the third time the pain returned Lynda knew that something was wrong, she thought "It's got to be something" and assessed herself as possibly having a urinary infection after consulting her books. Linda elected to see her GP who found that her blood pressure was high.

*He was mildly concerned about it, did the urine test and gave me antibiotics for a possible kidney infection. He asked me to see my midwife in three more days for another blood pressure check.*

It appears that the GP was not sufficiently concerned about the increase in blood pressure to order any blood tests that may have led to a diagnosis of preeclampsia. However he did ask Lynda to see her midwife for a further blood pressure check in three days time. There is a danger in not being in step with the potential rapid progress of preeclampsia. Paradoxically, the disease may be progressing rapidly even though the woman is less symptomatic or even feeling well:

*I went to see the midwife on the way to work. It was strange, I was feeling better by then but my blood pressure was 180/100 or something like that! The midwife took it, she sat down, took it on my other arm and then she took her own blood pressure with the same machine! By this time I thought-"Uh-oh-I'm in trouble now"*

Perhaps the midwife didn't believe the blood pressure reading and hence tested it again and then took her own blood pressure with the same machine. Perhaps she did not want

to have to tell Lynda that her pregnancy was probably now seriously complicated. As “guardians of normal birth” midwives may feel disappointment when a pregnancy becomes abnormal and may tend to want to “normalize the abnormal” or protect the woman from the knowledge that things are not going well. Lynda was actually feeling better at this stage and might have looked to the midwife for confirmation that all was well. It seems the midwife’s initial disbelief may have delayed her recognition that preeclampsia was now being announced through the blood pressure. This is how it can “hide” and “confuse”. However, the preeclampsia was by now announcing itself clearly and prompt action was necessary. It appears that Lynda’s “Uh-oh” signifies that she certainly recognized that she now had the condition yet again.

Lynda’s risk of developing preeclampsia was high following two previous affected pregnancies. When she had reported feeling unwell with flu-like symptoms it seems that her midwife was not alarmed. Perhaps she may have suspected reoccurrence but was thrown by a much earlier manifestation than in the previous pregnancies. When Lynda presented to the GP with an increased blood pressure and recurring back pain he also did not appear to be very concerned. This raises the important need to be aware of the increased risk for vigilance when women have a higher risk of developing the disease.

Sarah had a greatly increased risk of developing preeclampsia in her first pregnancy as she was expecting twins, had a family history of preeclampsia, an IVF pregnancy and gestational diabetes. At 32 weeks she was admitted for investigation of abdominal pain and malaise and discharged when the results of investigations were normal:

*Everything was perfectly normal with my pregnancy until about 32 weeks. I then developed some right upper abdominal pain which was so bad at one stage I rang the on - call obstetrician and went into the assessment unit. The pain was quite sharp, I had also had some vomiting and diarrhea, felt generally unwell and hot. They did tests for listeria and some liver function blood tests but they came back normal. They suggested the pain could have been caused by one of the babies kicking me or perhaps I could have had a gall stone and suggested that I have my liver scanned during the next ultrasound examination.*

*Over the next two weeks the pain got worse and definitely felt like liver pain. It was right under my ribs, almost like my ribs were being squashed in, quite*

*uncomfortable especially at night. I didn't have any swelling except a little in my fingers, but did have a slight headache at times.*

It was another two weeks before Sarah was diagnosed with HELLP syndrome. Her blood pressure remained normal and she had no proteinuria. Her condition had “shown itself” in a preliminary way at 32 weeks but remained hidden when all the test results were negative. She continued to be unwell and on reflection it seems there were very strong signs that all was not well between 32 and 34 weeks. It was fortunate that Sarah was in hospital when she was diagnosed as the condition announced itself with urgency:

*At 34 weeks I was admitted to hospital so that a series of Doppler studies could be done for one of my babies, James. They wanted to do daily measurements every day for a week to make sure there was a good blood supply getting through to him as the sonographer hadn't been able to visualize James's cord very well on my ultrasound and it seemed that he may not have been growing as well as Tim. As it turned out there was no time to do any Doppler studies on James as when I was in the ultrasound department waiting for my scan one of the doctors came rushing down with my blood test result and said I would have to be delivered immediately!*

James was the messenger who initially brought the information that Sarah's pregnancy was affected by preeclampsia. His suspected poor growth led to Sarah's obstetrician requesting hospital admission. Intra-uterine growth restriction is common with preeclampsia but in itself is just an indication that something is wrong and there are many complex possible contributing factors, especially with a multiple pregnancy. Sarah did not have any of the classic signs of preeclampsia and yet she had the condition and her pregnancy was becoming unsafe.

Smythe (1998) discusses the notion of safety and unsafety in regard to pregnancy. She explores the concept of where the safety or lack of safety lies, suggesting it may be in the darkness, where what is happening is not seen or even imagined. Over the two weeks prior to hospital admission, Sarah's pregnancy had probably already started to be unsafe heralded by her pain, gastro-intestinal symptoms and headaches. She was clearly unwell. For Sarah, there was unsafety. For her, the unsafety of her preeclampsia was initially “in the darkness” but revealed itself as the poor fetal growth of one of her babies:

*I had been in hospital just over night and had my first lot of blood tests in the morning, then a repeat test about three hours later just prior to going for my scan. I had a really awful night. I must have been deteriorating over night as I had been very restless and couldn't sleep much. I was really, really hot and flushed. I didn't have a fever, someone took my temperature and it was normal but I just felt absolutely dreadful. I was really uncomfortable, so hot that I was getting cold flannels to put on my forehead and felt like I had a temperature of 40°! I didn't think that I was right after a night like that. I knew I shouldn't feel that hot. I had the abdominal pain and back pain during the night as well.*

*I had a routine blood test that morning and my results were abnormal. My liver enzymes were high and the obstetrician told me that he thought there had been a mistake in the laboratory leading to someone else's results being reported under my name. He ordered a repeat test to be sure, although he did say there was a chance I might have to have the babies that day. I knew that the results were probably right as I was expecting to develop preeclampsia at some stage.*

*I walked down to the ultrasound department that morning to have my scan and waited for an hour, sitting there with a thumping headache. I hadn't had anything to eat or drink just in case I needed to have an anaesthetic for an emergency delivery and I was feeling really unwell. They were planning to scan my liver as well and the sonographer had just started to do that when the house surgeon came down and said "Right, We'll take you back in a wheel chair and we'll have to get you ready right now".*

## **Announcing**

There is no doubt about Sarah's diagnosis at this stage, although the obstetrician did not at first believe the blood test could be right. There could be a degree of surprise and disbelief when a woman presents atypically with preeclampsia. However, Sarah was certainly at increased risk for development of the disease because of her family and current pregnancy history and it seems she had a more realistic awareness of what was happening to her than did her obstetrician. Normal blood pressure may hide preeclampsia and falsely reassure professionals that all is well. However, the blood pressure may become elevated very late in the disease and so much can change so quickly.

The announcement via the laboratory results was urgent, the condition was revealed and there was no time to wait, Sarah had to be delivered. Prompt delivery resulted in a safe outcome for this woman and her twin sons. What might have happened if she had not

been admitted for assessment of fetal wellbeing? Sarah's symptoms could be described as a "semblance" of several other problems such as a viral infection or cholelithiasis:

*I wonder if I should have had some more regular blood tests as had James been growing normally I might not have been diagnosed early enough to have a safe outcome.... My blood pressure had been normal on the day I visited my obstetrician when she admitted me in order to monitor James. I guess if I had interpreted my symptoms as something like a viral infection I might not have been diagnosed had I been at home at that point. I didn't have the classic signs of preeclampsia. I probably would have thought "I was assessed two weeks ago and nothing was wrong, I'm just being paranoid..."*

A woman at home is perhaps more likely to think "It's probably nothing serious" so as not to bother anyone or appear to be a worrier. Had Sarah remained at home she may have dismissed her symptoms as she had earlier been investigated in hospital and discharged without any diagnosis. Nadia, when in her first pregnancy and 33 weeks described how she felt something "did not feel right". For her, the preeclampsia "announced itself" after her symptoms led to admission to hospital following two days of atypical intermittent pain:

*It was on a Monday, and I was at work. I just had a bit of pain in my chest, but only when I breathed in. It kept going during the day and so I rang the midwife that evening and talked about it and she said well you know its probably the baby kicking –you know, on your ribs and stuff which you know, is pretty normal. Anyway we came to the conclusion it must have been right because, that evening the pain just disappeared, and the next day Tuesday (I took the day off work just because I was feeling tired) I was fine. We went out that night for a Christmas BBQ and everything was fine, then it was about the middle of the night, 2 o'clock in the morning, and I had this back pain between my shoulder blades– constant pain, it didn't go away. So then, on the Wednesday morning I rang the midwife again and said "something doesn't feel right" and then she said "Well alright we'll go to the hospital, get us booked in and check it out". Previously I'd had just a little swelling in my ankles, and a little bit in my hands but nothing major, and my blood pressure was pretty OK.*

Nadia's pain was not the classic epigastric pain experienced with severe preeclampsia. According to Heidegger (1927/1962) a true phenomenon shows itself as it is. But when something shows itself under the guise of what it is not, then we are faced with a semblance, or a "seeming." As with the example concerning Lynda, the semblance confounded diagnosis, leading to delayed recognition of preeclampsia.

Nadia describes how the following day she decided to take a day off work as she felt tired. Whilst this is a normal experience in pregnancy, many women recall feeling tired and generally unable to cope prior to the onset of severe preeclampsia. Nadia's pain had settled for twenty four hours or more after first appearing. When symptoms hint that something may be wrong and then disappear the condition which may have been "shown" by the first onset of pain may seem less likely because of the fleeting or intermittent nature of the symptom. As with Lynda's experience, for Nadia the disease itself remained hidden while progressing silently. The second time the pain occurred Nadia had a sense that all was not well with her pregnancy, and her midwife responded by organizing a prompt specialist assessment.

Preeclampsia can announce itself with frightening urgency. In some cases after an apparent improvement or disappearance of symptoms the disease can fulminate and demand an emergency response. For Nadia, who was starting to feel that she was in hospital unnecessarily, the diagnosis of HELLP syndrome left her feeling shocked and incredulous:

*So they checked me out which took a while because they do your blood tests and everything was fine! I remember the consultant said it was probably gallstones or something like that because the blood tests came back OK. So we thought we might just go have a scan and check the baby out. Anyway of course by about 2 o'clock the pain had gone and I thought "What are we doing here?" Then it got to about 4 o'clock in the afternoon and I had more blood tests just to double check. The results came back at 5 o'clock showing the platelets were 39! (Normal range 150-450 x 10<sup>9</sup>) The level had been low earlier but nothing to be really concerned about-that was how fast it went. I was feeling better than I had in the morning. I mean - I was like "Are you sure this is right?" I was really upset.*

Initially Nadia's symptoms were incorrectly interpreted as discomfort from the baby kicking. Even after initial assessment in hospital the provisional diagnosis was possible gall stones. However, the cause of her symptoms was eventually "announced" as the phenomenon of preeclampsia by the conclusive laboratory result. This story shows that the blood picture can deteriorate without pain or visible symptoms. While Nadia said that her platelets were reduced earlier but nothing to be really concerned about there is a

suggestion that there *was* a concern otherwise the blood tests would not have been repeated. Nadia also felt that her midwife's persistence was a factor in the further investigation:

*I thought well yeah, if it wasn't for her, I mean, I guess it was me saying I knew something wasn't quite right – I didn't know what, but because she believed in me and said ok we'll check it out – and she did, she kept onto the doctors saying you know "it must be something!"*

This example shows the importance of listening to the woman. It would be easy to dismiss symptoms that are erratic or appear to be resolving but Nadia's midwife had faith in her client's feeling that something was wrong and was prepared to persist until an accurate diagnosis was made. Her concern led to timely intervention for Nadia and her baby Thomas. Delay may have been tragic.

## **Feeling better/deteriorating**

A paradox which may be very significant for midwives to be aware of is the fact that most of the women had started to feel better when their preeclampsia was deteriorating to the point where they needed urgent delivery. If a woman has been symptomatic of preeclampsia but her condition has not yet been "announced" by laboratory testing or other signs such as hypertension or intra-uterine growth restriction, it may be reassuring for the woman and the midwife when the symptoms improve or disappear. Had Nadia not been admitted for investigations her disappearance of symptoms could have dangerously reassured her and her midwife that all was well.

This reassurance may clearly prove dangerously false as some women can be very unwell without realizing the extent of their illness. Lynda queried the urgent decision to deliver her very premature baby when the specialist decided it was necessary to act promptly:

*I didn't actually feel that bad myself at that stage, but I knew the outcome was not good. I was worried for the baby but not really for me. I didn't know what all the fuss was about. I mean, it was preeclampsia but like I say I did not feel that wretched. I felt that I should not be there*

Lynda was in hospital when her condition deteriorated- there is the possibility that for some women deterioration may have gone unnoticed at home, with devastating consequences. In contrast to some of the previous data, Lynda did not feel progressively unwell as her condition deteriorated until the day her blood tests revealed a sudden further deterioration. Consequently she queried the urgency for delivery:

*I said well I don't actually feel much worse than I had- because I had felt so bad at places along the way anyway so I kind of thought well-do you have to do it now?*

For some women it was the baby that announced the urgency to deliver as shown by the following examples:

### **Baby as announcer**

For Victoria, it was the baby that “announced” the severity of preeclampsia and the time for emergency delivery. Victoria had been admitted for investigations after her blood pressure had become high. For this woman the revelation that her preeclampsia was deteriorating the day after admission to hospital came through awareness that her baby was not moving well and an ultrasound which showed an absence of fetal movements. At the time Victoria felt well herself, in fact she did not reach a point when she felt unwell at all: *I felt ok, and even right up to when they decided to take her out, I felt fine really.* Victoria was unaware until 30 minutes before her emergency caesarean section that her condition was dangerous:

*They kept asking me – can you feel the baby kicking? And (I was) thinking “well yeah kind of” – but on the Wednesday morning I didn't. They said “we want you to go down for an ultrasound” and I just sort of walked down by myself, down the elevator, and it was really – you know, compared to the ultrasound at the radiologist which was reasonably quick this was sort of a half hour of just, just probing, you know, no sort of comments or anything, it was just watching, just watching, and they didn't really say anything to me. I remember thinking it sort of looks the same as the previous scan but the baby wasn't moving. I remember sort of thinking – you know, it sort of looks like there was something wrong,, yes, it was quite surreal – like the first time I really realised, even then it took a while, when I left the ultrasound and the lady gave me my file, she said “I'm just going to call the doctors upstairs, you go back up with your file and go straight upstairs and go to your room, to your*



*bed, and don't get a coffee or anything on the way." And I remember thinking – oh that's odd- and it was like "Oh OK, yes."*

Victoria's baby's movements had slowed and there had been some concern over fetal wellbeing. The ultrasound revealed the very serious condition of her baby and there was no time to waste. Victoria had not experienced any symptoms of preeclampsia herself. Despite having a high blood pressure she had felt well and even though her baby was becoming compromised by the disease, the severity of the condition remained hidden until the ultrasound scan revealed the baby's critical condition. Walking back to the ward she was unprepared for the reception that awaited her:

*And so I went back up and I walked into the room and that's when I knew, because, and I walked down the corridor past the reception desk, and there were a few people there who kind of looked at me as if to say "Oh that's the one!" And I didn't – I kind of thought, I'll go back to my room and I had my file, and I went down to my room – there were about 8 people standing there, (Laughs) And then I knew – and even then they were just so quick, they were very good. They were like –Oh Hi Victoria, come on get back into bed, and they got me in the bed before they'd actually said "We're not happy with your baby- with what's going on, your baby's not moving we're going to get it out. Even then, this is like – so stupid, even then I said, Oh-what, tomorrow?-No- in half an hour. Now!*

Victoria had not realized the urgency of the scan and the degree of concern of the sonographer who so calmly directed her back to the ward alone and orchestrated the prompt preparation of the obstetric team for an emergency delivery. She had not experienced any symptoms associated with worsening disease but her reporting of baby's reduced movements had led to an awareness of deteriorating fetal wellbeing and the decision to deliver urgently. There was no time to become stressed or worried about the baby as everything happened so fast for Victoria:

*We're going to prep you now, we'll call your husband now, and you need to sign this form now. I thought it was too late to worry – and too late to argue, and I couldn't.*

## Unrecognized announcing

Preeclampsia is a disease which progresses unpredictably and its symptoms are often unexpectedly mild or unusual prior to the point where emergency delivery becomes necessary for the mothers safety. Even on an antenatal ward, symptoms which announce serious deterioration may not be recognized by staff. Kate remembers experiencing severe pain and breathlessness in the night and telling the nurse who seemed not to understand the significance:

*So the protein had been increasing and my blood pressure had been creeping up, but on the Friday night I had a lot of epigastric pain, pain with breathing and from my point of view I really did not feel good. I suddenly felt sick and threw up and it was all bile. I was having a lot of pain and really uncomfortable and I knew there was something not right. I'd buzzed from the toilet and nobody came. I waited about 20 minutes and I must have crawled back to bed after that and buzzed again. I said to the nurse - there's something wrong here. I was really uncomfortable with the pain. She didn't do anything about it. I couldn't sleep all night, had a lot of pain, it was shocking. Then the next nurse came on and I must have gone out to the desk and said look there's something not right here or asked to see a doctor or something. They found that my liver and kidneys had inflamed overnight and then they said - That's it you're going to have your baby now. That was it - I was having an emergency caesarean section that morning. Of course I was crying and I was really upset - I was really terrified for how well Lilly was going to do, I knew it wasn't good for her. Then when I went down to theatre I was so stressed out I was really shaking.*

For Kate, the epigastric pain which is considered to be a classic symptom of severe preeclampsia was not recognized by the staff nurse (or midwife) on the antenatal ward. She experienced severe pain throughout the night and knew that something was not right. The pain and fear and deterioration she experienced during the night culminated in an emergency caesarean in the morning when it was eventually acknowledged that she was very unwell. By the time she went to theatre she was so stressed she was shaking. While this may not be uncommon, for Kate, the previous few hours of pain with no support or reassurance were a "shocking" prelude to the birth of her baby. As well as the emotional and psychological stress it is possible that the apparent indifference of the nurse or midwife could have led to a very dangerous outcome as Kate's condition was clearly deteriorating rapidly. Even though Kate had been diagnosed with preeclampsia and admitted to hospital for monitoring, her deterioration was dangerously overlooked.

Kate recognized her serious deterioration but was thrown by her failure to convince the staff that she was so sick.

## Atypical Pain

The pain associated with liver complications in preeclampsia is mentioned in midwifery texts as epigastric (Henderson & McDonald, 2004). Several of the participants experienced a different sort of pain, leading me to question the completeness of information in reference books available to midwives, and the consequent advice given to clients. Lynda's back pain has been mentioned. Her initial pain was experienced in her upper back, between the shoulder blades and as she became more unwell in hospital she described her pain in this way:

*I just had that pain in my back but I was having Panadol the whole time I was in there. The pain was kind of between my shoulders and up to my head. It was just like a force, like something was pushing really hard. Yes, it went up to my head, it just felt like pressure basically. I tried to stay as still as I could but it was very uncomfortable-the bed was very uncomfortable and they'd puff up your pillows, and tilt the bed up but there wasn't much relief. If I took Panadol it just kind of took the edge off it- it was mostly just like pressure. I felt restless because I couldn't get comfortable.*

Pain between the shoulder blades is sometimes experienced when there is inflammation in the liver. Lynda never experienced classic epigastric pain at all and the pain that she described could have been attributed to another cause had her condition not been revealed by her hypertension. It has been mentioned that Nadia initially had intermittent pain on inspiration and later on developed back pain as her condition worsened. Kate also experienced pain on inspiration which she did not associate with her condition:

*I started getting some epigastric pain but I didn't realize what it was actually. I kept saying I was having trouble breathing, because I didn't realize that that was what they were talking about- in fact it wasn't until well after I'd had my baby that I read that was what they meant by epigastric pain, because it didn't appear like that it only hurt to breathe. - I can remember getting that the night after I was admitted and I'm sure that I said something to a nurse about it and of course I was really really tense at this stage and I was getting pretty paranoid about me. Stupid stupid stupid nurse that was on!*

*I remember when I was younger and I can remember it felt as if I was having trouble breathing, I could never explain it- I can't remember exactly what the*

*experience was but I really found it uncomfortable breathing and was really quite worried about dying in my sleep or not being able to breathe or something like that. And then when I get stressed my breathing is shallow so I can remember having all that going on. I wouldn't have buzzed the nurse about that, but I would have been silently scared about it.*

Kate recalled feeling afraid and reluctant to call for further help on the antenatal ward after she had initially mentioned her chest pain and difficulty in breathing to a nurse who had not realized the significance of the symptoms. She articulated the tension between being silently intensely afraid and the fear of being judged as “paranoid” by staff. Rather than recognizing that the symptoms were a sign of worsening preeclampsia, Kate wondered if her symptoms were caused by her own tenseness and stress. The feeling that she was possibly responsible for her symptoms perhaps contributed to her reluctance to seek help. It seems pain does not come pre-labelled to assist diagnosis. In the experience of pain the woman must make her own interpretation of what it could be and is often unlikely to have any prior experience to draw her understanding from. Experiencing epigastric pain and recognizing it for what it is are two different things.

### **Unrecognized typical pain**

Even when preeclampsia is heralded by the classic epigastric pain the significance may go unrecognized. Lorena experienced upper abdominal pain for several days before being admitted to hospital with severe preeclampsia: *At that time I had some pain under my ribs like a bit of indigestion or something.* Lorena was not aware of the significance of her pain. She had been asked by her midwife to have a blood test for preeclampsia suggesting that there had been some concern. This example illustrates the necessity for clear explanation of the symptoms that a woman may experience as the disease progresses, in order that she may report changes in a timely manner. Sarah's experience has been discussed and her story shows that classic symptoms may hint that preeclampsia is developing. However, in the absence of confirmation by laboratory tests, it may be falsely assumed that the pain is associated with another cause, taking the focus off the preeclampsia which is still hidden but soon to announce itself.

## Summary

There needs to be a more comprehensive understanding of the type of pain and other symptoms experienced by women with severe preeclampsia, realistic explanation offered regarding symptoms to report, an open communication to enable the woman to feel free to check out vague concerns and a vigilant continuation of surveillance when symptoms come and go. For the midwife who is watching and waiting, trying to keep in step with the woman so that she doesn't miss a sign which may herald the onset of disease, it can be an anxious time. It is likely that research will uncover a predictive test which may provide forewarning to the practitioner so that the identified 'at risk' woman may be provided with a level of antenatal surveillance which will keep ahead of the 'showing' and especially the 'announcing'. Until that happens, however, the confusing, hinting, coming-and-going showing of preeclampsia is all there is to initially guide the woman and her practitioner.

## Chapter Five

### The Revealing of Preeclampsia: Thrownness

Once a woman has been seen to have preeclampsia a period of urgent action swiftly unfolds. In this chapter I will discuss the women's experience of being told that they had preeclampsia, the revealing of the condition. In a sense this experience is a state of "thrownness" (Heidegger, 1927). Heidegger (Inwood, 1997) formed the noun "*Gerworfenheit*" which means "Thrownness". It is derived from "*Werfen*" meaning "to spin, turn or wind". A derivative of *werfen* is *Wurf*, a throw of a ball, and *entwerfen*, to project. For the women in this study there was a sense of thrownness, of being projected into the unforeseen as they struggled to come to terms with the realization that their pregnancies were seriously complicated.

The Heideggerian concept of thrownness is explained by King (1964). Firstly the existentials or "ways of being" *attunement* and *understanding* should be considered. Moods and feelings constantly "tune man" and "tune him in" to other beings as a whole. Attunement always has its understanding; understanding is always attuned (p.77). Different moods and feelings reveal man, in the generic sense of 'person' to himself in different ways. For instance if a man is experiencing a joyful mood, he is aware of himself as a person who is enjoying himself and if he is experiencing anxiety he is aware of being troubled by worrying thoughts. King explains that "moods and feelings rise from Man's thrownness and bring him face to face with it" (p.77). Heidegger's notion of thrownness is not about man being thrown by some unknown force but rather about "his own 'real' existence" being manifest to himself "in the curious way that he can always and only find himself *already* here" (p.78). King discusses the fundamental impotence and dependence of man and comments that this inability to make and master his own being is "elementally revealed by attunement".

The diagnosis of preeclampsia many weeks from the expected date of delivery inevitably involves many unforeseen changes to the present and future for each woman. Life in the present is suddenly thrown into turmoil and the future becomes uncertain.

The sense of “thrownness” is described by Lynda as she discusses the loss of control she experienced when diagnosed with preeclampsia at 24 weeks in her third pregnancy and for many weeks after the birth and neonatal death of her premature son:

*Because I think I live quite well and we eat quite healthily I think to a great degree you control your own destiny really don't you? I feel like you should be in control of your own body and it's a frustration when you are not -is that how people feel when they are ill? If you haven't been sick you have got no idea about what it's like and I just hated feeling sick and out of control. That feeling of being out of control started before the birth-that spinning out of control faster and faster. You don't expect it to be that bad (in pregnancy) losing a baby and being really sick as well.*

What can prepare a woman for severe preeclampsia that threatens her own life and leads to the death of her baby? Because Lynda felt that she should have some control over her health she felt frustrated to recognize that she had been able to do nothing to prevent the frightening tornado of devastation brought into her life by preeclampsia. When a pregnancy becomes seriously complicated others must be involved in the controlling, it is no longer just a personal responsibility. For Lynda there was a sense of disempowerment as she became attuned to the reality of her diagnosis. She described it like this:

*As a mother you take care of your family-that's what you do and when you can't that's not the way it's supposed to be. All of a sudden the cart spills over and you don't kind of know where you are. Everything's up for sale you know!*

Lynda's metaphor of the cart spilling over aptly describes the sudden turning upside down of her life when diagnosed with preeclampsia. Suddenly her life was in disarray, nothing was in its normal place anymore and nothing was ordered or predictable. Her identity and purpose were threatened as she could no longer carry out her most fundamental role – that of being a mother.

The statement that “everything is up for sale” suggests that familiar things may go; valued things may be taken away by others. The woman will no longer own the things that have shaped her life. There is the possibility that she may lose everything, and there

is a sense of uncertainty about the future. Even her dreams for her new baby are cruelly shattered. The notions of thrownness involving shock, fear and disbelief, lost time, lost dreams, the possibility of death and guilt are explored in this chapter.

## **Shock, Fear and Disbelief**

For the women in my study, the revealing of preeclampsia involved a degree of shock, fear and at times disbelief. Lynda was admitted to hospital at 24 weeks when her blood pressure became dangerously elevated. As she had experienced preeclampsia in two previous pregnancies when she gave birth at around 30 weeks, she expected to be in hospital for a while. Initially it was thought that her condition was not critical and after a few days there was discussion about going home for the weekend. Unfortunately, on the Friday afternoon, blood tests revealed that Lynda was becoming gravely ill with preeclampsia and needed to be delivered urgently. Whilst she had initially been relaxed and philosophical about her admission, she was then shocked, particularly as she knew that delivery would involve significant risks for her very premature baby.

*On the Friday night it just happened quite suddenly. You know they were there all the time taking my blood pressure. Someone else would come and take it, and somebody would tell someone else they did it wrong and they'd do it again. In the end the specialist said we've got to do it now- and I said well I don't actually feel much worse than I had- because I had felt so bad at places along the way anyway so I kind of thought well-do you have to do it now? (I had been told that morning that we had to get to 28 weeks). But I think it was just when I started to feel like I was going to throw up, all of a sudden you know-they had me wheeled down the hall. I knew the outcome for the baby- I knew he was small for gestation anyway and I knew the outcome probably wasn't very good. My husband was with me and the kids and they kind of panicked really because they wheeled me down the hall quickly and the kids were kind of just sitting in the hall worrying. I had a spinal anaesthetic and I was thinking things like this don't happen to people like me! Just really worried I think.*

Lynda experienced fulminating preeclampsia which involves very rapid deterioration of the disease and inevitably this involves a degree of shock for her and her family, even when they are aware of the diagnosis and likely progress to premature delivery. For Linda there was a feeling of disbelief as she found herself being rushed to theatre for a caesarean section at just over 24 weeks. The same morning, she had been told about the



aim to reach 28 weeks before delivery. As she was undergoing her spinal anaesthetic her sense of concern about her baby heightened as she realized that delivery for her safety would jeopardize her baby's life. This is an unenviable predicament for a woman, and Lynda's thoughts included doubt about the necessity for the urgency as she queried the need to operate so soon, although her symptoms immediately prior to surgery indicated her deteriorating condition.

Lynda's story powerfully illustrates the thrownness of preeclampsia. The disease throws Linda but so does the obstetrician who informs her of her need to deliver immediately. Linda's husband and children are thrown as they helplessly watch their wife and mother being rushed off to theatre when earlier in the day they had been expecting her to go home for the weekend. Like a stone thrown in to water the shock of immediate delivery has a ripple effect in the family and the maternity services. The obstetrician and theatre staff no doubt had their plans thrown by the need to perform an emergency caesarean section as the high dependency and neonatal units would have been thrown by new admissions.

Evelyn was also upset because of the insight she had into the challenges of prematurity, and her fear of what lay ahead. Heidegger's analysis of fear (King, 1964) includes the "fear of" experienced by Evelyn here as she anticipates the threat to her baby involved with premature birth. Her "fear of" is deepened by the insight she has gained from observing her friend's experience:

*[When I knew I had preeclampsia] I was absolutely devastated...Mainly because I had a girlfriend last year who had preeclampsia and had it very suddenly- within 24 hours she had delivered her baby who was born at 1100 grams and so I was very familiar with what her experience had been and the emotions that she'd experienced. Looking at her baby and going through the neonatal intensive care ward and the thought of the chance of that happening to me - knowing the statistics for it occurring just seemed unreal really. So yeah I was quite shocked and upset because I knew what was coming. A lot of the symptoms I had were what I would associate with the later stages of pregnancy because I had quite a lot of swelling in my feet, and in my legs, You know it was coming out of summer as well so it was still quite hot but I didn't feel unwell, there wasn't anything necessarily showing up in the tests apart from the standard tests with the midwife, and even though I had seen the obstetrician at 28 weeks*

*when my blood pressure first went up it was still a shock to know that I might have to deliver early.*

Evelyn's feeling of devastation was connected with the realization that she may have to be delivered very soon and concern for her baby. She had discounted the possibility of the same thing her friend experienced happening to her. The "hinting" of preeclampsia in the rising blood pressure, a visit to the specialist, and increasing oedema had not established in Evelyn's mind that she may be developing the condition as her friend had done previously. She was thrown by the probable imminent birth for which she was unprepared and the abrupt change in her plans.

Kate gave birth at 29 weeks when her preeclampsia became dangerously severe. She had felt that something was wrong for several weeks. At 25 weeks her mother was becoming alarmed at the amount of oedema Kate had developed. Her partner and mother-in-law were also very worried. Both mothers had themselves suffered preeclampsia but neither of them mentioned it to Kate until a year or two later. Perhaps they did not connect what was happening with Kate to their own experiences or it may have been that they did not want to worry her by introducing the idea. Kate stated that the midwife wasn't too concerned but it is clear that her close relatives were alarmed. When Kate was seen at the hospital because of a pinched nerve in her leg, a blood pressure check revealed a level of 160/90. Kate was asked to contact her midwife for follow up. According to Kate the midwife wasn't particularly concerned but did organize an assessment at the hospital. By then the blood pressure had gone up higher and there was significant proteinuria. By this time Kate and her family were very concerned:

*By this time I was getting really worried and Mum was losing the plot. John was really worried too-but my midwife wasn't particularly concerned about it. When I was admitted the registrar didn't give me much information. Probably he said we're concerned about it and we are going to keep you in hospital and then it wasn't until the next morning when they said 'you know things are not looking good and we'll try to hold out as long as we can but chances are you are going to have your baby in the next two or three days'. Of course I didn't realize until then what was going on, and I completely flipped out and lost the plot. It was a huge shock because you don't know what preeclampsia is really. Most women I think are not really aware of what it is.*

Kate was shocked by her diagnosis as nothing had prepared her for this sudden change in her pregnancy management, even though she had felt that something was not quite right for some weeks. Her family also felt that something was wrong in spite of the midwife's apparent lack of concern. Kate's midwife did refer appropriately and it may be that she had also been concerned for some time but had played this down in order to avoid alarming her. For midwives the balance between informing a woman about the potential risks without causing undue stress is challenging. It is important to be realistic as well as reassuring but to avoid false reassurances. Kate is a professional woman who appreciates a direct approach when discussing her condition. She felt that she had not been prepared realistically:

*I think a lot of the information I had in my books was really targeted for the majority of people who get it (preeclampsia) quite late in pregnancy and typically not that severe. Maybe you have an induction at 37-38 weeks and its no big deal. So that was the impression I had, yes it was a huge shock. My midwife had (it still astonishes me) belonged to APEC (an organization promoting awareness of preeclampsia) so she had information but she wouldn't give it to me at the time because she didn't want to scare me! By that point in time things were getting pretty scary anyway. So probably having the information would have been better than not having it.*

Kate was unaware of how unwell she was at the time of her admission to hospital at 29 weeks, and as she had already been feeling ill for several weeks she did not realize how critical her condition had become. After the shock of being admitted to hospital the waiting is an anxious time as the woman and her baby are monitored. When preeclampsia is diagnosed early in pregnancy the baby's survival can be jeopardised by the need to deliver as the woman's condition deteriorates and her own safety is threatened. For the women in my study the focus of their anxiety was not so much their own safety but that of their babies. Kate clearly indicates that for her, having information would have reduced, rather than heightened her anxiety.

## Fear for the baby

Following admission to hospital Evelyn questioned her ability to assess the movements as this was her first pregnancy and she was unsure of what degree of movement to consider “normal”.

*I found it very stressful watching Grace's heart beat on the monitor. They would ask me questions about her movements. I didn't know what was normal - in your first pregnancy everything is so new. I started feeling movements at 18 weeks and so I sort of measured everything against that. To me that seemed normal, but I kept being told that's not normal, not as big a range of movements as there should be and that was really hard. They would have me on the monitor for 45-50 minutes and I would just lie there looking at it and worrying. Yes, it was hard watching the monitor but in some ways it was comforting, I knew she was alive and every time I saw the movements recorded on the monitor it gave me courage.*

When women are asked by midwives to be aware of their baby's movements and report any concerns it creates a dilemma for them. How are they to recognize whether they are normal or not, particularly in a first pregnancy? How are they to know that their babies are safe? When women know that their preeclampsia can threaten their babies' survival, how does this affect their confidence in reporting fetal movements reliably? Smythe (1998) states “The Being of safe/unsafe is already there, whether it can or cannot be seen and predicted” (p.128). The challenge is to know what is hidden in the darkness. This is particularly challenging when the baby has been the announcer of preeclampsia, or heralds serious deterioration.

Evelyn had considered that her baby's movements were normal but when she was told that the range of movements was not big enough it made her worried and stressed. It may be that she felt no longer able to trust her own judgment about her baby's wellbeing and needed the reassurance of the monitor to convince her that her baby was alright. Even so, she would lie there worrying while the monitor was on even though there was a degree of comfort from the technological evidence that her baby was alive and had an acceptable heart rate.

For Evelyn the focus on the baby's heart rate on the cardiotocograph involved a tension between fear and courage. Seeing technological evidence that her baby was alive and moving gave Evelyn courage, yet as a pregnant mother she already knew her baby was alive by experiencing the movements. How does preeclampsia change a woman's confidence in her ability to assess her baby's wellbeing from awareness of movements? How does it affect her confidence in her ability to nourish and protect her unborn baby? Evelyn's comment suggests that the evidence of her baby's wellbeing was a factor that gave her courage.

Being admitted at 24 weeks, Lynda knew she needed more time for her baby and was worried about him:

*So I was up there for 5 days, just being constantly monitored, every hour, with them taking my blood pressure, and most of the time I felt OK. You're so aware of why you're there in hospital, your attention is so focused, because I had my own room some of the time and stuff like that. When I was admitted I felt alright, I felt quite relaxed actually. I was worried about my baby because I knew how small he was, but because the other pregnancies had gone on further, I thought, I might be in there for a few weeks, and also the specialist had said to me on Friday morning that it looked like it was going OK, so she'd probably send me home for the weekend. I didn't have the flashing lights, they asked me that a million times. I think I got dizzy, but I think that was because of some of the medication. I didn't want to tell them. I just answered questions. **If I didn't have the symptoms they mentioned I didn't have the preeclampsia did I?** They just did a couple of Doppler tests, and it indicated that the baby was small, but indicated that the flow was going forward and backwards, and they just said 'Well we need to get to 28 weeks, stay still, don't do much'.*

Because both of her previous babies had progressed well Lynda had assumed that the outcome would also be similar this time. She knew that even though her baby was small the umbilical artery blood flow was alright and she just needed more time to increase her baby's chance of surviving a preterm birth. She had been told that she needed to get to 28 weeks and had assumed that it would be possible. The fact that the specialist was thinking about sending her home for the weekend further strengthened Lynda's confidence in the prospects of a positive outcome.

It seems that even after admission and investigations Lynda was holding on to the hope that she perhaps did not have preeclampsia again. She did not have all the classical symptoms that staff questioned her about and was quiet about other symptoms as if the verbalizing of more problems may further confirm the diagnosis. She didn't want to tell the staff that she felt dizzy and just answered questions rather than reporting other symptoms. She said "If I didn't have the symptoms they mentioned I didn't have preeclampsia did I?" Was this associated with lingering disbelief or perhaps a desperate attempt to buy time for her vulnerable baby? The desire to hold on for her baby's survival may have conflicted with her realization that admission of symptoms would inevitably led to action that may have included an extremely preterm birth.

As time went on Lynda started to feel more unwell after admission to hospital. She knew she was unwell but still clung on to the hope that this was not preeclampsia as she had experienced it before. One may ask the question "Did Lynda feel that she may avoid developing the condition if she denied the possibility in her mind?" She had been given some hope that the baby may be able to stay in utero until 28 weeks and so was hoping that there would be no need for emergency delivery before then.

Lorena's experience further illustrates the shock and fear for the baby associated with the diagnosis of preeclampsia before pregnancy has reached full term. She was admitted to hospital at 34 weeks:

*After I got to (the base hospital) they started talking about the baby being born within the next few days. They were just monitoring me and the baby. They told me I would need to have another scan and the radiologist had to be called in from home-it was about one o'clock in the morning by then and we were very tired. I had blood tests as well and was still in the assessment unit the next day, which was Sunday. Everything seemed to be OK with the baby from what the radiologist said. **I felt quite scared and frightened because I wasn't expecting this to happen- I wasn't prepared for it.** They took us down to the special baby unit so that we could see the babies and that was very upsetting because they were very little and we knew our baby would be in there shortly. It was quite daunting seeing all the things the babies were connected up to and hearing the noise of the machines.*

Being unprepared for the experience of delivering a premature baby was a major component of the shock and fear experienced by the women in my study. Lorena was upset to see the premature babies and the unfamiliar technology associated with a special care baby unit. Perhaps midwives need to remind themselves that the sight of tiny babies attached to bleeping instruments may be familiar to them but can be frightening to women about to give birth to a premature baby. Lorena's experience reminds midwives that the orientation needs to be sensitive with sufficient time for debriefing. The orientation to a special care unit may do more to frighten than to reassure at the time. However there will always be fear attached to the experience of anticipating a premature baby in the harsh environment of a special care baby unit. The fear is there and cannot be taken away by avoidance of exposure to reality. Consideration needs to be given to discussion to prepare for the potential shock involved with the visit. For a woman likely to deliver early, the experience of seeing another woman's premature baby may be less traumatic than seeing her own with no preparation.

The fear mentioned by the participants invariably stemmed from concern for the baby. Suddenly there may be awareness that the baby may be unsafe and the perils of prematurity need to be weighed against the probability that continuation of the pregnancy may endanger the baby. Perhaps there is the more distressing situation that a very premature baby must be delivered for the safety of the mother. Kate recalls her concern about her baby:

*The anaesthetist came in and spoke to me about the caesarean, the paediatrician came in and spoke to me about Lilly although they don't give you any useful information- they say well there's a risk that you baby won't survive or I think I asked-you know is there a risk of my baby not surviving? They talk in quite general terms-oh yes there is a risk but you never have any idea of how big it is. Before she was born and actually right through when she was quite sick they would never give me anything. But then I ran into something the other day and it said that 90% of babies born over 28 weeks survive. And something like that then, would have been such a useful thing to know. I do remember, when the registrar came in the first day he definitely didn't give me much information because that's when I asked my midwife for more information. She gave me a little bit but not a lot. I would have wanted more I think. I was terrified about how Lilly was doing. Yeah really worried about how she was doing. I can remember lying there counting the kicks, and really keeping a close eye on how*

*often she was moving and things. In the night, the night before I had her, I definitely was concerned about how well she was doing. Probably a lot more worried about her than me, because you don't realize how sick you are.*

Kate has stated that she didn't realize how sick she was. Her focus was on her baby as she approached the challenge of prematurity. It is never easy to discuss the fact that a baby may not survive, particularly in a case where the baby's chance of survival has to be weighed against the risk of the woman continuing a pregnancy that has become seriously complicated. Kate felt that for her, the awareness of risk would have been more acceptable had the risk to her baby been quantified in some way. Not knowing the facts about her own particular risks puts a woman in a situation where she may be unrealistically pessimistic or optimistic. However, what a woman really wants to hear is that her baby will survive and even if she is told there is a 90% chance of survival, her baby could still be one of the 10% that dies. Statistics do not really indicate individual risk. Each woman's needs are different and for rostered hospital staff it is difficult to communicate therapeutically with individual women who they may meet for the first time at a point of crisis. The role of the LMC midwife as a key member in the team is often overlooked when the woman is under secondary care. The importance of the thread of continuity of care from a midwife who knows the woman well, albeit supportive rather than active, may be underestimated in this type of setting.

## **Summary**

The lives of women and their families are 'thrown' by preeclampsia. Much is lost in the throwiness impacting on the present and future reality for the woman. Following initial shock and disbelief, fear for the baby is uppermost in the minds of women admitted to hospital. The support of the woman's midwife following transfer to secondary care is therapeutic. The following chapter will explore the experience of loss and recovery following a diagnosis of preeclampsia.



## Chapter Six

### Loss, Guilt and towards recovery

#### Loss of time

The progression of preeclampsia is difficult to predict. When progression to serious disease is rapid there is little time to adjust. Two days after admission to hospital Lorena's condition deteriorated:

*The specialist came in to say they were going to induce me. But then while he was talking to us some more results must have come in because he came back in about half an hour and said "Your condition has got worse and your baby needs to be delivered straight away under a general anaesthetic" I was quite put off, in shock I think but because it happened so quickly I didn't have time to think about what was happening. So they prepared me for the emergency caesarean. **From being told to the actual birth was about half an hour.***

What is lost when a woman has to deliver weeks before her expected date of delivery? From being told that she would have to deliver to the actual birth was little more than half an hour. There is little time to think in that half an hour, so much happens. The woman is thrown from her imaginative anticipated experience to one that she has hardly considered. Lynda experienced even less time in this emergency decision: ...*Once they decided to do it was about 20 minutes before we were being operated on.* In the urgency there is no time to dwell on particular thoughts as physical preparation and delivery are rushed in order to improve the prognosis for mother and baby. Will the woman be able to articulate her loss? How is the woman to deal with the fear associated with her deteriorating condition? How do midwives support women experiencing such urgent delivery? Similarly Victoria experienced the urgent decision to deliver her baby. This left her with no time to think as the team gathered around her to rush her to theatre:

*I mean, everything just kind of happened – there was no, you know – there was no build up – **there was no 3 weeks of thinking** – how am I going to deal with this premature baby, or – what happens to my health or – there was just nothing – you know even those last sort of 10 minutes, I didn't know. But obviously by then I did! By then I had been in hospital only one night.*

For Victoria there was little time to fret about what might happen. As she had only known the day before that she had preeclampsia there had been little time to dwell on what was happening. It seems that she had not yet fully realized the seriousness of her condition. Victoria missed her time to think about having her baby, the build up to giving birth. What is important in this time to think and dwell on the approaching birth? For Victoria, who had only 24 hours from diagnosis of preeclampsia to emergency delivery there were huge steps of adjustment to be taken. From expecting to have another nine weeks of pregnancy to dwell on the approaching birth and enjoy the anticipation there was almost no time at all. There was no time to come to terms with the thrownness. No time to make sense of the new reality, attune and re-orientate to what was about to happen. No time to prepare for a premature baby. No time to relax and enjoy pregnancy as it was also expressed by Lorena:

*I was finishing on the Friday, so it really upset me because I was looking forward to my 6 weeks off! You know 6 weeks rest before the birth– and it wasn't to be.*

## **Loss of dreams**

Pregnancy is a time of planning for birth and in the final few weeks women may focus on preparing for birth and meeting the new baby. At around forty weeks women are generally physically and psychologically ready to give birth. Nadia described her loss like this:

*... I mean, what was dawning on me more was just this baby that was supposed to be this lovely healthy baby and full term natural birth– all those dreams went out the window. I think just like we were saying in order to be a woman and to have a baby, you should be able to carry a baby for 40 weeks and not have any problems with it you know, just that general thing- you know. I mean afterwards I thought about it and I thought it didn't really matter as long as Thomas was healthy but those feelings go through your head. And no labour you know- all these people were talking about birth– I didn't know what labour pain was or anything or, I guess I felt robbed*

The loss of her dream of a full term healthy baby was a concern to Nadia as she was rushed to hospital for an emergency delivery. The experience had been taken away from

her abruptly and she felt a sense of loss, particularly as she heard other women talk of their experiences later. The labour and birth that others had taken for granted had been taken from her. There is a sense that Nadia may have felt that she had not lived up to her ideal of womanhood expressed by bringing a baby to full term and natural birth.

Kate discussed her feelings about giving birth early:

*I was quite resentful of women having the whole pregnancy-my friends were all pregnant at the same time so I was really aware of their pregnancies and where they were at and stuff- and getting big was a big thing for me-because I never really got much of a tummy. That was really upsetting for me not to have a big tummy and I guess not really feeling as if I was ever really pregnant.*

Kate's disappointment about never having a "big tummy" suggests loss of growing ready to give birth. The end of pregnancy, with its tiredness, the general feeling of really being ready to give birth, being ready to meet the baby in a prepared way was taken away from her. She may be suggesting that being really pregnant is more about being "ripe with child" in a way that may be seen by society as a proof of womanliness. The things that normally happen in the last few weeks of pregnancy are taken away and the feeling of preparedness that most women reach by full term has not been reached. How does this affect a woman as she struggles to come to terms with her experience afterwards? How does she deal with the loss of her anticipated experience of feeling "very" pregnant, going into spontaneous labour, the anticipation of giving birth to a fully grown healthy baby that can be cuddled and nurtured immediately at her breast?

Kate discussed her frustration about being ill, which did not fit with her idea of herself as a well person:

*I mean, nobody's perfect but you like to think of yourself as being able to have a baby and doing that and not being sick and things like that. I just really struggled with the concept of having an illness. I'd always been really healthy and very physically fit as well, and I'd always been very proud of that fact as well. So having that sickness was a huge thing. Not being able to carry her to full term, it really was.*

Kate conveyed a sense of responsibility for her illness. She had been proud of always being really healthy and physically fit and conveyed a sense of having let herself down by becoming sick with preeclampsia. Kate seems to be saying that her image of herself as a healthy woman was shattered by her experience with preeclampsia. Having been proud of her wellness she now implies that she was ashamed of her illness. Does she see her body as “not good enough”, not being able to reach her ideal?

This is how Evelyn expressed her disappointment:

*So it was quite, quite a shock because I knew that there's no way I was going to get to full term with my pregnancy and that was pretty devastating in itself...*

The tension between holding on to a pregnancy that is potentially harmful to either the woman or her baby or perhaps both of them and premature birth involves so much more than physical wellbeing. A woman may not articulate her loss. She may feel that she should be grateful that she and her baby are alive and well. The challenge for her caregivers is to be make time to listen and to facilitate a safety network for the woman as she comes to terms with what has happened to her. Emotional adjustment needs time and it is possible there may be fears too frightening to address.

## **Facing death**

Women “see” the possibility of death for their babies but the risk of their own death is not discussed. Do women consider this risk? Are midwives aware of the underlying fear that may be submerged by concern about the baby? It is not likely that women will easily talk about their fear of death even if they recognize its possibility, however the challenge for midwives may lie in the recognition of the appropriate time to create an opportunity for the woman to share her fears. This may be appropriate before delivery but often time is limited and it may be more appropriate later as the woman tries to make sense of what has happened to her. As Deb arrived at the hospital in a serious condition with preeclampsia her condition rapidly deteriorated. Her blood pressure was 170/110, she was shaking and see flashing lights. She was commenced on a magnesium sulphate infusion prior to having an emergency cesarean section and recalls:

*I felt really terrible and really thought I could die, so much so I wrote a note to my husband to be opened if anything happened to me. For the first time I didn't feel in control.*

Lorena's comment about her unspoken prayer-like thoughts as she was taken to theatre also suggests there can be thoughts of possible death as well as the possibility of losing the baby:

*I remember thinking when I was told I would have to deliver- "I hope my baby's alright and please let me wake up after the anaesthetic".*

There is an understanding in our society that women will not die in childbirth. However, there remains the possibility of maternal death with preeclampsia and it seems that Lorena fleetingly considered this as she was hurriedly prepared for theatre. Perhaps this stemmed from a more general fear of general anaesthesia but the possibility of death was still raised in her mind.

Lorena also articulated concern about her baby and whilst there was a good chance of survival for her baby at 34 weeks, there was still the possibility of an unforeseen problem. For women who have experienced this fear of death as they approached their emergency deliveries or reflected on the possibility once their babies were born there is the possibility that the fragility of life may be with them as they move on. This realization may be sudden or gradual but may make moving on difficult for some women and can be associated with posttraumatic stress disorder.

Lorena discussed the feelings she experienced when she went home from hospital:

*When I got home I realised I could have died, well we both could have died. It was pretty frightening to realise that. I didn't realise that earlier at all and when I got home all I sort of wanted to do was talk about it. No one in my family has been through what I did-I have two sisters and a brother and my sister has three children, all births straight forward... So no one has been through an experience like I had. Although they understood I wasn't well, it was quite hard for people to understand. I needed to talk about it. I just wanted people to know that what I had been through was traumatic and I suppose I just wanted a bit more help as*

*well, just maybe with practical things. I don't always ask and actually say what I am wanting, and so people don't know. I put a brave face on, when really I was almost crying out for help. Once I got home I was just carrying on with you know, being a mother and everything else was just sort of put in the back of my mind, or not really talked about because that was that, we were home now...*

To become aware of the seriousness of her condition after discharge from hospital was clearly traumatic for Lorena. It is possible that she had been told about this in hospital and not fully appreciated how critical her condition had been. It is also possible that she had not been given an opportunity to debrief her experience. For a woman to be at home, possibly alone and come face to face with realizing she and her baby could have died is potentially very traumatic. Lorena's needs were put aside as she tried to fulfil her responsibilities as a mother.

She conveys a feeling of pressure to get on with life and avoid looking back at what had happened to her. Talking about her experience seemed inappropriate in her mind. Others in her life did not seem to open up opportunities for her to talk and she sensed an expectation to leave the experience behind as finished business. The loneliness of not being able to share those frightening feelings with family is suggested here. The importance of being able to talk at the appropriate time, rather than bravely trying to move on is shown by Lorena's subsequent experience:

*When I went for my three month check up the specialist had indicated that I was showing some of the signs of post traumatic stress disorder because when I got home I wasn't sleeping very well. I had dreams that I was still in the hospital and Brent was still down in the baby unit. I'd think about the same thing over and over. The specialist recommended that I see someone, but I didn't pursue it, I didn't do a thing at that stage. I thought I was OK, it's probably just because I'm a new mother but it would have definitely been a good thing to get some help at that stage because when my next baby was born last year, I didn't cope very well after his birth even though it was fifty times better than my experience with Brent. But I think what happened is that **all the trauma from Brent just came back to me when Steven was born.***

*So I did end up going and getting help this time. I saw a counsellor, we talked through what had happened and I just found that talking about it helped me a lot and I suppose time does help as well. I just was probably wanting people to understand what was happening but I suppose unless you've actually been through this experience yourself then you don't, can't really understand what's*

*happened. That's why after Steven was born I did ask for help. Although I didn't do that straight away either but when I did I was glad.*

Could Lorena have had a more positive experience if her postnatal care had involved time with a supportive care provider who had listened to her, created opportunities to revisit and assess her feelings over time and helped the family become aware of her needs? Her experience points to the importance of debriefing after the trauma of severe preeclampsia.

Nadia, who was also delivered at 34 weeks, was told after the birth that she had been dangerously ill:

*Well you don't take a fair amount in because everything's happening so fast – I mean, they did explain that yeah, they did say that I might end up having fits or convulsions or whatever, they seemed pretty positive, they didn't mention the fact that you know, I mightn't survive or anything, that was mentioned afterwards!*

There is no time to think about the enormity of what has happened until later. Who will listen to the woman's fears then? If women are unaware of their dangerously ill status at the time of emergency delivery their partners may be shouldering a lonely burden of anxiety as they await the outcome of surgery and the following hours or days. Angela commented on her husband's anxious vigil:

*My husband was just coping for me, because when I asked him he said "when you went to have the operation I thought I could lose both of you".*

There is regrettably little support available for the partners who are also thrown by the emergency of severe preeclampsia. Their emotional distress is often concealed beneath a veneer of strength.

Tragically for some women the fear of death is realized in the cruel loss of their baby. After being delivered by emergency cesarean section because of Lynda's seriously deteriorating preeclampsia baby Sean died when he was five days old:

*They said the right thing to do is take him out of the incubator and hold him and then they would disconnect the ventilator when we were ready. And they said if they didn't do that they'd just have to keep giving him more and more morphine, but they said there was nothing they could do, he was going to die. So, I mean there's nothing else they could have done, they were doing it for my health, but it's still in your face you know.*

The cruel choice of delivery for the sake of the mother at the expense of her child is illustrated in all its raw painfulness by Lynda's comment "*it's still in your face you know*". These words express exquisite grief compounded by the knowledge that death could have been avoided had preeclampsia not forced an abrupt end to Lynda's pregnancy for her own survival. Another week or two may have meant the difference between life and death for Lynda's baby but there was no choice for her but to deliver and deal with the consequence for Sean. A mother's burden can be very heavy.

### **Feeling Guilty**

Kate experienced feelings of guilt about having preeclampsia, feeling that she had perhaps brought it on by her own stress. When she was admitted to hospital at 29 weeks, her focus was concentrated on her baby's wellbeing:

*I remember feeling very scared about it and really really stressed because of course you get so worked up and everybody says that your blood pressure's connected to stress, so you know, every time you get your blood pressure checks I'd be trying to relax and feeling guilty because I'm probably quite highly stressed, quite highly strung anyway. I'm prone to that. So I felt, I can remember feeling really responsible for Lilly having preeclampsia because I was such a stressed out person anyway. I looked in books wondering-is stress a factor? Is the fact that you're really stressed out and not getting much exercise a factor? I definitely felt responsible for it at the time.*

The emotional burden of feeling responsible for developing preeclampsia and the effect it may have on one's baby is demonstrated by Kate's experience. Had she had someone explain that stress had nothing to do with the development of her condition it may have lightened this burden and relieved her stress considerably. She was very concerned about her baby's wellbeing as the following data reveals:

*I was terrified about how Lilly was doing. Yeah really worried about how she was doing. I can remember lying there counting the kicks, and really keeping a*



*close eye on how often she was moving and things. In the night, the night before I had her, I definitely was concerned about how well she was doing. Probably a lot more worried about her than me, because you don't realize how sick you are.*

Kate felt responsible for the risk she had thrust on her unborn child by becoming unwell with preeclampsia. The night before baby Lilly was born Kate was particularly concerned about her wellbeing and lay awake 'watching' the movements. The concern may have been compounded by guilt but perhaps Kate's vigil stemmed from an inbuilt intuitive knowledge that her baby was in fact starting to be compromised by the preeclampsia as she did not breath at birth and needed resuscitation:

*Lilly wasn't breathing at all when she was born. Her Apgars were pretty shocking. I didn't get to see her at all. They just basically ventilated her, found out she was alive and then said she was a girl and how much she weighed and then they just whisked her out, into the unit.*

Baby Lilly may not have survived much more time in a preeclamptic pregnancy. Her condition at birth did little to reassure Kate who had already fretted over her baby's safety as her own condition was worsening following diagnosis. At such an early gestation it would be some time before any reassurance could be optimistically given to Kate concerning Lilly's chances of survival and normal progress.

Evelyn asked herself questions as she struggled with feelings of guilt and failure:

*I felt a lot of fear as well, and a lot of guilt. I don't really know why I felt guilty, that may be the wrong word - it's just more the fact that I played a major role in bringing Grace into the world, and to say it's not my fault, or not to feel guilty about it (the preeclampsia) seems strange because I carried her inside me and so many questions would go through my mind like - Was it my diet before conception? Was it that half a glass of wine? Was it my age or something environmental? Did my husband have anything to do with it? However the main thing that was going through my mind was just wanting to hold on as long as possible.*

*But just getting back to the guilt thing, I think part of it too is just feeling like a failure. Just like feeling that your body hasn't been able to perform as it should and knowing that you haven't been able to give your baby the best start in life. Because I knew that everyday she was inside me was a real milestone I was literally counting the days in hospital hoping that she would stay in as long as*

*possible even though she wasn't growing, according to the scans but I just hoped that she was. I knew that gestationally, in terms of development, even if Grace wasn't growing every day counted. I had had steroids for her lung development so was reassured but I still worried a lot about her though.*

Evelyn struggled with the feeling that her body had become unsafe for her baby as she had developed preeclampsia which threatened her baby's health. There is a tension between wanting to hold on and nurture her growing baby, knowing that she would be better able to cope with life outside the womb if more mature, and the fear that her womb could now be a dangerous place. The ultrasound scans showed that Grace was not growing but Evelyn held on to a hope that perhaps the scans were wrong and her baby was in fact growing inside her. Each extra day was important. There was a sense of desperateness and holding on for the life of her baby. Perhaps a clinging on to a hope, a dream of reaching full term and a healthy well grown baby. There is a sense that nature has a perfect plan for pregnancy and something has gone very wrong.

Evelyn struggled with her idea of a perfect pregnancy and her feeling of failing her baby. Where was the failure? Where does the responsibility lie? Was the failure due to Nature? Had God failed? Had Evelyn failed? Had the baby failed? What complex tensions stress the mind of a woman awaiting delivery when preeclampsia has shattered her ideal pregnancy?

In her guilt Evelyn looked for factors that may have caused her preeclampsia and impaired her body's ability to "perform" and nurture her unborn child. Evelyn's sense of failure implies that she herself has failed in her pregnancy and in her ability to nourish her unborn baby in her womb. After Grace was born Evelyn still struggled with her guilt. The experience of seeing her premature baby was very emotional for Evelyn and caused her to experience further feelings of failure:

*Even just seeing her so tiny (she weighed 1365gm) and just seeing her, I guess the whole pregnancy was surreal really- you know you've got this life growing inside you but you don't have any real connection with it- apart from what you can feel. Actually seeing her as a real person and such a tiny baby was very, very emotional.*

*I mentioned feeling a failure, you know it was just all wrong, she wasn't meant to be there. I watched her over the next 6 weeks knowing that she was still supposed*

*to be inside me. I'm a bit of a perfectionist and I don't deal with failure very well and I felt like a failure because she had to be born so early.*

For women who are faced with the dilemma of having to deliver their babies early because of their own worsening disease, the experience of seeing their tiny newborns may be more traumatic than when the prematurity has another cause. For women who expect their bodies to perform pregnancy to a personally or societally constructed ideal, this feeling of failure may be acute. The tension between being the nurturer and potential harmer of the baby is acute and challenges the nature of motherhood.

Victoria also queried whether she could have prevented preeclampsia:

*Yeah, you do go through all those guilts, and I certainly did, but I don't think I hold to them that much because I'm more educated now. I've read a bit more and talked to some more people. And also, seeing other people, you know I think I did hold on for a while, to the over weight thing, I thought perhaps – why couldn't I have lost another 10 kilos before getting pregnant? And I feel that now, going through that now, having another baby, and um, well, I'm not pregnant but I think ahead. – I'd like to lose ten kilos but I know that it's incredibly hard. So I did kind of hold onto that a bit.*

Victoria may have been aware that an increased BMI is a risk factor for the development of preeclampsia, and regretted the fact that she had not tried to lose weight before becoming pregnant. There is no way of knowing whether this would have made any difference to her pregnancy outcome but Victoria was concerned about the possible significance of her weight.

The experience of severe preeclampsia may be profoundly distressing. Cherished dreams are dashed and there is little time to adjust to new realities. Women may blame themselves adding the burden of guilt to the acute emotional turmoil that follows diagnosis. The possibility of mortality may be faced for the first time by women whose illness reaches a critical level and for some like Lynda, extremely preterm delivery may lead to neonatal death. Recovery from severe preeclampsia thus involves many challenges.

## **The challenge of postoperative recovery compounded by preeclampsia**

Women who undergo early delivery for preeclampsia usually experience caesarean section. Postoperatively they struggle as the enormity of what has happened to them and their babies starts to sink in and they try to adjust to their new reality, often at the same time remaining very ill themselves. Kate described her struggle:

*I do remember when I was at day 2 or something I was in a wheelchair, going in to see Lilly, and I couldn't have stood up for that long, and I remember the nurse telling me off saying I had a caesarean two days ago and I shouldn't have a wheelchair anymore.! And really, -at the time I thought well I should have recovered faster of course but now looking back I mean I didn't really think. I had been feeling awful, you look at the photos and I had so much fluid on me, I was obviously not well, but you don't think about that, you just are kind of thinking that, you've had the baby, you've taken the problem away, you should be fine. You don't realise you're critically sick. It's not something you really are aware of. My BP kept going up, so they had to keep upping the medication I was on. They kept on doing the reflex thing and of course at the time I didn't really realize, because that's just sort of checking how close you are to a seizure isn't it. And of course I was kicking sky high (Hyper-reflexive). But I never really realised that either. Because you're sort of recovering from the caesarean as well, so you don't really realise that the two go hand in hand. And I was so worried about Lilly anyway that yeah, my health didn't really feature that centrally.*

Kate suggests a tension between striving to recover from her surgery whilst being held back by her continuing unwellness from preeclampsia. Hospital staff who do not have a sense of continuity of care for a woman with severe preeclampsia may not appreciate the challenges she has overcome and continues to face. Early ambulation is encouraged after surgery but the needs of a woman such as Kate are clearly different from those of a woman who has been well prior to caesarean section. Even the struggle to establish lactation can be more difficult as described by Kate:

*During that time I was expressing, and this was the other thing, really I think what a lot of women who have early babies experience, because of preeclampsia, they are expressing breast milk, and that is hell, it honestly is, because your baby is critically ill, you're not feeling 100%, and you're expressing every 3 hours and of course every express takes half an hour, at least. So you've got this unbelievably broken sleep. You know, you're feeling sick, your baby's critical, and you're unbelievably sleep deprived, and honestly, by the time I'd had that for 5-6 weeks, I was really losing it big time. I saw one of the mental health workers*

*and got assessed for postnatal depression. I didn't have it; she just said that I was behaving completely normally given the circumstances.*

It seems that Kate's need to recover from surgery and preeclampsia was forgotten in the quest to extract breast milk from her body. In her concern to do her best for Lilly, Kate may also have overlooked her own needs. Following weeks of struggling Kate sought help for her depression. Could more sensitive postnatal support have been provided? Do midwives need to ensure that continuity of support is provided postnatally in the time that secondary services have taken over the LMC role? Currently there is no funding available to provide for this sort of care and women may not see their LMC midwife again in the postnatal period. If they do, it is likely that the midwife is providing care without payment, at least until the woman is discharged into the community when sometimes the LMC role is transferred back to the original provider.

### **The challenge of illness compounded by grief**

When the experience of preeclampsia has involved death of the baby, the heavy weight of grief prolongs and complicates recovery for the mother. Lynda felt unwell for a long time after her experience of being delivered at 24 weeks and the subsequent death of her baby. Here she describes coming home from hospital:

*It was a dreadful few days. I think a lot of people have no idea how hard it is. It's alright now but initially it's just dreadful. I always thought when I had my kids the biggest drama would be to have a caesar and to lose your baby. It just is so terrible, so hard. But then getting sick as well you know. Very few people understood....I think when you're a mother you are kind of just expected to get on with it you know. You don't have a bandage or anything do you.*

Lynda describes feeling that she was expected to carry on with her life without support, not just for her physical recovery from preeclampsia and surgery but for her emotional wounds. Mothers nurture others and wrap bandages on their wounds but Lynda's wound felt painfully open as she struggled to cope. On the other hand her wound was hidden to others who may have had unrealistic expectations of her. Her husband tried to support her but he was grieving in a different way:

*Men don't really say much anyway-he just took himself out and planted trees-dug holes-that was his letting go. He needed to get outside and I felt like he was walking away from me. I felt like he got sick of me grieving like he wanted to move on. He wouldn't talk about Sean much; he doesn't now- like if you don't talk about it it didn't happen. I want it to be open I don't necessarily want to talk about it. I want not to put it away.*

Lynda needed to talk about her grief, not to move on and “put it away” so it was no longer able to be seen. Her husband’s coping strategy seemed to put distance between them when support and closeness was so important. To him the physical activity could have been a stress release. Linda needed more time to dwell with her grief in order to heal and mentions the feeling of grieving at a different pace than her husband. She needed time – he wanted closure and moving on. Her comments describe her struggle to overcome her illness and loss:

*I think it feels like there are lots of steps that you have to take and as you take them and as you are able to take them you can kind of look forward rather than looking back. The only thing was when I found out my blood pressure was so high because I just wanted to have the whole thing over with and when my blood pressure didn't come right just felt like I would never be able to get on top of it all. So physically I wanted to get better so psychologically I could get on with it. But I felt like the physical side stopped me getting better. I don't know if it psychologically made it worse physically or physically made it worse psychologically I think it's just the two – two really bad situations aggravating each other.*

For Lynda the persistent high blood pressure was a constant reminder of her complicated pregnancy with its tragic outcome. Moving on was impossible until she could recover her physical health. Her metaphor of climbing steps to recovery suggests constant striving. Coping with the grief of losing her baby was made harder by her continuing feeling of being unwell and she described her grief as a palpable presence:

*My grief was just like a foreigner that was there. It was just like there was somebody who had come in that I didn't really know, like somebody extra in the house. Like a presence.*

Lynda’s description of grief creates an image of something previously unknown coming into her reality, into her home and hovering, never moving away. For women of

childbearing age, grief may as yet be a foreigner. Parents are usually still alive and the loss of a baby may be a first experience of death in the family. The added strain of recovery from surgery and the severe preeclampsia which has contributed to the death of the baby culminates in a mountainous step of recovery to be climbed. Never having faced death and grief before it was as if Lynda was also in a foreign land herself, fearful and unsure about how to cope with her situation:

*It's like all the fear, trying to deal with a situation you never picture yourself in, like not having the tools of a job.*

Lynda knew what she needed to do but did not feel equipped for the job of getting better and accepting what had happened. Others may help or hinder the process. Lynda found her work colleagues' attitudes particularly distressing:

*People expect you to get on with it. People can't handle open grief-we don't do that in our society. Most of them at my work never said anything to me. They all knew I was pregnant and they all knew when I went back two months later that I wasn't. Most of them never said anything to me. You feel like saying, "Don't you know where I have been? Don't you know what I have been through?"*

The lack of acknowledgement from colleagues of Lynda's loss of her baby was hurtful and distressing. She just needed them to say something to show they at least knew what had happened, at least a word of consolation. To ignore her grief added to it. Gadamer (1976, p.235) recounts Heidegger talking about the loss of a familiar object, such as a pocket knife. He describes its being missing as something different from it simply being no longer there. Each time the hand automatically seeks out the knife that was once an integral and taken for granted tool in life's daily activities, its meaning will return afresh. Its absence reveals so much more about itself than its presence. When women lose the chance to experience a 'normal' life experience through the full term birth of a healthy baby, the things that are taken for granted show up as missing and their loss is acutely felt. Victoria expressed her disappointment at losing the opportunity to see her baby at birth:

*A very strong memory is the moment when she was born – it's not a memory of actually seeing her, it's the fact that I can't. Really, I can't visualize when they took her out of me ...that's quite hard...*

For Lynda, attending a SANDS (stillbirth and newborn death support group) conference was a very helpful healing experience:

*They did a really good memorial service. There's a big hill behind Napier (where the conference was held) and a big cemetery. In that cemetery they've got a special little children's cemetery. They've organized this little paved circle surrounded by a fence. And you can buy these little stars that have the child's name on it. They did a little candlelight ceremony up there and they had singers which was great. It was good because I like being out in the open and you didn't feel like you had to hide anything. You didn't feel like you couldn't cry. I felt like I couldn't cry before.*

Linda needed to acknowledge her baby son. She needed to say his name, see a tribute to his little life and dwell on her loss, to be allowed to live with it. Perhaps the societal expectation that time will heal and help the sufferer of grief to move on is not helpful. When a baby dies and the mother appears to be coping and “moving on” there may be a feeling of relief for those close to her, and those she works with.

She may be seen to be “doing well”, “handling it really well”, coping “as well as could be expected in the circumstances”. It is likely that the mother is doing more to help other people than herself by stoically keeping up an appearance of being able to manage. It may be that time reduces the shock of the loss but not the grief. Perhaps it is healthier to integrate the grief with the reality of the baby's death into life as it is lived every day. Emotional expression of grief inevitably changes over time, but trying to repress it too early may seem to be a turning away from the baby's life as well as his death. A mother can never do that.



## Summary

Preeclampsia can take away a great deal that many women take for granted. Time to develop a full rounded pregnant belly, time to dream of the beautiful full term baby, born naturally and ready to thrive at the breast - a healthy baby born to a healthy mother. This disease may appear late in pregnancy and cause nothing more than a few extra investigations and perhaps an induction of labour near full term. However, when it comes early in pregnancy it may throw the woman's life out of control, affecting her and many others in her life in a profound way. The sense of loss may leave her emotionally distressed and grief stricken. Recovery is complex, involving physical and emotional factors during a time where appropriate professional and societal support is crucial but often sadly lacking. Midwives who have traveled the journey with women who suffer loss through preeclampsia are in a position to acknowledge the grief and loss and offer support at this challenging time. They may recognize the need for further professional or extra social support which can be set in place at this time.

## Chapter Seven

### Discussion

#### Research Question and Aims

The focal question of this study is:

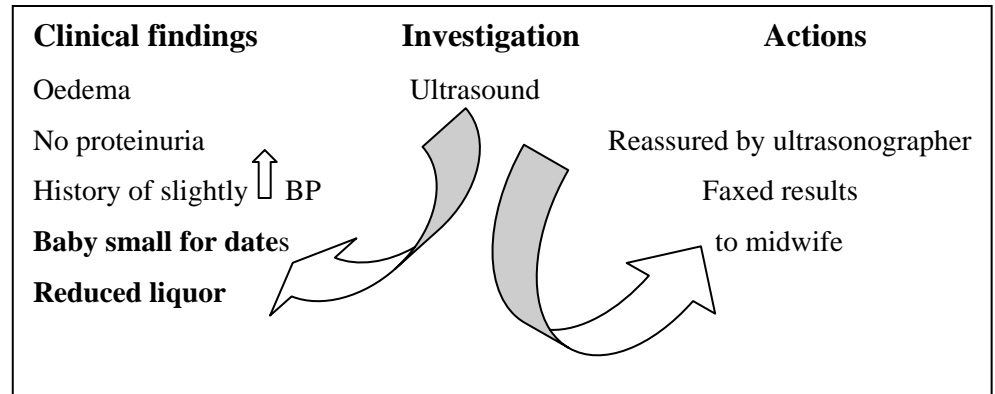
“What is women’s experience of severe preeclampsia?” The selection of participants who experienced diagnosis at a gestation up to 34 weeks ensured inclusion of rich data concerning iatrogenic prematurity and the implications of this for the unwell postpartum woman recovering from preeclampsia. The study aimed to describe the experiences of women who were diagnosed with preeclampsia early in pregnancy, uncover factors in women’s experience of preeclampsia that may warn caregivers of the need for more intensive surveillance and to identify ways in which midwives and other maternity caregivers may provide more sensitive care for women who develop preeclampsia. The following discussion will show how the aims have been achieved.

#### Uncovering the hidden

The clinical presentation of preeclampsia presents a challenge to the midwife and doctor who need to keep a high index of suspicion as many women are asymptomatic, at least initially (Duckett et al., 2001) and some remain asymptomatic despite the development of severe disease (Hayman & Myers, 2004b; Norwitz et. al., 2002). However, this study shows that for the participants in this study, there were warnings that preceded the eventual diagnosis of disease. Women who have become informed about preeclampsia may initiate contact with their midwife or doctor as this woman did:

*My blood pressure had been up a bit and I went to my midwife and said “I think there’s swelling.” I’d read about it and I hoped my midwife didn’t think I was being a hypochondriac. She did the protein in the urine – and I don’t think there was any – but she decided to send me for a scan, and I did have a scan on the Thursday. They said, “the baby’s a bit little, for 30 weeks, and there’s a little less amniotic fluid” and they said “we’ll fax this back to your midwife” – and I remember them kind of calming me and saying –It’s not a big deal, it just probably means she’ll want you to have another scan – in a week or two weeks, don’t worry about it. I remember thinking “it’s nothing” because they tried to play it down... (Victoria)*

In order to see Victoria's presenting picture more clearly the following diagram is offered:



The woman thought that there was nothing to worry about because her midwife made no contact to discuss the scan. Investigations such as ultrasound may be futile if results are not interpreted in the light of the full clinical picture and care adjusted as appropriate. Four days following this ultrasound examination Victoria visited her doctor because of severe asthma and a blood pressure check revealed a BP of 170/110. She was urgently admitted to hospital and had an emergency caesarean section the following day for fetal distress. This raises the possibility of risk for her baby had she not seen her GP. The next midwifery visit may have been too late, especially as Victoria herself had no symptoms apart from oedema to alert her of her underlying preeclampsia.

Harlow and Brown (2001) conducted a systematic review of one hundred and thirty five articles published between 1997 and 1998 researching the definitions and diagnoses of preeclampsia in nine internationally recognized journals. Articles were assessed to establish the major defining variables such as hypertension and proteinuria. 88% of articles included proteinuria in the definition of preeclampsia. According to Brown et al. (2000) true proteinuria is present in most women with preeclampsia, but some women will have other evidence of the disease without proteinuria. The definition of preeclampsia proposed by the Australasian Society for the Study of Hypertension in Pregnancy (ASSHP) allows for a clinical diagnosis of the disease to be made in the presence of hypertension arising after 20 weeks of gestation and one or more other criteria reflecting multisystem disease (see p. 12). Fetal growth restriction is one of these

criteria, indicating probable placental involvement and warrants close observation. It is important to remember that women may develop severe preeclampsia prior to hypertension. Almost 50% of women who present with eclampsia have no prior hypertension and proteinuria diagnosed (Shennan & Chappel, 2001). For Amanda, her baby's intrauterine growth restriction predated significant hypertension and although there was no proteinuria, it seems likely that placental pathology from preeclampsia was jeopardizing her baby.

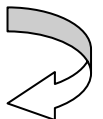
Yet, in the story above; the midwife found a woman who had some oedema, a history of slightly elevated blood pressure and whose baby may have been "a bit little". While she appeared to play down any concern, she did initiate further investigations. Cautious midwives act on mere suspicion, keeping the possibility of preeclampsia in their mind knowing it may be hiding.

## **The confounding nature of the diverse clinical presentation of preeclampsia**

Identification, appropriate treatment and intervention can significantly reduce maternal and perinatal morbidity and mortality associated with preeclampsia and therein lies the challenge! The classic symptoms of headache and epigastric pain were not experienced by all the participants in this study. One woman (Sarah) had a mild intermittent headache for two weeks prior to diagnosis and another (Deb) experienced severe headaches for five weeks prior to diagnosis. Neither woman had significant hypertension at the onset of headache symptoms. The experience of the latter is considered here:

Severe headaches for five weeks but no hypertension

What could be happening?

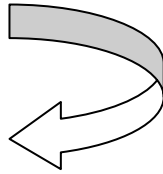


The question of the significance of elevated blood pressure is complex, especially when the level does not reach the diagnostic criteria widely accepted for hypertension in pregnancy.

*...the pregnancy progressed with no apparent problem until 28 weeks when a trace of protein appeared in my urine. I had also started to put on more weight than in my previous pregnancies and my normally low (90/56) BP had started to rise. By 32 weeks my blood pressure had risen to 120/80, my weight was really increasing but still preeclampsia was not considered.*

Clinical findings	Significance
28 weeks trace proteinuria	May be normal / several possible causes
Weight gain	Could be normal / could reflect underlying disease
32 weeks BP 120/80	Not usually considered high / significant rise for this woman

Is there a need for concern?



How significant is a considerable rise above booking blood pressure if it remains under the diagnostic level for hypertension of 140/90? This has been addressed by Brown et al., (2000). Harlow and Brown (2001) found that almost 80% of 135 articles concerning diagnosis of preeclampsia used absolute blood pressure thresholds of 140mmHg and /or 90mmHg to define hypertension in pregnancy. A rise above these levels, particularly of the diastolic pressure is associated with a sharp rise in perinatal mortality (MacGillivray, 1983). However, a study of almost 4000 pregnant women in New Zealand concluded that as a blood pressure of  $\geq 140/90$  was outside two standard deviations of the mean blood pressure in the normal pregnant population, this level was a reasonable cut off to define hypertension in pregnancy (Stone et. al., 1995). Detecting a rise, rather than relying on an absolute value has been considered useful for identifying women at risk of developing preeclampsia. A rise in systolic of  $\geq 30$ mmHg and /or a diastolic rise of  $\geq 15$ mmHg has been used by some authors to define gestational hypertension (National High Blood Pressure Education Program Working Group Report on High Blood Pressure in Pregnancy, 1990; Australasian Society for the Study of Hypertension in Pregnancy: Consensus Statement, 1993). Brown et al (2000) authors of the latest consensus statement from the latter society claim that the use of this rise was never

based on proper scientific evidence. They draw attention to the absence of data to adequately support or refute this as a method of defining hypertension in pregnancy. However these authors acknowledge that such a rise “may be significant in some women” (p.139). A low threshold of suspicion needs to be maintained with women who do not fit the criteria for hypertension in pregnancy but who do develop a significant increase in blood pressure, particularly in the presence of other symptoms. What is normal and safe for one woman may be a serious threat for another.

Consider a case such as this:

*By 32 weeks my skin was itching, my blood pressure had risen to 120/80, my weight was really increasing but still preeclampsia was not considered... When I was 35 weeks pregnant I had a terrible pain up high just under my ribs. I was checked at the hospital by my specialist and discharged as he did not consider that anything was wrong. A week later I went to an emergency after hours medical centre as I was still feeling very unwell but my blood pressure did not fit the criteria for preeclampsia so they said I was OK. At 37 weeks my waters broke and I was feeling very unwell. By the time I arrived in hospital my blood pressure was 170/120, I had a really bad headache; I was shaking and could see flashing lights (Deb).*

<b>Clinical findings</b>	<b>Action</b>
32 weeks itchy skin BP 120/80 Excessive weight gain	No action or advice
35 weeks terrible pain under ribs	Examined by specialist but no investigations/ discharged home
36 weeks feeling unwell	
Self referred to after hours medical centre	Sent home/did not fit preeclampsia criteria
37 weeks SRM Feeling very unwell Hospital admission Severe headache Seeing flashing lights	BP 170/120 Emergency C/Section for HELLP syndrome

Women such as Deb can develop HELLP syndrome in a manner that goes unrecognised before it is full blown. Even when the woman self refers, the experts still cannot ‘see’. ‘Unwellness’ and ‘pain’ are such nebulous conditions for both the woman and the midwife and doctor. This case clearly indicates the significance of a raised blood pressure below the criteria for classification of hypertension but also shows that epigastric pain can be misinterpreted even when it appears as the classic symptom described in many texts. I was unable to find literature concerning skin itching and preeclampsia but the symptom has been linked with a laboratory finding of elevated liver enzymes (Berg et al., 1986), making the symptom significant when screening for preeclampsia. Hayman and Myers (2004b) warn of the risk of inappropriate interpretation of pain such as epigastric tenderness and the consequent delay in initiating appropriate management. Pain and unwellness cannot be passed over lightly when the threat of developing preeclampsia looms. It is likely that in such cases women may be better judges of their deteriorating condition than the practitioner looking for symptoms that are not yet apparent.

However the greater challenge is associated with atypical pain which may confound the woman and her caregiver, as these two examples reveal:

*(I felt)...just like I had been knocked about really badly. I had a sore back...between my shoulder blades, quite high, and no energy whatsoever.” It was just like a bad flu you know. [Later the pain extended as her condition became critical] The pain was kind of between my shoulders and up to my head. It was just like a force, like something was pushing really hard. Yes, it went up to my head, it just felt like pressure basically (Lynda).*

Clinical picture	Action/Outcome
Multigravida / previous preeclampsia	
24 weeks sore back between shoulder blades No energy Flu-like symptoms	Phoned midwife-queried viral infection
Several days later BP 180/110 25+ weeks pain extends to head (pressure)	Admitted to hospital In hospital / condition deteriorated C/Section

Back pain was more common than abdominal pain for the women in this study, and the above example demonstrates the importance of investigation and follow up of atypical pain. The following example shows that even in hospital significant pain may be unrecognized:

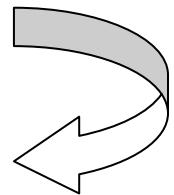
*I was admitted on the Wednesday and on Thursday night I started getting some epigastric pain but I didn't realize what it was actually because –stupid stupid stupid nurse that was on- I kept saying I was having trouble breathing, because I didn't realize that that was what they were talking about- in fact it wasn't until well after I'd had her that I read that was what they meant by epigastric pain, because it didn't appear like that it only hurt to breathe. (Kate)*

Having trouble breathing / hurt to breathe /alerted staff/no action

The pain in the above case was due to severe liver involvement. The significance of her pain remained unrecognized until a change of shift and another person was alerted to her deteriorating condition. Dyspnoea is not classically a presenting symptom but needs prompt investigation (Hayman & Myers, 2004b).

Sarah experienced right upper quadrant abdominal pain for two weeks before being diagnosed with preeclampsia in her twin pregnancy. In the absence of haematological signs or hypertension it was incorrectly assumed that her pain was likely to be caused by gall stones.

Right upper quadrant pain/laboratory tests normal/presumed gall stones

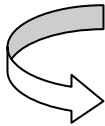


In a study on multiple pregnancies it was found that of sixteen women who developed preeclampsia only eight had blood pressure elevation before delivery and ten had symptoms including epigastric pain, visual disturbances or headache, and only nine had haematological changes reflecting liver involvement (Hardardottir et. al., 1996). The study included high order multi-fetal pregnancies rather than twins but illustrates the atypical nature of preeclampsia presentation and the need for vigilance.



For some women symptoms may come and go as shown by Nadia's experience after having abdominal pain, then a symptom free day before becoming ill with HELLP syndrome

Abdominal pain over several hours/ pain goes away and woman feels well/ pain returns but intermittent/ rapid deterioration of HELLP syndrome.



Practitioners need to be aware that temporary improvement in symptoms does not necessarily mean improvement in condition and may lead to false reassurance and untimely reduction in vigilance. The above examples illustrate the fact that diagnosis of preeclampsia is difficult as presentation is frequently atypical but may also be misdiagnosed when manifest in a typical manner. Heidegger's (1927) notions of "semblance" and "showing" of a phenomenon have served to illuminate my data analysis. The phenomenon of preeclampsia exists long before it is shown or recognized. The vigilant practitioner acts on the premise that 'it could be preeclampsia' without the evidence to confirm the diagnosis. Further, even when the symptoms are atypical and suggest alternative diagnoses, the wise practitioner remembers how preeclampsia fools and misleads. Any pain, any unwellness, any symptoms that cannot be clearly attributed to another cause must be considered a precursor to something that could rapidly deteriorate into severe preeclampsia or HELLP syndrome.

## **The Vigilant Practitioner**

### **Being attuned to the woman**

When preeclampsia does not announce itself clearly with hallmark signs such as hypertension and proteinuria the practitioner is challenged to recognize the hinting of disease that comes in the form of symptoms such as vague malaise, extreme tiredness, worsening oedema, and atypical pains. There is no checklist that a practitioner can

reliably use and the wise midwife or doctor uses a holistic approach which encompasses all about the woman that may influence her health. Because the signs and symptoms of preeclampsia can vary, continuity is important, enabling the midwife or doctor to know the woman well. It is possible that even the most attentive caregiver may still be taken unawares by the sudden announcement of severe preeclampsia but it is more likely that there will be some heralding of impending deterioration of disease which the attuned practitioner and informed woman will together recognize. Whilst there is still no predictive test for preeclampsia the need for vigilance is crucial.

### **Keeping watch-being sensitive to the showing**

The first main theme which emerged from this study was the “Showing of preeclampsia”. Preeclampsia may show itself, appear as a semblance of something else, hide itself, hint, and appear to come and go or announce itself with frightening urgency. It is widely accepted that preeclampsia originates early in pregnancy in defective placentation which eventually results in widespread multisystem disease (Crocker, 2004). A high index of suspicion is necessary in the detection of preeclampsia. Both practitioner and woman would be well served to err on the side of caution rather than ignore a vague symptom for fear of appearing over cautious. Practitioners need to be particularly aware of the manner in which preeclampsia may appear as a semblance of something else, for example, epigastric pain may be diagnosed as possible gall stones, or flu-like symptoms may be mistaken for a viral illness. The atypical nature of pain often confounds and leads to delays in correct diagnosis (Sibai, 1990). For the woman who merely feels unwell prior to her deterioration with severe preeclampsia, it is imperative that she feels comfortable about phoning to discuss any possible symptoms of preeclampsia rather than ignoring a sign that may lead to a costly delay.

A phone conversation may not allow full comprehension of the situation and the prudent practitioner will ensure that a sufficient assessment is made. The tension for the midwife is to reach a balance between keeping a focus on health and normality in pregnancy and a safe level of watchfulness and concern. It may be the woman who recognizes the showing of preeclampsia as the interval between antenatal appointments is often the time when the condition becomes manifest. Diagnosis depends on

recognition of clinical presentation and sensitivity to the showing. The woman may be educated about relaying any fears to the midwife or doctor but they in turn need to be sensitive to the possibility that a symptom, typical or atypical warrants investigation. If investigation of suspicious symptoms reveals nothing the cautious practitioner will maintain an alertness, staying open to the possibility of a later ‘announcing’ of disease perhaps hours, days or weeks later.

### **Partnership and the woman with preeclampsia**

Partnership in itself does not mean vigilance but it provides for a relationship within which vigilance can occur. According to Pairman (1999) women want midwifery care which is based on trust, respect, equality and openness. It is important therefore that both share the same ideology (Skinner, 1999). Open and realistic communication about the possibility or diagnosis of preeclampsia can prepare the woman and her family to be vigilant. Knowledge that complications may occur may engender fear in the woman but preparation for the challenges ahead with the support of a trusted midwife may help the woman to adjust to her new reality of pregnancy with its inevitable intervention. The midwifery partnership exists for the wellbeing of the woman and her baby (Pairman). Some women come out of the experience of preeclampsia feeling disappointed with their midwife:

*I think my midwife was way too relaxed because we were all worried...I was really finding it hard going. I was really really struggling, so tired and really didn't feel like I was coping at all. She never really took notice of that and then I really really had to push her to have her realize that there was something not quite right I was really upset. I just felt like she wasn't interested. I felt like she'd "stuffed up" and that was pretty much it.*

*I did actually start to put together a formal complaint. I was really upset by her behaviour and by her not being conscientious enough about it, because I think it should have been picked up much earlier with all that stuff that was going on. There had been several weeks before then that I had been definitely struggling to cope (Kate).*

When a woman feels that the midwife has not been attuned to how they are feeling, has not listened to their concerns, when they have to push and push the message that something is going wrong, it is hardly surprising they feel care has not been of an

appropriate professional standard. It is not only that they feel emotionally upset by the relationship but they also recognize that the health of themselves and the baby is seriously at risk, and yet they cannot seem to get the action they ‘know’ needs to happen. Other women, like Nadia, show the meaning of good practice:

*Yeah, I actually used her again with Georgia because I thought well yeah, if it wasn't for her, I mean, I guess it was me saying I knew something wasn't quite right – I didn't know what, but because **she believed in me** and said ok we'll check it out...*

Women may have a knowing that is already-there before the symptoms reveal themselves as preeclampsia. When a practitioner is willing to believe and trust the knowing of the woman, however vague or hesitant the telling, then ‘checking out’ leads to safe care.

### **Continuity of care**

Clearly, when a woman develops preeclampsia the involvement of an obstetrician and other expert practitioners is appropriate and necessary. When responsibility of care is taken over by a secondary service, the midwife may opt out of care or remain involved in a way that may be dictated by local secondary care guidelines and/or her own scope of practice as well as her other workload. The New Zealand system of bulk funding for maternity care does not adequately recompense the midwife who may need to monitor a woman frequently at home in the antenatal period, or to visit a woman in hospital under secondary care in a support role. In the current funding environment the individual woman and midwife negotiate an appropriate level of continuity of involvement. However, the commitment to continuity of support is clearly appreciated by women:

*I guess because I had quite a good relationship with my midwife I mean, I tended to yeah, follow what she was saying, asking her for guidance – as opposed to the doctors. My midwife was very helpful. I remember in the theatre I can remember my midwife holding my hand (Nadia).*

The midwife can help the woman make sense of what is happening and mitigate the effect of repetition and fragmentation experienced in secondary care. When a midwife is

not able to continue her relationship with a woman at the time when she feels very vulnerable the woman feels the loss:

*I thought I would hear from her and it thought it was a bit strange not to. It's kind of bizarre when you have that situation when you think that continuity is quite important. So you've got a point of contact with somebody that you know rather than going from staff to staff to doctors to whoever, like most of the time you don't even know who you are talking to... (Lynda)*

Another challenge for the midwife lies in working with the woman who has preeclampsia in a way which leaves the woman feeling that she has been fully informed and supported throughout complications and enabled to maintain some control. Ryding, Wijma and Wijma (2000) found that occurrence of traumatic stress reactions after emergency caesarean section was related to the woman's ability to feel confident during the delivery and on the difference between her expectation of and actual birth experience. While many practitioners contribute to the woman's birth experience the midwife who knows something of her background, her history and her expectations may go a long way towards reducing the risk of posttraumatic stress reactions. It is difficult for a busy midwife to maintain a high level of involvement once a woman is admitted to hospital but even a phone call reassures the woman that her midwife cares about her wellbeing.

The midwifery partnership can provide a thread of holistic normality for the woman within a situation which may be very abnormal. She is still a woman having a baby with hopes and dreams known to some extent to her midwife. Benn (1999) mentions that factors from preconception, the pregnancy and the social situation in which women live their lives have a major impact on what happens later. She says that "one aspect of a pregnancy cannot be seen in isolation from another or be separated from the context of women's lives" (p.18). Everything that happens to the woman shapes her future. What happened in the past, and what happens in the present will affect the way a woman sees her future. The concept of temporality (van Manen, 1990) suggests that all that happens to a person in the present effects a change on their outlook (horizon) for the future. An experience of preeclampsia is potentially stressful and traumatic, bringing an increased risk of postnatal depression and PTSD. The challenge for the midwife is to help support

the woman as she lives through her own reality of preeclampsia. In an existential sense she is a “lived other” (van Manen, 1990) who helps the woman make sense of her lived experience.

## **Relationship matters**

Lynda stated that she appreciated the familiar face of people that she knew well rather than yet another member of the team:

*You know I kind of look forward to familiar people coming, you think-well I know this person, she's not going to come in and ask me the same questions you know- another 50 times!*

Relationship matters during times of crisis and for Evelyn the presence of her LMC midwife as support was appreciated during surgery:

*My midwife was still with me which was really good because I'd developed a relationship with her over the last 7 months and I think that's, that's a really important thing for the hospital staff to be aware of, is that you do have people that you have formed a relationship with, it really helps to have them there.*

## **Walking with the woman through the “thrownness”**

“Thrownness” was the second major theme of the study. The Heideggerian concept of thrownness seems to fit the experiences of the preeclamptic women who related a sense of being projected into the unforeseen as they struggled to come to terms with the realization that their pregnancies were seriously complicated. Linda's comment reveals the essence of this theme: *That feeling of being out of control started before the birth - that spinning out of control faster and faster.* The diagnosis of preeclampsia may invoke in the woman the fear of dying or losing the baby. If she is unable to process this fear she may be at risk of posttraumatic stress reaction. She may not verbalize all her fears but needs to be given an opportunity to talk about them. What happens when a woman does not have the opportunity to talk about the fear born of the realization that she could have died?

*All I sort of wanted to do was talk about it. Although they understood I wasn't well, it was quite hard for people to understand. I needed to talk about it. (Lorena)*

Lost dreams, worrying about the baby, fear including fear of dying, shock, guilt, disbelief and postnatal distress were described by the participants in this study. The experiences described in this study may inform midwives as they support women with preeclampsia. Sometimes there is little warning and preeclampsia announces itself with frightening urgency, leaving insufficient time for explanation and emotional support. More commonly, there are earlier signs and symptoms, which provide a space for dialogue to prepare the woman for the possible course of management as the disease progresses. Continuing involvement once the woman is under secondary care needs to be negotiated between midwife and woman so that the woman does not feel abandoned in a system which can be frightening as she is thrown into her new reality of pregnancy.

The woman's "lived space" (van Manen, 1990) for a period of time will be a hospital room. According to van Manen, "home is where we can be what we are" (p.102). In hospital the woman may have a different sense of self as she comes to grips with her complicated pregnancy and vulnerable baby, in an environment which is unfamiliar and invasive. A woman's sense of "lived body" (van Manen, 1990) will be subject to change as she adjusts to loss of privacy, frequent examinations and investigations and the feeling that perhaps her body has let both herself and her baby down as expressed by Kate: *I just really struggled with the concept of having an illness. I can remember feeling really responsible for Lilly having preeclampsia.* The paradox of woman as both nurturer and potential harmer of her unborn baby was also acutely felt by Evelyn: *I knew that the longer Grace was inside me the better it would be for her as well.* As she reflected on her premature baby she questioned her role: *to say that it's not my fault, or not to feel guilty about it seems strange because I was the one who she was inside.*

The journey from diagnosis of preeclampsia to delivery is usually short but the road to recovery following the birth continues long after the midwifery partnership has been dissolved. It is important to ensure that sensitive antepartum care is provided to encourage the woman to share her fears and feelings prior to delivery as sensitive care

which enables a woman to prepare realistically for intervention may help avert postnatal distress (Ryding, Wijma & Wijma, 2000). Cesarean section is the most likely mode of delivery in severe preterm preeclampsia.

Preeclampsia and HELLP syndrome per se are linked with PTSD, post traumatic intrusive stress reactions and postnatal depression regardless of the mode of delivery (Engelhard et. al., 2002; van Pampus et al, 2004). If the woman also undergoes emergency cesarean section her risk is compounded (Boyce, 1992; Ryding, Wijma and Wijma, 1998, 2000). Birth can be traumatic in the absence of complications but for women who experience severe preeclampsia the potential for the birth experience to be associated with emotional distress needs to be acknowledged. The woman who has a caesarean section for preeclampsia needs extra physical and psychological support as she recovers from surgery and preeclampsia. Provision of information about the expected emotional responses to the trauma of preeclampsia and emergency preterm delivery may help reduce or avoid psychological morbidity.

The findings of this study strongly indicate that women are not being given enough opportunity to debrief after the experience of preeclampsia. An opportunity to talk about the experience with someone who has an understanding of what has happened may be all that is necessary. The woman's midwife may be able to provide this opportunity but another possibility is the availability of a post delivery stress clinic (Allott, 1998). Women who have felt distressed, traumatized, confused or frightened about their birth experience may discuss their experience with members of a multidisciplinary team, designed to meet the woman's needs in a holistic way. Maternity notes can be used in order for the woman and members of the team to mutually review the records. Although the LMC midwife is able to provide postnatal debriefing if she is still involved in the woman's care it may be some time after discharge from midwifery care that a woman becomes aware of her need for further support. It is therefore important that she is made aware of the support structures available in the community.

The woman who has lost her baby as a result of preeclampsia is likely to experience grief lasting up to two years (Hughes & Riches, 2003). As one woman who struggled to recover from preeclampsia, cesarean section and come to terms with her grief



commented: *two really bad situations aggravating each other (Lynda.)* This woman also shared her experience of grief as a presence “like a stranger”, and the different ways of grieving between herself and her husband.

For the woman who suffers perinatal loss, it is likely that she will be given information about support groups in the community but time to listen is a valuable contribution to healing that the midwife can offer, with appropriate referral on discharge from midwifery care. The findings of this study suggest several implications for education, practice and future research.

## **Implications for Practice**

Findings from this study indicate that it is not uncommon for practitioners to miss the warning signs of preeclampsia. Late diagnosis of severe preeclampsia leaves the woman and her practitioner shocked and bewildered as the disease seems to appear suddenly without warning. This study shows that there may be many unrecognized warnings prior to diagnosis as the condition worsens and starts to compromise mother and baby. Preeclampsia is perplexing and unpredictable in its onset and progression. The occurrence of preeclampsia is not restricted to women with recognized risk factors and the vigilant practitioner needs to ensure that no sign or symptom is ignored. Women need to know about preeclampsia. Knowledge may increase anxiety for the pregnant woman but can also be life saving for her and/or her baby. Informed partners and families may be aware of changes unnoticed by the woman, for example facial puffiness, and ensure that a professional opinion is sought in good time.

### **Individual risk based care**

As research has shown that many factors predispose a woman to preeclampsia it is possible to instigate an individual plan for each woman incorporating appropriate surveillance depending on accumulated risk factors. For example a woman with a family history of preeclampsia in a first degree relative has a three to four fold risk of developing the condition (Myers & Brockelsby, 2004) and the incidence of preeclampsia in a primigravida with a twin pregnancy is four to five times that of

singleton pregnancies (Sibai, 2000). Obesity is linked with an increased risk of developing the condition. Eskenasi et al. (1991) demonstrated that a BMI of greater than 25.8 kg/m<sup>2</sup> was linked with a 2.7 fold increase in the risk of preeclampsia. Past history of preeclampsia significantly increases risk in a subsequent pregnancy. Studies have indicated a risk of recurrence of up to 32% in women whose first pregnancy was complicated by preeclampsia and a recent finding is that a history of giving birth to a small for gestational age baby is associated with subsequent occurrence or recurrence of the disease (Zhang, Troendle & Levine, 2001). There are also many underlying medical conditions which predispose a woman to preeclampsia and these are well documented in related midwifery and obstetric texts. Perhaps the practitioner could formulate a chart which tracks any details of potential signs of impending preeclampsia so they are more visible rather than entered amongst regular notes where they may be less visible. A clear prompt sheet reminding women of symptoms to report urgently to the midwife or doctor is helpful, but checklists can never include every possibility and the woman and family need to know that any concern will be taken seriously.

For those women with early signs of preeclampsia appropriate investigations inform the practitioner about the need for more intensive surveillance or specialist referral. Initial clinical and laboratory monitoring should include:

- Blood pressure measurement (See appendix V for recommended technique).
- Urinalysis for protein. If proteinuria  $\geq +$  is detected on dipstick testing a mid stream urine (MSU), spot protein/creatinine ratio (PCR) or 24 hour urinary protein measurement should be requested. The PCR is a useful quantitative test. The MSU protein measurement is less useful as the protein level is affected by hydration status.
- Full blood count, serum uric acid, creatinine and liver function tests
- Careful assessment of fetal growth
- Record any symptoms
- Careful monitoring of fetal movements

(Brown et. al., 2000)

It is important that laboratory results are received and checked promptly **on the same day**. The practitioner should seek the advice of a consultant obstetrician if clinical or laboratory findings are abnormal. A day assessment unit may be used for further monitoring if admission is not indicated. If the woman remains at home close communication must be maintained between her and her LMC. Frequency of visits will be dictated by clinical and laboratory findings and specialist advice following consultation.

In order to 'see' symptoms as soon as they arise creative forms of antenatal surveillance may be instigated. Family members may notice subtle changes in the woman who is becoming unwell with preeclampsia, for example facial oedema, and an informed partner or family member is able to monitor blood pressure at home. Urine can be tested by the woman at home, and she may monitor any sudden weight gain reflecting generalized oedema. For those women whose geographical isolation makes frequent contact with the practitioner impractical, it is possible that in the future fetal wellbeing might be monitored by telemetry and face-to-face communication could be facilitated by computer video camera linkage. In this manner, specialist involvement could be accessed efficiently with avoidance of unsafe delay.

### **Recognize risk for psychological distress**

The experience of having preeclampsia, undergoing emergency caesarean section and having a baby in a special care baby unit have all been associated with postnatal psychological distress (Boyce, 1992; Engelhard et al., 2002; Ryding et al., 1997; van Pampus et al., 2004). Boyce suggests that an increased risk of postnatal depression following caesarean section is associated with a sense of disappointment, failure and loss of control. Immediately after the birth the challenges of physical recovery, initiation of lactation and involvement with the baby are the central focus for the woman but as time goes on she may experience an emotional reaction to the experience she has undergone. Engelhard et al. suggest that women may benefit from educative interventions such as written information about common responses and adaptive reactions to help them assess their own need for professional support at a later date. It is

important that any psychological distress is recognized and resolved as a subsequent pregnancy may reactivate unresolved PTSD.

### **Assess woman's ongoing needs on discharge**

The postnatal follow up of a woman who has experienced preeclampsia is often fragmented due to the need for secondary care initially and the likelihood that several weeks may be spent visiting a baby in hospital once the mother is discharged. My concern is that logistically it is difficult to provide optimal care for women at a time when they need extra support in order to adapt positively to their new reality. By the time a woman and her baby are home together she may be beyond the time span of midwifery postnatal care provided under the current Ministry of Health contract. It is at this time that extra support may be needed. The neonatal homecare nurse may be involved and her support is valuable but her focus is on the baby. It is important that the Ministry of Health considers funding for the LMC to be able to track the woman through the 'at risk time' after she is home with her baby. For some women this may be up to three months after delivery but it is a time when crucial support is often absent. The midwife could make any necessary referrals at that time so that the woman is well supported with the appropriate community and professional networks.

### **Implications for Education**

There have been a plethora of recent advances in the understanding and management of preeclampsia (Baker & Kingdom, 2004). Those caring for pregnant women need to ensure that their knowledge keeps pace with relevant research. This study has focused on women's experience of severe preeclampsia which deserves inclusion in both undergraduate and postgraduate education along with a strong focus on the relevant pathogenesis, investigation and management. Strong emphasis needs to be placed on the need for practitioners to be acutely aware of the need for vigilance because of the confounding nature of the presentation of the disease. Early detection of preeclampsia remains a primary reason for the provision of antenatal care. A grasp of the individual risk factors for each woman will enable the midwife or doctor to plan care which will minimize risk by ensuring adequate surveillance where it is most needed. Awareness of

women's lived experience of preeclampsia will inform practitioners striving to provide optimal holistic care.

Women may cherish the ideal of a full term pregnancy and healthy baby. Midwives share this ideal but the reality is that about one in twenty women will suffer from some form of preeclampsia (Reister & Kingdom, 2004). The subject of preeclampsia may be introduced early in pregnancy and the degree of information that is appropriate will depend on the individual woman's clinical, educational and emotional factors. As preeclampsia may be diagnosed from 20 weeks it is crucial that the woman is aware of symptoms which may potentially herald the disease during the time when antenatal examinations are infrequent.

## **Implications for follow-up**

For the woman with psychological morbidity it is important that an adequate support network meets her needs, as the sequelae of unresolved emotional trauma may continue long term affecting not only the woman but her children, partner and extended family.

In the light of evidence linking preeclampsia and an increased risk of metabolic and cardiovascular disease in later life (Sattar & Greer, 2002; Hannaford, Ferry & Hirsch, 1997; Jonsdottir, Arngrimsson, Geirsson, Sigvaldson & Sigvsson, 1995), there is a responsibility on the part of the maternity care provider to educate the woman about future screening and life style choices. The ASHHP guidelines (Brown et. al., 2000) recommend a follow up at three months postpartum to check blood pressure, urinalysis and microscopy. Callaghan and Hynan (2002) recommend that serious attention is paid to emotional aspects of recovery at obstetric follow up. Ramsay, Sattar and Greer (2004) suggest that adverse pregnancy outcomes such as preeclampsia could be recorded in general practitioner computer databases for targeted health screening programmes.

## Implications for Future Research

There have been very few studies concerning women's experience of preeclampsia. I conducted a wide search and found only two which specifically related to the topic. Both studies related to posttraumatic stress disorder and preeclampsia. There is clearly a need for qualitative studies to further explore the lived reality for the woman with preeclampsia, in particular the psychological sequelae of the condition (Engelhard et al., 2002). Further work on the atypical presentation would provide valuable information for practitioners. Research concerning continuity of care throughout the preeclampsia experience would be useful as this is a challenging area for midwives. Provision of educational information for women during pregnancy and in the postnatal period has not been evaluated and there is scope for this type of research in order to effectively inform women and their families about the condition and its possible effects.

There is a need for comprehensive education, debriefing and support for women after their experience of preeclampsia. My experience with the support group New Zealand Action on Preeclampsia has demonstrated to me that women are often left with many questions and concerns for a long time, even years after their experience with the disease.

The setting up and evaluation of a post delivery stress clinic could be a valuable research project. Women could self refer or be referred by midwives, nurses or doctors and in this way ongoing support could be instigated if necessary and the need for specialized intervention recognized.

A study which investigated midwives' experience of working with women who develop preeclampsia would be a useful follow up to this thesis.

## **Limitations of this study**

It may be considered that a limitation of qualitative work such as this phenomenological study is that it may not provide findings that are generalisable to other settings (Tobin & Begley, 2003). However this type of study does not set out to generalize findings to other settings, the intention is rather to gain a deeper understanding of the experience of the participants. Eight women were interviewed for the study. In the context of hermeneutic phenomenological research this is an appropriate number of participants. The data generated from interviews was rich and sufficient for a study of this size.

It is possible that a further study of the data would uncover more themes which have not yet been explored. The volume and richness of data has not been exhaustively analyzed in this study due to the constraints of time and the size limit of a masters thesis. All participants were European and married. It may be that women from more diverse ethnic and social backgrounds could have provided different narratives. Findings concerning continuity of care or support are set in the context of current maternity care and the funding restraints on the maternity caregiver who may provide midwifery support without due recompense.

## **Strengths of the Study**

Study findings have been discussed with colleagues and women who have experienced preeclampsia. Invariably there has been agreement with my analysis, confirming its authenticity. Several days ago I received a call from a woman who was distressed following her experience with preeclampsia several months ago. Her postnatal distress which has been acute has left her questioning her sanity and seriously undermined her emotional and physical wellbeing. Her phone call reinforced my belief in the strength of this study to add to the understanding of women's experience of severe preeclampsia.

## Closing remarks

This study has highlighted several key areas of concern for practice, and recommendations have been made to enhance the provision of care for women with preeclampsia. I have addressed the research question and fulfilled the aims of this study. There is still much work to be done in order to understand the phenomenon of women's experience of preeclampsia. My understanding has been influenced historically by my midwifery experience which shaped my horizon as I approached the study. I worked with the women's stories as their horizons intersected with mine to extend my horizon or range of vision (Walsh, 1996). This process is achieved through a hermeneutic reflective process which is circular, implying a dynamic nature and no endpoint. As I have moved between the parts and the whole of my data my circle of understanding has revolved and widened. The Gadamerian concept of the hermeneutic circle (Crotty, 1998) has taken me from my pre-understandings to a new view point from which I will still continue to seek further understandings therefore widening the philosophical circle.

The term 'practitioner' has been used in this discussion to acknowledge the provision of primary maternity care by medical practitioners. However this thesis is approached through the lens of a midwifery perspective. Midwives work closely with women in the New Zealand Maternity Care System. Their knowledge and support can contribute positively to women's experience of preeclampsia. In the future there may be a screening test which will enable safe and timely diagnosis, and it may be possible for an effective treatment to be developed. In the mean time midwives, who work in partnership with women, with a relationship based on trust and openness may be the practitioners most able to recognize preeclampsia as it shows itself and support the woman through the inevitable intervention and holistic recovery.



I would like to close this thesis with the words of Wendy Roberts (Cowan, 1997) whose experience with HELLP syndrome started my journey of research into preeclampsia.

Wendy wrote of her feelings on returning home after six weeks in hospital during which time she suffered multiple organ failure and disseminated intravascular coagulation:

*Day by day I gained more strength to enable me to finally come home...the home we had made for Finn to grow up in. My initial reaction was to cry. I realized that I may never have set foot in this house again, never seen grass so green and sky so blue and my cat-so loving and full of personality and my friend, our baby-my lifelong dream. And, of course and most importantly, my cherished husband, who was at my side every day and night for the entire time I was in hospital and every day since this ordeal-sometimes I think I could not have got through this without him. He was a tower of strength. But when it all boils down to it, we are all fragile creatures, we need to be loved and life is for living and loving.*

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# APPENDECES

## A. Ethics approval

*Please include the reference no. and study title in all correspondence/telephone calls.*

### Auckland Ethics Committees

Private Bag 92522  
Walesley Street  
Auckland  
Delivery Address:  
C/O Ministry of Health  
3rd Floor, Unisys Building  
650 Great South Road, Penrose  
Phone (09) 580 9105  
Fax (09) 580 9001  
Committee X Email: pat\_chainey@moh.govt.nz  
Committee Y Email: yvonne\_erixon@moh.govt.nz

23 April 2003

Joyce Cowan  
34 Ridge Road  
Howick  
Auckland

Dear Joyce

**Full Study title:** Women's experience with severe pre-eclampsia occurring before 34 weeks of pregnancy.  
**Investigators:** Joyce Cowan  
**Ethics Reference No:** AKY/03/03/069

The above study has been given ethical approval by the Auckland Y Ethics Committee.

#### Approved Documents

Information sheet and consent form version V2, dated 2 April 2003  
Non Disclosure Form for Typist(s)

#### Certification

The Committee is satisfied that this study is not being conducted principally for the benefit of the manufacturer or distributor of the medicine or item in respect of which the trial is being carried out and may be considered for coverage under ACC.

#### Accreditation

This Committee is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, March 2002.

#### Progress Reports

The study is approved until 31 October 2004. The Committee will review the approved application annually. A progress report is required for this study on 23 April 2004. You will be sent a form requesting this information prior to the review date. Please note that failure to complete and return this form may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.

#### Requirements for SAE Reporting

Please advise the Committee as soon as possible of the following:

- any study in another country that has stopped due to serious or unexpected adverse events
- withdrawal of investigational product for continued development
- withdrawal from the market for any reason
- all serious adverse events which result in the investigator or sponsor breaking the blinding code at the time of the SAE or which result in hospitalisation or death.

.../2

**Amendments**

All amendments to the study must be advised to the Committee prior to their implementation, except in the case where immediate implementation is required for reasons of safety. In such cases the Committee must be notified as soon as possible of the change.

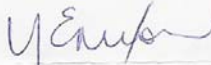
**General**

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Please quote the above reference number in all correspondence relating to this study.

Please note a new version of the application form (EA0502) is now available either by email from the Administrator or from the Health Research Council website, [www.hrc.govt.nz](http://www.hrc.govt.nz). Form EA0699 will not be accepted after 31 December 2002.

Yours sincerely



Yvonne Erixon  
**Committee Y Administrator**

## Auckland Ethics Committees

*Please include the reference no. and study title in all correspondence/telephone calls.*

Private Bag 92522  
Wellesley Street  
Auckland  
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C/O Ministry of Health  
3rd Floor, Unisys Building  
650 Great South Road, Penrose  
Phone (09) 580 9105  
Fax (09) 580 9001  
Email: [pat\\_chainey@moh.govt.nz](mailto:pat_chainey@moh.govt.nz)

3 November 2004

Joyce Cowan  
34 Ridge Rd.  
Howick  
Auckland.

Dear Joyce

**AKY/03/03/069      Women's experience with severe pre-eclampsia occurring before  
34 weeks of pregnancy. PIS/Cons V2, 04/2003.**

Thank you for your progress report, received in October 2004.

The Chairperson of Ethics Committee Y has reviewed the progress report for this study.

The study has received ongoing ethical approval for the next twelve months. The next progress report is due 31 October 2005.

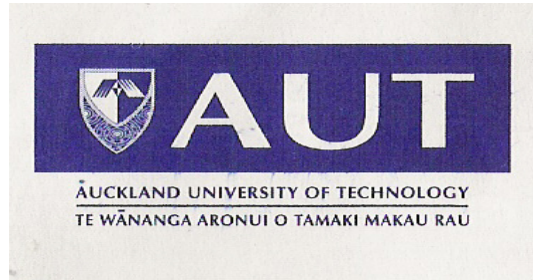
It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider, within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Yours sincerely



Sandra Sparks  
Administrator Committee Y, email: [sandra\\_sparks@moh.govt.nz](mailto:sandra_sparks@moh.govt.nz)

## Appendix B



### PARTICIPANT INFORMATION SHEET

Joyce Cowan  
C/o Marion Hunter  
Supervisor  
Auckland University of Technology  
Private Bag 92006  
Auckland

#### Title of Study

**“Women’s experience with severe early onset pre-eclampsia”**

Dear Participant,

I would like to invite you to take part in my study. My name is Joyce Cowan. I am an independent midwife and midwifery lecturer, currently undertaking a research study toward the completion of a Master of Health Science (Midwifery). If you are interested I would like to interview you during the next three months i.e. May-July 2003. If you join the study you will be free to withdraw at any time, and any information that you have provided on audio tape or any written transcripts made from the tapes will either be returned to you or destroyed.

### About the Study

My study will be qualitative, and concerns the experience of women with severe pre-eclampsia occurring before 34 weeks of pregnancy.

### The Participants

The participants selected will be fluent in English and have experienced severe pre-eclampsia at or before 34 weeks of pregnancy.

It is preferable that the experience occurred in the previous five years but not essential. I will be interviewing between six and nine women, at a mutually convenient and private location. The interview will last one to one and a half hours, and with your permission I will use a tape recorder. You are free to stop the interview at any time and you do not need to answer all of the questions.

A typist will transcribe the tapes, after signing a confidentiality agreement. The transcription will be returned to you in order for you to change if you want to do so. You will be able to delete any part of the transcript that you do not wish to be used in the analysis. You may withdraw from the study at any time until you return the transcript to me for analysis. If I need to clarify any information I will telephone you. Once you have returned the transcript to me I will assume you have given me your permission to commence analysis and use the data for my study, and any publication or presentation that may follow. You may ask questions at any time, and I will provide you with a summary of the study findings.

### Benefits, Risks and Safety

Participation in this study will provide an opportunity for you to talk about your pregnancy and birth. Many women find it helpful to talk about their experience with a midwife. I will pay for any costs incurred for childcare during the time of the interview.

If you experience any distress or anxiety when talking about your birth experience, I will stop the tape recorder. There will be no obligation to continue if you prefer to withdraw from the study at any time. I will provide information about agencies that are

available for debriefing or counseling for example the Trauma and Birth Stress Support group, or an individual professional.

If a cost is incurred for counseling, I will pay for the initial session and thereafter, the cost would need to be borne by you.

If you have any queries or concerns regarding your rights as a participant in this study, you may contact the Health Advocates Trust, telephone 0800 555 050 (Northland to Franklin).

### Confidentiality

Your name will not be used in this study. All participants will be given a fictitious name. There will be no material used that could identify you personally in any of the reports. Your transcripts and audiotapes will be stored in a locked filing cabinet throughout the duration of the study. Transcripts will be kept for ten years after the completion of the study. Audiotapes will be destroyed at the completion of the study or returned to you if that is your indicated preference. All information will be confidential to my supervisor, myself and a typist who has signed a confidentiality agreement.

### Results

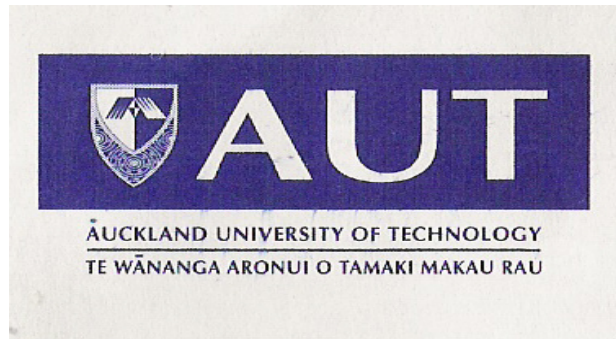
There will be a delay of several months between data collection and publication of results due to the time it takes to analyze data and write the report. You are welcome to contact me at any time during this process to ask questions about the study.

Thank you for your consideration

Joyce Cowan



## Appendix C



### **CONSENT TO PARTICIPATION IN RESEARCH**

#### **Women's experience with severe pre-eclampsia before 34 weeks of pregnancy**

**I have read and understand the information sheet for volunteers participating in the above study.**

**I have had an opportunity to discuss this study and am satisfied with the answers I have been given.**

**I understand that:-**

- **Participation in this study is voluntary.**
- **I may withdraw myself or any information that I have provided before the return of the transcript to the researcher for data analysis without being disadvantaged in any way.**
- **If I withdraw, all relevant tapes and transcripts will be destroyed.**
- **My participation in this study is confidential and that no material which could identify me will be used in the study report.**
- **The interview will be stopped if it should appear to distress me.**
- **Provision is made for debriefing and counseling should it be necessary.**



**I have had time to consider whether to take part**

**I consent to my interview being audiotaped, and transcribed.**

**I wish to receive a copy of the findings ---Yes/No**

**I\_\_\_\_\_ (full name)  
hereby consent to participate in this study.**

**Signature**

**Date:**

**Project Supervisor contact details: Marion Hunter, Senior midwife lecturer, AUT  
Ph. 9179999 ext.7365.**

**Researcher: Joyce Cowan, Midwifery lecturer, AUT. Ph.9179999 ext. 7192.  
(025)849874**

## Appendix D-Confidentiality Agreement for transcriber

**Title of study: Women's experience with severe pre-eclampsia before 34 weeks of pregnancy**

### **Non Disclosure Form for typist(s)**

I understand that information being transcribed is confidential in all respects. All information being transcribed belongs to the consenting research participant and will not be disclosed in any manner whatsoever.

I will not discuss the contents of the audiotapes, in general terms, or in specific terms with any person. I accept that any knowledge gained from the transcript of audiotapes, or through correspondence with the researcher is confidential and may not be discussed or revealed. I understand that I may not retain any copies of the transcripts on hard drive or on disc.

Signed:

Date:

Clare Conon  
18/8/03

Witness Signature:

Full name of Witness:

Conon

JOYCE COWAN

## **Appendix E-Recording of Blood Pressure in Pregnancy (ASSHP Guidelines)**

- The pregnant woman should be seated, with feet supported, for 2-3 minutes.
- An appropriate sized cuff should be used [standard cuff for arms  $\leq$  33cm circumference, large cuff (15 x 33cm bladder) for larger arms].
- Systolic blood pressure should be palpated at the brachial artery and the cuff inflated to 20mmHg above this level.
- The cuff should be deflated slowly, at approximately 2mmHg per second.
- Blood pressure should be recorded with a mercury sphygmomanometer.
- Systolic and diastolic blood pressure should be recorded. Diastolic blood pressure recorded as the phase V Korotkoff sound, i.e. when sounds disappear. If phase V is not present, Korotkoff 1V, i.e. when sounds muffle, should be recorded.
- Blood pressure should be taken using both arms at the first antenatal visit and thereafter using the right arm if, as anticipated, there is little difference in blood pressure between arms. If a significant difference in pressure is found, an opinion should be sought from a consultant physician.
- Automated devices and ambulatory blood pressure monitoring should not yet be used in routine clinical practice until more detailed information becomes available about their accuracy and effectiveness.

(Brown et. al., 2000)

It is acknowledged that aneroid blood pressure devices are used in the community where it may be impractical to transport a mercury device. It is important to calibrate such equipment every 6-12 months.