Australian women’s experiences of severe postpartum haemorrhage and emergency hysterectomy:

Stories of survival

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A thesis submitted to fulfil the requirements of a

Doctor of Philosophy (PhD) Degree

University of Western Sydney
Dedication

I would like to dedicate this thesis to the 21 women who unselfishly shared their stories and experiences of a severe postpartum haemorrhage and emergency hysterectomy. I am humbled by and indebted to you for your willingness to share your experiences.
Acknowledgements

I extend my gratitude to my best friend and husband Ahmad Merhi for his patience, support and undivided attention. Thank you to my precious daughter Fadia Merhi for her patience and allowing me to complete sentences in this thesis without requiring a feed or nappy change. Thank you to my father and mother for providing me with words of wisdom and believing in me every step of the way, never once doubting my abilities.

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Above all, deepest thanks to the 21 women who volunteered their time and shared their stories and experiences. I feel privileged and honoured to be given this opportunity, as without your willingness and generosity to share your experiences, this thesis would not have been possible.
Statement of Authentication

The work presented in this thesis is original to the best of my knowledge and belief, except where acknowledged in the text. I hereby declare that I have not submitted this material, either in full or in part, for a degree at this or any other institution.

...........................................

(Rakime Elmir)
Outcomes of this thesis

This thesis is presented as a series of five published papers. I am the first author on each of the papers and had full responsibility for collecting and analysing the data that are reported in each paper. I prepared the first full draft of each paper and my co-authors and supervisors provided feedback on each draft. Co-author and supervisor contribution involved assistance with the design of the study, confirmation of auditability of the data analysis and contribution to re-drafting or extending background material and or the discussion of the findings in each paper.

Publications


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GLOSSARY AND ABBREVIATIONS

Active management third stage: Interventions such as early cord clamping and uter tonic drug administered to manage the delivery of the placenta.

Advanced Life Support in Obstetrics (ALSO): A course designed to assist health professionals develop and maintain the knowledge and practical skills to manage emergencies that may arise in maternity care.

Amniotic fluid embolism: An obstetric emergency whereby amniotic fluid enters the mother’s blood stream through the placenta triggering an allergic reaction.

Caesarean birth: The birth of a baby through a surgical operation.

Controlled cord traction (CCT): A manoeuvre applied to assist in the expulsion of the placenta.

Cord prolapse: An obstetric emergency where the umbilical cord precedes the presentation of the baby. This can occur during pregnancy or labour.

DIC: Disseminated intravascular coagulation. A haemorrhagic syndrome that occurs following the uncontrolled activation of clotting factors that occurs in response to widespread clotting within blood vessels.

First stage of labour: The beginning phase of labour where the cervix dilates from 0 to 3-4 cm. During this time the cervical canal shortens from 3 cm to less than 0.5 cm long.

Grand multipara: A woman who has given birth five times or more.
**HELLP syndrome:** Referred to as hemolysis, elevated liver enzymes and low platelet count. It is a complication of pre-eclampsia and eclampsia (toxaemia) in pregnancy. It can also develop during the early period following the birth of the baby. It may be characterised by elevated blood pressure, proteinuria, malaise, nausea and vomiting. In the rare event, liver rupture, anaemia, bleeding and death can eventuate.

**Hysterectomy:** The surgical removal of the uterus.

**Indirect maternal death:** A pregnancy related death in a woman with a pre-existing or newly developed health problem unrelated to pregnancy.

**Labour:** Strong regular contractions with cervical dilation.

**Multipara:** A woman who has given birth more than once.

**Normal vaginal birth:** Spontaneous onset of labour without the use of medical interventions.

**Obstetric emergency:** A response called in respect to a threat to the life of mother or baby.

**Physiological management third stage:** The natural progression of the physiological changes that occur at birth and the delivery of the placenta.

**Placenta Accreta:** The placenta is embedded into the wall of the uterus.

**Placenta Praevia:** A condition where the placenta is lying close to or completely covering the cervix.
Postpartum haemorrhage (PPH): A blood loss of equal to or greater than 500 ml immediately following birth up until 12 weeks postpartum, or any amount of blood loss that causes haemodynamic compromise.

Postpartum period: A period following labour and birth, usually seen as the first six weeks.

Puerperium: A period following childbirth where the uterus returns to its non-pregnant state. This period usually lasts between six to eight weeks.

Pre-eclampsia: A condition in pregnancy known to be associated with hypertension, proteinuria and systemic abnormalities.

Primipara: A woman who has given birth once.

Second stage of labour: The cervix is fully dilated and the expulsion of the fetus occurs.

Severe PPH: A blood loss of equal to or greater than 1000 ml immediately following birth up until 12 weeks postpartum.

Shoulder dystocia: A condition that occurs following the birth of the fetal head, where the anterior shoulder cannot pass below the pubic symphysis. Certain manoeuvres are used to assist in the birth of the baby.

Syntocinon: A drug used in the treatment of PPH. It stimulates contraction of the uterine muscles thereby preventing atony of the uterus.

Third stage of labour: The separation of the placenta from the uterus and the expulsion of the placenta and membranes.
ABSTRACT

Postpartum haemorrhage (PPH) remains one of the leading causes of maternal mortality in Australia and internationally. Severe PPH is a life threatening birth complication that may require an emergency hysterectomy as a last, life-saving measure. Epidemiological studies in Australia have indicated that maternal mortality attributable to severe PPH is increasing. Yet despite this, research that focuses on women’s experiences of an emergency hysterectomy following a severe PPH is lacking and the experiential aspects of emergency hysterectomy remain relatively unexplored. Gaining a deep understanding of women’s experiences will assist health professionals in the provision of effective health care and appropriate support services.

This qualitative study aimed to explore the experiences of women who had undergone emergency hysterectomy following severe PPH. This thesis is presented as a series of four published papers and a fifth paper that is under review. Guided by a constructivist approach, participants were recruited through a purposive sampling technique. Data were collected through face-to-face, telephone and email interviews with 21 Australian women. The participants were from various socio-demographic backgrounds, and were aged between 24 and 57 years at the time of data collection. Data were transcribed verbatim and thematically analysed. Four major themes emerged: ‘between life and death’; ‘being a mother’; ‘loss of normality’; and, ‘moving forward’.

The first theme; ‘between life and death’ (reported in paper three) describes the trauma and shock that women experienced at the time of the PPH and emergency hysterectomy together with the realisation that they would be infertile. The
immediacy and finality of this, was extremely distressing for women and for some had devastating consequences. Some women experienced nightmares, flashbacks and intrusive thoughts that lasted well into the first and second years after the hysterectomy. These women were able to vividly recall the events along with the supportive and, at times, unsupportive actions of health professionals during the time of the emergency hysterectomy.

The second theme; ‘being a mother’ (reported in paper four), examines how these women struggled with the expectations of motherhood in the initial postpartum period. Women talked of lost bonding experiences and opportunities with their infant as some were admitted to the Intensive Care Unit (ICU), and others were unable to care for their baby due to physical restrictions and limitations of the hysterectomy. This meant some women had to temporarily relinquish the care of their infant to health professionals in hospital and to other members of the family when at home. Successful breastfeeding was important to some participants, as they saw this as a way to compensate for the lost time and opportunity to care for and develop a close relationship with their baby.

The third theme; ‘loss of normality’ (reported in paper five), describes the participants’ sense of incompleteness as a woman and their feelings of being in an unfamiliar and different body. Women reported that they felt disconnected from their social network of female friends, due to a firm conviction they were now somehow different from them. Relationships with their partners were compromised as women stated that they feared intimacy.

The final theme; ‘moving forward’, presented as an epilogue, describes the way in which women came to find meaning of life following their hysterectomy. These
women attempted to see the positive side of their experience, began to appreciate life and living by either spending quality time with their family, or redefining their priorities, focusing more on their well-being and happiness; ensuring they enjoyed life to the fullest.

This study is the first qualitative study in Australia, and possibly internationally, to provide a full description of the initial events and aftermath of severe PPH and emergency hysterectomy. The findings demonstrate the significant impact this experience has on women’s lives and interestingly, it is perhaps the first time that women have spoken positively to professionals of their experience during the initial shock and trauma of coming close to death.

Women in this study were extremely distressed that in the immediate post birth period and the early weeks at home, they had to temporarily “relinquish” their mothering role. Breastfeeding was one way that women sought to “redeem” themselves as “good” mothers. This study also found that women’s anxiety and or distress levels regarding sexual intercourse following the hysterectomy were mostly related to their thoughts of not having another child rather than whether they gained or lost sexual pleasure.

The findings of this study contribute to the extant literature on individuals’ experience of the awareness of the meaning in life following trauma. Most importantly it has contributed a new dimension to the literature on traumatic birth and more specifically severe PPH and emergency hysterectomy.

In order to better support these women, midwives, nurses and other professionals require information on the immediate events surrounding PPH and emergency hysterectomy and the experience of women in the aftermath. Useful educational
resources may also include explanations of how to manage obstetric emergencies, “mock drills”, in-services, attending Advanced Life Support in Obstetrics (ALSO) seminars and conferences and taking part in online tutorials. Collaboration among health professionals including midwives and child and family health nurses is needed in order to implement appropriate follow-up support services and models of care that are tailored to the needs of women who experience traumatic birth.
Life and death in the context of childbirth

I have learnt that giving birth brings a woman the closest she will ever come to the tender heart of life.

Life and death will be right in the room with you;

You will feel life’s breath upon your face,

You will sense and know the throb of life’s blood.

You will sense for a moment the meaning of existence,

how fragile the membrane is between life and death,

and then the curtains will close again on life’s mystery

and you will be left with only the vaguest dream (Susan Johnson, 1999, p.xiv).
CHAPTER 1: INTRODUCTION

1.1 Introduction

Pregnancy and childbirth for most mothers is filled with excitement and joy (Dahlen, Barclay & Homer, 2010a, 2010b). Of all life events, “the childbirth experience is consistently described as a significant life event of powerful psychological importance in a woman’s life” (Nichols, 1996, p. 71). Birth is described by many women as a normal, natural and amazing process that can be life enhancing (Walsh, 2007). However, for some women it can be a time of fear, disempowerment and suffering (Ayers, 2007; Beck, 2004a, 2004b; Thomson & Downe, 2010). Although birth is a normal physiological process; it can be associated with certain risks to health and in a rare event may pose a threat to survival of the woman and or her infant. Such events have the potential to impact significantly on the physical and emotional health and well-being of the woman, her infant and family (Ayers, 2004, 2007; Ayers, Eagle, & Waring, 2006). One such event is severe postpartum haemorrhage (PPH) and subsequent emergency hysterectomy.

The study reported in this thesis has used a constructivist qualitative approach to explore women’s experiences of severe PPH and emergency hysterectomy.


1.2 Researcher’s story

I am a midwife, and I work in the delivery suite of a large tertiary referral hospital. I feel very privileged to have had the opportunity to share in the joy of birth with many women and their partners and families. However, I have also supported women and families during unexpected events. My experience is that on most shifts unexpected events occur. Some women experience difficult and prolonged labours with complications and after birth women have talked with me about their emotional distress. I have also cared for women on the postnatal ward who have had a severe PPH and hysterectomy, this was challenging and emotionally demanding, often struggling with what to say, and I admit at times I chose not to initiate conversation with the women in fear of triggering a chain of reactions.

Furthermore, I have a familial history of PPH; my mother suffered from the condition and required a blood transfusion, and a close family friend died as a result of a severe PPH. After speaking with, and observing the women I have cared for during my practice as a midwife and talking with my mother, I have come to recognise the issues and concerns they have. This touched my heart and initiated my passion and commitment to conduct research in this area.

As a midwife, a mother and a woman, I come to this research with the view that the physical and emotional health of women following birth is often neglected, particularly when faced with a life threatening emergency. Support services and networks appear to be limited, leaving women to cope with the misfortune, pain and suffering on their own. These issues directed me to pursue this area of research. It became apparent during my practice that women who experience PPH and emergency hysterectomy want to be provided with an opportunity to talk about their
experience to an interested person, for someone to listen and validate their experience, hence my decision to undertake a qualitative study. In order to capture this experience, which to date is rarely reported in the literature, I decided to conduct a study on women who have had an emergency hysterectomy following childbirth.

1.3 Definition

Severe PPH is an adverse birth event that has the potential to impact profoundly on women’s perceptions and experiences of their birth (Dahlen, Barclay, & Homer, 2010a). Severe PPH is defined as a blood loss equal to or greater than 1000 ml, occurring immediately following birth up until 12 weeks postpartum, or any amount of blood loss postpartum that causes haemodynamic compromise (Department of Health New South Wales [NSW], 2005; Welsh et al., 2008). Severe PPH is an unpredictable and on occasions, catastrophic event and remains one of the leading causes of maternal mortality in developing countries (Khan, Wojdyla, Say, Gulmezoglu & Van Look, 2006; Ronsmans & Graham, 2006). According to Anderson (2007) approximately 3% of vaginal deliveries will result in severe PPH. However it can also occur during or following caesarean births, with an increased risk for women diagnosed with placenta previa and placenta accreta (Deneux-Tharaux, Carmona, Bouvier-Colle, & Breart, 2006; Department of Health New South Wales [NSW], 2005).

A systematic review (Rossi, Lee, & Chmait, 2010) of factors leading to, and outcomes of emergency postpartum hysterectomy for uncontrolled PPH, found that women at highest risk of emergency hysterectomy are those who are multiparous, had a caesarean birth in either a previous or the present pregnancy, or had placentas implanted abnormally, such as placenta previa or placenta accreta. Rossi et al.
(2010) concluded that although the incidence of postpartum hysterectomy may be low, the rising caesarean delivery rate in recent years and the increasing population of women with a scarred uterus may indirectly increase the incidence of emergency postpartum hysterectomy and its complications.

1.4 Incidence of PPH and postpartum hysterectomy

PPH is a birth complication that occurs worldwide and has the potential to lead to adverse maternal outcomes including death. Data from Australia, Canada and the United Kingdom indicate that the rates of PPH are increasing (Cameron, Roberts, Olive, Ford, & Fischer, 2006; Joseph et al., 2007; Roberts et al., 2009). The incidence of PPH in Australia is between 5 and 10% of all births (Marsden & Henry, 2006) and has been increasing over the past decade. In 2001 at one Australian hospital the PPH rate peaked at 16% (Henry, Birch, Sullivan, Katz, & Wang, 2005). There are increasing numbers of women who require a hysterectomy following severe PPH. For instance, in Australia, a Victorian report indicated that the rate of emergency hysterectomy following severe PPH doubled over the period 1999-2002 when compared to the previous triennium. During the period 1999-2002, it was reported that five out of 1,000 women required a hysterectomy following PPH (Haynes, Stone, & King, 2004). Similarly, in Canada, Joseph et al. (2007) commented on preliminary analysis of hospital data indicating that the rate of PPH with hysterectomy had increased. Although hysterectomy is rare and used as a last resort in an attempt to save the life of women, it may leave devastating physical and psychological consequences (Baskett, 2003; Thompson, Roberts, & Ellwood, 2011).
1.5 Maternal deaths attributed to PPH

Internationally, and most often in a developing country, women die from complications related to childbirth (Ford, Roberts, Simpson, Vaughan & Cameron, 2007). Over 600,000 women die annually worldwide (Brace, Kenaghan and Penney, 2007), a ratio of 400 per 100,000 births (Brace et al. 2007). It is estimated that 97% of these deaths occur in developing countries, although, it remains a significant problem in developed countries such as the United Kingdom, Canada and Australia (Cameron, et al., 2006; Joseph, et al., 2007; Knight et al., 2009). PPH significantly contributes to maternal mortality and morbidity (Roberts, et al., 2009; Thompson, Roberts, & Ellwood, 2011). The Australian Institute for Health and Welfare reported that in the period 2000-2002 obstetric haemorrhage accounted for 28% of direct maternal deaths (Sullivan & King, 2006). According to the Centre of Epidemiology and Research: NSW Department of Health (2010), in the Australian state of New South Wales (NSW), one direct maternal death as a result of severe PPH was reported in 2007. An increase in the incidence of PPH has been reported. One population-based study in Australia showed an increase in women with PPH who received a blood transfusion from 2% in 1994 to 12% in 2002 (Cameron, et al., 2006). In 2008 up to 8% of women who gave birth vaginally required a blood transfusion secondary to PPH (Centre of Epidemiology and Research: NSW Department of Health, 2010). Possible causes for the increase in PPH may be the increase in placenta accreta, inductions, augmentation of labour, maternal obesity and fetal macrosomia. Despite research that has reported an increase in PPH and the

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1 The result of a complication in pregnancy, delivery, or management of both

2 A fetal birth weight greater than 4500gms
associated health consequences for women, research into women’s experiences of severe PPH and emergency hysterectomy is minimal.

1.6 Women’s experience of PPH

There has been one Australian study reporting on the maternal effects of severe PPH. Thompson, Heal, Roberts & Ellwood (2011) undertook a cross sectional descriptive study of women who had experienced a severe PPH. Women completed surveys in the first week postpartum, and again at two and four months postpartum. The authors reported on the emotional and physical health outcomes for women following PPH and found that 71% of women reported physical exhaustion within the first month following birth, with 10% of women requiring re-admission to hospital. Evidence of fatigue and post-traumatic stress disorder were apparent among this cohort of women. Answers to open-ended questions in the surveys showed that women experienced extensive delays in initiation of breastfeeding which affected their ability to establish breastfeeding. In the Thompson et al (2010) study, 85% of women planned to breastfeed, however only 52% of women were able to breastfeed their baby within the first hour of birth. Emotional exhaustion contributed to the delay in breastfeeding due to a lack of energy and the physical drain from the severe amount of blood loss.

Another study by Mapp & Hudson (2005) used a Husserlian phenomenological design to study women’s experiences of obstetric emergencies during childbirth. In this study, severe PPH was included as a major obstetric emergency. Ten women were interviewed and seven of these had experienced a severe PPH with two women in this study having had a hysterectomy following the PPH. Women were asked to reflect on their experiences of the emergency situation, and reported feelings of
emotional detachment and loss of power and control over what had happened during the emergency. Detailed information and effective communication from health care professionals was found to be important to women’s psychological well-being during the emergency and in the months following. This study provided some important insights into women’s experiences of obstetric emergencies, particularly from the two women who had a severe PPH and emergency hysterectomy.

Despite the lack of research on women’s experiences of a hysterectomy following a PPH, it has been well documented that both a negative birthing experience and an adverse outcome can be traumatic to women (Ayers, 2004, 2007; Ayers & Pickering, 2001; Beck, 2004a, 2004b; Elmir, Schmied, Wilkes, & Jackson, 2010; Mozingo, Davis, Thomas, & Droppleman, 2002). A hysterectomy following a severe PPH may be considered a traumatic experience that can impact on the overall satisfaction and experience of childbirth. For the purposes of this study, the literature related to traumatic birth has been reviewed and is presented in the form of a meta-ethnographic study. The following chapter (paper one) reports the findings of the meta-ethnographic study synthesising 10 qualitative studies on traumatic birth.

1.7 Aim of the study
The aim of this study was to explore women’s experiences of severe PPH and emergency hysterectomy.

1.8 Significance of the study
It is clear that the incidence of both PPH and hysterectomy following PPH is increasing. Yet despite epidemiological data that suggests an increase in PPH and hysterectomy, the experiences of women during PPH and emergency hysterectomy
and the aftermath, remains unexplored. This is the first qualitative study in Australia and to my knowledge internationally to explore women’s experiences of severe PPH and emergency hysterectomy.

It is envisaged that findings from this study will contribute to the limited literature and provide a deeper understanding of women’s experience of emergency hysterectomy following severe PPH and the known impact of traumatic birth on women’s mental and physical health status. With increasing interventions such as caesarean births, induction and augmentation of labours, it is likely that the rate of severe PPH and emergency hysterectomy will increase. It is imperative that women with this experience receive the appropriate care and support.

Findings from the study will enhance health professionals’ knowledge and awareness of the impact of severe PPH and hysterectomy on women’s physical, emotional and psychological recovery. It is anticipated that findings from the study will contribute to improved care, in terms of the way health professionals interact with women as well as ensuring appropriate support services, including pathways or models of care are available for women who experience severe PPH and emergency hysterectomy, both in Australia and internationally.

1.9 Overview of the thesis

This study has explored women’s experiences of severe PPH and emergency hysterectomy. The completed body of work is presented in the form of a thesis as a series of publications. The five published papers are embedded within the thesis as chapters. In addition, unpublished chapters as outlined below, provide more detail on the methodology and the discussion of findings. As the first author of each publication, I was responsible for preparing the first full draft of each paper. I
prepared the literature review, collected and analysed the data and prepared first drafts of all discussion sections. My co-authors and supervisors provided guidance on the paper, confirmed the analysis of the data and assisted in preparation of the final draft of each paper.

Chapter one, the introduction, has provided a rationale for the study, an overview of the incidence of PPH, severe PPH and hysterectomy, maternal mortality attributable to PPH and women’s experience of severe PPH. The aims, significance of the study and the researcher’s position in the study are also addressed.

Chapter two is presented as a published paper that reports the findings of a meta-ethnographic study of women’s perceptions of and experiences from traumatic birth. As discussed earlier in this chapter, the literature on women’s experience of PPH is sparse. However, the literature on women’s experience of a traumatic birth may offer important insights into the women’s experience of PPH followed by a hysterectomy. The manuscript comprising chapter two was published in the *Journal of Advanced Nursing* 66 (10), 2142-2153.

Chapter three; the methodology, outlines the ontological and epistemological underpinning of this study and details the approach to data collection and analysis. Inductive thematic analysis was used to derive four key themes and subthemes. The ethical issues are addressed and the strategies used to maintain rigor and quality of the research discussed.

Chapter four presents published paper number two which describes in detail the approaches used to conduct the research in a sensitive manner, minimising distress to women who agreed to participate. The manuscript titled ‘Interviewing people about
potentially sensitive topics’, has been published in Nurse Researcher (2011), 19 (1), 12-16.

Chapters five, six and seven present the findings of the study. Each of these chapters is presented as a published paper. There is also some repetition of literature, methodology and methods according to specific journal requirements. Style, structure and content of each paper are according to journal guidelines. Chapter five presents the theme ‘between life and death’, and describes women’s experiences and recollections of coming close to death during the time of bleeding and when they required an emergency hysterectomy. The manuscript titled ‘Between life and death: Women’s experiences of coming close to death and surviving a severe postpartum haemorrhage and emergency hysterectomy’, is currently on line in Midwifery.

Chapter six discusses the study findings in relation to women’s experiences of ‘being a mother’ including the difficulties faced with establishing a relationship with their newborn infant and caring for their infant, particularly while they were in the intensive care unit. This paper describes the challenges women faced as they recovered from major surgery while at the same time wanting to care for their baby. The manuscript titled ‘Separation, failure and temporary relinquishment: women’s experiences of early mothering in the context of emergency hysterectomy’, is published in Journal of Clinical Nursing.

Chapter seven describes women’s experiences of adjusting to a “new” body and the ‘loss of normality’. This paper discusses the loss of womanhood, femininity and fear of intimacy that is experienced following severe PPH and emergency hysterectomy. The existing literature on women who choose elective hysterectomies for gynaecological issues and women who experience infertility issues is also discussed
in this paper. The manuscript titled ‘Less feminine and less a woman: The impact of unplanned postpartum hysterectomy on women’, is published in International Journal of Childbirth.

Chapter eight is presented as an epilogue, ‘moving forward’, briefly addressing women’s perceptions of how they recovered from this significant event. The final theme that emerged from the analysis focuses on women’s ability to reframe their lives and to find meaning in life in an attempt to move forward. This chapter has not been prepared for publication but it is important to present this final theme. The structure of chapter eight differs from chapters five, six and seven as it is presented as a more traditional thesis chapter with an introduction, description of finding and a conclusion.

Chapter nine provides a conclusion to the thesis and discusses the key findings with reference to existing literature while it also highlights new knowledge this study has generated. Implications for midwifery and nursing practice, education and policy development are discussed.

1.10 Conclusion

This chapter has provided an overview of the incidence of PPH, severe PPH and hysterectomy, maternal mortality, and women’s experiences of severe PPH and obstetric emergencies. The following chapter will present the published paper ‘women's perceptions and experiences of a traumatic birth: A meta-ethnography’. This paper provides a meta-ethnography study of women’s perceptions and experiences of traumatic birth.
CHAPTER 2: WOMEN’S PERCEPTIONS AND EXPERIENCES OF A TRAUMATIC BIRTH: A META-ETHNOGRAPHY


2.1 Publication: Relevance to thesis

Chapter two comprises the publication, ‘Women’s perceptions and experiences of a traumatic birth: a meta-ethnography’. The paper provides the background to this study of women’s experience of emergency hysterectomy following severe PPH.
CHAPTER 2: WOMEN’S PERCEPTIONS & EXPERIENCES OF A TRAUMATIC BIRTH

REVIEW PAPER

Women’s perceptions and experiences of a traumatic birth: a meta-ethnography

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Abstract

Aim. This study presents the findings of a meta-ethnographic study reporting women’s perceptions and experiences of traumatic birth.

Background. Childbirth is viewed by many as a life transition that can bring a sense of accomplishment. However, for some women, birth is experienced as a traumatic event with a minority experiencing post-traumatic stress. A traumatic birth experience can have a significant impact on the physical and emotional well-being of a woman, her infant and family.

Data source. The CINAHL, MEDLINE, Scopus and PubMed databases were searched for the period January 1994 to October 2009 using the keywords birth trauma, traumatic birth, qualitative research, birth narrative and birth stories.

Review methods. A meta-ethnographic approach was used. Quality appraisal was carried out. An index paper served as a guide in identifying particular findings and comparing them with other findings. This ‘reciprocal translation’ process started with a search for common themes, phrases and metaphors.

Results. Ten qualitative studies were included in the final sample. Six major themes were identified: ‘feeling invisible and out of control’, ‘to be treated humanely’, ‘feeling trapped: the recurring nightmare of my childbirth experience’, ‘a rollercoaster of emotions’, ‘disrupted relationships’ and ‘strength of purpose: a way to succeed as a mother’.

Conclusions. It is evident that a small percentage of women experience a traumatic birth. Although some women who experience a traumatic birth do not necessarily have physical or psychological adverse outcomes, others identify a significant personal impact. Healthcare professionals must recognize women’s need to be involved in decision-making and to be fully informed about all aspects of their labour and birth to increase their sense of control.

Keywords: childbirth, meta-ethnography, midwifery, nursing, qualitative study, traumatic birth
CHAPTER 2: WOMEN’S PERCEPTIONS & EXPERIENCES OF A TRAUMATIC BIRTH

JAN: REVIEW PAPER

Introduction

For many women, the birth of a child is a key life transition, and when they are well supported, this can be described as a moment of triumph, satisfaction and reward (Nelson 2003). There remain, however, a proportion of women who are deeply distressed following birth. In a study of Swedish and Australian birthing women, Waldenstrom et al. (2004) found that 3–7% continued to be dissatisfied with their birth experience after 2–4 months. Reports of dissatisfaction with the birth experience are frequently linked with descriptions of complicated, negative or traumatic birth experiences (Waldenstrom et al. 2004, Dahlen et al. 2010). Soet et al. (2003) in the United Kingdom (UK) suggest that up to 34% of women report the birth as traumatic, and an Australian study showed one in three women continued to experience trauma symptoms at 4–6 weeks after a traumatic birth (Creedy et al. 2000).

There is no consistent definition of traumatic birth and no systematic way to assess birth trauma, and the terms birth trauma and traumatic birth are used frequently synonymously. Beck and Watson (2008) define birth trauma as ‘actual or threatened injury or death to the mother or her baby’ (p. 229). Women may also perceive their birthing experience to be traumatic as a result of intervention during the process, the mode of birth (cesarean or vaginal) and the way they are treated by healthcare professionals (Allen 1998). Thompson and Downe (2008) state that women who have an apparently normal birth with no interventions may also perceive it as traumatic. This leads Beck (2004a, p. 28) to comment that birth trauma is perceived in the ‘eye of the beholder’.

A traumatic birth experience can have a severe impact on women and their families (Ayers 2004, Olde et al. 2006) and is associated with negative outcomes, such psychological distress and ongoing physical pain (Creedy et al. 2000, Caernocha & Slade 2000, Beck 2004b). Women who experience a traumatic birth often report that they have not had the opportunity to voice their distress, and they fear that their concerns will be dismissed (Reynolds 1997, Moyzakis 2004).

There is increasing recognition that, for some women, traumatic birth can lead to post-traumatic stress disorder (PTSD) (Beck 2004b, Ayers 2007). Large population-based studies from Australia and the UK indicate that between 1% and 6% of women will develop symptoms of PTSD following childbirth (Creedy et al. 2000, Ayers & Pickering 2001). Women experiencing PTSD related to childbirth report that they feared for their lives or the lives of their babies, or that they would experience physical damage during the birth (Anderson & McGuinness 2008). A traumatic birthing experience is often accompanied by fear, helplessness and terror, and is subsequently associated with a range of thoughts including vivid memories of the event, flashbacks, nightmares and irritability (Ayers 2004, Olde et al. 2006). Unfortunately, the ambiguity of the definition of traumatic birth and the criteria constituting PTSD result in delayed or missed diagnoses of PTSD.

Despite the increasing knowledge of traumatic birth experiences and PTSD, very few professional support services are available to help women after the event and prior to a subsequent birth (Thomson & Downe 2008). In order for healthcare professionals to provide greater support for women through birth and the transition to parenthood, further research into women’s experiences of traumatic birth is necessary. This study contributes to knowledge of this phenomenon by reporting the findings of a meta-ethnographic study of published studies about women’s perceptions and experiences of a traumatic birth.

A meta-ethnographic study is a rigorous and analytical process of synthesizing qualitative studies. The aim of the approach is to make interpretations about the phenomena from the translation of studies into each other (Noblit & Hare 1988). Unlike a literature review, a meta-ethnographic study involves the comparison and interpretation of similar contexts, studies and populations, thereby creating new meanings in the translation process (Noblit & Hare 1988). In this meta-ethnographic study, we sought to understand the commonalities and differences in the findings of studies with women who experience a traumatic birth.

The review

Aim

The aim of the study was to describe women’s perceptions and experiences of a traumatic birth.

Design

The synthesis of the literature presented in this study was guided by the original work of Noblit and Hare (1988) on meta-ethnography. Although they outline processes to synthesize ethnographic studies, they and others (Britten et al. 2002, Campbell et al. 2003, Pond et al. 2005, Downe et al. 2009) have used these techniques when synthesizing studies that have used a range of qualitative methodologies in diverse healthcare settings. The techniques described by Noblit and Hare (1988) include reciprocal translation (looking for similarities across studies), refutational investigation (identifying differences or challenges to the emerging concepts), and then
development of a 'line of argument' that takes into account both the similarities and differences found in the studies.

Search methods

The search was conducted in February to March 2009 and revised again in October 2009. It was limited to papers published in English in peer-reviewed journals during January 1994 to October 2009. Studies were included if they focused on women's perceptions and/or experiences of traumatic birth, birth trauma or PTSD, and used these terms in the title, abstract or keywords. Studies of women experiencing either their first birth or subsequent birth as traumatic were included. To be included, studies had to be primarily qualitative (including studies using grounded theory, phenomenology, ethnography and other descriptive qualitative approaches). We also included studies designed as large-scale cross-sectional surveys if the authors had conducted and reported on in-depth interviews with a subgroup of the sample.

The MEDLINE, CINAHL, Scopus and PubMed databases were searched using the Medical Subject Headings (MeSH headings) and keywords for traumatic birth, 'birth trauma', 'traumatic birth', 'qualitative research', 'birth narratives' and 'birth stories'. The terms were entered individually and in combination.

Search outcome

The search strategy identified 726 papers. The titles and abstracts of these papers were reviewed and they were excluded if they were discussion or opinion papers or studies reporting on birth experiences in general and not traumatic birth or PTSD following birth. This resulted in 32 papers for inclusion that were then read in full by two authors to ensure their relevance to the meta-ethnography. Papers were eliminated at this stage primarily because they did not report primary research, focused on women's perceptions of a negative or complicated birth but did not describe this as a traumatic experience, or were case studies or quantitative studies that did not have a significant qualitative component. This further reduced the number of papers to 11. Reference lists of these papers were read to identify additional relevant original research. This method is referred to as 'backchaining' (Downe et al. 2009) and resulted in a further two papers. These authors of retrieved papers were contacted to identify other relevant publications that might not have been retrieved, but no further papers were identified with this approach. The 13 papers considered relevant according to the inclusion criteria were then assessed for methodological quality.

Quality appraisal

Quality appraisal was considered an important component to prevent the inclusion of poorly conducted studies. Although the application of quality criteria has received much debate, currently there are no agreed criteria that should be applied (Atkins et al. 2008). We chose to assess papers for quality in order to provide clarity and achieve consensus on which papers were included in or excluded from the analysis.

To validate the inclusion of papers, a set of criteria was adopted from Spencer et al. (2003). This ensured that the findings were credible, and that knowledge gained from the study could be applied to the same population (transferrable), the sample was appropriate and reflected the inclusion criteria, data collection was appropriate, findings were presented in a coherent and succinct way, and level of depth and understanding were portrayed through the interpretation of the findings (Spencer et al. 2003). The majority of studies reviewed included a report of the philosophical basis that informed the research methodology, for example interpretive or descriptive phenomenology, and most made mention of ethical approval by an appropriate committee (Campbell et al. 2003). Three papers were excluded at this point. One (Sadler 2009) was excluded because it did not adequately describe the research methods and did not provide an audit trail of data analysis, with limited presentation of qualitative data to support the findings. Two further papers (Berg & Dahlberg 1998, Goldhor 2009) were excluded because their focus was on complicated birth (Table 1 shows the papers selected for review).

Eight studies included in the synthesis were designed as in-depth qualitative studies focusing on the experience of birth trauma (two [Allen 1998, Ayers 2007]) not only had a survey design with a larger sample, but also incorporated a qualitative component using semi-structured interviews with a subset of the sample and provided rich and authentic descriptions of women's experiences. All 10 researchers had collected data from interviews with women; in a study by Nicholls and Ayers (2007), both women and their male partners were interviewed. Another study by Thompson and Downe (2008) focused in particular on the 'redemptive' experience of having a positive birth event after a traumatic birth. Two studies by the same author (Beck 2004a,b) had a similar approach to data collection (Internet interviews), with the same number of participants and location. The author was contacted by email to clarify information on these studies. Confirmation was obtained that the two papers reported separate studies, presenting different findings, however, some women had participated in both studies. Included studies had been conducted in a number of countries.
CHAPTER 2: WOMEN'S PERCEPTIONS & EXPERIENCES OF A TRAUMATIC BIRTH

Table 1 Flow chart of search strategy

<table>
<thead>
<tr>
<th>728 papers retrieved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excluded qualitative studies, epidemiological studies, discussion papers, opinion papers and papers reporting birth experience in general</td>
</tr>
<tr>
<td>32 papers</td>
</tr>
<tr>
<td>Excluded quantitative studies that did not have a substantial qualitative component, were focused on complicated or negative birth experiences, were not primary research</td>
</tr>
<tr>
<td>11 papers</td>
</tr>
<tr>
<td>Hand search of reference lists</td>
</tr>
<tr>
<td>13 papers</td>
</tr>
<tr>
<td>Application of Spencer et al. (2003) quality appraisal</td>
</tr>
<tr>
<td>10 papers included in synthesis</td>
</tr>
</tbody>
</table>

including New Zealand, the United States of America (USA), the UK and Australia. The 10 studies represented a combined sample of approximately 398 women.

Data abstraction and synthesis

Data abstraction and synthesis was guided by the work of Noblit and Hare (1988) and others (Walsh & Downe 2005, Downe et al. 2009) and we began with one study (an index paper). This index paper served as a guide in identifying particular findings and comparing them with other findings. The process commenced with a search for common themes, phrases and metaphors described by Noblit and Hare (1988) as 'reciprocal translation'. This process of comparing findings continued across the 10 studies to highlight similarities in findings. Once themes became apparent, we then undertook a process of refutational inquiry (refutational translation), looking for differences across studies to ensure findings were rigorously presented and to ensure that the authors did not miss anything that may add or disprove the findings. Very few differences were uncovered during this process. Common themes were then summarized in a statement or 'line of argument synthesis' (Noblit & Hare 1988). Direct quotations from participants were used to illustrate their experiences.

Findings

The five themes developed through the processes of reciprocal translation and refutation investigation are outlined in Table 2. These themes will be presented using the original source of women’s narratives and the original authors’ interpretations. Table 3 presents the common themes, phrases, ideas and concepts across the 10 included papers.

Feeling invisible and out of control

Women described having no control over their birthing experiences (Allen 1998, Beck 2004b, Ayers 2007, Nicholls & Ayers 2007). They had expected, and indeed considered it essential, that healthcare professionals would communicate information to them about the labour process, including regular updates on its status. Participants considered this pivotal to being actively involved in decisions about labour and birth, and many women reported that they were not included in the decision-making process. They often became distressed when recalling conversations with healthcare professionals present during their labour and birth. Researchers reported that women’s opinions were ignored and that they were subjected to authoritarian decision-making. Information from healthcare professionals was not forthcoming, and women felt as though these people were ‘faceless’ (Thompson & Downe 2008, p. 271) or invisible, indicating healthcare professionals’ failure to consider them as individuals with a right to make informed decisions: ‘The hospital staff discussed my baby’s possible death in front of me and argued in front of me just as if I weren’t there’ (Beck 2004b, p. 33). Some women perceived staff to be ‘too busy’ to explain procedures and what was happening during the birth (Allen 1998, p. 117), creating feelings of anxiety and unease.
### Table 2: Qualitative studies of women's experiences and perceptions of traumatic birth

<table>
<thead>
<tr>
<th>Author/Location</th>
<th>Methodology</th>
<th>Method</th>
<th>Aim</th>
<th>Sample</th>
<th>Inclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allen (1998), UK</td>
<td>Qualitative</td>
<td>Questionnaire Semi-structured interviews</td>
<td>The process occurring during traumatic childbirth experiences, factors mediating development of PTSD symptoms and the impact on post-partum adaptation 10 months following childbirth</td>
<td>145 Women first stage (Questionnaire) 20 women second stage (interviews) Ages not specified</td>
<td>Stage 1: women who experienced labour which they perceived to be traumatic Stage 2: involved including women who rated their labour as extremely distressing and traumatic</td>
</tr>
<tr>
<td>Ayers (2007), UK</td>
<td>Qualitative</td>
<td>Interviews Questionnaire</td>
<td>Examine thoughts and emotions during birth, cognitive processing after birth, and memories of birth that might be important in the development of postnatal depression</td>
<td>50 Women PTSD symptoms mean age 29. With PTSD symptoms mean age 32</td>
<td>Post-traumatic stress group – scoring above the cut-off for severe PTSD Control group – birth experience similar to women selected for the PTSD group</td>
</tr>
<tr>
<td>Ayers et al. (2006), UK</td>
<td>Qualitative</td>
<td>Semi-structured interviews</td>
<td>Study the effect of traumatic birth on women, their relationship with their child and their relationship with their partner</td>
<td>6 Women (22–37 years)</td>
<td>Aged over 18 years Able to read and speak English fluently Psychological problems as a result of a traumatic birth experience Experienced PTSD attributable to birth trauma Willing to articulate her experience</td>
</tr>
<tr>
<td>Beck (2004a), New Zealand, USA, UK</td>
<td>Qualitative phenomenology</td>
<td>Internet interviews</td>
<td>Describe the essence of mothers' experiences of PTSD after childbirth</td>
<td>38 Women representing 4 countries (25–44 years)</td>
<td>Mother perceived the childbirth to be traumatic Her birth trauma had in some way had impacted her decision to breastfeed. Her breastfeeding experience or both At least 18 years Able to articulate her breast feeding experience Experienced birth trauma Willing to articulate her experience Able to read and write English Perceived her childbirth as traumatic She had experienced at least one anniversary of that birth trauma 18 years of age or older Able to articulate her experience Personal identity identified themselves as having experienced distress and/or trauma in childbirth</td>
</tr>
<tr>
<td>Beck and Watson (2008), New Zealand</td>
<td>Qualitative phenomenology</td>
<td>Internet interviews</td>
<td>To explore the impact of birth trauma on mothers' breastfeeding experiences</td>
<td>32 Women (31 primiparas, 21 multiparas) (&gt; 18 years)</td>
<td></td>
</tr>
<tr>
<td>Beck (2004b), New Zealand, USA, Australia, UK</td>
<td>Descriptive phenomenology</td>
<td>Internet stories</td>
<td>To describe the meaning of women's birth trauma experiences</td>
<td>38 Women (25–44 years)</td>
<td></td>
</tr>
<tr>
<td>Beck (2006), New Zealand, USA, Australia, UK, Canada</td>
<td>Qualitative</td>
<td>Internet interviews</td>
<td>Determine the essence of mothers' experience regarding the anniversary of their birth trauma</td>
<td>37 Women (19 primiparas, 14 multiparas) (24–54 years)</td>
<td></td>
</tr>
<tr>
<td>Moyzakirin (2004), UK</td>
<td>Qualitative feminist</td>
<td>Semi-structured interviews</td>
<td>To explore women's experience of distress and/or trauma in childbirth and to consider the depth and meaning of birth that was 'awful', birth that 'changed women forever'</td>
<td>6 Women (23–39 years)</td>
<td></td>
</tr>
</tbody>
</table>
Feeling out of control led to a sense of powerlessness, vulnerability and inability to make informed decisions about their care. They felt betrayed, and some indicated that they agreed to procedures such as epidural analgesia and vacuum extractions in an attempt to end the trauma they were experiencing (Goldbort 2009). Women believed that the lack of control and involvement in decision-making was primarily due to the fragmented care and lack of continuity in care, resulting in disconnection and lack of knowledge (Thompson & Downe 2008).

To be treated humanely

The theme ‘invisible and out of control’ is closely connected with women’s experiences of labour and birth care as inhumane and degrading. They used phrases such as ‘barbaric’, ‘intensive’, ‘horrific’ and ‘degrading’ to describe the mistreatment they received from healthcare professionals (Thompson & Downe 2008, p. 271). It was also distressing for them when larger numbers of people were invited to watch the birth without their consent: ‘nobody said to me... do you mind five or six complete strangers having a look at the most intimate parts of your body?’ (Nicholls & Ayers 2007, p. 496).

Other participants talked of feeling like a ‘lump of meat’ or a ‘slab on a table’ when describing the dehumanising way in which they were treated during birth, and described a total lack of acknowledgement of them as people, as though they were non-existent (Beck 2004b, Thompson & Downe 2008, p. 271). One woman described her experience as being treated ‘like nothing, just someone to get data from’ (Beck 2004b, p. 32). They wanted the ordeal of birth to end, with thoughts of death as a way to escape from the intense pain and trauma (Thompson & Downe 2008). Others reported feeling ‘like being a victim of a violent crime or rape’ (Beck 2004b, p. 32).

Feeling trapped: the recurring nightmare of my childbirth experience

In the months or even years after birth, women felt trapped and experience vivid memories of their traumatic birth, commonly reporting flashbacks and nightmares (Beck 2004a, 2006, Moyzaktis 2004, Ayers 2007, Beck & Watson 2008). One stated:

I can’t believe five years later that I feel such strong emotions and that my body responds physically. It is like birthing trauma and the anxiety, loss and pain associated with it seem to reside in every cell of my being, with a memory capacity that serves to never let me forget. (Beck 2006, p. 588)
| **Table 3** Common metaphors and phrases                                                                 |
|---------------------------------------------------------------|---------------------------------------------------------------|---------------------------------------------------------------|---------------------------------------------------------------|---------------------------------------------------------------|
| Feeling invisible and out of control                          | To be treated humanly                                          | Feeling trapped: the reoccurring nightmares of my child-       | A rollercoaster of emotions                                    | Disrupted relationships                                        | Strength of purpose: a way to succeed as a mother              |
| Allen (1998)                                                   | Pain from contractions, feeling out of control                | Ramsay, wellbeing,                                        | Anger, tearfulness,                                       | Lack of understanding from pacts, unable to cope with other    | Detached and overprotective of child                           |
| Ayers (2007)                                                   | Out of control, frustrated                                    | Medical interventions and internal examinations            | Grief, panic, feeling                                        | children                                                       |                                                                         |
| Ayensu et al. (2006)                                           | Not coping, lack of choice and autonomy                        | Invasive memories, flashbacks                              | Feelings of shame,                                        |                                                                         |                                                                         |
| Beck (2004a)                                                   | Lack of understanding from health providers                    | Nurturing and detach from former self, flashbacks,           | Anger, depressed,                                        | Avoidance and protecting baby, child, kin,                      | Overprotective behaviour                                         |
| Beck and Watson (2000b)                                        | Difficulties in sexual encounters: Lack of understanding from  | Suicidal, nightmares                                        | Anger, depressed,                                        | relationship with partner                                      |                                                                         |
| Beck (2004b)                                                   | Lack of communication, lack of care, powerlessness,            | Feeling distressed, flashbacks, hallucinations              | Anguish, physical pain                                     | Avoidance, being isolated from partner                        |                                                                         |
| Beck (2006)                                                    | Out of control, dragged up, strapped to the bed                | Distressing thoughts (suicidal)                            | Tense, angry, upset                                       | Breastfeeding to overcome trauma                               |                                                                         |
| Nichols and Ayers (2007)                                       | Pain, out of control, feeling, continuity of care, environment | Violated, humiliated, helpless, dehumanized, lack of        | Blunt, feelings of despair                                  | Anxious, hyper-vigilance, avoiding see and                     | Overprotective bonds to compense for trauma                     |
| Thompson and Dowse (2008)                                      | Power imbalance among healthcare professionals, lack of        | Flashbacks, vivid memories                                  | Upset, anger,                                             | intimacy, Fear of being pregnant                               |                                                                         |
| Mynakoko (2004)                                                | Feelings, torture, abused, felt 'robbed'                      | Intrusive memories, empty body and devoid of               | Depression                                                | 'Felt nothing for labour' lack                                 |                                                                         |
|                                                               |                                                               | personal identity                                           |                                                          | of emotional support and sexual difficulties, No help, or      |                                                                         |
|                                                               |                                                               | Detached from self                                          |                                                          | support and lack of opportunity to talk                        |                                                                         |
Re-experiencing the event affected their lives and ability to function on a daily basis; they felt trapped, with no way of escaping from their ordeal, as they experienced the constant reminder of the event (Moyzakis 2004, Beck 2006, Ayers 2007, Beck & Watson 2008): ‘I just kept thinking about it all the time and I felt I had some sort of car crash or something; I kept getting flashbacks all the time and I found it really upsetting’ (Ayers 2007, p. 261). Often they would avoid situations that would remind them of the original trauma, for example, watching a woman giving birth on television, entering a labour room or hospital (Moyzakis 2004), celebrating the anniversary of the birth (Beck 2006) or while breastfeeding (Beck & Watson 2008). Women avoided these situations and tried to push intrusive thoughts away (Ayers 2007) in an attempt to get closer to their ‘normal self again’ (Beck & Watson 2008, p. 234). For some, this meant ceasing to breastfeed.

A rollercoaster of emotions

The theme ‘a rollercoaster of emotions’ describes the mixed emotions women felt in response to their birth experiences. They described heightened levels of anxiety, panic attacks, depression and suicidal thoughts (Beck 2004a, 2006, Moyzakis 2004, Ayers et al. 2006). This had an impact on their mental health, and they doubted their ability to cope with day-to-day events and interactions. Some suffered long-term physical and psychological repercussions from the birth, including depression, and some contemplated ending their lives: ‘I was hugely depressed, I was suicidal’ (Ayers et al. 2006, p. 393). Women also expressed feeling ‘empty’ at themselves for not speaking up and voicing their concerns during their birthing experiences, particularly in relation to certain procedures being performed, such as having their membranes artificially ruptured (Beck 2004a, Ayers et al. 2006, p. 393). They needed their birth trauma to be acknowledged, and some felt quite angry if this need was not met (Allen 1998, Beck 2004a).

Disrupted relationships

For many women the experience of a traumatic birth results in some disruption in their relationships, both with their infants and partners.

Disconnected from the baby

The impact of birth trauma on the woman and her baby can be so detrimental that it affects the maternal-infant relationship and induces negative feelings and emotions towards the baby. For some women, feelings of disconnection or ‘not feeling love’ for their infant were short-lived, but for others they continued until the baby reached the toddler years (Nicholls & Ayers 2007). Some women, despite having had previous children, explained that they felt distant from their infant or child and reported feeling very little emotion and physical connection with their baby. Irrespective of the time that had elapsed, they continued to feel a sense of ‘numbness’ (Beck 2004a, p. 222) and were unable to feel a real closeness to their children, particularly while breastfeeding. Women sometimes ‘bared’ the thought of offering their breast to a stranger (referring to the baby) (Beck & Watson 2008, p. 234). They felt empty and demonstrated little emotion or feelings towards their baby during breastfeeding sessions; some would rarely make eye contact and interact with their babies (Beck & Watson 2008). In a few cases, breastfeeding was linked with the violation experienced during birth (Beck 2004a).

Recognizing these feelings, women spoke of working hard to establish a strong bond with their babies. They felt that they had ‘failed’ them and wanted to compensate them for the trauma experienced (Ayers et al. 2006, p. 395, Beck & Watson 2008). Some reported describing women using ‘overprotective behaviours’ (Allen 1998, Ayers et al. 2006, Nicholls & Ayers 2007) or being hyper-vigilant towards their infants. For example, they reported favouring the baby to other siblings and excluding their partners from caring and attending to their babies: ‘It’s made me so over-protective of her... I don’t like other people touching her’ (Nicholls & Ayers 2007, p. 503).

Never wanting to be touched: a constant reminder

Women’s traumatic birth experiences affected relationships with their partners, particularly when there was a lack of understanding in relation to the ordeal and the partner was not considerate to their needs. They emphasized a need for empathy and to feel supported by their partners when relaying their concerns about their birthing experiences (Allen 1998, Ayers et al. 2006, Nicholls & Ayers 2007). Women felt that their traumatic birth experiences were not acknowledged or felt by their partner (Ayers et al. 2006). Some received practical support to care for the baby from their partners, but emotional support and time to talk about their feelings and emotions were lacking (Moyzakis 2004). Conversely, other women spoke of receiving emotional support; however, this fell short of their expectations and needs.

For many women, sexual intimacy was a constant reminder of the birth event. They often reported avoiding sex for fear of becoming pregnant, and this led to difficulties in their relationships. Some found it difficult to engage in
any form of physical contact with their partners. 'You just don’t want to be touched by anybody ever again' (Nicholls & Ayers 2007, p. 499). Some women blamed themselves for falling short of their expectations as wives (Ayers et al. 2006). The study by Allen (1998) included partners, and these men also reported feeling rejected and were frustrated by the loss of intimacy and sexual contact. The tension in relationships was felt by both partners, and for some couples it resulted in relationship breakdown (Ayers et al. 2006).

**Strength of purpose: a way to succeed as a mother**

Breastfeeding provided an opportunity for some women to overcome the trauma of their birth experiences and prove their 'success' as mothers. They described having 'strength of purpose'; for example, some talked of their determination to succeed at breastfeeding. Some believed that they had committed a 'sin' (Beck & Watson 2008, p. 233) by 'failing' to have a normal birth, and practices such as breastfeeding were seen as a way of compensating for the birth and giving their babies a good start in life: ‘I breastfed her for 27 months’ (Beck & Watson 2008, p. 233). Breastfeeding and the close proximity of the baby assisted women to heal and recover from their ordeal; more importantly, it resulted in greater levels of personal satisfaction and confidence (Beng & Dahlen 1999, Beck & Watson 2008).

**Discussion**

**Review limitations**

A limitation of this meta-ethnography is that all relevant studies may not have been retrieved. This may have occurred because the keywords selected may not have been comprehensive, and because the search strategy was limited to four databases. However, every effort was made to ensure that a thorough and extensive database search was undertaken. In addition, only studies published in English were included, and all the studies had been conducted in developed or resource-rich countries.

**Consequence of traumatic birth**

This meta-ethnographic study has demonstrated that traumatic birth has profound consequences for women and their partners. Further, the impact of a traumatic birth on a woman can also result in poor outcomes for infants and children. Infants of women with poor mental health demonstrate poorer cognitive functioning, impairments in language functioning, physical, psychosocial, emotional and behavioural problems (McCain & Musard 2002, Murray et al. 2003).

Guided by Noblit and Hare (1988), we developed a 'line of argument' to summarize the key findings of this meta-synthesis. Women participants in the studies reviewed felt overwhelmed by the experience of a traumatic birth. They demonstrated feelings of disappointment, anger and loss, and many held vivid memories of the experience of a traumatic birth for many years. These feelings and experiences at times affected their ability to care for their babies, and their capacity to establish a close bond or connection with their infants and fulfil the expectations of the mother role. The support of their partners was considered paramount while they attempted to reconcile their feelings. Women's traumatic birth experiences sometimes created strain in relationships, as lacked interest in physical and sexual contact. Some felt depressed, and spoke of feelings of despair and occasionally suicidal ideations. Women's perceptions of dehumanizing treatment during labour and birth by healthcare professionals may result in feelings of lack of control and a sense of inadequacy. The findings of the studies were overall very similar and qualitative analysis only identified one area of difference. This related to whether women experienced breastfeeding as a positive and 'redemptive' experience or whether it was experienced as another burden or trauma (Beck & Watson 2008).

Our findings indicate that women are often traumatized as a result of the actions or inactions of midwives, nurses and doctors. The care received was sometimes experienced as dehumanizing, disrespectful and uncaring. This is supported more generally by research reporting negative birth experiences (Fraser 1999, Goldthorpe 2009). Women who report high levels of dissatisfaction with labour and birth care commonly describe midwives and other professionals as unhelpful, insensitive, abrupt and rude (Fraser 1999). Magill-Cuerden (2007) state that being sensitive to women's needs during labour and birth is the 'hallmark of respect' (p. 126), and that respect goes beyond continuity, choice and control.

Healthcare professionals' demeanour and interactions with women in labour have a major influence on women's feelings of control of their birth experience (Salter 2009). Research by Moxaming et al. (2002) and (Eliason et al. 2008) also identified feelings of powerlessness experienced by women who felt that they had no say in what happened during birth when explanations were withheld women were not able to make informed decisions. Goodall et al. (2009) identified that choice, information and the ability to make decisions may facilitate a positive rather than traumatic birth experience. Kitinger (2006) has previously highlighted that for some women birth is experienced as rape. The term 'birth rape' has
CHAPTER 2: WOMEN’S PERCEPTIONS & EXPERIENCES OF A TRAUMATIC BIRTH

What is already known about this topic
- Traumatic birth can have debilitating consequences for women and is associated with poor psychological and emotional outcomes.
- However, women’s distress following a traumatic birth is often not addressed by professionals or in the social context.
- A small number of qualitative studies with women who experienced traumatic birth have shown that they have not had the opportunity to voice their concerns.

What this paper adds
- Many healthcare professionals are not communicating effectively with women during labour and birth, causing distress for women.
- Support from healthcare professionals and continuity of care during birth are imperative to help women achieve a more positive birth experience.
- Support from partners and greater understanding of birth experiences can assist women to reconcile their feelings associated with their birth experience.

Implications for practice and/or policy
- Women need to be given the opportunity to talk about their birth experiences and should be assessed in the postnatal period for signs of psychological distress.
- Healthcare providers should work towards implementing continuity of care models as part of organizational change and care that is woman-centred.
- Further research is needed on the efficacy of debriefing and counselling interventions to support women who experience traumatic birth.

be traumatic during their childbirth experience. The literature suggests that many healthcare professionals ignore or do not recognize the signs of psychological and emotional trauma, due to their perception that birth trauma is a physical injury (Beck 2004a).

Some participants in these studies emphasized the importance of continuity of care during pregnancy, labour and birth, particularly in relation to choice, increasing their sense of control and having a satisfying birth experience. Recent evidence from a systematic review indicates that women experiencing midwife-led models of care are less likely to experience attendance at birth by an unknown midwife, have less intervention in labour and birth and feel more satisfied with their birthing experiences (Hatem et al. 2009).

Counselling and debriefing following traumatic birth
The findings highlight the need for women to have support following a traumatic birth. The opportunity to talk about the experience is viewed by some women as cathartic (Gamble & Creedy 2009). When individuals are able to tell their story, this indicates that people are willing to listen. Pembecker (2000) suggests that a woman who has the opportunity to talk about her experience with an active and engaged listener may also give additional details about her life, including 'her view of herself in relationships, her sense of power and her strivings to reach some sort of ideal self' (Jack 1999, p. 93). However, there is a debate in the literature as to whether debriefing sessions improve long-term outcomes for women (Small et al. 2000, Rose et al. 2003). The midwifery/maternity literature often wrongly uses the terms 'talking' and 'debriefing' interchangeably. Gamble and Creedy (2009) argue that most debriefing interventions have not been specifically designed for use in the immediate postbirth period, and they emphasize the need to design counselling interventions for this context. They also highlight that the difference between debriefing and a counselling intervention where women can share their stories and have midwives help them work through and understand what has happened and then offer a positive way forward. When psychological morbidity is not addressed, such as feelings of hopelessness and helplessness, women are more susceptible to recurrent episodes of trauma (Gamble & Creedy 2009).

Conclusion
Traumatic birth can have debilitating consequences for women and is associated with poor psychological and emotional outcomes. However, women’s distress following a traumatic birth is often not addressed by professionals or in the social context. Participants in these studies indicate that
CHAPTER 2: WOMEN'S PERCEPTIONS & EXPERIENCES OF A TRAUMATIC BIRTH

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they have not had the opportunity to voice their concerns. Healthcare professionals also need to be aware of the needs of women during labour and birth. Recommendations include educating healthcare professionals to support women appropriately during labour and birth to have a more positive birth experience.

Models of midwifery-led care can potentially increase the continuity of care and facilitate women's active participation in their birth experiences. Follow-up counselling and encouraging them to talk about their birth are the first steps in helping women to recover from such experiences. Findings also suggest that women who wish to breastfeed following a traumatic birth may benefit from additional support to ensure that this is successful. Further research should be directed towards identifying ways in which women feel supported and empowered during their birth experience and in instigating support services.

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Conflicts of interest

No conflict of interest has been declared by the authors.

Author contributions

RE, VS, LW and DJ were responsible for the study conception and design. RE, VS, LW and DJ performed the data collection. RE, VS, LW and DJ performed the data analysis. RE, VS, LW and DJ were responsible for the drafting of the work. RE, VS, LW and DJ made critical revisions to the study for important intellectual content. VS, LW and DJ supervised the study.

References


CHAPTER 2: WOMEN’S PERCEPTIONS & EXPERIENCES OF A TRAUMATIC BIRTH

JAN: REVIEW PAPER


Moyaalhies W. (200-4) Exploring women’s descriptions of incidents and/or trauma in childbirth from a feminist perspective. Evidence Based Midwifery 2, 8–14.


Women’s perceptions and experiences of a traumatic birth

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2.2 Conclusion

This chapter has presented the published paper ‘Women’s perceptions and experiences of a traumatic birth: A traumatic birth’, providing a background to the study on the issues and concerns women face during and in the aftermath of a traumatic birth. The literature on severe PPH and emergency hysterectomy is limited; therefore this paper sets the significance for conducting this research study. The following chapter will outline the methodological framework, including data collection and analysis used for the study. Ethical considerations and rigor for the study also be discussed.
CHAPTER 3: RESEARCH APPROACH AND METHODS

3.1 Abstract

Chapter three describes the methodological approach and methods used in this study. The constructivist paradigm was deemed most appropriate to guide this study that aimed to capture the experiences of women who have had a severe PPH and emergency hysterectomy. The constructivist paradigm allows in-depth explorations of an individual’s experiences and emphasises the importance of understanding experiences within a social and cultural context. Convenience and snowball sampling approaches were used to recruit participants to the study. Semi-structured, face-to-face in-depth interviews, telephone interviews and email correspondence were used to collect data from 21 Australian women. Data were analysed using inductive thematic analysis. The credibility of the inquiry was ensured through a process of prolonged engagement, maintaining a reflexive journal and peer debriefing. Parts of the research approach and methods to this study are published in peer reviewed journals.
3.2 Introduction

Chapter two presented the findings of a meta-ethnographic study on women’s experiences of traumatic birth. As discussed in chapter one there is virtually no literature on women’s experience of PPH and no studies of women’s experience of PPH that led to a hysterectomy. The meta-ethnographic study revealed however, the significant impact of a traumatic birth on women’s health and well-being.

In this chapter I describe the philosophical and theoretical underpinnings of this study, the constructivist paradigm and the naturalistic inquiry methods that guided this study in order to explore women’s experiences of severe PPH and emergency hysterectomy. The fundamental assumptions of the constructivist paradigm, methods of data collection and analysis are discussed. The ethical considerations and trustworthiness of this inquiry are also explained.

The naturalistic paradigm was chosen to guide this study because, as advocated by Guba & Lincoln (1989); Lincoln & Guba (1985), it is an appropriate approach to capture meaning and understanding of a phenomenon, in this case, living with an emergency hysterectomy that followed a severe PPH, from the participant perspective.

3.3 Constructivist or naturalistic paradigm

The constructivist paradigm or constructivism (Appleton & King, 1997; Guba & Lincoln 1989), originally known as naturalistic inquiry (Lincoln & Guba, 1985) is grounded upon the assumption that meaning is not discovered, rather formulated through our engagement with the world (Crotty, 1998). It refers to the knowledge or meaning that an individual creates of their world (Colliver, 2002). Each individual
will develop meaning according to their personal experience regardless of the phenomena of interest (Koch, 1996). Crotty (1998) explains the way in which we experience the world is a result of our experiences and not “prior to our experience of it” (p.43).

Constructivism is referred to as an interpretive theoretical approach to research. Interpretive based research focuses on humans as the subjects of inquiry. This approach is valuable as it provides knowledge and understanding of the phenomena investigated and generates greater insight into the human experience (Crotty, 1998). Interpretive research refers to the philosophical beliefs that human experience is a source of knowledge into the life world of individuals (Crotty, 1998).

### 3.4 Naturalistic methodology used for this study

Naturalistic inquiry employs qualitative research methods in the natural environment of participants in order to gain understanding and meaning of their realities (Lincoln & Guba, 1985). Naturalistic inquiry is based on the assumption that individuals cannot be removed from their physical, social and cultural environment. Individuals constantly engage in the surroundings, and are constantly influenced by interacting with the world. Philosophical beliefs and values, as well as environmental relationships of an individual’s world are what constitute knowledge and understanding. Childbirth is a life experience that has personal and intimate meaning to the individual. As the researcher, I was interested in how women who have had a severe PPH and emergency hysterectomy view and experience their world, and what particular events or interactions influence the meaning they made of their experience.

The constructivist paradigm guides the researcher through the process of inquiry by three basic theoretical assumptions that underpin the research, including ontology,
epistemology and axiology (Appleton & King, 1997). The philosophical underpinnings of naturalistic inquiry are summarised below.

**Ontology** refers to the existence and the nature of reality in a constructivist paradigm. There may be multiple realities constructed in the world. Individuals’ construction of their own reality can differ to others, or their construction can be similar (Appleton & King, 1997; Cheu-Jey, 2011; Crotty, 1998). **Epistemology** is concerned with knowledge between the inquirer and the knowable, which involves the interaction or relationship between the researcher and the participant (Appleton & King, 1997). The participants hold a central role to make understanding and meaning for the inquirer explicit. Formed meanings, interpretations and understandings are a result of the interaction between the inquirer and those inquired into (Cheu-Jey, 2011; Lincoln & Guba, 1985). The third theoretical assumption underpinning the naturalistic inquiry approach is **axiology**, which deals with the role of values in the process of inquiry. The values of the inquirer influence the research process, including values that are context driven, for example, where the inquiry was conducted. Values may include preconceptions, assumptions, beliefs, cultural or social perspectives and ideas (Guba & Lincoln, 1989; Lincoln & Guba, 1985).

Prior to conducting the research, Guba & Lincoln (1989) suggested the inquirer must satisfy the conditions of entry and begin forming the hermeneutic-dialectic interaction. These core proponents of naturalistic inquiry and how they have been applied to this study are outlined in table 3.1 below. Chapter four (paper two) discusses in detail the approaches the researcher used to gain entry into the field of inquiry.
3.5 Entry requirements

The conditions of entry to the field of inquiry as described by Guba & Lincoln (1989) requires that the researcher conducts the inquiry in a natural setting that is context bound, acts as an instrument and builds on their tacit knowledge, uses qualitative methods, purposive sampling, inductive data analysis, and ensures trustworthiness in the study is maintained.

Table 3.1: The application of naturalistic inquiry tenets to this study

<table>
<thead>
<tr>
<th>Naturalistic inquiry tenet</th>
<th>Application to this study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Natural setting</td>
<td>Data were collected in the participants’ homes or at a university campus familiar to participants.</td>
</tr>
<tr>
<td>Human as instrument</td>
<td>As the researcher, I conducted all aspects of data collection including face-to-face, email and telephone interviews.</td>
</tr>
<tr>
<td>Prolonged engagement</td>
<td>I interviewed 21 Australian women. The interviews lasted between 60 to 120 minutes.</td>
</tr>
<tr>
<td>Tacit knowledge</td>
<td>I reflected on my experience in caring for women who had experienced a severe postpartum haemorrhage (PPH) and emergency hysterectomy.</td>
</tr>
<tr>
<td>Use of qualitative methods</td>
<td>Qualitative methods such as face-to-face, internet email and telephone interviews were used to collect data.</td>
</tr>
<tr>
<td>Convenience sampling</td>
<td>Participants who had experienced a severe PPH and emergency hysterectomy were invited to participate in the study.</td>
</tr>
<tr>
<td>Inductive data analysis</td>
<td>Interview data were analysed, and commonalities</td>
</tr>
</tbody>
</table>
### 3.5.1 Natural Setting

Constructions of an individual’s reality can be best understood in the context in which they occur (Lincoln & Guba, 1985). Natural setting, as noted by Lincoln & Guba (1985) is a familiar context to the individual and “cannot be understood in isolation from their contexts” (p.39). Using other settings may not be conducive to study human experience and eliciting constructions of their experience (Guba & Lincoln, 1989). Therefore, a natural setting seeks to draw out the totality of the human experience of their world (Erlandson et al 1993). In order to grasp meaning and understanding, it is important for the researcher to carry out the process of inquiry in a specific context (Guba & Lincoln, 1989) this is to ensure that constructions of human reality are not influenced by other variables (Lincoln & Guba, 1985).

Participants in this study were from three different states in Australia; New South Wales, Victoria and Western Australia. Interviews were conducted at a time most convenient to participants. Face to face interviews most commonly occurred at the

<table>
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<tr>
<th>Naturalistic inquiry tenet</th>
<th>Application to this study</th>
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<tr>
<td></td>
<td>and differences in participants’ narratives were identified in order to allow for themes to emerge. These themes reflected women’s experiences of severe PPH and emergency hysterectomy.</td>
</tr>
<tr>
<td>Assessing trustworthiness</td>
<td>Documentation of field notes, clear interpretation of data analysis and the application of findings to other settings allowed for adequate assessment of trustworthiness in this study.</td>
</tr>
</tbody>
</table>
participants’ homes or if the participant preferred, at one of the university campuses. According to Streubert and Carpenter (1999) participant convenience is paramount. The more comfortable each participant is the more likely they will disclose and reveal the nature of their lived experience. For interviews that were conducted at the University, measures were employed to avoid interruptions and distraction. Chapter four (paper two) describes the approach of conducting sensitive interviews in detail.

### 3.5.2 Human as instrument

The researcher is considered as an instrument in naturalistic inquiry (Lincoln & Guba, 1985). The human instrument is in a position to expand on the knowledge and understanding of the experience by interacting with the situation and making it explicit (Lincoln & Guba, 1985). A higher level of understanding and interpretation can also be gained through summation of data, clarification and validation (Guba & Lincoln, 1989).

The human being as an instrument gives rise to the significance of the researcher as a person who seeks to understand and create meaning (Guba & Lincoln, 1989). The human instrument can also be a source of bias through the varying perspectives they bring to the naturalistic inquiry that may threaten the trustworthiness of research findings.

My professional background as a midwife and the experiences I have had caring for women who have had a severe PPH and emergency hysterectomy, have therefore influenced my understanding and perspective of women’s experiences in the aftermath of having a hysterectomy. My interest in this topic and my reflections on personal experience were described in chapter one.
3.5.3 Prolonged engagement

Prolonged engagement involves the researcher investing sufficient time in the research field. The purpose of prolonged engagement is to subject the researcher to multiple influences and contextual facets that may impact on the phenomenon being studied (Lincoln & Guba, 1985). Engaging with the natural setting is considered important for the researcher to familiarise themselves with the environment, milieu and culture and also assists in establishing reciprocity and rapport with participants.

In this research, I interviewed 21 women. Each interview lasted 60 to 120 minutes, and with the email interviews there were often multiple interactions as I sought to clarify issues the women raised. Approach to data collection is discussed in detail in section 3.7 on the interview process.

3.6 The hermeneutic dialectic process

Guba & Lincoln (1989) described hermeneutic dialectic process as a relationship or interaction between the researcher and inquirer. Guba & Lincoln (1989) state that this interaction is cyclic in nature and produces shared understandings or “non-consensus” (p.177) during the process of inquiry. The application of the hermeneutic dialectic process was as follows: selection of participants; continuous interplay of data collection, and data analysis and findings of the naturalistic inquiry. The selection, recruitment of participants and data collection methods are outlined in detail in chapter four (paper two).

To be suitable for inclusion in the study, a set criterion outlined certain requirements for participation. The inclusion criteria were that women had experienced an emergency hysterectomy following a severe PPH and were able to converse in English. Women were required to have a good command of English in order to be
informed about the study and understand consent procedures (Schneider, Whitehead, Elliott, Lobiondo-Wood & Haber, 2007). Interpreters were not used in the study as it was believed that the meaning and the richness of women’s experiences could be easily lost in the complex translation process (Schneider et al., 2007). The period and time since experiencing the PPH and hysterectomy was not crucial. It was considered likely that most women who have experienced this event will have strong memories of it even though five to eight years or longer may have elapsed. These women may still be interested in participating and sharing their story and experience. Guba & Lincoln (1989) highlight the significance of participants being inclined to participate in the study.

Following ethics approval from Human Ethics Committee at the University of Western Sydney (see Appendix B and C), I provided the women who responded to the posters (see Appendix D) and media advertisements in local papers (see Appendix E) to participate in this study with full information about the study. Participants were given the opportunity to ask questions prior to recruitment for the study. If they met the study inclusion criteria and remained interested in participating in the study, they were sent an electronic copy of the information and consent form to read in detail. A tentative date and time for the interview were made during this first encounter and if the woman agreed, her contact details were obtained in order to confirm the interview data and time after they had an opportunity to read the full information sheet. I then contacted the potential participants either by phone or email two to three days prior to the tentative interview date. This provided an opportunity to answer any questions they had and to confirm the address and time for interview.

Table 3.2 depicts the socio-demographic characteristics of the women interviewed in the study (see Appendix F for a more detailed description of the participants).
Table 3.2: Socio-demographic characteristics of women interviewed in the study.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age</td>
<td>34</td>
</tr>
<tr>
<td><strong>Parity</strong></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>15</td>
</tr>
<tr>
<td>Defacto</td>
<td>3</td>
</tr>
<tr>
<td>Single</td>
<td>3</td>
</tr>
<tr>
<td><strong>Education level</strong></td>
<td></td>
</tr>
<tr>
<td>School Certificate</td>
<td>4</td>
</tr>
<tr>
<td>Higher School Certificate</td>
<td>4</td>
</tr>
<tr>
<td>Tertiary</td>
<td>6</td>
</tr>
<tr>
<td>Diploma</td>
<td>5</td>
</tr>
<tr>
<td>Masters</td>
<td>1</td>
</tr>
<tr>
<td>PhD</td>
<td>1</td>
</tr>
<tr>
<td><strong>Employment status</strong></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>19</td>
</tr>
<tr>
<td>Unemployed</td>
<td>2</td>
</tr>
<tr>
<td><strong>Mode of birth</strong></td>
<td></td>
</tr>
<tr>
<td>Caesarean Birth</td>
<td>13</td>
</tr>
<tr>
<td>Vaginal Birth</td>
<td>8</td>
</tr>
<tr>
<td><strong>Total women interviewed</strong></td>
<td>21</td>
</tr>
</tbody>
</table>
3.7 The interview process

At the start of each interview the participant information sheet (see Appendix G) and consent form (see Appendix H) were provided to the women again. Participants were informed that the interview will be recorded using a digital recorder and were made aware that they were able to stop the interview and or withdraw from the study at any point in time if they felt uncomfortable. Participants were made aware of their right to refuse to answer any questions without penalty. A list of counselling services (see Appendix I) was provided to participants at the time of interview in the event of emotional distress.

Following informed consent procedures, the interview commenced. At the commencement of the interview all the participants were asked a series of questions in order to obtain their demographic details (see table 3.2 and Appendix J). An interview guide (see Appendix K) was used as a “reminder” for the areas or questions to focus on. The interview was not structured, rather it was conversational in style where the participant, in the main, led the interview. Interview questions included:

- Describe what first comes to your mind when you recall your experience of having a severe bleed following the birth of your baby?

- How did having a hysterectomy following the severe bleed affect you physically? Prompt for example, in carrying out daily activities, including caring for the baby; how did you feel in relation to losing your uterus?
• Describe your relationship with your partner / husband following your hysterectomy experience; following the hysterectomy, tell me about the early relationship you developed with the baby?

• Describe the impact of the surgery on this relationship? Describe the support you received from health professionals following the hysterectomy?

• Describe the impact that this event has had on other relationships with family and friends?

• Were you referred to and did you use any form of professional or social support services? If you did, was it helpful and in what way? If you did not use any additional professional or support services, what benefits do you perceive you may have gained?

The first few interviews served to guide subsequent interviews, with the key ideas and beliefs expressed by early participants, informing later interviews. Following each interview I recorded gestures and body language that were observed during the course of the interview. Verbal and non-verbal cues were also documented such as facial expressions, gestures, body language, depth and tone of voice and periods of silence. Observing and noting these cues provided me with additional insight into the participants’ constructions of their world. Each participant’s unique experience brought value within the context of the study. It created richness and quality to participants’ narratives (Guba & Lincoln, 1989).
3.8 Data analysis and interpretation

Naturalistic inquiry employs an “inductive method” of data analysis, utilising and categorising raw data. It also involves identifying commonalities and differences in participants’ narratives to form meaning and understanding. In order to become immersed in the data and form meanings and interpretations, I listened to each recorded interview in their entirety and for the first five, I transcribed the material myself. The remaining 16 recorded interviews were transcribed by a professional transcription company. Similarly email interviews were read several times. Each transcript was then reviewed to identify gaps in the transference of transcription verbatim. The interpretation of findings occurs as the researcher becomes familiar with the research findings. Consistently engaging with the data allows the researcher to grasp the multiple realities that exist (Polit & Beck, 2010).

In order for me to remain engaged in the process of inquiry, data collection and data analysis occurred concurrently, all the while facilitating subsequent interviews. For example, questions for the later interviews differed slightly in order to elicit greater depth and richness of the women’s experiences. Guba & Lincoln (1989) state that, responses from prior interviews are able to form the basis of inquiry for consecutive interviews. To facilitate new insight, I returned to some of the earlier interviews to seek clarification of responses and to follow up on avenues previously presented.

Transcripts were analysed on hard copy, examining each paragraph of text, often line by line to extract common identifying metaphors, statements and ideas that were salient in revealing how participants’ constructed their reality.

The transcripts were then uploaded into a data management software program QSR NUD IST Vivo (NVivo 1999). The steps of data analysis as described by Lincoln &
Guba (1985) were used. Common phrases, ideas and refutations in participant’s constructions about their experiences were identified and patterns in the data emerged. (Guba & Lincoln, 1989) Use of NVivo allowed for easy movement between categorised data and the original data source in an attempt to comprehend and interpret the entire context. Interpretation of findings was achieved by making sense of women’s experiences and through constant engagement with the data. Major themes and sub-themes were formulated as a result of this continuous interplay.

The hermeneutic process as described by Guba & Lincoln (1989) acts as a filtering method by minimising errors from occurring and becoming undetected. When the researcher constantly engages with data collection and analysis concurrently, as well as peer debriefing, and keeping a reflexive journal, this allows for shared constructs to surface (Walter, Glass, & Davis, 2001), hence mitigating erroneous outcomes and the possible introduction of researcher bias.

3.9 Rigor in this study

Rigor in any research is required to prevent error of either a constant or intermittent nature. Initially, “qualitative research was criticised because empirical researchers believed there was a lack of control over the validity and reliability of the findings” (Morse & Field, 1996, p.118). Since then, attention has been given to developing trustworthiness in qualitative research (Morse & Field, 1996).

Rigor in qualitative research involves the researcher being attentive to and confirming information (Roberts & Taylor, 2002). Researchers may deal with the data in a variety of ways. Use of open-ended interviewing techniques, audio
recording, and verbatim transcriptions is said to increase the accuracy of data collection (Holloway & Wheeler, 2002).

The ultimate goal of rigor in qualitative research is accurately representing the nature of participants’ lived experiences. In an attempt to address the issue of rigour in this qualitative study, I have been guided by the ideas of Guba & Lincoln (1989). According to Guba & Lincoln (1989) there are four general criteria in judging scientific rigour for qualitative research, namely credibility, transferability, dependability and confirmability, and how they have been incorporated into this study is discussed below.

### 3.9.1 Credibility

Credibility relates to the truthfulness of the findings judged by participants and others involved in the research (Beanland, Schneider, LoBiondo-Wood, & Haber, 2000). In this study, some participants were called on the telephone to validate findings in an attempt to clarify and verify the researcher’s interpretation of their experiences and constructions. Field notes were also documented following each interview and used reflexively in the analysis to gain further insight and interpretation of the women’s constructions of their world. Koch (1994) and Walter, Glass, & Davis, (2001) confirm that a field journal or a reflective journal enables the researcher to record reflections of the interview process including emotions and experiences, thus creating a more solid understanding of oneself.

Another method that was used to ensure credibility in this study was peer debriefing (Erlandson et al 1993). The purpose of peer debriefing in constructivism is to allow the researcher to reflect on the process of inquiry with “professionals outside the context being studied” (Erlandson et al 1993, p. 31), opening the study to peer
evaluation. Van Manen (1990) states, collaborative analyses are helpful in facilitating discussions, understandings and insights about the research process. Opportunities to talk with my supervisors and other higher degree research candidates enabled me to refine my thoughts and convey experiences and insight gained through the process of inquiry. Talking about my experience of interviewing women who have had a severe PPH and emergency hysterectomy also allowed me to freely vent emotions and frustrations at the lack of services available or offered to women. Presentations of my work at several state, national and international conferences and in front of academic audiences opened my work to peer review and helped me refine my thoughts in relation to the research.

3.9.2 Confirmability

“Confirmability is research that is judged by the way in which the findings and conclusions achieve their aim and are not the result of the researcher’s prior assumptions and preconceptions,” (Holloway & Wheeler, 2002, p. 255). In this study, the reader and other researchers will be able to follow the path I took in data collection and the way in which I arrived at the constructs, themes and their interpretation (Talbot, 1995). This is achieved by revealing details of the research, including raw data (participant quotes) to demonstrate the process of data analysis and synthesis, as well as recording and reporting on the background to the study. The thoughts and feelings of the researcher were collected in the form of debriefing notes and a reflexive journal. In this way data were traced to its original sources.

3.9.3 Transferability

Transferability alludes to the faithfulness of participants’ constructions of their world (Holloway & Wheeler, 2002; Annells & Whitehead, 2007), and whether the findings
can be applied to other contexts (Erlandson et al 1993). This is accomplished when participants are able to reflect back on their experiences and notice that the findings are meaningful and true to them. In this study, transferability was achieved in two ways. For example, I presented the research approach and study findings at a range of local, national and international conferences. Here I provided a clear description of the settings where the study was conducted and participants’ characteristics, the various approaches taken to data collection and how concepts and themes were generated.

3.9.4 Dependability
Dependability refers to how well the researcher has developed and explained the research process. If this is well done then another researcher or reader is able to follow the thinking or conclusions of the research (Beanland et al. 2000; Annells & White, 2007). Dependability has been achieved in this research, by providing the reader with a detailed description of all aspects of the research process, clearly describing the methods taken to collect and analyse the data. In this study I kept a daily reflexive journal (Erlandson et al. 1993), detailing specifics of the research inquiry, including methodological decisions at different stages.

3.10 Ethical considerations
“The conduct of nursing and midwifery research requires not only expertise and diligence but also honestly and integrity” (Burns & Grove, 1999, p.191). An essential aspect to consider in all research is the need to protect participants. The use of humans as participants in research requires the researcher to ensure the protection of human rights (National Health and Medical Research Council, 2002) (Polit & Hungler, 1999; Koch & Harrington, 1998). Qualitative research propagates unique
concerns and compels a broader view of protecting participants (Beanland et al. 2000).

The qualitative researcher must attend to potential ethical dilemmas when data collection involves interviewing participants about sensitive topics, such as women reflecting on their birth experiences, in particular if it has resulted in significant adverse events. As the researcher conducting the interviews, I compiled a list of appropriate and accessible support services for women who may have been distressed due to the sensitive nature of the study under investigation. Furthermore, participants’ narratives were at times distressing and I ensured that I took the opportunity to speak with my supervisors, and talk to colleagues and other PhD students in an appropriate way all the while maintaining the confidentiality of any individual participant.

Ethical approval was sought from the University of Western Sydney (UWS) and confidentiality was ensured. This was critical because participants shared and expressed intimate details of their lived experience (Talbot, 1995). In this study, data collection proceeded in the form of digitally recorded interviews; therefore true anonymity is not possible as the researcher knows the identities of participants (Roberts & Taylor, 2002). Thus, the reason to maintain confidentiality by other measures, such as erasing digital recordings once accurate transcription of data has been verified is paramount. Other measures to maintain confidentiality included storing transcript data in a locked filing cabinet for a minimum of five years.

3.10.1 Consent

An important element of the right to self-determination is informed consent, which is understood as, participants having sufficient knowledge in relation to the research,
comprehending information and consenting voluntarily or refusing participation (Burns & Grove, 2009; Roberts & Taylor, 2002). In this study participants were required to sign a written consent form prior to their participation. The consent form was written in everyday language, using the ethics committee template that can be easily understood and comprehended by the lay person. Participants were made aware of the opportunity to ask questions and clarify points in the consent form and information sheet. Participants were also reassured of the dissociation of my study with the hospital in which they had given birth.

### 3.10.2 Autonomy

The concept of autonomy refers to an individual’s right to decide. As an ethical principle, “autonomy prescribes that persons ought to be respected as self-determining choosers and that it is wrong to violate a person’s considered and autonomous choices,” (Johnstone & Ecker, 2001, p. 407). In this study all the women were aged 18 years and over, and were able to make informed decisions regarding participation and the right to withdraw without penalty (Beanland, et al., 2000; Borbasi, Jackson, & Langford, 2008). Holloway & Wheeler (2002), comment that participants have a right to make free, independent and informed decisions without intimidation. Once participants read the information sheet (See Appendix G) and the consent form (See Appendix H), they signed the consent form and were subsequently recruited in the study.

The principle of justice is a significant ethical principle in nursing research. Participants have the right to be fairly treated before the commencement of the study, during participation and following the completion of the study (Polit & Beck, 2010). The researchers may assure that this principle is respected by the fair distribution of
risks and benefits. In this study, each participant was treated fairly by providing them with detailed information regarding the research study and any associated risks or benefits. Also, each participant was entitled to withdraw from the study without penalty or consequences, and have access to counselling if necessary or time out during the interview process for composure and debriefing.

3.10.3 The principle of beneficence
The term beneficence refers to “doing good” (Burns & Grove, 2009). The researcher endeavours to do good by illustrating and justifying the value and significance of the research study (National Health and Medical Research Council, 2002). This was shown in this research with the consent form and the participant information sheet. My aim was to “do good” by conducting the research which also had an aim, and that was to generate greater awareness among clinicians regarding the host of issues women face following a PPH and subsequent hysterectomy. It is hoped that the dissemination of findings from this study will inform health professional practices and service design, for example the revision of management protocols leading to improved outcomes through enhanced support services and referrals for these women. To date there are no known support networks specifically related to women who have sustained an emergency hysterectomy following a severe PPH. This is a concern given the traumatic experience they have endured.

3.10.4 The principle of non-maleficence
The term non-maleficence refers to “do no harm”. This concept is different to the more active and positive principle of beneficence (doing good). Under no circumstances should research participants be open to overt or subtle exploitation (Agee, 2009; Burns & Grove, 2009; National Health and Medical Research Council,
2002). It was quite possible that participation in this study may have triggered some form of discomfort or harm, as the nature of investigation was one of sensitivity. Discomfort or harm arising from the study may have been physical or emotional. The physical discomforts could include fatigue, headache, or muscle tension. The emotional discomfort may have included anxiety or emotional distress associated with responding to certain questions (LoBiondo-Wood & Haber, 2006; Polit & Beck, 2010). Some women reported that they still experienced flashbacks and it is possible that the interview may have triggered another reaction. However, participants were notified of the possible discomforts or harm associated with the study, outlined unambiguously in the participant information sheet and consent form. I attempted to above all do no harm by conducting the interviews in a sensitive manner (see chapter four), and providing participants with details of appropriate professional counselling services. This intervention was chosen in an attempt to assist participants in dealing with the physical and emotional obstacles faced whilst reliving the nature of their experience (Staunton & Whyburn, 2000; Seidman, 2000). However, no participant required counselling due to distress during the interview. This is discussed further in chapter four (paper two).

Confidentiality and privacy were adhered to and were in keeping with the principle of non-maleficence. This involved withholding participant names and under no circumstances have I revealed their identities. Participants’ names were present on consent forms and digital recordings. These documents along with the hard copy of transcripts were placed in a cabinet under lock and key for five years. Only I as the researcher knew the identities of participants. Pseudonyms were used throughout the interviews, the data analysis process, during the process of writing up the transcripts and when referring to participants in any other form of documentation.
3.10.5 The criteria of authenticity

According to Erlandson et al (1993), trustworthiness goes beyond tenets previously described as a measure of quality in naturalistic inquiry. The constructivist paradigm “demands more” when seeking methodological adequacy (Erlandson et al. 1993, p. 151). Constructivism offers an approach to research that is grounded in the realities of individuals. These separate realities that exist as constructed by individuals must be given a status of authenticity, which can be characterised by fairness, ontological authenticity, educative authenticity, catalytic authenticity and tactical authenticity (Erlandson et al 1993; Guba & Lincoln, 1989).

The concept of fairness has been addressed in this study by ensuring women were able to freely disclose constructions of their world, presenting both convergent and divergent views of this construct, while simultaneously presenting a credible account of individuals constructions. Opening the study to all women who had experienced an emergency hysterectomy following severe PPH (with the exception of non-English speaking women) ensured that this study was conducted fairly.

Ontological authenticity and educative authenticity were maintained in this study as women’s understandings and knowledge of their own constructions, as well as others’ constructions were enhanced through involvement in the study. Women found it helpful knowing other women had also experienced an emergency hysterectomy and found the interview process helpful in reconciling their feelings and emotions.

Many of the women reported that they felt empowered by taking part in this study, and that they were listened to by a genuinely interested researcher. Some expressed a keenness to participate in support groups and to share their experiences and
interpretations with others. This is discussed in chapter four (paper two) using illustrations from the data.

### 3.11 Researcher as reflector

As discussed in chapter one, to a certain extent, the women’s stories affected me psychologically and emotionally. When I commenced my study I had not personally experienced pregnancy or birth. When I was interviewing the participants I frequently would think about the women who I had cared for following a hysterectomy after birth and this, I believe, enabled me to gain perspective into the possible emotions they were experiencing, including having a small insight into what this may mean for their lives or how this will change their lives. I was given opportunities to talk to academic staff, students, and my PhD supervisors. This created a greater level of understanding, and this understanding evolved into interpretation. It was difficult to bracket, and indeed not appropriate, preconceived ideas, feelings and assumptions in this study. These experiences and beliefs that I brought to the study influenced my interpretation of the women’s life experience and existence in the world.

I found it was difficult to exclude women who expressed an interest in the study but who did not fit the inclusion criteria of this study. I had several women ring to enquire about the study that had experienced a hysterectomy, but not following childbirth. These women were extremely dissatisfied with their experience surrounding their hysterectomy, as they felt they were treated poorly by health professionals who did not acknowledge the impact that a hysterectomy would have on their lives. Other women had experienced a severe PPH; but did not require a hysterectomy, as despite having blood transfusions, their bleeding was effectively
controlled. These women desperately needed someone to talk to about their experience; sometimes conversations would last up to 30 minutes, before being offered referral information about counselling services, which they declined. Through conversational dialogue with these women I came to realise the importance of talking to women following traumatic birth and or surgery procedures. Some of the women who participated in my study and the women, who expressed interest, needed someone to talk to and most importantly someone who would listen to their experiences.

During the final year of my candidature I was pregnant and I am now a proud mother to a gorgeous baby girl. Leading up to my labour and birth, I was immersed in the final stages of data analysis and re-reading the literature around PPH and maternal mortality and morbidity. The thought of going through childbirth was quite frightening and at times I felt quite anxious as I recalled the interviews with each of the women. At the time I gave birth (in October 2011), I vividly recall asking the midwives, “how much blood did I lose?” They replied saying “we’ll just start a syntocinon drip to help stop the trickle of blood”. I was praying that everything would be fine and kept thinking about the women I interviewed and what they must have been through. My blood loss was minimal compared to the litres of blood the women lost in my study. My recent experience of giving birth and being a mother provided with a different perspective and greater insight into women’s experiences of severe PPH and emergency hysterectomy. I am forever grateful for the level of care I received during the birth of my daughter and happy to have experienced birth in a positive way. Again I thank the women who shared their stories with me.
3.12 Conclusion

The methodology for this study has been guided by the work of Lincoln & Guba (1985) on naturalistic inquiry. The philosophical, theoretical and methodological underpinnings of this research have been presented in this chapter. Data collection and data analysis approaches have been discussed and the ethical considerations, trustworthiness and rigour of this study have been identified in detail and in accordance to the tenets set by Lincoln & Guba (1985). The following chapter presents the published paper ‘Interviewing people about potentially sensitive topics’, providing elaborative detail on the data collection methods used for this study.
CHAPTER 4: INTERVIEWING PEOPLE ABOUT POTENTIALLY SENSITIVE TOPICS


4.1 Publication: Relevance to thesis

This chapter presents the publication, ‘Interviewing people about potentially sensitive topics’. This paper is an adjunct to the research methods and approach to the study presented in chapter three and focuses on the considerations and strategies for interviewing women who may be a potentially vulnerable group. In this chapter I also discuss my experience of interviewing participants.
CHAPTER 4: INTERVIEWING PEOPLE ABOUT POTENTIALLY SENSITIVE TOPICS

Interviewing people about potentially sensitive topics

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Abstract

This paper explores the challenges of interviewing people about sensitive topics. It uses existing literature and the first author's experience of interviewing women traumatized by having an emergency hysterectomy following severe postpartum haemorrhage. It also highlights the strategies that can assist interviews.

Background Interviewing participants about sensitive topics requires skill and special techniques. Certain research topics have the potential to cause participants and researchers distress and discomfort. Identifying ways to prevent vicarious traumatization and researcher burnout is imperative to the integrity of the research.

Introduction

ALTHOUGH THERE is some controversy regarding the definition or identification of what constitutes a sensitive research topic, much nursing and health research focuses on aspects of life that may be considered sensitive (Jones and Bubhinder 2003). Lee and Renzetti (1990) argued that it is possible for any topic to be sensitive, although some topics may be more likely to cause distress than others. Lee and Renzetti (1990), Corbitt and Morse (2003), Cowles (1988) said that sensitive topics are those that have the potential to cause harm to participants, eliciting powerful emotional responses such as anger, sadness, embarrassment, fear and anxiety. Sieber and Stanley (1988) commented that sensitive research also includes topics that may cause distress to the research team involved in the inquiry. Some authors are more specific in their definition of sensitive research, referring to the subject or the topic under investigation. These topics may include HIV/AIDS (Davis et al 2004), mental health issues, death and bereavement, fertility, abortion, miscarriage, and terminal illnesses such as cancer (Ally and Rootham 1998, Davis et al 2004).

This paper draws on nursing and early feminist literature to explore the main elements of conducting research into sensitive topics. We will use the experience of the first author Ref who, as part of her doctoral studies, interviewed women who had emergency hysterectomies following severe postpartum haemorrhages (PPH), to illustrate these elements. The study was sensitive as it involved women (n=21) talking about their lived experiences of having hysterectomies following severe postpartum haemorrhages. For the purpose of this paper, we will use the work of Cowles (1988) and Sieber and Stanley (1988) to define a sensitive topic as one having the potential to cause physical, emotional or psychological distress to participants or the researcher. This paper reflects on the literature and the decisions made in the design phase of the study, as well as on the experience of collecting data...
regarding this potentially sensitive topic. We will also discuss key issues and challenges.

**Data collection methods:** Qualitative methods, such as in-depth semi-structured or unstructured interviewing, are best suited to investigating sensitive topics (Elum and Fenton 2003). The decision to interview people about sensitive topics stems from the epistemological and ontological stance that knowledge and reality can only be sought from those who experience it (Croty 1998). Knowledge about a particular phenomenon may be gained through face-to-face interviews, face-to-face interviewing involves human interaction and is a way of exchanging information that can be difficult to obtain through other methods of data collection such as questionnaires or surveys (Kvale 1996, Creswell 2007).

In addition, researchers can also draw on technologies known as computer-mediated communication (CMC) – such as email, instant messaging and online social networking forums – to collect data on sensitive topics. This technique can be advantageous for collecting data on sensitive topics, as some participants may consider disclosing intimate and personal experiences to be embarrassing, humiliating and awkward (Davis et al. 2004, East et al. 2010). Participants may feel more comfortable using CMC as opposed to face-to-face interviews, to participate in research, so its use may increase participant recruitment (Mann and Stewart 2000, East et al. 2008, 2010). Using CMC to interview participants who live far away saves time on travel, additionally, using CMC means there is no need as with oral interviews to transcribe sensitive data (Mitchell et al. 2008, East et al. 2008, 2010).

Despite the various benefits associated with CMC, some argue that data collected using this method may be viewed as “face-less and body-less” (Sonn 2009). However, to the contrary, East et al. (2010) highlighted the possibility of supportive participator-researcher relationships developing as participants value the opportunity to talk and receive support. CMC is therefore an “real” as face-to-face interviewing (East et al. 2010).

Telephone interviews may be well-suited to potentially sensitive topics because this technique provides participants with the opportunity to disclose intimate and closely held experiences without feeling uncomfortable (Sturgis and Hambranan 2004). Similar to internet interviewing, telephone interviews provide an opportunity for potential participants who live at a distance from the researcher to participate in research endeavours (Sturgis and Hambranan 2004, Opdenakker 2006).

Early in our study of women's experiences of hysterectomy following PPH, it became evident that it would be necessary for us to use a range of approaches to collect data, including face-to-face, telephone and email interviews. The phenomenon under investigation is relatively rare or a revenue, Haynes et al. (2004) indicated that between 1999 and 2002 in Victoria, Australia, five out of 1,000 women giving birth experienced hysterectomy following PPH (0.05% per cent). To increase participation, we invited all women who expressed an interest to participate in the study, even if they lived far away. Some participants in our study who lived locally also chose to be interviewed by email or over the phone for convenience; however, it was also apparent that these participants felt more comfortable discussing the sensitive topic in this manner.

**Issues and challenges** Qualitative interviewing involves entering the lifeworld of participants (Opdenakker 2006, Dickens-Swift et al. 2008). One of the most important elements of data collection during in-depth interviewing on a sensitive topic is the ability for the researcher to develop a rapport with participants (Liampattong 2007, Korneli-Liller et al. 2009, Dickens-Swift et al. 2007) suggested that developing a rapport with participants in qualitative interviews will enhance the researcher’s access to the interviewees’ lives. Booth and Booth (1994) believed that the way to develop a good rapport involves giving as well as receiving information in a two-way process between participant and researcher. Through this, the researcher can better form a trusting connection with participants, helping them to share their experiences (Seldman 2000).

In our study, the process of building rapport started with recruitment. In some cases, two to three phone conversations or email discussions occurred with women before meeting them for interviews, and they began to disclose their experiences, which initiated the building of rapport.

One way of judging the success of building rapport is in the depth and quality of information and experiences revealed by participants (Korneli-Liller et al. 2009). Lec (1993) warned that conducting research into sensitive topics can result in the researcher developing a closeness to participants that confuses the role of friend and researcher. This could be an issue if data collection involves repeated rather than single contacts between the researcher and the participants.

A major concern when undertaking qualitative interviewing is to minimise the power imbalances...
CHAPTER 4: INTERVIEWING PEOPLE ABOUT POTENTIALLY SENSITIVE TOPICS

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between the researcher and the participant (Beth and Buchanan 2005, Peters et al 2008). Reciprocity involves a mutual exchange of information and contributes to establishing rapport (Peters et al 2008). Feminist literature (Stanley and Wise 1983, Reisbord 1992) has highlighted the significance of building rapport in research, while others argue that efforts to build rapport may be seen as coercive or as a form of surveillance rather than support (Backover 2003). Participants may feel they are under 'examination' or 'scrutiny' and so not feel comfortable in relaying their experiences or telling their stories to researchers.

In our study, the interviewer [RE] endeavoured to minimise potential power imbalances and build rapport through small talk about the weather, work, participants' children, and how their days had been progressing, for example. The women noticeably became more relaxed and more inclined to talk about their experiences of PPH and their subsequent hysterectomies during the conversation.

Sensitive and open questioning: When asking interview questions, it is important to allow participants adequate time to respond fully (Nieswiadosky 1998). In qualitative inquiry, good interview questions are open-ended, clear and aimed at eliciting responses that reflect the participants' experiences (Fetterman 2002), while simultaneously being mindful of, and sensitive to, the needs of participants (Dickson-Swift et al 2007). In our study, we asked open questions such as 'Can you describe your thoughts when you were experiencing the haemorrhage or heavy bleeding?' and 'Can you describe the relationship you developed with your baby in the first few weeks and months?' to grasp the entirety of women's experiences. These questions elicited strong responses from the women and we allowed time during the interviews for the women to express their feelings, as well as to remain silent for fairly lengthy periods.

Demonstrating care and empathy during research is essential in eliciting information from participants (Coles 1988, Dickson-Swift et al 2007). This is particularly important when studying vulnerable participants and sensitive topics (Kavanagh et al 2005). In our study, I [RE] engaged with the women sensitively, respecting periods of silence and their readiness to continue with the interview. Women made comments such as 'Sorry,' 'I'm alright to continue,' or 'I said to myself I wouldn't cry.' In spite of the sometimes strong emotions the women demonstrated, they wanted to continue and later disclosed that they were pleased to have had the opportunity to discuss their experience.

Appropriate use of self-disclosure: Researcher self-disclosure is the process of revealing information about self to the participant (Peters et al 2008). Feminist researchers advocate this, highlighting the possibility for greater engagement by participants during the interview process; however, it can potentially lead to researcher vulnerability and scrutiny, depending on what the researcher has divulged (Reisbord 1992).

In our study, I shared thoughts and information with participants when appropriate. Women would often ask 'What interested you in this topic?' or 'What is the incidence of women having a hysterectomy following childbirth?' I answered questions honestly, which assisted in reaffirming to them that others had also experienced this phenomenon, as many described their experience as 'isolating'.

Self-disclosure during the interviews created a less intimidating environment and enhanced the reciprocal nature of interviewing. Although self-disclosure can enhance interviews, it also has the potential to cause confusion about the role of the researcher - what Dickson-Swift et al (2008) termed 'blurred boundaries' between the dual roles of healthcare professional and researcher. This can often occur as a result of the sensitive nature of the topic and prolonged contact with participants.

Creation of a comfortable interview environment: Environmental considerations and appropriateness of venue need to be thought through carefully. It is important for the participant and the researcher to feel safe (McCoole et al 2001). Interviews should be conducted at the times most convenient for participants and at places agreed by the participants and the researcher. Participant privacy and convenience are paramount, according to Speziale and Carpenter (1999). The more comfortable participants are, the more likely they are to disclose information and reveal the nature of their lived experiences.

To reduce the participants' sense of vulnerability, they were asked to choose places where they could most comfortably participate in an interview. Ensuring a private environment was also important. Most opted to be interviewed in their homes when other family members would not be present; only four had young infants or children with them. Those who chose to come to the university for the face-to-face interviews. These were conducted in a private and quiet room with soft lighting. A sign was placed on the door to avoid any interruptions. Comfort was a priority to ensure women were at ease during the interview. I offered breaks, tissues and refreshments, ensured privacy and temporarily terminated interviews when participants were distressed or emotional.
CHAPTER 4: INTERVIEWING PEOPLE ABOUT POTENTIALLY SENSITIVE TOPICS

Qualitative research

Consideration of the timing of interviews

There are varying views about timing and the optimum time to collect qualitative data after a traumatic personal experience (Cookson 1988, Enoch and Bushinder 2005). Researchers need to be mindful of participants' recent experiences and how these can influence their immediate responses to questions. According to Porter and Birt (2001), it is important to capture experiences close to the traumatic event as the memory is resolved, becoming less detailed, less vivid and more distant over time. However, other authors disagree. Pollio et al (2006), for example, commented that an individual is able to recall memories relevant to their personal lives despite the time period.

We interviewed women between five weeks and 28 years after they had a hysterectomy after birth. Despite the different time periods, all 21 participants had shared experiences of grief, loss and trauma. However, there were noticeable differences among the narratives, particularly with one woman who had her hysterectomy five weeks before the interview. It was difficult to interpret the complexity of her experience during the interview and transcription processes. Frank (1995) termed the difficulty in interpreting or understanding the narrative because the storyteller is still distressed and traumatised by the experience 'chaos narrative'.

Risks to the researcher

Conducting research into sensitive topics can be challenging, especially if the researcher is a novice and has limited expertise in interviewing about topics of a sensitive nature (Anderson and Hatton 2000). Qualitative research is the study of subjective experience, so it is difficult for researchers to distance themselves from studies. They cannot remain faceless interviewers (Dickson-Smith et al 2008). Researching in sensitive areas has the potential to pose a threat to researchers' wellbeing, particularly if they have strong feelings or have lived experiences of the phenomena under investigation (East 1993).

In our study, we were aware of the potential for "vicarious traumatisation". Vicarious traumatisation occurs when the researcher engaging with the traumatised women begins to develop feelings of fear, grief and intrusive thoughts (Dunkley and Whelan 2006). Researcher "burnout" (Dunkley and Whelan 2006) was another issue that concerned the researchers. In our study, we established processes to ensure that I had time between interviews to reflect on what had been said and what had occurred. I conducted at most two interviews per week and I met regularly with other members of the team to "debrief".

Potential benefits of interviewing

Individuals sharing their life stories and telling their stories to an interested listener can experience positive and therapeutic effects from participation (Corbin and Morse 2003, issue 2009, East et al 2010). Participants may find telling their stories to be cathartic (East et al 2010), since participants undergo a reflective process, which is a possible way of gaining closure (Carlson and Blier 2004). Reflecting during interviews has also generated some positive outcomes for women participating in research: for example, breast cancer survivors (East 2006). These women with sexually transmitted infections (East et al 2010) and women with postnatal depression (Beck 2005). This is because telling someone your experiences and sharing your story can contribute to healing (Leshe and Block 2005). Supporting and encouraging individuals to unveil their experiences will help reduce any insecurity they foresee in the future and in their life (Dalby 2002).

In our study, six women reported a perceived cathartic effect for telling their stories. "Gillian" (a pseudonym) participated in a face-to-face interview. Following the interview, she sent an email stating: "Just a note to thank you for coming round to interview me the other day. I found that a very positive experience and it was good to talk about my feelings. Thank you for all the work you are doing on the study which I'm sure will produce some very helpful information. If there is any way I can help in future please don't hesitate to let me know. I would be very willing to offer support to others or to be involved in a support group."

East et al (2010) noted that participants in their study also express a sense of empowerment from being listened to and heard. This also occurred with Beck (2005) who interviewed women by email about their traumatic birth experiences and revealed that participants found it particularly empowering and therapeutic to have someone listen to and respond to their stories even if that was over the internet. In our study, "Lousia" felt a sense of relief from talking about the trauma she experienced as a result of having the hysterectomy. She said: "I knew my family and friends are sick of me talking about it. It has been so good speaking to someone who is genuinely interested." Similarly, "Mantie" and "Nia" conveyed their willingness to participate in the study to have the opportunity to share their stories with an interested listener.

Mantie said she 'had to have a hysterectomy as I was unknowingly a victim of placenta accreta. I am
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happy to participate and I definitely have observed differences in my past birth experience compared with my first baby. It would be wonderful to speak to someone about this.

It had a hypnotic few weeks before the interview. She explained how talking about her experience had been therapeutic. I think what you doing is fantastic...it has been therapeutic talking about it. Every time you talk about it, it helps and makes it easier, and for a week I've been psyching myself up thinking, "Don't be an idiot and cry, don't be an idiot and cry," and all morning I've been thinking, "Yeah, I feel really good today," and as soon as I start talking about it, I start crying.

Peters et al. (2008) noted that participants who tell their story and what qualitative research may have to a sense of being valued or of being, researchers may also be inclined to share their experiences to gain a sense of purpose and contribution through increased awareness of their experience.

Conclusion

Employing strategies, such as building rapport, reciprocity, appropriate and sensitive use of open questions, self-disclosure, ensuring a comfortable environment and appropriate timing, helped with the interviews in this study of a sensitive topic. These measures were aimed at achieving trust between participant and researcher to enhance spontaneous exchange of information in a warm and supportive environment. Although interviewing: participants about sensitive topics has the potential to cause a degree of discomfort, talking about an experience in a safe and respectful environment can help with gaining a sense of personal control or efficacy over the event or situation.
4.2 Conclusion

This chapter has presented the paper ‘Interviewing people on potentially sensitive topics’, providing further detail on the methods and principle used to collect data in a sensitive manner, namely environmental concerns to ensure women felt comfortable, appropriate open-ended questioning, and minimising distress to women during the interview process. Potential risks to the researcher during sensitive researcher were also discussed. The following chapter presents the first published paper of the findings titled ‘Between life and death: Women’s experiences of coming close to death and surviving a severe postpartum haemorrhage and emergency hysterectomy’.
CHAPTER 5: FINDINGS: BETWEEN LIFE AND DEATH: WOMEN’S EXPERIENCES OF COMING CLOSE TO DEATH AND SURVIVING A SEvere PPH AND EMERGENCY Hysterectomy


5.1 Overview of themes

Four major themes emerged through the data analysis; ‘between life and death’; ‘being a mother’; ‘loss of normality’; and, ‘moving forward’. These themes and the related subthemes are outlined in Table 5.1 below.
Table 5.1: Themes and sub themes

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
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<tr>
<td>Between life and death</td>
<td>Being close to death: bleeding and fear</td>
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<tr>
<td></td>
<td>Having a hysterectomy: devastation and realisation</td>
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<tr>
<td></td>
<td>Reliving the trauma: flashbacks and memories</td>
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<tr>
<td>Being a mother</td>
<td>Initial separation: lost bonding time</td>
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<td>Feelings of failure</td>
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<td>Relinquishing care of the infant</td>
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<tr>
<td>Loss of normality</td>
<td>Being incomplete: half a woman</td>
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<td>Not myself: a changed body</td>
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<td></td>
<td>Being alone: isolation and disconnectedness</td>
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<td></td>
<td>Fearing intimacy: insecure and wary</td>
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<td>Moving forward</td>
<td>Appreciating life and living</td>
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<td>‘It’s just the way it is’</td>
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<td>Changed and positive perspectives</td>
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<td>Redefining priorities</td>
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### 5.2 Publication: Relevance to thesis

The first theme; ‘between life and death’ is reported in this chapter and describes the trauma and shock that women experienced at the time of the PPH and emergency hysterectomy together with the realisation that they would be infertile. The immediacy and finality of this was extremely distressing for women and for some had devastating consequences.
CHAPTER 5 FINDINGS: BETWEEN LIFE AND DEATH

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Between life and death: Women’s experiences of coming close to death, and surviving a severe postpartum haemorrhage and emergency hysterectomy

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ABSTRACT

Objective: To describe women’s experiences of having an emergency hysterectomy following a severe postpartum haemorrhage.

Design: A qualitative research approach was used to guide this study. Data were collected through semi-structured, tape recorded face-to-face, email, internet and telephone interviews.

Setting: Three states in Australia: New South Wales, Victoria and Western Australia.

Participants: Twenty-one Australian women who experienced a severe postpartum haemorrhage followed by an emergency hysterectomy participated in the study. The median age of participants at time of interview was 42 years and the median time since having the hysterectomy was four years.

Findings: A process of inductive analysis revealed the major theme, ‘between life and death’ and three sub-themes: ‘being close to death: bleeding and fear’, ‘having a hysterectomy: devastation and realisation’ and ‘living the trauma: flashbacks and memories’.

Conclusion: Formulating a plan of care for women identifiable at risk of PPH and ensuring appropriate follow-up counselling is made, is key to help reduce the emotional and psychological symptoms experienced by these women in the aftermath of severe postpartum haemorrhage and hysterectomy.

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Introduction

Severe postpartum haemorrhage (PPH) is a life threatening birth complication (Beck, 2004; Department of Health New South Wales [NSW], 2005) that can have long term consequences for women and their families. Severe postpartum haemorrhage (PPH) is defined as blood loss equal to or greater than 1000ml following birth up until 12 weeks post partum, or any amount of blood lost post partum that causes haemodynamic compromise (Welsh et al., 2008).

Postpartum haemorrhage remains one of the leading causes of maternal mortality in Australia and internationally (Carroll et al., 2008; Department of Health New South Wales [NSW], 2005; Marsden and Henry, 2006). The prevalence rate of PPH internationally is approximately six per cent. Africa has the highest rate of PPH at 10.3 per cent (Carroll et al., 2008). More importantly, the maternal mortality rate attributable to PPH, accounts for more than 30 per cent of maternal deaths in developing countries such as Africa and Asia (Carroll et al., 2008; Khan et al., 2006).

There are also increasing numbers of women having hysterectomies following severe PPH (Haynes et al., 2004). In Australia, a Victorian report indicated that the rate of hysterectomy following severe PPH doubled over the period 1998–2002 when compared to the previous triennium (Haynes et al., 2004). Similar figures have been shown in Canada (Joseph et al., 2007) and the United Kingdom (Atkinson and Allott, 2002), where the rate of PPH with hysterectomy has also increased over the past five years. Although hysterectomy is relatively rare and used as last resort in an attempt to save the lives of women, it may have devastating physical and psychological consequences (Barlett, 2003). Traumatic birth experiences have the potential to affect women’s functioning and the way they interact with others (Allen, 1988; Ayers et al., 2006; Elmir et al., 2010).

Epidemiological studies in Australia have indicated that maternal mortality attributable to PPH is increasing (Cameron et al., 2006; Ford et al., 2007). Yet despite this, research focusing on the women’s experiences of having an emergency hysterectomy following a severe PPH is lacking and their stories of coming close...
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in death and their experiences in the aftermath of emergency hysterectomy remain relatively unexplored.

Background

Women who have come close to death as a result of severe birth complications are commonly referred to as ‘near-miss’ obstetric cases (Cecati et al., 2007; Panesar and Hall, 2013). An obstetric emergency, which may include having a severe PPH occurs in approximately four per cent of births (McCowan, 2001). Near-miss obstetric cases arise with urgency, requiring immediate and decisive actions to work collaboratively to achieve the best possible outcomes for the woman, her infant and the family (Cecati et al., 2007). The nature of obstetric emergencies can be traumatic for women, as there is often little time for explanation and provision of information (Beck, 2004; Fallowsfield, 1992).

A traumatic birth experience can result when a woman perceives her life or the life of her infant to be in danger (Beck and Watson, 2003). It can be associated with negative outcomes including psychological distress and physical pain (Creedy et al., 2000; Carrincha and Slade, 2000). A traumatic birth experience can lead to symptoms of psychological trauma (Beck and Watson, 2008; Gamble and Creedy, 2004).

Previous psychological trauma can be compounded by a traumatic birth experience, Waldenstrom et al. (2004) suggest that some women who experience a traumatic birth go on to experience post-traumatic stress disorder (PTSD). The American Psychiatric Association, Diagnostic and Statistical Manual of Mental Disorders, 4th ed., Text Revision (DSM-IV-TR) (2000) define post-traumatic stress disorder as a persistent response to a threatened injury or death to one’s self or others. The symptoms of PTSD may include reliving the traumatic event, avoiding professions involved in their care, emotional numbing and insomnia (2000). Ayers (2007) reported that the prevalence of women experiencing PTSD following childbirth is between one and six per cent. Lems and Hargreaves (2003) explain that a number of factors are associated with the development of PTSD following birth. This may include experiencing intense pain during labor, as a result of inadequate pain relief and obstetric interventions such as forceps, ventouse or emergency cesarean section. Fear of death (Allen, 1998; Beck, 2004a) and experiencing feelings of powerlessness during labour can be associated with the development of PTSD (Kelland et al., 1998; Slade, 2000).

Mapp and Hudson (2005) investigated women’s experiences of obstetric emergencies during childbirth; they reported that women experienced significant distress during the emergency. Similarly, several studies have reported that women who experience an emergency cesarean section, four for their lives and worry about the health of their babies. They also have significant concerns about the possibility of death (Kylling et al., 1990a, 1990b). It is not uncommon for women to be unaware of the nature of their birth experiences with depression (Simkin, 1992), particularly if they experience unanticipated complications that threaten their lives. Research indicates that a woman’s experience of memory of her birth, particularly if it is a traumatic event, may linger months or even years following her birth experience (Waldenstrom, 2003).

The experiences of women coming close to death and surviving following severe PPH and an emergency hysterectomy remain unknown. This paper reports on women’s recollections of their birth experiences related to having a severe PPH and emergency hysterectomy. This paper focuses on the theme ‘between life and death’, drawn from a study that explored the experiences of women who had a severe PPH and emergency hysterectomy. Women’s early mothering practices, and the emotional and physical impact of having a hysterectomy, were other key themes derived from the study and have been published elsewhere.

Methods

Naturalistic inquiry was selected to frame this study, and the methods for this study have been previously described in detail. A naturalistic inquiry approach focuses on the human experience; in this case, women who have had an emergency hysterectomy following a severe PPH, as the basis of inquiry (Lincoln and Guba, 1985). Naturalistic inquiry was deemed most appropriate; it tends to construct meaning and experience as lived by the individual in their world. Multiple researchers can be involved in the process specific to the context of their experience (Lincoln and Guba, 1985). A deep understanding of the women’s experiences of having a hysterectomy following a severe PPH can therefore be facilitated through a naturalistic inquiry approach.

Participants and recruitment

Ethics approval was obtained from the institutional Human Research Ethics Committee. Information about the study was disseminated via media release and posters and flyers were placed in a range of locations including the university campuses, and public places such as pharmacies, and childcare centres. Inclusion criteria required participants had experienced a hysterectomy following a severe PPH, be willing to participate in the study, and be able to converse in English. For the purposes of this study, the period of time since experiencing the PPH and hysterectomy was not crucial. It was considered likely that most women who have experienced this event will have strong memories of the event, even though several years may have elapsed (Ehren 2002; Simkin, 1992).

Data collection continued until data saturation was reached. A total sample of 21 Australian women between the ages 24–57 years, participated in the study with the median age at the time of interview being 42 years. The time period since having had the hysterectomy at the time of interview ranged from five weeks to 23 years, the median time since having the hysterectomy was four years. Thirteen of the women had undergone a caesarean birth and eight women had a vaginal birth. Of those women who had a caesarean, six women had undergone one or more previous cesareans, and four women had a history of miscarriage. Women were selected for their representation of the Australian female population and the type of trauma they had experienced. The women were between the ages of 24–57 years. The median age was 42 years.

Data collection and analysis

In keeping with the naturalistic inquiry approach, data were collected through face-to-face, telephone and internet email interviews. These varied methods were chosen to facilitate women’s participation in the study, as some participants were geographically distant from the research team (Ehren, 2008). Furthermore, due to the sensitive nature of having an emergency hysterectomy following a severe PPH, it was hoped that providing alternative methods of participating in the study would create a sense of autonomy and enhance the women’s personal comfort during the interview process. Some of the women felt more relaxed

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Table 1
Sox-o-demographic characteristics of women interviewed.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n = 21</th>
</tr>
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<tbody>
<tr>
<td>Mode of birth</td>
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<tr>
<td>Vaginal birth</td>
<td>11</td>
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<tr>
<td>Caesarean section</td>
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<td>Parity</td>
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<td>4</td>
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<tr>
<td>Risk factors</td>
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<td>Pre-eclampsia</td>
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<tr>
<td>Referral placenta</td>
<td>1</td>
</tr>
<tr>
<td>Postpartum bleeding</td>
<td>2</td>
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<tr>
<td>Placenta accreta</td>
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<tr>
<td>Placenta previa</td>
<td>4</td>
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<tr>
<td>Marital status</td>
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<td>Secondary</td>
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<tr>
<td>Tertiary</td>
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<tr>
<td>Psychological symptoms following birth</td>
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<td>High anxiety</td>
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<tr>
<td>Nightmares</td>
<td>10</td>
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<tr>
<td>Depression</td>
<td>9</td>
</tr>
<tr>
<td>Other intrusive thoughts</td>
<td>3</td>
</tr>
</tbody>
</table>

Findings

The findings of this study indicated that women found themselves in a predicament of life and death. Women were able to sense an imminence of death and felt despair at the amount of blood they were losing. During this time, women wondered if they would make it through to see their children grow. The devastation and realization of almost losing their life and having had a hysterectomy continued to affect some women in the months following birth and even years later. A process of inductive analysis uncovered three sub-themes that exemplified women’s experiences of bleeding and surviving a severe PPH and emergency hysterectomy. They were: being close to death; bleeding and fear, having a hysterectomy; devastation and realization; and reliving the trauma: flashbacks and memories (see Fig. 1).

Women experienced the fear and uncertainty about their life and whether they would make it through to see their children. It was a frightening and disturbing thought that lead to profound feelings of emotional turmoil. During the emergency, a time when women described as being between life and death, women not only feared for their lives, but also for the lives and futures of their babies, their partners and other members of their families.

Fifteen of the women spoke of being close to death at the time of bleeding, or while being wheeled into theatre for an emergency hysterectomy. Fiona, who had a vaginal birth, later went to theatre to have a manual removal of her placenta, talked about the shock and distress at seeing such a large pool of blood:

... When the haemorrhaging started... it was like somebody was pouring buckets of blood... there was just so much blood... it was really frightening... it was absolute panic, and it was really ghastly... it was horrifying. It was like being in a... commercial, you know, except it was the sit and there was no car crash. It was just really ghastly... very, very traumatic (Fiona).

Fiona recalls the ‘shock’ she experienced during the period where doctors were trying to control the bleeding.

The trauma, I had to go to theatre because they manually removed my placenta, they couldn’t stop the bleeding. It was a life and death situation, it was a shock (Fiona).

Kayla had a vaginal birth and described her ‘body shutting down’ and almost dying:

... I’d lost so much blood so quickly, I was dying, basically, and I could feel myself dying and sort of slipping away which... I felt like, you know those really old TV’s, where you turn them off and the screen sort of disappears into a little circle before it goes black (Kayla).
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Some women were unaware of the severity of their blood loss. The realisation of what had occurred to them did not happen until they saw the number of blood transfusions they required:

I could see they were hanging all this blood to give to me and I remember thinking, God almighty, how much blood did I lose.... (Mia).

Women felt a real sense of loss of control; they used words such as ‘helpless’ and ‘weak’, and some described experiencing a type of out of body experience. Two women described feeling disconnected from their body:

Actually at one stage I can remember desisting as much as that I felt like I was looking at myself on the table with everyone around me... that really profoundly affected me inside... [jade].

Both women mentioned the anxiety she experienced and her sense of feeling disconnected from her body:

I had a major anxiety attack... I think I made the connection between feeling really well and the blood and the shock that I was going into, and the fact, you know, how close to death people can be in those times... I felt like I was kind of having a bit of an out of body experience. I was dissociating from it... [Ruth].

When women feared for their life; some turned to their religion and faith in order to help them get through the ordeal. These women prayed, asked for forgiveness and asked God to take care of their partners and children. For these women, turning to their faith, was the only thing they could do in the face of near death. The women who had a strong faith spoke of gaining some comfort and feeling calm when turning to their religion:

... I was praying, praying, out loud to get through... I had faith in God. So that helped me... (Ruth).

The severe amount of blood loss that women sustained and the news of requiring a hysterectomy caused great distress to their partners. The women were able to vividly recall the anguish and grief their partners experienced:

My husband was really upset. I can remember being wheeled out and him sort of rushing upstairs to him, and he just grabbed her, one last kiss goodbye... He was extremely distraught... My partners had been called... all I can remember is him [husband] crying over the bed... (Mary).

Women also recalled the fear their families experienced in response to them losing a large amount of blood:

My parents actually thought I was going to die because I was bleeding so much and I remember dad saying ‘should we get the press’... (Sue).

Fear was also related to women believing that if they died their children would grow up without their biological mother and their partner and the rest of the family would have to alter their lives to care for the children. There was also fear about leaving their young children behind to the unknown. This unknown was not because of whether or not a partner was left behind to care for these children but instead unknown as to what life changes their children would face and whether or not they would cope without a mother. This issue was raised in the context of women being seen as the backbone of the family and the primary care of their children. Sue describes the emotional ‘scar’ of her experience as being one of concern, rather than the physical ‘scar’ of her experience:

... my biggest scar was that my baby would not have a mum, that whole time wasn’t about me dying it was about my baby not having a mum growing up... (Sue).

Having a hysterectomy: preparation and realisation

Women experienced mixed emotions related to the reality of having a hysterectomy. Words such as shock, traumatic and horrifying were used to describe their experience and as they came to realise the consequences associated with having a hysterectomy.

I was filled with mixed emotions. It happened when I was in theatre having my placenta removed, so I didn’t know what was going on; I was asleep. I woke up the next morning in ICU... (Jayne).

Some women had clear recollection of what was said to them during and prior to having a hysterectomy. They were given an explanation by health professionals about the rationale for having a hysterectomy. Amongst all the information being explained to women, ‘hysterectomy’ was the only word they understood and started to focus on its impact on their life.

I remember being woken up and the doctor saying blah, blah, hysterectomy... so from all that they uttered I understood that I was going to have a hysterectomy... (Amy).

During the moments of being told by doctors of the need to have a hysterectomy, women knew having a hysterectomy indicated plans for children was no longer possible. Ruth was one of ten women in the study who was willing to have more children. While being told of the need to have a hysterectomy to save her life, Ruth’s world came crumbling down on her:

You’re going to have to do a hysterectomy... I said that means no more children, doesn’t it? He [doctor] said yes, (Ruth).

Although women were grateful for surviving a life-threatening emergency, the realisation of never being able to have children, saddened and caused women pain and grief:

I definitely would have liked to have more children; I know it was life saving for me. I guess I experienced mixed emotions, like you’re grateful you’re alive but deep down you really want more children. (Jane). Some of the women were grateful to have survived a life-threatening emergency. Throughout the interview, Marie, who had a vaginal birth and retained placenta, constantly referred to herself as having ‘surgery’ and being a ‘survivor’. The way in which Marie refers to herself indicates that she considers herself lucky to have survived a life threatening emergency:

I just remember, a doctor saying sign here... and the form I signed was to have a hysterectomy and I remember the doctor saying it will save your life... (Marie).

Not all the women had a hysterectomy immediately following the birth; six women who had a caesarean section were initially stitched up and packed with gauze and other material to help contain the bleeding. Three women returned to theatre sometime after their caesarean section to have a hysterectomy because the bleeding was not severe. They described their distress and reluctance to go back to surgery. They knew they had no choice and by this stage they had been through too much, all they wanted was for their pain to subside and for them to return home:

I said, I’m not going back in. You have to, you have to [doctor], You’ll die. The whole thing. You know... I wasn’t aware, and I was in pain. All I kept thinking about was, I’m already in pain. You’re going to cut me again? (Jane).

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Reflecting on the trauma: flashbacks and memories

Vivid memories, flashbacks and nightmares were a continuous reminder of the trauma women had experienced. Living each day with having had a hysterectomy was an ongoing struggle for some women. They tried to reconcile their feelings and move forward; however, this was a struggle for some, as they found it difficult to contain their emotions and block intrusive images they experienced in relation to having had a hysterectomy. In between women, their experiences during these episodes, their emotional moods ranged from being joyful to unhappier, the flashbacks experienced by some women were

it definitely brings back memories when you watch something on television that mentions hysterectomy, but yet you don't hear about hysterectomy following childbirth that often. (Tina)

Returning to the hospital environment brought back unplanned memories of women's experiences of being a hospital service user. Small details of health care professionals and seeing other service users in the hospital, triggered flashbacks, causing some women to hyperventilate and become quite apprehensive. Gillian, a registered nurse, recalled the day she returned to work one year following the hysterectomy:

I went back to work a year after and I thought I'd dealt with it all really well until one day I was told I had to go back to intensive care to work for the night and I couldn't go. I started to sweat, I started to shake, I started to hyperventilate, became hysterical so I they had sent somebody else. I just couldn't put a step through that door and I've worked in intensive care before. No, I couldn't have your back then. I would not have been physically able to step through the door. . . . (Gillian)

Some women avoided going to hospital and dealing with health professionals as it was a reminder of the treatment they received during and following their hysterectomy experience. Three women avoided visiting doctors, sometimes to the detriment of their own or their children's health:

I don't like going to the hospital or the doctors. Like my daughter is 11 years old. I don't take her to see the doctor until I had to do and she was really bad, she had tonsillitis and needed an operation. (Jenny).

In women's everyday lives, some described a fear of being out of control. This anxiety was perpetuated by being in a situation of having no control over their body and capacity to make decisions related to their birth:

I still get very anxious. Ever since it happened, I've hated being a passenger in a car and even worse, I don't know if it's the fear of being out of control but I can barely be a passenger in a car. I always have to be the person driving and I was never like that before and I just have this fear of car accidents. (Mary)

Women's memories of their hysterectomy experience and the pain they experienced were sometimes triggered by the sight of a pregnant woman. They talked of feeling angry and frustrated as well as a sense of loss when confronted with this situation. It was often not easy for women to associate with family and friends that were pregnant, without recalling their own experiences of being pregnant and their subsequent hysterectomy:

Something happens to my body when I see a pregnant lady now. Like I don't mean that in a bad way, because I've got quite a few people that are quite close to me that are pregnant, and one's

just had a baby... you get this cringe in your body. It's like I remember the pain... it was just physical, it was my last memory of all the pain, and all what I went through. The trauma... (Jane)

The sight of a pregnant woman, particularly if that person was a close family member or friend, caused women great emotional distress. Participants began to develop assumptions that women generally take pregnancy for granted:

It was like you either have a hysterectomy or bleed to death, I understood they had to do it. It upset me occasionally. It really frustrates me when my girlfriend get pregnant and then terminate the pregnancy. I never believed in abortions. I don't like this, the issues around that, when women take their bodies for granted, it upsets me that women do that knowing that I can't have any more children. (Jenny)

Flashbacks were not the only reminder of the woman's birth experiences, some women experienced disturbing nightmares. The memories affected some of the women's sleep patterns, causing insomnia and difficulty sleeping. Insomniac sleep patterns were debilitating for some of the women's ability to function during the day. Katie, who was admitted to intensive care for a few days, experienced frequent nightmares following her discharge from the hospital which continued up until four years:

The nightmares usually revolved around the past; where I am begging for help, it's really horrible. Because the pain is unbearable. I have nightmares where I am trying to see people's faces, cause I remember gasping for breath... In the nightmare, I don't remember pain. I always remember I am about to die. So the nightmares are about me dying to die after giving birth... (Katie).

Other women continued to suffer, despite the numbers of years that had elapsed. The time since having had the hysterectomy did not determine the level of acceptance among the women. They had to come to terms with having survived a life threatening emergency, along with adjusting to motherhood and a new way of life. With time, women reported they expected to heal, however, this was not always so. Rachel described the memories she had, six years following her hysterectomy experience:

Recently on the radio there was the, heard the story of the lady who had died from a postpartum haemorrhage... I remember I burst into tears. I just felt, I think I had that feeling of what is it's like needing blood... just that sense of yes I know what that would have felt like, dying like that would be yes it was quite upsetting... (Rachel).

Rosie, who had a hysterectomy 28 years ago after the birth her only child, described being 'edge' during her daughter's pregnancy and birth, feeling a support person to her daughter's birth. Rosie described the thoughts she experienced of her daughter possibly bleeding or even worse, requiring a hysterectomy to stem the bleeding:

My daughter now has a little boy almost two years ago. Her pregnancy and, course concerned me greatly as I did not want to go down my path. Fortunately, all was normal. I have been told placenta accreta is not hereditary but you never know (Rosie).

Dealing with having had a hysterectomy was overwhelming for some women to manage. These women found it difficult to manage living each day knowing they were unable to have another child. These women contemplated ending their life and escaping from what they perceived as an 'unbearable life'. Women often
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Discussion

The findings of this study shed light on women's experiences of coming close to death following a severe PPH and emergency hysterectomy, as well as the potential for long-term psychological and emotional impact. Our findings reveal that women feared for their life at the time of bleeding and while in theatre having a hysterectomy. The depth of women's despair was related to their perception that they were close to death. According to Grayson (2006) and Simpson (2001), near-death experiences are subjective events that may involve individuals dissociating from their body and becoming detached (Grayson, 2006). Our findings suggest that women experienced the inauspiciousness of life, fear, frustration, and grief during the emergency event. The women in Souza et al.'s (2007) study experienced extreme pain and dyspnea, which led them to believe that death was imminent. Fear seemed to be the driving force in the sense of impending death. Silverman, Cusack (2005) who found that women diagnosed with pre-eclampsia experienced shock, devastation, and fear for their babies' lives due to the life-threatening nature of pre-eclampsia. Another study by Ryding et al. (1996) noted that fear was a dominant feeling experienced by women in relation to the possibility of impending death, or serious injury as a result of having a caesarean section. According to Holman and Longpre (2006) feelings of fear and death during childbirth can be compounded by unmedicated ideal expectations of a perfect birth.

Women in the Souza et al. (2008) study also identified religion and spirituality as being helpful to them during their health crises. Similarly, our findings indicated that some of the women sought comfort from their faith and religion and as a way of helping them keep calm when they sensed their life was in jeopardy. Studies by van Lommet et al. (2001) and Wilde and Murray (2009) report that, people who experience coming close to death can have a spiritual awakening. Blackmore (1993) found that sometimes people develop strong religious beliefs following a close encounter with death in order to reduce the fear of death and dying.

Sometimes surgical procedures may cause women to feel anxious, particularly in relation to the associated risks with operations and anesthesia (Smith et al., 2004). In our study, some women underwent emergency hysterectomy to save their life, and mixed feelings were experienced in relation to having had a hysterectomy. Although women feared for their lives and the unknown, they were relieved to have survived a severe blood loss and an emergency hysterectomy. Other studies on women's experience of emotional bleeding validate our findings showing that women may experience shock and trauma at the sight of large pools of blood (Kadar et al., 1998; Smith et al., 2000). A study by Smith et al. (2005) found that women experienced shock and devastation when experiencing a miscarriage, particularly if the bleeding was severe and accompanied by clots. The women in the study were hesitant and in some cases resistant to undergoing an operation, in fear of exacerbating their trauma experience.

An unexpected emergency caesarean section also known to be a major surgical procedure, can be extremely distressing and traumatic for women. Similarly, in the findings of our study, a study by Ryding et al. (2000) on women's experiences of an emergency caesarean section, found that women experienced negative feelings of disappointment, despair and anger. However, following their operation, women were relieved to have survived and that their babies were unharmed.

Findings from our study revealed that women had vivid memories of doctors disclosing the need to have a hysterectomy as a life-saving measure. While women experienced a sense of being unwell during this time, the most common experience was shock, heart, an emotional reaction, was experienced by women in relation to the devastation feeling their their uterine. Fallows and Kyle (1993) highlights, the emotion of 'bad news' can be distressing for the individual, particularly if it involves life-changing consequences. Fallows (1993) goes on to explain that during a trauma situation, little time is available to discuss information with service users. During a time of distress, particularly if the loss is during pregnancy or birth, the way 'bad news' is delivered is remembered either positively or negatively (Wolsey and Shaw, 2003), thus impacting on the way women adjust during the postnatal period and beyond. Childbirth complications, such as severe PPH and emergency hysterectomy are rare; therefore it is understandable that none of the women do not perceive themselves to be at risk of potentially life threatening complications. Our findings showed that some women were shocked to realise that childbirth poses certain risks that could eventually lead to death. For some, the realisation of never being able to be pregnant again was extremely distressing for them and their partners. The inability to become pregnant and give birth can become the central focus of women's lives (Johnson and Berg, 2003), and women who have had a hysterectomy talk of living on an emotional rollercoaster as they try to come to terms with never being able to have another child.

In our study, findings indicated that women experienced flashbacks when placed in an environment that triggered reminders of their traumatic birth experience. Ongoing nightmares of bleeding, losing control and being admitted to the intensive care unit were frequent reminders of the trauma they experienced. Concerning with our findings, it is crucial to address the emotional issues of post-traumatic disorder following childbirth, who found that women who experienced a PPH vividly recalled the events of their birth and experienced a feeling of anxiety and isolation.

A study by Maay and Hudson (2005) on obstetric emergencies, which included PPH, found that women often experience recurrent nightmares following the event. Similarly, Morezkin (2004) suggests that women who experience trauma during childbirth are at risk of re-experiencing the event in the form of intrusive images, flashbacks and nightmares. This finding is also confirmed in a metanalytic study on women's perceptions and experiences of traumatic birth (Dreier et al., 2016). The synthesis of studies on traumatic birth in EI et al. (2019) study showed women experienced intrusive thoughts and images following their traumatic birth experiences. Some of the
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studies included in the synthesis also reported on women who had a PMH. Callahan and Borga (2008) and Beck (2000) note that negative birth reactions which extend beyond the postpartum period may be linked to previous traumatization and lack of support. As revealed in our current findings, sometimes blaming bigger thoughts of self-harm (Appley, 1996). However, some authors (Soet et al., 2003) contest this, asserting that only a very small percentage of women will experience physical and psychological symptoms related to their birth in the months or even years after.

Ayers et al. (2003) warn, that if psychological symptoms go unrecognized or left untreated, they may lead to depression and long-term consequences for women, including social isolation and alienation from their circle of friends. Byng et al. (1995b) highlight that women who are subjected to emergency caesarean section or instrumental vaginal births, are at greater risk of developing negative reactions to their birth when compared to women who have an elective caesarean birth or normal vaginal birth. Brown and Lamber (2000) concur with Howe-Murray and Fisher (2001), stating that poor physical health after childbirth contributes to poor mental health. Physical problems related to the birth can persist for months and are often undiagnosed and untreated (Gunn et al., 1998).

As this study has identified, childbirth can be accompanied with life-threatening complications, however many of these complications are unknown or go unheeded due to the relative rarity of severe PMH and emergency hysterectomy. Women are therefore surprised when faced in this situation, as it is in a lesser degree than ideal birth experience and far from their expectations. Even if women were prepared for such adversity, the very nature of being placed in a life and death situation can provide fear and anxiety.

The findings of this study concord with previous literature that suggests having a severe PMH is known to be traumatic for the women and their families. The viral recollection of severely bleeding and almost dying is also congruent with the extent literature on women’s experiences of maternal ‘near-misses’. Although findings from this study resonate with existing literature on traumatic births and near-miss obstetric complications, this study reports on new findings, that shed light on women’s experiences of coming close to death and surviving a severe PMH and emergency hysterectomy.

Limitations to the study

It may be considered that a limitation of qualitative work is the inability to provide findings that are generalizable to other settings. However, this study did not aim to generate findings to other settings, the intention here was to gain a deeper understanding of the experiences of women who had a severe PMH and emergency hysterectomy. Twenty-two women, were interviewed for this study, and data collection continued until saturation was reached. The data generated from these interviews were rich, authentic and sufficient for a study of this size.

This study focused on Australian women’s experiences of emergency hysterectomy following a severe PMH; therefore, women’s experiences from other than Australia were not studied. Non-English Speaking women were excluded from the study, as the true essence and experience may not have been captured. Further studies involving women from culturally diverse linguistically and social backgrounds may provide different perspectives. This study also involved being interviewed either face to face, telephone or internet, thus women who may have been geographically distant and had limited access to the internet or telephone, may not have been able to participate and their experiences captured. Therefore, a full representation of this sample of women may not have been studied.

implications for midwifery practice

Midwives and other health professionals hold a pivotal role in supporting women and keeping them informed during or following a traumatic birth event such as a severe PMH and emergency hysterectomy. The findings of this study indicate that all women need to be given the opportunity to talk about their experience of severe PMH and emergency hysterectomy. Given the equivocal findings related to detecting interventions following birth (Small et al., 2006; Gamble and Creedy, 2005), recent research suggests that offering women indirect counselling with the opportunity to talk with a midwife at six weeks post partum may provide more effective psychological support (Gamble and Creedy, 2009). Gamble and Creedy (2009) recommended, a counselling service model might be implemented for the women who experience a distressing birth. The aim of this model is for women to be given ample opportunity to voice their concerns in relation to certain events that occurred during their birth. It allows women to make connections and generate greater understanding of the event and subsequent emotions and behaviours experienced. However, current fragmented systems of maternity care do not provide women with the support that they need from midwives who were with them during labour and birth. Continuity models of midwifery care will allow midwives to providing follow-up until six weeks post partum. This is a significant time for the woman and the midwife to talk about the birth experience and for the midwife to initiate appropriate referrals to other health professionals when required (Hatem et al., 2009).

Data from our study showed that five women had a previous caesarean section one had a previous PMH and four women had placenta accreta, all potential risk factors for placenta accreta or PMH in a subsequent birth (Welsh et al., 2008). Therefore, an appropriate form of surveillance needs to be instigated so that women with risk factors for placenta accreta or severe PMH are counselled appropriately in a subsequent pregnancy (Johnson et al., 2004; Medda and Wallis-Barnes, 2001).

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CHAPTER 5 FINDINGS: BETWEEN LIFE AND DEATH

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5.3 Conclusion

Chapter five has presented the first theme of the findings ‘between life and death’ as a published paper, ‘Between life and death: Women’s experiences of coming close to death and surviving a severe postpartum haemorrhage and emergency hysterectomy’. This paper describes women’s experiences and recollections of coming close to death during the time of bleeding and when requiring an emergency hysterectomy. Details of women’s experiences in the aftermath of their emergency hysterectomy were also provided. The following chapter will present the second theme of the findings ‘being a mother’ as a published paper ‘Separation, failure and temporary relinquishment: women’s experiences of early mothering in the context of emergency hysterectomy’.
CHAPTER 6: FINDINGS: SEPARATION, FAILURE AND TEMPORARY RELINQUISHMENT: WOMEN’S EXPERIENCES OF EARLY MOTHERING IN THE CONTEXT OF EMERGENCY HYSTERECTOMY


6.1 Publication: Relevance to thesis

Chapter six presents the publication, ‘Separation, failure and temporary relinquishment: women’s experiences of early mothering in the context of emergency hysterectomy’. This paper describes detailed accounts from the women in the study about their experience of separation from their infants after birth, at times unable to initiate breastfeeding. The impact of the hysterectomy on the emotional and physical recovery caused many women to relinquish care of their infants and their role as “mother”, to health care professionals while in hospitals or members of the family when at home. Feelings of failure surfaced as women felt they were
unable to form a relationship with and care for their infant in the immediate postpartum period.

**JCN  Journal of Clinical Nursing**

**PREGNANCY AND PARENTING**

Separation, failure and temporary relinquishment: women’s experiences of early mothering in the context of emergency hysterectomy  
Rakine Elmir, Virginia Schmied, Lesley Wilkes and Debra Jackson

**Aim.** To describe the experiences of women who have had an emergency hysterectomy following a severe postpartum haemorrhage and the impact on their early mothering experiences.

**Background.** Postpartum haemorrhage and subsequent hysterectomy is a traumatic birth event. Traumatic birth experiences have the potential to impact on a woman's experience of motherhood and her initial relationship with her baby. The relative rarity of this event makes it easy to dismiss the experiences of women having a hysterectomy following childbirth. Little is known about a woman's early mothering experience in the context of having an emergency hysterectomy.

**Design.** Qualitative naturalistic inquiry approach.

**Method.** Data were collected through semi-structured qualitative interviews from 21 Australian women who had an emergency hysterectomy following a severe postpartum haemorrhage.

**Results.** Findings revealed three themes in relation to early mothering experiences in the context of having a hysterectomy following a severe postpartum haemorrhage. They were 'initial separation; lost bonding time', 'feelings of failure' and 'relinquishing care of the infant'.

**Conclusions.** This paper highlights the ways undergoing emergency hysterectomy following childbirth can impact on the experience of early mothering in the postnatal period.

Relevance to clinical practice. Greater recognition and attention to the specific needs of women who have an emergency hysterectomy following childbirth is required. Providing women with an opportunity to talk, debrief and ask questions related to their birthing experiences, will help women to reconcile their feelings. Giving women the opportunity to have their infants with them in an intensive care unit, together with ongoing emotional support and anticipatory guidance, may also be useful approaches in assisting women during this difficult and traumatic time.

**Keywords:** breastfeeding, hysterectomy, midwifery, mothering, nursing, postpartum haemorrhage, qualitative research

Accepted for publication: 21 November 2010

**Introduction**

Unexpected birth events can potentially threaten the lives of women and their babies, leading to varying degrees of maternal distress (Beck 2005). A life-threatening emergency such as, a severe postpartum haemorrhage (PPH), can impact strongly on women’s perceptions of their birth experience (Beck 2010). This has the potential to impact profoundly on
the way women adjust to motherhood (Beck 2004b) and the mother-infant relationship (Ayers et al. 2006). Severe postpartum haemorrhage is defined as a blood loss of equal to or greater than 1000 ml occurring immediately following birth up until 12 weeks postpartum (Department of Health New South Wales [NSW], 2005). In relatively rare cases (0.08%), treatment of PPH involves an emergency hysterectomy to stem the bleeding (Haynes et al. 2004). Where this occurs, women are likely to be transferred to intensive care for treatment and stabilisation while the baby is cared for in a special care nursery.

Little attention has been given to women who have experienced a severe PPH and subsequent hysterectomy. Information about the ways these women adjust to motherhood in the context of emergency hysterectomy following childbirth is also lacking in the literature. This paper is based on findings of a broader study that focused on women’s experiences of severe PPH and emergency hysterectomy. This paper aimed to reveal new perspectives on early mothering by describing the experiences of women adjusting to motherhood, while attempting to recover from an emergency hysterectomy following a severe PPH. Women’s experience of coming close to death and the emotional and physical impact of having a hysterectomy were other key themes published elsewhere. The research questions addressed in this paper are: what are the early mothering experiences and practices of women who have experienced severe PPH and emergency hysterectomy? How does having an emergency hysterectomy following severe PPH impact on a woman’s perception of her relationship with her infant in the early postpartum period?

Background

Pregnancy and childbirth are described by many women as normal, natural and remarkable processes that can be life enhancing (Dahlin et al. 2010, Fenwick et al. 2008) and are associated with profound change (Bryant et al. 2008). Negative feelings about birth or a traumatic birth experience can be very disturbing for women (Walldenström et al. 2004) and can occur when a woman’s birth experiences are short of their expectations, inducing feelings of disappointment, anger, loss of control and inadequacy (Beck 2010).

Studies which have investigated women’s mothering experience in the context of surgery or caesarean section indicate that women experience difficulties with the physical and psychological effects of their surgery, along with meeting the demands of motherhood (Bryant et al. 2007, Nyström et al. 2008, Herishanu-Glütze et al. 2009, Mojab 2009). An Australian study by Rowe-Murray and Fisher (2001) reveals that instrumental and surgical births impact negatively on the postnatal maternal-infant contract with an increase in negative outcomes for the mother, including a greater role of postnatal depression. Findings by Mojab (2009) resonate with this, stating that caesarean births, like any other form of major surgery require a significant amount of time for recovery. Maternal infant separation, a common outcome of operative birth (Rowe-Murray & Fisher 2002, Pollock 2006) and severe PPH (Thompson et al. 2010), can in some circumstances affect the maternal-infant relationship and reduce the incidence of breastfeeding initiation (Pollock 2006, Rowe-Murray & Fisher 2002). As a result, women may experience feelings of guilt, shame and failure (Mojab 2009), particularly as they strive to achieve normality following an unexpected birth outcome (Fenwick et al. 2009).

More specifically, women who have a hysterectomy as a result of PPH may require admission to the Intensive Care Unit (ICU) for monitoring and resuscitation (Pollock 2006). In Australia, the incidence of women admitted to ICU during pregnancy and the postnatal period is 1.84–2.6% of all pregnant women (Pollock 2006). Harrison et al. (2005) estimates that 0.9% of pregnant or postnatal women are admitted to ICU in the UK. One issue of concern to many critical care nurses is trying to initiate breastfeeding or begin the process of expressing breast milk in the event of the baby being admitted to the special care nursery while the mother remains in ICU (Pollock 2006). What remains unknown are mothers’ breastfeeding experience and their relationship with their infant following discharge from the ICU (Pollock 2006).

There appears to be almost no research on the experiences of women who have a hysterectomy following severe PPH and how they adjust to motherhood. However, studies on women who have experienced a hysterectomy for gynaecological issues provide some insight into this experience (Fleming 2003, Flory et al. 2005). Fleming (2003) reports that women may experience initial feelings of intense pain following their hysterectomy. Similarly, Lienberger and Cohen (2004) studied 65 women (mean age 42 years) who underwent abdominal or vaginal hysterectomies and found that the physical limitations of the surgery imposed restrictions on women’s daily activities, with participants reporting it was harder than having a caesarean section. It is well documented that surgical procedures such as caesarean section (Herishanu-Glütze et al. 2009) and hysterectomy require time to recover emotionally, physically and psychologically (Kinicki & Leners 1993, Fleming 2003, Flory et al., 2005). It remains important to study women’s experience of emergency hysterectomy following a severe PPH and the impact this may have on their early mothering experiences and practices.
CHAPTER 6 FINDINGS: SEPARATION, FAILURE AND TEMPORARY RELINQUISHMENT

Methods

A naturalistic inquiry or constructivist paradigm informed the design of this study (Lincoln & Guba 1983). The constructivist paradigm posits that an individual constructs meaning of reality through their engagement with the world (Lincoln & Guba 1983, Crotty 1998). Childbirth is a subjective life experience, which is personal and intimate, meaning to the individual, influenced by personal, contextual and structural factors influencing the experience (Applebaum & King 1997). In an attempt to capture the experiences of women who have had a hysterectomy following a severe postpartum haemorrhage, a naturalistic inquiry was deemed appropriate.

Participants and recruitment

Ethics approval was granted from the human research ethics committee at the university. Recruitment proceeded through media release and flyers and posters being disseminated around university campuses and public places, such as pharmacies, dentist's and child care centres. Good command of English and having experienced a hysterectomy following a severe PPH, were requirements for inclusion in the study. The time since having had the hysterectomy was not limited, as it allowed women interested in telling their story or sharing their experience to be heard and facilitated the capture of a range of perspectives. It was also believed, that time was not an indicator of women’s ability to come to terms with their experience. Simkic (1992) work on memory following childbirth suggests that women may recall events related to their birth despite the time that had elapsed since the event. Women’s memories may in fact intensify over time (Waldenstrom 2003). At the end of the interviews all participants were provided with a list of counselling services in their local area.

Participants were given an information sheet and following informed consent procedures, women were recruited in the study. A total of 21 Australian women between the ages 26–57 years with a mean of 42 years, were recruited into the study. The time since the hysterectomy ranged from five weeks to 28 years with a mean of four years. The women came from a range of cultural backgrounds. Thirteen women had a caesarean birth and eight women gave birth vaginally. Three of the eight women who had a vaginal birth also had a retained placenta and were subsequently transferred to theatre for a manual removal of the placenta. Eleven women were transferred to ICU following their hysterectomy for close monitoring (Table 1).

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Participant birth details</th>
<th>n = 21</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mode of birth</td>
<td>Caesarean Birth</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>Vaginal Birth</td>
<td>8</td>
</tr>
<tr>
<td>Postpartum haemorrhage</td>
<td>Hospital</td>
<td>19</td>
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<tr>
<td></td>
<td>Home following discharge</td>
<td>2</td>
</tr>
<tr>
<td>Parity</td>
<td>1</td>
<td>10</td>
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<td>2</td>
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<td>5</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Postnatal period</td>
<td>Mother transferred to ICU</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Transferred to postnatal ward</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Baby transferred to neonatal nursery</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Period of separation from baby while in ICU</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1–12 hours</td>
<td>1</td>
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<tr>
<td></td>
<td>12–24 hours</td>
<td>4</td>
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<tr>
<td></td>
<td>24–48 hours</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>48–72 hours</td>
<td>2</td>
</tr>
</tbody>
</table>

Data collection

Data were generated through semi-structured, face-to-face, telephone and email internet interviews, in a setting most convenient to the women. Eleven women were interviewed face-to-face, three women were interviewed via telephone and seven women were interviewed through email internet. These options provided women greater autonomy to disclose their experience in a way they felt most comfortable. It also facilitated participation for those women interested in participating in the study who lived at a distance (East et al. 2008). Previous studies have successfully used electronic communication, such as internet and text messaging to report women’s birth stories (Beck 2005, Fenwick et al. 2006, Dahlen et al. 2010) and to gather data on sensitive topics (East et al. 2008). Open ended questions were asked focusing on women’s recollections of bleeding and requiring a hysterectomy following birth and their admission to intensive care, women’s experience of the relationship they develop with their infant in the immediate postpartum period, including their breastfeeding experience and their health and well being in the months following the hysterectomy. This elicited detailed descriptions of their experience. Face-to-face interviews lasted from 40–120 minutes. Email interviews were more succinct and shorter yielding approximately four to eight pages of textual data. For each woman who participated through email, interviews were repeated at least two or three times, to elicit rich data from participants. Oral interviews were digitally recorded and transcribed verbatim.
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Data analysis

Transcribed data were entered into a data management software program Access (QSR International Pty Ltd, Victoria, Australia) and data were analysed using thematic analysis. According to Lincoln and Guba (1985), naturalistic inquiry favours an 'inductive method' of data analysis, which aims at uncovering embedded information and making it explicit (p. 203). This approach to analysis is deemed likely to capture the essence of individual realities found in the data. Transcripts were read repeatedly and coded for common phrases, ideas and descriptions (Lincoln & Guba 1985). Through a process of compare and contrast, essential themes emerged. Detailed descriptions of the women's experiences were formulated into written text (Frogatt 2001).

Results

Table 1 outlines details of the participants, including the type of birth, and duration of separation from baby. To protect the identity of participants, pseudonyms have been used with the excerpts of narrative.

The analysis revealed three broad themes that capture women's early mothering experiences following a severe PPROM and hysterectomy: they are 'initial separation: lost bonding time', 'feelings of failure' and 'relinquishing care of the infant'.

Initial separation: lost bonding time

In the initial postpartum period, eleven of the women were transferred to ICU. During this time they experienced lengthy periods of separation from their baby, causing significant emotional distress for women. This was mainly due to women perceiving the initial postpartum period to be an important time to develop a relationship with their baby.

I kept asking, when can I see the baby? I needed to know she was okay and I wanted to see her. . . . I kept going through things, there must be something wrong with her. Why are they keeping her? Why? I understood she was in newborn care . . . no one expects to have a baby and a day later you still haven't seen her... (Jane)

Marie, who had a vaginal birth and retained placenta, describes the comfort she felt when she finally had the opportunity to cuddle her baby:

I wanted my baby... When I had my baby with me... I felt alive then. It's really funny but, before then I was so scared, I was trapped, trapped. I was trapped [crying, upset]. (Marie)

Being a patient in the ICU was not the main focus of women's concerns. Rather, they were more concerned about the well-being of their baby, how they were being cared for and who was caring for them:

My biggest concern in ICU, I needed to get to my baby, I didn't know what they [nurses] were doing with her or what they were giving her and I needed to get to her... (Ruby)

The intensive care experience amplified the emotions women experienced. The environment in particular was not conducive to recovery, with many women describing it as 'weird' and 'noisy'. Other women found the ICU environment to be traumatic and perceived health professionals to be unhelpful in meeting their needs:

I was taken to intensive care. It was really, really horrific, it was harrowing. I had the central line, I couldn't eat anything in the ICU. They always have these nurses sitting at the end of your bed and it's always dark in there, it's horror and a place of horror that ICU... no one was friendly at all. (Marie)

Women also spoke of having to come to terms with the fact that their family had seen and touched the baby, while they had not yet made physical contact with their baby. The first point of contact between mother and baby was viewed to be an important time for developing a strong maternal-infant relationship. A strong consensus among the ten of the women's narratives was the belief that the mother should be given first preference to hold and see the baby, particularly given everything she had been through with the hysterectomy:

I was upset that I hadn't seen the baby, my husband, my mum and dad and all my family had seen the baby, I really needed to know what was going on with the baby. (Ruby)

One woman, Sandra, explains how she gave birth to a very premature baby at 23 weeks and it was hard for her to comprehend that she would be separated from her baby for some time. Seeing her baby fighting for his life, made her re-evaluate her own experience and re-channel her energy to focus on the baby. She considered her experience to be unimportant in comparison to what her baby was going through:

When I first saw my baby I cried. I got wheeled down in the wheelchair and was screaming to you this now I got quite emotional, it was probably about a day or a day and half later. Really I just hoped that he would survive. He was born at 23 weeks... (Sandra)

Feelings of failure

Developing a connection with the baby was viewed as the essential work of the first few weeks of parenting and...
CHAPTER 6 FINDINGS: SEPARATION, FAILURE AND TEMPORARY RELINQUISHMENT

Pregnancy and parenting

motherhood. Good mothering practices were believed to involve the ability to successfully breastfeed and form a close relationship with the baby. Breastfeeding was an important symbol for thirteen of the women, demonstrating their ability to nurture and be able to ‘give’ to their baby. The ability to successfully breastfeed was linked to women feeling confident, thus facilitating acquisition of the maternal role. However, when women were unable to establish breastfeeding and bond with their baby they reported feelings of shame and failure for not succeeding:

Breastfeeding was VERY important to me… I felt I had failed my newborn in not being immediately available to him for that first feed straight after birth… I felt very guilty for not being there in the initial phase, post birth, to breastfeed him and bond with him. I initially felt a sort of distance between us because of this. Then I think I probably overcompensated by being too smothering and unable to leave him alone… I felt a lack of confidence with him, because I had failed him so badly at the beginning of our relationship.” (Diana)

According to nine of the women having had an emergency hysterectomy was considered a form of failure because of all the trauma and distress they perceived to have inflicted on their baby. Women also felt this loss of a perfect or desired birth experience. Breastfeeding boosted women’s confidence and gave them a sense of accomplishment:

“I breastfed at day two or three… I was so driven to feed my baby, because of the whole stuff up. I want to succeed at this because I failed him…” (Mia)

In their narratives, the women sometimes used words such as ‘determined to succeed’ or ‘I wasn’t going to lose out on this [breastfeeding] as well’, to illustrate women’s persistence in continuing to breastfeed. Four of the women experienced excruciating pain, however, pain was no barrier when it came to providing what they viewed as ‘best’ for their baby:

“It felt like someone was slicing my breast or my nipple open…” I had to put a molded cup over my nipple so that the baby was not sucking from my nipple, so that worked for a few weeks and then I ended up expressing and feeding her through the bottle…” So she was still getting the breast milk… I know that breast milk is so much better for your child.” (Susan)

Despite women’s desire and strong determination to breastfeed, insufficient milk supply, secondary to the large amount of blood they lost and the trauma their body endured, forced some women to cease breastfeeding. This breastfeeding ‘failure’ as described by nine of the women, further affected their confidence, with four women seriously doubting their ability to be a good mother:

I wanted to breastfeed my child for the first 12 months, as it was with my first child. Unfortunately, I had to give it up after a few months because my body could not cope and supply enough milk for my baby. (Belinda)

As women strived to be a good mother, the added pressure from health professionals to ‘perform’ and succeed at breastfeeding heightened their feelings of inadequacy and failure:

“I felt a failure enough as it was, because I couldn’t deliver properly and my uterus gave up the ghost. I mean it was just horrible. So to then feel this terrible inadequacy because I couldn’t fully breastfeed and all the rest of it and I had these people handmanning my milk. It was just awful, unnecessary.” (Ruth)

However, not all women had a negative experience with health professionals. Fifteen of the women felt supported by health professionals, which helped them gain the confidence they needed to fulfill their maternal role, along with meeting the demands of caring for the baby:

“They kept me really up to date with what was going on. The staff in the maternity unit were fantastic, they gave me lots of support. They offered me counselling.” (Gillian)

Twelve of the women wanted to be everything, a good mother, a good wife and a person who was able to cope against all odds. Not being able to fulfill these roles was a sign that women were not coping and failing at their role as mother and a wife/partner. They wanted to be able to prove to themselves and the family that they were capable of performing such roles:

“I want to make sure I’m there for everything she [baby] needs as a mother… I’m still trying to find my balance and fulfill all the role.” (Lola)

Relinquishing care of the infant

The extent of women’s trauma from their hysterectomy experience, forced them hand over the care of the baby to their partners and other members of the family. For five women the period of relinquishment continued until 1 year after birth. It was often a period of struggle and intense emotional pain for the women, deep inside women wanted to attend to everything and be with their baby every step of the way. Having a hysterectomy restricted women’s ability to perform tasks they deemed significant to being a good mother. Members of the family stepped into role as ‘mother’. This hindered the fourteen of women’s opportunity to bond with or develop a close relationship with their infant:

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I could not even lift her out of the bassinet and ended up feeding her on my bed most of the time. Either my husband or my sister bathed her. During the first month of her life, I didn't seem to have much time to bond with her (Belinda).

Women began to feel guilty for not fulfilling their role as ‘mother’. The guilt women experienced was amplified when they noticed their baby was closer to other members of the family. The restrictions and limitations on being able to hold, cuddle and get to know their baby’s cues made it difficult for women to know what worked best in terms of settling their baby. Consequently, it began to impact on their relationship with their child because they began to believe they were ‘bad mothers’.

My husband bonded with my daughter more than I did. Because I couldn’t get up, I couldn’t get around. (Jade)

Suzie experienced difficulty in meeting these expectations and often questioned her ability to ‘mother’ and begin developing feelings of despair and dejection. It also affected her relationship with her mother and sister as she began to accuse them of taking the baby away from her:

I was pretty much drained and exhausted, so other people were caring for my daughter rather than me, then I began to feel guilty. I think then was me believing that I wasn’t a good mum and everyone else was better than me and it just went downhill from there until I got help. I actually didn’t feel human for the first 4 months of her life. (Suzie)

The role of ‘mother’ not only changed the women’s daily lives and their relationships, but also their sense of connection to life in general. Suzie goes on to explain how extreme tiredness and sleep deprivation affected her ability to function and properly care for her baby:

I had lost that bond with her [baby] until she was one. I came so close to strangling the kid when she was asleep, it got to a point where my husband would stay in bed, I’ll go get her because he just knew I was cracking. (Suzie)

Exhaustion and fatigue was experienced by many of the women, which prevented them from completing tasks that were considered ‘normal’ everyday activities. Marie explains:

I was just so tired and exhausted all the time. If it is was old age, like, I felt that life had been sucked out of me. (Marie)

Women believed their duty of care for the children and taking on responsibility for family and the household was part of their role as ‘mother’:

I felt helpless and vulnerable... I couldn’t do anything, I couldn’t cook dinner, just the normal things that any mother would do... (Mary)

Discussion

This study revealed that the women struggled with their role as mother immediately following the severe PPH and emergency hysterectomy and in the early weeks at home, following discharge. They experienced extreme exhaustion, fatigue and lethargy associated with the trauma, as well as, the surgical procedure of having a hysterectomy. This forced many of the women to temporarily relinquish the care of their babies to other members of the family. Morse (1997) suggests, women’s experiences of a traumatic birth has similarities with the experience of mothers recovering from an illness. As Vallido et al. (2010) found, mothering that has been interrupted by illness can perpetuate feelings of guilt, shame and a sense of failure (Fitch et al. 1999, Nystedt et al. 2008). Similarly, women who experience a traumatic birth can demonstrate feelings of inadequacy as a mother and self-blame (Beck 2004).

The findings of this study revealed that all the women expected and wanted to be with their baby in the early postpartum period. However, this was difficult for the women who were admitted to ICU, while trying to physically, emotionally and psychologically recover from the hysterectomy. Studies on mothering in the context of chronic illness highlight the dilemma women face as they strive to be a good mother through treatment and recovery (Merton et al. 2007, Emberger et al. 2008, Elmerger et al. 2010). Findings from Elmerger’s et al. (2010) study on young women diagnosed with breast cancer, showed that the women’s role as ‘mother’ was altered during the period of recovery from breast surgery. Emberger et al. (2008) study investigated women’s experiences of mothering through cancer and how this impacted on being a good mother. Despite having cancer, women continued to take responsibility for the care of their children. The women’s role as mother was deemed the most important thing, this finding by Emberger et al. (2008) was also represented in this study, as many women were determined to provide what was best for their baby against all odds. A review of the literature conducted by Vallido et al. (2010) on mothering disrupted by illness, that found mothers wanted to take on the role as primary carer, even at the expense of their own health.

Our findings indicated that women needed time to physically recover from their hysterectomies. This period of recovery restricted women’s ability to attend to their baby and fulfill other ‘mothering’ chores that were considered significant to their identity as a mother. This finding can be related to women who experience a caesarean section, also known to be a major surgical procedure. Nystedt et al. (2008) comments that extended recovery time is a common concern affecting
women who have a caesarean section. Research reveals that women who give birth by caesarean section when compared with women who have an uncomplicated vaginal birth, have a greater risk of developing negative perceptions of their birth experiences, themselves as a mother, their infant and may demonstrate poor parenting practices (Herishana-Gilchrist et al., 2009). The findings of this study also revealed that many women lacked energy and felt exhausted following their hysterectomy. The simple things, such as walking or showering, were overwhelming for the women. Tiredness and fatigue in the postnatal period can lead to a decrease in energy levels, lack of motivation and ability to concentrate can adversely affect women’s level of functioning (McQueen & Mander, 2003).

Murphy and Charlett (2002) suggest the postpartum period following a caesarean section, increases the risk of potentially fatal complications for women, particularly for women who have been admitted to the ICU for severe postpartum complications. Our findings showed that in the recovery period following a hysterectomy and severe PPH, women required time to adjust and absorb the series of events. Maddox et al. (2003) investigated patients’ recovery following discharge from the ICU. They found that following discharge ICU patients wanted to move on and resume normal activities, instead they experienced low levels of energy, exhaustion and fatigue. Maddox et al. (2003) suggests these are acute sequelae for patients recovering from trauma and critical injury.

As evident in our study, Pellock (2006) highlights that some women may require transfer to the ICU for close monitoring and adequate resuscitation. As a result, maternal-infant separation occurs and this in turn may delay initiation of breastfeeding and establishing lactation. Some of the women in our study were unable to breastfeed for at least the first two-three days postpartum. Thompson et al. (2010) study confirms our findings, suggesting that women who experience a severe PPH may experience delay in breastfeeding initiation. Rowe-Murray and Fisher (2002) study found that women, who had a caesarean section, experienced a longer length of time before initiating breastfeeding when compared with women who had a vaginal, uncomplicated birth. Nystedt et al. (2008) suggests that this delay in breastfeeding initiation may also be attributed to extreme tiredness, fatigue and general feelings of being unwell. Our findings indicated that the women were determined to breastfeed against all odds and hurdles that they may have faced.

Breastfeeding has generally been equated to good mothering practices (Marsh et al. 2007). This usually occurs as women strive to establish a maternal role, through commitment and investment in their child (Mercer, 2004). Maternal identity is developed through a process of transformation, self-growth and engagement with the infant (Nelson, 2003). Our findings also indicated that women equated their ability to breastfeed with being a ‘good mother’. Women talked of wanting to succeed at breastfeeding in an attempt to provide the best form of nutrition for their baby, along with forming a close bond with their infant. Achieving this was seen as a sign of good mothering. On the other hand, when women experienced issues with breastfeeding, they referred to themselves as ‘bad’ mothers and reported a sense of failure.

Johnson and Swanston (2003) comment, that mothers may feel pressured to continue breastfeeding in view of providing their baby with a good start in life. Therefore, mothers may feel morally obligated to continue breastfeeding in view of meeting ideal expectations. Similarly the findings of our study revealed that women felt they were pressured by health professionals to perform and meet expectations of breastfeeding and that only ‘breast is best’. Sheahan et al. (2010) suggests that ‘everybody’s best is different’ (p. 376), implying that health professionals need to provide care to women that is individualised.

Conclusion

The experience of becoming a mother following a traumatic event such as a severe PPH and subsequent hysterectomy has the potential to pose a threat to a woman’s identity as a mother. The woman’s feelings as a mother may sometimes be disregarded. Having an emergency hysterectomy following a severe PPH may be considered a misfortune, without considering the impeding factors that may result from this experience. Adjusting to motherhood following a traumatic birth event, irrespective of it being the first or a subsequent baby can challenge women’s ability to mother in many ways. As a woman establishes her maternal role, she also tries to recover from this life threatening emergency experience. Having a severe PPH and emergency hysterectomy represents a loss of normality and meeting the demands associated with motherhood may seem difficult and at times impossible.

Relevance to clinical practice

The findings from this study have strong implications for nursing and midwifery practice. This event is often catastrophic, unexpected and can potentially endanger the life of women. It is imperative to provide a follow up consultation with a woman discussing the series of events that led to her requiring a hysterectomy, in an effort to mitigate feelings of
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failure and self-blame. As evident in our study, mother and baby are often separated, therefore establishing the maternal-infant relationship may take longer than anticipated. Having a hysterectomy following childbirth will bring emotional and physical challenges for the woman as she tries to care for her baby and adapt to motherhood and a new way of life.

Recommendations for future policy development in ICU are required. Flexibility and an environment that is more conducive to meeting the needs of mothers and their babies are warranted, to minimise the maternal-infant separation. The benefits of keeping mother and baby together during the mother's stay in ICU may outweigh the concerns and logistics preventing this from occurring. Further research is required, to examine the longer term implications for women in their everyday life following a traumatic experience such a severe PPPE and emergency hysterectomy.

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Contributions

Study design: RE, VS, DJ, LW; data collection and analysis: RE, VS, DJ, LW and manuscript preparation: RE, VS, DJ, LW.

Conflicts of interest

None.

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Pregnancy and parturition


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1127
6.2 Conclusion

This chapter presented the second theme of the findings ‘being a mother’ as a published paper titled ‘Separation, failure, and temporary relinquishment: women’s experiences of early mothering in the context of emergency hysterectomy’. This paper describes the women’s experiences of ‘being a mother’ including the difficulties faced with establishing a relationship with their newborn babies and caring for their infants, particularly during their stay in the intensive care unit. This paper also described the challenges women faced as they recovered from major surgery, as they wanted so desperately to care and attend to their baby’s every need. The following chapter presents the third theme of the findings ‘loss of normality’ as a published paper titled ‘Less feminine and less a woman: The impact of unplanned postpartum hysterectomy on women’.
CHAPTER 7: FINDINGS: ‘LESS FEMININE AND LESS A WOMAN’: THE IMPACT OF UNPLANNED POSTPARTUM HYSTERECTOMY ON WOMEN


7.1 Publication: Relevance to thesis

Chapter seven presents a paper submitted for review to the International Journal of Childbirth titled, ‘Less feminine and less a woman: The impact of unplanned postpartum hysterectomy on women’. This paper reports on the impact of having an unexpected hysterectomy following childbirth. All of the participants reported distress at the loss of their ability to have another child and they discussed how this impacted on their emotional health and their relationships. The findings reported here also contribute to the extant literature on women’s experience of hysterectomy for gynaecological issues and their reports of loss of femininity and womanhood and the isolation and distance from their social network of family and friends. This paper also presents new knowledge about the psychological impact of infertility on women’s sexual relationships.
“Less Feminine and Less a Woman”: The Impact of Unplanned Postpartum Hysterectomy on Women

Rakime Elmir, Debra Jackson, Virginia Schmied, and Lesley Wilkes

AIM: This article is a report of the women’s experiences of unplanned emergency hysterectomy following severe postpartum hemorrhage (PPH).

BACKGROUND: Every year, thousands of women worldwide undergo hysterectomies for either gynecological issues or following childbirth to save their life from severe PPH. Little attention has been given to the experiences of women with secondary infertility; despite many of these women being of childbearing age. Some of the issues concerning this group of women are related to their feminine identity, sexuality, sense of being, and womanhood.

METHOD: Qualitative interviews were conducted with 21 Australian women between the ages of 24 and 57 years. The data were collected between May and October 2009. Data were analyzed using inductive thematic analysis.

FINDINGS: One major theme: loss of normality, and four subthemes emerged: “being incomplete: half a woman,” “not myself: a changed body,” “being alone: isolation and disconnection,” and “fearing intimacy: insecure and wary.”

CONCLUSIONS: This study shows that irrespective of the number of children women have, they may continue to experience significant emotional distress following their hysterectomy after childbirth. The distress these women experience is not only during the immediate postnatal period but continues long term, and affects social, familial, and interpersonal relationships. Health professionals, particularly those providing community-based child and family health services, are in a position to provide ongoing professional support to women who experience an emergency hysterectomy following childbirth.

KEYWORDS: hysterectomy; postpartum hemorrhage; infertility; midwifery; qualitative research

INTRODUCTION

Hysterectomy is one of the most frequently performed major surgical procedures for women with approximately 600,000 North American women, 100,000 British women, and 30,000 Australian women undergoing hysterectomy per year (Farquhar & Stein, 2002; Mäkinen et al., 2001). An estimated 0.05% of childbearing women will undergo unplanned, emergency hysterectomy per year in Australia (Haynes, Stone, & King 2004). Unplanned postpartum hysterectomy is different from the more typical hysterectomy performed for gynecological issues, despite similarities during the immediate recovery period and in the long term (Elison, 2002). Emergency hysterectomy following childbirth is generally unanticipated, and is performed to save the lives of women (Elmir, Jackson, Beale, & Schmied, 2010). Little research exists on women’s experiences of secondary infertility as a result of emergency hysterectomy following childbirth. Secondary infertility is commonly defined as the inability to have a child following one...
or more live births, and affects approximately 5%–23% of women aged 20–44 years (Larsen, 2000). Women may experience stigma related to what remains a common stereotype of being a woman and the expectations to have more children (Ulrich & Weatherall, 2000). Secondary infertility in women of childbearing age may be a consequence of medical or surgical procedures such as hysterectomy, or reproductive disorders such as endometriosis and uterine fibroids (Carlson, Miller, & Fowler, 1984; Guthrie, Clark, & Demmernstein, 2007). Other factors contributing to the loss of infertility include cancer (Connell, Patterson, & Newman, 2006), polycystic ovarian syndrome (Kistinger & Willmuti, 2002; Snyder, 2006), and early menopause (Boughton, 2002; Boughton & Halliday, 2008). This article addresses a significant gap in the literature by examining the impact of secondary infertility on women who have had an unexpected hysterectomy following childbirth.

BACKGROUND

Studies have shown that women who experience reproductive problems or infertility consider having a baby central to their lives with the inability to move forward (Johansson & Berg, 2005; Orshan, Furniss, Frost, & Santoro, 2001). According to Hollos and Larsen (2008), women who experience secondary infertility consider the ability to have further children to be of utmost importance, irrespective of the number of children they already have.

The existing literature reporting on women’s experiences of having a hysterectomy indicates that some women may experience body image disturbance and a sense of disconnection from their body. Elson (2002) interviewed 44 premenopausal women who had a hysterectomy for benign reasons and found that some of the women experienced issues with their sexual desire and attractiveness and perceived having a hysterectomy posed a threat to their identity as a woman. Markovic, Manderson, and Warren’s (2008) study on Australian women’s experiences of hysterectomy for conditions other than cancer found that women continued to experience distress about the loss of their uterus years following their surgery. This was primarily attributed to women believing that nature should determine the end of their reproductive life. Similarly, a review of the literature by Flory, Bissonnette, and Bink (2005) on women’s experiences of having a hysterectomy as a treatment for benign symptoms found that women may experience an impaired body image and sexual desire. Women are also left with a surgical scar, which is often seen as a form of mutilation, resulting in women possibly having a negative view of their body (Flory et al., 2005). Boughton’s (2002) study on women’s experiences of early menopause (younger than 40 years) found that women, some who already had children, experienced a sense of disembodiment that their body did not belong to them and was “replaced by a conspicuous unfamiliar body” (p. 427).

Previous published findings by Elmir, Schmied, Jackson, and Wilkes (2012) on women’s experiences of emergency hysterectomy following severe postpartum hemorrhage (PPH), reported that women feared for their lives at the time of the hemorrhage and were simultaneously shocked by the realization they required a hysterectomy. In the months, even years, following this, some women experienced psychological trauma, in the form of flashbacks, nightmares, suicidal ideations, and vivid memories of their hysterectomy experience.

THE STUDY

Aim

This article reports on one aspect of a larger study that aimed to explore the experiences of women following severe PPH and emergency hysterectomy. The aim of this article is to provide insight into the experiences of women with secondary infertility as a result of emergency hysterectomy following childbirth. Women’s experiences of coming close to death and surviving a severe PPH and emergency hysterectomy (Elmir et al., 2012) and the difficulty women faced in forming a close relationship with their baby in the immediate postpartum period (Elmir, Schmied, Wilkes, & Jackson, 2012) are findings from the larger study that have been published elsewhere.

Design

An interpretive qualitative design was used to gain rich data from participants. Interpretive qualitative research enables the worldview of individuals to be conveyed as lived and, therefore, allow for interpretation, meaning, and understanding to be formulated by the researcher (Beanland, Schneider, LoBiondo-Wood, & Haber, 2000).

Participants

A total of 23 women participated in this study. Selection criteria were that the participants had a hysterectomy
following severe PPH and able to converse in English.

For the purposes of this study, the period of time since experiencing the PPH and hysterectomy was not crucial. It is likely that most women who have experienced this event will have strong memories of the experience even though several years may have elapsed (Klein, Loftus, & Kihlstrom, 2002; Simkin, 1992).

Purposeful and snowball sampling approaches were used to recruit participants. Information about the study was disseminated via media release, and posters and flyers were placed in a range of locations including the university campuses and public places such as pharmacies and childcare centers. Twelve participants responded to an advertisement placed in the local media, and a further nine participants were referred to the study by their friends who had seen the advertisement in the local newspaper. The sample was therefore a purposive sample of those who responded to the advertisements.

Data Collection

Data were collected through face-to-face, telephone, and Internet e-mail interviews between May and October 2009. The range of methods for data collection facilitated women's participation in the study, as some participants lived in geographically-distant areas (East, Jackson, O'Brien, & Peters, 2008). Providing women with alternative methods of being interviewed also appeared to create a sense of autonomy and comfort during the interview process. The interview questions were based on review of the literature related to women's experience of traumatic birth. These questions were purposefully open-ended, and in the first instance, women were asked to tell their story of having a PPH and their response to having the emergency hysterectomy. Women, then, responded to open-ended prompts such as "describe your feelings in relation to having had a hysterectomy," "tell me about your relationship with your partner following the hysterectomy," and "describe the support you received from your family and friends following the hysterectomy." These questions were used to elicit rich descriptive responses from participants. In general, the participants were all asked the same questions. After the first five interviews, some commonly identified issues such as the importance of breastfeeding were then prompted in subsequent interviews. Interviews continued until data saturation was reached (Beanland et al., 2000). Data were collected by the first author. (More details on the method of sensitive interviewing used in this study are published in Elmir et al., 2011.)

Ethical Considerations

Ethics approval was obtained from the Human Research Ethics Committee at the university. Potential participants were given a consent form and participant information sheet, which specifically outlined the aim of the study and confidentiality, including de-identifying all data. The opportunity for participants to withdraw from the study without penalty was also mentioned. Written consent was obtained from all participants, and no participant withdrew from the study. A list of counseling support services local to the participants was provided. Pseudonyms are used in this article to protect the identities of participants.

Data Analysis

Interviews were transcribed verbatim and thematically analyzed. Transcripts were read several times, and digital recordings were listened to simultaneously in order to identify gaps in the transcription of data and to become more familiar with the narratives. A method of "inductive analysis," as described by Lincoln and Guba (1985), was used to analyze data. Raw data were categorized according to units and categories, where common statements and metaphors were grouped together. The initial analysis of all data was undertaken by the first author, and the second author and supervisor read through the transcripts to confirm the identification of categories and themes. Detailed descriptions of the participants' experiences were then formulated into written text (Lincoln & Guba, 1985).

Findings

The participating women were between the ages of 24 and 57 years. The time period between the hysterectomy and the time of interview ranged from 5 weeks to 28 years. Table 1 outlines the demographic details of participants. Ten women had one live child, and 11 women had two or more children. Thirteen women had a cesarean birth, and a further eight women had a vaginal birth.

One major theme; loss of normality and four subthemes emerged that illustrated women's physical and emotional response to having had a hysterectomy.

83
TABLE 1  Participants' Demographic Data

<table>
<thead>
<tr>
<th>DEMOGRAPHICS</th>
<th>N = 21</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at hysterectomy (years)</td>
<td>6</td>
</tr>
<tr>
<td>23–30</td>
<td></td>
</tr>
<tr>
<td>31–36</td>
<td>8</td>
</tr>
<tr>
<td>37–43</td>
<td>7</td>
</tr>
<tr>
<td>Number of children</td>
<td></td>
</tr>
<tr>
<td>1 child</td>
<td>10</td>
</tr>
<tr>
<td>&gt;1 child</td>
<td>11</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
</tr>
<tr>
<td>Partnered</td>
<td>15</td>
</tr>
<tr>
<td>Unpartnered</td>
<td>6</td>
</tr>
<tr>
<td>Employment status</td>
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<tr>
<td>Employed</td>
<td>19</td>
</tr>
<tr>
<td>Unemployed</td>
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</tr>
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</table>

missing. Women also described feelings of disempowerment due to the loss of power or capacity to make the choice to have another child.

For me the uterus symbolizes fertility. Femininity! New life! Being female! Hope! Possibility! Wholeness! Without it, I feel incomplete, less feminine, less a female and hopelessly infertile. —Dianne

The ideal or "perfect" family life that some women pictured and planned made their loss so much more difficult to endure. Having a sibling for their child was considered the norm for the ten participants who had one child.

...The terrible sadness of leaving an only child behind, without any family... it's an ongoing grief to both of us. So it has brought a lot of grief into our life. In that sense, it just grieves us, to no end, that we can't give that to her. It's one thing to have a brother or a sister and just simply not get on with them and to have that choice, if you like, but to not even have that, not having that sense of belonging, grieves us every day.—Ruth

Sometimes having a hysterectomy felt like "slap in the face" as their quest for another biological child continued. Ruth states, "to actually have a baby and then be told you can't anymore, well that's just really upsetting."

The feeling of incompleteness continued as women mourned the loss of their uterus and realized the enormity of never having more children. It was not only a loss on their part but also for their partner with future plans for more children at an end.

We have always wanted more children, I feel like I've let my husband down... our dreams are gone... —Rachel

Five of the women had difficulty conceiving naturally. For these women, they experienced the ordeal of going through in vitro fertilization (IVF) with several unsuccessful implantaions and recurrent miscarriages, then to finally conceive was considered a "miracle" by
CHAPTER 7: ‘LESS FEMININE AND LESS A WOMAN’

they. They perceived having had a hysterectomy to be a significant loss because their journey of having this baby involved such heartache, anguish, and disappointment.

... it was nearly up to 6 years going through IVF, it was definitely an emotional roller-coaster. I ended up pregnant through IVF so it was all a bit chaotic... the sad bit was for me not to be able to have another child and not feeling like a female... just upset that I wouldn’t be able to have another child, especially after everything that I had been through.—Suzie

For the women like Ruby who were satisfied with their family and the number of children they had, there was still an element of sadness experienced. Women reported that they wanted to be in control of making the decision to not have any more children, rather than the choice being made for them.

I have four children and they are beautiful. Sometimes I do think about it, but I think well didn’t want any more children but I didn’t want a hysterectomy I wanted to have a natural birth. Sometimes I do get really upset about having a hysterectomy and what could have been...—Ruby

Some women believed that females were in a position of power, because they were able to make a decision about pregnancy and to then giving birth. With this choice taken away from them, some women felt despair and powerlessness. Mia, who had four children, referred to herself as “half a woman” implying that she was a different person and no longer a “real” woman.

Not Myself: A Changed Body

Many of the women talked about their body as having “aged” or being “old.” Lethargy and low-energy levels were recurrent symptoms experienced by some women. The decision by some women to have children early in life meant that they could enjoy life while they were fit and energetic. However, this prospect was taken away when they had a hysterectomy. Some women believed they were deprived of their youth because of the symptoms experienced in the aftermath of their hysterectomy. Jade explains:

It’s an old woman thing you know and it’s a really, you know, this shouldn’t happen to somebody my age. So all those negative associations of hysterectomy and I just really felt it was a menopausal old woman thing and not something that happens when you’re in your childbearing years and not having heard of it much before either.

Sexual relationships were profoundly affected as women believed menstruation was a distinctive sign of reproductive potential and sexual maturity. When women held a strong association between menstruation and sexual identity, they began to form negative thoughts about themselves as sexual beings or to their bodies.

I feel like I’ve lost a part of myself. I feel empty, this empty feeling. I really don’t feel like a woman because I don’t get a period, my friends have said to me you’re lucky to not have a period anymore, but part of being a woman is to get your period.—Ruby

Living with a new self and a new body required significant adjustment for women. These women often compared themselves to their female counterparts who had a baby and managed to return to their prepregnancy appearance. Meeting this expectation, particularly when societal standards for female beauty emphasizes thinness, was imperative for some women to achieve in order to “fit in” and be classified as “normal” by society. Consequently, some women talked of being concerned about their body image as they struggled to lose weight and accept their body as it was following the hysterectomy. Women who displayed issues with their body and self-image talked about withdrawing from social gatherings and events, depressed, and upset.

... My stomach was never like this before, I don’t think I ever lost the weight after having the baby, and the hysterectomy, I don’t like the way I am and how I look, it just makes me feel upset that I just haven’t gone to what I was pre-pregnancy, if anything I have put on more weight to what I did when I was pregnant...—Suzie
Having a hysterectomy scar caused women to feel abnormal and was a constant reminder of their experience. Although there were times when women thought they were close to coming to terms with their experience, the scar as a mark of the trauma they experienced meant they were continually reminded of their experience. The physical appearance of their hysterectomy scar had strong psychological implications for the way some of the women perceived themselves and how they thought others would view them. Occasionally, the simple things such as wearing underwear and clothes caused distress for these women, primarily because of the pain of the hysterectomy scar and location.

...It's not the tummy I used to have. My bikini days are over. I had pretty bad scar adhesions where the scar tissue sort of sticks to the organs underneath. That carried on for months and months and months, so that was quite awful and kind of traumatic as well. ... —Kayla

The physical pain of their hysterectomy scar made it difficult for women to continue each day as normal. Many women described the type of pain they experienced and how it not only impacted on themselves but their whole family. Women held responsibilities within their households that they were sometimes unable to fulfill because of a body they believed to have changed.

Like, you'd bend over to pick up the baby, sort of thing, and all of a sudden you'd have this ripping pain in your abdomen, it was quite frightening ... I just kind of thought I was unravelling inside, you know. It's pretty darn ugly ... it's pretty foul. —Kayla

**Being Alone: Isolation and Disconnectedness**

"Isolation" and being "alone" were words used by some women to describe their experience, and this highlighted their perception and the reality that their experience was uncommon. Relationships with family and friends seemed to be essential in bringing consolation for the grief and loss caused by their experience. Some women believed that it would be difficult for others to understand their experience. This led to some women distancing themselves from women in general.

Having a hysterectomy at a young age created a sense of distance from their female friends. Occasionally, social contacts became estranged when friends of these women were having babies. They found it difficult to associate in this circle of friends and to attend mothers' groups and play groups. Women found socializing with women that were pregnant difficult. They were envious and felt guilty for feeling this way. During this process, close acquaintances and friendships were also lost.

Particularly my age, because I was only 26 when it happened ... you know, you get together with the mothers' group and everyone compares birth stories, and then you tell yours, and people, you know, their jaws just drop, and it's almost like they can't believe that that's happened. Yeah, it is. It's hard to relate as well. Like, yeah, I know that they have trouble relating to me, and they don't quite know what to say, and I have trouble relating to them, you know ... you feel happy for them [when someone is pregnant] but you kind of feel kind of a bit sad inside, you know; that you can't have that. So, yeah, it has been a bit hard. —Kayla

The difficulty of disclosing their experience to close family and friends caused some women to keep their hysterectomy experience a secret. Keeping this secret sometimes made it easier for women to cope with rather than having to repeatedly explain their birth experience, along with the reality of never being able to have children. Occasionally, some women were questioned by family and friends about their intentions to have more children.

... It took me a while, and it might just be me, but to be comfortable enough to actually say, this is what happened ... I know I've said it to people and I think they don't get it. Until you say, I was in intensive care, had 11 blood transfusions. I had a hysterectomy, until you actually give people the detail they don't get it ... No one has had the same thing. There's nobody who has had this. ... —Amy

Some women believed their experience was so personal and individualized that it was difficult to describe what had happened and to disclose their feelings to others. There was a strong belief that each woman will have experienced having a hysterectomy in a unique and exclusive way.
CHAPTER 7: ‘LESS FEMININE AND LESS A WOMAN’

Fearing Intimacy: Insecure and Warily
For some of the women, there was an “element of reserve” and hesitation in initiating and being sexually intimate with their partners. Intrusive thoughts lingered through some of the women’s minds. These thoughts were perpetuated by anxiety, fear, and pain associated with having sexual intercourse.

Being sexually intimate with their partner was considered important to the women’s relationship. However, it was a constant reminder of the trauma they experienced. Some women experienced strong emotional reactions to the reality of never being able to have a biological child. There was a common belief amongst the women that sex served as a purpose and that was to reproduce, as opposed to simply enjoyment and pleasure.

In these instances, the women described their partners as being generally sensitive and understanding of their needs, allowing them time to make sense of their experience. However, some women avoided sexual intimacy and close physical contact with their partner because of the degree of pain they experienced. Women spoke of their lack of sexual desire and interest, and others complained of having a low libido.

It has been 10 weeks since I’ve had the hysterectomy, last week was the first time we were sexually intimate. I just didn’t want to be touched; I was in a lot of pain—Ruby

Marital relationships were at risk of breakdown because of women developing insecurities about their relationship and whether their partner would remain loyal and faithful. These insecurities arose, as women believed their partners would view them as incomplete, infertile, and unable to fulfill their desire to have more children.

I’m very lucky in my husband because one of the hardest things afterwards for me was thinking, I can’t give him children. Well not anymore. And for some reason I mercied that more for him than I did for me I think because he could choose to go and have a child with another woman and that’s not something I could choose. But he has just taken it in his stride... we had intended to have more children. It was something that was important to us... —Rachel

Insecurities about their relationship were heightened for three women who were in a second marriage. The prospect of losing their husband was contemplated by these women. They viewed themselves as having failed disastrously as a woman and a wife in providing their husband with a complete family as promised. Powerlessness in the sense of having no control over the choice to plan for more children, over their relationships, and ability to make decisions in life emerged as an issue of concern to women.

... When my husband and I started to have sex again, I’d cry afterwards because I would think, no I’ll never, you know, I don’t know, I guess that’s what sex is for is to create life. I’d never have another child again so... He was very patient. He knew I just needed time... he was very understanding. —Mary

I still can’t believe it happened some days. I still think surely that didn’t happen. Surely I can have another child. That’s been the hardest thing. Is not being able to have another child because the eldest two children are from my first marriage and my husband and I were always going to have two together.

DISCUSSION

Study Limitations

This study explored the experiences of women with secondary infertility as a result of unplanned emergency
hysterectomy following a severe PPH. A possible limitation of this was that all participants in this study were Australian, English-speaking women. Therefore, the experiences of women from linguistically diverse backgrounds were not captured.

The Symbolic Meaning of the Uterus

The findings of this study revealed that many of the women strongly associated their uterus with their womanhood and female identity. Without it, women felt less like a woman, incomplete, and empty. For these women, the uterus held great significance and purpose, particularly in terms of childbearing. Although the women in this study all had live births, the predicament of suddenly becoming infertile was life-changing for some women who had planned to have further children. When that was not the case, many of the women still felt strongly about the loss of their uterus. This adds to the findings of other researchers (Markovic et al., 2008; Snyder, 2006; Williams & Clark, 2000), who have reported on the strong connection that women make between their uterus and their womanliness, sexuality, and femininity.

Dell and Papagianidou (1999) interviewed 10 women who had hysterectomies for benign conditions and found that women reported the loss of their uterus as having impacted negatively on their femininity and sense of self. Women in their study reported feeling a "gap" as though a part of them was missing. Similarly, our findings indicated that some women reported feelings of incompleteness and a sense of disconnectedness from their body.

Some of the women had a firm conviction that menopause is what defines a woman and her femininity, and in many ways, experiencing menopause is what distinguishes men and women. Our study revealed that many women believed they were in a "different" body or that their body had failed them. Concurring with this finding is a study by Kitzinger and Willmott (2002) on women's experiences of polycystic ovarian syndrome that found women with irregular or absent menses perceived themselves as freakish or abnormal. As evident in our findings, Kitzinger and Willmott's (2002) study showed that menstruation was considered central to womanhood. Moloney's (2010) study on women's perceptions of menstruation following birth found that women have an added appreciation to menstruating, often a spiritual significance to their being. According to Snyder (2006), many women believe that they are "abnormal" because they do not fit the "normal" ideology of being a woman, one with regular menses.

Social and Interpersonal Relationships

The findings of this study suggest that women who had experienced a hysterectomy following a severe PPH found it difficult to interact with pregnant women, their family, and friends. The sight of a pregnant woman created a sense of sadness and grief. Women also felt they were unable to talk about their experience to other women because many women did not understand the enormity of their hysterectomy experience and how close they came to losing their lives. Although all of the women in this study experienced a live birth, this finding can be closely related to studies on women's experiences of infertility and the sense of alienation or isolation they experience. Societal and cultural expectations can exacerbate the depth of women's pain and loss related to hysterectomy. According to Schwedtfeffer and Shreffler (2009), feelings of shame, guilt, isolation, and failure may also be experienced by women who had a hysterectomy because of an inability to meet societal and cultural expectations, desired goals, or status.

A study by Gonzalez (2000) in Florida, examining women's experiences of infertility, reported that women experienced difficulty in interacting with their family and close friends because they were unable to share the same experience, and they felt they were often singled out and stigmatized for not having children. Similarly, the women in our study who wanted more children experienced loss at the knowledge that they were no longer able to have children. Our research findings support the work of Gonzalez (2000) and add a different perspective on the cause of infertility by exploring the impact of unplanned emergency hysterectomy on women and bringing to light the additional burden women hold in terms of having to deal with justifying their status of "infertility" because of societal expectations to have children.

Grief and loss associated with hysterectomy and loss of fertility at a young age can consume women's lives and become a chronic life stressor (McQuillan, Greif, White, & Jacob, 2003; Schmidt, 2009). According to Amir, Horesch, & LeStein (1999), reproductive problems and infertility can be one of the most serious life stressors a woman can experience, negatively impacting her interpersonal relationships and sexuality (Lechner, Kolman, & van Dullen, 2007; Schmidt, 2009). This may then result in depression and social isolation because women feel they are unable to associate with their fertile family and friends, often becoming the object of pity and sympathy (Boughton, 2002; Elson, 2002; Orshan et al., 2001) causing some women to
doubt their significance and sense of worth in society. Our findings reinforce the prior research, as some of the women felt disconnected from other women, particularly from other mothers and pregnant women.

Sufficient and appropriate sources of support are paramount for women to help them cope with the grief and loss of having had a hysterectomy or infertility issues (Akizuki & Kai, 2008). Our findings revealed that when women felt supported by their family and friends, they were able to better cope with their loss and their hysterectomy experience. A study by Akizuki and Kai (2008) confirms this and found that listening and showing understanding and interest are positively received by women who experienced infertility issues. However, if a woman feels unsupported by her social network, then it may negatively impact her and cause greater emotional and psychological distress (Lecner et al., 2007; Verhaak et al., 2005).

CONCLUSION

These women’s responses add new knowledge in relation to women who have either experienced primary or secondary infertility because of hysterectomy and other causes. The findings of this study have revealed that women who experience unplanned emergency hysterectomy following severe PPH experience issues related to their identity as a woman, their sense of being, and sexuality. This study has implications for nursing and midwifery practice to better support women who experience issues related to their fertility as a result of surgical procedures such as unplanned emergency hysterectomy following childbirth. Sometimes women who have a child may be overlooked by health professionals as not having any issues related to their fertility, when, in fact, the findings of this study demonstrate that women who experience secondary infertility face an array of issues related to their personal identity and integrity as a woman. Psychological counseling and professional support should be offered to all women who experience secondary infertility, particularly following childbirth.

REFERENCES


**Acknowledgements.** We would like to thank the women who generously participated in this study and shared their thoughts and experiences.

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7.2 Conclusion

This chapter has presented the third theme ‘loss of normality’ as a published paper titled ‘Less feminine and less a woman: The impact of unplanned postpartum hysterectomy on women’. This paper describes women experiences of their perceived loss of womanhood and femininity. Women’s experiences of their fear of sexual intimacy with their partners following severe PPH and emergency hysterectomy is also described and discussed in relation to the existing literature on women experiences of infertility and women who have hysterectomies for gynaecological issues. The following chapter presents the final theme ‘moving forward’ as an epilogue illustrated by women’s narratives.
CHAPTER 8: EPILOGUE ‘MOVING FORWARD’

8.1 Epilogue: Relevance to thesis

This chapter presents an epilogue to the thesis focusing on the final theme ‘moving forward’. Women attempted to reframe their lives so they could keep living with the ordeal of an emergency hysterectomy. Although future prospects, such as having more children were lost, they were determined to re-build and develop a more positive outlook on life. Their appreciation for life in general was enhanced as was their appreciation for their family and child/ren. A “second chance” at life enabled women to redefine their priorities and invest time in themselves and their families.

Table 8.1 Theme and sub-themes

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subtheme</th>
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<tbody>
<tr>
<td>Moving forward</td>
<td>Appreciating life and living</td>
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<td></td>
<td>‘It’s just the way it is’</td>
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<td></td>
<td>Seeing the positive</td>
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<td></td>
<td>Redefining priorities</td>
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8.2 Introduction

The theme ‘moving forward’ encapsulates women’s search for meaning related to PPH as a life-threatening event and their hysterectomy experience. Some participants described their attempts to reframe their experience of having an emergency hysterectomy by finding the positives, rather than focus on the negatives. In each of the participants’ stories there was a palpable sense of relief for their second chance at life, fortunate enough to have survived the ordeal of a large bleed followed by an emergency hysterectomy. Participants talked about what it meant for them to be alive in this world, to be there to see their child/ren grow up, spend time with them, play, laugh and attend social outings with their families. For many women, the family unit took precedence over their own health. Women acknowledged the effects of a hysterectomy on their bodies, their life, their relationships and their emotional wellbeing, however, a second chance meant opportunities, possibilities, and the quest for what really matters in life.

8.2.1 Appreciating life and living

The women in this study described the efforts they made to try to find meaning in their hysterectomy experience, and regain a more positive perspective on their life. From their experience the women reported that they learned not to take things for granted and to cherish every moment with their loved ones. They had an added level of appreciation for their children, husbands, partners and life in general and devoted time to spend with them. Women talked of being grateful for the opportunity to have at least one child in comparison to being childless. They perceived having a child to be a privilege;
I think it probably has changed the way I parent, how I think I would have parented... I think I would be more appreciative of things. You only appreciate what you’ve got when it’s gone! In some ways it’s sort of like a depth to me that you only get to see if you talk to me. [crying] (Ruby)

Many of the women stated that they were grateful for the “second chance at life” that meant opportunities, possibilities, and a search for what really matters. They believed they were extremely “lucky” to have survived and were determined not to take this for granted.

I feel like I have a new life... I was close to death but I think what I felt mostly afterwards was that I had a chance, yes a new chance at life again. That this was something that I was saved from that by the care I got and that it’s something that I shouldn’t take for granted... (Rachel)

I appreciate still being here and the blood donors for saving my life. I would have been so ripped off and my family would have been so ripped off if I hadn’t made it through that because there is so much to be here for. I’m really glad that I got through it (Dianne).

As women reflected on their experience, they became clearer about having a sense of purpose in life and to “do good”. This as Jane described, enabled women to come to terms with the hysterectomy.

I think it definitely matured me emotionally as a person, not that I feel I was immature before, but I really feel like I’ve grown a lot since that happened. Like, it really gives you a sense of how lucky you can be in your life, and how there’s others out there who aren’t as fortunate, and it’s sort of in a way a moral obligation to try and do as much good in the world while you’re here. So that’s
definitely something I was always aware of, but now it’s something that’s really a part of me now. (Jane)

8.2.2 ‘It’s just the way it is’

Women spoke of incorporating this experience into their lives by learning to accept what happened and to move on. Some described taking this in their stride, holding the view “well it happened”. Gillian explained, “rather than lie on the floor, kick and scream poor me, poor me, I just thought well its happened move on”. Similarly Fiona states

“...you eventually go, it’s just the way it is, you have to accept it. I could cry a river and it wouldn’t have changed the fact.”

One participant believed that her initial perspective on birth helped to think more positively about the outcome;

“I didn’t have a sense that a birth has to be a good experience. I had a sense that a birth has to be a safe experience and I think that helped afterwards to respond to it positively.” (Rachel)

In accepting what happened, other women however became more cautious about life in general and birth in particular. These women emphasised that unexpected situations or events occur that one has little control over;

Certainly a bit more cautious, a bit more wary about some things. I sit back and I think, yeah, well, anything could happen. So I think sometimes, in some ways, it’s been because of the grief and the sadness, the loss, from the perspective of, well, you know, you never know what life is going to give out to you... Never in my life did I ever think like anything like that would happen to me. Left
me feeling like well you just don’t know what life has install (sic) all for you... you don’t know what’s around the corner. (Fess)

You never know what life is going to give out to you. Never in my life did I ever think like anything like that would happen to me. I knew I might have a bad time. I might have some stitches. I might be sore for a while. I might not be able to breastfeed... there’s nothing you can do about it. (Ruth)

8.2.3 Seeing the positive

Eleven of the women described the positive aspects of their experience. For some, there were positive outcomes of the hysterectomy in that they no longer had menstrual pain, heavy bleeding, they did not need pap smears (if their cervix was removed) and the hysterectomy was a good form of “contraception”. According to Amy:

“I try to seek a positive out of my experience and think well at least we don’t have to use contraception.”

Heavy bleeding during menstrual periods had previously been embarrassing and these women talked of limiting their social activities for fear of leaking through their pants or clothing;

I actually quite enjoy not getting my periods, I have to say. Really it’s actually heaven. The first two days of my periods, I could drown a small nation. I would bleed that much. It got to the point where I actually didn’t even like going out in case it sort of leaked through. (Jane)

To fulfil their desire to complete their family, a couple of participants held onto the notion that they could consider options such as fostering and adoption. They
described this as a potentially positive opportunity to bring another child into their family, particularly if they had one child and felt the need to have a sibling for their child.

“I’ve said to him that we could go down the path of adoption if you really wanted more kids. At least we have that option... it would be nice to have a sibling for her [child], I have siblings...”

(Jade)

Another woman Ruth talks about her willingness to seek alternatives such as adoption in an attempt to experience motherhood again.

Obviously we’d love to experience it again. We’d love to have the chance to have another little person in our family. But we’d all certainly love to have another brother or sister to hang out. Adoption and all that kind of stuff.

Women incorporated physical, psychological and spiritual activities in their life, as a way to help them cope with their experience. Some women took up yoga and meditation in order to ease their mind, relieving stress and tension as they learned to cope with their hysterectomy. They reported that this helped them “heal” internally and increase their level of concentration.

Yoga and meditation have been really good, in yoga, when they talk about relaxing and mediating, you really do learn to almost remove yourself from your body and the bodily stresses and you recognise them and ignore them in yoga so that you can just relax your mind... You’ve got so much to think about all the time so yoga is excellent and you can see how important it is to relax.

(Jade)

Finally, Ruth emphasised the importance of support;
There are people out there that care about you. You’re not alone. I just sort of thought you didn’t die. You have a baby, you know, to look after. I think just talking myself down helped with the anxiety and I was able to go back to sleep eventually and live. (Ruth)

8.2.4 Redefining priorities

The need to redefine priorities was identified as a necessity by many of the women. Redefining priorities was related to putting what mattered first. Through change women attempted to reflect on previous facets of their lives and lifestyles to gain the courage to reorganize and adapt to new ways of seeing this world. Some women were able to gain strength from the experience. For example, Mia stated, “what doesn’t kill us makes us stronger”. With this came a clearer sense of purpose particularly in being able to enjoy time with the family and do the things they have always wanted to. A new life was created through a reassessment of definitions of the meaning of life, family and the fragility or importance of being alive. Re-channelling their thoughts in a positive way assisted them to survive the trauma and distress of their experience. Some women expressed a strong desire to improve and promote health behaviour change as they were willing to use this “second chance” as some sort of wakeup call as evident in Marie’s narrative.

I was determined to make the most of it, I am usually a people pleaser, but thought, hang on a minute, I am going to put me first for once... I now swim with the kids once a week, play tennis, walk. (Marie)
Redefining priorities implied reframing thinking and defining what really matters in life. Women developed a different perspective on life, with the view of worrying about what really “counts”.

... A positive thing about having a hysterectomy was being able to not stress about silly little things, just worry about what counts. I never used to be like that, it wasn’t until you are put in a life and death situation that you start to think about what really counts.

(Jade)

8.3 Conclusion

This chapter has revealed some of the rethinking, the actions or activities that these women engaged in to reframe this distressing experience into something positive. Women reflected on all aspects of their lives and lifestyles to gain the courage to reorganize and adapt to new ways of seeing this world. Some women gained strength from the experience and with it came a sense of purpose in life particularly to enjoy time with the family and do the things they have always wanted to. The following and final chapter of thesis presents a discussion of the findings in relation to the extant literature.
CHAPTER 9: DISCUSSION

9.1 Introduction

The aim of this study was to describe the experience of women who had a severe PPH and subsequent hysterectomy. To achieve this, 21 women across Australia were invited to take part in the study and data were collected through face to face interviews, telephone interviews and email correspondence.

The study is the first qualitative study to use in-depth interviews and generate a rich description of women’s experiences of the initial trauma and the aftermath of a severe PPH and emergency hysterectomy. Thematic analysis revealed four themes, each reported in a previous chapter:

- Between life and death (chapter 5)
- Being a mother (chapter 6)
- Loss of normality (chapter 7)
- Moving forward (chapter 8)

This chapter will discuss the key findings as mentioned above in relation to the existing literature and highlight the significance of this study in contributing to new knowledge and corroborating or refuting related literature.
9.2 Initial trauma of severe PPH and emergency hysterectomy

The initial trauma of severe PPH and emergency hysterectomy discusses women’s experiences of the initial impact of bleeding and requiring an emergency hysterectomy to save their lives. The trauma, shock, fear of dying and the long lasting effects on women will be discussed below.

9.2.1 Between life and death

Having a severe PPH and emergency hysterectomy is considered by women to be a traumatic experience. Traumatic birth has been described by previous scholars as the fear and dread of women losing their lives during the birthing experience (Beck, 2004a, b; Beck & Watson 2008). Walsh (2007) adds, “with traumatic experiences the body, mind, spirit and relationships with others can be wounded” (p. 207). The women in this study described in vivid detail fear and dread of losing their life. The unexpectedness of bleeding and the need for an emergency hysterectomy impacted on women’s birthing and early mothering experiences, leading to distress and sadness at a time when social expectations are of joy and triumph (Dahlen, et al., 2010). Not only did the women fear for their own lives but they also feared that they would not be there as a mother for their newborn baby. This aligns with what has been documented in prior literature reporting experiences of traumatic birth and was discussed in the paper in chapter 2 (Ayers, 2004, 2007; Ayers, et al., 2006; Beck, 2004a, 2004b, 2006, 2010; Beck & Watson, 2008; J. Thompson & Downe, 2008; Thompson, et al., 2010; Thompson, et al., 2011; Thomson & Downe, 2010).

Furthermore, women in this study talked of flashbacks and nightmares long after the initial trauma. This has been documented in prior literature in relation to other types
of traumatic birth such as emergency caesareans (Ryding, Wijma, & Wijma, 1998a; Ryding, Wijma, & Wijma, 1998b; Ryding, Wijma, & Wijma, 2000), instrumental births (Beck, 2006) and severe perineal trauma (Salmon, 1999). The women’s recollections and memories of almost bleeding to death and losing their lives were also accompanied by emotions such as disbelief, sadness, anger, despair and distress and “being out of control”. A study by Mapp & Hudson (2005) found that women who experience obstetric emergencies, reported fear and distress during the emergency. Similarly, several studies have reported that women who experience an emergency caesarean section, fear for their lives and worry about the health of their babies. They also have great concerns about the possibility of death (Ryding, et al., 1998a; Ryding, et al., 2000).

Concurring with this finding is a study by Souza, Cecatti, Parpinelli, Krupa & Osis (2009) who studied 30 women and their experiences of a “near-miss” during pregnancy and childbirth. They found that women experienced the imminence of death, fear, frustration and grief during the emergency event. The women in the Souza et al. (2009) study experienced extreme pain and dyspnea which led them to believe death was imminent. Likewise, Cowan (2005) found that women diagnosed with pre-eclampsia, experienced shock, devastation and fear for their babies’ lives due to the life threatening nature of this condition. Another study by Ryding et al (1998a), noted that a dominant fear from women who experience a caesarean section was the possibility of impending death or serious injury. While these emotions are well documented previously in traumatic birth literature (Ayers, 2007; Beck, 2004a; Elmir, Schmied, et al., 2010), this current study adds to this body of knowledge as it is the first time the emotional impact of an emergency hysterectomy following a severe PPH has been described in detail.
Women could also easily recall the shock they felt when doctors disclosed the need for a hysterectomy as a life-saving measure. However, a striking finding of this study was that the women expressed their gratitude to the health professionals for their survival. Many studies of traumatic birth have reported women’s dissatisfaction with their birth experience, feeling as though they were “invisible” during the labour and birth process and that they experienced “maltreatment” at the hands of health professionals during their birth (Beck, 2004a, 2004b; Nicholls & Ayers, 2007; Thompson & Downe, 2008). In contrast, this study found that women praised health professionals and were appreciative of the care they received. The women were informed of the potential need for a hysterectomy, consented for procedures and reported that they were mostly treated with dignity and respect.

9.3 Aftermath of trauma of severe PPH and emergency hysterectomy

As described in chapters six, seven and eight, the three key findings that describe the aftermath of severe PPH and emergency hysterectomy were the ‘effects of the trauma on mothering’, ‘feeling of loss of normality’ and ‘moving forward’. The effects of the trauma on mothering left many women unable to take responsibility and care for their infants. Often, either their partners or families stepped into role as ‘mother’. Consequently, this affected women’s perception of being a ‘good mother’, with many women perpetuating feelings of guilt, failure and being a ‘bad mother’.

9.3.1 Being a mother

Society has an expectation that new mothers provide and care for their newborn by feeding the infant with a particular emphasis on breastfeeding, attend to their everyday needs (Burns, Schmied, Sheehan, & Fenwick, 2010; Sheehan, et al., 2010),...
and be present as the infant’s primary carer (Vallido, et al., 2010). The women in this study could not do this. The women struggled with their role as mother immediately following the severe PPH and emergency hysterectomy and in the early weeks at home following discharge. All the women expected and wanted to be with their baby in the early postpartum period. Participants reported experiencing a sense of guilt as they believed they could not meet society’s expectations of “normal” “good” mothering. This powerful feeling of guilt has been discussed in previous literature regarding the aftermath of other traumatic births and preterm births (Beck & Watson, 2008; Fenwick, et al., 2008; Thompson, et al., 2010).

Other effects of separation from the newborn such as feelings of inadequacy and failure as a mother and being a “bad mother” have been documented in previous research on preterm babies (Fenwick, et al., 2008), caesarean sections (Fenwick, et al., 2006), or when women are in intensive care for other reasons such as pre-eclampsia (Cowan, 2005). However, many of these women are able to “redeem” themselves through a subsequent positive birth experience as evident in Thomson and Downe’s (2008) study on women’s experience of redemptive birth following a traumatic birth experience. A redemptive birth as described by the women in Thomson and Downe’s (2008) study was a “cathartic and self-validating” birth (p. 394), that enabled them to re-internalise traumatic memories and enjoy motherhood. This study differs as the women are not able to “redeem” themselves as mothers through a positive or “redemptive” birth experience.

Just as women who have endured caesarean sections (Ryding, et al., 2000), the women in this study also experienced severe exhaustion, fatigue and lethargy. This was intensified by the significant volume of blood lost. This meant that in many cases the women were forced to temporarily relinquish the care of their infants to
other members of the family or while in hospital to health professionals. In order to resolve this feeling of guilt and loss the women believed they could become a “good mother” by breastfeeding. However only a few (eight) did succeed in doing this and therefore the women’s perception of not “being a good mother” were accentuated. This concept of being a good mother if you breastfeed has been reported in many studies of women’s experiences of breastfeeding (Burns, et al., 2010; Sheehan, et al., 2010). The association of breastfeeding and good mothering stems from societal and cultural constructions of women as mothers (Schmied & Lupton, 2001), and often when health professionals emphasise the message “breast as best”, that may inadvertently place women under pressure to conform to the ideal that breast milk is the best form of nutrition for their infant (Sheehan, et al., 2010).

Sometimes women who are unable to breastfeed feel as though they have failed as “mothers” (Schmied & Lupton, 2001). Women in this study reported that health professionals pressured them to perform and meet expectations of breastfeeding and that “only breast is best”. Research by Sheehan et al (2010) on the experiences of women who breastfeed suggests that “everybody’s best is different” (p.376), emphasising that health professionals need to provide care to women that is individualised.

A recent study by Thompson et al (2011) on women’s breastfeeding experiences following a significant primary PPH found that despite losing large amounts of blood and needing to recover physically and emotionally, 85% of women hoped to breastfeed their babies. Thompson et al (2011) report however that only 52% of mothers who intended to either fully or partially breastfeed were able to give their baby the opportunity to suckle with an hour of birth. Similarly less than half of the women in this study of severe PPH and emergency hysterectomy were able to
initiate breastfeeding within the first few hours following birth. Feelings of loss, guilt and being a 'bad mother' for not being able to breastfeed were heightened due to the fact that unlike other fertile mothers these mothers would never have the opportunity to retrieve the “good mothering” image, as the opportunity to have another biological baby was no longer possible.

**9.3.2 Loss of normality**

This study has reemphasised that the loss of a uterus is traumatic whether it be the result of illness (Boughton & Halliday, 2008; Fleming, 2003; Markovic, et al., 2008), birth injury such as ruptured uterus, or in this case severe PPH. Similar to other studies (Boughton & Halliday, 2008; Fleming, 2003) participating women reported they no longer felt complete and talked of a sense of emptiness at the thought they were no longer fertile. Unlike women who have surgery later in life, the women in this study felt they aged prematurely. This has been previously examined in relation to women who experience early menopause or surgery during child bearing years, and emphasises the symbolic meaning of the uterus (Dell & Papagiannidou, 1999). As indicated in chapter seven that similar to women with infertility issues, such as Polycystic Ovarian Syndrome (PCOS) (Kitzinger & Willmott, 2002; Snyder, 2006), this can become a significant and chronic problem and can result in isolation or disconnection from other women of their own age who are meeting society’s expectations of having children (Boughton, 2002; Boughton & Halliday, 2008; Kitzinger & Willmott, 2002; Schmidt, 2009; Snyder, 2006).

There is limited literature on women’s experiences of a hysterectomy and the impact on their sexual relationships (Lechner, et al., 2007; Schmidt, 2009). This study

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3 Is a problem in which a woman’s hormones are out of balance
contributes to this knowledge base describing in detail the women’s feelings of loss of normality in relation to their sexual relationships, which in some cases were interrupted because of the physical effects of the surgery and their feelings of inadequacy due to their sudden infertility. The literature that is available on sexuality following hysterectomy tends to discuss the inability of women to reach orgasm or experience sexual pleasure (Lechner, et al., 2007; Rhodes, Kjerulff, Langenberg, & Guzinski, 2000; Schmidt, 2009) and experiences of dyspareunia (Rhodes, et al., 2000). In contrast, the women in this study spoke more about their anxiety that they were unable to have more children rather than the effects of the hysterectomy on sexual intercourse. This could be related to women’s cultural or religious beliefs that the prime reason for sexual intercourse is procreation.

9.3.3 Moving forward

As discussed previously, women in this study often had flashbacks and nightmares and never forgot the experience of almost losing their lives whether it was five and a half weeks or 28 years ago. This reflects the effects of trauma whether it be during childbirth or in other events where a person comes close to death (Walsh, 2007) or is stressed by a traumatic event such as terrorist attacks (Linley & Joseph, 2004), rape or crime (Campbell & Raja, 1999). This study has confirmed that a severe PPH and emergency hysterectomy is a traumatic event and can have long term repercussions. The way in which women deal with the long-term consequences of their trauma can differ.

The data available from the study on how the women moved forward following severe PPH and emergency hysterectomy is limited but because it has not been documented in the literature, it is important to discuss it here. The majority of
women in this study had changed their life to some extent because of the traumatic birth. Similar to other literature on life changing events where people are given a second chance if they are close to death (Elmir, Jackson, et al., 2010), some of the women described how they valued life more now and tended to emphasise or focus on the positive rather the negative aspects of life.

Johnson (1999) states that during birth, women are in many ways faced with “life and death” (p.xiv). The findings of this study resonate with this, as many of the women regarded their experience of an emergency hysterectomy to be a life and death situation, with some women viewing their experience as coming close to death. Women were grateful to have survived, hence appreciating life and re-channelling their thoughts in a different way. Their perspectives and horizons for the future had taken a sudden turn for the better. Callister (2004)’s study on the significance of sharing birth stories, coincides with the findings of this study, stating that as women begin to understand the event of their birth, they formulate meaning and mastery, which are fundamental in enhancing women’s birth experiences.

The findings of this study also indicated that women acknowledged the loss of fertility, hopes and dreams as a result of a hysterectomy. However, as a way to move forward some participants had considered or had explored options such as fostering and adoption in an effort to feel complete as a woman and fulfil her desire for more children. Although infertility is often linked to depression in women, loss of identity, confidence and social roles (Deveraux & Hammerman, 1998), it can also be a time that fosters meaning in life and strength (Paul et al., 2009; Tedeschi & Calhoun, 1995). According to Peters (2006) in the study on childless couples, women find “strength” to live each day as it comes, despite the failed attempts at inducing
fertility. Some of the women in the Peters (2006) study tried to come to terms with and accept their involuntary childlessness.

### 9.4 Implications of the findings for clinical practice and education of health professionals

In this section 9.4 a summary of the findings and its contribution to new and the extant literature are provided. Implications of the study findings for clinical practice and education of health professionals are discussed.

#### Table 9.1: Summary of study findings and contribution to knowledge

<table>
<thead>
<tr>
<th>Study findings in relation to extant literature</th>
<th>Extant literature</th>
<th>Contribution to knowledge</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Description of the experience of women having postpartum haemorrhage (PPH) and emergency hysterectomy</strong></td>
<td>Report of a survey of 200 women who had a PPH or PPH and hysterectomy. Limited studies on the experience of traumatic birth in Australia.</td>
<td>First qualitative study using interviews, email to provide in-depth description of initial event and aftermath of a severe PPH and hysterectomy.</td>
</tr>
<tr>
<td><strong>Description of the traumatic birth experience</strong></td>
<td>The fear, dread, loss and being out of control has been well documented.</td>
<td>First time reported that women have spoken positively of the experience with health professionals during the initial shock and trauma of coming close to death.</td>
</tr>
</tbody>
</table>
### Description of aftermath of severe PPH and hysterectomy

The impact of a traumatic birth or unexpected event such as premature birth on being a mother and being able to perform mothering tasks is well documented in particular the importance that some women place on breastfeeding as something that a “good” mother does.

Limited research describes the aftermath for young women of having a hysterectomy. Available studies describe the aging effects, both loss of and enhanced sexual pleasure and being socially isolated.

Few reports describing women’s experiences of finding meaning in life following traumatic birth.

The emphasis on the fact that women after hysterectomy have no way of “redeeming” the loss of opportunities to provide care to another baby immediately following birth or to breastfeed another baby.

The women post hysterectomy described in more detail the anxiety and guilt of having sexual relationships without the prospect of conceiving a child.

This study adds new knowledge about efforts that women may make to find meaning following traumatic events.

<table>
<thead>
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</tr>
</tbody>
</table>

Table 9.1 summarises the findings of this study and its contribution to knowledge.

The implications of the findings will be discussed in relation to clinical practice and education of health professionals and to society.

As discussed in the published papers in chapters two, five, six and seven; clinicians including midwives, child and family health nurses and other members of the multidisciplinary team need to provide women with an opportunity to talk about
their traumatic experience of having a severe PPH and emergency hysterectomy. The findings of this study indicate that women who have a traumatic birth experience require time to comprehend events during their birth and the rationale for interventions implemented. In this current study, some women had experienced their severe PPH and emergency hysterectomy as long as 28 years ago. Listening, supporting, showing understanding and empathy and providing explanations are important measures that midwives and nurses use to help women understand and come to terms with the events during and after their childbirth experience. Both non directive and directive counselling has a place and women should, at an appropriate time, be offered a referral to a counsellor. However timing is important and women may not be ready to talk in-depth about their experiences for many months. Some evidence suggests that the provision of an opportunity for women to make sense of their birth experience is a method of psychological healing and catharsism (Beck, 2005). Despite this however, women are often discharged from hospital with minimal acknowledgment of the events that occurred during their birth and afterwards (Beck, 2004a; Gamble & Creedy, 2009). In many maternity facilities, planned and appropriate postnatal support pathways following a traumatic childbirth, are not available or are not yet developed.

Most importantly, midwives, nurses and other health professionals need to be trained to use communication skills effectively, to be able to continue to work in partnership with women who have suffered a traumatic event. Given the relative rarity of severe PPH and emergency hysterectomy, education programs for midwives and other health professionals need to focus on better dealing with and managing obstetric emergencies. “Mock drills”, in-services, online obstetric emergency tutorials, seminars and conferences are important to prepare the workforce. Preparation and
greater understanding of obstetric emergencies enhances meaning and creates vigilance and attentiveness to at-risk women. It is also important that effective “serious incident review processes” are in place to examine such a “near miss” event. Student midwives should be encouraged, under the supervision of an experienced midwife, to be involved in the care of women who experience a severe PPH and emergency hysterectomy in order to familiarise them with the complexities associated with childbirth.

Training and education of nurses in the intensive care to support women who are admitted to intensive care is paramount to provide care that is tailored to women needs following birth. Following birth, women require regular support and assistance with breastfeeding and to care for their newborns. Minimising the separation between mother and baby in the newborn period while mother is in intensive care is vital to ensure early bonding and to help initiate and establish breastfeeding. Nurses in intensive care need to be educated on the needs of women following birth, and the associated bodily and hormonal changes. Society needs to be made aware that unexpected events can occur during or after birth. Antenatal education needs to focus on the provision of information for women and their partners to help them become well informed of the potential risks during and after birth.

9.5 Strengths and limitations of this study

9.5.1 Strengths of this study

While a number of epidemiological studies have reported on the incidence of PPH, there remain significant gaps in the literature on women’s experiences of severe PPH and emergency hysterectomy. As illustrated in table 9.1, this study has contributed to
the body of knowledge on traumatic births and to generic literature on unexpected life crises.

Adopting a qualitative, naturalistic method of inquiry in this study allowed for a full exploration of the women’s experiences. Women were able to convey their experiences as lived, of bleeding during or after birth, and the need for an emergency hysterectomy. The naturalistic inquiry method allowed for meaning to be interpreted and greater insight into the women’s experiences to be generated.

This study used email, telephone and face-to-face interviews to collect data from participants. These three modes provided an opportunity for women across Australia to participate, rather than being confined to the smaller geographic area of Sydney. Women were able to choose the method that they felt most comfortable with to communicate with me. Email and telephone interviewing allowed for women to freely express their concerns, feelings and personal views of their experience. Face-to-face interviews allowed for rapport to be established with participants and for non-verbal cues to be observed.

9.5.2 Limitations of this study

It may be considered that a limitation of qualitative work is the inability to provide findings that are generalisable to other cultural settings. However, this study did not aim to generalise findings to other settings, the intention rather was to gain deep understandings of the experiences of women who had a severe PPH and emergency hysterectomy. Twenty one women were interviewed for the study, and data collection continued until saturation was reached. The data generated from these interviews was rich, authentic and sufficient for a study of this size.
This study focused on Australian women’s experiences of emergency hysterectomy following a severe PPH; therefore women’s experiences from countries other than Australia were not studied. Non-English speaking women were excluded from the study, as the true essence and experience may not have been captured. Further studies involving women from culturally diverse and linguistically diverse backgrounds may provide different perspectives. This study also involved interviews that were either via face to face, telephone or internet correspondence, thus women who were geographically distanced as well as with limited access to the internet or telephone, were potentially not able to participate and have their experiences captured. Therefore a full representation of this sample of women may not have been studied.

9.6 Recommendations for future research

The findings from this study indicated that having a severe PPH and an emergency hysterectomy had emotional and physical impacts on the women’s well-being and sense of womanhood irrespective of the years that had elapsed since the hysterectomy. Further research into the experiences of women following other obstetric emergencies such as 4shoulder dystocia, 5amniotic fluid embolism, 6cardiac

4 Shoulder dystocia occur following the birth of the fetal head, the anterior shoulder cannot pass below the pubic symphysis. Certain manoeuvres are used to assist in the birth of the baby.

5 Amniotic fluid embolism is an obstetric emergency whereby amniotic fluid enters the mother’s blood stream through the placenta, triggering an allergic reaction.

6 Cardiac arrest is a life threatening event when blood to the heart is diminished and the heart stops beating.
arrest and cord prolapse is needed to identify similarities or differing experiential experiences in women to those women who had a severe PPH and emergency hysterectomy. Research comparing primigravida’s and multigravida’s experiences of obstetric emergencies is required to distinguish possible differences of the impact. Gaining insight into women’s experiences of obstetric emergencies will help inform clinical practice by informing policies and guidelines and providing ongoing professional support for women. Implementing interventions to assist women to cope with their experience in the aftermath is further warranted.

As a result of limited information and availability of resources to women, this current study has emphasised the need for a support group that is tailored specifically to women who experienced a severe PPH and emergency hysterectomy. Online services are also required to provide flexibility in women accessing support services, educational material and information.

### 9.7 Conclusion

This study explored women’s experiences of severe PPH and emergency hysterectomy and provided insight into the needs of women in the aftermath of their experience. Women needed understanding, support and at times someone to listen to them as they “debriefed”. This was at times lacking as many women in this study were not referred to appropriate professional support services. This study has provided a new body of knowledge and provided insight into the fear women experienced in terms of losing their lives due to the bleeding. They had concerns

---

7 Cord prolapse is an obstetric emergency where the umbilical cord precedes the presentation of the baby. This can occur during pregnancy or labour.
about the welfare of the family, in particular their child/ren. The shock and trauma of their ordeal left women with vivid and distressing memories of their experience. This study revealed that women experienced a period of separation from their infant due to admission to the ICU and the limitations associated with an emergency hysterectomy. Temporarily relinquishing the care of their infant was a distressing time for women, and impacted on their identities as mothers and ability to initiate and establish breastfeeding and bond with their babies. These findings contribute to and build on existing literature on women’s experiences of separation from their infant in the Neonatal Intensive Care Unit (NICU).

This study indicated that the unexpectedness of an emergency hysterectomy left women feeling upset, angry and saddened that their future plans to have more children were lost. A sense of emptiness was experienced as women believed they were no longer complete and normal. Interpersonal, familial and social relationships were subsequently affected, as women feared the close contact and intimacy of their partner. Difficulty in relating to female friends and social networks exacerbated women’s feelings of isolation and difference. The findings of this study are important in providing new insights and extending previous findings reported in the existing literature on women’s experiences of elective hysterectomy for gynaecological issues, and offer directions for future research.

The ability for the women in this study to find meaning in life was a gradual process. Each women differed in her approach and the length of time it took to find the positive side of their experience, and to be able to “move forward” with their lives.

Internationally, the incidence of PPH is rising and this may be attributable to an increase in the rate of caesarean births, induction labour and the use of other
unnecessary interventions. As a result, the incidence of emergency hysterectomy following severe PPH will most likely rise.

Chapter nine has provided a discussion of the key findings with reference to the existing literature. The contribution of this study to the body of literature and new knowledge is also highlighted. Implications for midwifery and nursing practice, education and policy development are discussed.

9.8 Final thoughts

My pre-understandings, ideas and beliefs informed my decision to conduct research on women who had an emergency hysterectomy following severe PPH. I was able to connect to women on many levels, personally (as a close family member died of a severe PPH), and professionally, as a midwife and I have cared for women who experienced this phenomenon. Through my engagement in the women’s constructions of their world, I was able to gain insight and understanding of their experiences. I can honestly say that I connected with many of the women and built a strong rapport and therapeutic relationship.
CHAPTER 9: DISCUSSION

I would like to end this thesis by sharing this letter, written by one of the participants following a face-to-face interview in her home.

Dear Rakime,

Just a note to thank you for coming round to interview me the other day. I found that a very positive experience; it was good to talk about my feelings, and I appreciated the chance to do so. Thank you for all the work you are doing on the study, which I’m sure will produce some very helpful information. If there is any way I can help in future, please don’t hesitate to let me know. I would be very willing to offer support to others or to be involved in a support group, if that comes to pass in future. Talking about my experience would be fine; I think it is a good thing to share such stories, both for others in a similar situation, and for staff involved in childbirth care. I did find it therapeutic; I was very impressed with the level of support I received. Thank you for your support also, it is much appreciated.

With regards and thanks
REFERENCES


Dear Mrs. Elmir:

Thank you for sending us your revised paper which has been considered with care. I am pleased to inform you that your paper has now been accepted for publication in the Journal of Advanced Nursing and we hope to publish it within 6-8 months.

Online Open
OnlineOpen is an optional pay-to-publish service from Wiley-Blackwell that offers authors whose papers are accepted for publication the opportunity to pay up-front for their manuscript to become open access (i.e. free for all to view and download) via the Wiley Interscience website. Each OnlineOpen article will be subject to a one-off fee of £1250 (equivalent to $2500) to be met by or on behalf of the Author in advance of publication. Upon online publication, the article (both full-text and PDF versions) will be available to all for viewing and download free of charge. The print version of the article will also be branded as OnlineOpen and will draw attention to the fact that the paper can be downloaded for free via the Wiley Interscience service.

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Please send these forms to the Editorial Office, Journal of Advanced Nursing, Wiley-Blackwell Publishing Ltd, 9600 Garsington Road, Oxford, OX4 2DQ, UK.

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material submitted, please inform the editorial office or production editor.

Please note that JAN welcomes updated reviews and/or commentaries discussing changes in practice or recommendations for practice since the time original publication.

Congratulations on the acceptance of your paper. We are delighted to be publishing it in JAN.

Yours sincerely

Debbie Kralik
Senior Editor
Journal of Advanced Nursing
APPENDIX B: ETHICS APPROVAL

HREC Approval 16778 - UWS Student Email - Msg

From: "Jay Buckley" <J.BUCKLEY@uws.edu.au>
To: "Virginia Schmied" <V.SCHMIED@uws.edu.au>, <09240667@student.uws.edu.au>
Subject: HREC Approval 16778

Notification of Approval

Email on behalf of the UWS Human Research Ethics Committee

Dear Virginia and Railime

I'm writing to advise you that the Human Research Ethics Committee has agreed to approve the project.

Title: Women's life experiences: life after a hysterectomy following a severe postpartum haemorrhage

Railime Elmire (Doctoral candidate)

The Protocol Number for this project is H778. Please ensure that this number is quoted in all relevant correspondence and on all information sheets, consent forms and other project documentation.

Please note the following:

1) The approval will expire on 2 March 2016. If you require an extension of approval beyond this period, please ensure that you notify the Human Ethics Officer (humanethics@uws.edu.au) prior to this date.
2) Please ensure that you notify the Human Ethics Officer of any future changes to the research methodology, recruitment procedure, set of participants or research aim.
3) If anything unexpected should occur while carrying out the research, please submit an Adverse Event Form to the Human Ethics Officer. This can be found at http://www.uws.edu.au/research/oa/ethics/human_ethics
4) Once the project has been completed, report on its ethical aspects must be submitted to the Human Ethics Officer. This can also be found at http://www.uws.edu.au/research/oa/ethics/human_ethics

Finally, please contact the Human Ethics Officer, Kay Buckley on (02) 4736 0888 or at k.buckley@uws.edu.au if you require any further information.

The Committee wishes you well with your research.

Yours sincerely

Dr Janette Perez
Chair, Human Research Ethics Committee

Kay Buckley
Human Ethics Officer
University of Western Sydney
Locked Bag 1957, Penrith NSW 1797
Tel (02) 4736 8833

APPENDIX C: AMMENDEMENT TO ETHICS

APPROVED

Dear [Name]

Notification of approval for an amendment to an existing project

H6778  Women's lived experiences after a severe postpartum haemorrhage

Please ensure that you notify the Human Ethics Officer of any future changes to the research methodology, recruitment procedure, and the research team.

At the completion of the project, please submit a report on its ethical aspects to the Human Ethics Officer (humanethics@uws.edu.au). This can be found at http://www.uws.edu.au/research/irs/ethics/human_ethics

Please don’t hesitate to contact me on (02) 9213 6838 or at k.luckley@uws.edu.au if you have any further queries.

regards

Kay Buckley
Human Ethics Officer
University of Western Sydney
Locked Bag 1470, Penrith NSW 2750
Tel: (02) 9213 6838
Appendix D: Poster

Have you had a hysterectomy?

- Have you had a hysterectomy following a severe postpartum haemorrhage (severe bleed after childbirth)?
- Are you English speaking?
- Can you spare 1-2 hours of your time?

If you answered yes to the above questions, I would sincerely like to talk to you about your experience. The information you provide will contribute to a better understanding for health professionals of the issues and concerns women face in the aftermath of a hysterectomy following a severe postpartum haemorrhage.

All information provided will be treated with privacy and confidentiality.

For more information regarding this study, please contact Rekime Elmir (researcher) via email 1024066@student.uws.edu.au or r.elmir@uws.edu.au alternatively, phone (02) 98554773.

This research study has been approved by the University of Western Sydney ethics committee, approval number H6778.
Hawkesbury Gazette
20/05/2009
Page: 35
General News
Region: Western Area NSW
Circulation: 7728
Type: Regional
Size: 105.99 sq.cms

APPENDIX E: MEDIA RELEASES

HAWKESBURY COMMUNITIES

Your once-monthly dose of news for the
UWS Hawkesbury campus community. To
contribute any story, big or small, please call
Justine Oake on 4588 8660 or, alternatively,
email editor.hawkgazette@rusipress.com

GET the facts on social financial issues and
question the experts at a series of three seminar
sessions starting later this month, run by the
University of Western Sydney The Whitting
Institute of UWS and the UWS School of
Economics and Finance will bring together
leading economists for the 'Getting to Gras
s with the Economy' series. A question and
answer session in each forum will be a high-
light and a rare opportunity for the commu-
nity to question the experts directly. The first
forum is on from 5 pm and costs $15. Book at
the Riverside on 8839 3399.

THE emotional impact of hysterectomy is
a focus of a new study beginning at
University of Western Sydney. The academics
leading the study are calling for women
who have had a hysterectomy following severe
bleeding during childbirth to take part. The
findings of the study will help build better
survivor networks for such women in the future
and help shape the care they receive in the
health system. To enquire about participating
in the study, contact Rakima Amin at
rakima@uws.edu.au or call 9555 4773.

A UNIVERSITY of Western Sydney researcher
has revealed that the majority of Australians are
supportive of Muslim women's decisions to wear tra-
ditional Islamic headscarves. Professor Zeva
Dan, a multiculturalist expert from the UWS
School of Social Science, has conducted an
analysis of recent public opinion polls and atti-
tude surveys of more than 1,500 people. The find-
ing reveals that, although there is a level of dis-
cordance toward the Islamic faith and people if
Muslims from countries in Asia, there is lit-
tle public objection to the hijab or the women who
wear them.
Women asked to reveal experiences for PPH study

A UNIVERSITY of Western Sydney study will seek the emotional and physical experiences of women who have undergone severe bleeding during childbirth. School of Nursing and Midwifery PhD candidate Islam Elmir is seeking local women who have had a severe postpartum haemorrhage (PPH) to participate in confidential face-to-face or internet-based interviews. PPH is a life-threatening condition in which women suffer excessive blood loss after childbirth and can result in hysterectomy. To participate, email iremir@wusu.edu.au or phone 9632 4773.
UWS surgical study

A UNIVERSITY of Western Sydney study wants to reveal the emotional and physical experiences of women who have undergone a hysterectomy. School of Nursing and Midwifery PhD candidate, Raizume Elmir is seeking women who have had severe bleeding after a hysterectomy to participate in a confidential or internet-based interview. Mrs Elmir says the responses collected in the study and the analysis of the data will be used to shape future medical services and support. For further information phone Mrs Elmir on 9631 4773.
Traumatic experience

WOMEN who have undergone a hysterectomy after severe bleeding during child birth are being asked to speak about their experience for a new study to be used to shape future medical services and support.

The University of Western Sydney study will reveal the emotional and physical experiences of women who have undergone a hysterectomy following severe bleeding during childbirth.

School of Nursing and Midwifery PhD candidate, Bakine Elmir is seeking women who have had a postpartum haemorrhage (PPH) to participate in confidential face-to-face or internet based interviews.

PPH is a life threatening condition in which women suffer excessive blood loss during the first 24 hours after childbirth and can result in the patient requiring an hysterectomy.

"The incidence of PPH in Australia is between five and 10 per cent of all births, but it has been increasing over the past decade," Mrs Elmir said.

"However, to date there has been very little research on the impact this traumatic experience has on women in the longer term."

Anecdotally, PPH has devastating consequences for women.

"Women can have difficulties establishing and initiating breastfeeding, bonding with their baby and their relationship with their partner can be affected," Mrs Elmir said.

"Their self image and perception of their own bodies can also be changed."

The responses collected in the study and the analysis of the data will be used to shape future medical services and support.

"The insights achieved from talking to women about these deeply personal thoughts and emotions will help build the knowledge needed for women's support networks and enhance the level of care offered by health services," Mrs Elmir said.

To participate in the study contact Bakine Elmir on r.elmir@uws.edu.au or call 9852 4772.
Support for mums

WOMEN who have undergone a hysterectomy offer advice bleeding during childbirth are invited to join a UWS study into the emotional and physical impacts of the procedure. Researchers hope the results will help improve medical services and support. Contact Rukiru Birir on r.alex@uws.edu.au or call 9852 4773 to participate.
An insight into hysterectomies

A University of Wollongong Sydney study will reveal the emotional and physical experiences of women who have undergone a hysterectomy following severe bleeding during childbirth. Rachel Time, a PhD candidate in the school of nursing and midwifery, is seeking women who have had a severe postpartum hemorrhage or PPH to participate in confidential face-to-face or internet-based interviews. PPH is a life-threatening condition in which women suffer excessive blood loss during the first 24 hours after childbirth. It can result in the patient requiring a hysterectomy. Ms Time said the identification of factors that increase the rate of hysterectomy were increasing. The experiences collected in the study will be used to shape future medical services and support. Details to participate in the study: r.time@iwu.edu.au or 9852 4773.
Childbirth trauma subject of research

By Jo Anklesar

LIFE is never the same again for women who undergo a hysterectomy after hæmorrhaging childbirth.

A study at the University of Western Sydney hopes to uncover the emotional and physical experiences of women who have undergone hysterectomy following severe bleeding during childbirth.

About 2% of women suffer from post-partum haemorrhage (PPH), a life-threatening condition in which women suffer excessive blood loss during the first 24 hours after childbirth, and can result in the patient requiring a hysterectomy.

A midwife for six years, Râkime Elmir said between 5 and 10% of all births in Australia result in PPH and no studies had been conducted on the long-term affect of the condition.

"I have come across women who have had a hysterectomy following a severe bleed after giving birth and the traumatic experience they encounter is quite detrimental to their physical and mental ability to cope."

"Women face difficulties establishing and initiating breastfeeding, bonding with their baby and their relationships with their partner can be affected."

Ms Râkime said there was often a lack of support from health professionals, family and friends.

"People just don’t understand that it’s very traumatic. As well as giving birth, they also have to endure major abdominal surgery. They feel they are a victim, that they were trapped. They realise it’s a life-saving procedure but there’s no choice."

Ms Râkime hopes the information obtained from talking to women about their deeply personal thoughts and emotions will help build the knowledge needed for women’s support networks and enhance the care offered by health professionals.

To join the study, contact Râkime Elmir on râkimir@ms.owen.edu.au or call 0432 4774.
Study targets PPH impacts

By J. Arlnter

LFEIs not the same for women who undergo a hysterectomy after haemorrhaging in childbirth.

A study at the University of Western Sydney hopes to uncover the emotional and physical experience of women who have undergone a hysterectomy following severe bleeding during childbirth.

About 0.02 per cent of women suffer from postpartum haemorrhage (PPH), a life-threatening condition, in which women suffer excessive blood loss during the first 24 hours after childbirth, and can result in the patient requiring a hysterectomy.

A midwife for six years, Rakime Elmir said between five and 10 per cent of all births in Australia result in PPH and no studies had been conducted on the long-term impact of the condition.

"I have come across women who have had a hysterectomy following a severe bleed after giving birth and the traumatic experience they encountered is quite detrimental to their physical and mental ability to cope," she said.

"Women can have difficulties establishing and initiating breastfeeding, bonding with their baby and their relationship with their partner can be affected," Ms Elmir said there was often a lack of support from health professionals, family and friends.

"People just don't understand that it's very traumatic. As well as giving birth, they also have to undergo major abdominal surgery," she said.

"They realise it's a life-saving procedure but they just don't have a choice," Ms Elmir hopes the information obtained from talking to women about their deeply personal thoughts and emotions will help build the knowledge needed for women's support networks and enhance the level of care offered by health professionals.

To participate in the study contact Rakime Elmir at r.elmir@uw.edu.au or call 08 9222 4773.
APPENDIX F: INTRODUCING THE PARTICIPANTS

A brief synopsis of each of the participants will be presented to allow greater insight to the participant’s position within the context of their experience. Pseudonyms for the participants are referred to throughout the text to protect their identification.

The synopsis provides information on the participant’s age, occupation, educational status and marital status. Other information obtained were details of women’s birth, time since the hysterectomy, mode of birth, type of hysterectomy, total or subtotal and any medication they were receiving as a result of the hysterectomy.

Table B1: Participants’ background

<table>
<thead>
<tr>
<th>PARTICIPANTS</th>
<th>BACKGROUND</th>
</tr>
</thead>
<tbody>
<tr>
<td>MARIE</td>
<td>Marie was 40 years old at the time of the hysterectomy. She is currently a stay at home mother to four children and married to Fred. She had a vaginal birth that resulted in a retained placenta, which exacerbated the bleeding. Marie was rushed to the operating theatre for a manual removal of placenta and hysterectomy.</td>
</tr>
<tr>
<td>MARY</td>
<td>Mary was 32 years old at the time of the hysterectomy. She works part-time two days a week in administration. She is married to Mike and has three children. She had a Caesarean birth accompanied by a subtotal hysterectomy as a life-saving procedure to control the bleeding. Mary was commenced on anti-depressants as a result of the hysterectomy.</td>
</tr>
<tr>
<td>JANE</td>
<td>Jane was 38 years old at the time of her hysterectomy. She has an Advanced Diploma in Business and works from home in the</td>
</tr>
<tr>
<td>PARTICIPANTS</td>
<td>BACKGROUND</td>
</tr>
<tr>
<td>--------------</td>
<td>------------</td>
</tr>
<tr>
<td>Jane</td>
<td>role of office administration. She has three children and married to Elias. She was diagnosed with placenta accrete, and so required a caesarean section. Following the caesarean Jane had a severe PPH resulting and a subtotal hysterectomy.</td>
</tr>
<tr>
<td>Gillian</td>
<td>Gillian was 38 years old when she was faced with a hysterectomy. She is married to Tom with twin boys. She had a caesarean birth leading to a subtotal hysterectomy.</td>
</tr>
<tr>
<td>Sandra</td>
<td>Sandra was 38 years old at the time of her hysterectomy. She is in a de-facto relationship and has one child who was born at 23 weeks gestation weighing 470 grams. Sandra was diagnosed with placenta praevia, she began to bleed and had an emergency classical caesarean section. Following the birth Sandra bled severely and had a subtotal hysterectomy to control the bleeding.</td>
</tr>
<tr>
<td>Ruth</td>
<td>Ruth was 33 years old at the time of her hysterectomy. She lives with her husband Henry, and has a four and a half year old girl. She holds a Bachelor’s degree and works as a contract writer. Ruth had a caesarean birth and subtotal hysterectomy.</td>
</tr>
<tr>
<td>Jade</td>
<td>Jade was 35 years old at the time of her hysterectomy. She has a Bachelor’s degree in Medical Science and works part-time as a hospital scientist. She is married to Victor and has two children aged four and 18 months. Jade had a caesarean birth and subtotal hysterectomy.</td>
</tr>
<tr>
<td>Rachel</td>
<td>Rachel holds a PhD and works as a scientist in medical research. She was 36 years old at the time of her hysterectomy eight years ago. She is married to Trever and has one daughter. Rachel had a vaginal birth accompanied by a severe PPH and a subtotal hysterectomy.</td>
</tr>
<tr>
<td>PARTICIPANTS</td>
<td>BACKGROUND</td>
</tr>
<tr>
<td>--------------</td>
<td>------------</td>
</tr>
<tr>
<td>AMY</td>
<td>Amy was 35 years old at the time of her hysterectomy. She has a Masters degree and works as a psychologist and currently is in a de-facto relationship. She has one child and had a caesarean birth and a subtotal hysterectomy.</td>
</tr>
<tr>
<td>SUZIE</td>
<td>Suzie was 35 years old at the time of her hysterectomy. She is married to husband Liam and has one child. Suzie and Liam tried to have a baby for eight years; six of those years they used IVF. Suzie works part-time as an administrative assistant and lives in Sydney. She had a caesarean birth and was discharged home, four weeks later she presented to the Emergency department with a secondary PPH. She had a total hysterectomy.</td>
</tr>
<tr>
<td>MIA</td>
<td>Mia was 36 at the time of her hysterectomy. She is married to John and has three children aged four, two and five weeks. She had a caesarean birth and a subtotal hysterectomy.</td>
</tr>
<tr>
<td>KAYLA</td>
<td>Kayla was 27 years of age when she had a subtotal hysterectomy. She is married with a five year old daughter. Kayla had a vaginal birth.</td>
</tr>
<tr>
<td>SARAH</td>
<td>Sarah was 39 years old at the time of her hysterectomy. She is married to Nicolas and has three children, eight, 16 months and an eight week old. She was diagnosed with placenta accrete and was told by her Obstetrician of the possibility of a hysterectomy. Sarah had a caesarean birth, a 2.5 litre blood loss and a subtotal hysterectomy.</td>
</tr>
<tr>
<td>RUBY</td>
<td>Ruby was 33 years of age at the time of the hysterectomy. She is married with four children; the youngest 10 weeks. Ruby had antenatal foetal complications; her pregnancy was initially a twin pregnancy. She miscarried the first twin at twelve weeks secondary to rhesus disease. The remaining twin required</td>
</tr>
</tbody>
</table>
several blood transfusions in utero as a result of a fall in the baby’s haemoglobin. Ruby had a caesarean birth and a subtotal hysterectomy. Ruby was seeing a psychiatrist and prescribed anti-depressants (Zoloft).

<table>
<thead>
<tr>
<th>PARTICIPANTS</th>
<th>BACKGROUND</th>
</tr>
</thead>
<tbody>
<tr>
<td>LOUISE</td>
<td>Louise was 27 at the time of her hysterectomy and was married. She is currently divorced and has one 27 year old daughter. Louise had a forceps birth after which she was discharged home. She was re-admitted to hospital eight days later with a secondary PPH. She required a subtotal hysterectomy.</td>
</tr>
<tr>
<td>DIANNE</td>
<td>Dianne was 37 years old at the time of her hysterectomy. She is a registered nurse and midwife and works in Victoria. She is married to Geoff and has one child Jacqui. Dianne had a vaginal birth and a subtotal hysterectomy.</td>
</tr>
<tr>
<td>JENNY</td>
<td>Jenny was 23 at the time of her hysterectomy. She is in a de-facto relationship and has one daughter. She had a vaginal birth and a subtotal hysterectomy.</td>
</tr>
<tr>
<td>FIONA</td>
<td>Fiona was 25 years old at the time of the hysterectomy. She is single and works as a carer / social educator. Michelle has one child aged seven. She had a vaginal birth and subtotal hysterectomy.</td>
</tr>
<tr>
<td>ROSE</td>
<td>Rose was 29 years old at the time of her hysterectomy. She is now 56 years old and still discusses her hysterectomy experience with her husband. Rose had a vaginal birth resulting in a healthy living daughter and had a subtotal hysterectomy.</td>
</tr>
<tr>
<td>BELINDA</td>
<td>Belinda was 37 years at the time of her hysterectomy. She works as a receptionist and is married with two children aged five and four. She had a caesarean birth and a total hysterectomy.</td>
</tr>
<tr>
<td>PARTICIPANTS</td>
<td>BACKGROUND</td>
</tr>
<tr>
<td>--------------</td>
<td>------------</td>
</tr>
<tr>
<td>FESS</td>
<td>Fess was 38 years at the time of her hysterectomy. She works as an administration officer and has three children and is separated from her husband. She had an emergency caesarean due to placenta accrete and a total hysterectomy.</td>
</tr>
</tbody>
</table>
APPENDIX G: PARTICIPANT INFORMATION SHEET

Project Title: Women's lived experience: Life after a hysterectomy following a severe postpartum haemorrhage

Who is carrying out the study?
Rakima Elmir to fulfil the requirements for the degree of Doctor of Philosophy. Supervised by Associate Professor Virginia Schmid, professor Debra Jackson and Professor Lesley Wilkes.

The research will form the basis for the degree of Doctor of Philosophy at the University of Western Sydney under the supervision of associate Professor Virginia Schmid, Professor Lesley Wilkes Dean of research and Professor Debra Jackson research coordinator.

What is the study about?
The purpose is to investigate and explore the lived experience of women who have undergone a postpartum haemorrhage and subsequent hysterectomy. This research study aims to uncover the concerns and issues women face in the aftermath of a hysterectomy following a severe postpartum haemorrhage.

What does the study involve?
The study will involve you to participate in a digitally recorded face-to-face interview at a time and place convenient to you.

How much time will the study take?
Interviews will be approximately 1-2 hours in length

Will the study benefit me?
You may find it beneficial talking about your experience to a researcher.

Will the study involve any discomfort for me?
The study may cause you some discomfort as you re-live your experience. You may experience feelings of becoming upset, anxious and anguish. A list of counselling services and community centres/agencies will be given to you.

How is this study being paid for?
The study is being sponsored by the University of Western Sydney
Will anyone else know the results? How will the results be disseminated?
A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report. On completion of the research study, you are welcome to receive information on the findings of the research.

Can I withdraw from the study?
Participation is entirely voluntary: you are not obliged to be involved and - if you do participate - you can withdraw at any time without giving any reason and without any consequences.

Can I tell other people about the study?
Yes, you can tell other people about the study by providing them with the chief investigator's contact details. They can contact the chief investigator to discuss their participation in the research project and obtain an information sheet.

What if I require further information?
When you have read this information, Rakime will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact Rakime (principal researcher), on 0433244080 or email 12240667@student.uws.edu.au

What if I have a complaint?
This study has been approved by the University of Western Sydney Human Research Ethics Committee. The Approval number is [H778]

If you have any complaints or reservations about the ethical conduct of the research, you may contact the Ethics Committee through the Office of Research Services on Tel 02-4731 0083 Fax 02-4730 0013 or email humanethics@uws.edu.au. Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

If you agree to participate in this study, you will be asked to sign the Participant Consent Form.
APPENDIX H: PARTICIPANT CONSENT FORM

Participant Consent Form

Project Title: Women's lived experience: Life after a hysterectomy following a severe postpartum haemorrhage

I, ____________________________, consent to participate in the research project titled 'Women's lived experience: Life after a hysterectomy following a severe postpartum haemorrhage.'

I acknowledge that:

I have read the participant information sheet (or where appropriate, 'have had read to me') and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s.

The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.

I consent to the procedure of being involved in a face-to-face audio-taped interview.

I understand that my involvement is confidential and that the information gained during the study may be published but no information about me will be used in any way that reveals my identity.

I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher/s now or in the future.

Signed: ____________________________

Name: ____________________________

Date: ____________________________
# APPENDIX I: COUNSELLING SERVICES

## Family Counselling Services

<table>
<thead>
<tr>
<th>Name</th>
<th>Phone</th>
<th>Address</th>
<th>City</th>
<th>State</th>
<th>PC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aboriginal Family and Community Counselling Services</td>
<td>0410539905</td>
<td>Suite 4, 154 -156 Queen St</td>
<td>St Marys</td>
<td>NSW</td>
<td>2760</td>
</tr>
<tr>
<td>Auburn Community Health Centre</td>
<td>02 9646 2233</td>
<td>9 Northumberland Road</td>
<td>Auburn</td>
<td>NSW</td>
<td>2144</td>
</tr>
<tr>
<td>Blacktown Community Health Centre</td>
<td>02 9881 8700</td>
<td>Unit 1, Cnr. Marcel Cres and Blacktown Rd</td>
<td>Blacktown</td>
<td>NSW</td>
<td>2148</td>
</tr>
<tr>
<td>Mt Druitt Community Health Centre</td>
<td>02 9881 1200</td>
<td>Cnr. Burran Cl and Kelly Cl</td>
<td>Mt Druitt</td>
<td>NSW</td>
<td>2170</td>
</tr>
<tr>
<td>Hills Community Health Centre</td>
<td>02 8853 4500</td>
<td>183-187 Excelsior Ave</td>
<td>Castle Hill</td>
<td>NSW</td>
<td>2154</td>
</tr>
<tr>
<td>Merrylands Community Health Centre</td>
<td>02 9682 3133</td>
<td>14 Memorial Ave</td>
<td>Merrylands</td>
<td>NSW</td>
<td>2160</td>
</tr>
<tr>
<td>Parramatta Community Health Centre</td>
<td>02 9843 3222</td>
<td>158 Marsden St</td>
<td>Parramatta</td>
<td>NSW</td>
<td>2150</td>
</tr>
<tr>
<td>Dundas Community Health Centre</td>
<td>02 9638 6511</td>
<td>12 Sturt St</td>
<td>Dundas</td>
<td>NSW</td>
<td>2177</td>
</tr>
<tr>
<td>WSAHS Child Protection (PANOC) Team</td>
<td>02 9840 3880</td>
<td></td>
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<tr>
<td>Figtree Cottage Cumberland Hospital</td>
<td></td>
<td>11 Hainsworth St</td>
<td>Westmead</td>
<td>NSW</td>
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<tr>
<td>Lower Mountains Family and Adolescent Counselling</td>
<td>02 4754 5411</td>
<td>PO Box 161</td>
<td>Springwood</td>
<td>NSW</td>
<td>2777</td>
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<tr>
<td>Lifeline 24 Hour Counselling</td>
<td>131114</td>
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# Church Based Counselling Services

<table>
<thead>
<tr>
<th>Name</th>
<th>Phone</th>
<th>Address</th>
<th>City</th>
<th>State</th>
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<tr>
<td>Anglicare Counselling</td>
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<td></td>
</tr>
<tr>
<td>Ashfield</td>
<td>02 9799 931156</td>
<td>Bland St</td>
<td>Ashfield</td>
<td>NSW</td>
<td>2131</td>
</tr>
<tr>
<td>Bondi Beach</td>
<td>02 9799 9311</td>
<td>60 Wairoa Ave</td>
<td>Bondi Beach</td>
<td>NSW</td>
<td>2026</td>
</tr>
<tr>
<td>Cabramatta</td>
<td>02 9728 0200</td>
<td>40 Cumberland St</td>
<td>Cabramatta</td>
<td>NSW</td>
<td>2166</td>
</tr>
<tr>
<td>Campbelltown</td>
<td>02 4621 6666</td>
<td>1 Reddall St</td>
<td>Campbelltown</td>
<td>NSW</td>
<td>2560</td>
</tr>
<tr>
<td>Moss Vale</td>
<td>02 4868 1780</td>
<td>471 Argyle St</td>
<td>Moss Vale</td>
<td>NSW</td>
<td>577</td>
</tr>
<tr>
<td>Mt Druitt</td>
<td>02 4731 6467</td>
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<td>Mt Druitt</td>
<td>NSW</td>
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<tr>
<td>Narrabeen</td>
<td>02 9799 9311</td>
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<td>Narrabeen</td>
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</tr>
<tr>
<td>Newtown</td>
<td>02 9799 9311</td>
<td></td>
<td>Newtown</td>
<td>NSW</td>
<td></td>
</tr>
<tr>
<td>Nowra Family Relationship Centre</td>
<td>02 4429 1400</td>
<td>38-44 Berry St</td>
<td>Nowra</td>
<td>NSW</td>
<td>2541</td>
</tr>
<tr>
<td>Parramatta</td>
<td>02 9895 8181</td>
<td>Ground Floor 18 Parkes St</td>
<td>Parramatta</td>
<td>NSW</td>
<td>2150</td>
</tr>
<tr>
<td>Penrith</td>
<td>02 4731 6467</td>
<td>161 Derby St</td>
<td>Penrith</td>
<td>NSW</td>
<td>2750</td>
</tr>
<tr>
<td>Rouse Hill</td>
<td>02 4731 6467</td>
<td></td>
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</tr>
<tr>
<td>Nowra &amp; Outreach Centres</td>
<td>02 4423 1018</td>
<td>Sussex Inlet</td>
<td>Ulladulla</td>
<td>NSW</td>
<td></td>
</tr>
<tr>
<td>Bega, Berry, Bomaderry, Huskison Moruya, Nowra, Sanctuary Point</td>
<td>02 4228 9612</td>
<td>152 Keira St</td>
<td>Wollongong</td>
<td>NSW</td>
<td>2500</td>
</tr>
<tr>
<td>Wollongong</td>
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<tr>
<td>Catholic Care</td>
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</tr>
<tr>
<td>Illawarra</td>
<td>02 4227 1122</td>
<td>25-27 Auburn Street</td>
<td>Wollongong</td>
<td>NSW</td>
<td>2500</td>
</tr>
<tr>
<td>Name</td>
<td>Phone</td>
<td>Address</td>
<td>City</td>
<td>State</td>
<td>PC</td>
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<tr>
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</tr>
<tr>
<td>Macarthur</td>
<td>02 4628 0044</td>
<td>35A Cordeaux Street</td>
<td>Campbelltown</td>
<td>NSW</td>
<td>2560</td>
</tr>
<tr>
<td>Shoalhaven</td>
<td>02 4421 8248</td>
<td>68 Shoalhaven Street</td>
<td>Nowra</td>
<td>NSW</td>
<td>2541</td>
</tr>
<tr>
<td>Family Services Sydney</td>
<td>02 9390 5366</td>
<td>Level 13, 133 Liverpool St</td>
<td>Sydney</td>
<td>NSW</td>
<td>2000</td>
</tr>
<tr>
<td><strong>Salvation Army Counselling</strong></td>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Brisbane</td>
<td>07 3349 5046</td>
<td>5/46 Mt Gravatt-Capalaba Rd</td>
<td>Upper Mount Gravatt</td>
<td>QLD</td>
<td>4122</td>
</tr>
<tr>
<td>Brisbane North</td>
<td>07 3349 5046</td>
<td>32-54, Hayward St</td>
<td>Stafford</td>
<td>Qld</td>
<td>4053</td>
</tr>
<tr>
<td>Campbelltown</td>
<td>02 4731 1554</td>
<td>27-31 Rudd Rd</td>
<td>Leumeah</td>
<td>NSW</td>
<td>2560</td>
</tr>
<tr>
<td>Canberra</td>
<td>02 6248 5504</td>
<td>Suite 3, Southwell Park Offices, Montford Cres,</td>
<td>North Lyneham</td>
<td>ACT</td>
<td>2602</td>
</tr>
<tr>
<td>Penrith</td>
<td>02 4731 1554</td>
<td>20-24 Castlereagh St</td>
<td>Penrith</td>
<td>NSW</td>
<td>2750</td>
</tr>
<tr>
<td>Sydney</td>
<td>02 9743 2831</td>
<td>15-17 Blaxland Rd</td>
<td>Rhodes</td>
<td>NSW</td>
<td>2138</td>
</tr>
<tr>
<td>Tuggeranong</td>
<td>02 6248 5504</td>
<td>Cnr Anketell &amp; Reed Sts</td>
<td>Tuggeranong</td>
<td>ACT</td>
<td>2602</td>
</tr>
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### Information and Referrals

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<tr>
<th>Name</th>
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</tr>
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<tbody>
<tr>
<td>Mental Health Information and referral</td>
<td>1800 674 200</td>
</tr>
<tr>
<td>Aboriginal Children’s Services</td>
<td>02 9698 2222</td>
</tr>
<tr>
<td>NSW Family Services INC.</td>
<td>02 8512 9850</td>
</tr>
<tr>
<td>Blacktown</td>
<td>02 9621 6633</td>
</tr>
<tr>
<td>Hills/Holroyd/Parramatta</td>
<td>02 9687 9901</td>
</tr>
</tbody>
</table>
APPENDIX J: DEMOGRAPHIC QUESTIONNAIRE

Demographic profile

- What is your age?
- What is your occupation?
- What is your marital status?
- How many children do you have? And how old are they?
- What nationality or ethnic background?
- What suburb do you live in?
- What level of education have you reached?

Birth Experience

(The following questions may be asked following the interview)

- How long has it been since the event?
- Did you have your last baby by normal delivery or caesarean section?
- Have you had a total or subtotal hysterectomy?
- Are you currently on any medication or treatment as a result of the hysterectomy?
APPENDIX K: INTERVIEW SCHEDULE

Interview Questions

Describe what first comes to your mind when you recall your experience of having a severe bleed following the birth of your baby?

Prompt: Tell me a bit more about what you recall following the severe bleed?

- How did having a hysterectomy following the severe bleed affect you physically? For example in carrying out daily activities, including caring for the baby.

- How did you feel in relation to losing your uterus?

- Describe your relationship with your partner / husband following your hysterectomy experience.

- Following the hysterectomy, tell me about the early relationship you developed with the baby? Describe the impact of the surgery on this relationship?

- Describe the support you received from health professionals following the hysterectomy?
• Describe the impact that this event has had on other relationships with family and friends?

• Were you referred to any form of support network? Describe the pros and cons of this support system? Has it been helpful?

• If not referred, what benefits do you perceive to have gained?
APPENDIX L: LETTER OF ACCEPTANCE

NURSE RESEARCHER

Dear Rakime

Re: The strategies and benefits of in-depth research interviews on sensitive topics – Article ref: NR177

Thank you for your article, which I am pleased to accept for a future edition of Nurse Researcher. It is now assumed that this article will be solely published in Nurse Researcher and not submitted elsewhere, if this is not the case, please inform the editor immediately. Please note that in common with all professional publications your article will undergo editorial changes before going to print, which may include changes to headlines and summaries. I can offer you a fee of £90 payable six to eight weeks following publication. A complimentary copy of the issue will be sent to each author following publication.

Please find attached an author details and publisher’s agreement form for you to complete and return. Because of the large number of articles awaiting publication, it may take around eighteen months before your article is published. You will get a chance to update if necessary at the proof stage.

Helen Hyland
Administration Manager - Specialist Journals

RCN Publishing Company
The Heights, 59-65 Lowlands Road, Harrow-on-the-Hill, Middlesex HA1 3AW
Tel: 020 8872 3138
Fax: 020 8872 3198
Email: helen.hyland@rcnpublishing.co.uk
Dear Rakime,

I am pleased to inform you that your paper "Between life and death: women’s experiences of coming close to death, and surviving a severe postpartum haemorrhage and emergency hysterectomy." has been accepted for publication in Midwifery.

Thank you for submitting your work to Midwifery.

Yours sincerely,

Debra Bick, BA, MMedSc, PhD, RM
Editor-in-Chief
Midwifery
APPENDIX N: LETTER OF ACCEPTANCE

JOURNAL OF CLINICAL NURSING

Dear Mrs. Elmir,

It is a pleasure to accept your manuscript entitled "Separation, failure and temporary relinquishment: women’s experiences of early mothering in the context of emergency hysterectomy" in its current form for publication in the Journal of Clinical Nursing.

Please find attached your manuscript, which I have edited so please do not make any further changes but address the highlighted queries and return by email attachment to jcneditor@hotmail.co.uk within 1 week of receiving this letter or at your earliest convenience. PLEASE USE THE ATTACHED VERSION TO MAKE AMENDMENTS AND RETURN AND DO NOT CHANGE BACK TO THE ORIGINAL ANY CHANGES THAT I HAVE MADE. If you have used a tracking facility for changes please remove all tracking and highlighting prior to returning your manuscript. NOTE, please save your final version in the same form as the one attached here, ie DATE-PAPER NUMBER (eg 2008-1234) and also send it to me using the ‘Reply’ facility in your email; this way it is very easy for us to keep track of your paper and send it to production.

The manuscript is accepted pending attention to any changes indicated and any of the aspects outlined below, if relevant:

TABLES AND FIGURES - please incorporate these into the main document (after the references).

ABSTRACT - please check that this is in the style of the journal with ‘Aims’ first and ‘Relevance to Clinical Practice’ last. Followed by Keywords.

KEYWORDS - (up to 6 words relevant to the paper). To be placed at the end of your
structured abstract, at the beginning of your manuscript (main document) file. This is a requirement so that your paper can be easily cited after acceptance.

DISCUSSION – please ensure that any limitations to the study are explained and that there is a sub-heading ‘Relevance to Clinical Practice’.

REFERENCES - please pay attention to the following and make amendments where necessary prior to final submission. When citing references with more than two authors in the text the first author should be named followed by ‘et al.’ from the first citation. ‘et al.’ should be presented in italics followed by a full stop only. Where more than one reference is being cited in the same pair of brackets the reference should be separated by a comma; authors and dates should not be separated by a comma, thus (Smith 1970, Jones 1980). Where there are two authors being cited in brackets then they should be joined by an ‘&’, thus (Smith & Jones 1975).

CONTRIBUTIONS - please make sure that ALL authors who have contributed to the paper and who are listed as authors put their initials to at least one of the following; these should be listed as follows at the end of the manuscript, prior to the references.

Study Design:
Data Collection and Analysis:
Manuscript Preparation:

ACKNOWLEDGEMENTS - should be inserted at the end prior to the references, the manuscript will not be seen by any more reviewers and so anonymity is no longer required.

HEADINGS AND SUB-HEADINGS - please present headings of original articles in the manuscript in bold capitals, sub-headings in lower-case and bold, and subsequent headings in italics. Headings must follow the following pattern:

INTRODUCTION (putting the paper in context - policy, practice or research);
BACKGROUND (literature);
METHODS (design, data collection and analysis);
RESULTS;
DISCUSSION (Results and discussion may be combined in qualitative papers);
CONCLUSION;
RELEVANCE TO CLINICAL PRACTICE.

Review articles headings should be presented as follows:

INTRODUCTION
AIMS AND METHODS
RESULTS
DISCUSSION
CONCLUSION
RELEVANCE TO CLINICAL PRACTICE.

CONFLICT OF INTEREST - It is important to make sure that this statement is included within the manuscript (whether you have any to declare or not), after the contributions, before the references.

COPYRIGHT TRANSFER AGREEMENT - If you haven’t done so already, please complete the form located here: www.wiley.com/go/ctaaglobal and return to the Editorial Assistant Rosalind Thomson 9600 Garsington Road, Oxford, OX4 2DQ UK.

IN PRESS PAPERS - if any have been cited, can you make sure that, if this is accepted by the time of proof, you give the full details; if that is not possible can you provide us with proof that the paper has been accepted; failing that please refer to it as unpublished.

As part of the Journal’s continued commitment to its authors, the Editorial Office and Publisher wish to keep you informed about what will happen next and, as the attached document contains important information regarding journal publication and services for authors, you may wish to save it for future reference.

For your information and to save you contacting the editorial office enquiring as to
the publication status of your paper, please note that currently the average time from acceptance to publication is approximately 9 months. In accepting your paper, both JCN and Wiley-Blackwell give no commitment about date of publication. Therefore, while we can inform you of a likely date in the event of an enquiry, we are unable to accommodate individual requests to have papers published at a particular time to coincide with, for example, the requirements of grant awarding bodies or promotion boards.

Thank you very much for your patience and we would like to re-assure you that we are working to reduce the length of time it takes to publish accepted papers.

Please note that due to the volume of submissions received by the Journal we are unable to send out any letters of acceptance. However, please accept this e-mail, pending final submission of your paper, as proof of acceptance by JCN.

Thank you for your contribution, we look forward to your continued contributions to the Journal.

Yours sincerely,

Prof. Roger Watson
Editor-In-Chief, Journal of Clinical Nursing
Dear Mrs Elmir,

I am pleased to tell you that your work has now been accepted for publication in International Journal of Childbirth.

It was accepted on Jan 08, 2012

Comments from the Editor and Reviewers can be found below.

Thank you for submitting your work to International Journal of Childbirth.

With kind regards

Kerri Schuiling, PhD

Editor-in-Chief

International Journal of Childbirth

Comments from the Editors and Reviewers:

Thank you for attending to the questions and comments from the peer reviewers. Elements of the paper are now much clearer and I believe the paper will be better understood by our readers.
Call for women to participate in study on the emotional impact of hysterectomies

Note: 29/04/2009

A new University of Western Sydney study will reveal the emotional and physical experiences of women who have undergone a hysterectomy following severe bleeding during childbirth.

School of Nursing and Midwifery PhD candidate, Mrs Rakime Elmir is seeking women who have had a severe postpartum haemorrhage (PPH) to participate in confidential face-to-face or Internet-based interviews.

PPH is a life-threatening condition in which women suffer excessive blood loss during the first 24 hours after childbirth and can result in the patient requiring a hysterectomy.

"The incidence of PPH in Australia is between five and 10 per cent of all births, but it has been increasing over the past decade," says Mrs Elmir.

"However, to date there has been very little research on the impact this traumatic experience has on women in the longer term."

Anecdotally, PPH has devastating consequences for women.

"Women can have difficulties establishing and initiating breastfeeding, bonding with their baby and their relationship with their partner can be affected."

"Their self image or perception of their own bodies can also be changed," she says.

Mrs Elmir says the responses collected in the study and the analysis of the data will be used to shape future medical services and support.

"The insight achieved from talking to women about these deeply personal thoughts and emotions will help build the knowledge needed for women's support networks and enhance the level of care offered by health services."

To participate in the study contact: RakimeElmir@uws.edu.au

Ends

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