



## **Doing time: The experiences for women hospitalised for an extended time in pregnancy**

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for the degree of Masters Health Science (MHsc).

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## **Abstract**

Pregnancy and childbirth are regarded as physiological processes that usually follow a normal pathway to a positive outcome for mother and baby. For some women, this normal process is interrupted by a complication arising in their pregnancy causing the pregnancy to be reclassified as high-risk. A high-risk pregnancy often requires the woman to be hospitalised with bed rest, prescribed for varying amounts of time, until either the condition has resolved, or the baby is born safely.

There has been some international research exploring the effects bed rest has on the physiological and psychological health of women. However, there are few studies, particularly in New Zealand, that explore the experiences of hospitalised women once they have safely birthed their baby and returned home. This hermeneutic phenomenological study aims to explore the experiences of women hospitalised for an extended time in their pregnancy, once they are discharged home. The expectation is to uncover any detrimental effects this may have had on the women's postnatal well-being.

Seven women from three District Health Boards in New Zealand were interviewed about their experience of being hospitalised for an extended time in their pregnancy. The women of this study were hospitalised for a period of between two and twelve weeks antenatally and from two days to two weeks postnatally. The women's interviews were transcribed verbatim, written, read and re-read. van Manen's (2016) methodological framework of the lifeworld existentials were used to analyse the data. Four themes emerged from this analysis: 'feeling unsafe', 'feeling displaced', 'doing time-being imprisoned', and 'coming out the other side'.

The findings of this thesis suggest that extended hospitalisation during pregnancy caused women to feel like prisoners with no control over their bodies, time, or decisions. These experiences had a long-term effect on the women's mental well-being reaching into the postnatal period and beyond.

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## **Attestation of Authorship**

“I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.”

Signed:

Dated: 17/07/2019

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# Chapter One. Orientation to the Study

## Introduction

The aim of this study is to explore the lived experiences of women who have spent a long period of their pregnancy in hospital. This study considered the possible effect extended hospitalisation has on the women, their families, and their experiences of the New Zealand maternity health system. There is some international research on women's experiences of bed rest and hospitalisation; however, no studies exploring the experiences of New Zealand women. The New Zealand perspective of maternity services, including pregnancy, birth, and the postnatal period is unique, and may provide different insights into the experience of long-term hospitalisation in pregnancy. This hermeneutic phenomenological study explored the lived experiences of seven women who had spent from two to twelve weeks in a New Zealand hospital during their pregnancy. The participants were interviewed in the postnatal period from four weeks to one year after having baby. The expectation is that the impact of these experiences will provide a basis on which to inform maternity services on improving the experience and satisfaction for women and their families, when the women are hospitalised in pregnancy.

This chapter outlines the research question, background, and justification for the study; along with a brief overview of maternity care in New Zealand and the process of referral. High-risk pregnancy and some complications of pregnancy are explored, and the admission process to a maternity ward described. An outline of the thesis structure will be presented, as well as the impetus for the study and my personal history in relation to the research.

## Research question and aims of the study

This study sought to answer the question: *“What is the experience for women hospitalised for an extended time in their pregnancy.”*

The aim of the study was to explore and understand the participants' experiences of being hospitalised for an extended time during their pregnancy. It is the intention of this study to uncover any positive or negative impact on the participants and their families. Understanding the impact of these women's experiences offers the opportunity to explore what health professionals' practices were beneficial or disadvantageous to the

participants' experience. Identifying the positive or negative impact would then provide an opportunity to recommend improvements in the health sector to ensure the experience for women and their families, in this situation, is beneficial.

## **Background for the study**

Hospitalisation and/or bed rest in pregnancy is recommended by specialist obstetricians and has been used extensively world-wide. It is prescribed for women with high-risk pregnancies; for example, in the prevention of preterm labour, multiple pregnancies, obstetric or existing medical conditions (Crowther & Han, 2010; Meher, Abalos, & Carroli, 2005; Sosa, Althabe, Belizan, & Bergel, 2015). However, extensive research over the last 30 years suggests that bed rest to prevent preterm labour, preeclampsia, or in uncomplicated multiple pregnancies, is not beneficial and has, in some circumstances, had adverse effects on the women and babies (Crowther & Han, 2010; Maloni, 1993, 1994; Maloni, Brezinski-Tomasi, & Johnson, 2001; Maloni et al., 1993; Maloni & Kasper, 1991; Meher et al., 2005; Sosa et al., 2015). Some high-risk pregnancies do benefit from hospitalisation. These pregnancies are ones in which either mother and/or baby are at risk of serious morbidity or mortality. Preterm birth<sup>1</sup> is one of the most common causes of neonatal morbidity and mortality and accounts for 7.5% of live births in New Zealand (Howie & Marshall, 2017). Serious pregnancy complications such as from pre-eclampsia or HELLP (Haemolysis, Elevated Liver enzymes, Low Platelets) syndrome are often the cause of maternal morbidity and mortality (Howie & Marshall, 2017). In normal pregnancies, the woman is cared for in partnership with her Lead Maternity Carer (LMC). When a pregnancy becomes high-risk, the LMC is able to handover care to the relevant health professionals.

## **Maternity care in New Zealand**

Maternity care in New Zealand is funded by the Ministry of Health (MOH) and is provided free to New Zealand citizens. Pregnant women can choose a (LMC) for their maternity experience (Guilliland & Tracy, 2019). The definition of a LMC in New Zealand is a health professional who provides maternity care from early pregnancy, labour and birth, and up to six weeks postnatally (Midwifery Council, 2015). A LMC may be a midwife, based in the community or a hospital, General Practitioner (GP),

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<sup>1</sup> Preterm is the terminology used for a baby born before 37 completed weeks gestation. The World Health Organization (WHO) further defines preterm as: <28 weeks, extreme preterm, 28-<32 weeks, very preterm and late preterm as 32 to <37 weeks gestation (Howie & Marshall, 2017).

with a diploma in obstetrics, or a private obstetrician. Ninety two percent of women in New Zealand choose a community-based midwife as their LMC (MOH, 2019b). In New Zealand, the LMC is responsible for all primary care related to the woman's pregnancy, labour, birth, and postnatal care for four to six weeks. An LMC will care for the woman while her pregnancy remains low-risk or is classed as primary care (Guilliland & Tracy, 2019).

New Zealand maternity care is a unique model introduced in the early 1990s due to a rise in consumer demand for more choice in their maternity options. A change in legislation restored midwives' right to be autonomous practitioners able to provide primary care to women (Midwifery Council of New Zealand, 2010). Midwives are registered with the Midwifery Council of New Zealand and are able to provide maternity care under the Maternity Advice notice, more commonly called Section 88, of the New Zealand Public Health and Disability Act 2002 (Guilliland & Tracy, 2019). LMC midwives provide continuity of care, working in partnership with women and their whānau<sup>2</sup> from early pregnancy, labour, birth, and up to six weeks postnatally (MOH, 2019b). During any stage of the pregnancy, labour, birth, or postnatally, if the midwife identifies the woman or baby is at risk, they will consult with the appropriate health professional within the maternity services of the District Health Board (DHB<sup>3</sup>) in which they reside (MOH, 2012). In New Zealand, the MOH (2012) provides guidelines for the provision of consultation in the *Guidelines for Consultation with Obstetric and Related Medical Services*.

## **Referral and consultation practice in New Zealand**

Although the vast majority of pregnancies, labours, and births in New Zealand are regarded as within the scope of 'normal,' there are some that will fall, at any stage in the maternity experience, into the 'at risk' or 'high risk' category (Skinner, 2011). For many women, this may mean their LMC consults with the appropriate health professional. At this point, the woman either remains under the care of her LMC or primary caregiver, or a referral made for her care to be transferred to an appropriate health professional (Skinner, 2011).

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<sup>2</sup> Whanau-New Zealand Maori term for family/extended family

<sup>3</sup> In New Zealand there are 20 DHBs—a publicly funded service with a common goal of improving public health. The DHBs differ in size and services offering secondary or tertiary level care to the population throughout New Zealand (MOH, 2011).

Under the *Guidelines for Consultation with Obstetric and Related Medical Services* (MOH, 2012), there are three levels of consultation or referral. In primary referral, the LMC discusses with the woman the need for consultation, such as smoking cessation services or advice from a lactation consultant. In a primary referral the ongoing management of the woman remains the responsibility of the LMC. A consultation referral requires the LMC to recommend the woman (or baby) have a consultation with a specialist. In this case, the LMC negotiates with the woman and specialist as the specialist does not automatically take over the care. A transfer referral occurs when the LMC must recommend the woman (or baby) be transferred to a specialist. The woman's care is then the responsibility of the specialist and the LMC may have a role within that process (MOH, 2012). LMC midwives often maintain contact with the woman and her family when her care is transferred into a secondary<sup>4</sup> or tertiary hospital<sup>5</sup>. However, when the care has been transferred to a tertiary hospital, the LMC is no longer involved in the decision making. Care is often transferred back to the LMC when the condition has resolved or baby has been born; thus, providing a continuity of care (Skinner, 2011).

### **High-risk pregnancy**

During pregnancy, some women may experience uncomfortable and inconvenient symptoms that are mild and transitory, which are usually referred to as 'minor disorders of pregnancy.' Such symptoms can include; nausea and vomiting, heartburn, backache, constipation, and fatigue (Patrick, 2017b). A high-risk pregnancy, however, is defined as one in which the health and life of the mother, fetus, or both is threatened by a disorder coinciding with, or unique to, pregnancy (Richter, Parkes, & Chaw-Kant, 2007). Some women experience much more complicated conditions or complications in their pregnancy and these complications are often the cause of preterm birth. Conditions that require transfer of care to a specialist vary; although there are some common pregnancy complications that require women to be hospitalised for varying lengths of time (Richter, et. al., 2017).

The participants of the current study were hospitalised following vaginal bleeding due to placenta praevia, preeclampsia, prolonged rupture of membranes, shortened

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<sup>4</sup> A secondary hospital refers to a hospital that provides 24 hour acute services, including (but not limited to) general medical and surgical services, diagnostic facilities, and speciality services such as maternity, paediatrics, and community care (MOH, 2011).

<sup>5</sup> A tertiary hospital is a hospital that provides all the services of a secondary hospital plus a greater number of specialised services including sub-specialities, public health services, primary response services, and forensic mental health units (MOH, 2011).

cervix/threatened preterm labour, monoamniotic twins, and a non-pregnancy related condition—gall stones with chronic pain. Following is a brief overview of these conditions.

### **Placenta praevia/vaginal bleeding in pregnancy**

Any bleeding from the vagina during pregnancy is considered abnormal. In early pregnancy, implantation bleed, miscarriage, and some infections cause bleeding and is of concern. Vaginal bleeding that occurs later in pregnancy, from twenty four weeks, is called an ‘antepartum haemorrhage’ and can be a serious complication. The main causes of antepartum haemorrhage are from the placenta. A placenta that is implanted in the lower segment of the uterus is called ‘placenta praevia’ and can vary in severity (Patrick, 2017a). Clinical management for antepartum bleeding depends on the severity of the blood loss. Mild to moderate blood loss is treated conservatively, usually in a hospital, with the intention to monitor blood loss, maternal and fetal condition, until at least thirty eight weeks’ gestation to avoid a preterm baby (Patrick, 2017a).

### **Preeclampsia**

Pre-eclampsia is a condition of pregnancy where the maternal blood pressure becomes abnormally high, along with significant protein present in the urine. Severe pre-eclampsia is diagnosed if there is also biochemical or haematological involvement and the woman becomes symptomatic. As with bleeding in pregnancy, moderate to severe pre-eclampsia can be managed conservatively with hospitalisation. Women and their babies are monitored closely while hospitalised with the intention to prolong the delivery until at least 38 weeks to prevent a preterm baby (McEwan, 2017).

### **Premature prolonged rupture of membranes (PPROM)**

PPROM is defined as a breaking of the amniotic sac surrounding baby before 37 weeks gestation for >than 24 hours without labour beginning. PPRM is associated with an increased risk of infection, placental abruption, cord prolapse, and prematurity (Buchanan, Crowther, & Morris, 2004). Keeping the woman and baby safe includes hospitalisation with monitoring for signs of infection and/or fetal compromise.

Timing of delivery depends on how prematurely the membranes ruptured and the health of both woman and baby, as some research has shown that long term expectant management has an increased risk of maternal infection (Buchanan et al., 2004). Generally aiming for birth at >37 weeks gestation is preferred to prevent a preterm

infant (Buchanan et al., 2004). New Zealand DHBs have protocols and guidelines in place to ensure the protection of women and babies is paramount, though exact management may vary (Auckland DHB, 2015).

### **Monoamniotic twins and cord entanglement**

Monoamniotic twins are identical and share the same placenta and amniotic sac, creating a high perinatal mortality risk due to cord entanglement. The risk of cord entanglement and fetal mortality has been reported as high as 42% (Dias, Mahsud-Dornan, Bhide, Papageorghiou, & Thilaganathan, 2010). Expectant management with intensive monitoring from 20 weeks gestation is reported to have a high success rate despite cord entanglement. Often preterm delivery via caesarean is recommended to avoid the risk of further entanglement and fetal mortality. However, with close monitoring, avoiding very preterm delivery is possible (Dias et al., 2010).

### **Shortened cervix and the risk of preterm labour**

The cervix of a pregnant woman is normally 2.5-3 cm in length and closed until nearing term where it begins to soften, shorten, and open. In some pregnancies, premature shortening of the cervix can occur. This can lead to premature rupture of membranes, premature labour and birth (Abbott, To, & Shennan, 2012). Treatment to prevent preterm birth can be cervical cerclage—a stitch is surgically placed in the cervix and removed once labour begins (Higgins, Kornman, Bell, & Brennecke, 2004). If there are no other risk factors, then expectant management is preferred. This involves hospitalisation and bed rest with ultrasound monitoring of the cervical length and the treatment of vaginal progesterone pessary (Alfirevic et al., 2013).

### **Gallbladder and pancreatic disease in pregnancy**

Gallbladder disease, most commonly caused by gallstones, is uncommon in pregnancy; however, it is the most common surgical intervention occurring in pregnancy.

Pancreatitis (infection of the pancreas) has an increased risk of maternal and fetal morbidity. Management of these diseases in pregnancy is often conservative. Women are provided with pain relief during episodes of ‘biliary colic,’ surgical options are usually not considered unless in first or third trimester when the risks of spontaneous preterm labour are less likely to occur (Angelini, 2002).

For the conditions discussed above, in an effort to prevent preterm birth or worsening condition of mother or baby, the current recommendation is for the woman to be

hospitalised, in some cases on strict bed rest. Often the hospitalisation will be until baby can be safely born which, for some conditions, can require an extended hospital stay. A brief history of hospitalisation and bed rest in pregnancy will be discussed below.

### **History of bed rest in pregnancy**

Bed rest to prevent preterm birth or to protect multiple pregnancy has been used for many years, despite 30 years of research suggesting that the harm outweighs the benefits (Meher et al., 2005). A plethora of research since the 1990s has explored the numerous physical and psychological side effects from bed rest in pregnant women. These side effects included muscle wastage, deconditioning, risk of deep vein thrombosis, and dysphoria (Maloni, 1993, 1994; Maloni, et. al., 2001; Maloni et al., 1993; Maloni, Kane, Suen, & Wang, 2002; Maloni & Kasper, 1991; Maloni & Park, 2004; Maloni, Park, Anthony, & Musil, 2005; Maloni & Ponder, 1997). Cochrane reviews have found bed rest is not beneficial for woman whose pregnancy is high-risk with non-life-threatening complications (Crowther & Han, 2010; Dowsell, Middleton, & Weeks, 2009; Meher et al., 2005; Sosa et al., 2015). The review studies' inclusion criterion was only randomized control trials. For each review, two to seven studies met these criteria and all four Cochrane reviews found that there was no clear evidence supporting or refuting bed rest in pregnancy. Bed rest is still extensively used as a treatment for preterm labour, preterm rupture of membranes, hypertension, and multiple pregnancy (Sosa et al., 2015).

### **Admission to a New Zealand maternity ward**

There are some serious conditions that occur in pregnancy, such as those described above, that would require a woman to be referred, care transferred, and admitted to either a secondary or tertiary maternity ward under specialist obstetric care. Initially, the woman would either be reviewed by her LMC or, in the incidence of severe pain or bleeding, may self-admit through the emergency department (ED). Once a primary assessment is done, and the woman's care has been transferred to specialist obstetric care, she is admitted to the maternity unit. New Zealand midwives provide continuity of care; however, in the case of the care being transferred to the hospital due to a complication, the midwife would hand over care to the specialists (Skinner, 2011). The midwife may still remain in contact with the women but will have no clinical decision-making ability until care is transferred back. The health professionals caring for the

woman once admitted will be midwives, obstetricians, physicians, paediatricians, and other health professionals as required (Skinner, 2011).

New Zealand midwives working within a DHB are known as core midwives, defined as a registered midwife employed within a DHB. Core midwives fill a wide variety of roles within a facility working across the service in high-risk maternity antenatal, birthing, and postnatal (Gilkison, McAra-Couper, Fielder, Hunter, & Austin, 2017). Core midwives provide the same level of care as LMC midwives, working in partnership with the woman, ensuring she is kept informed and empowered to make decisions for herself. Core midwives often have a range of skills as their work encompasses primary to high-risk care, working within a multidisciplinary team (Gilkison et al, 2017).

The physical environment usually comprises of shared two or four bedded rooms with shared toilet and shower facilities. There is often some form of patient kitchen with a public fridge and microwave. Some hospitals provide tea/coffee making facilities for the women. There is usually a family/whanau lounge for visitors. Most hospitals have no outside area for patients and, if fresh air is needed, patients are expected to leave the hospital if they are able. Each DHB has its own maternity setting and can include specialist wards with only high-risk antenatal women, mixed postnatal/antenatal wards, or small separate antenatal assessment units.

## **Methodological overview of the study**

The methodological framework chosen for this qualitative research is hermeneutic phenomenology, informed by van Manen (1990). Phenomenological research explores the lived world of the human experience and is more a method of questioning than answering. The emphasis of phenomenology is on the meaning of the lived experience, borrowing from the participants' experiences to understand the meaning behind their experience (van Manen, 1990). Phenomenology is the best methodology for this research as its intent is to explore personal experiences. Hermeneutics is a word derived from Greek meaning 'to interpret' or 'to understand' by reading, writing, and re-reading the transcripts of the participants' experiences, finding meaning within (Crotty, 1998). Qualitative data collection differs from other data collection; there is less separation between gathering the data and analysis. With qualitative research, data collection and analysis may occur contemporaneously, to some extent (Gibbs, 2007). Data were analysed using the framework of van Manen's (1990) existential lived worlds; lived

body, lived space, lived relationality, lived time. The methodology and methods will be explored in depth in Chapter Three.

### **My interest in high-risk pregnancy**

My personal interest in exploring the experiences of women hospitalised due to high-risk pregnancies came initially from personal experience with my first pregnancy 30 years ago. The experience and subsequent hospitalisations for each pregnancy stays with me; I have never forgotten and often wondered if the parent I became was influenced by this time. When I became a midwife in my 40s, I initially enjoyed working with women within the normal pregnancy experience. After a short time, I found myself drawn to working in high-risk maternity. I was determined that the women hospitalised due to pregnancy complications would still have the midwife experience. I soon noticed that my personal experience may have differed—30 years ago there was no informed consent, as a young pregnant woman with a high-risk pregnancy condition I just did as I was told. Thankfully, in today's society, women appear to have more control over what is done and can question and challenge recommendations. Yet, even with this freedom, I soon noticed that women who were hospitalised for a significant amount of time became quiet, accepting, and appeared to become depressed.

Talking with the women I cared for in hospital, I found the impact of their experience resonated with me. As a midwife working in tertiary hospitals, I often cared for women for many weeks during their pregnancy. Often, we would develop a close professional relationship and the women would trust me to talk about their deepest fears and hopes for the future. I found I would be supporting them as they told me of their mental health changing and how hard they found the time in hospital. I would see them struggle with children visiting and then watched as they cried when their family had to leave. I became emotionally involved with the women I cared for and wanted to ensure their voices were heard and their challenges acknowledged.

One such woman made me realise that somehow things needed to change. Over one Christmas, I was working on the high-risk ward where a wonderful woman was with us for 12 weeks due to a pregnancy complication. She was cheerful and positive and needed each of us (midwives) to talk to her daily, catch her up on news, and what was happening in our lives. We all became attached to this woman and her pregnancy. Towards the 10<sup>th</sup> week she became depressed and was begging us to talk to the doctors

to “get this over with.” It was still too early for her baby to be born. The midwives, myself included, got her through with companionship and empowering her to make informed decisions. Eventually, her very small baby was born and she, at last, could go home; but her family and her mental health suffered. She kept in contact with a few of the midwives and it took a considerable amount of time for her to feel back to normal. I am forever grateful for her enthusiastic support of my research, although by the time I was searching for participants her baby was two years old and did not fit the inclusion criteria.

With my own experiences on my mind, while I was a midwife working with high-risk women, I began thinking about furthering my post-graduate experiences. After many discussions with midwives I was working with I was encouraged to further my exploration of maternity care in the New Zealand context. I changed the DHB I had been working in as I was overwhelmed providing care for the women such as the one discussed above. I had become so emotionally involved in these women’s lives while in-patients that I had to step away to gather my energy and renew my enthusiasm for midwifery. Shortly after, I began to consider undertaking a Masters degree and the challenges faced by women hospitalised in pregnancy became my focus. Reflecting on my own past experience of hospitalisation and the ongoing care of women in a similar situation became the obvious focus that led me to my question.

Following is a brief outline of the structure of my thesis.

## **Thesis structure**

### **Chapter One: Orientation to the study**

In this current chapter, I have detailed the research question and my personal motivation to study this subject. I have outlined the background of the study and briefly described high-risk pregnancy in the New Zealand context.

### **Chapter Two: Literature review**

This chapter explores the literature relevant to the current study. As a qualitative study, some of the literature was reviewed after the data analysis.

### **Chapter Three: Methodology and methods**

In this chapter I describe the methodology of hermeneutic phenomenology and van Manen's existential framework. The study design and methods are outlined.

### **Chapter Four: Introduction to the findings. Feeling displaced**

The women's experience of the challenges with being away from home are explored in this chapter.

### **Chapter Five: Feeling unsafe**

This chapter explores the participants' experiences of feeling unsafe while hospitalised.

### **Chapter Six: Doing time being imprisoned**

My first findings chapter begins with the theme feeling like they were imprisoned, doing time.

### **Chapter Seven: Coming out the other side**

In this chapter, the challenges faced by the women once they had given birth and were discharged home are explored.

### **Chapter Eight: Discussion**

This chapter situates the current research in relation to previous research. The implications for health professionals, healthcare facilities, and ongoing research are explored.

### **Summary**

This, the first chapter of the thesis, has provided the rationale for exploring the experience of women who are hospitalised during their pregnancy. The orientation to the research was described, along with my journey to undertaking this study. The New Zealand maternity system was outlined. High-risk pregnancy and some of the complications that the study participants experienced were described, along with an overview of the New Zealand referral and consultation process, and what admission to a maternity ward would be like for a woman. Methodology was outlined, as was a declaration of my interest. Lastly, a structure of this thesis was provided.

The following chapter will discuss and critique the literature reviewed for this research.

## Chapter Two. Literature Review

This chapter explores the literature relevant to hospitalisation in pregnancy. Reviewing the literature, prior to undertaking the study, assists with understanding the focus of the experience and identifies any gaps within the field of interest. van Manen (2016) also recommended examining the existing literature once data analysis has been completed. Examining existing human science research prior to beginning analysis of the data could influence the researcher's own interpretation. Thus, I ensured that the early literature review focused on the studies' approach and methods used to provide rich data, which further helped inform the study methodology.

This study focuses on the experiences of New Zealand women hospitalised in pregnancy as there is limited study of the experiences of New Zealand women in this context. Due to the unique nature of New Zealand's maternity system, women are cared for antenatally by midwives both in the community and if hospitalised. In the international context, antenatal care appears to be predominantly provided by specialist doctors, nurses, or nurse-midwives. This study may, therefore, provide a differing perspective.

Both the initial and subsequent reviews were carried out using international search engines: EBSCO, Medline, Wiley online, CINAHL, Cochrane database, and Google Scholar. The initial pre-data gathering search terms included: antenatal hospitalisation, bed rest, women's experience of hospitalisation in pregnancy, long term and extended hospitalisation, anxiety and depression in pregnancy. After data analysis, further searches were performed using the search terms: sleep in pregnancy, hospital environment, safety in healthcare, trust and privacy in healthcare, idealised motherhood, and risk perception in pregnancy and postnatal depression.

The initial review of the literature found extensive exploration of women's experiences of high-risk pregnancy and bed rest; the majority of studies conducted in the United States (US). The studies by Maloni (1993, 1994), Maloni et al. (1993), Maloni and Ponder (1997) and Schroeder (1996) focused on the physical and psychosocial effects of prescribed bedrest in pregnancy. Maloni et al.'s original study was conducted using pregnant women (n=35); 10 were on full bed rest, 7 on partial, and 18 normal pregnancies. Measurements included physical variations, such as muscle wastage and function, weight, and mental health. Mental health was measured using three different

checklists. Maloni and colleagues found significant negative physical effects that led to a longer postpartum recovery. A significant stressor was found to be separation from the family (Maloni et. al.,1993). This study was repeated by Maloni and Park (2004) in a longitudinal repeated measures study. Measurements were collected using a self-reporting Postpartum Symptom Checklist (PSC). The outcomes supported the prior study, with delayed physical recovery a common theme. Subsequent studies used similar mood state measurements of 63 pregnant women who had participated in a larger study earlier. These participants were required to complete two obstetric risk tools to ascertain the level of high levels of dysphoria found in previous studies (Maloni & Park, 2004). Maloni, Park, Anthony and Musil (2005) repeated the previous studies using a different depressive symptoms measurement instrument. Similar results were found despite the methodological difference.

Three further studies, around 1990, used a qualitative design exploring the experiences of women hospitalised on bed rest. These studies had smaller groups of women (12-24) and found the major stressors related to bed rest in pregnancy were; separation from family, perceptions of risk, the experience of time and restricted movement, lack of control, feeling like a prisoner, uncertainty, lack of privacy and loneliness (Gupton, Heaman, & Ashcroft, 1997; Heaman & Gupton, 1998; Maloni et al., 2005; Schroeder, 1996). These early studies focused on stressors of hospitalisation in pregnancy and less on what the women's' experiences were; thereby forming a search basis for the current study.

The studies reviewed were from countries globally, including the US, United Kingdom (UK), Iran, Australia, Canada, and France. Only three pieces of literature were from New Zealand; one of these was in regard to privacy in healthcare and, though not pregnancy related, was relevant to the concept of privacy while hospitalised (Malcom, 2005). The initial literature review at the commencement of this research consisted of 22 studies. After analysis of the data, a subsequent search and review was completed which revealed a further 37 studies.

The studies in the literature review used a varied number of participants, from 8 to 400. The majority of studies (n=29) were of a qualitative nature, using phenomenology, descriptive, interpretive, and grounded theory designs. The qualitative approach used semi-structured face to face interviews and focus groups. Six quantitative studies used multiple questionnaires (n=3-7) to answer their question, needing high numbers of

participants to reach their goals. There were two systematic/metasyntesis reviews of risk perception in pregnancy. Very few used hermeneutics for analysis, and most of the qualitative designs used thematic software to interpret data. Using data analysis software may not provide the in-depth analysis that hermeneutic analysis offers.

Four themes emerged from the 37 studies: 1) listening to the women's voices, 2) maternal identity, 3) lived space, and 4) antenatal and postnatal anxiety and depression. In the first theme, listening to the women's voices, I discuss the literature which explores women's experiences while hospitalised in pregnancy. The second theme explores maternal identity in pregnancy, idealised motherhood, and the effect on women's risk perception. In the third theme, lived space, the impact of the surrounding space in a hospital setting and the affect the environment can have on hospitalised women is discussed. In the fourth theme, I consider the literature which explores anxiety and depression in the maternal experience. The literature is compared and contrasted to discover any agreements or disagreements in the results. Following the discussion of the literature review themes there will be a conclusion.

### **Theme one: Listening to the women's voices**

Several different stressors were identified during the experience of women hospitalised in pregnancy and are described in the literature. These stressors have been identified under the following subheadings: loss of control, feeling a fraud, and restrictions and limitations.

#### **Loss of control**

Several of the studies reviewed, found that women hospitalised in pregnancy experienced a feeling of losing control. Using phenomenological designs, Doyle, Monga, Kerr, and Hollier (2004) and Richter et al. (2007) found that the women felt a loss control both of their bodies and their lives. The simple daily tasks of caring for themselves and their family were taken from them; and though they found themselves physically removed from their home life, they remained emotionally tied. The women of these studies found the worry of the burden they were placing on their family at home a major stressor while hospitalised (Doyle et al., 2004; Richter et al., 2007).

Leichtentritt, Blumenthal, Elyassi, and Rotmensch (2005) held 10 focus groups with Israeli women hospitalised for high-risk pregnancy. They found the women experienced a sense of loss and grief for their normal pregnancy. The women of this study also

experienced feelings of anger, frustration, fear, and anxiety. In the final analysis, Leichtentritt et al. identified a core theme underlying the women's entire experience and discovered a feeling of 'ambivalence' in the participants. The women felt hope and were confident they were doing the right thing, while torn by leaving their families behind (Leichtentritt et al., 2005).

Currie and Barber (2016) used inductive, semantic, qualitative analysis to understand the experiences of New Zealand women with medical complications in pregnancy. Currie and Barber utilised semi-structured interviews with 12 women with high-risk pregnancies, six of these women were hospitalised in their pregnancy. This study found the women described feelings of loss of control due to the unpredictability of their condition. The hospital stay caused feelings of being out of depth and helpless, leading to feeling disempowered. Women in this study found they could not advocate for themselves and handed over control of any decisions to family or the health professionals caring for them (Currie & Barber, 2016).

In contrast, in a grounded theory study by Bendix, Kjaergaard, and Zoffmann (2014), loss of control was an essential theme and the women felt trapped in their situation. However, for some women, handing over of control made them feel safer. If the control was handed over voluntarily, the women felt less stressed than if they felt control had been taken from them (Bendix et al.). The women felt helpless and dependent but did not feel a nuisance. Some of the women had a clear sense of the inevitability of loss of control of their lives and accepted this in order to protect their babies; however, others were impatient for the baby to be born so they could move forward (Bendix et al., 2014).

Rubarth, Schoening, Cosimano, and Sandhurst (2012) employed the phenomenology of lived experiences, using women's journaling of their experience while hospitalised in two large obstetric units in the US. Eleven women participated and the data were analysed using Colaizzi's (1978) data analysis. The women described a 'daily battle' leading to an overall imagery of 'war' to describe their experience (Rubarth et al.). "The war within" described the roller coaster of emotions the women felt with fear and worry for their family at home and for their fetus. The women in this study described the feeling of loss of control of their body and came to regard their bodies as 'failures,' which led the women to a process of self-blame as they searched to find a meaning for their complication (Rubarth et al., 2012).

Alcalde (2011) used a non-medical, feminist-based analysis to explore the experiences of women hospitalised on bed rest. Surveys were initially conducted with 25 participants, followed by 10 face to face interviews. The women of this study also reported the experience of loss of control that led to feeling their body had 'failed' them. Alcalde reported that the women felt they did not embody the culturally acceptable role of natural pregnancy. However, once reconciled to the reality of hospitalisation, the women began to make adjustments in their lives to accommodate the situation in which they found themselves. The women were reconciled to needing to be in hospital for the safety of their pregnancy, but this experience took away the women's idealised pregnancy. The women attempted to take back control of their lives through creating routines for the day, relying on the power of positive thinking, and resisting the sick role (Alcalde, 2011).

The negative emotions caused by being separated from family were found to be a major stressor for women hospitalised in pregnancy and for many of the women in the above studies, being hospitalised when they did not feel unwell caused them to feel an imposter.

### **Feeling a fraud**

Barlow, Hainsworth, and Thornton (2008) and Bendix et al. (2014) found that women who were hospitalised due to complications often felt like they should not be there. For many women, leaving home and family was not made easier when they felt well or had no visible symptoms of the complication. Barlow et al. (2008) used semi-structured interviews with 12 women admitted with hypertension, to explore the women's understanding of the condition and their expectations of a high-risk pregnancy diagnosis. The participants felt the incongruity of their position as they felt well; however, they were in hospital so something must be wrong. These women felt like 'frauds' and that they were taking up beds and felt they were not unwell which led them to become averse to the treatment offered (Barlow et al., 2008). The women tried to find symptoms to provide meaning for their hospitalisation, which made them overly anxious and uncertain. Similarly, the women of Bendix et al.'s study were challenged with trying to find meaning for their hospitalisation with no visible symptoms. These women described the experience of hospitalisation when feeling normal as peculiar, while others in the study felt safer close to medical assistance as needed (Bendix et al., 2014). For the women of these studies the experience of feeling well while

hospitalised caused feelings of uncertainty and the restrictions and limited options while hospitalised posed a challenge.

### **Restrictions and limitations**

Being hospitalised, for some women, meant restrictive bed rest or restrictive movement in an effort to mitigate or prevent worsening of their pregnancy conditions. Bendix et al. (2014) found the women attempted to tolerate the limitations on their movements but felt like prisoners; their body and condition held them captive and they tolerated their time in hospitalisation and the loss of control. Similar to feeling a prisoner, “Fighting each battle” was one of the themes of Rubarth et al.’s (2012) phenomenological study. The women of this study were found to be markedly aware of any physical changes and noticed the passage of time. The participants described fighting a daily battle against themselves and found the restrictions placed on their activity added to their fear and anxiety. They referred to the activity restrictions as feeling like they were imprisoned. The notable passage of time and restrictions affected their ability to cope while hospitalised (Rubarth et al., 2012).

Bendix et al. (2013) found women who were hospitalised with physical activity restriction as part of their treatment felt trapped. The women did not feel that the loss of control they experienced was voluntarily given. They could not see how restricting their physical activity would be of any benefit for their pregnancy complication and the experience of hospitalisation caused them to feel like a prisoner of their condition. Although they could ultimately see the purpose of needing to be in hospital, they remained feeling trapped by their bodies’ limitations (Bendix et al.,2013).

The previous studies outlined how women’s experiences of hospitalisation during pregnancy caused them to feel trapped, losing control of their bodies. Their pregnancy was overshadowed by the condition that caused them to become high-risk. This leads to changes in how the women perceive their personal identity.

### **Theme two: Maternal identity**

Recent research has been undertaken to explore maternal identity development in regard to how women take on the early role of mother when hospitalised in pregnancy. Sutherland (2010) suggested that the mother or ‘self as a mother’ identity is drawn from cultural norms and that “motherhood” can be defined as a woman who worries, cares for others, nurtures, and sacrifices (Curran, McCoyd, Munch, & Wilkenfeld, 2017). The

pervasive ideology is that the 'good' mother is an all giving, all consumed, self-sacrificing superwoman (Lowe, 2016b). The reality of motherhood can be vastly different from the idealised concept of being a mother, especially when a pregnancy becomes high-risk and requires hospitalisation. The subthemes identified in the literature reviewed are of; maternal guilt, idealised motherhood and how this may influence a woman's perception of risk.

### **Maternal guilt**

Shame and guilt are described as emotions of the 'moral' self or the 'self-conscious' (Kim, 2017). These emotions come from evaluating oneself against societal norms. According to Dunford and Granger (2017), guilt is caused by specific behaviours and the fear of doing something wrong. Shame, however, comes from the feeling of being judged or being seen in a negative way.

Curran et al. (2017) examined the development of maternal identity of women hospitalised in pregnancy. This study used a phenomenological approach using data from a larger study exploring women's experiences of medically high-risk pregnancies (MHRP). The data were analysed using Atlas.ti 6.0 software and focused on maternal identity. Findings revealed that women hospitalised in pregnancy felt guilty if they perceived they had done something wrong to cause their condition. The women experienced a sense of bodily failure that led to maternal guilt. The women also felt guilt by choosing not to follow the restrictions placed on them, feeling like they were then putting the health of their fetus at risk by placing their needs before their baby (Curran et al.). Other women in this study felt less or no guilt if they voluntarily agreed to the recommended treatments, relying on the medical intervention to improve the outcomes of their pregnancy (Curran et al., 2017).

Markovic, Manderson, Schaper, and Brennecke (2006) used grounded theory to explore the experiences of women hospitalised for high-risk pregnancies in Australia. The women of this study experienced feelings of guilt as knowing little about their pregnancy condition caused them to feel they had caused the complication. Self-blame was evident among the participants as they blamed their behaviours for their hospitalisation. Lack of supporting evidence from the health professionals did nothing to resolve these feelings of guilt. Other participants had maintained a healthy lifestyle and were frustrated that regardless of their healthy lifestyle they experienced pregnancy complications (Markovic et al., 2006).

Dunford and Granger (2017) used a cross-sectional correlation design implemented on-line questionnaires to explore the relationship of maternal guilt and shame with postnatal depression. The measures they used were; Edinburgh postnatal depression scale (EPDS), the inventory of attitudes towards seeking mental health services (IASMHS), the test of self-conscious affect (TOSCA), event related shame and guilt scales (ERSGS) and the social support questionnaire. The findings from this research proved to be consistent with previous research and demonstrated a higher risk of postpartum depressive symptoms with women who experienced shame (Dunford & Granger, 2017).

Sutherland (2010) suggested that good mothering is a source of stress and strain and can lead to women experiencing guilt and shame; summing up motherhood in the 21<sup>st</sup> century with “as long as mothers are exposed to this ideology they risk been locked into a kind of prison, bound by the myths of motherhood” (p. 313). Liss, Schiffrin, and Rizzo (2013) also suggested that the elevated, high standard of ideal motherhood that has become the current discourse would have a negative impact on women’s mental health. Women who report that they felt they had not lived up to society’s expectations experience high levels of guilt and shame (Liss et al., 2013).

Feelings of guilt and shame for women hospitalised in pregnancy may be caused by the discrepancy of the expectations of how their pregnancy should progress, then failing to live up to the expectations of the ideal pregnancy society places on women.

### **Idealised motherhood**

Curran et al. (2017) explored the phenomenology of the maternal role and identity in women who were hospitalised in the antenatal period. Their study found that the identity of ‘mother’ was constructed earlier, while still pregnant, when women were hospitalised for high-risk pregnancy. This study found that women saw worry as a sign of being a good mother drawing on their cultural norms of motherhood. Worry was a central part of their changing identity and perceiving themselves as a mother, while pregnant, gave the women a closer early connection to the fetus. The notion of sacrifice gave the participants a positive reason for having to leave behind their husbands and children when hospitalised. They accepted the restrictions and separation from family as “worth it” to ensure a safe and positive outcome (Curran et al., 2017).

Markovic et al. (2006) also found that women would refer to themselves as mothers, rather than pregnant, once diagnosed with a high-risk pregnancy. This heightened early development of the ‘mother’ identity gave woman the strength to face whatever challenged them. Assuming the role of the protector, though they felt miserable, gave the women the opportunity to keep their baby safe. Despite the stressors of experiencing hospitalisation in pregnancy, the women felt safer sacrificing personal choice for the recommendations of the health professionals. This allowed the women to feel they were protecting their pregnancy even when conflicting advice caused them concern (Markovic et al., 2006).

The previous section described the experience of mothers’ guilt and how the expectations of idealised motherhood forms a woman’s maternal identity. The following section will explore how research found maternal identity has an impact on a woman’s risk perception.

### **High-risk women’s perception of risk**

Several studies reviewed explored how women with high-risk pregnancies understand risk (Lee, Ayers, & Holden, 2012, 2014; White, McCorry, Scott-Heyes, Dempster, & Manderson, 2008). Lee, Ayers, and Holden’s (2012) systematic review identified seven quantitative studies measuring risk perception of women with high-risk pregnancies. These eighty three articles were reviewed for eligibility; of these, six included in the review were studies from Gray (2006); Gupton, Heaman, and Cheung (2006); Headley and Harrigan (2009); Heaman, Beaton, Gupton, and Sloan (1992); Heaman and Gupton (2009); and White et al. (2008). The systematic review of these studies found that though the women were aware there was some risk associated with their pregnancy, they were unaware of the severity of that risk. There was disparity between the women’s perceptions of risk and those of the health professionals caring for them. This disparity may result in misguided and misinformed communication between the women and health professionals and influences the choices women make in their pregnancy (Lee et al., 2012). Heaman et al. (2004) determined that for pregnant women, “pregnancy risk has been determined “for” women and not “with” women” (p. 112).

Lee, Ayers, and Holden (2014) conducted a metasynthesis of qualitative research of women’s experience of high-risk pregnancy. The synthesis used meta-ethnography to read and re-read the literature to find key themes from the six studies. The literature included studies from Corbin (1987); Heaman, Gupton, and Gregory (2004); Jackson et

al. (2006); Patterson (1993); Simmons and Goldberg (2011); and Stainton (1992). Initially, 19 themes were identified which were then organised into 5 key themes of 1) determinants of risk perception; 2) not seeing it the way others do; 3) normality vs risk; 4) if the infant is OK, I'm OK; and 5) managing risk. The participants across the studies reviewed found their perception of risk was influenced by interactions with the health professionals. For some women, these interactions were reassuring, for others a source of concern if there was discordance in the information they received (Jackson et al., 2006; Simmons & Goldberg, 2011). Participants in some studies, though aware there was risk, considered the health professionals to be overstating the risks. They preferred to see the positives and be hopeful; where the health professionals were negative (Jackson et al., 2006; Stainton, 1992). They also found that the women had their minds more on their husbands and children at home and, though the pregnancy must take priority, they were conflicted when making decisions (Lee et al., 2012).

White et al. (2008) conducted a large quantitative study (n=119) using nine questionnaires given in a pack to women hospitalised in pregnancy. The questionnaire pack consisted of a demographic and medical history questionnaire, Maternal Antenatal Attachment Scale (MAAS), State-Trait Anxiety Inventory (STAI), Hospital Anxiety and Depression Scale (HADS), Prenatal Distress Questionnaire (PDQ), Prenatal Coping Inventory (PCI), Short Form Support Questionnaire (SSQ6), and Maternal Risk Appraisal. The medical chart of each woman was also reviewed to provide a pregnancy risk score. The women were asked to complete the questionnaires while in-patients. Although a large number of participants returned the pack of questionnaires, the authors stated that many more declined as there were too many to fill out. Researchers found that the women's appraisal of the risk in their pregnancy impacted on the maternal fetal attachment. Due to their complicated pregnancy, women formed early attachments to their babies as a coping strategy. They also found that the women had a differing appraisal of risk from the health professionals and that health professionals need to be aware of this discrepancy (White et al., 2008).

The literature reviewed above explored the perception of risk women hold when hospitalised in pregnancy. This perception may impact on their experiences while in hospital and change the meaning of feeling safe for them.

### **Theme three: Safety in healthcare**

Feeling safe involves trusting the health professional providing care; yet, the environment can also impact feelings of safety. Smythe (2010) used hermeneutic phenomenology to explore the concept of safety in childbirth. The study found that women seek to be safe in pregnancy and childbirth, while not always feeling safe. Uncertainty and anxiety can impact a woman's experience of feeling safe, causing her to perceive she is unsafe in a safe situation. The notion of safety in healthcare is explored under the subheadings: trust in healthcare and healing environments, including the impact of lack of privacy and sleep deprivation.

#### **Trust in healthcare**

Goldberg (2008) described trust as revealed by the honesty and integrity of the interactions between health professional and patient. Goldberg, using a feminist phenomenological approach, explored the understanding of trust between perinatal nurses and birthing women, and found that trust in health professionals can be easily lost if patients feel they are not heard or acknowledged. The study found that when a woman trusts the health professional, she will have self-trust and be empowered to make decisions. However, if a woman has experienced hurtful or negative interactions with health professionals, she will struggle to have trust in the system. Goldberg also found that a woman then feels she has no option but to place her trust in her failing body or non-medical others. This misplaced trust can leave the woman vulnerable to negative outside influences that may impact her ability to make positive choices. Goldberg's study was of pregnant women birthing in Canada, where they were attended by perinatal nurses they had never met prior to birthing. Continuity of care, such as the maternity service in New Zealand, has been shown to have better outcomes for women and babies. Women who receive continuity of care for the entire maternity experience develop a partnership with their LMC. Trust is thought to be one of the elements of the partnership that develops (Currie & Barber, 2016; Guilliland & Tracy, 2019).

Ward (2006) conducted qualitative research, using five focus groups, and explored the nature of trust in the medical system in the UK. Ward found the issue of mistrust in the healthcare system which had been falling in recent years. People had put their trust in the healthcare system to "anticipate, predict and control the future" (Ward, p. 145). Ward's study found that as the medical system cannot, in reality, be 'all-knowing,' this led to public mistrust. The participants discussed mistrust, particularly of their GP,

which led to unacceptance of the diagnosis and led to consumers being less confident taking or purchasing prescribed medications. Ward found that trust cannot be taken for granted and requires work. Face to face sustained encounters with a reliable health professional was suggested as a way to build a trusting relationship (Ward, 2006).

In contrast, Mander and Melender's (2009) hermeneutic phenomenological study found that the women of Finland took great pride in their health system and were confident enough to trust that, when necessary, their choices could be safely delegated to the health care providers. A trusted system and the ability to obtain substantial supportive information gave the women a feeling of safety and security in decision making around their pregnancy and birth (Mander & Melender, 2009). For consumers, when requiring hospitalisation, trust in the health system designed to treat and keep them well can be affected by the environment they are in.

### **Healing environments**

As discussed in Chapter One, the maternity hospital environment configures to a normal hospital and is medically focussed, causing pregnancy, labour, and birth to be experienced by women in a medicalised domain. There was no literature found that explored the experiences of pregnant women hospitalised. The following literature that was reviewed was from patients hospitalised due to illness.

Both Douglas and Douglas (2004) and Schweitzer, Gilpin, and Frampton (2004) explored patients' expectations and experiences of hospital environments. The participants described the need for personal space with a welcoming, home like environment. The feeling of being at home and having the ability to look after oneself in privacy were the most important aspects of hospital space identified by the patients. The participants, who felt these needs were not met, felt vulnerable and exposed (Douglas & Douglas, 2004; Schweitzer et al., 2004).

According to Schweitzer et al. (2004) there has been a drive in the UK to improve the hospital environment in an effort to aid quicker healing times. Schweitzer et al. surveyed existing research on elements of natural and built environments and found that the ambience of a space had an effect on the people using that space. Other aspects of the hospital environment affecting patient mood and recovery were also explored. Noise levels in hospitals had negative effects on both patients and staff. The harmful effects for patients included; sleep disturbance, increased blood pressure and heart rate, and

lower pain tolerance). Schweitzer et al. discussed the positive ways in which the hospital environment could improve patient outcomes, including fresh air, as being beneficial for increased energy; natural light as beneficial to both mood and physiological processes, and encourages faster healing; being able to view nature as having a positive effect on mood, as studies have associated anxiety and depression with lack of windows (Schweitzer et al., 2004).

For the midwives working and caring for women in hospitals the environment they worked in also impacted on their attitude and satisfaction. Workplace designs can have either negative or positive effects on those working within them. Hammond, Homer and Fourer (2017) research explored the characteristics of hospital birthing rooms that supported midwives practice. They found three themes; friendliness, functionality and feelings of safety had positive impact on the midwives and therefore could influence the midwives provision of care.

Douglas and Douglas' (2004) qualitative study explored patient perception of the environment of an National Health System (NHS) general hospital. The objective was to have the participants describe what they found helpful/non helpful for recovery (Douglas & Douglas). One of the main themes is that patients felt safest and comfortable when the hospital rooms felt more like home. The participants also commented that a variety of spaces were needed, such as personal, private space, and somewhere to socialise when needed. Single bedrooms had positive aspects such as better communication, fewer medication errors, decreased infection rates, and minimal room transfers (due to roommate conflict). Patients also described the effect lack of privacy had on their well-being, particularly those that were long-term patients (Douglas & Douglas, 2004).

Privacy is a consumer right, protected for consumers by the New Zealand Code of Health and Disability Services Consumers Rights (MOH, 2019a). Malcom (2005) used a qualitative co-constructionist approach to interview patients hospitalised in New Zealand. Although these were not maternity patients, the research is relevant as the experience with shared rooms is similar to the current study. Malcom found that the lack privacy, though unwelcome, was provisionally accepted as part of being in hospital. However, participants were most uncomfortable with the realisation that their conversations with health professionals could be overheard, as they could overhear their roommates' conversations (Malcom, 2005). The participants raised concern that

conversations holding disturbing news or diagnosis should be held in a more private setting. Malcom suggested a consulting room would give patients control over who hears their private information. Lack of choice, in contrast, could affect the ability of patients to disclose important medical/personal information if they feared they would be overheard. Malcom noted that fabric curtains are used to provide a modicum of visual privacy but do nothing to prevent conversations being heard (Malcom, 2005).

Persson, Anderberg, and Kristensson Ekwall's (2015) hermeneutic phenomenological approach used face to face interviews with 16 non-pregnant patients living in Sweden. These patients were in newly designed hospitals providing mostly single rooms. The essential theme uncovered was the patients felt safe and secure within their own space where they could create a personal home-like environment. This allowed them to focus their energies on recovery. The participants also found the perceived personalised care was beneficial and a source of security, and they were comfortable to take the time to ask questions of the health professionals (Persson et al., 2015).

van de Glind, van Dulmen, and Goossensen (2008) compared patient/health professional conversations in single and four bedded hospital rooms. Using audiotaped conversations combined with an observational checklist, they found the conversations in single bedded rooms more informative and it gave the patient time to ask questions around clarifications of care. Patients were also more likely to disclose personal information essential for their care. van de Glind et al. also found the more intimate conversations took longer and the health professionals' reactions were more empathetic, and they responded more often.

Swenne and Skytt's (2014) qualitative descriptive study also found that the patient's participation in their care was essential for their well-being. The ward rounds served as a forum for the patients and health professionals to provide a sense of coherence to their care. Swenne and Skytt's main theme revealed the patients were determined to make the most out of the short time they had with their health professionals during ward rounds. The participants described the consultations as too short and the conversations were from the health professionals' medical point of view. They found their mental and emotional well-being was not given time to be considered. In contrast to previous studies, Swenne and Skytt found the participants were not concerned that their roommates could overhear their consultations as long as they did not feel exposed if distressing diagnoses were been discussed. They did, however, feel that they would

prefer a private setting for important, personal information to be discussed (Swenne & Skytt, 2014).

Another negative aspect of room sharing that impacts patient well-being is the interruption to normal sleep. Sleep deprivation or disturbances has been linked to increased risks of cardiovascular disease and diabetes. Short sleep duration in pregnancy has also been linked to the increased risk of gestational diabetes. Two studies, both using actigraphy (sleep monitoring) and surveys/questionnaires, found that as well as the normal physiological sleep changes, prolonged hospitalisation during pregnancy caused significant sleep disturbances (Gallo & Lee, 2008; Spehar, Mission, Shupe, & Facco, 2018).

Gallo and Lee (2008) collected data from 39 pregnant women hospitalised due to high-risk pregnancies using medical records, questionnaires and actigraphy. This study found that the women were able to initially get to sleep relatively normally but could not stay asleep for long periods. The results found the women often had existing sleep disturbances prior to hospitalisation, but these disruptions increased during their stay. Gallo and Lee found that some of the sleep interruptions were due to the participants' high-risk pregnancy as they required frequent monitoring often during the night or early morning. Gallo and Lee recommended that as frequent sleep interruptions could be harmful for pregnant women implementing strategies to minimise the interruptions should be the focus of health providers.

Spehar et al. (2018) explored the sleep patterns of hospitalised pregnant women using actigraphy and self-reported sleep logs. The study confirmed previous studies that hospitalisation increases the physiological sleep disruptions related to pregnancy. Spehar et al. allowed that though disturbed sleep is perceived to be a normal part of pregnancy, the constant interruptions from staff, noise, and roommates while hospitalised in pregnancy does not allow for the women to achieve restorative sleep. Poor sleep quality could lead to negative outcomes impacting both physical and mental well-being. Poor decision making and coping skills were identified as caused by lack of good sleep while hospitalised (Spehar et al., 2018).

#### **Theme four: Antenatal anxiety/depression and postnatal depression**

There was limited research on the postnatal effect after experiencing long hospitalisation during pregnancy. However, there was extensive research on the effect

of antenatal stress and anxiety, and the current literature agreed that stress or anxiety in pregnancy was a known risk factor for postnatal depression (Dunford & Granger, 2017; Patel, Wittkowski, Fox, & Wieck, 2013; Zadeh, Khajehei, Sharif, & Hadzic, 2012).

Of the studies found in the review of anxiety and depression in pregnancy and the postnatal period, many used multiple self-administered questionnaires including the Multiple Affect Adjective Checklist Revised (MAACL-R), the Profile of Mood States (POMS), Centre for Epidemiologic Studies Depression Scale (CES-D), STAI, Pregnancy-Specific Anxiety Scale (PSAS), Edinburgh Postnatal Depression Scale (EPDS), Generalised Anxiety Disorder 7 Scale (GAD-7), revised Prenatal Life Events Scale (PLES), High Risk Pregnancy Stress Scale (HRPSS), Revised prenatal Coping Inventory (NuCPI), Questionnaire du Soutien Social Perçu (QSSP), Rosenberg Self-Esteem Scale (RSES), Beck Depression Inventory (BDI), Spielberger Standard Test, and the Postpartum Symptom Checklist (PSC) ((Barber, Panettierre, & Starkey, 2017; Barber & Starkey, 2015; Byatt et al., 2014; Denis, Michaux, & Callahan, 2012; Maloni & Park, 2004; Maloni et al., 2005; Zadeh, et. al., 2012).

### **Antenatal anxiety and depression in high-risk pregnancy**

Byatt et al. (2014) employed a descriptive statistics approach using the EPDS self-administered questionnaire with 62 high-risk antenatal women hospitalised in a tertiary hospital. They found that women hospitalised with a high-risk pregnancy often experienced depressive and/or anxiety symptoms. Byatt et al. also found extremely low rates of symptoms recognised and/or treated while they were hospitalised. Their study, as with previous research, found high rates of depressive symptoms evident in hospitalised pregnant women (Maloni et al., 2002; Schroeder, 1996). Consistently, studies found that the symptoms declined the longer the women were in-patients; however, scores remained higher than normal (Byatt et al., 2014; Denis et al., 2012; Maloni et al., 2005).

Barber and Starkey (2015) measured the anxiety levels of New Zealand women hospitalised for high-risk pregnancy (n=118) and a comparison group of pregnant women with no complications (n=114) using the State Trait Anxiety Inventory (STAI). The main focus of this study was to investigate the psychosocial factors affecting pregnancy anxiety in women hospitalised in pregnancy. The study found that anxiety in both groups was higher than the non-pregnant population but the anxiety levels in hospitalised pregnant women was extremely elevated and would be of concern. Barber

and Starkey also found that the women who exhibited the highest rates of anxiety were those with a decreased level of optimism about their pregnancy.

Barber et al. (2017) investigated the health perception ratings between women hospitalised in pregnancy and the midwives caring for them. They conducted a quantitative, cross-sectional exploration to understand the experiences of women hospitalised for a high-risk pregnancy. This study used questionnaires provided to both women and their midwives measuring their perception of health and anxiety levels. Sixty-eight women hospitalised in a high-risk pregnancy and a comparison community group of 33 women participated (Barber et al.). As in the previous study, many of the women hospitalised in pregnancy exhibited extreme levels of anxiety and depressive symptoms. Of these women, the midwives did not consistently realise the signs and symptoms were due to anxiety and depression. They recommended that midwives need to be more aware of the signs and symptoms of escalating anxiety when women are hospitalised in pregnancy (Barber et al., 2017).

Denis et al. (2012) used five questionnaires to evaluate if depressive or anxiety symptoms were impacted by self-esteem, social support, or coping strategies. The 55 women of this study were hospitalised for high-risk pregnancy in France. This study used five scales measuring stress, depression, anxiety, and coping mechanisms. Denis et al found that more than half the women that participated exhibited signs and symptoms of antenatal depression and that all the participants showed the signs and symptoms of anxiety. Initially, 61 women were recruited; however, six declined after finding there were too many questionnaires to complete. The authors stated that the results were in line with previous studies. Denis et al suggested that health professionals need awareness and ability to recognise and treat anxiety and depression in women hospitalised with high-risk pregnancy.

Maloni and Park (2004) conducted a methodological study designed to repeat three previous studies. This study used three standardised instruments designed to measure antenatal depressive symptoms. This study supported previous studies and found that depressive symptoms were high on admission to hospital and decreased over time. Maloni and Park also found that depressive symptoms continued to decline up to six weeks postpartum but remained higher than women who experienced a normal pregnancy.

Zadeh et al. (2012) used convenience sampling of 939 women, who were first interviewed to determine if they fit the inclusion criteria. 400 women remained in this study evenly split into a high-risk pregnancy and low risk pregnancy group. These participants were then asked to complete three questionnaires. Depression symptoms were measured using the Beck Depressive Inventory (BDI). High-risk pregnancy and postpartum depression were found to be influenced by maternal age as older women were found to have higher rates of post-partum depressive symptoms. Zadeh et al. (2012) suggested that high-risk pregnancy increases the risk of postnatal depression and anxiety in women.

Patel et al. (2013) used grounded theory with face to face interviews to explore the illness beliefs of mothers with postnatal depression. Many of the women were torn between their desire to be a good mother and admitting to the affect postnatal depression had on their perception of a good mother. They described the differing symptoms of postnatal depression with normal depression; with postnatal depression being harder to recognise as the effects of caring for a new-born are similar (fatigue, low mood). Depressive symptoms in the postnatal period were often due to the difference between perceived idealised motherhood and the realities they faced (Patel et al.). This discordance often left the women feeling something was not right. Any difficulties were minimised, and other reasons found for the wrongness they experienced, such as the normalities of early motherhood (Patel et al.). The women in these studies were found to be slow to seek help for their experiences as they were unwilling to admit they were not coping. The perceived stigma attached to the diagnosis of postnatal depression was seen as a judgment on their mothering abilities (Patel et al., 2013).

The most recent research by Abrar, Fairbrother, Smith, Skoll, and Albert (2019), found five articles that met the inclusion criteria. Although these studies were quite different in their approaches Abrar et al. found that they all agreed that anxiety was elevated in women admitted to hospital with high-risk pregnancies compared to women with a normal pregnancy.

## **Summary**

This literature review has been used to support the exploration of the question “what are the experiences for women hospitalised for an extended time in their pregnancy?” The review has shown there is some understanding of the short-term effects long term

hospitalisation can have on women. Most of the literature is from overseas, with only a small contribution from New Zealand authors. The majority is from a nursing/obstetric point of view rather than midwifery. However, the literature acknowledged the voices of the women hospitalised in pregnancy and the challenges they faced.

Women were found to experience loss of control of their bodies and minds, they were sent away from their homes and families and placed in hospitals due to complicated pregnancies. The hospital environments were described as unwelcoming and unfamiliar. Restrictions on movement and personal space led to the women feeling trapped or like prisoners. Societal norms in regard to pregnancy and motherhood, creating the 'myth of motherhood,' generated discordance with the women hospitalised who experienced feelings of failure for not living up to the ideology of the 'good mother.' Feelings of guilt and shame were acknowledged as increasing risk factors for anxiety and depression symptoms in both pregnancy and post-partum. The low rate of recognition of these symptoms, by both mother and health professionals, was acknowledged as needing to be addressed.

From the literature reviewed, recommendations for further research arose from the findings. These recommendations included exploring the views of the staff caring for high-risk women (Barlow et al., 2008), longitudinal research exploring the causality between postnatal depression, guilt, and shame (Dunford & Granger, 2017), systematic intervention strategies for antenatal depression/anxiety (Barber et al., 2017), clinical interventions for anxiety and depression in pregnancy (Denis et al., 2012), and risks and cause of physiological symptoms after bed rest (Maloni & Park, 2004). These recommendations highlight the paucity of knowledge around the anxiety and depression that is often not recognised, diagnosed, or treated while women are hospitalised. The review also highlighted the importance of my research study.

As the majority of the literature in this review was not from New Zealand, there was only some similarity to the experiences of the women hospitalised overseas. As discussed in Chapter One, maternity care is unique in New Zealand; within the tertiary hospital setting, midwives would be the primary care providers for women hospitalised. This may provide a different context to the outcome of this study. Some of the literature is ageing; however, the recommendations from more recent literature show that ongoing phenomenological research exploring the women's experiences when hospitalised is relevant, especially in the New Zealand context.

## Chapter Three. Research Methodology and Methods

### Introduction

In this chapter I describe the philosophical underpinnings that have informed the way in which I researched the question, “What is the experience for women hospitalised for an extended time in their pregnancy?” I also discuss how and why I chose hermeneutic phenomenology, to undertake this research. The methods used for this research such as recruitment of participants, interviewing, data analysis, trustworthiness, and ethical approach are discussed.

Bergum (1991) described hermeneutic phenomenology as “phenomenology has to do with description of experience, and hermeneutics with interpretation of experience” (p. 56). Phenomenology is a way of engaging in an enquiry looking to reveal and understand the lived experience of another. Hermeneutics is seen as a theory of interpreting the lived experiences, bringing knowledge and understanding from the text (Miles, Chapman, & Francis, 2015).

Phenomenology, as a research philosophy, has become increasingly popular in midwifery as it enables the researcher to delve deeply into participants’ personal life experiences and discover rich data to learn from (Crotty, 1998). This study researched the lived experiences of women who were hospitalised for an extended time in their pregnancy. Researching lived experiences can be done in many ways including observation, literature, diaries and journals, observing art or writings, and interviewing. For this study, open interviews were used. Interviewing is a way of exploring the personal lived experience of individuals, to hear their story. Stories provide us with a range of possible life experiences, enable us to feel emotions and have experiences that we would not normally be exposed to. The stories that appeal to us can also impact on a very personal level (van Manen, 1990).

The interview process in hermeneutic phenomenology, serves a very specific purpose by exploring pre-reflexive experiential accounts, not personal views or narratives (van Manen, 1990, 2016). It is often easier for the interviewee to provide an account of his or her experience rather than tell of the lived experience (van Manen, 1990, 2014).

Interviews will gather narratives that reveal deep and rich experiences and help the researcher better understand the human lived experience. van Manen (2016) suggested that in hermeneutics, interviewing should be approached with an essential open question

that provides guidance to the experience the researcher hopes to understand. Though phenomenological research does not necessarily need to have a ‘question,’ it is beneficial to begin with a question at the start of the research process. To begin an interview with a totally unstructured process may either give the researcher too little data or too much material to do the experience justice. If there is too little data, in the form of a story, then the temptation could be to over interpret what little there is and rely on the researcher’s own experience or pre-conceived ideas. Too much material can lead to confusion and a total lack of clarity leading the researcher to not give the narratives proper attention. Face to face interviews provide the participant with the opportunity to stay close to the life experience; and a focussed question aids both the interviewer and interviewee to stay close to the story (van Manen, 1990, 2014).

van Manen (1990) suggested that “methodologically speaking a story is important because it allows the human science text to acquire a narrative quality that is ordinarily characteristic of a story” (p. 121). Experiences that have a major impact on our lives, such as pregnancy and birth, are remembered, reflected on, and recalled for many years after the experience. Depending on the experience, the ‘birth story’ is used to find meaning, to heal or help others from the re-living and telling of the experience. Using van Manen’s guide for reflective analysis gave the women of this study a voice within my research. van Manen’s lifeworld existentials guided the thematic analysis.

Wrathall (2005) suggested phenomenological research often begins with a sense of wonder and can only be pursued with the researcher giving themselves over to this wonder. Discovering a phenomenological question often comes from the researcher’s own lived experience (van Manen, 1990). This is where my question began, as I wondered what women thought and felt at, what could be considered, a difficult time of their life.

For me, being a midwife essentially means listening and telling stories, and reflecting on these experiences. So much background and knowledge is learned from just listening to a woman’s lived experience. Midwives gather experiences from women, colleagues, and academic writing; and reflect on what they read, hear, or observe to enhance their own experience and skills. This important aspect of ‘data’ collection enables us to understand ours’ and others’ lived experience. Becoming a parent is a major life development and the impact this has on parents cannot be taken lightly. Any experience, depending on perspective, can impact lives positively or negatively.

To explore the experiences of hospitalisation at such a vulnerable time, a hermeneutic phenomenological method appealed to me in many ways and appeared to fit the study. For me, the joy of reading began when I was very young and has continued throughout my adult life. The art of a good novel is to build a life world other than our own and be able to draw the reader in, enabling them to live in that world (van Manen, 1990). To be able to take this love of reading to listen, write, and read women's stories of their experiences in hospital, and learn from them, aligned with my love of books, reading, and experiencing lives different from my own. This led me to the question, "What is the experience for women hospitalised for a significant time during their pregnancy?"

### **van Manen's hermeneutic phenomenology**

Phenomenological research is essentially a study of lived experience, with the basic aim of trying to understand or explore what everyday life is about. van Manen's (1990, 2016) phenomenological method of research is described as a way of being thoughtful or mindful of the purposes and outcomes of practical, normal lived everyday experiences (Smythe, 2011; van Manen, 1990, 2016). Though phenomenology can be used to explore and describe the human world, it is not used to diagnose or treat but to discover and wonder at the meanings of life. Phenomenology is more a methodology of questioning rather than finding answers and aims to interpret and describe the experiences of everyday life (Dahlberg, 2011; van Manen, 1990).

Phenomenology, as a methodology, is described as the need to investigate the real world of lived experience, and to uncover and describe any relevant meanings in this world (van Manen, 1990, 2016). The use of hermeneutic phenomenological theory is to investigate, interpret, and describe the phenomena in rich contextual language that will enable the reader to easily understand the lived experience (Smythe, 2011; van Manen, 2016). Through this reflective process of thoughtfulness, the researcher's aim is to write in such a way that they can create partnerships or relationships between who we are and how we act (Smythe, 2011; van Manen 1990, 2016). The emphasis of phenomenology is on the meaning of lived experience. The point is to 'borrow' other people's experiences, and their reflection on their experience, in order to better understand the deeper meaning or significance of human experience (van Manen, 1990).

van Manen (1990, 2016) explored lived experience as a fundamental aspect of phenomenological research within the concept of the 'lifeworld.' Our experiences, as we go through our world, can be described and then interpreted into 'themes' or

meanings that constitute how complex life can be. The lifeworld can be experienced and interpreted in as many ways as there are people, as fundamentally humans lives, and therefore lifeworld's, are different (van Manen, 1990, 2016). van Manen, (1990, 2014) contended there are four fundamental lifeworld themes that can be used to provide a lens in which life stories can be analysed. van Manen called the four lifeworlds 'existentials,' which he suggested are guides for researchers as they reflected on experiences. These four existentials are: *lived space* (spatiality) *lived body* (corporeality), *lived time* (temporality), and *lived other* (relationality). These four existentials give the researcher a lens to explore how humans live in their world (van Manen 1990). The four lifeworld existentials are explained as follows;

*Lived space* (spatiality) is felt space and is more difficult to define than the space of mathematics, distance, or the dimensions of space. Lived space refers more to the way we feel when in a space, such as the different way you would feel being in your home in contrast to a hospital. Our fundamental state of being resides in our home space and is often described as our safe place or inner sanctity where we feel safest.

*Lived body* (corporeality) refers to the sense of always being bodily in the world. Our physical body can both reveal and hide who we are within the same moment. If the body has become subject to the gaze of another, our actions may become less natural and may become awkward, clumsy, or reserved.

*Lived time* is subjective time as opposed to measurable calendar or clock time. Time can appear to go quickly during an enjoyable experience and may drag while involved in something that is causing boredom, anxiety, or fear. In a temporal sense, our past shapes our now and our future. Our forgotten past can shape how we act and live in the now, such as sayings or gestures that we have absorbed from our parents. The past may also change our perception of the future. For example, a woman who had a perfectly normal pregnancy will be expecting the next to follow the same pathway; for that to not happen, can colour the 'now' experience.

*Lived other* or relationality is how we interact with others within an interpersonal space. We often greet another in a corporal way such as handshake or hug, depending on the relationship already in place. We can also make impressions or judgements of people by means of the outer shell and, after meeting, develop a conversational relationship, or not. Feeling the same as the 'other' can help develop a relationship (van Manen, 1990).

Though phenomenological research can use these concepts individually to form an idea of the researched lived world, these four existential aspects weave together to form our lifeworld (van Manen, 1990, 2016). These guides to reflecting on the experiences of the women I interviewed, were invaluable and made the process of evaluating themes more coherent. Listening, writing, reading, and writing again separates the researcher from what they know while revealing those things they do not know, leading them to discover what they do know (van Manen, 1990, 2016). This description of philosophies for research resonated most with me as I found it imperative that the voices of the women I interviewed be heard and their life stories be interpreted in the best way possible (van Manen, 1990, 2016).

van Manen's philosophical approach to phenomenology is considered contemporary thinking and was influenced by traditional human science philosophers such as Heidegger, Gadamer, and Merleau-Ponty. These philosophers and their influential are discussed below.

## **Philosophical underpinnings shaping van Manen's thinking**

### **Heidegger (1859-1938)**

One of the major forces or influencers of modern philosophy and van Manen was Martin Heidegger. Heidegger is regarded as one of the most influential philosophers of the 20<sup>th</sup> century (van Manen, 2014). Heidegger was born in 1889 and began the study of theology at his parents' request. He then turned to the study of philosophy, mathematics, and physics and had a very successful and long career (van Manen, 2014). Heidegger was a pupil of Husserl, who had begun to change phenomenological focus from transcendental ego to a more pre-reflexive life-world of everyday experience. Husserl's focus was on the nature of knowledge or epistemology; while Heidegger went beyond this concept, focussing more on the nature of existence in the world, or ontology (Healy, 2011). Heidegger's major contribution to phenomenology is his work *Being and Time* which was to change how phenomenology was used and to unite it with hermeneutics, to make sense of the 'life-world' (Healy, 2011; Wrathall, 2005). van Manen's thinking on phenomenology, in particular the concept of the 'life world,' was developed from his interest in philosophers such as Heidegger (Smythe, 2011). Heidegger continued to expand and change this work to a focus on how things reveal themselves to us as 'Beings' or Dasein (essentially human) (Healy, 2011). Heidegger

encouraged practitioners of phenomenology to be aware of the way things (beings) are in the world, as he explained:

Thus “phenomenology” means ...to let that which shows itself seen from itself in the very way it shows itself from itself. This is the formal meaning of that branch of research that calls itself “phenomenology.” But here we are expressing nothing else than the maxim... “To the things themselves!” (Heidegger, 1962 as cited in van Manen, 2014, p.104)

Heidegger focused on the very nature of human existence (ontology) and the interpretation of phenomena leading to the discovery of hidden meanings (Healy, 2011; van Manen, 2016; Wrathall, 2005). Heidegger’s strongest suggestion was that by delving deeply into language, understandings can be made. Phenomenological research challenges us to go back to the beginning, to the inception of thought, and that this can be found in the primordial sense of lived experience (Wrathall, 2005). Language, when used in a phenomenological sense, can then reveal to the researcher the ontologies of life (Smythe 2011, van Manen 2014). This concept of using language to reveal hidden meanings is what drew me to van Manen’s philosophy as I personally find discussing, reading, and conversing the best ways to learn and improve. Listening and reading women’s narratives of their experiences while hospitalised, became an intimate exploration of the nature of the lived experience.

### **Hans-George Gadamer (1900-2002)**

Gadamer is regarded as one of the most noteworthy representatives of modern hermeneutic phenomenology. Philosophical hermeneutics became Gadamer’s focus after studying under Heidegger, whom he found restrictive and so chose to focus on classical Greek philosophers leading to his developing hermeneutics (van Manen, 2014). Gadamer’s major literary contribution *Truth and Method* was released in 1960; which, contrary to its title, was not written to provide a ‘method’ to human understanding (van Manen, 2014). Gadamer explored the role of language in interpreting human understanding and looked at the nature of conversation. Gadamer believed that all human understandings come from dialogue and that human existence cannot, therefore, be approached as a methodological problem. According to Gadamer:

all knowledge consists of prejudice, really pre-judgements... the significant difference between prejudice and pre-judgement is that prejudice cannot be traced back to a single source-prejudices are deeply embedded in historical consciousness. (van Manen, 2014, p. 133)

Gadamer clarified that his interpretation of contemporary hermeneutics does not provide a procedural method to follow when interpreting human experience. Gadamer stated “indeed it has been said that *the method of phenomenology and hermeneutics is that there is no method*” (van Manen, 1990 p. 30). When analysing text, Gadamer suggested that the reader cannot be separate from the text, that they belong to what they are reading. Interpretation of the dialogue includes taking up the traditions that the researcher finds themselves and may become answers to possible questions (Gadamer, 1976; van Manen, 1990).

### **Maurice Merleau-Ponty (1908-1961)**

Maurice Merleau-Ponty was a French philosopher born in 1908. He received his qualifications as philosopher from the École Normal Supérieure in 1930. Merleau-Ponty was regarded as a serious and conservative philosopher whose main contribution to phenomenology was his *Phenomenology of Perception* (1962). Merleau-Ponty re-interpreted Husserl’s work on transcendental phenomenology and expanded this work towards existential phenomenology (van Manen, 2014). He argued that phenomenology reflects on what occurs before reflection; in other words, the lived experience (Marshall, 2008; Merleau-Ponty, 1992; van Manen, 2016). Merleau-Ponty was a major influence on van Manen and his concept of the ‘lived body.’ Merleau-Ponty (1992), discussed the concept of ‘bodily space;’ that the body is more than just another object in the world but that the space inhabited by the body is apparent because of the body. Body image is a way of stating that the body is in-the-world or that we live in and through the world (Dahlberg, 2011; Merleau-Ponty, 1992). The body is essential in phenomenology as it cannot be just observed as a subjective thing that can be not seen, we can never turn away from the body (Dahlberg, 2011). van Manen (1990, 2014) developed his concept of the existentials of spatiality, corporality, temporality, and relationality as being the basic foundation of the lifeworld from Merleau-Ponty’s discussion of lived body (van Manen, 1990, 2016).

### **The hermeneutic circle**

The hermeneutic circle can be seen as a symbol of the unlimited and unending possibilities that a narrative or text provides (Miles et al., 2015). To gain maximum insight from the stories, the art of reading, writing, rereading, and rewriting is referred to the ‘hermeneutic circle’ in traditional phenomenological research. There is an expectation that the researcher/reader has a basic understanding of what the text is about

as a beginning point in interpretation (Crotty, 1998; Warnke, 2011). By following the hermeneutic circle, the researcher can go from the small parts of the data to eventually see the whole and back inwards again. The circle can often be seen more as a spiral moving inwards and outwards to reveal themes within the data (Miles et al., 2015).

Warnke (2011) described the purpose of the hermeneutic circle as:

In other words, we test our understanding of the meaning of each part of a text against our understanding of the meaning of the whole and our understanding of the meaning of the whole against our meaning of the parts. We bring scientific maturity when we can understand each in terms of the other. (p. 94)

To write then re-write does not mean just to edit or proof re-read; the hermeneutic circle cycle refers to going deeper and wider into the text to find understanding. Re-reading, reflecting, thinking, and re-writing is taking all the available data and narrowing it down to a few manageable themes that matter most to the writer and the participants (Crotty, 1998). The themes I began to uncover were wide ranging and the theme titles were changed, merged, changed again as I delved further into the intense range of experiences the participants provided. These major themes are the ones that can be best argued. This does not mean the smaller, but just as significant themes, get discarded; rather, they are recognised as supporting the major findings. They become ‘sub-themes’ within the whole (Crotty, 1998).

## **Pre-understandings**

van Manen (1990) suggested we make our beliefs, assumptions, and understandings explicit when conducting phenomenological research. Putting aside our pre-understandings and suspending innate knowledge of the processes enables the researcher to approach the experiences with an open mind (van Manen, 1990).

Phenomenology is itself a method of ‘abstemious’ reflection, taking the act of reflection as far away from any personal beliefs, emotionality, or knowledge that may detract from the lived experience (van Manen, 1990, 2016). ‘Reduction’ refers to the opposing methods of being able to suspend in-built beliefs or ideas and frees the researcher to openly see the meaning of the experiences they are analysing (van Manen, 2014).

Needing to be aware of my own assumptions became an important part of my research process. I was coming from a place of personal reflection, having been in the situation as the women I was interviewing. I held an assumption that these women, after their babies were born, might have had postnatal depression or post-traumatic stress disorder.

During my time in a tertiary hospital setting, I had worked clinically with similar women and was privy to their highs and lows. All of these pre-understandings could have affected the way I initially interviewed the women, or while analysing the data, by putting my own thoughts or voice into the data. This was a significant challenge for me as I needed to be vigilant that I was not hearing what I wanted to hear or reading the same. During transcription, I often had to go back as I found that I was writing what I thought I heard and realised swiftly that was not what the woman had actually said. Transcribing was a long process as I am not an auditory person and found that I could only listen to very short parts of the narrative while writing it out. Once the transcriptions were in writing, I was then able to easily read them and hear the women's voices. I acknowledged my own pre-understandings throughout the interview process, transcribing, and analysis.

## **Research method and design**

In this section, I discuss how the philosophy of van Manen informed the study method. I also explain how I achieved ethical approval, as well as participant recruitment, confidentiality, anonymity, data collection and analysis.

## **Ethics**

Ethical approval for this study was received from the AUT Ethics Committee (AUTEC) on the 21<sup>st</sup> March 2017, reference number 17/9 (Appendix A). The application process gave me a chance to consider how my research topic could impact on the women I was proposing to interview, and the wider community. Taking into consideration the founding document of New Zealand, Te Tiriti o Wāitangi (The Treaty of Waitangi), the principles of protection, participation, and partnership were acknowledged. In the anticipation there would be Māori participants, and after discussions with my supervisor, I consulted with a Māori midwife representative from Kawa Whakaruruhau. A letter was sent to Kawa Whakaruruhau and approval was given (Appendix C). Approval for a 'Low Risk Study' (Appendix B), was also sought and obtained from the tertiary DHB, where I intended to recruit. I had previously worked in this DHB, but had not worked there for over a year, avoiding any women for whom I may have personally cared. Approval was also given for any Māori involvement for Waitemata DHB (Appendix D). After approval for the low risk study was obtained, I met and consulted with the charge midwives on the wards where I would be recruiting participants, as well as discussing the best way to recruit (i.e., time of day) without disrupting the day-to-day

working of the ward. The participants identities were protected by providing anonymity of the participants. Each was given a pseudonym using a randomly generated name, other than their condition, participants were not directly linked to a DHB and no addresses or other identifying information is provided in this research . Recordings and transcripts of the interviews were kept securely in a locked cabinet at my home. Transcribing was done by me to protect anonymity and to begin analysis while transcribing. The transcribed interviews were then emailed to the participants for feedback. Only one returned feedback, to say thank you; no changes were made.

## **Protection**

Protection of participant anonymity and mental well-being were considered crucial. As some of the women interviewed may have had distressing experiences, I ensured that there was free counselling available for them through AUT counselling services. Contact information for the counselling service was part of the information sheet provided to the participants (Appendix E); I also ensured that at any time they could discontinue the interview. Two women became tearful during the interview but were happy to continue to have their story told. No participants opted to end the interview. Personal protection was ensured with a researcher safety protocol (Appendix F) in place, ensuring I was in contact with my close family member who was aware of generally where and when I was going, and contact was made at the end of the interview.

## **Participation**

Understanding, unpacking, and reflecting on the participants' experiences was the main focus of my study. To enable this to happen, the participants drove the structure of the process. Following the methodology, and the principles of Te Tiriti o Wāitangi, I provided information regarding the why and how of my study when I initially met the women. I also emailed a copy of the information sheet to participants to ensure they were fully informed of the purpose and process of the interview. The participants were given time to consider the opportunity and were also offered time to ask questions or raise concerns. The participants were offered a choice of place to interview, all chose their home. In the spirit of partnership, the participants could stop or conclude the interview at any time. Many ended quickly due to the needs of a hungry baby; the rich experiences gained even in a short interview were truly appreciated.

## **Partnership**

In keeping with the principle of partnership, the participants were equal partners in my research. Due to the nature of the interview possibly being upsetting, I ensured the interview process was in the woman's control. The place of interview is important. For the woman to feel comfortable sharing what could be an emotive experience, the place should be of their choosing. In this study all women chose to be interviewed in their own home where they could move about and tend to their children when needed. This meant occasionally needing to postpone due to illness, childcare, or just needing time. All the women chose to be in their home, and I was welcomed as a guest. I would often bring coffee and muffins, if the timing was right. One interview was held via Skype where the woman was in her home, with her partner caring for their child in the background. Children were also involved and the interview was interrupted with time to care for the children. This also reflects the existential 'lived space,' as the home is often where we feel safest.

van Manen, (2014) also suggested choosing a time that means the interview will not feel rushed. The women I interviewed all had young children, so the interviews were often intermittent and, in some cases, needed to end earlier than anticipated. One interview was in the evening as her partner put the children to bed. At the end of the interview I would ask the question, "Is there anything else you would like to add?" to prompt any forgotten thought. At the end of each interview a small card with a koha (petrol or food vouchers) was given as a thank you for participants sharing their time for me.

## **Recruitment**

Inclusion criteria for this research were women who had been admitted to hospital during their pregnancy for more than two weeks. Initially they were to be between four weeks and four months postpartum; however, due to slow recruitment, an AUTECH amendment was made and approved (Appendix G) to include women who were four weeks to two years post-partum. The participants also needed to be able to speak English.

A combination of purposive sampling and snowballing methods were used. After receiving approval from the DHB, I approached the Clinical Charge Midwives (CCM) on the ward that cared for the women with high risk pregnancies. A short meeting was held and I explained my research and gave them posters to display in the midwives station (Appendix I). I did not receive feedback from these posters and, when I visited

the ward, I discovered that the midwives were unaware of my project. I then began to drop in weekly or fortnightly and ask the midwives if there were any possible candidates. Once identified and reassured they would not be disturbed by my inquiry, I talked to each woman face to face. I briefly outlined my study and left a copy of my information sheet (Appendix E). I decided to contact the participants while they were in hospital with the view to interviewing them after baby was born. The reason women were not interviewed while still pregnant was to give the women time to reflect on their experience. The prospective participants were given my email and phone (on the information sheet) and were encouraged to contact me when/if they wanted to participate.

My decision to approach women while still in hospital with the view of interviewing once they reached the criteria of four weeks postnatal did not work as expected. Of the seven women recruited, only four were as a result from this contact. I changed tactics when I realised that leaving the information sheet and initial contact up to the women was not working. I then began to note down the email addresses of interested women and contacted them after an appropriate amount of time. If they did not reply to this email, I did not contact them again. One woman was keen to participate but after several emails back and forth declined due to not having time. I then began contacting midwifery colleagues for possible contacts. They approached women who fit the criteria, giving my email and phone details, and it was then up to the women to contact me if interested. In this manner I gained a further three participants. I had anticipated between six to eight women and eventually conducted a total of seven interviews. It became evident that this would be adequate numbers as themes arising from phenomenological research can have as little as one participant to provide rich data. Phenomenological research cannot gain 'saturation' of data as the nature of the lived world is unique. Phenomenology is about looking for differences or the new, not for repetition, a single theme may be all that is needed to provide rich data (van Manen, 2014).

### **The participants**

A total of seven women were interviewed, six face to face in their home and one via Skype as she was out of my region. Five women were New Zealand European, one Chinese, and one Indian. For four of the women it was their second pregnancy and, in the case of one woman, her second and third (twins); for two it was their first baby. The participants were from three different DHBs in New Zealand. Hospital stays were from

two to twelve weeks. Reasons for admission were pre-eclampsia, placenta praevia and bleeding, premature rupture of membranes, threatened preterm labour and chronic pain. To avoid any chance of the women being identified, and to protect their privacy, I will not provide any further history. A pseudonym was chosen based on their initials to provide a more engaging profile. Participants were given a copy of the information sheet (Appendix E) directly when recruiting and via email when contacted again. Once they had read and were happy with the information provided and were willing to continue, a consent form was signed at the beginning of the interview (Appendix H). The distance participant signed her consent form and returned it electronically.

## **Interviewing**

I interviewed all seven women face to face, the timing was variable and lasted between 30 to 90 minutes. My interview technique and open-ended questions developed from each interview and depended on the woman (Appendix J). I started the interview with, “When were you first told you needed to go into hospital, how did you feel?” This would provide me with the information such as what gestation they were admitted and what prognosis they had. This initial question also gave the participants the opportunity to share their experiences when first hospitalised. I would then ask the participants to, “Tell me about your experience while in hospital.” van Manen (2014) suggested that “It is helpful to keep the question focused on a single and concrete moment that the experience was lived through or took place” (p. 299). By doing this, I tried to stay as close as possible to the original focus of my research; as by asking what happened first, we were then able to move into the experience of being in hospital. Beginning with the question focusing on their experience while in hospital, and eventually leading to their experience in the post-natal period, the women I interviewed meandered through the timeline of their experiences. This was not that obvious at the time of interview; however, when it came to transcribing, I found it challenging to write the stories as they were frequently out of sequence. Some of the participants needed more prompting during the interview if they went from telling of their experience to stating facts. This needed the simple question “how did you feel when... .” To stay true to the women’s voices, I refrained from changing how or what order they spoke in while transcribing. In some early interviews, we had gone to the very end and I had turned off the recording device when the woman would suddenly recall an important part of the experience. I would then hurriedly turn the recording back on and write down

in a notebook anything I had missed recording. After the first couple of times this occurred, I did not turn the recording device off until leaving.

## **Transcription**

I personally transcribed all recordings as soon as I was able in order to remember the emotions of the participants as they reflected on their experiences. I also took notes straight after each interview as I sat in my car to reflect on the emotions of the women interviewed. I decided early in the process to do the transcriptions myself to maintain confidentiality and to become fully immersed in the women's stories. Reading and re-reading these transcriptions, and pulling the first lot of data, ensured I could begin grasping emerging themes. Although the interviews were spread out over 6 months, I was struck each time at the similarity of the women's stories. I was encouraged that sharing these women's stories of what it was like to be hospitalised in pregnancy was essential. After listening and transcribing by hand, I then listened again while transcribing onto my laptop. By listening, reading, and writing again, I was able to be fully immersed in the rich data.

## **Reflection and data analysis**

Though there are now computer programmes available that aide qualitative analysis, finding the themes in a phenomenological lived experience research is complex and not bound by algorithms but guided by the feelings invoked in the reader (van Manen 2014). Rather than analysing the frequency of a word or phrase, phenomenological thematic analysis is more being able to see the meaning in the text and should not be bound by a thematic application. Though themes can give a sense of control and order to writing it should be more focused on the meaning of life (van Manen, 1990, 2014). van Manen provided three options to guide the researcher in discovering themes within the transcriptions of the interviews:

1. The "wholistic reading approach" - considering the text in its entirety.
2. The "selective or highlighting approach" - reading the text several times and highlighting the most relevant or essential parts that describe the experience.
3. The "detailed or line by line approach" - considering single sentences or sentence bundles which might reveal something that contributes to the experience (van Manen, 1990).

In my first read through of the seven transcripts, I utilised several different coloured highlighters, as suggested by van Manen's 'selective or highlighting' approach, thereby

beginning to isolate thematic statements. However, this became quite overwhelming as the initial data consisted of seven colours. I then combined this method with single sentence or a 'line by line' approach. I used coloured paper to match the coloured highlighters. These single lines were then pasted onto boards broken down into van Manen's existentials—lived body, lived space, lived relationality, and lived time. I then grouped the single lines into similar themes, such as "feeling scared." Next I re-read each transcript and worked the narratives into a more coherent pattern. I found that while I was using van Manen's existentials as a lens while reading, I could not break the narratives into separate existentials as they wove through each theme. I then pulled out parts of the narrative that told part of a participant's experience and highlighted specific phrases or words that resonated with me. The following example of my interpretation shows how 'lived space' affected Nancy in the hospital environment.

*This was really getting me down been in this dark little room with the curtain around me and just sitting around for 12 hours a day until it's time to go to sleep again. They moved me over to the other ward and that was a big game changer. Just having a window with a view is so significant when you're in there for a period of time. I think for most of the 3 months I was there I ended up in a really nice room. It had a huge bay window and it looked straight out over Sky tower and over the city. It had a couch for visitors to sit on, I was lucky I had visitors pretty much daily. Even periods when I was on my own, I could sit on the couch and do my crossword, or read a book, or observe what was happening in the outside world. (Nancy, 12 weeks in hospital)*

After initially reading and finding the theme of dark rooms, and the affect this had on Nancy's mental health, I read more of the participants' transcripts to see if this theme showed again. Nancy's description of experiencing 'dark, dark rooms' made her feel unsafe. Her mood improved when moved to a room with a view. I used van Manen's concept of 'lived space' to interpret this paragraph as this showed how the space around us can impact on how we feel (van Manen, 1990, 2016). Following this theme of dark rooms, I discovered a pattern of similar experiences within other participants' stories. These experiences were grouped together and a title given from the interpretation, "feeling unsafe." The titles were changed and moved around as the parts of the data merged into the whole from the participants' stories. Interpretation of the data began slowly as I read and reread the participants' stories. I found my interpretations improved as each chapter evolved.

My initial thematic analysis was sent to my supervisor multiple times as I interpreted the data. After our discussions, I would then re-read and re-write discovering how each of the themes fit together. As I delved deeper into the narratives, I found sub-themes within the whole and bit by bit these came together. I was able to then identify four main themes with sub-themes embedded. This structure enabled me to read, write, and re-read to begin to see where in the big picture each of the interpretations would fit.

During this process, I began to understand the purpose of the hermeneutic circle, that it was not about editing but about moving through the narratives over and again, narrowing the smaller parts into a greater whole, without losing the important data. I reflected on what I had read, written, and re-read and checked in with my supervisor that she also could see the whole. I was able to gain further insight from presenting at research symposiums and found my data resonating with other midwives.

### **Trustworthiness**

Phenomenological reflection is only one interpretation of the narratives. In my interviewing, transcribing, uncovering and analysis of the themes discovered, I discussed my own description of the women's experiences. There is always the possibility that another researcher could read the transcripts and see something quite different (Brink, 1991). Validity is a term from the Latin *Validus* which means strong (van Manen, 2014). For a phenomenological study to be valid or strong involves the process of suspending the researcher's pre-understandings and acknowledging any bias at the beginning of the analysis. Other measures of validity used in non-phenomenological research such as content criterion and context validity, and coding do not apply (Koch, 2006; Rolfe, 2006; Smythe, Ironside, Sims, Swenson, & Spence, 2008). Koch (2006) argued that trustworthiness may be established if the researcher is able to provide evidence of events, prejudice, or researcher actions. Prejudices are carried with us as experience in the world and are not necessarily a negative in phenomenological research. Our value positions can, instead, make the research meaningful (Koch, 2006). I acknowledged my pre-understandings at the beginning of my research as I had been in a similar situation to the women in my study. My experiences provided an idea of the challenges these women faced, focusing the analysis on what the women were saying.

Establishing trustworthiness in phenomenological research can be enhanced when discussing or describing the research to peers and checking for resonance with them.

Resonance can mean the ability of sound to resonate in your hearing or that a particular phrase or word resonates in your mind or memory (van Manen, 2016). While immersed in the data, I often discussed with family and friends some of the words or phrases that had particularly spoken to me. I found these words often resonated with the people to whom I spoke. I presented some of my findings at a research symposium and had midwives I had worked with come to me and say they had seen and heard the very stories my participants had given. These words and phrases would resonate with the person to whom I was talking, and this was important to me as it indicated that what I thought I was reading in the reflections could truly be important. With this sharing of my thinking, I was testing the validity of my findings. Smythe et al. (2008) described resonance as “an attunement that is ‘known’ but cannot be pinned down, is the hallmark of trustworthiness” (p. 1396).

Analysing the extensive narratives of the women hospitalised in their pregnancy eventually provided my answer to the question, “what is the experience for women hospitalised for an extended time in their pregnancy?”

## **Conclusion**

Finding the best design for research was an essential part of the research process. In this chapter I have discussed the design of this study including which methodology and methods were used. The background of the chosen methodology, the history, and influence was discussed, as was the reasoning behind my choice of methodology. The ‘hermeneutic circle’ was considered and how using this became evident in my analysis. van Manen’s (1990, 2016) hermeneutic approach to phenomenology and thematic analysis of the data using the lifeworld existential framework was described. My pre-understandings and biases, what my experience meant as a midwife and a childbearing woman, were explored and acknowledged. The practical aspects of research methods such as recruitment, participants, ethics, interviewing, data collection and analysis were described. Trustworthiness was also discussed within the framework of phenomenological research.

The following four chapters will discuss the findings and explain the themes uncovered from the data.

## Chapter Four. Findings

### Introduction

I sought an answer to the question “what is the experience for women hospitalised for an extended time in their pregnancy?” As described in the methodology chapter, van Manen’s (2016) four lifeworld existentials—lived body, space, time, lived human relation—provided a lens to analyse the participants’ stories of being hospitalised during pregnancy. Interpretations of the participants’ experiences revealed the following four themes:

1. Feeling displaced
2. Feeling unsafe
3. Doing time-feeling imprisoned
4. Coming out the other side

The following chapters will explore each of these four themes and the sub-themes. The four existentials of lived body, space, time, and lived human relation can be differentiated, but not fully separated, as they form the lifeworld in which we exist. During analysis, I separated the themes but discovered that I could not do the same for the four existentials. Therefore, these are intertwined within the themes (van Manen, 2016).

To stay true to the women’s stories, I have woven their voices—their recollections and reflections—through the findings. This means that the analysis is not in chronological order but stays true to the women’s recollections of their experiences. The participants were as follows:

- I. Katherine, hospitalised for 2 weeks due to chronic pain
- II. Jemima, hospitalised for 6 weeks for placenta previa and bleeding
- III. Veronika, hospitalised for 12 weeks for bleeding, low lying placenta
- IV. Felicity, hospitalised for 6 weeks, rare twin pregnancy
- V. Kristin, hospitalised for 13 weeks, threatened preterm labour
- VI. Daisy, hospitalised for 2 weeks, premature rupture of membranes
- VII. Siena, hospitalised for 2 weeks, pre-eclampsia

## Feeling displaced

Having control over our body, mind, decision making, and surrounding space creates an autonomous state of being. For the study participants, the experience of being hospitalised removed this autonomy and limited the control they had over daily activities and decisions. This loss of control led to feelings of guilt and fear, impacting their relationship with others, and their physical and mental well-being. Many of the women described feeling, in some way, a loss of control due to not being in their home and away from family. This, the first findings chapter, explores the theme of not feeling “at home” or feeling displaced. Three subthemes emerged that show this theme:

1. Feeling shock when hospitalised
2. Feeling scared
3. Feeling guilty

Participants spoke of the biggest challenge as suddenly leaving their home and family to be hospitalised indefinitely. Having to be somewhere that was not their home led to a feeling of displacement. They described being in a shocking, scary situation, and felt the added burden of wondering how the family left at home were coping. This feeling of guilt added to the already dreadful burden of not knowing how long they would be away, concern for the unborn child, and the feeling of being unable to do anything about the situation. The participants’ feelings of no control left them feeling like they were prisoners, trapped by their condition and the recommendations of the health professionals.

### Feeling shock when hospitalised

Kristen was still working the day she was suddenly flown to another city, 26 weeks into her first pregnancy. She had spent the day at work and went for a scheduled scan.

Within minutes she became an inpatient and was sitting, waiting to be taken in a plane.

*I was shocked, I think I was in shock for most of it. I'd worked the night before, I did a clinic that morning... I was only working up to 27 weeks, because I knew my pregnancy was probably going to be high risk... I wasn't too shocked in the mix of that, in the sense I knew something would happen. I didn't know I was going to hospital though; I didn't think that was kind of how it would go. I had to go have a scan and then after the scan I'm being wheeled back round to maternity and I'm what's going on?*

For Kristin, the shock of needing to be sent away was in contrast with what she imagined her pregnancy to be like. She was prepared for some aspects of a high-risk pregnancy; but not prepared for it involving such early intervention and being sent away from home completely into the unknown. Kristen was thrown into a situation that could not be planned for or predicted. Heidegger (as cited in Wrathall, 2005) discussed ‘thrownness’ as being thrown into a mood. Shock, such as Kristin described, has not come from within or from outside sources but has affected how one feels by changing one’s state of mind (Gadamer, 2005; Wrathall, 2005). Kristin felt that what was happening could not be real, the shock of the moment made her feel displaced from herself and her situation. Her situation appeared dire and she was left wondering what would happen.

Kristen sat in a hospital contacting her husband, who was away, and her work partners. She described this time as a “bit of a scramble.”

*I had to hand over my list of clients and all that stuff and my husband commutes to Auckland for his job, so he does a week a month and he’d just left, and I was like “what?” So, it was all a bit of a scramble. There was no closure, I didn’t even get to say goodbye to my cat and then I was gone for two months.*

Kristen was shocked and thrown by the suddenness of her hospitalisation; she needed to reorganise her life quickly and leave. Not only was Kristen hospitalised so unexpectedly, but she was flown to a different region from her home. She was moved away from home, family, work, and familiar surroundings. Kristen was not in control of where she lived or what her body was doing. Her individuality was gone and now she was a ‘high-risk’ woman, her body was no longer her own. van Manen (2016) spoke of the ‘lived body’ as how we are bodily in the world. The body we show to the world is how we would like to be seen and can hide or reveal who we feel we are. Kristen was no longer just her body but now a ‘pregnant body’ and a high-risk pregnancy. Kristen’s experience of separation from her family included her concern towards family members that had needed to take on new responsibilities. She was left feeling completely displaced and uncertain of the future. We predict our future based on our past and present experience; when the present changes, the future can become vague, unreliable, and unpredictable. The lifeworld existential ‘lived time’ describes the future as “the horizons of a person’s temporal landscape” (van Manen, 1990, p. 104). For Kristen, being flown to a different city, and separated from everything, changed her future landscape and she was now unsure what to do—shock turned to fear of the unknown.

Siena recalled the shock on the day she went to see her obstetrician for a routine visit.

*He (the doctor) received my blood work results the day prior and couldn't wait, he asked me to go into his office right away. That same day, on the spot, he told me I had pre-eclampsia. We had to go in that day (to hospital). We got a shock, the week before I was tested for high blood pressure so I kind of knew something was coming up. My doctor and I had an understanding it was just hypertension and it would be treated with hypertensives; I think for both of us it was quite a shock. He was trying to be calm when telling us the implication of pre-eclampsia and hence the reason I must be hospitalised right away. It was quite a shock.*

Siena had an understanding with her doctor that she was developing hypertension in her pregnancy but was not prepared for needing to be hospitalised. She and her husband (she included him in her experiences) were shocked. An unexpected diagnosis and the following admission to hospital threw Siena. The concept of 'thrownness' is described by Heidegger, as cited in Wrathall (2005), as the state of being thrown into the world of being. Siena tried to cope with the implications of the sudden hospitalisation while noticing that her doctor was *trying to be calm* while informing her of the diagnosis. The implication of been hospitalised had not yet occurred to Siena due to the shock she was feeling. Siena displaced her own feelings and focused on what she thought the doctor was experiencing, worrying for someone else rather than herself. Coping with an unexpected diagnosis and then discovering that she was being hospitalised for an unknown period of time, shocked Siena to the core. To also realise that this would mean leaving her home and family to go to unfamiliar surroundings impacted dramatically on Siena's well-being and led her to feeling displaced from her normal life.

Shock from been thrown into an unexpected situation can turn to fear for themselves, their family, or of the unknown. Following on from the initial shock of hospitalisation, some of these women began to experience fear and felt scared. Being thrown into an unfamiliar situation, in a place not home, and with people they did not know or trust, was detrimental for the participants' mental well-being.

### **Feeling Scared.**

Felicity described how the fear she felt for her son at home and needing to share her space combined to negatively impact on her health. Felicity was in hospital for 6 weeks during her pregnancy and described her initial experience of being away from home as:

*It was pretty scary, especially being away from my 2-year-old son... It's just living somewhere that isn't your home for that period of time and also knowing I will be stressed every day, it was quite overwhelming.*

Felicity was hospitalised at only 26 weeks pregnant with a rare type of twins. Felicity found this separation from her family, especially her 2-year-old son, to be *pretty scary*. Felicity felt overwhelmed with fear being away from her older child; a fear compounded by now living somewhere that was not her home. For Felicity, this fear was experienced as overwhelming stress and feeling displaced from her normal way of being. Living with a high level of fear and stress would have a serious negative impact on Felicity's mental well-being. van Manen's (2016) concept of the existential 'lived body' permits us to acknowledge the impact this fear would have had on Felicity's physiology and mental well-being, the body as well as the mind is a connection to the lived world. Heidegger (as cited in Healy, 2011), spoke of moods, such as fear, coming from being in the world. The world around us can affect how we feel in a positive or negative way and is often out of our control (van Manen, 2016). Living with that amount of fear, and knowing it was only making the experience worse, impacted negatively on Felicity's psychological balance and physical health. Felicity's fear was not only for herself but her family at home and the burden she was placing on them and for her personal space which was being invaded by strangers at all hours of the day.

Felicity felt more fear when she came back after day leave at home to find her property, in her bed space on the hospital ward, had been disturbed. She voiced her concerns to the staff who offered to talk to her neighbour.

*I felt very, very unsafe. I came back after being home during the day and some of my things in my room had been moved. I told one of the staff and they said, "do you want me to talk to them about it?" I said "please, please don't (talk to my neighbour)," I'm scared, you know. You just can't relax, always worrying. It was just really hard. I was so worried about it (the stress), I was trying to stay calm, but I couldn't when things that bad were happening.*

Felicity begged the staff not to talk to her roommates as she was worried about the repercussions of them knowing she had noticed her belongings been touched. Felicity not only feared the person with whom she shared the room but feared the consequences of the staff talking to that person. Felicity now felt she could not leave her belongings unattended and worried for her own physical safety as her roommates did not respect personal boundaries. Finding her belongings had been touched was difficult for Felicity

as she could now leave nothing in her own space in the hospital and know that it was safe from strangers. Felicity began to feel physically unsafe in the environment she was forced to be in and felt she had no control over her space. Felicity found that the bed in the hospital was less secure than home, even more foreign and impersonal. Her need to be at home grew even more.

Felicity described the impact this feeling of displacement had on her.

*The pregnancy was stressful, I wasn't sleeping and then that (her belongings touched). I was worried for them (babies) because I wasn't able to cope, it was too much. I started seeing them (Maternal Mental Health, MMH) and it was a godsend. Then we talked to the doctors and that was when I could go into my own room. After that I could just relax and not be tense and not be scared and use the bathroom without men in there.*

Felicity was struggling to stay positive in a challenging situation but found that having her belongings touched was one stressor too many. Felicity was feeling so overwhelmed with fear and stress that she found it difficult to remain positive and calm for both her own and her babies' health. The impact of the stress and fear made Felicity feel mentally unsafe as she could not relax her vigil at any time. Felicity eventually felt she could no longer cope and told the staff how stressed she was feeling and how it was impacting on her well-being. Felicity was seen by the MMH team and, with their input, was able to be assigned a single room with a private bathroom. For Felicity, the relief of having her own space in which to relax and centre her thoughts on her growing babies was a positive turning point. She could now focus on keeping mentally and physically well for her twins. van Manen (2016) discussed how our lived space can affect how we feel in the world and, subsequently, how this feeling can impact what our place out of our normal space could feel like. van Manen (1990) stated:

lived space is more difficult to put into words since the experience of lived space (as lived time, body) is largely pre-verbal; we do not ordinarily reflect on it. And yet we know that the space in which we find ourselves affects the way we feel. (p. 102)

For Felicity, forced into sharing a room with strangers whom she could not trust, elevated her fear and stress, negatively affecting her mental health. Felicity was out of her home and felt displaced from her normal reality. Felicity was very aware how the space she was forced to be in impacted on her health, it took until she was almost overwhelmed by the experience before she felt she could speak up. Feeling displaced from her normal life, Felicity was not in control of her feelings or decisions until the

need became urgent. Having the support of the MMH team and the health professionals, who were asked to acknowledge the impact of the shared space on Felicity, enabled Felicity to assume more control of herself and her choices. It took until she was close to becoming mentally very unwell before this happened.

Jemima also shared how she was not prepared for the shock and suddenness of her hospitalisation, which led her to fear losing the baby.

*I was going to fly down for my father's 70<sup>th</sup>, but they (doctors) said I probably shouldn't do that. The doctor said, "to be honest if it was me, I'd be saying no, just in case you have a heavy bleed." I thought, that sounds a bit dramatic but fine. I hadn't cancelled the flight, just playing it by ear, but then I woke up in a pool of blood. I thought, this is exactly what she told me could happen. I was really, really surprised, but I got what she had been saying, she wasn't overreacting. I woke up thinking, what's this? Am I in labour? You're not really thinking in the middle of the night and I thought I was losing the baby when we were driving into the hospital. My God am I losing the baby with this? I'd had a miscarriage previously. So I guess any bleeding, that was a warning sign. It took quite a while to trust my body because all the monitoring showed he was fine. With all that monitoring though, it does kind of make you nervous of something wrong with the baby.*

Jemima recalled how she did not really believe the doctor's warnings that she may bleed dramatically. She decided to "play it by ear," thinking that, more than likely, nothing was going to happen unexpectedly. For Jemima, waking up in the middle of the night in a *pool of blood* was surprising and frightening. Jemima spent the drive to the hospital fearing she was losing her baby. Jemima had experienced a miscarriage prior to this pregnancy and knew that any bleeding was not a good sign. She regarded herself as healthy; and pregnancy is a normal part of being healthy. Gadamer (cited in Dahlberg, 2011) spoke of health as a hidden character and that our health is taken for granted. It is not until something unexpected occurs and we become aware that our body is not always healthy, that we become fearful and begin to distrust our body (Dahlberg, 2011). Jemima found the continuous monitoring of her baby both reassuring and concerning as she began to worry that something was actually wrong, regardless of the machine saying otherwise. Jemima's shock and fear for the future of her pregnancy caused her to feel out of place. Being out of her home and away from family with her body not acting as she expected made Jemima feel displaced from her normal reality. Jemima began to doubt her body could hold onto the baby and feared the imminent loss.

Fear is described by Heidegger (Mulhall, 2002) as a state of temperament that we can be thrown into and caused to suffer by the actions of others. Moods, such as fear, are aspects of our being in the world and can affect many facets of our existence (Mulhall, 2002; Wrathall, 2005). Heidegger also described “thrownness” as a way we can find ourselves in a situation that is beyond our control, and that this sense of being thrown can lead us to fear or that we can be thrown into fear. Fear cannot always be controlled as we submit to being thrown into the situation; however, we can adjust to the circumstances to come out of the feeling of thrownness. Fear arises from being part of the world and our place within it. Moods, such as fear, can affect or be affected by our surrounding atmosphere. Feeling fear can also arise depending from the situation we are in at any one time (Healy, 2011; Wrathall, 2005).

For the women of this study, the initial shock and fear when first hospitalised changed to feeling guilty for needing to be in hospital.

### **Feeling guilty**

The women spoke of feeling guilty when hospitalised in their pregnancy; guilty, not because they had done something wrong, but because they had left their family at home to cope without them. They also felt guilt from taking up a bed in a hospital when they did not feel sick.

Jemima was admitted to hospital at 30 weeks’ gestation with a significant bleed. Jemima said she felt completely normal; and then she experienced a dramatic amount of bleeding and the possibility of losing both her and her baby’s life.

*It was a few days before Christmas and I knew I had placenta praevia already, but they (the obstetrician) were hoping that it would resolve itself. I hadn’t known I was going to have a big bleed and then one night woke up with a lot of blood. We didn’t know what to expect but I thought one night in hospital but that turned into three and then I wasn’t allowed to leave the hospital again. The hardest thing for me was guilt being away from my family, when physically I felt fine, felt very normal. There was the bleeding but that was painless, I had absolutely no pain for those 6 weeks.*

Even with this obvious threat, to both herself and her unborn child, Jemima said she remained unconcerned of her own health and felt more concerned about her family at home. Jemima found the hardest challenge of being hospitalised was the guilt she felt being away from her family. She goes on to say:

*So, the hardest thing was not so much my own health... my main concern at that stage was being away from my toddler for so long. Because he was struggling with it... I'm lying there in hospital on bed rest, not able to leave, not doing anything to help, just lying in bed and having this terrible guilt of my toddler at home and my husband at home doing a fulltime job and trying to balance all these things. I'm in hospital not doing anything, just knowing its chaos out there and I'm sitting there doing nothing.*

Jemima pushed her own health into the background; worrying about how her family was coping without her, rather than her own situation. She felt like she was lying in hospital “*doing nothing*” and “*feeling very normal.*” Feeling normal and a fraud, lying around doing nothing, Jemima ignored the fact that she was growing a baby and that the pregnancy was fragile. These feelings meant Jemima did not focus on the reality of why she was hospitalised in the beginning. Jemima felt “*terrible guilt*” about leaving her toddler at home and worried for her husband needing to take on the responsibility of work and home. Jemima felt that her role was to be at home for her toddler, she was more concerned of the affect her absence would have on her family. Any concern or real fear of what was happening to her or her unborn child did not occur to her. Jemima felt torn between the orders to remain on bed rest and her more primal need to be with her older child at home. Lying in a hospital bed, worrying about the impact her absence might be having on her family, caused her to feel she was not being the mother she thought she should be. Jemima also felt guilt for potentially ignoring her growing baby, wanting to feel attachment to the baby, while feeling more concern for her existing older child. Trying to balance the guilt she felt for her family at home with the guilt of not concentrating on her pregnancy caused Jemima to feel displaced from both. Feeling this burden made her hospital stay so much more challenging and did not leave space for looking after herself or her unborn child. Feeling guilty for taking up a hospital bed when she did not feel unwell caused Jemima to feel displaced from home, family, and her normal routines. This feeling of displacement made Jemima feel like she had lost control of her body and normal life, a prisoner of her condition and her perceived imperfect body.

Felicity also experienced feelings of guilt when she was hospitalised so early in her pregnancy. Like Jemima, she too left behind her husband and son and felt terrible guilt that her husband had to cope with both working and caring for their son.

*Just being away from my family, my son especially, he didn't understand why I wasn't there. I was feeling guilty not been there for him. It was just living somewhere that wasn't your home for that period of time and also knowing I will be stressed every day; it was quite overwhelming.*

Felicity found staying in a room that was not her home stressful and she was overwhelmed with feelings of guilt, knowing there was nothing she could do. Her pregnancy was so fragile and her worry for both her unborn babies was compounded by the guilt of how her husband and young son were coping at home. She was aware that stress could have a detrimental effect on her pregnancy and the feelings of guilt for the health of her family added to the already stressful pregnancy. van Manen (1990) suggested that as our home space is so meaningful for us, it is the only place in which we feel comfortable and can cope better with stressful situations. Not being at home, in her rightful place, made Felicity feel displaced from what she considered her normal. Felicity said her son could not understand why she was no longer there for him. She could not help him to understand as she was not in her rightful place at home caring for him and her husband. Felicity described being allowed to have day visits home later in the pregnancy.

*When they dropped the CTGs (monitoring) back to morning and night I could go home during the day. That did so much for my mental health. Coming home, seeing my son, seeing my family and just go back (to hospital) overnight. That really helped.*

Felicity found it difficult to cope with trying to keep the stress she was feeling normal for her babies' sakes. Being able to go home during the day helped Felicity feel less stressed as she was able to see her son and family. This made her feel more in control of her space and time and enabled her to relax and feel at ease in her own home. Felicity felt caught between two places; one her home, the other hospital. Felicity felt it was difficult to settle into home, relax and feel safe, knowing there was a time limit to returning to hospital; a place which was not home and made her feel guilty every day she returned to the hospital. There was also the added discordance Felicity felt knowing she felt safe at home but that her babies were safer been monitored in the hospital.

van Manen (1990) explored the concept of "role of a parent" and described the parenting relationship as "one of togetherness, homeness, being there for the child, intimacy, closeness. It is the relation of family, of living together by growing familiar together" (p. 108). Jemima's and Felicity's feelings of guilt stemmed from the feeling

that they were not doing something right or expected of a mother. They could accept that they needed to stay in hospital for the safety of their babies but found it difficult to reconcile this with the guilt they felt. Felicity and Jemima could have felt guilty as they were no longer in their rightful place, caring for their older child.

## **Summary**

This chapter explored the theme of feeling displaced due to not being in their own home. The participants described feeling “shocked” when the unexpected occurred and they were “thrown” into an unfamiliar and uncomfortable space that was not their home. Sometimes this shock remained with them for the whole of their hospital stay. This feeling of shock moved to fear or feeling scared; fear of the unknown, of what the future holds, of their mental health and even possessions. This fear or mood was ongoing for the participants and led to anxiety and stress, with a devastating and long acting effect on their mental well-being. Guilt became a challenge for the women as they were suddenly removed from the familiar family home and placed in a hospital room with a complete stranger, leading to a feeling of displacement. These women felt a terrible guilt from leaving their older children, partners, and family to pick up the load they had left behind. Some of the guilt felt was due to needing to stay in a hospital bed. These women felt like they were *doing nothing* or *just lying there* regardless of the fact that their pregnancy was fragile, and they were in fact doing a lot by keeping themselves and their baby healthy. Being somewhere that was not home negatively impacted on these women and their families, causing them to feel displaced from their normal lives. This feeling caused stress and anxiety at a time when they should have been concentrating on themselves and their health. The extent of the participants feelings of being displaced causing anxiety and in some cases depression contributed to feelings of being unsafe.

## **Chapter Five. Feeling Unsafe in Hospital**

The previous chapter discussed the findings of “feeling displaced,” where the participants felt shock when hospitalised, and fear and guilt due to not being in their own home with their family. This chapter explores the concept of safety and what makes us feel physically, mentally, and spiritually safe. According to Smythe (2010), women who are pregnant or birthing will expect to be kept safe and will ensure they make choices to keep themselves and their baby safe. Maternal anxiety can sometimes change how the woman perceives safety even if she is in a safe place. Smythe (2003) discussed understanding safety in maternity:

Understanding the meaning of being safe in the maternity services would be of no consequence if childbirth was always safe. Experience teaches us, that even with the best intentions, childbirth is not always safe. (p. 202)

What makes us feel safe varies between people and situations, and is influenced by cultural, emotional, psychological, and spiritual aspects of a person’s lifeworld. Women make choices for their health based on their personal perception of safety (Howarth, Swain, & Treharne, 2013).

The participants in this study discussed the experience of sharing their bed space with complete strangers and the challenges they faced. Sharing rooms impacted on their sleep, mental health, and physical safety. Participants spoke of feeling violated, and of sleep deprivation making them “loopy.” Some participants felt they were not being listened to, which led to distrust of the people attempting to help them and unsafe disengagement from the process.

Within the theme of feeling unsafe, there are three subthemes:

1. Feeling mentally unsafe
2. Feeling exposed - breach of privacy
3. Disengaging from safe care

### **Feeling mentally unsafe**

Sleep deprivation was a strong theme among participants who were challenged with the noise and constant disruptions while in hospital. Sleep is an essential component of

promoting healthy healing and to keeping mentally safe. Disturbed sleep in pregnancy can be a normal process of late pregnancy and the body learns to adjust. The constant interruptions—day and night—the participants experienced, however, was not normal pregnancy sleep.

Veronica was in hospital for three months and felt unsafe in an environment that did not allow for adequate healing sleep. She said,

*The sleep thing was a major challenge. I was shocked because hospitals are meant to be places where people are supposed to get better, yet they don't create an environment for that. It was awful. I remember a few short stints I managed to get at home it was incredible to sleep. I feel like they should be able to create an environment where people can actually get decent sleep.*

Veronika described being unable to sleep as a *major challenge* and could not comprehend how it was safe for her health. Getting adequate sleep when pregnant is a challenge in normal circumstances. Add in the constant interruptions that happen in a hospital ward and good sleep becomes impossible. Hospitals are where one generally goes when unwell; however, the participants who were hospitalised in pregnancy, but otherwise well, found the environment of noise and interruption impacted on their mental health. Veronika considered keeping physically healthy equally important as staying mentally healthy and connected the two in her mind. Veronika considered the hospital environment as unhealthy and unsafe for her. She considered her home the safest place to be.

Veronika recalled the first few weeks to be especially challenging:

*It was bloody hard, the first week was hell. Oh my God, this is awful, and it sounds petty, but I think it came down to lots of the rooms I was in. The first week I was in these rooms on the dark side of the ward. I had no view of the outside world whatsoever and I reckon I quickly started getting depressed, it was just awful. For me a dramatic situation, didn't know what was going to happen with baby, suddenly put into sharing these rooms with women I had nothing in common with and these dark, dark rooms.*

Veronika used strong words to describe her first week hospitalised. She called that time *hell*, *awful*, and *bloody hard*; and felt that it was due mostly to the room she was in. Veronika was unable to see the outside world and found living in the dark made her feel mentally unsafe. She feared not knowing what the future held for her pregnancy and

being in the *dark, dark room* began to affect her attitude, quickly making her feel both physically and mentally unsafe. The experience of having to stay in a room that was not her own space, away from the safety and familiarity of home, had a negative impact on Veronika's mental health. She described how she went to the midwives and explained how the room she was in was affecting her. Veronika did not know how long she was going to need to stay but realising it might be more than a few weeks encouraged her to speak up and make changes to keep herself healthy.

*This was really getting me down being in this dark little room with the curtain around me and just sitting around for 12 hours a day until it's time to go to sleep again. They moved me over to the other ward and that was a big game changer. Just having a window with a view is so significant when you're in there for a period of time. I think for most of the 3 months I was there I ended up in a really nice room. It had a huge bay window and it looked straight out over Sky tower and over the city. It had a couch for visitors to sit on, I was lucky I had visitors pretty much daily. Even periods when I was on my own, I could sit on the couch and do my crossword, or read a book, or observe what was happening in the outside world.*

Veronika had been sitting in a bed all day with the curtains around her unable to move away from that space, waiting for the day to end so she could try and sleep. Moving to a room *with a view* made a significant difference to how safe Veronika felt in the hospital. The large windows provided a view to the outside world. Veronika went from a dark room to a room filled with light, night and day, making her feel less confined and providing a feeling of safety. Veronika felt unsafe not knowing what was going on in the world or knowing what the weather was like. Being moved to a room with a window to the outside world had a positive impact. Veronika felt herself *lucky* to have visitors to relieve the boredom most days and found she could bear the long periods alone due to the outside view of the world. Sitting behind closed curtains for most of the day formed a personal space and the curtains were used to define this space as belonging to Veronika. The ability to be able to choose when, or if, she wanted to see or converse with her roommate was in her control. Most of the time the curtains would have been pulled around the beds precluding any attempt at connecting with the person next door. Developing a connection with her roommate may have helped Veronika cope with the situation; however, it can be difficult to develop any relationship with a person that is behind a curtain day and night. Veronika found safety in being able to keep busy while being able to watch the world go by had a significant positive impact on her mental well-being.

van Manen (1990, 2016) described the concept of 'lived space' and how the space we are in can impact on how we feel. A hospital is deemed safe; however, becoming an unsafe environment impacted negatively on the mental and physical well-being of the participants. 'Lived relationality' also weaves through Veronika's experience as she may have felt less stressed if there was someone right there to share experiences with but could, or would not, as they were separated by a curtain.

Jemima was also negatively affected by the interruptions and noise, impacting her ability to sleep. She struggled with sharing a room and recalled how after just two days she began to feel 'crazy'.

*I think the thing I really struggled with was with having a shared room, with sleep deprivation. I could handle it for a couple of days in a row, then when it got to more than that. Once I had a neighbour, she had to leave in the middle of the night...so she left at 12pm, then someone came in to clean her room, and someone at 1, 2, 3, 4, 5, 6. So I was getting woken up every hour, and hadn't got any sleep from the day before.... Doctors and nurses coming in all the time and so there wasn't a window for me to sleep. That was literally dozens of interruptions a day... it would get to 10am and I would literally feel completely crazy. So one night I got to the point that I said to the midwives "I need to go home I haven't slept it feels like a couple of days, I'm starting to go loopy."*

Jemima felt strongly that not being able to sleep, when she needed, impacted her mental health. She talked of feeling *loopy and crazy* from constant disturbed sleep. The disturbances came frequently, day and night, and caused Jemima significant distress. Jemima felt she was unable to have good sleep unless she was safe in her own bed, in her own home. Jemima was trying to cope with the challenges of a fragile pregnancy and sharing a room with constant interruptions had a significant impact on her mental health. Jemima continued to struggle with the shared rooms and lack of sleep until she finally felt she had reached the end of her endurance. For Jemima, the dilemma of being kept in hospital but needing to go home to sleep became a major challenge. Jemima was desperate for a good night's sleep as she felt herself tipping over the edge into unsafe mental wellness. For Jemima, the only safe place for her to feel mentally well and safe was her home. Whether the space around us is perceived as safe or unsafe is affected by the experiences within that space (van Manen 1990, 2016).

Jemima recalled when she recognised she was not able to cope anymore.

*I didn't want to sound petty; I knew it wasn't a hotel or anything... it was about survival mode. I felt like I'll wait until it gets worse, but it*

*gets to the point that I'm so, you're going loopy and verging on tears all the time and once you've had a night's sleep it's a huge thing. So, they let me sleep in the procedural room, which didn't have a bathroom in it, but there was a bathroom next door in the cleaning cupboard. I was having to move cots and things out of the way in the middle of the night to go to the bathroom, but it was my choice to be there to get some sleep. The sleep deprivation was an absolute killer, but then I got a private (single) room and after that my sanity levels went from rock bottom to abundant. I could get some sleep when I needed it.*

A significant change in her space impacted positively on Jemima's mental well-being; in such a way that she felt that she was able to do more than just survive. Jemima described sharing a room was a matter of being in *survival mode* and felt she should hold on and not say anything until she needed to. A hospital is meant to be a place of safety; however, the simple act of sharing a room quickly sent Jemima into *survival mode* and made her feel unsafe in her room. Struggling for sufficient sleep to function, made Jemima feel mentally and physically unsafe. Jemima knew something needed to change; thus, arranging to sleep in a procedural room to get some sleep was about "survival." The staff *let* Jemima sleep in the procedural room and, though less than ideal, being alone for a night's sleep was significant for Jemima. Having her own space for a short amount of time enabled her to store up enough energy reserves to be able to cope with the ongoing hospital stay. Jemima described how she felt *abundant* once moved to a single room with her own space, as she could sleep when she needed and was able to cope more effectively with the stress and anxiety of hospitalisation. As a result, she began to feel safer in that environment.

van Manen (1990, 2014) described the 'lived space' surrounding us as having a significant influence on how we feel and act. Feeling so unsafe in a place of supposed healing caused a dilemma for the participants who felt that the safest place for them was their home. Lowe (2016b) suggested the social discourse that women who are mothers must sacrifice everything to ensure a healthy baby means, that as a mother, Jemima would be expected to "put up with" not having enough sleep in the interests of keeping her baby healthy. For Jemima, sleep deprivation caused her to feel more unsafe than the threat of the pregnancy complications.

Felicity experienced challenges with the woman with whom she had to share her room. The lack of privacy was a challenge and added to Felicity feeling unsafe in the hospital environment. Felicity recalled the experience of trying to cope with a shared room.

*The first night there was someone sharing the room with me and then they went the next day and I thought I had the room to myself. In the beginning a new person came in every night at 2am, and I wasn't getting much sleep at all, and I was tense from being out of home. Most people were OK, it was just hard, sharing a room with someone and their partners would come too. Even though they weren't supposed to use the bathroom they were. Some of them would stay until 11.30 at night, when I went to go shower there is a strange man in the toilet, it was quite violating.*

Felicity used an emotionally strong word *violating* to describe how unsafe she felt while sharing a room with a complete stranger. Her roommate had people coming and going at all hours when they were not meant to be on the ward. Felicity tried to shower late at night to avoid meeting these strangers only to be confronted by a *strange man* in the toilet at 11.30 at night. This caused Felicity to be fearful of moving around in her room and made her physically unsafe. Felicity was very aware of the affect fear and anxiety could have on the safety of her unborn twins and this also impacted negatively on her mental health. Her pregnancy was high risk and she worried each day that she could lose one or both of her babies at any time. Felicity felt so unsafe due to the strange men in the shared bathroom that this feeling of being *violated* overshadowed her worry for the pregnancy.

A perception of what is 'our space' is embodied in van Manen's (1990, 2016) existential 'lived body' and what constitutes 'home.' Our home is our sanctum and provides feelings of protection and privacy, where the choices made are our own. The way we feel and act is often influenced by the place we are occupying. 'Home is where the heart is' is a common adage and can be a fundamental part of our 'being' (Lawn, 2006). Needing to be somewhere that is not 'home', could impact a person's inner being and have devastating effects on their mental health (van Manen, 1990). For the study participants, not being in their home led to their experiences of feeling unsafe in the hospital.

### **Feeling exposed-breach of privacy**

Lack of privacy was a major challenge for the participants. The only barrier in the shared rooms was a cloth curtain that obscured the view of the person in the adjoining bed but did nothing to block out conversations. Knowing their personal conversations were being overheard led to the women feeling their personal history was at risk and, subsequently, they felt unsafe being in hospital.

Felicity described how the beds were only separated by a curtain and she could hear everything being said to the other person. Then, of course, realised that they could hear her conversations too.

*You could hear everything about people's terminations and miscarriages and that's such a personal conversation, a stranger could hear. They could hear all my information too. There was a lady that came into the next bed and we had mutual friends, we didn't realise it at the time. She said, "oh did I hear you were having twins?" We hadn't actually announced it yet because it was such a high risk. I was thinking, "is she going to go out and tell people I'm here?" Luckily, she didn't.*

Felicity realised that in sharing her room she would be sharing her private information—not by choice. Felicity was unable to control what her roommates were hearing and unable to know who they may speak to in the outside world. Felicity felt her private life was exposed to the outside world against her will and she felt the safety of her personal life was at risk. Felicity felt very unsafe, with the person sharing her space because of what they had overheard; she did not want her personal history repeated outside the hospital. van Manen's (1990, 2014) existential of 'lived other' or relationality describes how we live with others in our world and the connections we form with them. Before physically meeting, we often make assumptions of whom the person is through talking with them or from overheard conversations. Whether we perceive that person as safe is coloured by what intimate details that we already know (van Manen, 1990, 2016).

Veronika found that over the course of the three months she was in hospital, there were few women who shared her space with whom she had any connection. She also found the lack of privacy made her feel unsafe in the hospital as normally we choose with whom we share our personal information. Veronika had no control over who overheard the very private conversations with the doctors. Veronika found the daily visits from the doctors challenging and described overhearing the conversations her roommates had with their doctors.

*I would have much preferred my own space over the course of the 3 months. I had one or two roommates that I connected with and we'd chat a bit. But, you know, it is such a private thing that you're dealing with and it's horrible to talk to the doctors knowing there's someone right there, or equally hearing their stories that they probably don't want you hearing. I had people who would bring in relatives and they would all sit around the bed. I heard another talking to her doctor about*

*having a separate medical condition and I asked the doctor if I was at any risk sharing a bathroom with this person.*

Veronika found that the necessity of sharing a room meant she would overhear private conversations between the other patients and their doctors. Veronika found these overheard conversations worrying and felt the personal details she heard were sometimes concerning. She overheard a discussion around medical issues that made her feel physically unsafe, due to sharing a toilet. Veronika stated she would have preferred to be in her “*own space*.” She felt safer at home and had control over what personal information she might choose to share. Lived space is an existential concept that describes the space surrounding us. The surrounding space can make us feel safe and comfortable or unsafe and scared. One’s home provides the safest space as it is familiar; being forced to stay in a place that is not home can make us feel insecure and unsafe (van Manen, 1990, 2014).

Kristin found that while she was hospitalised, other women wanted to share their stories. She describes how challenging she found these conversations.

*There’s no room, especially for the women who are in here together, where they can talk, like a lounge space. So, I found myself having conversations, telling me quite personal stuff about their lives and their pregnancies in the middle of the corridor. Because there’s nowhere for the women to be. I found that a bit challenging from a professional point of view. Anyone could be hearing you chat about this (their pregnancy), there should be somewhere to make a cup of tea with another Mum and go “how are you today?” It’s mentally incredibly hard work and it’s not always a box of fluffies, when you’re away from your family. You’re going to have good days and you’re going to have crap days, and some of those crap days are awful.*

Kristin was disturbed to find that the corridor was the only place that women had to talk about personal issues. Mentally, Kristin found this aspect of her hospital stay incredibly hard work and found other women’s experiences difficult to cope with at such a challenging time of her life. Kristin was trying to cope with her own stressful situation and found she was targeted by the other women wanting to share their experiences. Kristin would have liked to be able to sit down and chat with the other patients to share their stories. She found the concept of sharing personal stories while in a public place unsafe and this impacted on her own mental health. A private space for the women in hospital to talk openly about their pregnancies, complications, or families at home, and share their experiences with others that would understand the challenges would have

helped in making the experience less stressful. van Manen (1990), described the existential concept of 'lived relationality' as the way we maintain a relationship with others with whom we share interpersonal space. As human beings, we search for this connection and begin to trust another once we have learnt about them. Kristin found that she wanted to get to know and share her story with other mothers in the same place but felt unsafe doing so in a public corridor.

### **Disengaging from safe care**

The participants needed to be in hospital under specialist care due to their pregnancy not going as planned. For some, this became a challenge due to negative experiences within the hospital which led to them feeling mentally and physically unsafe. As a result, they then disengaged from the care that was intended to keep them safe.

Katy, early in her pregnancy, found herself in pain that did not seem normal. She discussed the pain with her doctor after a routine pregnancy scan detected gallstones.

*I went to my doctors, 20 weeks pregnant and said "I have gall stones, what can I do to manage it, is there something you can do?" and they said "there's nothing we can do, you can manage it with diet" ... "you'll need to go to a dietician for that." I said, this is pregnancy related, because pregnancy causes gall stones, and then she charged me for the visit. I thought "this is awful."*

Katy described the experience of asking the doctor for help as *awful*; she felt strongly that the doctor was not listening to her concerns. As the doctors could not help Katy, she lost confidence that any doctor could help. This disengagement with the first health professional she consulted led to Katy feeling unsafe. Katy began to disengage from the very people she thought would care for her when she was feeling so much pain. Katy's expectations of her pregnancy did not include crippling pain. She struggled from early in her pregnancy to enjoy her wanted pregnancy due to the pain she was enduring. Chronic pain is draining on the body and mind, and Katy had little energy left to fight for herself. Katy was unable to form a trusting relationship with the health professionals she met and felt her physical safety was in danger. A trusting relationship is an important aspect of engaging in care during pregnancy.

Katy recalls going to hospital, as her mother suggested. She presented several times to the hospital due to the pain.

*... they kept discharging me, they were "we can't do anything because you are pregnant, you'll just have to wait it out, go home, call us if it*

*gets worse.” I could tell that they were suggesting I stop coming in and wasting our time, we can’t do anything for you.*

Katy felt she needed to go back to hospital each time as the pain was unbearable but felt unwelcome. She thought the hospital did not take her pain seriously. The amount of pain she was feeling and the drugs they gave to help her with the pain meant that Katy’s impression of the health professionals was that they did not care. Katy thought she would be in safe hands in hospital but felt unwelcome. It caused her to wonder if she was actually unwell or she just did not understand her body’s messages. Katy began to feel unsafe and did not trust the professionals trying to help her. She assumed the doctors were there to keep her safe and would inform her if there really was something wrong, instead she thought they were suggesting that she was wasting their time.

Katy recalls how the pain she was experiencing suddenly worsened.

*It felt like something was wrong, something long term wrong. I went to the hospital and they said, “Oh it’s just biliary colic again.” But it wasn’t going away, they were giving me morphine and it still wasn’t going away. I felt a bit like they thought I was drug seeking, they would come in and say, “you can’t have any more medication because you’re pregnant and codeine is the only safe thing, we can give you.” Everyone that I talked to told me I shouldn’t take pain medication when I’m pregnant, there was real pressure to just push through it.*

Katy felt that the staff looking after her were not listening to her concerns; brushing off her feeling that something was *long-term wrong*. Katy felt that she was to try and *push through* and that she could not speak up and advocate for herself. Feeling this way, Katy distrusted the system even further and felt the hospital was not a safe place for her. The pregnancy was not going as expected and the condition she was suffering from was not pregnancy related. Katy reluctantly took the medication they gave her and felt unsafe asking for more when it did not work. She was aware that some pain medications could be unsafe in pregnancy but the pain she was in overrode that knowledge. Pain can make us feel unable to cope with anything. Feeling so much pain and not been able to articulate her feelings impacted on Katy’s well-being; making her feel mentally and physically unsafe.

van Manen (2014) described Buytendijk’s theory of pain, which states that modern society leaves no room for pain or illness and that it should not need to be endured at all. Pain can be helpful to keep the body safe. If we suffer pain, we will endeavour to

stop whatever is causing that pain or remove ourselves from the cause (van Manen, 2014). Katy assumed that the doctors would do their best to alleviate her distress and lost confidence in their abilities to treat her when they ignored her. Katy found that the obstetric team did not listen to her and she did not feel that they were safely caring for her. She felt they were not interested and instead accused her of not coming in early enough to be treated.

Katy recalled how her mother had to come to her rescue;

*My mum came to see me and had me moved to maternity and pushed for a scan to be done. When they did the scan that afternoon, they found there was a stone lodged in my common bile duct, which they could have picked up on Thursday when I went in, and if they had done that, they could have removed it and I would have been better... a consultant came and he said, "if you had come in the second trimester, we could have taken the gall bladder out," I said "I came in 4 times" (crying). So, they didn't want to do the procedure that would potentially put me into early labour or anything, but I was "but what about me?"*

Katy felt safer in her mother's hands and was able to leave the decision making to her. She recalled how the obstetric team, who had been involved in the early stages of her hospital visits, had told her that they did not want to do a surgery due to her pregnancy, that it was not safe for the baby. The suggestion from the doctor that she should have come in earlier distressed Katy, who had visited four times in early pregnancy. Katy understood that her pregnancy was important and felt the doctors overlooked how much pain she was in. She wanted to keep her baby safe but found she could not cope with the pain she was experiencing. Katy felt that her own safety was ignored and that the doctors only seemed concerned that the baby was not harmed. Katy's trust in the doctors was low. She had little control of her decisions and did not expect their care to keep her safe. Feeling her voice could not be heard by the doctors caring for her, Katy let her mother take over as she felt safer; further disengaging from the service that was meant to be keeping her safe.

van Manen's (1990, 2016) existential 'lived self-other' or relationality describes the phenomena of community and connection. How we connect with those around us depends on the relationship we have with them. This relationship may not form or could be damaged when trust is broken. Katy would have lost trust in the health professionals treating her, felt unsafe in their care, and felt they were not listening to or acknowledging her concerns.

Daisy also experienced feeling unsafe when hospitalised in her pregnancy. She recalled the day she had a small amount of bleeding and, after meeting with her midwife in the hospital, discovered that her waters had broken too early in her pregnancy.

*I was admitted and on that first day went into very early stages of labour, they gave me medication to stop it. I didn't react well to it, it was horrible. Then I stayed overnight, and they said it was highly likely I would go into labour again. Nothing happened and I didn't go into labour, so I was just admitted indefinitely. The next day after a scan one of the doctors came into my room and said, "My goodness they do like babies the right way around." I said, "Are you sure?" And she was "I have looked at the scan and everything is right way around, you can go home if you like." I said to her, "I really don't think he has moved, because they say that when they move you know about it." But she told me I could go home.*

Daisy's baby was in the breech position and she was admitted to hospital due to the risk of labouring. She recalls been surprised, but doubtful, when the doctor decided to send her home. For Daisy, this was a confusing and stressful time. She recalled that it was not safe for baby to be born normally as he was breech and being told that she was safer to remain in hospital until baby was ready to be born. Daisy was sent home when she knew that her baby was still breech, she was quite sure that the baby had not turned. Daisy did not trust what the doctors had told her, so she went to her regular midwife's appointment. Her midwife confirmed that the baby had not moved and was still in the breech position. Keeping safe, for Daisy, meant staying in hospital and doing as the doctors had suggested. Women, such as Daisy, will ensure that everything is done to keep their unborn baby safe. Being safe does not always mean that a good outcome is achieved as we can be thrown into situations or circumstances that cannot be controlled. However, ensuring that safety is part of the experience, and of making the best decisions at the time, gives the safest of cares (Smythe, 2003). Daisy wanted to trust the doctors had given her the right recommendations. Finding this was not the case, led Daisy to lose trust in the doctors and feel unsafe with their decisions.

Daisy described how she felt as she headed back to hospital.

*I had to go back, didn't even get to go home, I was so, so mad. I went back and I think by this time it was about 6pm and no-one came to see me. Me and my husband waited and waited and eventually a woman came in with a bedside scanner, but I could tell she had no idea what she was doing, not a clue. She kept scanning around going like "oh, not too sure, that looks like a head don't you think? What do you think that looks like?" I just looked at her and said, "I don't know I'm not a*

*sonographer.” So basically, she kept doing that saying, “Oh what do you think that is?” I was looking at my husband and thinking, get this woman out of my room!*

Daisy described how *mad* she was having to return to the hospital and then feeling upset when she had to wait for a doctor to see her. Daisy and her husband were made more nervous and anxious with every moment and felt unsafe in the hospital. Daisy felt less trusting of the health professionals’ opinions at this time and felt that their decisions seemed to be putting her baby’s safety at risk. This distrust grew when a different doctor came into the room late at night with a bed-side ultrasound scanner. Daisy felt she could not trust this doctor as she seemed incompetent and wanted her out of her space. Daisy had very little confidence and felt physically unsafe at this stage and began to disengage further from care. She felt very unsafe in hospital as some doctors would advise her of the risks of leaving the hospital; yet, others “allowed” her to go on home leave. Daisy felt her safety was at risk from being in hospital and not being at home where she felt safe.

*I got the sense, and I totally understand that I wasn’t a high-risk patient... but I felt they kind of pushed me off to the side. It got to the point I was sick of the doctors coming into my room. In the end I thought I don’t care anymore; I’m going to get the CTG (monitoring) done and go out. I thought I don’t really care what the doctors have to say anymore because it’s not anything new, it’s not interesting, I’d wait in my room and some days no-one would come to see me at all.*

Daisy felt disengaged and distrusted what the doctors were saying as they were contradicting their recommendations. As a result, she decided they were not worth listening to and felt her safety was not been considered. Daisy decided that as there was no consistency with what she was been told, she would do as she felt best. Daisy was aware of the potential risks to her pregnancy but felt that if the doctors had so little interest in her that everything was fine. Daisy had little control over her situation as she felt that there were unsafe inconsistencies in what the doctors were telling her. With lack of consistent reporting from the doctors, Daisy decided to take control and do what she thought best.

van Manen (2014) described how our fears can be alleviated if an explanation is given. If a physician can give a good explanation of what may be happening, or going to happen in the near future, it lessens the anxiety and distrust (van Manen, 2014). Gadamer also spoke of our dialogue being held in a place of trust, that communication

will happen if both parties are willing to trust that what is being said is essentially the truth (Gadamer, 2005; Lawn, 2006). A trusting relationship between patient and doctor ensures safe outcomes. For Daisy, the lack of a trusting relationship with the doctors led to her feeling unsafe and disengaging from their care.

Veronika describes how, when she was hospitalised, she discovered her own doctors as her LMC, would no longer be caring for her.

*I was given these hospital doctors because I was a patient on the ward, so I was under the care of the team. They would come in and do their rounds daily, a lot of the time they didn't seem to know my story. I'd see someone different every time. I found the whole me, as a patient sitting in a bed and five doctors staring at me, quite awkward. I felt like I was having to tell the doctors why I was in there and then there was this weird thing going on for a while, when there was this tension going on between the two of them (hospital and private doctors).*

Veronika found that on a day to day basis she would have different doctors from the hospital teams coming in to discuss her case. Veronika trusted and felt safe with her private doctors as she knew them but did not feel safe with the hospital team. Veronika described having five doctors stand around her bed discussing her as *awkward*; and though she was right in front of them, she was ignored in the process. This 'medical gaze' made Veronika feel unsafe as she had no control over who would enter or speak in her bed space. van Manen's (1990, 2016) concept of the 'lived body' suggests that the way in which we feel another's gaze or observation of our body changes the way in which we present that body. Veronika felt unsure of her place as she was not in her own space and the added gaze of these unknown doctors made her feel personally unsafe. Veronika also found that while the hospital team were in charge of her care while she was on the ward, her own obstetricians seemed to have little say in her care.

Veronika described how she did not trust the team doctors to make decisions.

*For me it was, well I'm paying for a private obstetrician and I'm told he is the best and if he thinks I should have a scan, I really trust him, I don't know you from a bar of soap. I found that hard as a patient to be kind of stuck in the middle of that at the time. I'm sure he stood up for me, obviously I wasn't privy to the conversations they had, but it was just a bit of an interesting dynamic too, the "who's in charge?"*

Veronika had no relationship with the teams of hospital doctors as they changed frequently and often offered conflicting advice. As an in-patient, Veronika felt "stuck in

the middle;” a situation that made her feel unsafe. Veronika was under enough stress and worried who was making the decisions and whether they were keeping her safe. Feeling unsafe with the team caused Veronika to disengage from their care as she questioned the lack of continuity and thought “who’s in charge?” This caused her to mistrust the hospital team, preferring to listen to her private obstetricians.

Communication is an essential tool in gaining and maintaining trust, conversing as an equal will give both parties control of the situation and the ability to commune at an equal level; trust gives a sense of safety (van Manen, 1990, 2016).

Siena also found being in hospital, suddenly under the care of someone she did not know or trust, made her feel unsafe.

*After I got admitted to the ward, I wasn't told much what was happening. I suppose that was up to the doctors to tell me. I have to say that overall the midwives that I met were extremely helpful; they were professional, really, really good. The only thing I kind of thought throughout the time was the doctors that were providing care. I didn't know that I was going to see different doctors every day. That wasn't so much an issue until when it comes to the weekends.*

When Siena found herself an in-patient, due to the pregnancy complication preeclampsia, it threw her into confusion. She found the lack of communication from the hospital team of doctors frustrating. Siena recalled not being told what was happening or what would happen, she felt they were not keeping her safe. She trusted her private doctor to keep her safe while in hospital as the hospital team were not providing this reassurance. Siena was also not aware that she would be seeing different doctors every day and found this difficult as she was unable to form any sort of trusting relationship with the team. This distrust made Siena feel unsafe with their care and she disengaged from them. Siena recalled that the midwives supported her and often explained or ensured some consistency to her care, making her feel safer with their support. Weekends became particularly challenging as the plan that had been made by the doctors during the week would be challenged or abruptly changed by the weekend doctors.

Siena recalls when the weekend arrived, and the doctors changed again.

*There was one time that during the week the team doctors were saying that I didn't really need to start on the medication yet, because there was no need to start on it, trying to keep the perfusion up so there was still blood flow to the baby. When the weekend came and it was a different doctor, he decided to start me on the medication. The midwife*

*that was checking my blood pressure at the time saw that I was kind of hesitating and she offered to check with the doctor whether he really wanted to do it. That was hard, but it was good I felt that it was someone on my side.*

Siena found the lack of continuity and consistency one of the biggest challenges during her stay. She knew that she did not need the medication that weekend but was not confident she should challenge the doctor's decision as she did not have a working relationship with the weekend doctor. Siena described going from a trusted practitioner to a completely different system that she did not know or understand made her feel unsafe in their care. Siena felt the weekend doctors did not understand how she was kept safe under the care of the other doctors and felt the changes they made put her and her baby in unnecessary danger.

van Manen's existential of lived body suggests we are seen by others in the world by our physical body. Under the gaze of a critical health professional we may become less confident in what we know of our body (van Manen, 1990, 2014, 2016). The women in my study felt they lost all trust in the health professionals they were dealing with and were unsure that the advice they were given was right for them. This led to them disengaging from the service that was meant to be keeping them safe.

## **Summary**

This chapter explored ways in which the participants felt unsafe while in hospital for an extended time during their pregnancy. Hospitals are deemed to be a place of safety, to go and be healed—not harmed (Douglas & Douglas, 2004). The health professionals, wards, and treatment are meant to provide a safe haven for the body and mind to heal and be able to go back into the world healthy and safe. For the participants, their experience of being hospitalised during their pregnancy proved anything but safe to them. Analysis of the data showed three subthemes emerging.

The ways in which the participants found that sharing a bed space with a stranger created a feeling of becoming mentally unsafe was discussed. Often this feeling of instability was due to sleep deprivation. One participant described the experience of lack of sleep making her feel *loopy* or *crazy*. Some chose to make 'sacrifices' such as sleeping in a procedural room if they were unable to go to the safety of their own home, just to get a night's sleep. Other challenges described by the participants included *violation* of personal space and the realisation that they were not safe in their designated

bed space. Participants described the *dark, dark rooms* causing a rapid decline in mental wellness and safety. Simply changing to a room with an outside view, from dark to light, created a much healthier atmosphere and, consequently, made them feel safer.

Sharing a room separated only by curtains, made the participants feel emotionally and personally unsafe as their personal discussions could be overheard by the neighbouring roommate. A curtain provided a barrier to seeing the person in the other bed it did not stop personal conversations from been heard. Sharing a room meant sharing their health history and, consequently, knowing a complete stranger's history. Being aware someone could hear one's every conversation with doctors, midwives, or visitors made the participants feel uncomfortable and unsafe. The information they were overhearing caused them to feel physically vulnerable and mentally unsafe.

Participants who lost trust in the health professionals charged with keeping them safe in their pregnancy and led to a disconnection from the carers. The participants found there was noticeable lack of communication or collaboration occurring between themselves and the health professionals. If there was a loss of trust, the women disengaged from the health professionals' care, as they felt unsafe. The women of this study described times when the health professionals they engaged with did not listen to their concerns or appeared incompetent. This led to a lack of trust in the system and disengagement from the very care that was to keep the women safe in their pregnancy.

## Chapter Six. Doing Time-Being Imprisoned

Following on from the previous chapter, which discussed feeling unsafe, the third chapter considers how the women felt trapped or prisoner while hospitalised during their pregnancy. They found they were unable to move around or leave if they wanted, unable to eat food they enjoyed or considered healthy, and that their perception of time was changed. This chapter comprises three sub-themes of:

1. Feeling imprisoned in the room
2. Loss of control of diet-imprisoned by the food
3. Losing time

### Feeling imprisoned in the room

Many of the participants were unable to move around the hospital or out of the hospital grounds due to the fragile nature of their pregnancies. They struggled with feeling trapped by the restrictions on their movements. The women spoke of how they were either 'allowed' or 'not allowed' to leave their rooms or hospital grounds and how this made them feel as if they were prisoners, with no choice but to do as they were told.

Kristen recalled spending the first 5 weeks in a tertiary hospital before being ambulated to another hospital closer to home. Kristen was not 'allowed' to go back to her own home, she recalls how she felt at that time.

*They kept me in hospital from the 23 weeks up until just 28 weeks and then they transferred me (to another hospital). I'm an hour away from the hospital, 45 minutes at a push, I could have gone home, and we would probably still be fine. I'm thinking all this stuff (baby viable) and they refused to let me go, and then they said if you go, we can't necessarily take you back and it was almost like a kind of threat. I'm thinking, well that's bullshit because if I turn up, you're still going to have to take care of me, because that's your premise for the hospital.*

Kristen's experience of the demands of the doctors over her own self-awareness caused her to feel she was losing control. Kristen felt that her condition was stable, that baby was of a viable age, and that she only lived a short distance from the hospital. She argued that she was sensible and that she was close enough to the hospital should labour begin. Kristen felt the doctors put pressure on her to remain in hospital and she felt trapped in a place she did not want to be. Kristen knew, from personal experience, how labour and birth worked, and she knew her own body. She challenged the hospital on

their threat if not accept her if she chose to go home, as she knew they would have to accept her if something happened. The pressure to stay or face the consequences caused Kristen to begin to lose confidence in her own body. She felt sure her instincts were right but with the admonishments from the hospital team insisting she remain on the ward; Kristen began to distrust her instincts. Kristen was not ‘allowed’ by the doctors to leave the hospital and they used intimidation to ensure she made the decision to stay. This intimidation made Kristen worry that she was wrong and that they might not *take care* of her if she chose to leave. van Manen (1990, 2016) discussed how the ‘lived space’ we occupy can affect how we feel and act. Kristen found this feeling of being trapped against her own desires disempowered her and made her distrust her own feelings. Feeling trapped in the hospital impacted negatively on Kristen’s mental well-being.

Kristen described when she realised that she could not stay trapped in the hospital any longer.

*I was in hospital after being transferred for 3 days and then it was the weekend. My husband and I booked a motel across the road from the hospital as they wouldn’t let me go home. I went back to the hospital Monday morning and I realised I couldn’t be there anymore. I fell apart then, and I think it was the whole thing with being institutionalised and understanding all the rules and all the procedures. I had a breakdown, and of course, they did all the Edinburg stuff, because I was emotionally wrecked. They were asking if I wanted to kill myself, No I don’t want to kill myself I just don’t want to be in your hospital anymore. Written all through my notes was “declined intervention, declined this” and I’m are you frikken kidding me?*

Kristen was so distressed with the long hospitalisation that she felt as if she “*fell apart.*” Her mental health declined, and Kristen felt misunderstood; she knew the risks and was confident in her knowledge of herself, only to feel accused of not looking after her pregnancy. Kristen had been hospitalised for so long that she felt “*institutionalised.*” Trapped in a place she did not want to be, and having no control over the situation, caused significant harm to Kristen’s mental well-being. van Manen (2014) spoke of “the body of the self-observed” (p. 332) as postulated by Merleau-Ponty. If our bodies are perceived as unreliable due to illness, pain, or the diagnosis of a physician, we lose confidence and begin to worry that our body will fail us. Kristen felt she knew if she was going to labour, but self-doubt crept in with the insistence from the doctors that the only safe place for her was the hospital ward, not home. Kristen found the health

professionals caring for her did not understand how she felt. Feeling trapped caused Kristen emotional distress. She could see a way forward that the hospital did not support, giving her few alternatives.

Kristen recalls how she talked to the doctors. She says she told them

*There's no way as a first time Mum I'm going to labour in 45 minutes, and not know. There would have been stuff. That was all my thoughts. By this time, it had been 4 and a half weeks been away from home, I just wanted to go home, but I only half dubs in this baby (her husband been part of the baby). So, my partner he put his foot down a bit and said, "if this is the best place for baby then you have to stay." We came to a compromise and I stayed at a motel and did twice weekly CTGs (monitoring) and scans through the hospital. There was all that stuff that happens when you've been there too long. That's what happens when you lose the plot.*

Kristen felt a desperate need to go home and escape from the hospital confines and the intense observation but felt she could not leave without feeling like she was putting her baby at risk. Kristen's husband was the person who grounded her. He "put his foot down" and challenged her to remember that even if she felt that all was fine, she needed to listen to what the doctors were saying. Kristen was so focused on her body and self that she had forgotten that there were two people contributing to this baby. According to van Manen's (1990, 2016) 'lived body' existential, we are always bodily present in the world we live in and regard our body as our own. For Kristen, the realisation that it was not just about her own health but that of *their* baby, and that her husband also had a right to contribute his feelings, made her take stock and accept the need for hospitalisation. Kristen felt she had to "lose the plot" for the health professionals to acknowledge her deep distress of being away from home. The acknowledgment from the staff was to attempt to find out how deeply Kristen's mental distress had impacted. Kristen felt trapped and disempowered while hospitalised, not suicidal or wishing harm for her baby. Kristen tried to take back control of the situation by making choices as to where she could stay and how often she would be monitored. Kristen mediated between the health professionals caring for her, her husband's wishes, and her own desire to have control of her space and body.

Kristen was normally an active person and found the physical restrictions imposed on her movement around the hospital also took a toll on her mental and physical health.

*I was allowed to go out and have walks, my whole thing was how many, how much? Because I was essentially on bed rest, but the research*

*doesn't support bed rest, it's stupid what they're doing. I was scared too, I thought, what if the baby falls out? I said to one registrar, how much walking can I do? Give me a number, I've been doing 10,000 steps regularly, but where are we at now? She said, "you can do 3000," which is not a lot, but great I'll do 3000. I was able to go across the road to the coffee shop and do other things. At least I got to go out a little bit.*

Kristen found she disagreed with the doctors, at times, regarding the imposing of bed rest. Her knowledge of the risks and benefits of the treatment caused her to feel conflicted as to the effectiveness the physical restriction imposed on her. Kristen felt trapped by something she regarded as unnecessary and negotiated a deal with the doctors about moving outside the confines of the hospital. Kristen felt that with a goal of steps to reach, "I'll do 3000," she could get out of the hospital into the real world, for a while, and this helped her feel less trapped. Having a number of steps to aim for meant Kristen could cope with the restricted bed rest within her own limits and regained some control over her situation. van Manen's (1990, 2016) 'lived body' existential explains that while our body is in the lived world, we often do not think on what or how the body is working. When something goes wrong, due to illness or accident, we suddenly become aware of our lived body and of its fragility in the world (van Manen, 2014). Kristen trusted her innate awareness of her body and found it challenging to accept when it was not functioning as expected.

Veronika also found being allowed to go outside for a time during the day helped her to maintain a sense of normality.

*I would have gone crazy if I couldn't move around. I was allowed as far out as the Domain or if someone came and picked me up in a car we could go out for a coffee or something. I found it really helpful for my sanity, but a little bit stressful as well. Because the further away from the hospital could be that one time I bleed. I can remember going to the Domain with a friend and then I had a huge bleed there and it was scary.*

Veronika stated that she would have felt trapped inside the hospital and "gone crazy" if the doctors had not allowed her to go outside for short walks. She found that though getting outside helped her sanity, the thought of an impending episode of bleeding did not make the time outside stress free. Veronika was desperate to get out of the hospital but struggled with the knowledge that a big bleed could happen any time. This did not make her feel comfortable or in control of her body, even though it helped her maintain

her mental well-being. Veronika was trapped by the knowledge that she may bleed if she chose to leave the hospital. She knew that it could happen any time and was uncertain if it was worth the risk to get out for a while. van Manen (2104) discussed how if a person's well-being is suddenly changed and they become aware of their body and its frailties, it can change our relation to the lived world. Jean-Luc Nancy (2008), as cited in van Manen 2014, discussed how "when we sense something conspicuous, then we tend to worry. It is when this relation remains disturbed in a disquieting manner that we exist in a protracted state of "dis-ease", literally, un-easiness" (p. 329). Veronika's 'un-easiness' came from the concern that at any time she could bleed. This concern conflicted with a desperate need to be outside the hospital and the freedom that being outside offered.

Jemima described how restricted her movements became when she came into hospital during her pregnancy, also due to bleeding.

*To protect my sanity, they let me have some casual leave at home. Then after once I came home, I had a bleed at home and had to get an ambulance. So, after that I wasn't allowed to leave the hospital again from then. It was tough because they didn't want me leaving the level without being accompanied, which meant I couldn't even go down to get a coffee or visit the bookshop by myself without someone supervising me. The midwives are so busy, I couldn't really ask them, and I didn't have family in the North Island. I couldn't go downstairs.*

Jemima was imprisoned on the level she was hospitalised in due to the need to be accompanied at all times. Not being able to move freely about the hospital trapped Jemima on the ward and narrowed her world to a small shared room. van Manen (1990, 2016) suggested that our surroundings can have a negative or positive impact on our well-being and who we feel we are. For Jemima, not being able to move about as she needed made her feel like a prisoner on the ward. She described it as *tough* and did not feel she could inconvenience the busy midwives just so she could go for a walk downstairs. Jemima could not move about freely, even on the ward, and was confined to her room, unless she could find a midwife or family member to accompany her. This restriction caused Jemima to become less inclined to leave as she did not want to inconvenience anyone just to leave the ward.

Jemima described the impact visitors had on her mental well-being.

*My family bought in some different books and that kind of thing. If you don't have visitors and you don't have books to read, there's really*

*nothing else you can do. I guess another thing because I wasn't allowed to leave the hospital grounds there was a couple of weeks in a row that I couldn't get some sun on my skin, some Vitamin D and you really feel disconnected.*

Jemima described feeling *disconnected* as she was not able to leave the hospital and see the outside world. Her life world became confined to a small shared room without her daily visitors to relieve the monotony. Jemima was affected both mentally and physically; feeling trapped within the confines of the hospital she felt her health was affected by the lack of fresh air and sunshine. According to van Manen (1990, 2014), we are social beings and we seek to connect with the people around us to form relationships. Social connections are central to our mental well-being and building relationships helps us to form a community life world and give meaning to our lives. Jemima was forced to wait for visitors each day to feel connected to the outside world and felt trapped with only the health professionals to depend on for human contact.

Daisy described how she also felt disconnected when she was unable to go outside of the hospital.

*I was in there (in hospital) so long that when I would go outside it was like my senses had been dulled down in there. So, when I went outside, I felt overwhelmed, not emotionally but physically. I remember going for a walk down to the lake... I was walking back, I almost fainted. Just because I hadn't had any outside contact, really at all. When I did go outside, I felt a bit off and it kind of made me feel nervous to leave the hospital for good. When I did go home on a couple of day leaves when I was there (home) I felt a bit off as well and I wanted to go back to the hospital.*

Daisy *felt a bit off* whenever she was allowed outside or on home leave and it made her anxious about leaving. Daisy had been trapped in the hospital room for so long that her body could not cope with being outside in fresh air. Daisy's experience of feeling *off*, when leaving the hospital for a brief trip outside or the occasional home visit also made her feel nervous about being away from the hospital. She became so comfortable within the hospital-controlled environment that stepping into the outside world overwhelmed her. Daisy began to feel less like a prisoner and instead became comfortable, feeling safer in the hospital. Daisy became unsure that she could go home as in the hospital they would monitor her and baby's health. Her lack of control of her environment impacted on her physical and mental well-being. van Manen (1990, 2014) used the existential 'lived space' to describe the effect of the space around us and the atmosphere it created.

Daisy lost the feeling of being trapped and became more secure in the hospital environment. Daisy's 'lived space' became the hospital room as it made her feel safe and comfortable and was familiar to her.

The following subtheme discusses the feeling of being a prisoner due to having no control over what the participants were able to eat.

### **Loss of control of diet-imprisoned by the food**

Hospital food has long been the discussion of food critics and people who have been in hospital and subjected to eating these meals. In a short-term hospital stay, the lack of one's normal diet would not have much impact on day to day life. For the participants in my study, being trapped within a hospital meant the provision of hospital food for an extended length of time.

Veronika struggled within the environment she was hospitalised in for an extended time. Of the challenges she faced, a major one was the food she was presented with.

*The other major challenge was the food. I just, the food was absolutely ghastly and not even healthy or even safe for pregnant women. The dinners were pretty much inedible most nights. There was no nutrition in them whatsoever! It was a real battle to actually even to have food that I enjoyed eating and I felt was giving nutrition to the baby. You're a prisoner there you can't just jump in your car or cook something.*

Veronika felt trapped with limited food choices and forced to eat what was served or food she could purchase within the hospital grounds. Veronika described the food as *ghastly, not healthy or safe* and struggled with how she was supposed to stay healthy and grow a healthy baby with what she was being offered. Veronika became so concerned about her and her baby's health that she refused to eat the meals provided by the hospital. Veronika described feeling like *a prisoner*. She could not just leave and get what she needed, she was trapped on the ward and unable to go out of the hospital to buy or make food she considered healthy. Veronika felt like a prisoner, unable to choose what or when she ate, or who she would eat with. Veronika also described the experience as a *battle* to have food she felt was healthy or even enjoyable. She felt she was at war with the hospital and her own needs as the food provided was forced upon her and left few choices. van Manen's (1990, 2014) 'lived space' discusses how the space around us and how we experience that space has an impact on how we feel. Lived

space, such as a room in a hospital, could make us feel like a prisoner, not able to freely move about or able to practice our day to day life as normal.

Felicity explained what she thought of the food she was forced to eat while hospitalised.

*The diabetic food was not very diabetic, there were a lot of carbs and sugar, which I thought was quite strange. In the end I started bringing in avocados and tomatoes and making my own breakfast. At first, I thought it was quite nutritious and well balanced, but at the end it all tasted the same, quite bland. Especially the mystery fish, I didn't quite know what it was.*

Felicity was also trapped on the ward unable to look after her own needs, even when it came to meals. Felicity had the added complication of being diabetic in her pregnancy and knew what foods she could eat that would better control her diabetes. She felt the food she was provided did not appear to be healthy. Felicity took back control and began bringing in her own food to ensure that she remained healthy. Nutrition in pregnancy is important for the growth of the baby and to keep the mother healthy and fit to maintain the pregnancy. Felicity, like the other women, had a pregnancy complication that required her to remain physically trapped on hospital grounds or within the rooms. Hospital food was the only option for Felicity. Confined to the ward, she took the initiative and asked her family bring in some basic ingredients so she could take back control of what food she ate.

For the women in this study, the added burden of unhealthy food that, to them, did not appear nutritious caused them anxiety that they were not providing good nutrition for their bodies or babies. The existential theme of 'lived body' discusses how we are present in our lived world and would not necessarily be aware of our body at all times. If we perceive that we are doing our body harm by eating what we regard as not suitable, we become focused on the body experiencing a disconnection from the world (van Manen, 1990, 2014, 2016).

Being trapped within the hospital environment caused the participants of this study to find time moved differently. Their experiences of losing time will be discussed below.

### **Losing time**

Many of the participants found the time they spent in hospital a challenge as they lost a sense of reality. The four walls of the hospital enclosed them and separated them from the outside world. This gave them a feeling of being in a different time; time spent

waiting, moving slowly, time speeding up in stressful situations, and time that became normal to them.

Jemima described when the time seemed to go so slowly after a significant bleed in the middle of the night.

*The plan was to get me through to 39 weeks then it was pulled forward to 37 weeks, but he came 4 and half weeks early. I had a big bleed one night, within minutes everyone was in there and everyone was caught off-guard, not because it would happen, but it was the middle of the night. I was nervous because everyone else seemed caught off-guard. I got sent off to the birthing unit for one to one monitoring. I thought I would just have a C-section that night, just because of what the obstetricians had been telling me, if there was a really heavy bleed, they would want him out in 10 to 20 minutes, that sort of thing. But this was hours on the monitor...*

Jemima was suddenly rushed away the room she had spent so much time in. For her it seemed rushed and everyone, including herself, was “*caught off-guard.*” Time was suddenly moving very fast and Jemima struggled to comprehend what was happening. Even being prepared for this scenario to occur at any time did not help at the time. Jemima thought that the staff did not seem prepared for it, even though she had spent six weeks waiting for something like this to happen. Jemima then felt that time was moving unexpectedly slow as she was certain that her baby would be out soon after arriving on the ward; instead, it felt like hours. Her expectation was of baby been born quickly, as her doctors had told her many times, when in fact she spent what felt like *hours on this monitor*, causing her to worry that something was wrong. Jemima recalled she was rushed away to be handed over to staff on another ward, who appeared unready for her and did not seem to know her full story.

*The green team that I had got to know really well over the last 6 weeks were gone and I was left with this midwife and the handover was literally a couple of minutes. During that time, I was not quite trusting of what was happening because I'd been told that a really heavy bleed, they'd want him out and I was still on the monitor. I was worried something was going to happen to him because I'd been told he'd have to come out and I'd spent hours on this monitor. Then they discharged me back to the ward, then it was back to the normal waiting game.*

What Jemima experienced was not what she had prepared herself for and this made her extremely anxious. She felt time going slowly while she waited to find out what was going to happen. Jemima lost trust in what was happening and the people around her as

they seemed to be taking too little time to have a handover, and too much time to do something to help her baby. Jemima's concern for her unborn child was determined by the length of time she perceived they were taking to ensure his safe birth. Her past experiences and conversations with the doctors had indicated that if such a scenario arose that they would act immediately as her and baby would be in danger. Jemima found it harder to comprehend when, after what seemed like hours of waiting, wondering, and worrying, she was transferred back to her original room. van Manen (1990, 2016) discussed the concept of relative time, or 'lived time.' The past can impact the now and the future. Jemima recalled her LMC doctors explain that if there was a significant bleed, baby would be born quickly. The experience, then, of spending hours on the monitor instead of the baby been born changed Jemima's concept of the 'now.' Jemima spoke of how everything went back to normal after she was sent back to her room as they had chosen not to birth baby that night. She went back to the "*normal waiting game*." For Jemima, going back to her room indicated all was back to the 'normal' she had experienced the last six weeks. Jemima's perception of waiting for something to happen and then being sent back to her old room to wait, gave her more control of herself and time began to flow more normally for her. Later that morning, Jemima was visited by the obstetric team. She describes how she felt.

*It was funny, not funny, it was interesting that during the night when I had the bleed, I was shaking, I think I was in shock and I was thinking I don't want this to happen, this is a nightmare. But when I had an hour's sleep and then you are woken by the consultant with, "we are going to do it today (cesarean)." My first thought was, my God, this is really exciting, I can't wait to meet him finally and it was just a different mind-set.... more control over my body and everyone else was more relaxed about it and it was a completely different vibe.*

Jemima had felt she was in shock and not ready for the baby to be born, she was out of control and not prepared for the baby as it was too early in her mind. Jemima described the time waiting for a decision to be made earlier as a *nightmare*. Though she knew something like this would probably happen and had been prepared, the long period of waiting meant Jemima did not feel ready. After getting some sleep she began to feel like the night was a bad dream and changed her perspective, she felt more normal and able to cope. When a consultant came to talk to her about bringing her cesarean forward, Jemima thought they meant by a week and was surprised to hear that baby would be born that day. Time suddenly was moving faster, Jemima felt more prepared this time and found it was not as distressing as the previous night. Jemima found that instead of

the anxiety and stress of being rushed into theatre, it was much more civilized, calmer, and she felt it was time to meet her baby. van Manen, (1990, 2014) told us that when we feel bored or anxious this can make time seem to go slower; in contrast, time can seem to go quickly when we are happy and relaxed. Time can also affect how we see our past and could change how we perceive the future (van Manen, 1990). Jemima perceived the time her baby was to be born as in the future and was not prepared for the immediate present when stressed and anxious.

Daisy recalls how she did not know from day to day if she could go out and lost time waiting.

*I would sit in my room and wait for them (doctors) and sometimes they wouldn't come until 3 or 4pm and I'd just be sitting there waiting. So, in the end I thought I don't care anymore I'm going to get the CTG (monitoring) done and go out. It got to the point some doctors would come in one day and say, "no you are not allowed to go on day leave" and others would say "you're totally fine, go on daily leave." If no-one came to see me, it would go on the day before. A lot of days I wasn't allowed to leave. But I was like I'm going to go, it got to the point where I thought I don't care what the doctors have to say anymore.*

For Daisy, waiting in a room all day, not knowing each day whether she could go out or not, became frustrating. Daisy was trapped in her room waiting for the doctors to come and give her permission to go out on home leave. When the doctors either came too late in the day or not at all, Daisy felt that her time had been wasted and she remained trapped. The lack of continuity around day leave made Daisy annoyed enough to decide to do her own thing and not wait around for the doctors. Daisy then took control and went out regardless of what the doctors were saying. Daisy found her days, sitting in her hospital room waiting, were frustrating as she had no idea how long she was to remain in hospital.

*For me what was really annoying is that no-one was giving me a clear indication of when I would be leaving, when I would have baby. I had no idea, I needed to prepare myself for how long I'm going to be in here. It's mind numbing, but if I'd had a date insight or a day then it would be OK. One day one doctor would say, "we will deliver you early at 36 weeks," then another day someone would say late 37 weeks. I was sitting there thinking am I going to be here until 40 weeks pregnant?*

Daisy became frustrated with not having an end in sight. She felt that the time she was spending trapped in hospital was impacting on her mental health and she began to worry

that her time in hospital would never end. Daisy wanted to be able to prepare herself for however long it would be. To Daisy, this would have made the time pass easier with an end in sight. van Manen (1990, 2016), discussed the concept of 'lived time' having an impact on how we perceive the past, present and future, it is our way of being in the world. Daisy was living in the now with no concept of when, in the future, she would be able to leave the hospital with her baby. This lack of fore knowledge impacted on her mental health and she became frustrated with waiting.

### **Summary.**

This chapter has revealed the theme of "doing time." The subthemes of feeling trapped in the room, trapped with the food, and losing time, made the women feel like they were prisoners, trapped in a situation they had no control over. The women lost control of their bodies, mental health, and sense of real time. This caused them to become anxious and depressed. The participants found they made an effort to make changes, to take back some form of control of their lives. Taking back control was achieved by going outside, even if they felt anxious of the consequences, choosing what and when to eat and challenging the way they were made to endlessly wait, by not waiting. The participants chose to become active participants in their time in hospital, giving them confidence to make decisions for their care.

The next chapter discusses how the women felt once baby was born; from the early experiences still in the hospital, to going home and the future.

## **Chapter Seven. Coming out the other Side**

The previous findings chapter considered the participants' feelings of being trapped within the hospital. This, the final findings chapter, discusses how the women felt after baby was born. Some of the babies were born early and required time to grow and become used to feeding. Being trapped for longer in the hospital, in the early postnatal period, challenged the participants who were already physically and mentally exhausted from the extended hospitalisation. The relief of finally coming home became problematic; settling into a new situation and attending to the needs of the baby with unsettled older children. Physical recovery was often longer after extended hospitalisation, especially as the participants were restricted to bed rest. The stress of being in hospital had also impacted on their postnatal period in the form of ongoing anxiety, undiagnosed postnatal depression, and post-traumatic stress disorder. Some participants worried for the future and the possibility that being hospitalised for an extended time would have long lasting effects on their children. Four sub-themes emerged from the data:

1. Released into the unknown
2. Released home
3. Checking in on myself
4. Worrying about the future

### **Released into the unknown**

The women in this study had spent from two to twelve weeks in hospital while pregnant and a further two days to two weeks recovering in hospital after the birth. The participants found that the environment and people changed from their antenatal hospitalisation. Transitioning to a different type of care caused considerable stress and anxiety. The participants had become familiar with the previous environment and the people caring for them. Due to the extended hospitalisation, after the initial shock and fear began to decrease, they had developed a relationship and trust with the antenatal health professionals. Thus, transitioning from the intense monitoring antenatally to what appeared to be an un-caring environment, added to the negative impact of extended hospitalisation.

Jemima found the six weeks prior to baby being born a challenge. However, by the time baby was born, she was used to the routine and the midwives looking after her.

*Because I was in for a week after my birth, it couldn't have been a more different experience as to the 6 weeks before the birth, the incredible people. The week after (the birth) was quite horrible. I had quite a few experiences with mistakes. I was given the wrong milk and another time I got given the wrong drugs. So, my trust in the system dropped a bit at that point.*

Jemima felt her experience after the birth of her baby was very different from the six weeks in the hospital before the birth. Antenatally, she felt she received great care from “*the incredible people*,” the midwives and doctors caring for her pregnancy. Yet, she felt that the week after involved many mistakes; she lost all trust in the people caring for her and became anxious and distressed. Jemima described the experience of trying to recover from a traumatic birth after the long hospitalisation as *horrible*. Jemima struggled with the transition from incredibly caring people to health professionals whom she found unreliable. Jemima felt she received two types of care from the health professionals at the different stages of her stay. The care she had received prior to baby being born was professional and caring; in contrast, the postnatal care seemed disjointed and unprofessional. The relationships she had formed with the antenatal care team enabled her to trust their recommendations. Jemima had no time to build trusting relationships with the postnatal health professionals which left her feeling out of control. van Manen (1990, 2016) suggested that the existential ‘lived relationality’ reflects how we develop relationships as a way of searching for meaning in our lifeworld. When we find this meaning, trust will develop in relationships. Developing a trusting relationship takes time and it is difficult adjusting to sudden changes. Jemima’s trust was further damaged by mistakes made in her postnatal care. Jemima felt she had no power to make decisions for herself and found herself needing to second guess anything that was offered or suggested to her.

Jemima recalls how she felt trying to adapt after her traumatic birth.

*The biggest difference was probably not the care itself but my mental state. I was so drugged up on morphine and lots of other drugs. I'd lost 3 litres of blood in the procedure. I think all of these things meant I was at rock bottom and sleep deprived again. So, everything was going a bit wrong. I really felt it wasn't the greatest experience as I didn't feel empowered in my decisions, nothing was my choice. I felt like I had lost control over, I couldn't do things in the way I wanted and that last week was miserable*

Jemima described the struggle she had to enjoy or even cope with the initial stages after having baby. The stressful birth, significant blood loss, negative reactions to pain relief, and lack of sleep impacted on her physical and mental well-being. Jemima felt everything was going “*a bit wrong*,” though she had a healthy baby and an end in sight after such a long time waiting. Jemima felt she had once again lost control of herself and her situation and felt unable to speak up and make decisions. Jemima had begun to have some control of her life and decision making in the antenatal period and struggled with going back to having no control of her body or mind. Jemima described the last week after baby was born as “*miserable*.” Jemima found the transition from a highly monitored and exhausting pregnancy to an equally exhausting postnatal experience was not as she expected. For Jemima, starting a new life with a new baby, and feeling so miserable, impacted negatively on her mental health. She needed to try and claw her way up from “*rock bottom*” again. van Manen’s (1990, 2016) existential ‘lived body’ suggests illness changes our sense of self and how we perceive our body. When our body is not functioning in the expected way or dramatically changes from ‘well’ to ‘unwell’ we can lose control of emotions and find decision making challenging. Jemima had become used to her body as pregnant and the future that held; the present was not as she expected and caused her to feel disembodied, she had “*lost control*” again. For Jemima, this feeling of loss of control continued to impact on her mental health until she was finally able to go home with her baby.

Veronika described her experience of the change in care after baby was born.

*Postnatally it was almost like they forgot I was there. The care was pretty much non-existent. They wheeled me out to NICU (to see baby) then to my room, then basically said, you go for it. The only people I was seeing were not even midwives, the nurses I was seeing were a different one every shift. They had no idea of my history, no idea of what was going on with baby. They just didn't seem to have any idea what was going on.*

Veronika found it difficult to adjust to the change in attitude and care after three months of intensive monitoring. As soon as the baby was born and safe in NICU, Veronika felt abandoned by the staff she had previously known. Veronika was taken back to a different room from her antenatal stay and advised to “*go for it*.” Veronika’s transition from high-risk patient to a postnatal woman left her feeling confused and un-cared for. Veronika’s new environment and people threw her into a sense of mistrust as the new staff had “*no idea of my history*.” She was expected to know what to do now that baby

was born and, as she no longer needed intensive monitoring, felt she was no longer cared for. Veronika expected the new staff looking after her to have some idea of how long she had been in hospital and that she would still need a certain level of care. Veronika had become reliant on the health professionals telling her what was happening with her body. Veronika's trust in the new people caring for her declined and she felt she was forced to look after herself. Van Manen (2002) discussed the nature of "care-as-worry;" that caring is of an ethical nature. This human response to others who may need our care, van Manen (2002) described as;

Usually, we think of other people as ourselves who are in the world just as we are in the world as selves. And so, we are cohabitants, fellow human beings who live in reciprocal relationships... This is especially true of situations in which we meet the other in his or her vulnerability... This is the originary caring encounter. (p. 269)

Veronika felt that if she was the health professional, looking after someone like her, she would have been more caring or worried that she was well. We can appear un-caring as we are not worrying. Veronika had been cared for intensively in the antenatal hospital stay and found it difficult to adjust to the feeling that she had been abandoned by the health professionals now that her baby was safely born.

Daisy also noticed a change in the care she received after baby was born.

*Once I'd had him, I noticed the midwives changed. I felt like the midwives antenatally were generally younger. Then when I went to postnatally, I found that they were a bit older, it might have just been my experience. I felt like the midwives I had then weren't as nice and understanding. I almost felt like they were over their job.*

For Daisy, the change of midwives seemed quite profound, she felt the midwives looking after her once baby was born were not as caring and helpful as the previous midwives. Daisy had not met these new midwives while in hospital prior to the baby being born and had not developed a relationship with them. Daisy felt these midwives did not know her and she did not trust their care as she was unfamiliar with how they worked. Daisy felt the change of care as negative, as the care she had received prior to the baby being born was much more intensive with the monitoring of both her and baby's health. Once her baby was born, the risk that something could happen was gone and intensive care was no longer needed. Daisy felt the change of care as a lack of understanding and that they were "over their job" when it was from the scaling down of

the intensity of care required. Transitioning from the intensity she had while still pregnant was not easy. Daisy was adjusting to the new normal of the baby now safely outside her body and found it a challenge to accept the lower level of care she perceived she was getting.

For Siena, the immediate postnatal period was also about changing. However, in contrast to Daisy and Veronika, Siena found the transition easier.

*Antenatally I kind of know that all the midwives and everyone needs to kind of keep tabs on my blood pressure. Postnatally, I think, for the first few days we were kind of having that routine but slowly dropping off. Actually a few days I had just one blood pressure done a day. They missed a few doses of my medication. But the dynamic is different. I suppose the important thing is we were there for baby. I was there for so long I was actually looking forward to going home and towards the end of the second week of the postnatal stay we were basically waiting for baby to grow a bit before we can go. I was grateful we got the help we did at the hospital, we had to be in the hospital, or the other option would be her going to NICU and I get discharged home, but we didn't want that.*

Siena felt that the care she received became less intensive over the time she remained postnatally in the hospital. Her transition from intensive, anxiety ridden antenatal care to relaxed, postnatal care went well for Siena. She felt that the only reason she remained in hospital was for the baby and she was grateful the attention was no longer on constantly monitoring her. Siena was now less concerned about her health and how it could affect baby, instead focused on doing all she could to ensure she could leave hospital with the baby. Siena had an end in sight and was determined to leave hospital as soon as baby was ready to go home. This meant Siena was not concerned about the change of care for her, she had stepped out of her 'sick' role and now was focused on getting home. Siena was happy to sacrifice another two weeks in hospital to be with her baby and help the baby transition to life outside the hospital. The alternative was to go home and leave the baby in the neonatal care unit.

The fragile nature of the participants' pregnancies, and the ensuing extended hospitalisation, meant the women were focused on keeping the baby inside and safe for as long as possible. Hence, they were not thinking too far into the future.

Felicity described how relieved she was once her babies were born.

*At 32 weeks we decided it would be safer for them to be out than in. It was kind of a gamble to keep them in longer. On one hand they would grow more, but if they pulled those cords, that's it. I stayed 5 days (after the babies were born), just to have the catheter out. It was good that NICU was just down the hallway, so I could go see them. That was good because we were on cloud 9 that they'd made it, because their cords were so knotted.*

Felicity had spent six weeks on edge not knowing if her babies would make it to be born. The stress and anxiety she felt day to day during her antenatal stay was finally gone. Felicity described feeling “on cloud 9” and her transition to postnatal care was much less stressful. Though the babies had been born early, and were in NICU, it was, for Felicity a preferable option from the waiting, worrying something would happen to them. Felicity stayed in hospital for another five days, as the babies were in NICU in the adjoining ward. For Felicity, now the babies were born and safe, her focus could be on getting them home and reuniting with her family. van Manen (1990, 2016) described the concept of ‘lived time;’ how time is subjective rather than clock or calendar time and how the ‘now’ and the past affects our view of the future. Felicity had not looked forward to the future as there was a high risk of her babies not making it to their birth. For Felicity, the long period of waiting had ended with a good result and she could now look towards the future. Felicity’s past experience of living day to day with the anxiety of her baby’s fragility turned to the joy of looking towards their future and their new family. Felicity was happy to be able to stay in hospital for as long as needed knowing she would initially go home without her babies.

Veronika felt she had been so focused on the time waiting for baby to be born and counting down the days to go home that she forgot that, as the baby was born early, she would need to stay longer.

*I had this diary that I would cross off the days and I'd always been working towards him being born and I had not factored in that I'd have to stay for another week. I was, ‘Oh my God, how long are we going to be in here, when will this nightmare end?’ My husband had to give me a good talking to. We got there (home) eventually but, God, it was amazing to leave that hospital.*

Veronika described the final few weeks of her hospital stay as “a nightmare.” She had felt trapped in the hospital during her antenatal stay and was then shocked to realise she would need to stay longer. Veronika had been so focused on getting to a safe time for baby to be born that she did not take into consideration that, as he was born early, she

would still need to stay to establish his feeding. Veronika felt that she would never be able to leave the hospital and get back to her normal life with her family. Veronika struggled with knowing that she was again a prisoner on the ward in the hospital she had already been imprisoned for so long. Veronika described the feeling of finally leaving the hospital as “*amazing*” and was able to go home and settle into her normal life. Veronika was so focused on keeping her pregnancy safe that she had not looked forward to the future. van Manen (1990, 2016) discussed the concept of ‘lived time,’ as temporal time. Temporal time includes our past experiences affecting the present and impacting on the future. Veronika was trapped in the ‘now’ antenatally in hospital, living day to day stressed and anxious that her baby survived. When the future arrived, it was different from the imagined freedom Veronika would have once baby was born. Veronika found it difficult to see out the other side as she remained trapped in hospital once baby was born.

### **Released home**

After so long hospitalised during their pregnancy, and for even more time after their babies were born, the time to go home was met with joy and anticipation of the future. Felicity went home five days after her twins were born, leaving them to be cared for in NICU.

*It was hard leaving them, but it was a relief that they were in such good care and they were out of imminent danger, being in my stomach with those cords. They had a chance now. They spent another 5 weeks in NICU, just feeding and growing.*

Felicity was torn over going home and leaving her twins in hospital, though she was now confident they were receiving the best care and would be coming home soon. Felicity was relieved they were born and she considered them safe, now they were separate from her body and the risk of entangling cords. van Manen (2002) explored the concept of ‘care-as-worry,’ that parents commonly experience continual worry for their children. Often the concern is unwarranted and consists of the ‘what ifs?’ Felicity had spent six weeks of her pregnancy in hospital constantly worried about the twins and the high risk of their cords tangling and one or both passing away. Her worry very real, her ‘what ifs’ tangible. Once the babies were born, and separated from her body and their tangled cords, she could relax her vigilance and worry about the more normal aspects of parenting new-borns. van Manen (2002) spoke of parental worry, “worry-rather than duty or obligation-keeps us in touch with the one for whom we care. Worry is the

spiritual glue that keeps the mother or father affixed to the life of their child” (p. 264). Felicity went home worrying for her twins in NICU, and this worry maintained the connection between them even while separated. Felicity was home, empty without her babies, while also relieved they were finally safe. Felicity felt trust in the hospital staff to look after her babies as she had developed a relationship with them in the time she had been hospitalised. The concern Felicity now had for her babies was more normal; she had more control over their well-being once removed from what she had considered the dangerous environment of her womb.

The women also found that finally getting home made them grateful to be there. Even as they settled into a new family dynamic, they were still finally free from the hospital environment and restrictions. Veronika found that when time came to leave the hospital, her first few days at home took some adjusting to.

*I think it was a bit weird the first few days, and it was the same when I had my few stints at home during the ordeal. Almost like Stockholm syndrome, you get institutionalised, you get so used to your surroundings. Then to be home and have my toddler jumping at me and life normal again, it just felt really weird. You can shower in your own shower and sleep in your own bed. I think we adjusted pretty quickly, and I had a new-born and a toddler, so you just get on with it. I remember just being really grateful for the small things, like being able to eat a salad for dinner, if that's what I felt like. Or walking outside and feeling the sun on my face and fresh air. When you're locked in a hospital you just don't get to do that, it definitely made me appreciate it (being home) more.*

Veronika described her first few days finally home as “weird” and talked of the effect of “Stockholm syndrome.” Stockholm syndrome is considered a condition in which hostages develop a psychological connection to their captors as a survival strategy. It is often used in the media to describe cases where a ‘captive’ develops a positive bond with a captor. Stockholm syndrome has also been used in literature to describe an abusive relationship (Namnyak et al., 2008). Veronika felt she was being held against her will in hospital and had made sacrifices to survive the experience. Veronika had come to a place in herself where she had begun to trust the hospital and its staff. She initially felt “weird” going home where she was able to do what she wanted, when she wanted. Veronika found that finally being home she had no time to dwell on the experience of being in hospital as she needed to attend to her older child’s needs and reassure him that she was not leaving again. Veronika had found the restrictions of

hospital life, including the food, a challenge and was relieved to finally be home and able to cook and eat what she wanted, rather than having to rely on the limited choices given to her. For Veronika, the small things of normal life were what she enjoyed the most when first getting home. It made her realise the day-to-day things she took for granted. Veronika had felt trapped in the hospital and realised what she had missed once able to leave. Fresh air and exercise was one of the biggest challenges Veronika faced while in hospital. Her life had been restricted to a small room in a large impersonal hospital. 'Lived space' is the space around us and it can have an effect on what and how we feel. Home is where we feel safest and most ourselves (van Manen, 1990, 2016). Veronika felt much more herself in her own home and grateful to be able to be herself in an environment she was most comfortable.

Jemima's initial experience going home was challenging due to having extended family in the home to help. Her husband's family had been staying in Jemima's home, during her extended hospitalisation, to care for her older child. Jemima had not been home for two months and had not seen her older child properly in that time. Jemima described how she felt when she first arrived in her own home.

*I really wanted to focus on my toddler because he needed me more at that point, because his whole world had been turned upside down and he needed the security that I wasn't going back to hospital. That transition, tough, because I was torn between looking after myself and looking after him. It took quite a while physically, took a while to recover and I felt groggy still for a few weeks and I didn't know to what extent it had an impact on me until I came out the other side, that first few weeks were challenging. Sounds like dark times, but we had lots of time out and that was just great. I just couldn't go out and walk. I'd been exhausted after been in hospital for so long and physically took a long time to recover.*

Jemima's focus was on re-establishing her normal home life now she was finally home. She felt the transition from hospital to home was more challenging due to her husband's family living in her home while she was absent. Jemima felt she needed to re-establish herself in her own home. This meant ensuring that her older child felt secure and had not been affected by her lengthy absence. Jemima felt torn between the needs of her own body, her new baby, and those of her older child. From van Manen's (1990, 2014) 'lived body' point of view, a child is a separate entity; however, they are still regarded as part of one's body. 'Lived body' also refers to how we are bodily within the world. Our trust in how our body should work can be disturbed when the body does not work

as we expect, such as in illness. Jemima found she took a long time to physically heal from her experience in hospital. Jemima had been on bed rest for six weeks, unable to exercise or even walk often, and her body had lost muscle tone. It took time for Jemima to physically transition back to normal activity, to spend time outside as her physical fitness had deteriorated. Jemima's trust in her own body was low as she expected to be able to transition back to her normal life quickly. Jemima found adjusting to her new physical normal a challenge and the recovery from her long hospitalisation a difficult experience.

In contrast, Siena's experience of finally getting home was easier than expected.

*I was pretty glad when I came home and when we came home, she (the baby) was feeding quite well then. We had NICU involved at the end, they were coming to visit us every few days for the first week. My midwife was coming twice a week too. We never felt alone when we came home, that was a good thing. We were having quite a lot of people in and out, we tried to live with that. It's been 3 weeks now, it's certainly, in that aspect, it's great being home because everyone is in one place. That was the hardest thing, being in hospital and with another small kid at home.*

Siena's transition back to her home was easier as she already had one baby and felt she understood the new-born process well. Siena found that with everyone at home in one place, life had become much easier. Siena had visiting health professionals from NICU homecare as well as her midwife, and with these people keeping an eye on her and her baby's progress, they never felt alone for the first week. Siena, though, found it difficult trying to get back to normal family life with so many different people visiting. Siena had to adjust to people coming and going who were helpful but also prolonging the time until she was truly back home with her family and able to adjust to this new life. Siena was now in her own space, home, with all her family together and good support from visiting health professionals. She was able to regain some control over who entered her space and though there were continuous interruptions from visiting healthcare professionals, she was able to "try to live with that." van Manen's (1990, 2016) 'lived relationality' discusses the interpersonal space we share with others. Human beings search for the communal and this could include the immediate family. Siena was adjusting to her new family dynamics that were disturbed on a daily basis by strangers coming into her home. As part of maintaining the continuity of her family, she "lived with" these interruptions and chose to accept them as necessary.

For the participants of my study, adjusting to their new home life came with concerns that their extended time in hospital, during their pregnancy, could have had a long-term effect on their mental health.

### **Checking in on myself**

Jemima spoke of the concerns of her doctor and midwife that she may suffer from post-traumatic stress disorder or postnatal depression after the long hospitalisation and dramatic birth. Jemima reassured them that she did not feel unwell and kept a careful check on her mental health. She described how she remembers the time of the birth.

*I'm feeling well and back to the new normal, feeling good and being out socialising helps. Those first few weeks I think the midwife was worried I was going to get post-traumatic stress disorder, because I was so drugged up, I don't really remember a lot of what happened in terms of getting separated from him. Sometimes I look back on photos to find the point I first met him and remember it. I think, not getting flashbacks but keep on thinking back to that first week in hospital (after the birth) and try to piece things together for myself.*

Jemima found herself constantly “checking in” on her mental health to be sure that she did not fall into postnatal depression. She described thinking about the bleeding and the birth and decided she was not depressed, although very mindful of making sure of herself. For Jemima, the first few weeks of being home involved regularly looking back on photos of her new baby after the birth and trying to process what had happened. Jemima’s process of “checking in” on herself can be seen through the lens of the existential ‘lived time.’ Time, according to van Manen (1990), is temporal, with our past, present, and future all part of our now. The past can change our present and our future. Jemima’s lifeworld had changed from her previous existence as she found herself unsure of what affect her past few months of pregnancy might have had on her. Though she denied that she had postnatal depression or post-traumatic stress disorder, she also described looking back at photos trying to pinpoint when she first met her new son.

*I didn't feel like I would get postnatal depression, I had a handle on it. I was checking in on myself and seeing how I was feeling. I wasn't depressed because I kept thinking about it (the birth), I was very mindful that I didn't slip into it. It didn't affect my bonding with baby. I guess in a way it might have made me stronger. I'm so obsessed with this little guy after what we went through so much together and I think I'm grateful that he turned out OK, grateful and everything.*

Jemima felt stronger after the ordeal she had gone through with her baby. Her bond became stronger as they had survived a battle to get to where they could finally be at home. Feeling a bond with one's child is an essential part of nurturing and protecting a vulnerable infant. Jemima felt that she and her child had been in the fight for survival together, as one. Jemima was careful to reflect on the birth as it happened and how much she could remember without falling into a state of despondency, due to what she may have missed. van Manen (2002) discussed care-as-worry and how self-care does, in fact, come from caring for others. This care of self/others combines the existentials of 'lived body' and 'lived others' through our physical body that we are unconsciously caring for while caring for others in a communal relationship (van Manen, 1990, 2002).

Even with fore knowledge of pregnancy complications, Kristen found it hard adjusting to transitioning home.

*I knew there were probably going to be issues and I knew he would probably arrive by caesarean. It's probably only in the last two months (baby is now one) that I've realised or recognised that I probably had post-traumatic stress, slash post-natal depression, but I was so busy in it that I didn't really recognise it as that either. Your hormone levels are kind of fluxy and all of that kind of stuff. I think, probably, there really was some postnatal depression there. I don't think it was easy and I was stoked with my baby. You know, it took a long road to get to that place. I'm through, I think I'm through it now. I feel better and a lot more myself.*

Kristen found the first year of her baby's life challenging in many ways and did not outwardly recognise that she was suffering from postnatal or post-traumatic stress disorder. Kristen's new reality with a newborn left her little time to think about how she was feeling. Kristen felt she had lost herself in the time before and directly after baby was born and it took a year before she was feeling more like herself. During this one year, Kirsten did not have the time or energy in the early months of new parenthood to check in with herself and reflect on what or how she was feeling. It was not until nearly a year later that Kirsten was able to sit back and look at what had happened and reflect on her feelings around that time. Kirsten did not, until then, realise that she was suffering from postnatal depression, rather than just the business of new motherhood. Being able to reflect on and acknowledge what she had felt during that time enabled Kirsten to make a start at ensuring she was feeling herself again. Kirsten was able to look into the past experience, reflect on what had happened, and move into the future aware of how her experiences now shaped her lifeworld. van Manen (1990, 2016)

discussed ‘lived time’ as how our past experiences influence the present and the future. The past can change how we see the future unfolding before us and changes the way in which we can expect to live these future events.

### **Worrying about the future**

Veronika continued to feel concerned about her time in hospital and its effects on her pregnancy and baby. She found herself always wondering if there was an adverse effect on him.

*I found the first year quite hard. It's like I have this constant worry about him. He's fine and everyone tells me he's fine, but I think that he was SUCH a hard pregnancy. He has been a bit behind on his milestones.*

Veronika was 15 months past her hospitalisation and birth, still teary and upset, when reflecting on her experience. Veronika cried as she shared that she still worries about the effect her extended hospitalisation may have on her child's future. The impact of being in an unfamiliar environment without what Veronika considered healthy food and the ability to have good sleep was profound. Veronika's experience of “*SUCH a hard pregnancy*” continued to affect her day-to-day thoughts and concerns. Veronika was happy to be home with her family and for the ordeal to be over, though the worry and anxiety continued. For Veronika, her ongoing concern of the “normal” growth of her child after her long hospitalisation tarnished the joy of bringing home her baby boy. Despite the assurances from health professionals that her child was growing as expected, Veronika remained concerned. van Manen (2002) discussed caring for someone can be regarded as ‘care-as-worry’ and the more you care the more you worry. This care-as-worry is seen through the lens of ‘lived relationality’ as we develop relationships and become part of a community, such as family, giving one a sense of purpose in one's lifeworld (van, Manen 1990, 2016). Veronika felt responsible for the possible impact her hospitalisation would have on her child's life. Veronika had no control over the environment she was in during her pregnancy but blamed herself for the impact her hospitalisation had had on her child. She found herself watching and wondering if her child will develop normally.

Kristen found that the loss of the pregnancy and birth she imagined created a grieving process when she was home.

*It is recognition of not just the physical experience but the spiritual and emotional experience. It's about recognising the grieving process that goes with it, because you get a whole bunch of stuff done to you and then its "It's OK because your baby's alive, at least your both alive and well" and I'm "Not really." Emotionally I'm a frikken wreck, mentally I'm a frikken wreck and no-one has acknowledged that part of the journey. Then of course you're thrown in the deep end with a newborn, that chaos as well.*

For Kristen, though her baby eventually arrived safely, she found it difficult to reconcile the way in which her pregnancy journey had impacted on her. Kristen found that people insisting she was well, her and baby were alive, took away from her dramatic loss of a 'normal' pregnancy and birth. Kristen felt as if she was not important in her own right and had become only a receptacle for her baby. Once the baby was removed from Kristen's womb, she felt she was no longer needed or important. As no-one recognised the trauma she was dealing with, Kristen just kept going. There was no recognition that she was not happy with the turn of events that saw her hospitalised for an extended time, away from home and family. Kristen was expected to go home with a new baby and get on with being a new mum, without time to reflect and properly debrief around the pregnancy and birth. Our bodies indicate that we are bodily within the world and what we show or hide from others is not conscious or deliberate. If the body is viewed by others in a critical or judgemental way, we will show less of ourselves (van Manen, 1990, 2016). Kirsten was hurting emotionally and mentally but was unable to show to others how or what she felt. Kirsten did not have the energy to tell people how she felt and mental fragility was not acknowledged or dealt with. The first few weeks, if not months, are a challenging time for a new mother and Kirsten's tiredness and emotional frailty was seen as a normal part of the new-born process. Kirsten took almost a year to come to terms with the grief she felt over the loss of a 'normal' pregnancy.

## **Summary**

This chapter has discussed the ways in which the women experienced the time after their babies were born. The transition from antenatal hospitalisation and postnatal care was profound and had negative effects on the participants. The women of this study were expected to transition back to normal life with a newborn with no support. 'Released into the unknown' described how the women struggled to cope with the transition in care from the postnatal health professionals. The sudden change in relationships caused the participants to lose trust in the health professionals. The

participants struggled with no longer being seen as high-risk patients and the discontinuation of intensive monitoring. There was a feeling of being a receptacle for the child; that once the child was safely outside the womb, the women found they no longer felt important or needed.

‘Released home,’ the participants described adjusting to life at home with new babies as well as energetic toddlers. Physically the participants found they were weaker than expected and took longer to ‘come out the other side.’ The participants acknowledged the risk of postnatal depression and were proactive in monitoring their own mental health. For the women of this study, ‘checking in’ was protective of postnatal depression. In contrast, some participants found that the effect of being trapped for an extended time in hospital had an ongoing negative impact on their mental well-being. For the participants, there was anxiety around the long-term impact the restriction of food and exercise might have on the child’s future health and development. The women, ‘worrying about the future,’ discussed how they felt the negative impact of the hospitalisation was seen later in the post-natal period when they were past the initial hectic stages of a newborn.

The next chapter discusses the data and implications of the findings. The limitations of the study, and implications for education and practice will be explored. Recommendations and suggestions for further research will also be discussed.

## **Chapter Eight. Discussion**

The question of this research was “What is the experience for women hospitalised for an extended time in their pregnancy?” Four essential themes emerged from the findings describing the lived experiences of women hospitalised in pregnancy. The findings of this study revealed that when women’s pregnancies became high risk they were hospitalised for an extended period of time and that they experienced feeling like a prisoner or doing time, feeling unsafe, feeling displaced and, postnatally, coming out the other side.

In this chapter I describe and discuss the major findings and their sub-themes compared with previous literature. The findings of this study have revealed some significant recommendations for midwifery practice and education. Recommendations for health professionals who are involved in the care of women hospitalised during their pregnancy and for hospitals where high-risk women are cared for will be detailed. The strengths and limitations and suggestions for further research will be discussed. Ways of addressing the psychological and physical needs while hospitalised will also be explored.

### **Introduction**

The seven women who were the focus of this study had spent from two to twelve weeks antenatally and up to two weeks postnatally, as an inpatient at a secondary or tertiary maternity hospital. They were more than willing to share their stories in the hope of being able to make sense of their time and to reflect what, for some, was an extremely stressful and transformational time. Some of the women were deeply impacted by their experiences; while others had already moved on and had begun to live their new normal. Using van Manen’s existential concepts of lived body, lived time, lived space, and lived other to analyse the data, I was able to move through the incredibly rich and slightly overwhelming data I was gifted by these women. From the findings described in the previous four chapters I was able to identify the core theme of the women’s experience while hospitalised during their pregnancy. Looking again at the women’s narratives as a whole, the overwhelming theme was of the concept ‘doing time’. The experience of feeling trapped, a prisoner of their condition while pregnant and in a hospital environment, became the essential theme of this study.

## **Doing time: Feeling like a prisoner**

Across all four of the findings and sub-themes, the participants' experiences left them feeling unsafe, physically, emotionally and, most significantly, mentally. Being hospitalised for an extended time in a place that was not their home, with their physical movements restricted, made the women feel like prisoners. The lack of privacy, trust, sleep, and loss of control contributed to a feeling of being imprisoned for these women. This finding has been described in a previous study by Rubarth et al. (2012) whose participants described the restriction to their physical activities as feeling like a prisoner. The women of this current study sacrificed their physical freedom and mental well-being to protect the health of their unborn. These women were not sick or injured and regarded themselves as normal and well. The complications that arose in their pregnancy caused considerable concern and stress for the women and their families. For the participants, the suddenness of their diagnosis and subsequent hospitalisation left no time to mentally prepare for hospitalisation.

Feeling like a prisoner of the complication and hospital caused the women to become mentally unwell. There is an expectation that we will feel safe in the hospital environment, with the people caring for us, and that hospital is a place that will provide help and healing for whatever ails us, keeping us safe (Mander & Melender, 2009). Hospitals are seen as places that provide a 'healing space' offering a physical and emotional/spiritual space in which one can become well (Schweitzer et al., 2004). Hospitals were not designed by experts in healing but by architects with the task of producing a building that was efficient and cost-effective. Consequently, hospitals have become places for diagnosing, treating, and curing with little emphasis on protecting the patient's mental health while confined there (Schweitzer et al., 2004).

The participants of my study described the significant negative impact of being suddenly thrown into an unfamiliar, unknown, and restrictive environment away from family and home. They were suddenly transformed from pregnant to being unwell in pregnancy, leading to a change in the way they identified themselves. van Manen (2016) described the existential 'lived space' as the space we are in, or the space that surrounds us that effects how we feel and can change how we act. For my participants, suddenly not being in their home, but in an unfamiliar environment, caused them to feel 'displaced.' Displacement is described as a feeling of not being in one's own home or place, where one feels safe and comfortable. Displacement can be forced or due to a disaster, as in being displaced from home to hospital without warning. For the

participants, being displaced from their normal home environment and family caused feelings of shock, fear, and guilt. Once hospitalised, the realities of what they faced became apparent early in their stay. For many of the participants, their stay was protracted and the majority of their time in hospital they were forced into sharing a room with another woman. Multi-bedded rooms are common in hospital in-patient settings as they provide more beds for the space and can make it more efficient for the health professionals to see the patients. Having two or more patients per room may be beneficial for the hospital cost-effectiveness but not for the patients.

## **Privacy**

Pregnancy and childbirth are regarded as an incredibly private experience. For the women in my research, lack of privacy was a challenge in the hospital environment. For the participants, sharing a room with a stranger seriously impacted on their experience. The women in my research also experienced the shock and feeling of being violated when encountering strange men in the bathroom intended for patients only. Maintaining a patient's confidentiality in a shared room situation is impossible as the only barrier is a fabric curtain. The curtains may provide a visual barrier but not auditory (Kent, et.al., 2015; Malcom, 2005). Malcom (2005), found that in a hospital environment fabric curtains are able to be pulled around the bed space to provide a separation between patients. These curtains only provide a visual barrier to provide a sense of separation. The patients in Malcom's study, as my participants, soon become aware that their private conversations with health professionals or family would be overheard by their roommates and they could also overhear the other person's health issues. The women in Malcom's study also reported how uncomfortable they were overhearing other patients' health problems and realising that the other women could hear their private information.

Kent et al.'s (2015) participants stated they felt they held back disclosing some possibly important information due to the knowledge that the person in the next bed would be able to hear. This finding was also reported in earlier studies where participants found the lack of privacy a major stressor in their hospital stay (Kent et al., 2015; Richter et al., 2007; van de Glind, et.al., 2008).

The concept of privacy can depend on an individual's cultural norms and what constitutes privacy may differ within communities. The effect of having our privacy broken can impact on a person's spiritual, mental, emotional, and physical well-being (Malcom, 2005; Richter et al., 2007). Personal privacy is considered an innate human

right and could be described as the periphery between the private and public world. In New Zealand, there are laws protecting an individual's privacy (Kent et al., 2015; Malcom, 2005). Health professionals are expected to protect a person's individual right to privacy from public scrutiny. All health professionals, including midwives, are provided guidelines in protecting individual rights in their code of conduct. The New Zealand Code of Health and Disability Services Consumer Rights, 1996, acknowledges a person's right to privacy and for the health professional to respect that privacy (MOH, 2019a). There is no specific guidance on how health professionals are able to carry this out.

The women of my research were trapped in their rooms, imprisoned by their conditions, and were made very aware that their intimate details could be heard by their neighbour and conversely, they could hear every detail about them. Though this lack of privacy could be accepted as part of the experience of hospitalisation, it had a negative impact on the mental health of the women. Additional to the lack of privacy in a shared room, being able to sleep normally was a challenge for my participants.

### **Interrupted Sleep**

The women in my study found the hospital environment did not provide adequate opportunity for healthy sleep, and the daily routines of the medical staff did not provide any opportunity to "catch up" with sleep during the day. As in other studies, my participants found their nights disturbed by new admissions or women leaving at all hours which, combined with cleaners and staff making beds, made sleep or remaining asleep almost impossible at times. Lack of sleep often impacts on a woman's physical and mental well-being causing increased anxiety and depression (Katz, 2001). For the participants of my study, this interruption in normal sleep patterns contributed a decline in their mental well-being. Interrupted sleep was also described in existing literature, which found that women struggled to have adequate sleep while hospitalised and that this had a profound effect on the participants' well-being (Gallo & Lee, 2008). Some of the women studied by Gallo and Lee needed to resort to sleep aids, such as sleeping pills, to try and achieve a healthy amount of sleep, as found by the current study. The inability to get a normal amount of sleep due to sharing a room impacted negatively on the participants' mental well-being. Sleep is essential for health; it gives the body time to heal and for the brain to consolidate learning and memories from the day. Sleep disturbances have been implicated in increased morbidity and mortality, particularly cardiovascular disease. Insomnia is strongly linked with depression and anxiety (Highet,

Stevenson, Purtell, & Coo, 2014; Okun, Roberts, Marsland, & Hall, 2009). Some of the risk markers for cardiovascular disease are relevant to adverse pregnancy outcomes such as pre-eclampsia, pre-term labour and birth, and intrauterine growth retarded babies (IUGR). Pre-eclampsia can lead into cardiovascular disease in the future (Okun et al., 2009). Sleep disturbances in pregnancy are often described as an expected part of pregnancy. Some common pregnancy related sleep disturbances are noted as poor sleep quality with frequent awakenings, insomnia, restless legs, and breathing disorders such as snoring. For the women of my study, as in previous studies, these normal sleep disturbances were further disrupted when sharing a room when hospitalised in pregnancy (Gallo & Lee, 2008; Katz, 2001; Okun et al., 2009; Spehar, et. al., 2018). Lack of sleep caused the participants to feel they were losing control over their minds and bodies.

### **Losing control**

For the participants of this study, the isolation and restriction on their movements and ability to look after themselves caused them to feel like they were losing control. The transformation from a normal pregnancy and independent life to hospitalisation and close monitoring caused the women to feel their bodies were not working as expected and they had lost control. The women felt like prisoners trapped by their pregnancy complication with no control over what they could do. They had suddenly moved from well pregnant women to a 'high-risk' pregnancy. Trying to change their mind set from well to 'high risk' challenged the participants, especially as they did not consider themselves 'unwell.' Many of the women were under the care of a LMC, either midwife or private obstetrician (described in Chapter One). These women were able to choose the person caring for their pregnancy and chose when to visit by appointment. Now, in hospital under the public system, the women were reliant on the ever-changing health professionals within the hospital. The participants' unsteady relationship with the health professionals caring for them caused them to lose trust in their bodies and led to a feeling of losing control. The women of this study were often made to wait, trapped in their rooms, for the doctors' consultation visits. They had no concept of when the consultation would happen leaving them with no option but to wait indefinitely. The participants would then, in frustration, decide that they were not important and would leave their space before the rounds were complete. To try and gain back some control of their lives and decision making, some participants would choose not to follow the

recommendations and this caused them to be labelled 'non-compliant' by the health professionals.

Alcalde (2011), in contrast to the current study, found that the women's choice not to follow the recommendation of the doctors compounded the feeling of loss of control and led the women to feel they had put their baby at risk or that their bodies had failed them. As the women adjusted to how vulnerable their pregnancy was, they came to terms with their limitations and began to seek ways to gain back control (Alcalde, 2011). For the women in my study, taking back control included negotiating time out of the ward, goals of steps to walk, bringing in their own food, and sleeping in a procedural room. By gaining some small amount of control of their situation, the women were finding the right balance between maintaining their own well-being, while being aware of the well-being of their baby. Gaining control over the situation, the women made personal sacrifices to keep themselves well while continuing to make sure their baby was protected. Taking back control, often against the health professionals' advice, the women had decided within themselves that their actions were worth the risk to protect their own mental well-being and to try and feel less like a prisoner.

### **Lack of trust**

The participants found that due to the changing nature of a large tertiary hospital, there were times they were unable to develop a trusting relationship with the health professionals treating them. Often the information would be conflicting, such as the ability to go out on ward leave. A lack of continuity from health professionals led to some women being given conflicting information. The conflicting information led women to distrust some of the health professionals caring for them. Goldberg (2008) stated that if a woman has had a negative or hurtful experience within healthcare, they often place their trust in a misguided way, such as trusting their body rather than medical recommendations. For some of the participants in my study, due to the conflicting information they were given, they chose to believe that their body would indicate if there was something wrong, as they felt well. The lack of continuity with doctors, losing the trust they had with their LMC, and the conflicting advice they were given led them to disengage from the system. They instead turned to either how they physically felt or to outside influences such as parents, relying on outside advice. For some of the participants this led to the health professionals branding them as 'non-compliant.' Trust needs to be worked on and earned. A confident trustful relationship is

essential for pregnant women to be able to make decisions for themselves and their baby (Mander & Melender, 2009).

The women of my study found they were hesitant to trust the recommendations from the health professionals looking after them while hospitalised. The participants had moved from a trusting working relationship with their LMC in the community to unknown and unfamiliar doctors. Societal norms in modern society have led to lay people losing trust in their medical professionals; due, in part, to the belief that health professionals should be able to anticipate the future and, therefore, treat accordingly (Ward, 2006). As these health professionals cannot predict the future the public have begun to distrust medical practitioners. Some of the women in my study found that the health professionals who should know about their complication and how to treat them were giving conflicting advice from their previous carers. This led the women to feel unsure that these medical professionals were actually correct. A trusting relationship with a health professional, such as a midwife, can give the women the ability to trust in herself and her decisions. Developing a trusting relationship takes time and requires the health professional to appear honest and interact with integrity. If the woman feels that the health professional is holding information back or gets conflicting information, she will be distrustful of the recommendations of the professionals. In contrast, research by Markovic et al. (2006) found women willingly surrendered control of their pregnancies to the health professionals and, despite the challenges of hospitalisation, became a passive patient complying with medical recommendations, thereby protecting their pregnancy.

### **Perception of risk**

The women were aware that they were hospitalised for a good reason. However some struggled with the feeling they were not really sick or unwell enough to be taking up a bed that somebody else could be using. Many had, earlier in their pregnancy, been advised that they may need extra vigilance due to a developing pregnancy complication. Yet, for the women of this study, hospitalisation was still a shock. Perception of risk in pregnancy appears to differ between women and health professionals. The women did not feel 'sick' when hospitalised for pregnancy complications. Many struggled with the need for hospitalisation and their own perception of their pregnancy. Health professionals were then informing the women of their high-risk pregnancy and recommending restrictions on movement and, for some, complete bed rest. The perception of risk of the health professional often differs to that of the women as they

felt well and considered this a good indication that their pregnancy was not at risk. Until something changes and symptoms, such as a sudden bleed, the women of this study felt the risk to themselves and their pregnancy to be low. How women perceive their pregnancy will impact on their perception of risk and affect their behaviour if they are hospitalised. van Manen (2016) discussed the existential of the 'lived body' as our body is who we are and how we are in the lived world. When a woman is challenged with changing her perception of her own body (well to sick/injured) the shift in thought processes may take time. The differences in risk perception between women and health professionals can lead to a breakdown in communication, putting both the woman and her baby at risk. Lee et al., 2012; Markovic et al., 2006 also found a break-down in communication can also lead to conflict as the health professional does not intend to cause harm.

## **Conflict**

The participants accepted the role of high-risk pregnancy, making personal sacrifices, such as leaving their home and family, not being able to eat when and what they usually would, and being physically inactive to keep their pregnancy safe. Participants sacrificed their dignity by needing to beg for somewhere to sleep, ending up sleeping in a procedure room in an attempt to maintain mental wellness. For some, this became difficult when the needs of the fetus were placed ahead of the needs of the woman. Protecting the fetus, while trying to maintain their own physical and mental well-being, became a challenge. Health professionals were often perceived by the women to be more interested in the health and well-being of the fetus than of them. Women felt a conflict between their own needs and those of their babies. Leichtentritt et al. (2005) found that women who were hospitalised on bed rest were conflicted with the desire for the baby to be born and the ordeal over, and the need to remain pregnant as long as possible. Supporting this finding, Curran et al. (2017) found that "sacrificing their own desires for the fetuses' perceived needs was understood as a defining feature of motherhood" (p. 820). However, for my participants, making these sacrifices caused conflict within their lives and led to feelings of guilt.

## **Guilt**

The women of my research shared their guilt for leaving the home and family to cope without them while they lay in bed "doing nothing." The women in my research expected to have a normal pregnancy, continuing to do what was expected of them.

However, the unexpected hospitalisation meant that they were taken away from their normal lives and expected to adjust to a situation far from normal. For some, the guilt they feel could be due to the feeling they have caused the problem. The participants felt guilt from leaving their family at home to cope without them and being trapped in a situation out of their control. These women found themselves in a place they were not meant to be. They felt undeserved guilt that they were not conforming to societal expectations of normal motherhood. Long term feelings of guilt could impact on the women's' mental health as research has made links with maternal guilt and shame as a significant predictor of postnatal depression (Dunford & Granger, 2017; Markovic, et. al., 2006; Patel, et.al., 2013; Sutherland, 2010).

Guilt has been described as a feeling due to a negative self-evaluation resulting from a specific act or behaviour. Guilt could mean taking responsibility for a wrongdoing or the negative feeling caused by thinking you have done something wrong. Shame is described as a feeling of not acting in an expected way. Feelings of guilt stem from the fear of been punished for a wrongdoing; whereas shame is felt when not meeting social norms (Dunford & Granger, 2017; Kim, 2017). Sutherland (2010) suggested many women strive to meet the expected standards of the societal norm they live within. When these cultural norms are deemed to not be met the woman may then experience feelings of guilt or shame. "Mother's guilt" has been explored by several researchers. Guilt felt by mothers could be seen as socially constructed. Societal pressure is placed on women to be the "best mother" and they can feel judged by their peers for not conforming. The idealisation of the 'perfect mother' in current society presents a model that women are hard pressed to meet society's expectations of motherhood (Dunford & Granger, 2017; Sutherland, 2010). Sutherland described the danger of this ideology as "As long as mothers are exposed to this ideology, they risk being locked into a kind of prison, bound by the myths of motherhood" (p. 313).

For the women in my research, the feelings of guilt came from their perception of what it means to be a good mother. Being in hospital away from their family for an extended period did not fit with their perception of motherhood; although these feelings of guilt were unfounded, as they had no control of the situation they were in. The participants were trapped by feelings of guilt due to being hospitalised away from what society perceives as their 'natural place.' Katz (2001), Kent et al. (2015), and Leichtentritt et al. (2005) found that women worried about the extra work placed on their husbands left at home and felt they were a burden. The participants may have, in fact, felt shame rather

than guilt as they felt that they were not doing as expected of them (Dunford & Granger, 2017; Liss et al., 2013; Sutherland, 2010).

In Western society, women become an ‘idealised woman;’ women are expected to become pregnant easily, have the “perfect pregnancy,” labour and birth. They are then expected to juggle children, home, and often work commitments without appearing to struggle—being the “perfect mother” (Lowe, 2016a). Schroeder (1996) discussed how their participants felt guilt for not been able to perform their normal roles and they felt this put extra burden on their older children. The women in my study essentially made personal sacrifices, such as leaving family and home, to maintain their fragile pregnancies. They continued to worry that their actions or choices could impact poorly on their babies’ health. Participants felt that their needs were secondary and that their goal was to protect their baby as long as possible as per medical advice. For some, however, the challenges of hospitalisation for an extended time caused them to feel their mental well-being was affected. These women then made decisions to go against the recommendations of the health professionals in an effort to maintain their mental well-being. The guilt they felt from going against the societal norms of maternal sacrifice caused an internal conflict.

### **After baby**

For my participants, once the baby was born safely they found they were practically ignored. They felt after their job of nurturing and protecting the baby until it was well enough to be birthed, they were suddenly unnecessary and experienced a different type of care. Many of the participants felt abruptly abandoned by the health professionals and struggled to return to their normal life. Persson, et al., (2015) also found that participants felt abandoned when they became well and did not need such intensive care. My participants were challenged by the change in care and most struggled once home with their baby. Physical restrictions and the dramatic birth left the women exhausted and stressed, while trying to adapt to their new normal. Motherhood can be stressful and transformative but for the women of this study it was worthwhile.

Recent studies have found a relationship between a high-risk pregnancy, stress and postnatal depression. The transition from antenatal high-risk woman to mother at home can cause feelings of abandonment, fear, and guilt (Forster et al., 2008; Zadeh et al., 2012). Some of the women found the transition to motherhood, once home, a challenge. The stress of the long hospitalisation and having felt like a prisoner for so long made

them feel nervous about how they would cope at home. The adjustment from constant monitoring to nothing made some of the women feel unprepared to look after themselves and their new family. There were concerns from some that they may suffer from postnatal depression. These women maintained a careful watch on their mental health once home. Some, however, were not aware they were suffering from postnatal depression until well after the baby was born, and only recognised they had once beyond the exhausting new-born period. This is supported by Highet et al. (2014) who found that health professionals often missed recognising the symptoms of postnatal depression and that there were low rates of referral and treatment for women.

The women who participated in the study showed me the most amazing strength of will. They overcame the suddenness of being thrown into an unfamiliar, foreign environment and adjusted with dignity and strength. I was amazed at their ability to take such a difficult time and make sense of their time. The quote below, I think, sums up the extraordinary sacrifices these women made to ensure the safe birth of their child.

The endless and selfless devotion required of women within intensive motherhood often goes beyond what is necessary to ensure the welfare of the children. In other words, it is maternal sacrifice that is the key component of good motherhood, and the need for sacrifice remains. That women need to do to be good mothers changes over time, but the need for them to make sacrifices is a constant feature. (Lowe, 2016b, p. 216)

## **Strengths and Limitations**

Seven women were interviewed for this study, which is considered adequate for hermeneutic phenomenological research; the strength is that the seven participants came from three different DHBs in New Zealand. A limitation is they represented only three ethnic groups as I was unable to recruit a more diverse section of the New Zealand population. Four of the seven participants were from a higher socio-economic group affording the services of private obstetric care, which could be considered a limitation. All the interviewing, transcribing, and writing of the data was performed by myself, which could be considered a strength as it allowed for more in-depth analysis. It could also be a limitation as my interpretation may differ from another researcher. A further strength comes from the similarity of the findings to the existing literature; thereby adding to the reliability of the findings from this study.

## **Recommendations for practice and education**

The findings showed how thrown the women were when first hospitalised and how this made them feel trapped as if they were prisoners. The women felt guilty due to having to abandon their perceived home duties. There was fear of the unknown and unfamiliar, and the change from known practitioner to unknown. The lack of continuity with health professionals and conflicting information led to the women distrusting some of the information and made their stay feel unsafe. These women felt trapped in an unfamiliar and restrictive environment and this caused them to feel mentally and physically unsafe. In an effort to ensure women who are hospitalised in their pregnancy feel safer and comfortable, more able to make informed decisions about their care, I recommend the following strategies.

### **Midwifery education and practice**

- Strategies for recognising antenatal depression or anxiety and the changing psychological picture. Consider how the woman's care is transitioned from the community to the hospital and back again, including who is in
- Implementing the principles of Tūranga Kaupapa<sup>6</sup> to ensure involvement of the woman and family in decision making around their care. Making sure the woman is part of the 'team.'
- Ongoing education on privacy and protecting the woman and family's confidentiality.
- Interprofessional/multidisciplinary education highlighting the importance of communication, language in documentation and collaboration with care planning, decision-making and advice.
- Ongoing education on advocating for women's rights.
- Spending time conversing with the woman get to know her well.

### **Recommendations for health professionals and facilities**

- A change in DHB hospital policies to ensure fewer interruptions, especially overnight to minimise the effects of stress.

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<sup>6</sup> Tūranga Kaupapa is the cultural framework gifted to New Zealand by Nga Maia to guide midwives in their practice (New Zealand College of Midwives, 2015)

- Acknowledge that privacy and interrupted sleep will impact on how the woman feels and the effect it may have on her decision-making skills. Provide the best possible environment, such as single rooms for long stay women.
- Allow the woman to control her schedule of care, flexible booking of obstetric consultations.
- Continuity of care is important, the woman's LMC should be included in reviews and decisions made. Ensure the LMC has a thorough case history when care is handed back to the community.
- Offer childbirth and postnatal classes, as well as recreational classes such as art, craft or reading groups.
- Facilitate group meeting between in-patients to gain a sense of community in a room specifically designed for in-patients.
- Recognise that the sudden withdrawal of intensive monitoring may make the woman feel abandoned. Keep the woman at the centre of the care with shared care planning that is reviewed each day. Acknowledge her long journey. Gear postnatal care to the individual.
- Single rooms and improvement of the hospital environment. Make the hospital setting more 'home like' with a view to the outside.
- Better food options, able to 'order in'; a proper dining room for women to gather together (dining/living/entertainment room). Alternatively, a kitchen facility providing space to prepare their own meals. These areas need to be private, away from visitors.
- Provide an outdoor environment with natural light and fresh air for women to improve mood and faster recovery.
- Better control with visitors, limiting visiting hours, other than immediate family. With single rooms this would not be an issue.
- Ensure the women have good support from close family members; encourage a support person to be able to stay.
- Separate consultation rooms for privacy and for the obstetric teams to communicate with the woman and family in a private setting.

### **Recommendations for further research**

- Investigate and compare how each DHB provides care and facilities for long stay antenatal in-patients.

- Explore how midwives and other health professionals see their role in maintaining and supporting a woman's mental health during extended antenatal stays.
- Investigate long term implications for the health (physical and psychological) of the women and their children.
- Investigate better ways to provide care for women and their families with high-risk pregnancies.

## **Conclusion**

My study revealed the experiences of women who had been hospitalised during their pregnancy and the impact this had. Using van Manen's (2016) existential guidelines to analyse the extraordinary experiences of the women revealed how women who are hospitalised for an extended time in their pregnancy can feel trapped, feeling like a prisoner. These feelings impacted significantly on the women's mental health as long-term antenatal in-patients. The experience of feeling like a prisoner, trapped in a place they came to find unsafe while hospitalised in pregnancy was not attributed to just one portion of the participants' experiences. The coming together of many experiences contributed to an end state of mental unwell-ness for these women. The participants experienced feelings of being trapped or feeling like a prisoner of the hospital ward, with no control over their body, space, food, or decisions. Societal norms dictate how women, pregnancy, and birth should proceed; however, the women of this study no longer conformed with the 'normal'. This feeling of not conforming led them to feel guilt while hospitalised. The women sacrificed their own hopes, desires, and well-being to become absorbed with carefully maintaining their pregnancy until the baby was able to be safely born. The effects of the experiences the women had while hospitalised continued into the post-natal period once baby was born. For some of the women, these negative effects on their mental well-being continued significantly into their future. The women continued to be negatively affected by their experiences. Prior studies had explored the experiences of women while still in-patients, this study sought to explore the experiences of women once they were back at home after their baby was born.

The four themes and sub-themes have added to an established body of evidence, as well as providing deeper insight into the long-term implications of an extended hospital stay. The women's experiences revealed how being thrown into an unexpected and unknown situation caused them to feel shock, fear, and guilt. The unfamiliar, foreign environment

of the hospital, with the restrictions placed on the women's space and ability to care for themselves, became an uncomfortable, challenging experience. The women experienced feelings of loss of control due to the intensive monitoring and hospital routines. Sharing a room with another in-patient with constant interruptions from staff and visitors had a significant impact on their mental well-being. The women spoke of feeling 'loopy' and 'going crazy' due to the interrupted sleep and lack of privacy. Concern was raised as to who was able to hear their personal history and where that information may go. Communication between professionals and the women was also revealed to be a stressor, with a lack of continuity and miscommunication causing the most distress.

In answering the research question, the experiences of the women of this study raises the concern that antenatal anxiety and depression are not recognised, acknowledged or treated by the women their families and health professionals involved in her care. Another concern is that once discharged home, postnatal depression and post-traumatic stress disorder are also often unseen and undiagnosed. There is also the concern that antenatal depression and anxiety is largely ignored as the women are expected to 'cope' for the benefit of their unborn child. Health professionals caring for women, such as those in this study, need to be made aware of the challenges women face while hospitalised. Care needs to be taken to ensure that in the business of a hospital ward the individuals' needs are not ignored or misinterpreted. The women of this study were prepared to sacrifice control of their pregnancy to ensure the safety of their unborn child. The heavy cost of their mental well-ness does not seem a good price to pay.

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## Appendix A: AUTECH Ethics Approval

21 March 2017

Andrea Gilkison  
Faculty of Health and Environmental Sciences

Dear Andrea

Re Ethics Application: **17/9 What is the experience for women requiring hospitalisation for an extended time in their pregnancy?**

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTECH).

Your ethics application has been approved for three years until 20 March 2020.

As part of the ethics approval process, you are required to submit the following to AUTECH:

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 20 March 2020;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>. This report is to be submitted either when the approval expires on 20 March 2020 or on completion of the project.

It is a condition of approval that AUTECH is notified of any adverse events or if the research does not commence. AUTECH approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTECH grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz).

All the very best with your research,



Kate O'Connor  
Executive Secretary  
**Auckland University of Technology Ethics Committee**

Cc: mlomaxmasters@gmail.com

## Appendix B: ADHB Low Risk Study Approval



19<sup>th</sup> July 2017

Michele Lomax  
c/- Women's Health Directorate  
National Women's Health  
Auckland City Hospital

Dear Michele,

Re: Research project A+7608 (AUTEC 17/9) What is the experience for women requiring hospitalisation for an extended time in their pregnancy?

The Auckland DHB Research Review Committee (ADHB-RRC) would like to thank you for the opportunity to review your study and has given approval for your research project.

Your Institutional approval is dependent on the Research Office having up-to-date information and documentation relating to your research and being kept informed of any changes to your study. It is your responsibility to ensure you have kept Ethics and the Research Office up to date and have the appropriate approvals. ADHB approval may be withdrawn for your study if you do not keep the Research Office informed of the following:

- Any communication from Ethics Committees, including confirmation of annual ethics renewal
- Any amendment to study documentation
- Study completion, suspension or cancellation

More detailed information is included on the following page. If you have any questions please do not hesitate to contact the Research Office.

Yours sincerely

On behalf of the ADHB Research Review Committee Dr Mary-Anne Woodnorth  
Manager, Research Office  
ADHB

c.c. Sue Fleming, Cindy Farquhar

.../continued next page

### Auckland DHB

Research Office  
Level 14, Support Bldg  
Auckland City Hospital  
PB 92024, Grafton, Auckland  
Phone: 64 9 307 4949 Extn. 23854  
Fax: 64 9 307 8913  
Email: [mwoodnorth@adhb.govt.nz](mailto:mwoodnorth@adhb.govt.nz)  
Website:  
<http://www.adhb.health.nz/health-professionals/research/>

**Institutional Approval**

## Appendix C: Letter to Kawa Whakaruruhau Komiti



Kawa Whakaruruhau.

Tui O'Sullivan

Chairperson

Kawa Whakaruruhau Komiti

School of clinical Sciences

AUT

Dear Tui,

I am writing to Kawa Whakaruruhau Komiti for advice regarding my Masters Research proposal "What is the experience for women requiring hospitalisation for an extended time in their pregnancy?"

My name is Michele Lomax, I am a registered midwife currently employed at Waitemata District Health.

I am hoping to recruit approximately 8-10 women who have spent at least 2 weeks of their pregnancy in a tertiary hospital, due to pregnancy complications. I plan to interview these women in the post-natal period 4 weeks to 4 months once baby is born.

Though I am not specifically targeting Maori women I am hoping that some of the participants will identify as Maori to ensure a diverse range of experiences.

I am aware after working in such an environment that Maori women are represented in this demographic and hope to gain a unique perspective that will influence my research and hopefully provide good guidelines for policy development.

I would appreciate any guidance or suggestions on ways to ensure that Maori women would be comfortable to be interviewed by myself.

I attach my research proposal (PG1), EA1 and Information sheet and I am happy to come to meet the komiti with my supervisor at your next meeting, my supervisor is Dr Andrea Gilkison.

The interviews are planned to be in the participant's homes, at a time their choosing. I will be providing a small koha (\$20 petrol voucher), as thanks for participating. The interview is semi-structured and I do have a list of questions to prompt the conversation, however these are purely a guideline to keep the researcher (myself) on track.

Thank you for your consideration.

Regards

Michele Lomax

Mob; 0212481141

Email; mlomaxmasters@gmail.com

## Appendix D: Māori Approval from ADHB and WDHB



**He Kamaka Waiora**  
**Waitematā and Auckland DHB**  
Level 2, 15 Shea Terrace,  
Auckland 0740,  
New Zealand  
Private Bag: 93-503

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03/07/2017

Michele Lomax  
Women's Health  
(No address provided)

**Re: What is the experience for women requiring hospitalisation for an extended time in their pregnancy?**

Thank you for providing the following documents the:

- RRC application
- Study protocol
- PIS/CF
- HDEC application

---

The study is qualitative investigation of women's experiences of extended hospitalisation during pregnancy. There will be between 8-10 participants recruited locally. The researcher is unsure how many participants may be Māori. It is recommended that the researcher access admissions data to support estimates for future studies where applicable.

**Māori responsiveness:**

The focus of this study is potentially of significant interest to Māori because evidence suggests that Māori women are more likely to have high risk pregnancies and to receive less adequate pre-natal education and support for healthy pregnancies (e.g. see Ratima and Crengle, 2013). The study will not include analysis by ethnicity. Despite this, the research methodology is interesting and would potentially suit an exploration of Māori women's perceptions of health care and hospitalisations during pregnancy.

The researcher has given consideration to the involvement of whānau including during the interview process.

The information sheet has been amended to include the contact details for the Auckland and Waitematā DHBs Māori Health Team (He Kamaka Waiora), Māori Research Committee, and Māori Research Advisor.

On behalf of the Waitematā and Auckland District Health Boards Māori Research Committee the study has been approved.

## Appendix E: Participant Information Sheet

### Participant Information Sheet

Date Information Sheet Produced:

14/01/2017

Project Title

**“What is the experience for women requiring hospitalisation for an extended time in their pregnancy?”**

**You have been invited to participate in research exploring your experience of been in hospital during your pregnancy.**

My name is Michele Lomax, I am a Registered Midwife and I am working towards completing a Masters in Midwifery.

To complete this I will be conducting a research project that will be listening to your stories and interpreting the experiences that women, such as yourself, may have had after spending a lengthy time in hospital during their pregnancy.

**What is the purpose of this research?**

I am conducting this research in the hope that by talking to women who have experienced a lengthy hospital stay during their pregnancy I will uncover any adverse or positive effect of this experience.

This research will be reported at Midwifery Research Forums, Midwifery Journals and the Biannual Midwifery conference. I am expecting to inform midwifery practice in better ways to support women in this situation and the best way to support women and their families in the weeks after baby is born.

**How was I identified and why am I being invited to participate in this research?**

You may have spent more than 2 weeks at any time during your pregnancy in hospital and may have had your baby or be about to soon. The interviews will be held in the postnatal period when your baby/babies will be over 4 weeks old.

**How do I agree to participate in this research?**

You will be given contact details of the researcher (below) and will contact her if you would like to participate. If you choose to participate you will need to sign a Consent Form, which will be done at the beginning of the interview.

After your initial contact I will then email or phone, whichever is easiest for you, to arrange suitable times to meet.



Your participation in this research is voluntary (it is your choice) and whether or not you choose to participate will neither advantage nor disadvantage you. You are able to withdraw from the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

### **What will happen in this research?**

To gather the data for this research I will be conducting one to one interviews with you. This will involve semi-structured questions as a prompt that will give you the opportunity to talk about your experience. I envision these interviews to take up to 1 hour and will be flexible in that it may require more or less time.

The interviews will be recorded and I will also be taking brief notes. These recordings will then be transcribed and I will then read these to determine if any themes emerge from your stories. These transcriptions will be individually sent to you by email for you to also read and add to or make changes if you need to.

### **What are the discomforts and risks?**

Depending on your experience while an inpatient talking about this may become uncomfortable or upsetting. If this is the case we can stop at any time and reschedule or do not need to continue.

### **How will these discomforts and risks be alleviated?**

If any of the questions cause any distress you are not under any obligation to answer and will not be disadvantaged in any way.

AUT Health Counselling and Wellbeing are able to offer three free sessions of confidential counselling support for adult participants in an AUT research project. These sessions are only available for issues that have arisen directly as a result of participation in the research, and are not for other general counselling needs. To access these services, you will need to:

You can find out more information about AUT counsellors and counselling on <http://www.aut.ac.nz/being-a-student/current-postgraduates/your-health-and-wellbeing/counselling>.

If you require Māori cultural support talk to your whānau in the first instance. Alternatively, you may contact the administrator for He Kamaka Waiora (Māori Health Team) by telephoning 09 486 8324 ext 2324.

If you have any questions or complaints about the study you may contact the Auckland and Waitematā District Health Boards Maori Research Committee or Maori Research Advisor by phoning 09 4868920 ext 3204.

### **What are the benefits?**

I am hoping that this research will reveal any potential changes or support systems that could be made available to women required to spend an extended time in hospital.

As this time in hospital may have an impact on your postnatal experience I am hoping that by analysing the experiences of women after having their babies may provide insight of the best care in this time.

This research is also to complete a Masters in Health Science in Midwifery.

### **How will my privacy be protected?**

Your privacy will be protected by assigning a pseudonym, chosen by you, known only to the yourself and the researcher, no identifying features will be published in any written material

Only the researcher and the supervisor will read the transcriptions of the interviews.

### **What are the costs of participating in this research?**

I would expect up to 1 hour participation for the interview will be the only cost.

### **What opportunity do I have to consider this invitation?**

I would hope to hear from you within 1 week of receiving this invitation to participate, however as I am planning to interview in the 4 weeks to 4 months after you have your baby there is plenty of time to consider participating.

### **Will I receive feedback on the results of this research?**

You will receive a copy of your personal transcript notes to read and comment on. A copy of the outcome of the research can be provided to you if required.

### **What do I do if I have concerns about this research?**

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor,

Dr Andrea Gilkison:

P 09 921 9999 ext 7720 M 021905369 E [andrea.gilkison@aut.ac.nz](mailto:andrea.gilkison@aut.ac.nz)

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEK, Kate O'Connor, [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz), 921 9999 ext. 6038.

### **Whom do I contact for further information about this research?**

Please keep this Information Sheet for your future reference. You are also able to contact the researcher as follows:

#### ***Researcher Contact Details:***

***Michele Lomax.***

***Email:*** [mlomaxmasters@gmail.com](mailto:mlomaxmasters@gmail.com)

***Phone:*** 0212481141

## Appendix F: Researcher Safety Protocol



### **Researcher Safety Protocol.**

As the interviews, will mostly be held in the participant's homes and the Researcher will have no prior knowledge of the circumstances of their home life she will;

- Provide an emailed list of participants and arrival times for that day to the Supervisor and a family member.
- Phone or Text the Supervisor and Family member at the beginning and completion of the visit.
- Not take any unnecessary risks and will be sensible when visiting a person's home.

# Appendix G: Ethics Amendment



## AUTEC Secretariat

Auckland University of Technology  
D-88, WU406 Level 4 WU Building City Campus  
T: +64 9 921 9999 ext. 8316  
E: [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz)  
[www.aut.ac.nz/researchethics](http://www.aut.ac.nz/researchethics)

23 March 2018

Andrea Gilkison  
Faculty of Health and Environmental Sciences  
Dear Andrea

Re: Ethics Application: **17/9 What is the experience for women requiring hospitalisation for an extended time in their pregnancy?**

Thank you for your request for approval of an amendment to your ethics application.

The minor amendments to the inclusion criteria (up to one year post baby) is approved.

I remind you of the Standard Conditions of Approval.

1. A progress report is due annually on the anniversary of the approval date, using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>.
2. A final report is due at the expiration of the approval period, or, upon completion of project, using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>.
3. Any amendments to the project must be approved by AUTEK prior to being implemented. Amendments can be requested using the EA2 form: <http://www.aut.ac.nz/researchethics>.
4. Any serious or unexpected adverse events must be reported to AUTEK Secretariat as a matter of priority.
5. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEK Secretariat as a matter of priority.

Please quote the application number and title on all future correspondence related to this project.

AUTEK grants ethical approval only. If you require management approval for access for your research from another institution or organisation then you are responsible for obtaining it.

For any enquiries please contact [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz)

Yours sincerely,

A handwritten signature in black ink, appearing to read 'K O'Connor'.

Kate O'Connor  
Executive Manager  
Auckland University of Technology Ethics Committee

Cc: [mlomaxmasters@gmail.com](mailto:mlomaxmasters@gmail.com)

# Appendix H: Consent Form



O TĀMAKI MA

## Consent Form

*Project title:*

*What is the experience for women requiring hospitalisation for an extended time in their pregnancy?*

*Project Supervisor:     **Dr Andrea Gilkison***

*Researcher:             **Michele Lomax***

- I have read and understood the information provided about this research project in the Information Sheet dated .....
- I have had an opportunity to ask questions and to have them answered.
- I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.
- I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.
- I agree to take part in this research.
- I wish to receive a summary of the research findings (please tick one): Yes     No

Participant's signature: .....

Participant's name: .....

Participant's Contact Details (if appropriate):  
.....  
.....  
.....  
.....

Date:

**Approved by the Auckland University of Technology Ethics Committee on *type the date on which the final approval was granted* AUTEK Reference number *type the AUTEK reference number***

*Note: The Participant should retain a copy of this form.*

## Appendix I: Recruitment Poster



### **PARTICIPANT REFERRAL**

“WHAT ARE THE EXPERIENCES FOR WOMEN REQUIRING HOSPITALISATION FOR AN EXTENDED TIME DURING THEIR PREGNANCY”

I am completing a Master's Thesis **investigating the experiences of high risk women who are hospitalized during their pregnancy due to complications.**

I am hoping to recruit around 10 women to interview after they have had their baby.

To be eligible they need to have spent at least 2 weeks of their antenatal journey in hospital, be English speaking and be at least 4 weeks to 2 years postnatal.

They will be asked to consent to an interview of up to 1 hour and be happy to talk about their experience. If you have a woman you think may be eligible, please pass on my contact details with an information sheet provided, or if the woman permits send her details to me as below.

FOR MORE INFORMATION CONTACT: MICHELE LOMAX M 0212481141 OR EMAIL  
MLOMAXMASTERS@GMAIL.COM

## Appendix J: Questions



*“What is the experience for women requiring hospitalisation for an extended time in their pregnancy?”*

QUESTIONS: These are to keep the researcher on track and for prompting only as this interview is for the women to tell their stories

1. If there is anything I don't mention or ask that you would like to add please bring them up as they occur to you.
2. Tell me how you felt when you were first told to go to hospital.
3. How did you feel once baby was born?
4. How did you feel when you got home after baby was born?
5. Can you tell me if this is what you expected?