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**Challenges of a Pregnancy Gone Wrong:  
Pregnancy Complications, Illness Perceptions and Distress**

A thesis

submitted in fulfilment

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of

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## **ABSTRACT**

Women with pregnancy complications need to cope with a pregnancy that can have life changing consequences. The objective of this research project was to understand the experience of women who had been diagnosed with a pregnancy complication. The research involved an exploratory investigation into illness perceptions of pregnant women with complications and how these relate to depression and anxiety. First a literature review was divided into two parts. The first part dealt with anxiety specific to pregnancy complications. The second part dealt with illness perceptions. Since no published literature on illness perceptions in pregnancy complications was found, a literature review was conducted into illness perceptions in hypertension, diabetes and pain which are all closely associated to pregnancy complications.

The research was divided into two studies. The first was a mixed method study in which six women were interviewed regarding their experience in dealing with a pregnancy complication and a pilot was conducted using the Illness Perception Questionnaire (Revised). The second study consisted of an online survey further exploring the relationship between illness perceptions and distress in this population. Recruitment for participation proved very difficult and there were only thirty-six participants who complete the full online study. This survey comprised of a battery of self-report questionnaires including background information, rating of health scale, the Illness Perception Questionnaire (Brief), Edinburgh Postnatal Depression Scale and State Trait Anxiety Inventory Scale (State).

Results from both studies indicated that women in experienced significantly higher degrees of distress and anxiety than those in normal populations. They perceived their pregnancy complications as being outside of their personal control and they don't see treatment as likely to be effective in controlling their medical condition. They also perceived their pregnancy complication as having high consequences in their lives and they are concerned about the impact of the pregnancy complication has on themselves and on their child. The women who did not have detectable symptoms (asymptomatic) and who could not directly experience cues to their illness were significantly more depressed.

This research adds to the international findings on illness perceptions in general and is a starting point for understanding illness perceptions for women with pregnancy complications. The psychological needs of women with pregnancy complications are significant, and are often under-rated and under-evaluated by treatment providers. Understanding illness perceptions of this population can provide a framework for the development of further interventions for this vulnerable population.

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## CHAPTER ONE: INTRODUCTION

Over the past 40 years, the psychological aspects of childbearing, pregnancy and the transition to parenting have come under the spotlight (C.C. Barber, 2012; Brockington, 2005). There has been a realisation that pregnancy and transition to parenthood is complicated. 'From the standpoint of psychological medicine, childbearing is the most complex event in human experience' (Brockington, 2005, p. 11). A woman has to adjust to a wide array of changes while she is pregnant and deal with the realities of her new identity as a mother-to-be. Being pregnant itself can result in higher levels of anxiety, which have been recorded over this time as higher than in non-pregnant population groups (Moss, Skouteris, Wertheim, Paxton, & Milgrom, 2009).

There is a growing body of research on the detrimental effects that stress, anxiety and depression during pregnancy have on the development of the child (Dunkel Schetter & Tanner, 2012; Glover, Bergman, & O'Connor, 2008). High anxiety levels can also have a negative effect on the pregnant woman in her transition to motherhood, as they are associated with postnatal depression and attachment issues with the new-born child (Mauri, et al., 2010). Anxiety has been implicated as a causal factor with some different types of pregnancy complications (Johnson & Slade, 2003).

When there is a health threat during pregnancy, either to the pregnant woman or her foetus, there is a growing body of literature that indicates that pregnant women are at an increased risk of experiencing psychological distress during and after pregnancy (Brandon, Pitts, Robinson, & Stringer, 2007; Brandon, et al., 2008; Breilkopf, et al., 2006; Da Costa, Larouche, Dritsa, & Brender, 1999; Robinson, Pennell, McLeane, Oddy, & Newnham, 2011). There is also evidence

that pregnant women have a different perception of their pregnancy complication in comparison to medical professionals and it is the woman's perceptions that are most strongly associated with their distress and coping levels (Currie, 2012; Keith & Weinman, 2006).

It is important to understand the relationship between the women's perceptions of their pregnancy complication(s) and their levels of anxiety, to enable health researchers and clinicians to identify the influences on a pregnant woman's emotional wellbeing, and to assist in the development of useful strategies to lower anxiety levels over this period.

The purpose of this research is to identify the levels of anxiety experienced by pregnant women who have a medical complication and to understand the mother's own perceptions of her complications and their relationship to anxiety. The pregnant woman's perceptions of her complications are likely to have an impact on her ability to cope and recover. This has been established in a number of studies of other illnesses, but not in pregnant women with complications (Hagger & Orbell, 2003).

Chapter One of this thesis reviews the relevant literature regarding the psychological functioning of a pregnant woman facing a medical complication. Since there is no published research on illness perceptions of pregnancy complications specifically, a review was conducted on perceptions of illnesses that were often experienced during pregnancy such as hypertension (high blood pressure), diabetes and pain. Chapter Two describes a mixed method study that was conducted to explore the lived experience of women with a pregnancy complication and to pilot a measure of illness perceptions. Chapter Three presents a quantitative study that was conducted to explore the relationship between illness

perceptions and distress. Chapter Four discusses the overall conclusions and their implications for clinical practice and research.

### **Types of pregnancy complications**

Pregnancy complications include any medical issue, present prior to gestation or during pregnancy, which impacts the health of either the mother-to-be or unborn infant (Health on the Net Foundation, 2014). They can range from mild symptoms (such as morning sickness) to more serious conditions (such as hyperemesis gravidarum, severe vomiting which can cause dehydration) that can have life threatening consequences and require hospitalisation (Wegrzyniak, Repke, & Ural, 2012). Pregnancy complications often require additional monitoring by health professionals such as a midwife or doctor (Barlow, Hainsworth, & Thornton, 2008; Thompson, 2003). The two most common serious pregnancy complications are issues with blood pressure (hypertensive disorders) and gestational diabetes (Levy-Shiff, Lerman, Har-Even, & Hod, 2002; Sibai, 1996) (See Table 1.1).



Table 1.1

*List of common pregnancy complications (Carrie Cornsweet Barber & Starkey, 2013)*

Type of complication

---

Hypertension – commonly known as high blood pressure

Diabetes

Hyperemesis gravida

Preterm labour/false labour

Placenta problems- placenta abruption and placenta previa

Other medical issues of mother

Maternal infection

Premature rupture of membranes

Poor foetal growth

Multiple gestations

Other medical issues of foetus

---

### **Anxiety and pregnancy complications**

Many pregnant women are screened for depression, but much less frequently are they screened for anxiety (Stephen Matthey, Barnett, Howie, & Kavanagh, 2003). Consequently, women who are not depressed are often seen as functioning well, and the role of anxiety is ‘under-reported and under-investigated’ (Moss, et al., 2009, p. 346).

Anxiety is a mood state which is ‘characterised by fear, apprehension, and somatic symptoms of tension, in which an individual anticipates impending danger, misfortune or catastrophe’ (VandenBos, 2007, p. 63). It may be experienced as a constellation of physical symptoms, including headaches, tightness of the chest, stomach discomfort and restlessness, as well as a mental

awareness of being nervous or frightened. It has been linked to the ‘flight or fight response’ of the sympathetic nervous system, whereby anxiety gives rise to an alerting signal of an internal or external threat (T. A. Brown & Barlow, 2007).

There are a multitude of reasons why the transition to parenthood can be anxiety-provoking (Boyce & Condon, 2000). There are changes in relationships, especially with the father-to-be and other family members. The women’s social identity changes with either ending employment or putting employment on hold. This can have an impact on her economic choices and her own self-identity. How she is viewed in society changes, especially when the pregnancy becomes more visible. A woman undergoes a substantial number of hormonal and biological changes and has physical demands placed on her through the process of pregnancy. Nausea can occur in the first trimester, as can sleep deprivation throughout pregnancy (which can escalate as the foetus grows larger). Pain can also occur due to the biological and hormonal changes. Pregnancy requires screening for complications and often intrusive gynaecological examinations which may also be anxiety provoking. Some women may also suffer from fear of the process of childbirth. Pre-existing medical and emotional problems are also likely to be exacerbated over this period of transition (Boyce & Condon, 2000).

Pregnancy is often associated with breathing difficulties as the uterus expands to accommodate the growing foetus, and the heart rate increases to bring further oxygen and blood flow to the baby (March & Yonkers, 2001). Increased heart rates and shallow breathing are also symptoms of anxiety and it has been suggested that women could misinterpret these symptoms as manifestations of anxiety which could trigger further anxiety in vulnerable women (Wenzel, 2011).

Another way by which pregnant women may become more anxious is through the stress mechanism within the woman's own body. These stress mechanisms are activated when hormonal changes occur which are required for developing foetus and giving birth (Jolley & Spach, 2008). Prior anxiety and/ or trauma primes the stress response, thereby making those women who have experienced prior trauma even more vulnerable to further anxiety and depression (Kendall Tackett, 2013). Kendall Tackett (2007) investigated the effect of interpersonal violence and childhood abuse on pregnant women and concluded that both abuse and interpersonal violence can increase health problems in this population. These problems can include increased anxiety and depression during pregnancy (Kendall-Tackett, 2007).

There is some variable evidence that maternal anxiety may play a causal role in certain pregnancy complications such as preeclampsia (a hypertension disorder which can result in eclampsia, a life threatening medical condition), difficulties during labour, preterm birth and/or negative perinatal outcomes (Dunkel Schetter, 2009; Dunkel Schetter & Tanner, 2012; Littleton, Bye, Buck, & Amacker, 2010).

There is mixed evidence regarding anxiety and its relationship to pre-eclampsia. Sikkema et al (2001) studied a cohort of 250 women, of whom nine developed pre-eclampsia late in their pregnancy. They utilised salivary cortisol levels (as a biochemical marker for stress), as well as self- report measures of anxiety, and discovered that salivary cortisol levels and anxiety levels did not differ significantly between the group of women who later developed

preeclampsia and the group that did not. In a much larger Swedish study of 2601 women, a positive history of maternal mood or anxiety disorder (as determined by medical records) was associated with a two-fold increase in the risk of pre-eclampsia, with the risks demonstrably higher when anxiety was diagnosed during the pregnancy (Qiu, Williams, Calderon-Margalit, Cripe, & Sorensen, 2009). These mixed results suggest that more research is necessary to establish at what level anxiety starts to have an impact on the prevalence of pre-eclampsia and other medical complications.

Some studies have also suggested that anxious women have more negative birth experiences (Beebe, Lee, Carrieri-Kohlman, & Humphreys, 2007). A small longitudinal study with thirty-five women study was conducted in 2007 to evaluate the relationships between selected bio-psychosocial factors in late pregnancy and pre-hospitalization labour. Results showed that measures of anxiety were negatively correlated to reported self-efficacy for childbirth. The higher the scores for anxiety corresponded to lower scores on the woman's confidence in her ability to adopt relaxation and coping techniques during labour and birth. Women with higher anxiety also experienced more pain and were hospitalised earlier than those women with lower anxiety. It has been proposed that this is linked to the pregnant women's confidence in facing birth and that pain is particularly daunting for anxious women (Wenzel, 2011).

It is suggested that anxiety has a direct effect on the developing foetus. One of the mechanisms by which this might occur is by disrupting the balance of the neurotransmitters called catecholamines (Wenzel, 2011). These

catecholamines have the effect of restricting blood vessels, which could reduce the blood flow to the developing foetus and could reduce the amount of oxygen and nutrients flowing to the developing baby (Dunkel Schetter & Tanner, 2012). Excessive amounts of these neurotransmitters have been associated with the disruption of the development of the baby's central nervous system (Dunkel Schetter, 2009). The stress hormone cortisol is also released when anxiety is experienced and has been associated with problems in the development of the foetal brain as well as childhood problems later down the track (Dunkel Schetter & Tanner, 2012). In an article summarising research into stress and pregnancy, Dunkel Schetter noted that stress also is a major risk factor when predicting pre-term birth. (Dunkel Schetter, 2009)., Littleton et al (2010) conducted a review on 35 studies to evaluate the relationship between stress in pregnancy and negative perinatal outcomes. They found that stress was significantly correlated to some perinatal outcomes such as birth weight although the correlation was small (Littleton, et al., 2010).

Furthermore, research shows that highly anxious pregnant women may be more likely to engage in unhealthy behaviours to lower stress, such as alcohol abuse and smoking, which again have negative effects on the developing foetus (Arch, 2013; Bull, Burke, Walsh, & Whitehead, 2003; Goedhart, van der Wal, Cuijpers, & Bonsel, 2009). Arch (2013), using an online survey with 311 participants, found that there were distinct domains of pregnancy-related anxiety that were associated with increased alcohol consumption. These included fears of giving birth to a handicapped child and anxiety related to the effect of pregnancy on one's appearance. Anxiety was not found to be a predictor of alcohol consumption, or vice versa, but rather

that they were often found together (Arch, 2013). Goedhart et al (2009) discovered that pregnant women who most often continued to smoke after finding out they were pregnant had high levels of pregnancy anxiety and /or high job strain and/or exposure to physical or sexual violence. It could be argued that anxiety during pregnancy increases the risk of adverse outcomes for both mother and child by a range of mechanisms, but the mechanisms by which this occurs remain unclear.

Fifteen to twenty percent of pregnancies end in miscarriage (DeBackere, Hill, & Kavanaugh, 2008; Graziosi, Mol, Ankum, & Bruinse, 2004). The prospect of miscarriage as well as the worry of a birth defect, stillbirth or preterm delivery, mean that a medical complication during pregnancy is often associated with increased anxiety for women (Andersson, 2012; Brandon, et al., 2007; Klier, Geller, & Ritsher, 2002). In a survey utilizing the Cambridge Worry Scale, ninety percent of pregnant women were concerned by the possibility that something was wrong with their baby. This suggests that a medical problem diagnosed in pregnancy, which could heighten the worry that something may be wrong with their unborn child will further heighten anxiety for pregnant women (Green, Kafetsios, Statham, & Snowden, 2003).

One study by King et al (2010) found a positive correlation between medical complications in pregnancy and anxiety. The British study was conducted with sixty pregnant women with pregnancy complications and sixty pregnant women with no medical complications. Results showed that women with pregnancy complications had considerably higher distress (depression

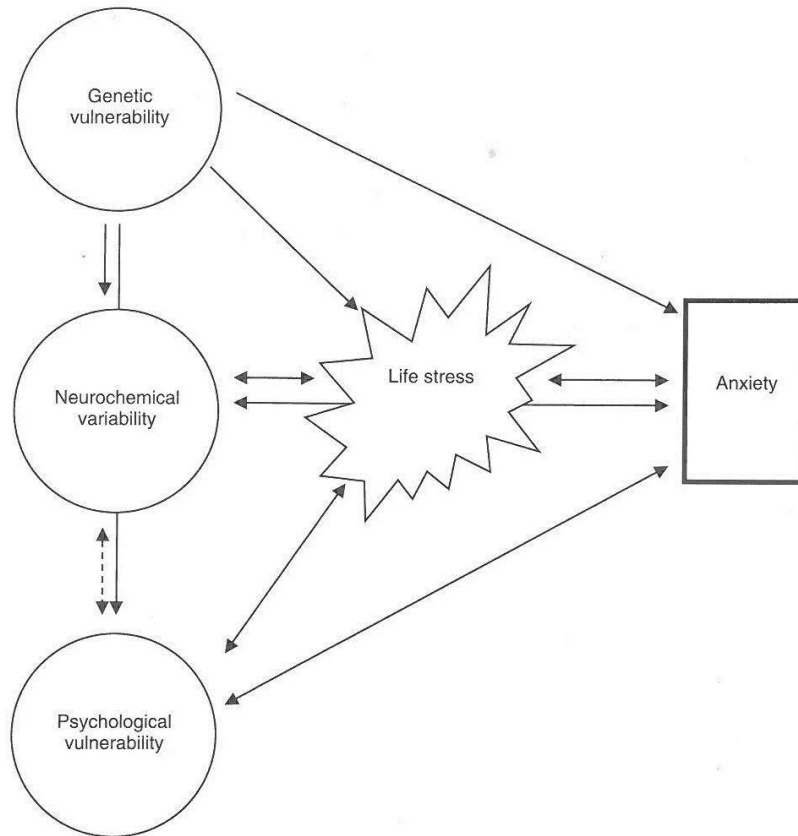
and anxiety), than the control antenatal women. Nearly half of the complicated pregnancies group scored equal to or higher than 40 on the State Anxiety Scale. It has been argued that at least half of this group would qualify with an anxiety disorder diagnosis (Grant, McMahon, & Austin, 2008).

### ***General Bio-psychosocial Model of Anxiety in Pregnancy***

Ross et al (2004) developed a bio-psychosocial model to explain mood changes during pregnancy and postpartum. This model was based on a stress-diathesis framework and explained the relationship between two classes of risk factors – biological and psychosocial and two classes of symptomology- anxiety and depression (L. E. Ross, Sellers, Evans, & Ronach, 2004). Wenzel (2011) has further refined this model to explain anxiety in childbearing women (See Figure 1.1)

In this model there are three types of vulnerabilities: genetic, neurochemical variability and psychological, all interacting with life stress, which in turn impacts anxiety level. Wenzel (2011) defines genetic vulnerability as the family history of anxiety – whether the individual or their close family member has experienced high anxiety (Wenzel, 2011). If they have had to deal with chronic high anxiety personally, or in close family members, genetic vulnerability is regarded as high; if not, genetic vulnerability is regarded as low. Neurochemical variability refers to the individual's response to the dramatic changes in hormones that accompany pregnancy, and their interaction with neurotransmitters, which are associated with mood. Some women are particularly sensitive to the rapid changes in hormones. Psychological vulnerability refers to the cognitive styles that

characterise people with high anxiety as well as their coping mechanisms that come into play at times of increased stress (L. E. Ross, et al., 2004).



**Figure 1.1 Bio-psychosocial model of anxiety in pregnancy (Wenzel, 2011, p. 129).**

These three domains of vulnerabilities interact with one another and with life stress, which could prompt the onset or exacerbation of anxiety during pregnancy (as shown in Figure 1.1). Utilising this model, Wenzel asserts that women with few genetic vulnerabilities, neurochemical variabilities and /or psychological vulnerabilities are only likely to experience high perinatal anxiety in the context of a significant life stress above and beyond that of a normal pregnancy and childbirth (Wenzel, 2011).



The question arises of whether a pregnancy complication is enough of a life stress to tip not only vulnerable women into high anxiety states, but also women who don't normally demonstrate anxiety traits. This places a pregnancy complication in the centre of this model – interacting as a life stress, which mediates between the genetic vulnerabilities, neurochemical sensitivities and psychological vulnerabilities and the anxiety experienced by the pregnant woman.

In an analysis of data from a New Zealand study investigating health and stress perceptions and relationships between pregnant women and their midwives, stress scales were utilised to assess anxiety and depression (Currie, 2012). Sixty-eight pregnant women based in the community and thirty-four who had been hospitalized with a medical complication were asked to rate their health over the previous week as a measure of perceived health and to complete the State –Trait Anxiety Scale and Pregnancy Specific Anxiety Scale. Women in the hospital rated their health as worse than women in the community. Positive correlations were found between the women's perceived level of health and pregnancy related anxiety, but research has not yet closely investigated this relationship. Midwives, like other clinicians, found it difficult to identify those with psychological distress. There was a no relationship between how women, who were hospitalised, viewed their health and how their midwife viewed their health. It was concluded from this study that further research should be conducted into illness perceptions amongst those with pregnancy complications (Currie, 2012).

## **Illness perceptions**

### *A Theoretical Model of Coping with Illness*

The common sense model developed by Leventhal in the 1990's has been widely utilized in Health Psychology as a means for understanding the effects of an illness/health threat (Diefenbach & Leventhal, 1996; Wearden & Peters, 2008) (See Figure 1.2). This model illustrates the first steps an individual takes in seeking assistance, engaging in a coping strategies and/or adopting a treatment or health management regime. The health threat is initially evaluated in terms of the pool of information already available to the patient about the illness, stored in memory as well as from external sources (such as a medical professional) (Hagger & Orbell, 2003). The health threat is also evaluated in terms of the presence or absence of symptoms (symptomatic and asymptomatic). An example of this is a patient with no symptoms, who has an emotional reaction when told by a doctor that they are suffering from hypertension, after having a blood pressure test.

The recipient of this information creates two parallel information-processing streams. On the one side are logical and cognitive interpretations of the health threat or illness, which are developed from concrete experiences and prior knowledge as well as information gleaned from others and sources such as the Internet (H. Leventhal, Diefenbach, & Leventhal, 1992; Weinman & Petrie, 1997). An example could be a pregnant woman who, when diagnosed with gestational diabetes, searches for facts in her pregnancy handbook and does not find much information so she looks up further information on the internet. This represents a cognitive processing of the current danger to health, which includes five dimensions.

According to research into illness perceptions to date, people typically develop cognitive schema of their illness around five dimensions (Baumann, Cameron, Zimmerman, & Leventhal, 1989; Diefenbach & Leventhal, 1996; Hagger & Orbell, 2003; K. J. Petrie & Weinman, 2006). A schema has been defined as ‘a pattern imposed on a complex reality or experience to assist in explaining it, mediate perception or guide response’ (VandenBos, 2007, p. 814). The dimensions that make up the schema in this model include illness identity (what’s wrong with me?). This includes labelling the illness and associating certain symptoms to the illness (e.g. arthritis as “morning joint pain” or high blood pressure as “throbbing headache”), causal beliefs (what caused my illness?), timeline beliefs (what is the length of time that my illness will impact?), beliefs about cure through treatment and personal control (can I cure or control this illness?) and consequences (what is the impact of this illness?) (Kucukarslan, 2012; K. J. Petrie & Weinman, 2006).

The second information-processing stream concerns the emotion engendered by the health threat, which could include shock, anger and distress such as fear (present focussed) or anxiety (future focussed) as well as depression (H. Leventhal, et al., 1992). An example is the distress a woman might feel on being told of the negative consequences of having gestational diabetes. Weinman and Petrie (1997) reported that the patient’s thoughts and emotions about their health threat/illness are often private and not discussed with doctors because of the relationship dynamics between patient and doctor.

Both information-processing streams are associated with coping strategies. Cognitive coping strategies include avoidance and/or denial, cognitive reappraisal,

problem focussed coping and seeking social support. Emotional coping strategies include strategies to deal with the reactive emotions engendered (Hagger & Orbell, 2003). According to Leventhal et al (1980), both information-processing streams impact medical as well as emotional outcomes in terms of the state of disease in the patient, their physical functioning, psychological wellbeing, distress, vitality and their social functioning. This model is dynamic with each step being appraised by the patient and creating an appraisal feedback loop which further influences each part of the overall schema.

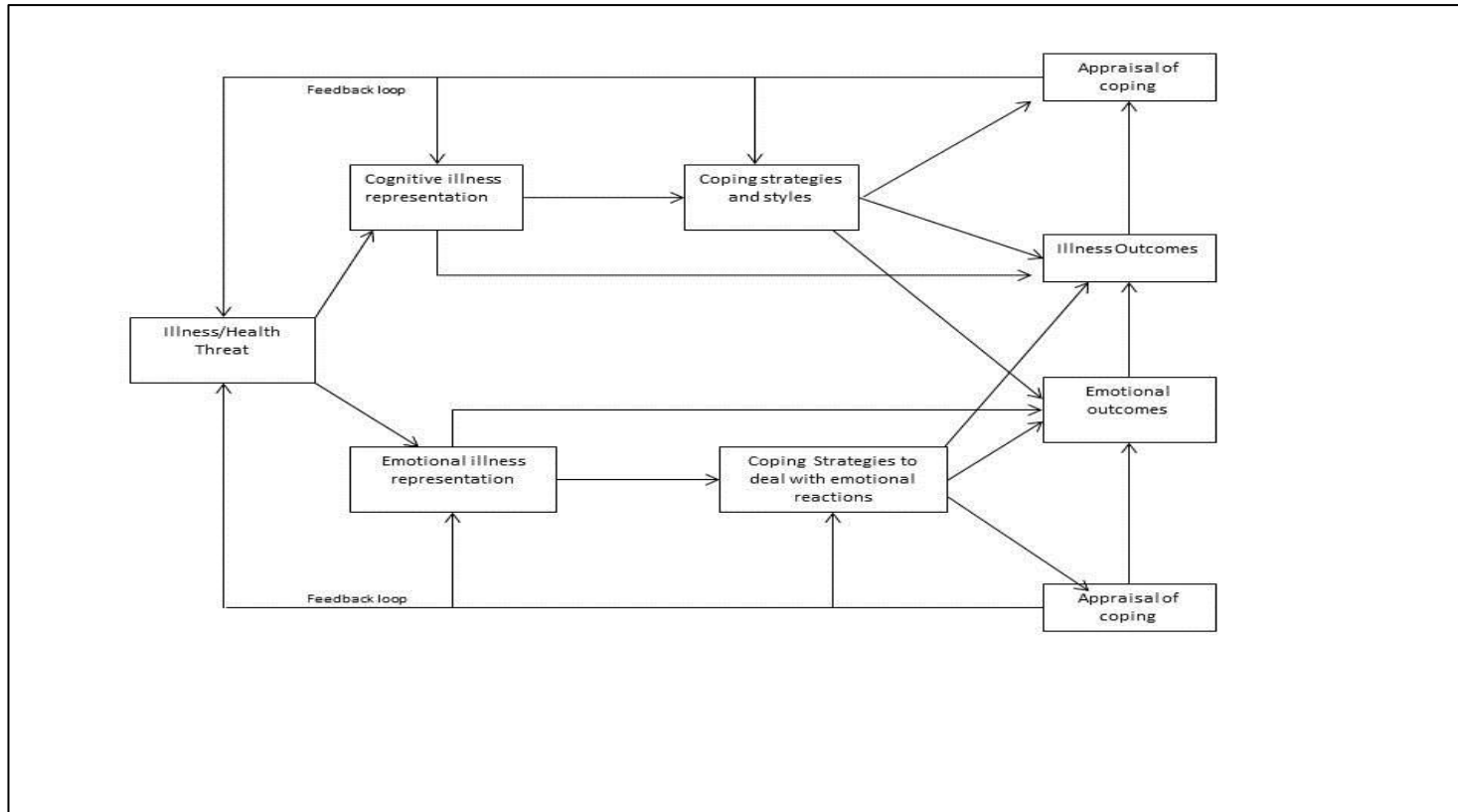


Figure 1.2 Schematic representation of Leventhal et al's (1992) Common Sense Model of Illness Representation.

So far this model has been utilized to understand chronic illnesses such as diabetes, cancer, asthma, and some acute illness such as the common cold (Wearden & Peters, 2008). The common sense model was used as the basis for the development of illness perception questionnaires. These questionnaires have enabled researchers to predict health behaviour, and have been used successfully in assessing patients' illness perceptions that form the basis for the development of interventions. These interventions have been aimed to reduce stress and anxiety, as well as improving medicine compliance, and have had some success in activation of improved health related behaviour (Wearden & Peters, 2008; Weinman, Petrie, Moss-Morris, & Horne, 1996).

Assessments of illness perceptions were originally conducted utilising open-ended interviews, which allowed the patient to divulge their ideas of their own illness (Weinman, et al., 1996). In 1996, Weinman and colleagues designed an Illness Perception Questionnaire (IPQ) as a scale to evaluate the cognitive illness perceptions of a variety of illnesses (Weinman, et al., 1996). This scale has been adapted for a variety of illnesses as well as being revised to divide the dimension of control into treatment control and personal control (Illness Perception Questionnaire (Revised) – IPQ(R))(Moss-Morris, et al., 2002). Broadbent and colleagues developed an illness perception questionnaire based on the IPQ(R), which was easier to use across illness types and quicker to administer for clinical practice. This was called the Brief Illness Perception Questionnaire (IPQ (B) (Elizabeth Broadbent, Petrie, Main, & Weinman, 2006). The questionnaires are composed of eight different items that make up the illness schema. Items include consequences (what effect does the illness have on one's life?), the timeline (how long do you think your illness will last?), personal

control (how much control do you have of your illness?), treatment control (how effective is your treatment in treating your illness?), illness identity (how many symptoms do you have from your illness- how sick you feel?), concern (how concerned are you about your illness?), understanding (how well do you feel you understand your illness?) and emotional representation ( how emotional do you feel regarding your illness?) (Elizabeth Broadbent, et al., 2006).

The illness perceptions of women with complicated pregnancies are important to consider because they may help predict the woman's ability to function and cope with these stressful circumstances (H. Leventhal, et al., 1992). They may also predict adherence to treatment and enable understanding of mood and anxiety levels, which in turn can impact on mother and foetus (E. A. Leventhal, Leventhal, Shacham, & Easterling, 1989). Interventions based on illness perception questionnaires in other populations, which target improving coping strategies, have been shown by previous research to increase immunity and hasten wound healing (Weinman, Ebrecht, Scott, Walburn, & Dyson, 2008). These interventions could have an impact on the mood and wellbeing of mother, mother-child interactions and outcomes for the child (E. A. Leventhal, et al., 1989; Wearden & Peters, 2008).

Research to date utilising the common sense model and illness perceptions have been used to explain behaviour following heart attacks, responses to cancer screening and how patients cope with cancer treatment, disability in chronic fatigue syndrome, and a variety of illnesses such as diabetes and rheumatoid arthritis (K. J. Petrie & Weinman, 2006). Since this model has not been applied to pregnancy complications, a literature review was conducted regarding three areas

that are closely related to the experience of a pregnancy complication. These include diabetes, hypertension and pain.

### ***Illness perceptions of people experiencing diabetes***

Diabetes is a condition where insulin levels in the blood are insufficient to regulate blood sugar levels. This can have the consequence of damaging internal organs such as the liver and kidneys as well as the eyes and the vascular system of the pregnant woman (McCance, Maresh, & Sacks, 2010). In particular it can have a direct effect on a growing foetus, with increased risk of congenital malformation if the diabetes is not controlled during early pregnancy (McCance, et al., 2010; Ramírez - Torres, 2013). Two types of diabetes that can impact pregnancy are pre-gestational diabetes mellitus (PGDM) and pregnancy induced diabetes known as gestational diabetes mellitus (GDM).

Gestational diabetes mellitus (GDM) is defined as carbohydrate intolerance of variable severity with onset or first recognition during pregnancy. It is the most common metabolic complication of pregnancy, with an incidence of between 3% and 5% of all pregnancies (Levy-Shiff, et al., 2002). A requirement of pregnancy is almost double the insulin than normal and therefore GDM often resolves itself when the woman is no longer pregnant. It can, however, have an effect on the foetus, with post birth risks of insulin resistance, hypertension, kidney damage and an eight-fold increase in risk for the infant of developing pre-diabetes, diabetes and metabolic syndrome later in life (Lawrence, 2011; McCance, et al., 2010). All women diagnosed with diabetes, especially while they are pregnant, require close monitoring, The infant mortality rate due to diabetes in pregnancy has dropped from 25% to 2% since the discovery of insulin in the 1920's (Levy-Shiff, et al., 2002). Diabetic treatments consist of insulin injections, medications,



and diet and exercise regimes that can be complex and difficult, especially if the woman is also dealing with a comorbid medical complication such as high blood pressure and obesity. Research has found that women with PGDM have higher levels of distress during their pregnancies in comparison with women with GDM and healthy pregnant women (Levy-Shiff, et al., 2002).

Illness perception research regarding diabetes has focused on treatment compliance and outcomes mainly in terms of controlling diabetes (Barnes, Moss-Morris, & Kaufusi, 2004; Glasgow, Hampson, Strycker, & Ruggiero, 1997; Griva, Myers, & Newman, 2000; Mc Sharry, Moss - Morris, & Kendrick, 2011). Even though people with diabetes often have no symptomology when their diabetes is under control, they are required to undertake a complex range of tasks to ensure glycaemic control. New Zealand research has demonstrated that higher self-efficacy and lower distress have a direct correlation with higher medication adherence (E Broadbent, Donkin, & Stroph, 2011).

A study conducted in Wellington in 2010 with over 600 participants with Diabetes Type 2 (adult-onset diabetes, often related to obesity and to a lack of insulin in the body) showed that illness perceptions accounted for 15% of the variability in distress about diabetes, substantially higher than for other variables (Paddison, Alpass, & Stephens, 2010). This research also demonstrated that ‘making sense of diabetes’ or understanding the illness may be central to successfully managing the emotional consequences of diabetes (Paddison, et al., 2010, p. 47).

The emotional burden of having diabetes has been seen as significant in a number of studies (Eiser, Riazi, Eiser, Hammersley, & Tooke, 2001; Holmes, 1990; Ludman, et al., 2004; Mc Sharry, et al., 2011). The relationship between depression and diabetes has been found to be complex and bidirectional mediated by eating habits, regarding whether diabetes causes the depression, or depression causes the diabetes (Mc Sharry, et al., 2011).

Patient beliefs have been found to be a useful predictor of behavioural outcomes in diabetes self- management, and those with stronger self-efficacy demonstrate better physical and psychological outcomes (Griva, et al., 2000). Self- efficacy has been defined as ‘an individual’s capacity to act effectively to bring about desired results especially as perceived by the individual’ (VandenBos, 2007, p. 829). Strong illness identity, which is when one relates strongly to the symptoms of their illness, has been positively correlated with a high belief in the seriousness of the consequences of diabetes, and a stronger diabetes-specific self-efficacy. Diabetic specific self-efficacy refers to the individual’s perceived ability to act effectively in controlling their diabetes. This results in fewer diabetic symptoms and fewer perceived consequences (Griva, et al., 2000; Paschalides, et al., 2004). This is different from what is experienced with the illness perceptions of hypertension.

### ***Illness perceptions of people experiencing hypertension.***

Hypertension (or high blood pressure) is common in pregnancy (8-10% of pregnancies) and when it is mild, causes little or no risk (Health on the Net Foundation, 2014; Sibai, 1996). Three types of conditions related to hypertension in pregnancy include chronic hypertension (pre-gestational hypertension), gestational hypertension, and pre-eclampsia, which is also associated with

toxaemia (Sibai, 1996). When blood pressure is too high it can produce high risk for both mother and child, including placenta abruption (which is the abnormal separation of the placenta after 20 weeks of gestation and usually presents as combination of vaginal bleeding, uterine contractions and pain) and prematurity (Health on the Net Foundation, 2014). Pregnant women with hypertensive disorders often have no symptoms and this can be disconcerting and anxiety provoking for women who are then unable to self-monitor their complication from their own sensations (Barlow, et al., 2008). The diagnosis of hypertension means that the woman often has to deal with the unexpected increased risk to her unborn child and sometimes to her own life (Leeners, et al., 2008).

Research on illness perceptions with regards to hypertension (outside of the context of pregnancy) has largely focused on medication compliance (Anthony, Valinsky, Inbar, Gabriel, & Varda, 2012; Chen, Tsai, & Chou, 2011; Figueiras, et al., 2010; Ross, Walker, & MacLeod, 2004). It is estimated that less than 50% of those with chronic hypertensive disorders comply with treatment recommendations. Non adherence has been associated with misunderstanding of the condition, negative illness perceptions and general disapproval of medications and their side effects (Ross, et al., 2004). Since hypertension is largely asymptomatic, not feeling unwell may well encourage non-compliance. Compliance also becomes more problematic as the medical regime becomes more complex (Ross, et al., 2004)

Figueiras (2010), in a Portuguese study with 191 participants, utilised the Illness Perception Questionnaire (Brief) (IPQ (B)) to develop an illness schema for hypertension (Elizabeth Broadbent, et al., 2006; Figueiras, et al., 2010). An illness

schema is a pattern of scores by patients on the different items that make up their illness perceptions (See Figure 1.3).

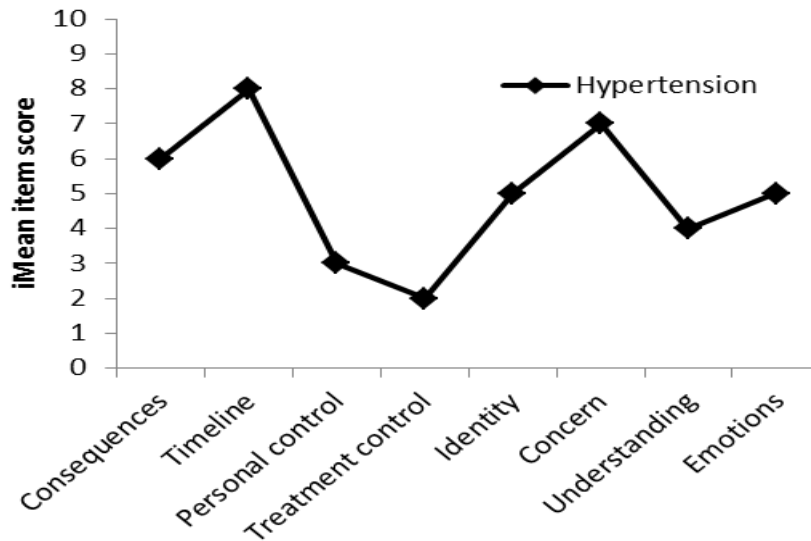


Figure 1.3 Illness schemata of hypertensive patients (n=191). Mean of the items of IPQ (B).

In the graph above, higher scores relate to more negative illness schemata. The results of this research showed that patients with hypertension, on average, had a strong belief that they could personal control their illness (often related to self- efficacy) and had a high degree of faith in the efficacy of treatment as well as a belief that they had a good understanding of their illness (Figueiras, et al., 2010). Figueiras et al (2010) conducted a cluster analysis and discovered three distinct clusters of illness schemata. The first cluster contained those with a negative model of hypertension. They perceived hypertension as having serious consequences in their life, and that hypertension would last a long time (chronic timeline). They also believed that they could personally influence the outcomes and that treatment would have an effect on their medical condition (strong belief in personal and treatment control). They experienced a number of symptoms to be

related to their hypertension (strong illness identity). They were highly concerned about the illness (high concerns) and felt highly emotional regarding their illness (high negative emotional representation), though they believed they had a good understanding of their illness. Patients in the second cluster showed less negative beliefs about consequences and identity, and their levels of concern and emotional representations were lower. Participants in the third cluster did not identify many symptoms, had lower beliefs in the consequences, a more acute timeline, weaker beliefs in terms of personal and treatment control and lower illness concerns and understanding of their illness (Figueiras, et al., 2010).) The different schema of the three clusters all impacted choice of treatment, with patients with a more serious model of hypertension more likely to choose a brand-name medicine, whereas those with less negative perceptions of their illness would be more likely to choose a generic medicine (Figueiras, et al., 2010).

### ***Illness perceptions of people experiencing pain***

Over 50% of pregnant women will experience significant pain during their pregnancy, the most common being lower back pain (MacEvelly & Buggy, 1996). It is known that this often disrupts sleep and causes distress, but it is often not viewed as a medical complication of pregnancy but rather a normal feature of pregnancy (MacEvelly & Buggy, 1996). Chronic pain on the other hand, especially when identified pre-gestation, is regarded as a pregnancy complication.

Research to date regarding illness perceptions for pain outside of pregnancy has focused on chronic pain and acute pain but with an emphasis on treatment compliance, medication choices and clinical outcomes (medical and psychological) (M. Brown, Dean, Hay-Smith, Taylor, & Baxter, 2010; Foster, et al., 2007; Hallegraeff, van der Schans, Krijnen, & de Greef, 2013; Nicklas, Dunbar, & Wild, 2010; Sharpe, Sensky, & Allard, 2001).

A large study of 1591 participants conducted in the UK in 2007 investigated the relationship between illness perceptions of patients with pain and their medical outcomes (Foster, et al., 2007). Results demonstrated that those who expected their pain to last well into the future (chronic timeline), who perceived severe consequences or who held weaker beliefs about the controllability of the pain, were more likely to have poor medical outcomes six months later. When they believed their pain to have lower consequences, perceived their pain could be controlled (through treatment or their own actions) and the pain would be short term in duration, the patient often improved their fitness and self-care, which in turn lowered their pain (Foster, et al., 2007).

A small New Zealand study with seventeen participants utilised the Brief Illness Perception Questionnaire (IPQ (B)) to understand the illness schemata of muscular skeletal pain in conjunction with a qualitative study to understand the use of conventional and complementary treatments (M. Brown, et al., 2010). Negative illness perceptions were related to a chronic timeline (pain lasting longer than three months), low beliefs in personal and treatment control, and lack of understanding of their condition. The qualitative part of this study highlighted the power of the health practitioners, which was strengthened by the lack of understanding the participants had about their condition. This in turn lowered the patient's self-efficacy of the patient with pain. The lack of ability to diagnose the cause of pain as well as the ineffectiveness of some treatments also reduced self-efficacy. Choice of utilizing complementary treatments was often determined by a conventional health practitioner rather than the patient themselves. The patient accepted treatment recommendations of the health practitioner even if they had

differing personal views on the effectiveness of such treatment (M. Brown, et al., 2010).

Another small study of twenty-two participants investigated the course of pain in the development of a chronic illness (early onset rheumatoid arthritis) and the relationship between illness perceptions and onset of depression (Sharpe, et al., 2001). Results demonstrated that while illness perceptions seemed stable, mood deteriorated over time as the pain developed into a chronic illness. Negative illness schema of the pain predicted depression and lack of coping strategies. Sharpe et al (2001) recommended that those at risk from depression, as identified by their negative illness perceptions, would benefit from cognitive interventions.

#### ***General research on illness perceptions/illness representations***

Three reviews have been conducted using the Common Sense model and illness perceptions (Baines & Wittkowski, 2013; Hagger & Orbell, 2003; Kucukarslan, 2012). Baines and Wittkowski (2013) reviewed illness perceptions in mental health. No study was found that investigated illness perceptions for anxiety, as a diagnosable disorder or generalised worry. How a person coped with their depression was associated with beliefs around their illness and symptoms of their depression, self-efficacy and belief in treatment to control the depression as well as the impact the depression was having on their lives (consequences). Medication adherence was associated with their beliefs around what caused their depression, self-efficacy and treatment control and the timeline of their depression (Baines & Wittkowski, 2013).

Baines et al (2013) conducted another small British study with forty-three participants on illness perceptions in mothers with postnatal depression. These mothers recognized a moderate number of symptoms, did view their depression as having negative consequences on their lives, and as being short-lived (acute timeline). The illness perceptions of mothers experiencing depression for the first time were not significantly different from mothers who had experienced depression before (Baines, Wittkowski, & Wieck, 2013). Depression severity was associated with certain illness perceptions such as endorsing more depressive symptoms, responding to their depression with higher intensity of emotions and believing their depression was more long term (chronic). In terms of attachment to their baby, mothers who viewed their depression negatively also had more difficulties bonding with their baby. Baines et al (2013) recommended helping mothers with postnatal depression to gain a more coherent understanding of their depression in order for them to develop adaptive coping strategies.

Hagger and Orbell (2003) conducted a review of the common sense model of illness representations for medical conditions. Forty-five studies were included, but it was dominated by a number of studies on diabetes. Consistent results show that when a person believes that consequences of an illness are high, when a patient can identify many symptoms associated with the illness and that when the illness is expected to last a long time there is likely to be lower beliefs in personal or treatment control over the illness. If the patient has a strong belief in high consequences as well as is able to identify many symptoms associated with the illness the patient is likely to express strong emotions and also utilise avoidance/denial type coping strategies. When the patient believed that they can cure or control the illness either by personal action or through treatment, they



were more likely to be problem focussed and be able to cognitively re-appraise the situation, generally cope better and seek social support. It should be noted that this review emphasized that psychological health and vitality was reliably and positively correlated to high perceived control over the illness (Hagger & Orbell, 2003). Hagger and Orbell (2003) conclude that there is a consistency in the pattern of correlations between the illness perception dimensions across illness and this supports the common sense model's validity.

Kucukarslan (2012) conducted a review on published research on medication adherence and illness perceptions. Decisions made around medication adherence were impacted by the patient's beliefs about personal and treatment control over their illness as well as how long they believed the illness would last. One area of illness perception that was not correlated to medicine adherence was the patient's belief about how much they understood their illness. The label and symptoms that patients attributed to their illness had the strongest impact in terms of medication adherence even when medical professionals thought no symptoms were present (Kucukarslan, 2012).

## **Summary**

Women with pregnancy complications are likely to experience heightened anxiety that can impact the women's ability to cope as well as affect the development of the foetus. Anxiety and medical complications in pregnancy seem to be interrelated. How women make sense of and understand their pregnancy complications in terms of their perceptions of their illness has yet to be investigated and could be important in understanding how women react to and cope with their pregnancy complication. Illness perception studies in other

illnesses common in pregnancy such as hypertension, diabetes and pain demonstrate different patterns within their illness schemata but also show that the common sense model of illness perceptions can be useful in understanding and supporting the patient. Illness perceptions matter in designing interventions that could assist women with pregnancy complications to lower anxiety and manage their illnesses over this time.

## **Conclusion**

Since this was an exploratory research project into illness perceptions associated with pregnancy complications and the relationship between illness perceptions and anxiety, the research was divided into two studies. The aim of the first study was to understand the lived experiences of women currently pregnant, who had medical complications; this included a qualitative interview and a pilot of the Illness Perception Questionnaire (Revised) (IPQ (R)). The aim of the second study was to investigate the relationship between illness perceptions of women with pregnancy complications and distress (anxiety and depression); this included an online survey utilising measures of illness perception, anxiety and depression and a health rating scale.

## **CHAPTER TWO: MIXED METHOD STUDY**

### **Aim**

The aim of this study was to explore illness perceptions of women in the context of her lived experienced of a pregnancy complication. This included a pilot of a measure of illness perceptions with this population and collecting data to inform the follow-up quantitative study.

### **Method**

The theoretical perspective utilised was based on Leventhal et al's (1992) Common Sense Model. A mixed method approach was employed, which used both qualitative and quantitative data A concurrent triangulation strategy was used at the stage of the data analysis with the qualitative and quantitative data utilised to cross validate the findings (Terrell, 2012).

### ***Ethical Approval***

This portion of the study gained ethics approval from the Ethics Review Committee of the School of Psychology, University of Waikato, for research on human participants in January 2013.

### ***Participants***

Participants in this study were six women who were currently pregnant who had been diagnosed with a medical complication either pre-gestation or during pregnancy. They were recruited via Waikato midwives and social media. Participants for the study were chosen with regards to several criteria. These included:

- 1) Currently pregnant with a medical complication being treated on an outpatient basis
- 2) Living in Waikato
- 3) Ability to undertake an hour interview in English

While eight participants offered to be interviewed, six participants were selected using the criteria above. One woman gave birth before the interview could be scheduled and one was suddenly hospitalised. Each participant was contacted prior to the interview to discuss the interview process as well as schedule the interview timing. Four of the interviews were conducted in the participant's own home while two were conducted in a café. Three of interviews were conducted with only the participant present. Three were conducted with other family members present (two husbands and one mother of the participant), but with no participation in answering the questions posed. Each participant read the information sheet and signed the consent form prior to being interviewed (Attachments A and B).

Four of the women interviewed were NZ European, while one was NZ European/Maori and one woman identified herself as Indo- Fijian. Ages ranged from 23 to 40 years old and gestation ranged from 7 weeks to 37 weeks.

### ***Materials and scoring***

The materials used in this study were:

- Study Information Sheet (Appendix B)
- Consent Form (Appendix C)
- Background Information Form (Appendix D).
- Interview questions (Appendix D).
- Edinburgh Postnatal Depression Scale (Appendix E).

- Illness Perception Questionnaire (IPQ-R). (Appendix F)

### Background Information Form

The background information form collected data from each participant on

- Age of participant
- Weeks of gestation at the time of interview
- Marital status
- Number of pregnancies (including current pregnancy)
- Ethnicity(ies)
- Type of pregnancy complication(s).

### Interview questions

Interview questions were open- ended and broad based to capture the women's lived experience. The questions had a focus on the different domains of illness perceptions. The questions were designed by the primary researcher with input from Dr Carrie Cornsweet Barber and Dr Waikaremoana Waitoki for this preliminary study and followed a similar format to what had been used in a previous qualitative study with pregnant women who had been hospitalised for their pregnancy complication (Currie, 2012).

### Edinburgh Postnatal Depression Scale (EPDS)

EPDS is a ten item self-report scale, which assesses the common symptoms of perinatal depression. It includes three items on anxiety. It has been well

validated and is widely used internationally and is regarded reliable in community settings (Cox, Holden, & Sagovsky, 1987). A cut-off score above (>) 13 is strongly suggestive of depression (Crawford, Cayley, Lovibond, Wilson, & Hartley, 2011). Positive predictive value has been reported between 70-90% (Crawford, et al., 2011).

#### Illness Perception Questionnaire (Revised) IPQ(R)

IPQ(R) is a three part self-report questionnaire. The first part covers symptoms of the illness / pregnancy complication. The participant is asked whether they have either experienced a symptom (14 symptoms are listed) either since their pregnancy or related to their pregnancy complication. The part which relates to their pregnancy complication assesses illness identity i.e. the degree to which the woman identifies with an illness label and its associated symptoms. The second part utilised a 5-point Likert scale from strongly disagree, disagree, neither disagree nor agree, agree and strongly agree to assess how the participant views 38 statements made about their illness. Thirteen of these statements were reversed scored. The statements covered timeline, consequences, personal and treatment control, illness coherence and emotional representation. (See Appendix E (i) ). Each participant was asked to rate 'illness' as if it equated to the particular complication/ health issue in her pregnancy.

The final part of the IPQ(R) utilises a self-report on probable causes of the illness – where 18 options are provided and each cause is rated with a 5-point Likert scale from strongly disagree to strongly agree. The participant is also requested to rank order the three most important causes.

Research has shown good internal consistency reliability of the subscales, and short (3-week) and longer (6-month) test-retest reliability. It is widely

regarded as a reliable tool to assess illness perceptions over a wide variety of illnesses (Moss-Morris, et al., 2002). There has been no validation of this tool with a perinatal population. The illness perception questionnaire (revised) was piloted with all six women during the interview process. The questionnaire was not adapted in any way apart from telling women that the term 'illness' should be replaced with medical issue in pregnancy/pregnancy complication.

### ***Data Analysis***

Audio-recorded interviews were transcribed and thematic analysis was applied which was deductive and theoretical in nature, based on illness perception research, and semantic (explicit) to determine underlying themes. Semantic deductive thematic analysis was used because it enables researchers to generate insights focussing on the theoretical underpinnings of the research as well as allowing researchers to usefully summarize a large amount of data (Braun & Clarke, 2006). Results reported used direct quotations from participants and compared their answers to the scores on the IPQ(R) and EPDS.

## **Results**

### ***Participants***

The six respondents that participated in the mixed method study had a variety of pregnancy complications. These included carpal tunnel, gestational diabetes, and high blood pressure, which are fairly common types of complications. Two participants had been diagnosed with incompetent cervixes, which can lead to miscarriage or stillbirths. Three participants had previously miscarried and two had experienced a stillbirth (a pregnancy loss at gestation over 20 weeks). Four participants had multiple complications. Two of the pregnancies were conceived via in vitro fertilization (IVF). One participant had a highly complex heart condition. Each of these participants were based and interviewed in the community and all were cohabitating with a partner and in either a de facto or marriage relationship.

### ***Main Themes***

Thematic deductive ( theoretical) semantic analysis of the qualitative interviews of these six participants was conducted on the transcripts of the recorded sessions:

#### ***Experience of pregnancy as distressful***

Five of the six participants used language that could be characterised as distress when they described their pregnancy, and this seemed to correspond to high levels of emotional representation score on the IPQ as well as high anxiety scores on EPDS (See Table 2.1)



Table 2.1

*Language used to describe pregnancy compared to scores on emotional representation (as a subset of the Illness Perception Questionnaire) and the anxiety score on the EPDS.*

Language to describe pregnancy	Emotional Score on IPQ (R) %	Anxiety Score on EPDS %
<i>Dread- hate being pregnant</i>	90	100
<i>Good but not last third</i>	47	44
<i>Nerve wracking</i>	80	67
<i>Worried</i>	77	78
<i>Anxious</i>	83	44
<i>Live in fear every day</i>	87	100

While the sample size and qualitative nature of the study do not allow for statistical tests, this does suggest that the emotional representation score in the IPQ(R) is detecting strong reactions to pregnancy complications.

***Lack of perceived control over the pregnancy complication***

Five of the six respondents described feelings of lack of control when questioned regarding whether they felt control during their pregnancy. This was most strongly expressed by women who had experienced previous miscarriages or

stillbirths and felt that things, over which they had no control, could go wrong quickly.

*No, I was, before the pregnancy I felt quite in control, because I knew it was coming on and knew how to stop it. They can't always stop it now.*

*Just complete lack of control especially from 20 weeks onwards.*

*The amount of scanning felt unnecessary, but I felt quite out of control to do anything about it.*

*There is no control. That is what scares me is that I have no control and if this baby decides to come, it is going to come. There is nothing I can do to stop it.*

A high score on the IPQ (B) equates to a negative illness perception.

The comments made by women about their lack of control over their pregnancy seems to be validated by the women's scores on the item of personal control on the IPQ (B), where a higher scores equates to less control. (See Table 2.2)

Table 2.2

*Comparing answers given in interviews about control over their pregnancy complication and scores on personal control and treatment control on the IPQ(R)*

<i>Comment</i>	<i>Personal Control Score* %</i>	<i>Treatment Control score* %</i>
<i>Have very little control (hypertension/carpel tunnel)</i>	<i>51.4</i>	<i>34.2</i>
<i>Feeling very unsafe and out of control (heart condition)</i>	<i>60.0</i>	<i>51.4</i>
<i>Fair bit of control (hypertension)</i>	<i>60.0</i>	<i>51.4</i>
<i>No symptoms so don't feel in control (poor growth of foetus)</i>	<i>37.1</i>	<i>31.4</i>
<i>No control but take one day at a time (incompetent cervix/ gestational diabetes)</i>	<i>40.0</i>	<i>51.4</i>
<i>Totally out of control (incompetent cervix)</i>	<i>60.0</i>	<i>57.1</i>

### ***Lack of symptoms may increase anxiety***

Women also described their increased levels of anxiousness when asymptomatic. Two of the six participants had active symptoms, while four were asymptomatic. A general lack of symptoms seemed to increase anxiety, and this was because the women could not determine for themselves when they should be taking a more direct approach in seeking treatment.

*Having no symptoms made it worse –I felt more at risk, as I didn't know what I was reacting to. (Incompetent cervix)*

*Felt like a fraud- I did not know how to react, as I did not feel as if I was having a complication. (Low growth of foetus)*

The IPQ(R) measures symptoms through the domain of ‘illness identity’, which equates with how someone identifies with the label of their illness and identifies with the symptoms of their illness. The higher the number of symptoms recorded the stronger is their illness identity. In this sample the highest number of symptoms also related to the highest score on the depression scale of EPDS, but the true relationship between number of symptoms from pregnancy complications and depression remains unclear (See Table 2.5). It does illustrate however that low number of symptoms can also be associated with high levels of distress.

Table 2.3

*Type of complication, number of symptoms recorded in IPQ(R) and EPDS scores*

Type of complication	Number of symptoms	EPDS total score
Hypertension and carpal tunnel	6	9
Heart condition	8	17
Hypertension	1	8
Poor growth of foetus	2	13
Gestational diabetes & incompetent cervix	3	14
Incompetent cervix	2	16

### ***Experience equates to increased support seeking behaviours***

The two participants who had undergone previous losses (still births) had both taken up opportunities to increase their support for mental health over their pregnancies- one through a grief counsellor and one through the Perinatal Mental Health Services and extra midwife support.

*I use the hospital midwives. When I have a panic day- I can always get someone on the phone. I find other midwives take on too many clients and don't have time for my multiple complications. (Gestational diabetes and incompetent cervix)*

*I asked to be referred to them (Perinatal mental Health Services) at 10 weeks –so I was quite early. They have been ringing me each week as I am not very good at asking for help and now they are coming to visit me at home. (Incompetent cervix)*

The other participants all considered stress management as a priority and attributed some of their complications to stress and anxiety. There were concrete ideas of how to operationalize a stress management plan. Some support structures were helpful while others were viewed in a more negative light. When asked ‘what sorts of things helped when you are worried?’ participants had a variety of responses.

*Nothing really (Incompetent cervix)*

*Oh, family and friends are the worst because their advice is more to put your mind at rest but it is not actually productive or they try and ignore it which makes it even harder especially when you are having one of those anxious upset days.(Gestational diabetes and incompetent cervix)*

Positive coping strategies included:

*Hot baths and talking to my parents. (Low growth of foetus)*

*Ring my midwife; it is important to put your mind at rest. (Hypertension)*

*Listen to classical music and just relax. We have to try and remain positive.*

*Some days it is just hard. (Incompetent cervix)*

*That my pregnancy is going to come to an end and things will get back to normal. I make a lot of phone calls to friends and swimming, yes swimming helps a lot. (Carpel tunnel and hypertension)*

Family were often utilised to assist in practical matters:

*So for the last couple of weeks I have been staying with at my parents' place quite a bit because especially my Dad who has worked so long at the ED (Emergency Department). It gives me peace of mind, but I have had to leave my kids and stuff, because I have been so scared. (Heart condition)*

*My sister comes with me to all my doctors' appointments. I am too nervous to go alone. My brother in law keeps up to date with all the research on high blood pressure in pregnancies. (Hypertension)*

*To relax, my hubby says "Just relax, everything's fine, don't worry"- well it is easy for you to say, because you have not been through it, but I have a very supportive family, because I can't do the vacuuming and things like that and they come over and vacuum the house and things like that, yeah they are there for me. (Incompetent cervix)*

## ***Consequences***

All participants believed that their pregnancy complications would have little to no long term effect on themselves even the participant with the heart condition (this was likely to resolve itself when she was no longer pregnant), but when asked directly, four participants actively talked of the baby being currently ‘at risk’ or at risk in the future.

*When she is born I will grab her (the baby) too tight, because at the moment I cannot hold an egg without crushing it with the pins and needles and I will hurt her. (Carpel tunnel and hypertension)*

*I live in fear every day of losing this baby even though so far everything is going really well. It is, I know, in the back of my mind, it is things can go wrong overnight. (Incompetent cervix)*

*With gestational diabetes, the children are more at risk at getting obese and getting diabetes 2. It has made me very cautious of the future. (Gestational diabetes and incompetent cervix).*

This aspect of illness perceptions is measured in part by the item ‘consequences’ in the IPQ (R). This concept in the IPQ (R) covers future concerns as well as the current impact that the pregnancy complication has over the woman’s life. (See Table 2.4). There seems to be a positive relationship between the domain of consequences on the IPQ (R) and EPDS.

Table 2.4

*Type of complication, Consequence score on the IPQ (R) and EPDS total score*

Type of complication	Consequence Score %	EPDS total score
Hypertension and carpal tunnel	31.4	9
Heart condition	63.8	17
Hypertension	58.3	8
Poor growth of foetus	63.8	13
Gestational diabetes & incompetent cervix	69.4	14
Incompetent cervix	69.4	16

### ***Perceived causes***

Midwives or other health professionals discovered most of the pregnancy complications through pregnancy checks. The participants had mixed views on the causes of their complications with over half regarding their pregnancy complications due to hereditary factors. Other causes cited included *bad luck* and *medical mis-management in past*. No one attributed blame towards themselves for their pregnancy complication.

The information collected by the illness perception questionnaire was the similar as that collected by the interview process. . In the illness perception questionnaire portion, hereditary factors were given as the primary cause of their pregnancy complication by three of the participants. Two other participants gave primary causes as weight and an IVF procedure. Stress was given as the primary cause of their pregnancy complication by one participant and stress was ranked second and third by four other participants.



### *Common Sense Model*

The common sense model predicts that patients develop their own mental model of their illness (Diefenbach & Leventhal, 1996). Perceptions about their illness will vary according to their personal circumstances, prior knowledge and the presence and absence of symptoms. Placing women who were interviewed into their lived context can illustrate these principals. The following two cases are provided in detail to demonstrate where women place their focus.

Amanda (pseudonym)

Amanda was a twenty-three year old woman pregnant for the first time. She had been pregnant for thirty-eight weeks and was due to deliver in ten days. She had multiple complications – high blood pressure, carpal tunnel in one hand with pins and needles and swollen hands and feet as well as pain. She lived with her partner and she fell pregnant unexpectedly, but was delighted about being pregnant. She had enjoyed her first two trimesters of pregnancy but explained ‘*the third has been horrible*’. She felt she had been pregnant a long time. ‘*Ten months – it feels like a ten-month pregnancy*’. She believed her complications were caused ‘*by stress and by heat*’. Her midwife was monitoring her blood pressure status regularly. She voiced concern about her potential lack of support when the baby is born and what reactions she will have towards her own child considering her own mother committed suicide several years before. She has been pleasantly surprised at how her father and her partner support her to date. She plans to work after the baby is born, but she is unsure if she will be able to *leave it at home*. She currently works full-time in a café where she is an Assistant Manager and she

reported that there was job-related stress. She was energetic and found working easy while she is pregnant, except from symptoms of her carpal tunnel (loss of feeling and tingling in her hand) and swelling feet. She was particularly concerned about her carpal tunnel because she dropped things at work. She cannot have it strapped up, which is what the doctor recommended her to do, as she found that impractical. *I don't feel in control- not much at all. I saw my midwife and told her about the pins and needles, which were driving me nuts. I practically had a mental breakdown one morning. Completely lost it, rang in sick for work and then went to the doctor and lost it at the doctor and they said to all you can do is take paracetamol and strap it, wear a brace and to me that is not very helpful. I just had to put up with it.* She mentioned that she was concerned that she will hurt her new-born baby if the carpal tunnel does not resolve itself. Her doctor had told her that her carpal tunnel will likely clear up once she is no longer pregnant, but she had not been able to verify this from her own sources and *it plays on my mind.* She was also experiencing the effects of disrupted sleep . *Sleeping was fine for the first lot of my pregnancy. It is only since I got to thirty-two weeks that my sleeping has really gone downhill. Sleeping is now horrible.*

Interpretation of Amanda's scores on the IPQ (R) showed that she recognised the large number of symptoms she was experiencing. She believed the complications and their symptoms would not last long and that the pregnancy complications did not have high consequences for her life. She did not perceive that she could personally control the outcome of her complications. She seemed sceptical of the advice from the doctor due to her belief that it was impractical for her situation at work. Not surprising her belief in treatment effectively controlling

or curing her illness was low and this was reflected on her treatment score on the IPQ (R). She viewed her current situation as *irritating* and not anxiety provoking and this was reflected in her score of 9 on the EPDS, which well below clinical levels of distress.

Amanda's focus is aimed at the symptoms of her carpal tunnel, she seemed to be ignoring the diagnosis of hypertension, but this might be due to it being mild, asymptomatic, due to her lack of understanding of the condition, believing that it was outside her control and/or thinking that the midwife had the situation in hand. She seemed practical in her approach and was well aware of her need to utilize strategies to reduce stress.

Felicity (pseudonym)

Felicity was a forty year old who was pregnant for the fourth time. She was divorced and had only recently moved in with her new partner. She had experienced three stillbirths. All of those pregnancies were due to IVF. Her current pregnancy was unexpected, conceived naturally and was welcomed. She was fifteen weeks pregnant. She was diagnosed with an incompetent cervix and had placenta abruption in the past, which had been misdiagnosed. The day of the interview she also had morning sickness. She had lost forty kilograms in the previous year and had become fit enough to run a ten kilometres. Her new partner had two children and Felicity was co-parenting them. She was working part-time in a before and after school programme. Her dying mother in law predicted a viable pregnancy resulting in the birth of a son. Her approach to her pregnancy

was *day by day and practical*. She laughed a lot during the interview and appeared quite relaxed. She also came across as a strong woman who had turned her life around by *taking personal responsibility for my life*. She compared the experience of her current pregnancy against the backdrop of her previous pregnancies. She believed she was now fully supported by a loving, interested partner and that this pregnancy seemed a lot less stressful and that so far things were going smoothly.

She was fully aware that this pregnancy could end quickly. *I basically live in fear every day of losing this baby even so far everything is going really well. It is I know in the back of my mind, it is things can go wrong overnight*. She had good support networks with her parents providing practical support. She also attended grieving counselling. She did complain of her new partner finding it difficult to understand her approach of not wanting to buy new items for the baby-to be and this made her feel slightly isolated. Felicity was focused on maintaining balance in terms of her physical and mental wellbeing to ensure a positive outcome. She carefully controlled her diet. She had built up a reservoir of coping strategies that she could utilise and was happy to request assistance when she needed it. *I generally listen to classical music and just relax. I am going through counselling at True Colours. My parents come in and do the vacuuming*.

Felicity's score on the IPQ (R) showed she did not identify with symptoms of her pregnancy complication, which is unsurprising as she was asymptomatic. She also believed that the complication was short lived. She perceived that the complication had a high level of consequences for her life and that of her unborn child. It is interesting to note that her high level of self-efficacy is reflected on her

scores of the IPQ (R), which showed that she believed that she could have some personal control over her illness. Her EPDS score was 14, which is slightly above the clinical cut-off score of 13, which demonstrates a moderate level of distress under her circumstances.

These two cases demonstrate the different mental models that patients develop in order to understand illness. In the case of Amanda, her focus was on her symptoms of her carpal tunnel and her swollen feet and hands, which she believed would be short-lived and have few consequences. While Felicity, with her previous experiences of loss and having no symptoms, focussed on trying to manage different aspects of her life, including her emotions, due to her knowledge of the high consequences her complication could have on herself as well as her unborn child and her belief that she could have some personal control over the outcome.

## **Discussion**

The common sense model of conceptualising illness seems to fit for women with pregnancy complication(s). The information collected on the illness perception questionnaire seemed similar to that captured in the interview process. There also seems to be a positive correlation between scores on the IPQ (R) and EPDS. The experience of a pregnancy complication appears to be traumatic for the women interviewed and it is characterised by feelings of loss of control and distress. It seems particularly anxiety provoking when no symptoms were present. Women were aware of the high medical consequences that the pregnancy complications could have on themselves and of the risks to their children. They were also knew that the complication had a short time frame and was likely to resolve itself when they were no longer pregnant.

Women had a variety of coping strategies and utilized social support, especially family and friends. This finding is reiterated by recent research showing that perceived family support directly impacts in reducing psychological distress ((Sanguanklin, et al., 2014). Interestingly enough only those that had undergone a previous loss (stillbirth) in a pregnancy chose to seek professional mental health advice. Previous research showed that over half of pregnant women who suffer from depression do not receive professional care (Dimidjian & Goodman, 2014). This suggests that the women are generally unaware of other sources of intervention for these high levels of depression and anxiety that they are experiencing or there are other barriers to women seeking profession assistance.

It is proposed that the barriers for treatment for postnatal depression will be similar to prenatal distress. Barriers identified include lack of screening, under recognition of distress by medical professionals, the cost of treatment and lack of knowledge of treatment providers (Horowitz & Cousins, 2006). There is also the issue of the stigma associated with mental health concerns, which could keep women from reporting their emotional symptoms (Byatt, et al., 2013). A further barrier could be their concerns about medication treatment especially for the foetus (Byatt, et al., 2013). It is clear that these pregnant women with complications do need extra support and it will be important to take patient preferences into consideration as well as lower the barriers to access appropriate treatment (Dimidjian & Goodman, 2014).

## **Conclusion**

Utilising the Common Sense Model, when conceptualising the steps that women undertake when diagnosed with a medical complication in their pregnancy, seems to fit. The illness perception questionnaire seems to capture similar information as the interview process. Illness perceptions seem to be related to emotions and understanding the illness perceptions of women with pregnancy complications is important in terms of supporting women in dealing with their emotions and behaviour over this period. From this study it appears that certain aspects of illness perceptions seem particularly important for women with pregnancy complications. These are the consequences of the pregnancy complication, personal control over the complication and the level of emotions associated with a pregnancy complication. Women who did not experience symptoms seemed particularly anxious.

### ***Research objectives for Quantitative Study***

Considering the literature review and results of the mixed method study, the following hypotheses were made with regards to the perceptions of pregnant women regarding their pregnancy complications and understanding its relationship to anxiety.

Firstly, negative illness perceptions (or higher scores on the illness perceptions questionnaire) will correlate with higher state anxiety and distress scores. This means that there will be a positive correlation between scores on the illness perception questionnaire and measures of distress, depression and anxiety.

Secondly, the highest mean scores on the illness perception questionnaire for pregnancy complications will be on the dimensions of consequences (how much does your medical issue affect your life?), personal control (how much control do you feel you have over your medical issue in pregnancy?) and emotions (how much does your medical issue in pregnancy affect you emotionally, does it make you angry, scared, upset or depressed?).

Lastly, women with pregnancy complications who don't experience subjective symptoms related to their complication (asymptomatic) will have higher rates of anxiety and depression than those who have symptoms they can detect (symptomatic).



### ***Implications for planning the quantitative study.***

Based on the results of the mixed method study, several decisions were made regarding the quantitative study. Firstly the term ‘pregnancy complications’ seemed to not be well known amongst participants of the mixed method study, and it was also felt that this term invoked fear for some participants. Since the online survey would require participants to identify with the term used for their medical complication it was decided to use ‘medical issue in pregnancy’ to widen the participation base and to lower barriers to participate. It was also decided that participants would be asked in an open-ended manner about the symptoms associated with their medical issue in pregnancy. This is due to the wide array of types of pregnancy complications and would ensure that participants were not ‘prompted’ to remember symptoms that they did not experience.

It was also decided that The Brief Perception Questionnaire (IPQ (B)), adapted for pregnancy complications, would be more appropriate to use for an online survey. The body of the IPQ (R) questionnaire was seen as ‘*too long*’ and ‘*asking questions several times in different ways*’. Several participants expressed their frustration as to the length of the questionnaire but persevered, probably due to prompting by the researcher. The main advantages of the IPQ (B) are brevity and speed of completion for patients and this was seen as important when conducting an online survey.

## CHAPTER THREE: QUANTITATIVE STUDY

### **Aim**

The aim of this study was to understand illness perceptions of pregnant women with medical complications and to identify the women's levels of anxiety and depression. A further aim was to investigate the relationship between perceptions of illness and distress of this population. Distress included anxiety and depression.

### ***Hypotheses***

The following hypotheses were tested: Firstly, negative illness perceptions (or higher scores on the illness perceptions questionnaire) will correlate with higher state anxiety and distress scores. Secondly, the highest mean scores on the illness perception questionnaire for pregnancy complications will be on the dimensions of consequences, personal control and emotions. Lastly, women with pregnancy complications who don't experience subjective symptoms related to their complication (asymptomatic) will have higher rates of anxiety and depression than those who have symptoms they can detect (symptomatic).

## **Method**

### ***Design***

The study design was cross-sectional and correlational to ensure that the information collected was appropriate and that the hypotheses that had been identified could be tested.

### ***Ethics Approval***

This portion of the study gained ethics approval from the Ethics Committee of the School of Psychology at the University of Waikato in September 2013.

### ***Participants***

Early on in the research process three hospitals were approached to recruit participants for this study and in one case initial ethical approval was attained. Unfortunately, staffing constraints within maternity departments of the District Health Boards of Waikato, Waitamata and Counties Manakau prevented the research process from taking place in these settings. It was then decided to recruit participants online. Participants for this study were recruited via the Internet (social media/ Facebook), via midwives and WINTEC midwifery students and via e-mails to sixty Parent Centres that conduct antenatal classes throughout New Zealand (over 450 leaflets were sent to the fifteen Parent Centres that indicated that they would distribute information to participants of their antenatal classes). News releases regarding the study were also sent to 41 local newspapers in New Zealand.

This population proved hard to recruit in large numbers despite repeated efforts to do so. One hundred and three participants accessed the online survey, but not all of these participants completed the survey and some were not currently pregnant. Pregnancy was determined by the question “How many weeks pregnant are you?” and this filtered the sample to 44 participants who were pregnant at the time of completing the survey. A further filter was utilised to assess who had completed the Brief Illness Perception portion of the survey. Thirty-six participants remained in the study after the processing of this additional filter.

Ethnicity information was coded according to a method recommended by Statistics New Zealand (2006) utilizing ‘total response’ method. This means individuals who reported more than one ethnic group were counted once for each group reported. The total percentage number of responses may therefore be greater than 100%. The majority of respondents were NZ European, followed by Māori, other European, Pasifika (Cook Islanders, Tongans, Samoans and Nueans), Indian Chinese and other ethnicities (New Zealand Statistics, 2006).(See Table 3.1)

Table 3.1

*Ethnicities of participants and of New Zealand women of childbearing age.*

Ethnicity	N	% of sample	% of NZ women of childbearing age*
European	29	80.6	72.5
NZ Māori	1	2.8	16.1
Indian/Asian	1	2.8	12.9
Pacific	0	0.0	7.5
Other	5	13.9	1.1
Total	36	100.0	

*Note: N= number of participants*

*\* Source :Statistics New Zealand (2006) Childbearing age is from 15 to 46 years old.*

The largest group of participants were in the age range from 30 to 34 years old (41.2%). The minimum age was 24 years old and the maximum age was 41 years old (see Table 3.2.)

Table 3.2

*Ages of participants and age at time of live births of women in New Zealand.*

	$x$ N=36	<25 yrs	25-29yrs	30-34 yrs	35-39yrs	40+yrs
Participants	32.2	5.9%	23.5%	41.2%	11.8%	5.9%
NZ woman's age at time of live births	30	24.9%	24.3%	30.5%	18.0%	2.2%

Notes: N = total number of participants and  $x$  = mean age of participants

\* Source: Statistics New Zealand (2006).

Seventy five percent of respondents lived in an urban area in New Zealand, while a further 13.9% lived in a rural area and 11.1% lived outside New Zealand.

The majority (69.4%) of participants were married with a further 27.8% living in a de facto relationship. One participant was pregnant and single.

## *Materials and Scoring`*

The survey was developed online utilising Qualtrics Research Suite and could be accessed directly online (Qualtrics, 2014) from a phone or computer.

The materials used in this online study were: (Appendix H)

- Research Information sheet
- Background questions
- Health Rating Scale
- Illness Perception Questionnaire (Brief) – IPQ (B) - Adapted for pregnancy complications/medical issues in pregnancy.
- Distress Scales
  - Edinburgh Postnatal Depression Scale (EPDS)
  - State- Trait Anxiety Scale (State) – STAI- (S)

### Research Information sheet

This information sheet covered background information about the research study and invited participation. It explained rights of participants, details of procedures of confidentiality and methods of keeping anonymity as well as the contact details of the researcher. Participation and submission of the online survey was taken as consent and no identifying information was collected from respondents.

## Background Information

The Background information form collected data from each participant on

- Age
- Where they lived- Urban NZ /rural NZ/ outside New Zealand
- Marital status
- Ethnicity(ies)
- Type(s) of pregnancy complication.
- Number of pregnancies
- Number of children
- Length of gestation at time of completing online survey
- Experience of previous pregnancies
- Medical treatment for infertility
- Whether the current pregnancy was the result of infertility treatment
- Medical professional who diagnosed pregnancy complication
- Description of initial diagnosis and what they were told on diagnosis
- Sources of information pertaining to pregnancy complication
- Feelings about diagnosis
- Symptoms associated with the medical issue in pregnancy
  - Respondents were asked open- ended question about their symptoms, to determine which symptoms were ‘top of mind’ with no prompting.
- Treatment being received for complication.

## Health Rating Scale

This scale was originally designed by was designed by Dr Carrie Barber and Dr Nicola Starkey of Waikato University as part of the Perinatal Mental Health Survey conducted in 2009. The health rating scale included a self-report perceived health scale (5 point Likert) to rate health during this pregnancy in the last week.

Anchors on the scale were:

1. Healthy, no medical problems.
2. Mild medical problems that aren't any risk to me and/or my baby.
3. Moderate medical problems that require some monitoring by the midwife or doctor
4. Major medical problems that require intervention or create some risk.
5. Severe medical problems that are a significant risk to me and/or my baby.

.Illness Perception Scale (Brief) – IPQ (B).

The IPQ (B) is a nine item self-report scale designed to quickly assess illness perceptions. The IPQ (B) was adapted in this study for medical issues in pregnancy by replacing the concept “illness” with “medical issue in pregnancy”. Each question is answered using a 10-point Likert scale (See Table 3.3 and Appendix F).



Table 3.3

*Questions and items in the IPQ (B) (Adapted)*

Item	Question
Consequences	How much does your medical issue in pregnancy affect your life?
Timeline	How long do you think your medical condition will continue?
Personal Control	How much control do you feel you have over your medical issue in pregnancy?
Treatment Control	How much do you think treatment can help with your medical issue in pregnancy?
Identity	How much do you experience symptoms from you medical issue in pregnancy?
Concern	How concerned are you about your medical issue in pregnancy?
Understanding	How well do you feel you understand your medical issue in pregnancy?
Emotions	How much does your medical issue in pregnancy affect you emotionally e.g. does it make you angry, scared, upset or depressed?

Research shows that the IPQ (B) has had good test-retest reliability over 3- weeks and 6-weeks, high discriminant validity between illnesses and good predictive validity (Elizabeth Broadbent, et al., 2006). The psychometric testing of this tool has been conducted mainly in New Zealand. The IPQ (B) has been translated into over 20 languages and is widely used around the world.

Distress Scales

Edinburgh Postnatal Depression Scale (EPDS)

EPDS is a brief ten item self-report scale, which assesses the common symptoms of perinatal depression. It includes three items on anxiety. It has been well validated, is widely used internationally and is regarded reliable in

community settings (Cox, et al., 1987). A cut-off score above (>) 13 is strongly suggestive of depression (Crawford, et al., 2011). Positive predictive value has been reported between 70-90% (Crawford, et al., 2011).

State-Trait Anxiety Inventory–State (STAI- (S)).

The STAI-S consists of a 20 item self-report scale that measures state-anxiety. State-anxiety is defined as ‘anxiety in response to a specific situation that is perceived as threatening or dangerous’ (VandenBos, 2007, p. 890). State-anxiety fluctuates over time and in intensity (Spielberger, 1985). State-anxiety is often compared to trait-anxiety, which is conceptualised as a ‘proneness to anxiety’ (VandenBos, 2007, p. 950). The STAI-S has been widely used internationally for the past 30 years. In a normative study in Australia, a cut-off score of above (>) 41 is strongly suggestive of clinical levels of anxiety (Crawford, et al., 2011). The STAI-S was chosen due to previous research showing a negative correlation between STAI-S and perceptions of health and the STAI-S being used in a number of other studies investigating anxiety in pregnancy (Breitkopf, et al., 2006; Currie, 2012; Da Costa, et al., 1999; Faisal-Cury & Menezes, 2007; Figueiredo & Conde, 2011; Gunning, et al., 2010).

### ***Data Analysis***

The data collected for the study was screened for errors. Frequency and descriptive statistics were examined to determine normality of distribution and correlations conducted between distress scales of EPDS and STAI-S with the domains within illness perceptions. The data analysis for the survey was conducted using SPSS Version 21.0. Free- answer questions were examined using

qualitative thematic analysis, which was inductive and semantic. The patterns of scores on the IPQ (B) were also compared with patterns from previous research on other illnesses.

## Results

This section presents the descriptive information regarding the results of the study measures. This is followed by an evaluation of the study hypotheses with an exploratory analysis of illness perceptions as measured by the IPQ (B) and results of the qualitative portion of the online survey.

### *Pregnancy History*

While the thirty-six participants had been pregnant seventy-three times in total, they recorded as having thirty-five children. For thirteen women (25%) this was their first pregnancy and they had no other children. Many women had experienced pregnancy losses. One participant had been pregnant nine times and had two children.(See Table 3.4)

Table 3.4

*Frequencies of women's previous pregnancies and number of children.*

	<i>x</i>	None	1	2	3	4	5+
	N=36						
No of pregnancies	2.03	25.0 %	22.2%	25.0%	8.3%	8.3%	11.1 %
No of children	0.97	36.6%	41.7%	16.7%	0.0%	5.6%	0.0%

*Notes: N = total number of participants and x = mean number of pregnancies and mean number of children.*

Twelve (30.8%) of the participants had experienced at least one miscarriage, while one (2.6%) had experienced a stillbirth. Six (15.4%) of the participants terminated a pregnancy.. Four participants (11.1%) had received

treatment for infertility and three participants (8.3%) were currently pregnant due to infertility treatment.

### ***Status of Current Pregnancy.***

For their current pregnancy, 22 (61.1%) participants reported they had planned their pregnancy and actively tried to get pregnant, 8 (22.2%) did not plan their pregnancy but desired it once pregnant, 4 (11.1%) partially desired to be pregnant but were not actively trying to become pregnant, while 2 (5.6%) participants had not planned to become pregnant and did not desire to be pregnant.

The mean length of gestation (number of weeks pregnant) of the thirty-six participants was 27.2 weeks (SD=7.4). Length of gestation ranged from seven weeks to thirty-nine weeks at the time of completing the survey (see Table 4.2). Two participants were in their first semester (1-12 weeks gestation), 14 (38.9%) were in their second semester (13-26 weeks) while 20 (55.6%) were in their third semester (27 weeks plus) of their pregnancy.

### ***Pregnancy complications***

Doctors informed 14 (38.9%) of the participants of their medical issue /pregnancy complication, 15 (41.7%) were informed by their midwife, 3 (8.3%) by another health professional and 4 from another information source. Twenty-eight (80.0%) then searched for further information via the Internet, 12(34.4%) participants asked family and friends for information, 7 (20.0%) sought a second

opinion from a medical professional, and 9 (25.7%) sought information from other sources.

### *Types of pregnancy complications*

The thirty-six participants recorded fifty types of pregnancy complications (see Table 3.5). Six participants (16.7%) recorded multiple complications.

Table 3.5

#### *Frequencies of types of medical complications of pregnant women.*

Types of Complications	No of cases	% cases
Hypertension	6	12.0
Pain	5	10.0
Heartburn	5	10.0
Slow /small growth of foetus	4	8.0
Hyperemesis gravida	4	8.0
Gestational Diabetes	4	8.0
Blood problems	4	8.0
Low lying placenta/placenta previa	3	6.0
Low Blood pressure	3	6.0
Carpel Tunnel	3	6.0
Problem with cervix	2	4.0
Other	6	12.0

Other pregnancy complications included history of premature baby, a pre-gestational medical condition (which was affecting the pregnancy and still under medical investigation), cholestasis (chronic itching), umbilical artery notch (rare malformation of the foetal umbilical cord), two-vessel cord (malformation of umbilical vessel cord which now has two blood vessels rather than the normal three blood vessels) and chicken pox (with possible resulting abnormalities in foetus).

### ***Types of Treatment for pregnancy complications***

Twenty-eight (77.8%) participants gave information on thirty-five types of treatment they were receiving for their pregnancy complication(s). Fifteen (41.7%) participants were on medication for their pregnancy complication, 12 (33 %) had extra monitoring, 4 (11.1%) were required to modify their diet and 4 (11.1%) had physiotherapy/ massage treatments for their medical issue in their pregnancy. Eight (22.2%) recorded no treatments.

### ***Health rating in previous week***

Participants were asked to rate their health over the previous week from 1 ('Healthy, no medical problems') to 5 ('Severe medical problems that are significant risk to me and my baby'). Six participants (16.7%) rated their health as 'healthy, no medical problems', which is interesting considering they had already reported their pregnancy complication in the survey. The distribution of scores for this scale had a normal distribution in terms of skew but not in terms of kurtosis at 1.629, which was likely caused by the restriction of range. Mean for this scale was 2.25 with a standard deviation of 0.88. (See Table 3.6)

Table 3.6

*Rating of women's health in past week*

Rating Scale	Overall % N=36
Healthy, no medical problems	16.7
Mild medical problems that aren't any risk to me and/or baby	50.0
Moderate medical problems that require some monitoring by a midwife or doctor	27.8
Major medical problems that require intervention or create some risk	2.8
Severe medical problems that are significant risk to me and/or the baby	2.8

***Depression/Anxiety Scales***

The STAI-S scores and EPDS scores were examined for univariate normality and found to have acceptable level of skewness and kurtosis. Mean for the STAI-S was 45.84 with a standard deviation of 13.84. The STAI-S scores ranged from the 2 to 75. The mean for EPDS scores was 11.46 with a standard deviation of 7.08 with a range in scores from 0 to 30. One sample T-tests were carried out in order to examine whether there were significant differences between the mean EPDS scores in this sample and in a normative British sample of pregnant women in their last trimester (Evans, Heron, Francomb, Oke, & Golding, 2001). Mean EPDS scores were found to be significantly higher among pregnant women in this sample than in the normative sample of 11,968 pregnant women. Significant differences were also discovered through one sample T-test between the mean STAI-S scores in the sample and an Australian normative sample of



adults over 18 (Crawford, et al., 2011). The mean STAI-S scores were significantly higher in this sample than that of the normative sample (see Table 3.7).

Table 3.7

*One Sample T-Test- EPDS and STAI-S mean scores*

	Current Sample		Normative Sample		T-test	2-tailed <i>p</i> Sig.
	<i>x</i>	SD	<i>x</i>	SD		
EPDS	11.46	7.08	7.07	5.08	3.67	0.00
STAI-S	45.84	13.84	33.16	11.69	5.42	0.00

*Notes: x= means, SD= standard deviation,  $p < 0.01$  is significant.*

Using a clinical cut-off score of 13 for the EPDS, 14 (40%) participants scored equal to or above this score (S. Matthey, Henshaw, Elliott, & Barnett, 2006). On the STAI-S a clinical cut –off score of 41 was used with 23 participants (65.7%) scored equal to or above this score meaning these participants scored high in terms of the anxiety (Crawford, et al., 2011).

### *Illness Perceptions*

The total IPQ (B) scores were assessed for univariate normality, and found to have acceptable levels of skewness and kurtosis with a mean of 44.08 (SD=12.88, N =36). Total Scores ranged from 16 to 71 (See Table 3.8 for means scores of each item).

Table 3.8

*Means of items of the IPQ (B) in pregnant women with medical complications.*

Item	Total sample <i>x</i> ( <i>SD</i> ) N=36
<i>Consequences</i>	5.92(2.59)
<i>Timeline</i>	4.89(2.67)
<i>Personal control</i>	7.06(2.76)
<i>Treatment Control</i>	5.78(3.41)
<i>Identity</i>	4.97(3.21)
<i>Concerns</i>	5.64(2.93)
<i>Understanding</i>	3.53(2.85)
<i>Emotions</i>	6.31(2.87)

*Notes: x= means and SD=standard deviations*

In interpreting item and total scores for the IPQ (B), the higher score relates to more negative illness perceptions about the participants' pregnancy complication. (Elizabeth Broadbent, et al., 2006). The items on the IPQ (B) which had a mean score over five, with this sample, included consequences (how much does the pregnancy complication affect my life?), personal control (how much control do I feel I have over the pregnancy complication?), treatment control (how much do you think your treatment helps your complication), concern and

emotional response, while items which had a mean score lower than five included timeline (how long do you think your medical condition will continue?) and understanding (how well do you feel you understand you pregnancy complication) (See Figure 3.1).

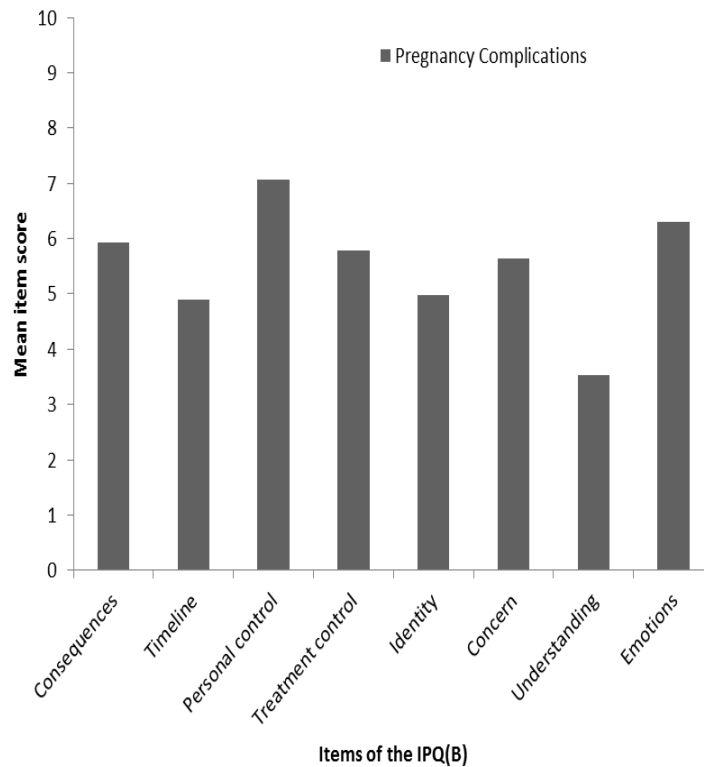


Figure 3.1 *Illness schemata of patients with pregnancy complications.*

### ***Correlations between illness perceptions, health ratings and psychological distress.***

In order to address the research hypothesis regarding whether negative illness perceptions (or higher scores on the illness perceptions questionnaire) will correlate with higher state anxiety and distress scores, correlations were conducted between the distress scales, IPQ (B) total scores and the health rating

scores. Spearman's correlations were chosen due to the inclusion of the health rating scale, which had a restriction of range in its distribution of scores. Scores on the IPQ (B) were significantly positively correlated with rating of health in the last week, EPDS and STAI-S, while rating of health was also significantly positively correlated with the distress scales of EPDS and STAI-S (See Table 3.9).

Table 3.9

*Spearman's correlations amongst IPQ (B), distress scales (EPDS and STAI-S) and health rating in the past week.*

		IPQ (B) Total	EPDS Total	STAI-S Total
EPDS Total	Spearman	.632		
	Sig (2-tailed)	<. 001		
	N	35		
STAI-S Total	Spearman	.557	.748	
	Sig (2-tailed)	.001	<. 001	
	N	35	35	
Health Rating	Spearman	.518	.481	.436
	Sig (2-tailed)	.001	.003	.009
	N	36	35	35

In order to better understand the relationships between dimensions of illness perceptions and anxiety, correlations were conducted between STAI- S and individual items of the Brief IPQ. Significant correlations were found between

consequences, concerns and emotions with the STAI-S. There was no correlation found with personal control, treatment control or illness identity (symptom identification) (See Table 3.10).

Table 3.10

*Correlations between STAI-S and items of the Brief IPQ*

		STAI-S Total
Consequence	Spearman	.527**
	Sig (2-tailed)	.001
	N	35
Timeline	Spearman	.352*
	Sig (2-tailed)	.038
	N	35
Personal Control	Spearman	.112
	Sig	.521
	N	35
Treatment Control	Spearman	.042
	Sig	.809
	N	35
Identity	Spearman	.052
	Sig (2-tailed)	.769
	N	35
Concerns	Spearman	.613**
	Sig	< .001
	N	35
Understanding	Spearman	.330*
	Sig	.053
	N	35
Emotions	Spearman	.622**
	Sig	< .001
	N	35

\* $p < 0.05$  correlation is significant

### ***Illness perceptions in pregnancy complications in comparison to other illnesses***

To understand the illness perceptions as represented by item scores on the IPQ (B) for pregnancy complications in comparison to other illnesses, a graph was utilised to compare mean item scores on the IPQ (B) of pregnancy complications to mean item scores on the IPQ (B) for hypertension, diabetes, colds and asthma and hypertension (Elizabeth Broadbent, et al., 2006) (See Figure 3.2). Unfortunately the significance of such differences could not be statistically tested, as the researcher did not have access to the standard deviations from the other studies. The graph is presented in order to illustrate general patterns, but comparisons need to be made with caution.

Pregnancy complications seemed to have a higher mean score, in comparison to other illnesses, on the IPQ (B) items of personal control and emotions, and were on a par with hypertension for consequences and identity. Pregnancy complications seemed to have had the lowest mean score in comparison to all the other illnesses on the IPQ (B) item of timeline.

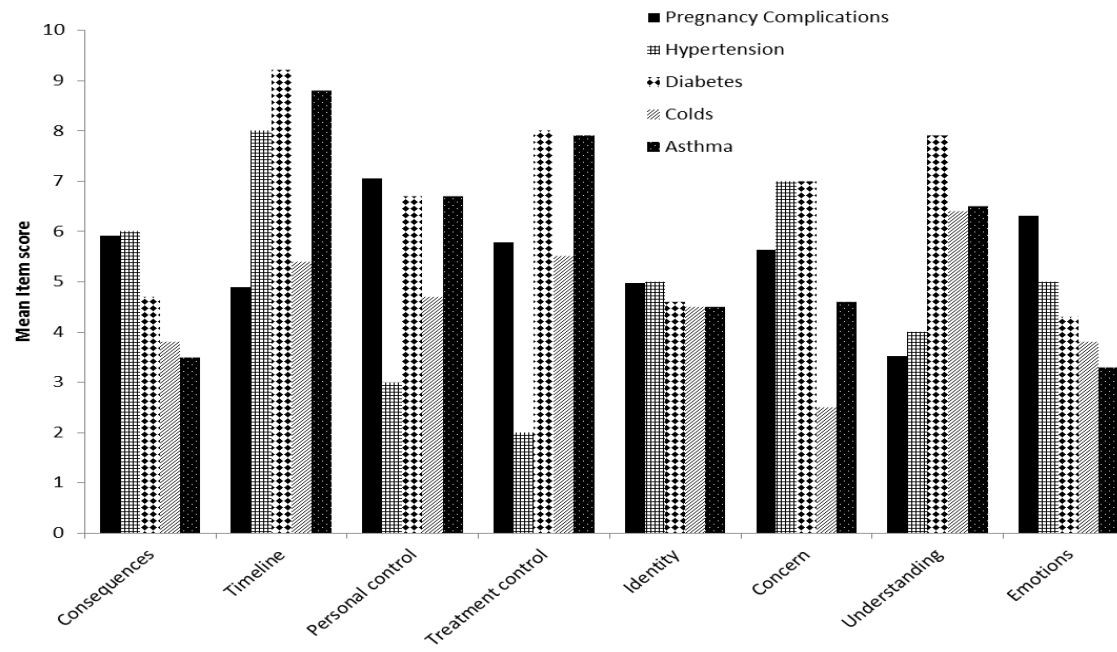


Figure 3.2: *IPQ(B)* mean item scores in patients with pregnancy complications, hypertension, diabetes, colds and asthma (Broadbent et al, 2006).

### *Symptoms of pregnancy complications*

The following information was collected and analysed with reference to the last hypothesis proposed, which was women with pregnancy complications who don't experience subjective symptoms related to their complication (asymptomatic) will have higher rates of anxiety and depression than those who have symptoms they can detect (symptomatic).

Twenty-one participants (48.8%) were asymptomatic, i.e. they did not report any physical symptoms related to their pregnancy complication. The total number of physical symptoms was 58 and the mean number of symptoms was 1.35 (SD 1.66) (See Table 3.11.).

Table 3.11

*Frequencies of number of physical symptoms experienced by women and related to their pregnancy complications.*

	None	One	Two	Three	Four	$\geq$ Five
No of symptoms	41.7%	13.9%	13.9%	11.1%	16.7%	2.8%

The types of physical symptoms related to the women's pregnancy complication included swelling, dehydration, sensitivity to lights and sounds, itching, nausea, hunger, not eating, light-headedness, back ache, pelvic girdle pains, painful to walk/bend/move fatigue, headaches, numbness and acid taste in



mouth. Other psychological symptoms mentioned included frustration, anxiety and depression.

### ***Health rating and symptoms***

The sample was split into asymptomatic (women who recorded no symptoms related to their pregnancy complication) and symptomatic (women who related different symptoms to their pregnancy complication) and a cross-tabulation conducted with rating of women’s health in past week. (See Table 3.12)..

A chi- squared analysis was conducted to assess the relationship between the health rating and number of symptoms of pregnancy complications. Results showed no significant relationship ( $\chi^2 = (4), 2.35, p=0.67$ ).

Table 3.12

*Cross tabulation of health rating with pregnant women who were asymptomatic and symptomatic.*

Rating Scale	Asymptomatic % N=15	Symptomatic % N=21
Healthy, no medical problems	3	3
Mild medical problems that aren’t any risk to me and/or baby	7	11
Moderate to severe medical problems that require some monitoring by a midwife or doctor	5	7

### ***Symptoms and distress scales***

The last research hypothesis tested was that women who do not experience subjective symptoms related to the complications (asymptomatic) will have higher rates of anxiety and depression than those who have symptoms they can detect.

Table 3.13 presents a cross-tabulation for asymptomatic and symptomatic by whether or not participants met the clinical threshold for anxiety (STAI-S) or depression (EPDS).

Table 3.13

*Cross tabulation between number of participants who were asymptomatic and symptomatic and the number of participants with distress scores—STAI-S under 41, STAI-S over and equal to 41 and EPDS under 13 and over and equal to 13.*

Distress Measure	Asymptomatic	Symptomatic	Total
STAI-S<41	3	9	12
STAI-S>=41	11	12	23
Total	14	21	35
EPDS<13	4	17	21
EPDS>=13	10	4	14
Total	14	21	35

Sixty-five percent of the total sample reached the clinical threshold for anxiety. Eleven (78.5%) of the asymptomatic participants reached the threshold for anxiety while twelve (57.1%) of the participants with symptoms reached the anxiety threshold. Forty percent of the total sample reached the clinical threshold

for depression, seventy one percent (10 participants) of these were from the asymptomatic group. Twenty percent of the participants with symptoms reached the clinical threshold for depression. Mean for STAI –S for the asymptomatic group was 50.3, while the mean on the STAI-S for the group with symptoms was 42.9. The mean for the EPDS for the asymptomatic group was 14.8 while the mean of the EPDS in the symptomatic group was 9.2. Independent T-tests were conducted and while there was no significant difference between the two groups in terms of anxiety, there was a significant difference in terms of depression ( $t=2.42, p<0.05$ ).

### ***Symptoms and illness perceptions***

Means and standard deviations of asymptomatic and symptomatic groups of the items of the Brief IPQ score can be seen in Table 3.14. Independent sample T-tests were conducted amongst the means between the asymptomatic and symptomatic groups. Significant differences were found between the means of the items of personal control and identity and understanding.

Table 3.14

*Means of items of the IPQ (B) in asymptomatic and symptomatic pregnant women.*

Item	Asymptomatic x(SD) N=15	Symptomatic x(SD) N=21	T-test	2-tailed p Sig.
<i>Consequences</i>	5.53(3.02)	6.19(2.27)	-0.75	0.46
<i>Timeline</i>	5.13(2.62)	4.71(2.76)	0.46	0.65
<i>Personal control</i>	8.13(2.56)*	6.28(2.70)*	2.66	0.05
<i>Treatment</i>	6.27(3.47)	5.43(3.40)	0.73	0.48
<i>Control</i>				
<i>Identity</i>	2.80(2.83)*	6.52(2.48)*	-4.15	0.00
<i>Concerns</i>	6.20(2.60)	5.24(3.14)	0.97	0.34
<i>Understanding</i>	4.60(2.75)*	2.76(2.73)*	1.98	0.05
<i>Emotions</i>	6.60(2.80)	6.10(2.98)	0.51	0.61

*Notes: x= means and SD=standard deviations*

*\* p<=0.05 significant difference between means of IPQ item between asymptomatic and symptomatic groups.*

### ***Qualitative Results***

#### ***Initial diagnosis***

An open-ended question was asked ‘What were you told about your medical issue in your pregnancy?’ The qualitative answers were assessed utilising an inductive thematic approach. The three categories that emerged from this question included:

### 1) Basic medical information

Examples of this information included:

*Told there were problems with my placenta*

*It affects my liver*

*Explained what gestational diabetes is*

*Oversensitivity to hormones*

*I had chickenpox*

### 2) Treatment recommendations

This included determining course(s) of action where women were encouraged to take specific actions or treatments that could impact the outcomes of their pregnancy complication that could benefit themselves and their child to be.

Examples given by participants included:

*How to control my blood sugars*

*To avoid certain foods*

*Need to try and eat small meals and take medication if needed and can get support for my hands and feet if things get worse.*

*To wear pelvis belts and use crutches when it gets really bad.*

*Offered termination at 24 weeks.*

### 3) Consequences

Informing of possible outcomes of the pregnancy complication for both the mother during her pregnancy and for the foetus and child after birth. The following are examples of such information:

*Likelihood of an early birth*

*Antibody E can cause poor growth for the baby*

*Will likely need to be induced and baby may have blood sugar instability at birth*

*Low blood pressure is dangerous and I could pass out and might not be able to have certain pain relief in labour.*

*It is common and usually lasts the first trimester (severe morning sickness).*

*Chickenpox might well have been passed onto baby, but they can't tell until the baby is born-may have: mental retardation, nerve problems, vision and hearing problems.*

### ***Feelings about pregnancy complication***

The participants were asked about their feelings when told about their medical issue/pregnancy complication. The following themes were derived from the participants' answers to the open-ended question "How did you feel when told about your medical issue in pregnancy?"

A wide variety of answers were given to this question and fell along a spectrum of what could be regarded as positive feelings (positive in the circumstances), neutral feelings (which were neither markedly positive nor

negative under the current circumstances) as well as more negative feelings.

Negative feelings contained negation or denial of the their current situation. (See Table 3.15).

Table 3.15

*Examples of feelings of women when told about their medical issue in pregnancy*

Type of feeling	Feeling	Type of complication
Positive	<i>Relieved</i>	Cholestasis
	<i>Not too bothered</i>	Heartburn
	<i>Pretty accepting</i>	Heartburn
	<i>Felt OK</i>	Blood problems
	<i>Glad it was not my mind playing tricks on me</i>	Hyperemesis gravida
Neutral	<i>Expected</i>	Heartburn
	<i>I was not surprised, I already knew it was on the table</i>	Gestational Diabetes
	<i>Just want to keep track of it</i>	Hypertension
Negative	<i>Scared</i>	Incompetent cervix
	<i>Upset, worried, angry, frustrated and worried</i>	Chicken pox and low blood pressure
	<i>Anxious, worried, disappointed, defective</i>	Gestational Diabetes
	<i>Twins! Very afraid</i>	Twins
	<i>Worried for my baby</i>	Slow growth of foetus
	<i>Sad</i>	Hypertension, slow growth of foetus and two-vessel cord.
	<i>Worried</i>	Suspected placenta stopped working
	<i>Wasn't surprised but scared</i>	Short cervix
	<i>Annoyed</i>	Sciatica

Participants expressed 36 (69.2%) feelings that could be classified as negative, 9 (17.3%) feelings were classified as neutral, while 7 (13.5%) feelings were classified as positive under the circumstances.

***Causes of their pregnancy complication***

Participants were also asked about their understanding of the causes of their medical complication. Five participants said the main cause of the pregnancy complication was hormones, while four participants gave genetics as the main cause. Six participants gave multiple causes. (See Table 3.16.)

Table 3.16.

*Causes for the medical complication in pregnancy in rank order.*

Main Cause	2 <sup>nd</sup> Cause	3 <sup>rd</sup> Cause
Hormones	Weight	Psychological
Genetics	Genetics	Anxiety
Bad Luck	Diet	Previous Medical history
Pregnancy		
Diet		
Nothing		
Environment		
Pre-cancer operation		
Age		



## **Discussion**

The main aim of this study was to understand illness perceptions of women with a pregnancy complication and its relationship to distress in general, and anxiety in particular. The results indicate that women in this sample experience significantly higher degrees of distress and anxiety than those in normal populations. They perceive their pregnancy complications as being outside of their personal control and they don't see treatment as likely to be effective in controlling their medical condition. They also perceive their pregnancy complication as having high consequences in their lives and they are concerned about the impact of the pregnancy complication has on themselves and on their child. The women who did not have detectable symptoms (asymptomatic) and who could not directly experience cues to their illness were significantly more depressed.

### ***Distress Levels- Anxiety and Depression***

According to the results of the EPDS and STAI-S, depression and anxiety for this sample did differ significantly from that found in normative, non-pregnant samples (Crawford, et al., 2011; Evans, et al., 2001). In the case of EPDS, depression was higher than for normative pregnant populations (Evans, et al., 2001). This finding has been replicated in number of other studies that suggest that significant distress including anxiety is a problem for pregnant women in general and for pregnant women with medical complications in particular (C.C. Barber, 2012; Currie, 2012; Evans, et al., 2001). This can be considered in terms of a theoretical framework of the bio-psychosocial model of anxiety for pregnant women (Wenzel, 2011). In this model, the pregnancy complication can be viewed

as a life stress, which will interact with the woman's inherent vulnerabilities to anxiety to impact her level of anxiety. This was reinforced by qualitative interviews in which women described their pregnancies as traumatic and frightening. They also discussed their feelings when told of the complication, with nearly 70% of the quantitative sample describing negative feelings. The literature suggests that a number of aspects of a woman's medical complication in pregnancy (such as diagnosis, severity, treatment options, consequences for the woman and concerns for the child-to be) will all impact the woman's level of anxiety and distress (Silvia, 2012). In the interviews, women discussed the experience of a pregnancy with complications as traumatic and this was reinforced by the number of high scores on the EPDS and STAI-S in the subsequent online survey. The levels of clinically significant distress presented in this sample are of concern as this distress places women at increased risk of developing postnatal depression and other psychological disorders as well as child development (Doan & Zimmerman, 2003; Milgrom, et al., 2008; Moss, et al., 2009).

### ***Health ratings***

Nearly 1 in 5 women who were participating because they had medical problems rated themselves as having no medical problems. Currie (2012) found that 20.3% of women who were hospitalized for pregnancy complications also rated their own health this way. In this sample, there was no relationship between whether she experienced symptoms or not regarding her rating of health problems over the past week. Other research has shown that medical professionals and patients differ in terms of how they rate a patient's health (C.C. Barber, 2012; Currie, 2012; K. J. Petrie & Weinman, 2006, 2012). Previous research has

demonstrated that some women develop perceptions about their pregnancy complication that seem unrelated to the actual medical complication as diagnosed (Currie, 2012; K. J. Petrie & Weinman, 2006). The women who did not view themselves as sick in this sample showed lower levels of anxiety and depression. Research shows that patients with the same illness or injury can have widely different perceptions of their medical condition and these perceptions can lead patients down very different illness trajectories ((K. J. Petrie & Weinman, 2006). It is these perceptions that often influence emotional and physical wellbeing (K. J. Petrie & Weinman, 2006) . The results of this study suggest that believing that you are healthy is related to less distress regardless of actual medical condition.

### ***Illness perceptions***

Women, when faced with a health threat such as a pregnancy complication, will build a mental model of this threat and this mental representation will determine how they respond (Diefenbach & Leventhal, 1996). These models are often not discussed in medical consultations (K. J. Petrie & Weinman, 2006). Using the illness perception questionnaires derived from the common sense model of illness, researchers and clinicians are able to investigate these mental models. This study confirmed the hypothesis that the most prominent features of illness perceptions of pregnant women with complications would be the consequences for the women's life, personal control over the medical complication and concerns that the women has over her pregnancy complication and its impact on her child-to-be, as well as her emotions surrounding her pregnancy complication. This sample also scored high on treatment control, indicating their lack in belief in treatments in curing and /or controlling their pregnancy complications.

Results suggest that women in this sample believe that there are some serious consequences associated with their pregnancy complications. Women are well aware of the impact that their medical condition can have on their life. When diagnosed with a pregnancy complication, the women reported that they were told of the probable consequences of their complication by a medical professional, with short term and long-term consequences. The short-term consequences could include immediate changes the women may need to make to manage her illness. For gestational diabetes, for example, this could include dietary changes and monitoring insulin levels ((McCance, et al., 2010). For hypertension, it may require reduction of workload in an attempt to reduce stress, and taking of medication (Kent, 2012). Long-term consequences could include future issues with childbearing, health outcomes for the child-to be, longer term health issues for the mother – such as being diagnosed with gestational diabetes and this raising the woman’s possibility of developing diabetes Type 2 in the future.

Pregnant women in this sample seemed to perceive that they lacked personal control in terms of their illness. Personal control equates to the woman’s belief that she cannot personally control the outcome and is related to a woman’s reduced self-efficacy in dealing with their pregnancy complication. Lack of self-efficacy in pregnancy in general has been related to some negative outcomes for woman during pregnancy. These included lack of exercise (for those that have advised that they can still exercise) and weight gain (Cramp & Bray, 2009; Womack, Bauer, Paneth, Feltz, & Pivarnik, 2014); and with relapse in smoking (Mullen, Pollak, & Kok, 1999); as well lack of adherence to treatment (Hagger &

Orbell, 2003). Literature shows that lack of medicine adherence could also be impacted by lack of belief in treatment control, which was also experienced by women in this sample (E Broadbent, et al., 2011).

Future concerns are related to risk to child as well as risks to the pregnant woman themselves. These concerns could generate worry for a pregnant woman with complications – which has been noted to be high in women who are pregnant in general (Green, et al., 2003). The emotion scores of women in this sample suggest that the women were highly affected emotionally by their medical condition in terms of being angry, scared, upset or depressed. This was further confirmed with high scores on the EPDS and STAI-S in comparison to normative samples as well as with significant correlations found between EPDS and the STAI-S with the total IPQ (B). This fits with the literature on anxiety in pregnancy with complications (Denis, Michaux, & Callahan, 2012). It also further highlights how women with pregnancy complications are prone to distress, regardless of characteristic vulnerabilities to anxiety or depression (Wenzel, 2011).

While medication is may be prescribed to pregnant women with depression, research suggests that this is not seen as a preference by most pregnant women, who would prefer an psychological intervention such as mindfulness based cognitive therapy or interpersonal therapy, both of which are evidence based (Dimidjian & Goodman, 2014; Mendelson, Leis, Perry, Stuart, & Tandon, 2013; Querstret & Cropley, 2013). A novel psychosocial treatment called ‘ CALM pregnancy’ has been recently developed to specifically deal with perinatal anxiety (Goodman, et al., 2014). This intervention utilises mindfulness cognitive behavioural therapy (MCBT) and psycho-education and initial evidence

for this intervention looks promising (Goodman, et al., 2014). The reliance of women with pregnancy complications on their social support structures may play a part in the success of interpersonal therapy with this population. Music therapy has also been researched as a positive intervention for pregnant populations with mental health issues, utilising lullabies in a group format (Friedman, Kaplan, Rosenthal, & Console, 2010).

The hypothesis was confirmed that negative illness perceptions (higher scores on the illness perception questionnaire) correlated with higher state anxiety and depression. Significant correlations were found between anxiety and the IPQ (B) items of consequences, concerns and emotions. Surprisingly, there was no significant correlation found between anxiety and personal control. The majority of the participants of the interviews discussed their perception of the pregnancy being out of control and the impact this had on increasing distress, including anxiety, so it was expected that there would be a positive correlation between anxiety and experience of personal control in the quantitative study. What was found was a limited range of scores for personal control and this might have contributed to the non-significant correlation. Another reason for this result may have been that the women who chose to volunteer for the interviews had more intense negative feelings associated with their lack of control and maybe they chose to do the interviews in order to regain some sense of control by telling their stories. Since the quantitative and qualitative findings are conflicting this is an important area for further exploration.

The comparison of illness perceptions in pregnancy complications with other illnesses such as hypertension, diabetes, colds and asthma should be made with caution, as the only data available were the mean scores of each item on the IPQ (B). This means that we were unable to conduct statistical tests for comparison purposes. This sample of pregnant women with complications scored the highest mean score in emotions in comparison to the other illnesses, which is consistent with the rest of the study and reflects the literature, which indicates a considerable degree of distress in pregnant populations (Brandon, et al., 2007; Brandon, et al., 2008; Breitkopf, et al., 2006; Robinson, et al., 2011). This may well be because pregnancy complications have high impact not only for the mother's health, but also for her child's health. There is a high baseline level of uncertainty and anxiety in pregnancy (Breitkopf, et al., 2006).

The women with pregnancy complications and patients with hypertension held similar beliefs in terms of the seriousness of consequences that the medical condition would have on their life. Both pregnancy complications and hypertension, often with no symptoms, are characterised by unpredictability and having life threatening consequences, which could be called the 'ticking time-bomb' syndrome.

Women with pregnancy complications perceived their illness to be short-lived in comparison to the other illnesses. This makes sense, as hypertension, diabetes and asthma are often chronic. Women in the sample felt they had less control over their illness in comparison to the other illnesses. This could be related

to their perception of risk related to the pregnancy complication. Research shows that pregnant women have a tendency to overestimate risk and underestimate self-efficacy (Robinson, et al., 2011). Antenatal education with a focus on accurate assessment of risks and taking appropriate steps to manage these risks leads to higher self-efficacy and better decision-making (Robinson, et al., 2011).

Women with pregnancy complications believed that they had higher level of understanding of their illness in comparison to patients with other illnesses This may be that this belief in understanding their illness helps counteract their lack of personal control. High belief in their understanding of their illness may occur due to the continual monitoring that women undertake with medical professionals (Hatta, Kawakami, Goto, Kadobayashi, & Iwamoto, 1999; Scamell, 2011; Verny, 1986); this high level of interaction may raise their understanding. The on-going relationship that pregnant women have with their midwives may also facilitate understanding of their illness. This also fits with the amount of information gathered by participants about their pregnancy complication; over 80% of respondents searched on the internet for further information, 34% asked family and friends for more information, 20% sought a second opinion from a medical professional and 25% sought information from other sources. Perhaps this information gathering occurs as a result of lack of belief in personal control and high consequences and concerns that women perceive about their pregnancy complication. This will require further research to confirm.



### *Asymptomatic and symptomatic illnesses*

As expected, women with pregnancy complications who didn't experience subjective symptoms had higher levels of depression than those who had symptoms, but this difference though in the same direction, did not reach significance for the measure of anxiety. The reason that there were not significant differences between the two groups for anxiety, may have been due to the small number of participants, who were asymptomatic. Seligman (1972) discussed the concept of 'learned helplessness' with depression. The theory of learned helplessness conceptualizes that people who are placed in an uncontrollable negative situation, for long enough, develop passive and distressed states similar to depression. It is possible that women might develop 'learned helplessness' due to their inability to personally control their medical complication (Lobel, Marie Yali, Zhu, DeVincent, & Meyer, 2002; Seligman, 1972). Those with no detectable symptoms might find it difficult to determine when and if the medical complication was becoming worse or better. This means that they would be unable to take appropriate action and this might impact their decision-making and mood.

The results also suggest that pregnant women who were asymptomatic perceived themselves as having lower understanding about their complication. They found it difficult to perceive what was actually wrong with them and had difficulties in labelling their illness due to their lack of associated symptoms (Baumann, et al., 1989). The majority of the women regarded their pregnancy complications as being caused by hormones and genetics, which are issues outside

out their control. This may have impacted the reason why women in this sample felt little personal control

### *Summary*

Pregnant women with pregnancy complications experience high levels of anxiety and depression. This seems particularly relevant to the woman who is asymptomatic. Scores on the Illness perception questionnaires seem to reflect the lived experience of women with pregnancy complications and is a useful tool for assessing pregnant women's perceptions over this time period. With the high level of correlation between the scores on the illness perception questionnaire and distress scores, illness perception scores can be used as an indicator of high distress, which may warrant further investigation for vulnerable women.

## **CHAPTER FOUR: CONCLUSIONS**

The purpose of this research was to identify the levels of anxiety experienced by pregnant women who have a medical complication and to understand the mother's own perceptions of her complications and their relationship to anxiety. The first mixed method study focused on the lived experience of women with a pregnancy complication and included a pilot of an illness perception questionnaire with this population. The second was a cross-sectional correlational study into illness perceptions and its relationship to distress in general, and anxiety in particular.

Overall the two studies demonstrated that the common sense model could be applied to the steps women take (cognitively and emotionally) when diagnosed with a pregnancy complication. Pregnancy complications are characterised by women experiencing high levels of distress and anxiety, especially when consequences of the complication are believed to be high. Women perceive that they do not have personal control over the outcomes of their pregnancy complication and treatment is often perceived as ineffective. In both studies women believed that the complication would be short-lived. Both studies demonstrated that women who were asymptomatic experienced heightened distress.

## **Limitations**

The exploratory nature of this study and lack of literature on illness perceptions of women with pregnancy complications meant that the study's results could not be validated against a comparison study with a similar population. We were unable to enlist the collaboration of medical services for at risk pregnant women making recruitment difficult and thus the sample size in the quantitative study at thirty-six was small. This means that the significant results found can be regarded as important results, but it also means also that the statistical tests that did not show significance should be regarded as inconclusive results rather than insignificant (Aron, Aron, & Coups, 2009).

The scale developed to assess perceptions of health (health rating scale) by Dr Carrie Cornsweet Baber and Dr Nicola Starkey is not validated, so its reliability and validity is unknown. The IPQ (B) has also not been previously used with pregnant women with complications, and the structure of the IPQ (B) was also a limitation as each domain of illness perception was only evaluated by one item. The survey was conducted online, and this meant that the women needed to use self -interpretation of the questions asked. The measure of whether they had symptoms or not was not validated.

Another limitation of this research is the culture bias towards New Zealand Europeans in the sample. Research shows that there are cultural differences in estimation of risk (Robinson, et al., 2011); and in perception of illnesses (K. Petrie, 2012). The sample collected does not reflect the cultures that make up the New Zealand population and further research is needed to determine illness perceptions of pregnancy complication in New Zealand. The study also includes 50 types of pregnancy complications, which have vastly different treatment regimens and possible medical outcomes, which were combined them all into the concept of 'pregnancy complications'.

## **Conclusions and Future Directions**

This research adds to the international findings on illness perceptions in general and is a starting point for understanding illness perceptions for women with pregnancy complications. It concurs with the literature (Brandon, et al., 2008; Breitkopf, et al., 2006; Robinson, et al., 2011); that women with pregnancy complications are highly anxious and often depressed and this research shows that asymptomatic women are particularly distressed. Future research might look more closely at the specific drivers of distress in this population. This might include understanding in more depth the concept of personal control and pregnancy specific self-efficacy in dealing with a pregnancy complication. Another avenue of research could be to understand the information gathering process of women with pregnancy complications and to understand the barriers to mental health treatment and psycho-education for this population. Future investigations could include understanding qualitative aspects of women's experiences of a pregnancy complication when asymptomatic as this is seen as a particularly vulnerable

population. Research might also look at illness perceptions of different types of pregnancy complications such as gestational diabetes or pregnancy induced hypertension. There has also been no published research into interventions utilising illness perceptions for this population and this could be helpful.

The results of this study show that the psychological needs of women with pregnancy complications are significant. Further examination is needed of what types of psychological interventions and services would be helpful for these women. We also need to determine ways to lower the barriers for access to psychological services. This research project has only started the exploration process of illness perceptions in women with pregnancy complications in New Zealand. The use of the common sense model with this population is practical and the use of illness perception questionnaires is an easy method for a clinician to access women perceptions about her pregnancy complication. It could also be used as a basis for psychological interventions. This could benefit not only women with pregnancy complications but also their unborn child.

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## Appendix A: Flyer for Interviews

### Are you pregnant? Are you having any health problems?



Researcher and Psychology student, Jane Currie would love to talk to you. Jane is investigating the experience of a health problem(s) in pregnancy such as high blood pressure, bad morning sickness, diabetes and other medical issues.

If you could help and are willing to share your pregnancy story then please contact her on 021 373150 or [jchc1@waikato.ac.nz](mailto:jchc1@waikato.ac.nz)

This research has been approved by the University of Waikato's School of Psychology Ethics Committee in January 2012.  
Supervisor: Dr Carrie Barber : Tel: (07) 838 4466 ext 6685  
Head of Ethics Committee : Dr Nicola Starkey Tel: 07 838 4466



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**(021 373150)**

## Appendix B: Participant Information Sheet

Appendix A

**School of Psychology**  
The University of Waikato  
Private Bag 3105  
Hamilton, New Zealand

Telephone 64-7-856 2889  
Facsimile 64-7-858 5132



### Information Sheet:

Thank you for offering to participate in our in depth look at complications in pregnancy. The story of your pregnancy and what helps you and what hinders you over this time has the potential to help others in a similar position in the future.

The purpose of this research is to investigate the illness perceptions of woman who are pregnant with complication(s), i.e. your thoughts about your pregnancy complication(s). We are looking for the strategies that you use to help you reduce your anxiety and stress over your pregnancy. We are trying to find ways which will help others during this stressful time. The interview will take around an hour and will follow the following format. Please note you can choose not to answer any or all of these questions at any time. Please just inform the lead researcher, Jane Currie, if you would like to withdraw from participation. The interview has three parts. The first is a series of interview questions designed to understand your pregnancy, the second is a Edinburgh Postnatal Depression Score and the third is an Illness Perception Questionnaire, which we are testing for use with women who have complications in their pregnancy.

#### A) Interview Questions:

1. When you think about your pregnancy now, what do you think of?
2. What do you think caused your pregnancy complication?
3. Who told you that you had a complication?
4. What advice were you given? From friends? From family? From professionals ?
5. What symptoms did you have being diagnosed with a complication?
6. How much do you feel in control over your pregnancy complication? Please expand.
7. What sorts of things help when you are worried?
8. Do you think the pregnancy complication's treatment has a long-term effect on your health? The baby's health?
9. Any other comments?

The other three questionnaires are attached.

In the study each participant is allocated a pseudonym so your privacy is protected.

This study has been reviewed and approved by the University of Waikato School of Psychology Ethics Committee. If you have any questions or concerns about your rights as a participant in this research study, you can contact the chair of that committee, Nicola Starkey ([nstarkey@waikato.ac.nz](mailto:nstarkey@waikato.ac.nz); 07 838 4466 ext 6472). If you have any questions about the project, please feel free to call the lead researcher, Jane Currie at 021 373 150 or email her at [jchel@waikato.ac.nz](mailto:jchel@waikato.ac.nz) or her supervisor Carrie Barber, at 07 838 4466 ext 6685 or e-mail at [cbarber@waikato.ac.nz](mailto:cbarber@waikato.ac.nz).

***Thank you very much for your participation!***

## Appendix C: Consent Forms

### Consent Form



#### PARTICIPANT'S COPY

Research Project: Understanding the experience of complications in pregnancy.

Name of Researcher: Jane Currie

Name of Supervisor (if applicable): Dr Carrie Barber, at 07 838 4466 ext 6685

I have received an information sheet about this research project or the researcher has explained the study to me. I have had the chance to ask any questions and discuss my participation with other people. Any questions have been answered to my satisfaction.

I agree to participate in this research project and I understand that I may withdraw at any time. If I have any concerns about this project, I may contact the convenor of the Research and Ethics Committee (Dr Nicola Starkey, phone: 838 4466 ext.6472, e-mail [nstarkey@waikato.ac.nz](mailto:nstarkey@waikato.ac.nz))

Participant's  
Name: \_\_\_\_\_ Signature: \_\_\_\_\_ Date: \_\_\_\_\_

### Consent Form



#### RESEARCHER'S COPY

Research Project: Understanding the experience of complications in pregnancy.

Name of Researcher: Jane Currie

Name of Supervisor (if applicable): Dr Carrie Barber

I have received an information sheet about this research project or the researcher has explained the study to me. I have had the chance to ask any questions and discuss my participation with other people. Any questions have been answered to my satisfaction.

I agree to participate in this research project and I understand that I may withdraw at any time. If I have any concerns about this project, I may contact the convenor of the Research and Ethics Committee.

Participant's Name: \_\_\_\_\_ Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Admin\_com/psychology forms/consent form



# Appendix D Background Information Form and Interview Questions

## Section A: Background Information Form

ID Number: \_\_\_\_\_

Age: \_\_\_\_\_

Weeks of gestation: \_\_\_\_\_

Marital Status: \_\_\_\_\_

Number of Pregnancies: \_\_\_\_\_

Number of Children: \_\_\_\_\_

Your Ethnicity(ies): \_\_\_\_\_

Type of complication: \_\_\_\_\_

## Section B: Interview Questions

1. When you think about your pregnancy now, what do you think of?
2. What do you think caused your pregnancy complication?
3. Who told you that you had a complication?
4. What advice were you given? From friends? From family? From Professionals?

5. What symptoms did you have being diagnosed with a complication?
6. How much do you feel in control over your pregnancy complication? Please expand.
7. What sorts of things help when you are worried ?
8. Do you think the pregnancy complication's treatment has a long-term effect on your health? The baby's health?
9. Any other comments?

## Appendix F :Edinburgh Postnatal Depression Scale

ID #:

### EPDS

Please mark the answer for each question that comes closest to how you have felt in the past week, not just how you feel today.

IN THE PAST WEEK,

1. I have been able to laugh and see the funny side of things
  - a. As much as I always could
  - b. Not quite so much now
  - c. Definitely not so much now
  - d. Not at all
2. I have looked forward with enjoyment to things
  - a. As much as I ever did
  - b. Rather less than I used to
  - c. Definitely less than I used to
  - d. Hardly at all
3. I have blamed myself unnecessarily when things go wrong
  - a. Yes, most of the time
  - b. Yes, some of the time
  - c. Not very often
  - d. No, never
4. I have been anxious or worried for no good reason
  - a. No, not at all
  - b. Hardly ever
  - c. Yes, sometimes
  - d. Yes, very often
5. I have felt scared or panicky for no very good reason
  - a. Yes, quite a lot
  - b. Yes, sometimes
  - c. No, not much
  - d. No, not at all

- 6.
- 7.
- 8.
- 9.
10. Things have been getting on top of me
  - a. Yes, most of the time I haven't been able to cope at all
  - b. Yes, sometimes I haven't been coping as well as usual
  - c. No, most of the time I have coped quite well
  - d. No, I have been coping as well as ever
11. I have been so unhappy that I have had difficulty sleeping
  - a. Yes, most of the time
  - b. Yes, sometimes
  - c. Not very often
  - d. No, not at all
12. I have felt sad or miserable
  - a. Yes, most of the time
  - b. Yes, quite often
  - c. Not very often
  - d. No, not at all
13. I have been so unhappy that I have been crying
  - a. Yes, most of the time
  - b. Yes, quite often
  - c. Only occasionally
  - d. No, never
14. The thought of harming myself has occurred to me
  - a. Yes, quite often
  - b. Sometimes
  - c. Hardly ever
  - d. Never

EPDS, from the *British Journal of Psychiatry*  
June, 1987, Vol. 150 by J.L. Cox, J.M. Holden, R. Sagovsky

## Appendix F: Illness Perception Questionnaire (Revised)

### ILLNESS PERCEPTION QUESTIONNAIRE (IPQ-R)

Name.....

Date.....

#### YOUR VIEWS ABOUT YOUR ILLNESS

Listed below are a number of symptoms that you may or may not have experienced since your illness. Please indicate by circling *Yes* or *No*, whether you have experienced any of these symptoms since your illness, and whether you believe that these symptoms are related to your illness.

	I have experienced this symptom since my illness		This symptom is <i>related to</i> my illness		
	Yes	No	Yes	No	
Pain	Yes	No	_____	Yes	No
Sore Throat	Yes	No	_____	Yes	No
Nausea	Yes	No	_____	Yes	No
Breathlessness	Yes	No	_____	Yes	No
Weight Loss	Yes	No	_____	Yes	No
Fatigue	Yes	No	_____	Yes	No
Stiff Joints	Yes	No	_____	Yes	No
Sore Eyes	Yes	No	_____	Yes	No
Wheeziness	Yes	No	_____	Yes	No
Headaches	Yes	No	_____	Yes	No
Upset Stomach	Yes	No	_____	Yes	No
Sleep Difficulties	Yes	No	_____	Yes	No
Dizziness	Yes	No	_____	Yes	No
Loss of Strength	Yes	No	_____	Yes	No

We are interested in your own personal views of how you now see your current illness.

Please indicate how much you agree or disagree with the following statements about your illness by ticking the appropriate box.

VIEWS ABOUT YOUR ILLNESS		STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP1	My illness will last a short time					
IP2	My illness is likely to be permanent rather than temporary					
IP3	My illness will last for a long time					
IP4	This illness will pass quickly					
IP5	I expect to have this illness for the rest of my life					
IP6	My illness is a serious condition					

	<b>VIEWS ABOUT YOUR ILLNESS</b>	<b>STRONGLY DISAGREE</b>	<b>DISAGREE</b>	<b>NEITHER AGREE NOR DISAGREE</b>	<b>AGREE</b>	<b>STRONGLY AGREE</b>
IP7	My illness has major consequences on my life					
IP8	My illness does not have much effect on my life					
IP9	My illness strongly affects the way others see me					
IP10	My illness has serious financial consequences					
IP11	My illness causes difficulties for those who are close to me					
IP12	There is a lot which I can do to control my symptoms					
IP13	What I do can determine whether my illness gets better or worse					
IP14	The course of my illness depends on me					
IP15	Nothing I do will affect my illness					
IP16	I have the power to influence my illness					
IP17	My actions will have no affect on the outcome of my illness					
IP18	My illness will improve in time					
IP19	There is very little that can be done to improve my illness					
IP20	My treatment will be effective in curing my illness					
IP21	The negative effects of my illness can be prevented (avoided) by my treatment					
IP22	My treatment can control my illness					
IP23	There is nothing which can help my condition					
IP24	The symptoms of my condition are puzzling to me					
IP25	My illness is a mystery to me					
IP26	I don't understand my illness					
IP27	My illness doesn't make any sense to me					
IP28	I have a clear picture or understanding of my condition					
IP29	The symptoms of my illness change a great deal from day to day					
IP30	My symptoms come and go in cycles					
IP31	My illness is very unpredictable					
IP32	I go through cycles in which my illness gets better and worse.					
IP33	I get depressed when I think about my illness					
IP34	When I think about my illness I get upset					
IP35	My illness makes me feel angry					
IP36	My illness does not worry me					
IP37	Having this illness makes me feel anxious					
IP38	My illness makes me feel afraid					

### CAUSES OF MY ILLNESS

We are interested in what you consider may have been the cause of your illness. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your illness rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your illness. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

	POSSIBLE CAUSES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
C1	Stress or worry					
C2	Hereditary - it runs in my family					
C3	A Germ or virus					
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care in my past					
C7	Pollution in the environment					
C8	My own behaviour					
C9	My mental attitude e.g. thinking about life negatively					
C10	Family problems or worries caused my illness					
C11	Overwork					
C12	My emotional state e.g. feeling down, lonely, anxious, empty					
C13	Ageing					
C14	Alcohol					
C15	Smoking					
C16	Accident or injury					
C17	My personality					
C18	Altered immunity					

In the table below, please list in rank-order the three most important factors that you now believe caused YOUR illness. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:-

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

## Appendix G: Flyer for online survey

### Pregnant and having health problems?



Jane Currie is a Masters student conducting nationwide research into the experience of health problems in pregnancy such as high blood pressure, extreme nausea, diabetes, multiples, previous pregnancy problems and other medical issues. Any medical condition that would require extra monitoring by health professionals.

Please fill in the **simple confidential online survey** at <http://psychology.waikato.ac.nz/pregnancyproblems.htm> or contact Jane 021 373150 or [jhc1@waikato.ac.nz](mailto:jhc1@waikato.ac.nz) and she will send you the link.


This research has been reviewed and approved by the University of Waikato's School of Psychology Ethics Committee in August 2013. Supervisor: Dr Carrie Barber : Tel: (07) 838 4466 ext 6685  
Head of Ethics Committee : Dr Nicola Starkey Tel: 07 838 4466 ext6685



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## Appendix H : Online Survey:

Qualtrics Survey Software



**Information Sheet**

**Participant Research Information**

Kia Ora/ Greetings

**Project Title**  
Experiences of pregnant women with medical issues

**Information about the research**  
My name is Jane Currie and I am a Masters psychology student at the University of Waikato. I am conducting research into what women experience when they have a medical problem in their pregnancy. My interest stems from my own experience in having medical problems in both my pregnancies and discovering that it is a fairly common experience.

There is little research on the experience of having medical issue in pregnancy on New Zealand women.

YOU are invited to complete an online questionnaire, which takes about 15 minutes, if you are CURRENTLY pregnant and experiencing a medical issue that requires further monitoring or treatment over and above normal pregnancy monitoring and treatment. The questionnaire consists of simple questions about your pregnancy and your medical issue. The information collected will be used in data analysis and will be reported in a thesis. This research is supervised by Dr. Carrie Barber.

**Participants' Rights**  
A medical issue in pregnancy can be stressful and anxiety provoking. You are not obliged to complete the questionnaire and can choose to opt out at any time without penalty. You have the right to not answer particular questions. This study has been reviewed and approved by the University of Waikato School of Psychology Ethics Committee. If you have any questions or concerns about your rights as a participant in this research study, you can contact the chair of that committee, Nicola Starkey ([nstarkey@waikato.ac.nz](mailto:nstarkey@waikato.ac.nz); 07 838 4466 ext 6472).

**Anonymity and Confidentiality**  
Your details will be kept anonymous and confidential. You will not be able to be identified in the data as the filled in questionnaires will not be linked to any identifying details. The filled-in questionnaires will only be seen by me and my supervisor and will remain confidential.

By submitting the completed questionnaire you are consenting to the data being used in the study. If you would like a brief summary report of the research please email me and I will send you a summary of the research findings after the study is finished.

**Contact Details**  
Jane Currie MOB: 021373150/ Email: [jhc1@waikato.ac.nz](mailto:jhc1@waikato.ac.nz)  
Dr Carrie Barber (supervisor) Email: [cbarber@waikato.ac.nz](mailto:cbarber@waikato.ac.nz)

**Background Questions**

What is your age?

Where do you live?

- In an urban area (city or town) in New Zealand
- In a rural area in New Zealand
- Outside New Zealand in

[https://eu.qualtrics.com/ControlPanel/Ajax.php?action=GetSurveyPrintPreview&T=4jcRze\[23/04/2014 7:34:50 p.m.\]](https://eu.qualtrics.com/ControlPanel/Ajax.php?action=GetSurveyPrintPreview&T=4jcRze[23/04/2014 7:34:50 p.m.])



What is your marital status?

- Single
- Married
- De Facto/Living together
- Widowed
- Separated

What is your ethnicity?

- NZ Maori
- NZ European
- Other European
- Pacific Islander
- Chinese
- Indian
- Other

What medical issue has been diagnosed during your pregnancy? please answer for all types of complications

- Gestational Diabetes
- Carpel Tunnel
- High Blood Pressure
- Slow/small growth of foetus/baby
- Placenta Previa/Abruption
- Foetus abnormalities
- Low lying placenta
- Corroded cervix
- Other

How many times have you been pregnant before?

How many children do you have ?

How many weeks pregnant are you ?

Was this a planned pregnancy ?

- Not planned and not desired
- Not planned but once pregnant desired
- Partly...desired but not actively trying
- Yes planned and actively trying to get pregnant

Have you ever had any experiences of

- Miscarriage
- Abortion
- Stillbirth
- None

Have you had medical treatment for infertility?

Yes

No

Is this pregnancy a result of infertility treatment?

Yes

No

Who told you that you had a medical issue in your pregnancy ?

- Doctor
- Midwife
- Other health professional
- Other

What were you told about your medical issue in your pregnancy?

How did you seek out other information on your medical issue in pregnancy?

- Searched the internet
- Asked family and friends
- Sought a second opinion from a medical professional
- Other

How did you feel when told about your medical issue in your pregnancy?

YOUR VIEWS OF YOUR MEDICAL ISSUE IN YOUR PREGNANCY

What symptoms do you associate with your medical issue in your pregnancy?

What treatment (if any) are you receiving /did you receive for your medical condition/ medical issue in pregnancy?

How would you rate your health during this pregnancy, in the last week?

- Healthy, no medical problems
- Mild medical problems that aren't any risk to me and/or the baby
- Moderate medical problems that require some monitoring by a midwife or doctor
- Major medical problems that require intervention or create some risk
- Severe medical problems that are a significant risk to me and /or the baby

For the following questions, please tick the number that best corresponds to your views :

	No effect at all							Severely affects my life		
	1	2	3	4	5	6	7	8	9	10
How much does your medical issue in pregnancy affect your life	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please tick

	A very short time									Forever
	1	2	3	4	5	6	7	8	9	10
How long do you think your medical condition will continue?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please tick

	Absolutely no control						Extreme amount of control			
	1	2	3	4	5	6	7	8	9	10
How much control do you feel you have over your medical issue in pregnancy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please tick

	Not at all							Extremely helpful		
	1	2	3	4	5	6	7	8	9	10
How much do you think treatment can help with your medical issue in pregnancy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please tick

	No symptoms at all							Many severe symptoms		
	1	2	3	4	5	6	7	8	9	10
How much do you experience symptoms from your medical issue in pregnancy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please tick

	Not at all concerned							Extremely concerned		
	1	2	3	4	5	6	7	8	9	10
How concerned are you about your medical issue in pregnancy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please tick

	Don't understand at all							Understand very clearly		
	1	2	3	4	5	6	7	8	9	10
How well do you feel you	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

understand your medical issue in pregnancy?

Please tick

Not at all affected emotionally

Extremely affected emotionally

1 2 3 4 5 6 7 8 9 10

How much does your medical issue in pregnancy affect you emotionally e.g. does it make you angry, scared, upset or depressed ?

In the box below please list in rank order the three most important factors that you now believed caused YOUR medical issue in pregnancy .

Please mark the answer for each of the following question that comes closest to how you have felt IN THE PAST WEEK, not just how you feel today

I have been able to laugh and see the funny side of things

- As much as I always could
- Not quite so much now
- Definitely not so much now
- Not at all

I have looked forward with enjoyment to things

- As much as I ever did
- Rather less than I used to
- Definitely less than I used to
- Hardly at all

I have blamed myself unnecessarily when things go wrong.

- Yes, most of the time

- Yes, some of the time
- Not very often
- No, Never

I have been anxious or worried for no good reason

- No, not at all
- Hardly ever
- Yes, sometimes
- Yes, very often

I have felt scared or panicky for no good very good reason?

- Yes, quite a lot
- Yes, sometimes
- No, not much
- No, not at all

Things have been getting on top of me

- Yes, most of the time I haven't been able to cope at all
- Yes, sometimes I haven't been coping as well as usual
- No, most of the time I have coped quite well
- No, I have been coping as well as ever

I have been so unhappy that I have difficulty sleeping

- Yes, most of the time
- Yes, sometimes
- Not very often
- No, not at all

I have felt sad or miserable

- Yes, most of the time
- Yes, quite often
- Not very often
- No, not at all

I have been so unhappy that I have been crying

- Yes, most of the time
- Yes, quite often
- Not very often
- No, not at all

The thought of harming myself has occurred to me

- Yes, quite often
- Sometimes
- Hardly ever
- Never

A number of statements which people have described themselves are given below. Read each statement and then tick the appropriate answer to indicate how you feel RIGHT NOW this is AT THIS MOMENT. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which best seems to describe your present feelings best.

I feel calm

- |                                  |                       |                       |                       |
|----------------------------------|-----------------------|-----------------------|-----------------------|
| Not at all                       | Somewhat              | Moderately so         | Very much so          |
| <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

I feel secure

- |                                  |                       |                       |                       |
|----------------------------------|-----------------------|-----------------------|-----------------------|
| Not at all                       | Somewhat              | Moderately so         | Very much so          |
| <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

I am tense

- |                                  |                       |                       |                       |
|----------------------------------|-----------------------|-----------------------|-----------------------|
| Not at all                       | Somewhat              | Moderately so         | Very much so          |
| <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

I feel strained

- |                                  |                       |                       |                       |
|----------------------------------|-----------------------|-----------------------|-----------------------|
| Not at all                       | Somewhat              | Moderately so         | Very much so          |
| <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

I feel at ease

- |                                  |                       |                       |                       |
|----------------------------------|-----------------------|-----------------------|-----------------------|
| Not at all                       | Somewhat              | Moderately so         | Very much so          |
| <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

I feel upset

Not at all	Somewhat	Moderately so	Very much so
<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I am presently worrying over possible misfortunes

Not at all	Somewhat	Moderately so	Very much so
<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I feel satisfied

Not at all	Somewhat	Moderately so	Very much so
<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I feel frightened

Not at all	Somewhat	Moderately so	Very much so
<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I feel comfortable

Not at all	Somewhat	Moderately so	Very much so
<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I feel self-confident

Not at all	Somewhat	Moderately so	Very much so
<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I feel nervous

Not at all	Somewhat	Moderately so	Very much so
<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I am jittery

Not at all	Somewhat	Moderately so	Very much so
<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I feel indecisive

Not at all	Somewhat	Moderately so	Very much so
<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I am relaxed

Not at all	Somewhat	Moderately so	Very much so
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	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel content				
Not at all		Somewhat	Moderately so	Very much so
	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am worried				
Not at all		Somewhat	Moderately so	Very much so
	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am confused				
Not at all		Somewhat	Moderately so	Very much so
	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel steady				
Not at all		Somewhat	Moderately so	Very much so
	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel pleasant				
Not at all		Somewhat	Moderately so	Very much so
	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Block 2**

Thank you for completing the questionnaire.

Thinking about your pregnancy and medical issues can raise emotions for some - if you find that answering this questionnaire has been emotionally difficult for you and you would like to talk to someone about your feelings and experiences, there are people to talk to. Your Midwife or health professional can help. There is also a free, confidential telephone counselling service called Lifeline and you can contact them by calling 0800 543 354.

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