

# **An exploration of women's experiences of attending a high risk obstetric clinic**

A thesis submitted to the University of Manchester for the degree of  
Master of Philosophy in the faculty of Medical and Human Sciences

**2011**

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# Abstract

The University of Manchester

Suzanne Thomas

Master of Philosophy (MPhil)

## **An exploration of women's experiences of attending a high risk obstetric clinic**

2011

**Background:** Fetal Growth Restriction (FGR), the failure of a fetus to reach its growth potential, affects 3-5% of pregnancies. FGR is a key cause of stillbirth and has serious short and long term health implications for babies who survive. Currently there is no effective treatment to prevent or reverse established FGR, therefore management is focused on detection, surveillance and timely delivery. The high risk multidisciplinary clinic at the focus of this research provides care for women at risk of placental dysfunction, the leading cause of FGR, and is the first of its kind in the UK. This research sought to explore women's experiences of attending a high risk obstetric clinic, with the aim of informing care. Ethical approval was given by the local research ethics committee.

**Methods:** A qualitative method, using a hermeneutic phenomenological approach was used. A purposive sample of five women with pregnancies at risk of FGR, were included. Data were collected longitudinally, using three semi-structured interviews, from referral to the high risk clinic through to the postnatal period to capture evolving experiences and needs. Thematic analysis was conducted to identify the emerging phenomena.

**Findings:** Three main themes and several subthemes emerged from the data. These included; 'Evolving coping strategies', 'Management of expectations' and 'It doesn't just happen to me'. Synthesis of the main themes and subthemes led to the emergence of the overarching phenomenon which underpins women's experiences of attending this particular high risk clinic. This study found that women utilise multiple internal and external factors to negotiate their pregnancies, drawing upon experiences, relationships and evolving coping strategies.

**Conclusion:** In conclusion, this journey provided an opportunity for women to voice their experiences within the context of a high risk obstetric clinic. This has provided a unique phenomenon which adds to the body of knowledge surrounding high risk pregnancies and has informed the future care of other women in the high risk obstetric clinic.

## **Declaration**

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

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## **Dedication**

This work is dedicated to Alyn, who became my husband during this process.

Thank you.

## **Acknowledgments**

I would like to thank my supervisors; Professor Tina Lavender, Dr Linda McGowan and my advisor and colleague, Dr Tracey Mills. I am indebted to you all for your patience and encouragement which gave me the confidence to continue through challenging times. The benefit of your knowledge and experience has provided me with the confidence and skills to pursue new knowledge with the hope of improving care and outcomes for women and their families.

This research would not have been possible without the co-operation and support of Dr Ed Johnstone and the dedicated clinic team.

I can never thank my parents enough for their unrelenting love, support and encouragement that it is present in everything I do.

Thank you to Richard and Mair Thomas for the hours of proof reading and for your constant love, support and encouragement.

Most of all I would like to thank the women and their families who let me into their lives and homes. They participated without hesitation because they wanted their experiences to benefit other women and families. I hope that I have not let them down.

I would also like to acknowledge and thank Tommys and The Maternal & Fetal Health Research Centre (The University of Manchester) for their part in funding this research and my postgraduate training.

# Glossary of Terms

## **Antenatal**

The period from conception to birth

## **Down syndrome (or Trisomy 21)**

A chromosomal condition caused by the presence of all or part of an extra 21<sup>st</sup> chromosome

## **Fetal Biometry**

The measurement of fetal anatomy used to assess fetal growth

## **Fetal Growth Restriction (FGR)**

The failure of a fetus to reach its genetic growth potential

## **Fundal height**

The height of the fundus (the top) of the uterus, measured in centimeters from the top of the symphysis pubis to the highest point in the midline at the top of the uterus

## **Gestation**

A measurement, in weeks, of fetal / pregnancy age. Gestational age is calculated from the first day of a woman's last menstrual period and is from 0 to 42 weeks in human

## **Haemolysis Elevated Liver Enzymes Low Platelets (HELLP)**

A life-threatening obstetric complication usually considered to be a variant of pre-eclampsia. Both conditions usually occur during the later stages of pregnancy, or sometimes after childbirth

## **Liquor Volume**

The volume of liquor or amniotic fluid surrounding the fetus in utero

## **Placenta**

An organ that connects the developing fetus to the uterine wall to allow nutrient uptake, waste elimination, and gas exchange via the mother's blood supply

## **Pre-eclampsia**

A disease characterised by hypertension and proteinuria after the 20<sup>th</sup> week of pregnancy

## **Small for Gestational Age (SGA)**

Fetal birth weight, length, or head circumference lies below the 10<sup>th</sup> percentile for that gestational age

## **Termination of Pregnancy (TOP)**

An abortion which is induced

## **Umbilical Doppler**

An ultrasound measurement of fetoplacental blood flow used to assess placental function and fetal well-being

## **Uterine Doppler**

An ultrasound measurement of the utero and fetoplacental blood flow

## **Preface**

I, the author, am a research and clinical midwife; I provide care for women at risk of Fetal Growth Restriction (FGR) as a result of placental dysfunction. I have also been involved in several multi-centre trials and observational studies, this is my first experience of leading midwifery research. In 1997 I completed a first degree in a non-healthcare subject and in 2001 I completed midwifery training at Diploma level. I am currently employed by a large tertiary referral maternity hospital in the North West of England.

Please note that during the course of this research I have married and changed my surname. There are some references to my maiden name in the documentation included in this thesis.

# **Chapter 1 Introduction & Background**

## **1.1 Introduction to the thesis**

This thesis provides an in-depth exploration of the experiences of five women who received care through a novel, high risk obstetric clinic, in a large tertiary referral unit in the North West of England, during 2009 - 2010. Longitudinal qualitative inquiry was undertaken to understand the construct of the experience.

The remainder of this chapter provides the background to the study and an explanation of the motivation for conducting the research. The setting in which the research was conducted is described, to provide context to the study. A review of the existing literature relating to women's experiences of high risk pregnancy is provided and the search strategy employed to gather evidence is discussed in detail. The chapter concludes with the affirmation of the research aim, thus setting the scene for the purpose of this exploration.

Chapter two explains the methodological and the theoretical perspectives which underpinned the research. The methodological considerations relating to the sample, study design, data collection methods and data analysis are presented in this chapter. The ethical principles and due considerations are also described in this chapter.

The study findings are presented in chapter three. To contextualise the findings and in keeping with the chosen methodology, a brief introduction is provided for each participant. The findings are illustrated with verbatim quotes. The main themes and subthemes that emerged from the data are presented and synthesised to offer an understanding of the over-arching phenomena.

Chapter four presents the discussion of the thesis. The findings of the study are discussed in relation to the existing literature and clinical application. The use of the chosen methodology is also appraised. This chapter presents an examination of the strengths and limitations of the study and provides recommendations for practice and future research. The personal reflections, of the author, on the research experience are also presented.

Finally, a summary of the thesis and a conclusion of the study bring the thesis to a close.

It should be noted that due to the qualitative nature of this work parts of this thesis are written in the first person, where deemed appropriate. As according to Webb (1991): "It is acceptable to write in the first person when giving a personal opinion or when one has played a crucial role in shaping the data or the ideas presented" (Webb, 1991:747).

## **1.2 Introduction to the study**

### **1.2.1 Societal perceptions of risk**

*"Risk surrounds and envelops us. Without understanding it, we risk everything and without capitalising on it, we gain nothing"*

(Breakwell, 2007: xi)

Breakwell acknowledges that 'risk' is present in every aspect of life and that we should seek to understand it. We may encounter risk or some appraisal of risk during the conduct of daily life, therefore it is acceptable that individuals will have some perception of 'being at risk'. This study explored 'risk' from the perspective of women with increased obstetric risk. In considering women's experiences of risk it is necessary to examine the wider societal perceptions of risk.

Seminal work by Deborah Lupton (1999) has closely examined the societal changes in the perception of 'risk'. She concludes that in twentieth century contemporary Western society, the meaning of risk has more to do with danger than probability and the term 'high risk' refers to high levels of danger (Lupton, 1999). It is important to acknowledge this societal concept of risk, as offered by Lupton (1999) when considering a woman's perception of high risk pregnancy. Multiple factors influence the public perception of risk, including media coverage and understanding and acceptance of a risk (Fischhoff et al., 1978). Perception of risk is also influenced by individual personality traits (Horvath and Zuckerman, 1993; Breakwell et al., 1994) and can be altered by an individual's self assessment of their hold of power in society; white men perceive an associated lower risk with public health hazards than non-white women (Flynn et al., 1994; Graham and Clemente, 1996).

It has been acknowledged that a layperson's concept of risk is different to that of an expert, "the laypersons [conceptualisation of risk] reflects legitimate concerns that are typically omitted from expert risk assessments" (Slovic, 2000: 231). Current research into perception of pregnancy risk supports Slovic's claims and acknowledges that women draw upon a combination of experiences and perceptions when appraising their risk status (Heaman et al., 1992; White et al., 2008; Carolan, 2008). Despite targeted communications it can be difficult to shift the public risk perception of a particular issue (Krewski et al., 2006).

Strategies which seek to minimise the uncertainty and fear associated with a particular risk often have the opposite effect by increasing anxiety about risk through focusing on the risk (Lupton, 1999). It is, therefore, necessary to understand the experience of risk in order to provide effective strategies which do not result in increased anxiety.

This thesis examines risk in relation to obstetric risk, however, the sociological and psychological perceptions of risk were considered throughout this exploration, as the concept of risk cannot be viewed in isolation.

### **1.2.2 Risk in pregnancy**

Women construct an understanding of pregnancy risk before conception and throughout pregnancy and are required to adjust their behaviour accordingly, for example; the reduction of alcohol and the taking of supplements, to minimise risk to their unborn child (Lupton, 1999). Lupton (1999) describes that the behaviour associated with pregnancy is constructed through a 'discourse of risk' and that the media, technology, professional and lay opinions contribute to this discourse by enforcing that pregnant women should take 'extra care'. As a result, the rejection of health promoting behaviour suggests a lack of care and responsibility for herself and her child, therefore placing both at increased risk (Lupton, 1999). Carolan (2008) agrees that societal messages place the emphasis of responsibility for the health of the fetus on the mother.

#### Identifying pregnancy risk

An important aim of antenatal care is to identify a woman's level of risk and to make an appropriate referral to specialist services. The majority of pregnancies are uncomplicated, proceed with minimal intervention and achieve a positive outcome for a mother and her baby, however, approximately 15-20% are considered to be high risk (Behruzi et al., 2009). A pregnancy is defined as high risk if the mother has a significant past medical history, for example; diabetes, or if she develops a condition during pregnancy, such as pre-eclampsia, or if fetal malformations, such as Fetal Growth Restriction (FGR) are detected (Blincoe, 2007). Women with complex psychological and/or social needs are also defined as 'High Risk' (NICE, 2010), where such conditions are present the well-being of mother and baby are potentially at risk. Pregnancy risk can be divided into four categories; existing maternal disease, obstetric complications, fetal conditions and psychosocial risk.



Due to the complexities of particular complications these categories are not mutually exclusive, as a result a woman's risk status can be made up of several factors. For example; pre-existing maternal diabetes can lead to increased fetal compromise in pregnancy and heightened obstetric risk. This thesis primarily explored risk in relation to obstetric risk and fetal complications, however some overlap exists between areas.

Attempting to identify those women at risk of a pregnancy complication was initiated as a means of trying to reduce maternal and neonatal morbidity and mortality (Stahl and Hundley, 2003). Health professionals currently establish risk status by examining a woman's history; using physical assessment such as blood pressure measurements and utilising markers of maternal and fetal well-being. Some current methods of screening for pregnancy complications, such as pre-eclampsia, do not consistently identify those at highest risk, therefore biomedical science seeks to establish more accurate methods of predicting poor outcomes by developing tests which can identify those women at the highest risk. An example of such a test is the development of an early predictive test to identify women at risk of developing pre-eclampsia. The accurate identification of those at risk of a pregnancy complication will enable the appropriate direction of resources and reduce intervention for low risk women. Increased risk of pregnancy complications can be identified at any stage; from pre-conception to the postnatal period, therefore a woman's risk status can change at any given time.

### **1.2.3 High Risk Obstetric Clinics**

High risk obstetric clinics provide one way of managing high risk pregnancies by focusing appropriate resources on women who most need specialised care (Jackson et al., 2006). Such clinics exist in the majority of regional hospitals and provide care for women with a range of pregnancy problems such as diabetes, HIV and blood disorders.

The demand for high risk care continues to rise as more women with co-morbidities are surviving well into their reproductive age, such as women with cardiac anomalies (Strauss et al., 1984; Corbin, 1987). Societal and cultural changes have also increased the demand for high risk obstetric care, for example; the rise in obesity and the delaying of childbirth both increase a woman's risk of complications in pregnancy (Davies and Olson, 2009; Lampinen et al., 2009).

The identification of the women at highest risk will allow the focus of appropriate antenatal services which may improve outcomes and minimise intervention for low risk women.

#### **1.2.4 The Research Setting**

The high risk obstetric clinic which provided the setting for this research aims to identify those women at highest risk of Fetal Growth Restriction (FGR) as a result of placental dysfunction. This particular clinic is the second of its kind in the world; the clinic at the focus of this research is based on the pioneering model established by Dr John Kingdom and Dr Rory Windrim in Toronto, Canada, in 1998. The UK clinic is situated within a large tertiary referral unit and teaching hospital in the North-West of England; the clinic is one of several high risk obstetric clinics within the hospital.

#### **1.2.5 Fetal Growth Restriction**

Fetal growth restriction is defined as a failure of the fetus to reach its growth potential (Bamberg and Kalache, 2004; Tower and Baker, 2006). Fetal growth restriction must be differentiated from the small-for-gestational age (SGA) fetus; SGA refers to the normal but constitutionally small healthy fetus (Alberry and Soothill, 2006; Grivell et al., 2009). The definition of FGR is problematic as it is difficult to determine the genetic growth potential of an individual fetus (Mari and Hanif, 2007). The use of an arbitrary assessment (<10<sup>th</sup> centile for gestational age) of growth restriction results in a proportion (50-70%) of fetuses being

diagnosed as growth restricted when, in truth, they have achieved growth appropriate for their parental size and ethnicity (Alberry and Soothill, 2006). A birthweight centile lower than the 5<sup>th</sup> percentile can be described as pathological fetal growth restriction (Holmes & Baker, 2006). Pathological growth restriction may affect 3%-5% of all births (Kinzler and Kaminsky, 2007). FGR is a significant cause of perinatal mortality and morbidity (Bamberg and Kalache, 2004; Lalor et al., 2008). Despite the absence of an effective treatment for FGR, improved detection and management will result in a reduction of avoidable deaths (Perinatal Institute, 2009). The term Fetal Growth Restriction (FGR) is synonymous with Intra-uterine Growth Restriction (IUGR); however FGR is used throughout this thesis.

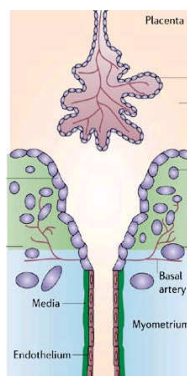
#### **1.2.6 Fetal Growth Restriction and Placentation**

The placenta is the means by which the fetus extracts nutrients from the maternal bloodstream in pregnancy; normal placental function is essential for optimal fetal growth and development. Pregnancy complications including fetal growth restriction, pre-eclampsia and placental abruption which account for a significant proportion of poor pregnancy outcomes, including stillbirth and preterm delivery are associated with abnormal placental development or function (Toal et al., 2007). Abnormal placentation is characterised by the failure of the maternal spiral arteries at the placenta site to adapt to pregnancy, as shown in Figure 1, this results in the anomalous development of the placental blood supply (Kingdom et al., 2000). Aberrant blood supply decreases blood flow to the placenta and thus to the fetus as fetal oxygen demand increases (Mari and Hanif, 2007).

Evidence of abnormal placental development or function indicate increased risk of FGR which can result in stillbirth, premature birth and prolonged neonatal intensive care and increased risks of long term health problems extending into adult life (Barker and Osmond, 1986; Ravelli et al., 1998). FGR is the most common factor identified in stillborn babies (Cox and Marton, 2009).

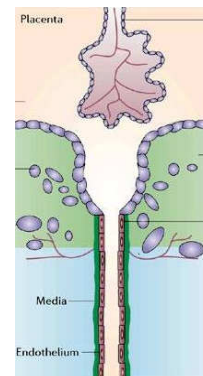
The 2007 Confidential Enquiry into Stillbirths with FGR found that 86% of the deaths were potentially preventable (Perinatal Institute, 2007). A large proportion of these cases would be attributed to abnormal placentation. In addition to being a key cause of stillbirth, FGR has serious consequences for babies who survive. FGR within the range of 501 to 1500g birth weight is correlated with increased risk of neonatal death, necrotizing enterocolitis and respiratory distress syndrome (Bernstein et al., 1999). Fetal growth restriction is associated with cerebral palsy and morbidity extending into adult life (Jarvis et al., 2003; Jacobsson et al., 2008). Therefore, it represents an important clinical problem, and interventions aimed at managing and preventing FGR offer the opportunity to both treat the current disease and prevent adult ill health (Tower and Baker, 2006). Currently there is no effective treatment to prevent or reverse the course of established FGR, therefore the management is focused on, detection, careful surveillance, optimising the timing and conditions of delivery with the aim of minimising neonatal morbidity and preventing stillbirth (Grivell et al., 2009).

**Figure 1: Maternal Spiral Arteries**



Normal placentation

(Dilatation of the maternal spiral arteries)



Abnormal placentation

(Constriction of the maternal spiral arteries)

(Moffett and Loke, 2006)

Current screening methods aimed at identifying the FGR fetus involve examining a woman's medical and obstetric history for relevant risk factors such as underlying medical conditions and previous history of SGA or low birthweight. In addition,

fetal growth is assessed at regular intervals during the antenatal period by clinical measurements of fundal height (Figure 2) and the use of customised growth charts (Appendix 1) (RCOG, 2002; NICE, 2008). Despite a clinical trial (Gardosi and Francis, 1999) showing that these methods significantly improve the detection of FGR, the antenatal identification rate is only 15 to 30% (Perinatal Institute, 2009). Where FGR is suspected, an ultrasound scan is advised to assess fetal growth and well-being; this is achieved by measuring the level of amniotic fluid (Liquor Volume) present and a measurement of umbilical Doppler flow velocity, which provides an assessment of placental function. The results of the ultrasound scan inform the management of care.

**Figure 2: Measuring Fundal Height**



(Perinatal Institute, 2011)

Given that the routine use of customised growth charts and fundal height measurement have a limited ability to predict FGR (Neilson, 2000), the high risk obstetric clinic at the focus of this study aims to identify those women at highest risk of fetal growth restriction as a result of placental dysfunction. This is achieved by an integrated assessment of placental function using ultrasound, known as the placental profile.

### **1.2.7 Identifying those at highest risk of FGR**

#### Maternal Serum Screening Markers

Since the early 1980's a link has been established between abnormal maternal serum screening markers used to screen for Down syndrome and pregnancy complications, particularly placental insufficiency (Pahal and Jauniaux, 1997).

During recent decades Maternal Serum Screening markers (MSS) have been routinely used to screen for neural tube defects, such as spina bifida and trisomy 21 (Down syndrome) (Pahal and Jauniaux, 1997). The markers detected in the maternal serum are produced by the fetus and the placenta; they are present in varying concentrations throughout pregnancy. Initially, screening for Down syndrome took place in the second trimester of pregnancy, this test is referred to as the Quadruple test as four markers are measured; Inhibin A, alpha-fetoprotein (AFP), human chorionic gonadotropin (hCGb) and oestriol (uE3).

In 2008 the UK National Screening Committee (UK NSC) recommended a shift to first trimester combined screening for Down syndrome and neural tube defects to aid early detection and decision making (DOH, 2008). The UK NSC (2008) endorse that screening in the first trimester should combine the maternal serum marker; Pregnancy Associated Plasma Protein A (Papp A) with a physical marker; Nuchal Fold thickness, which is identifiable by ultrasound scan (DOH, 2008). The test has demonstrated a higher detection rate than the Quadruple test and is therefore is regarded as the preferred method of screening; however both tests remain available to women. In 2010 only 41.4% of women in the region opted to take up screening for neural tube defects and Down syndrome (GM FASP, 2011).

Unexplained elevations in either Inhibin A, AFP, hCG or a decrease in Papp A in the MSS test for spina bifida and Down syndrome are associated with placental dysfunction (Toal et al., 2007). As a result, women with abnormal serum screening markers are referred to the dedicated high risk clinic, at the focus of this research, to determine their risk of FGR. The addition of ultrasound assessment of uterine artery Doppler flow and placental morphology has been shown to increase the predictive power of maternal serum screening markers to detect FGR (Dane et al., 2010).

Evidence of SGA and/or abnormal placentation, such as placental abruption, in a previous pregnancy indicates increased risk of developing FGR (Holmes and Baker, 2006). Therefore, women with such a history are referred to the high risk clinic for an assessment of their risk. Where FGR, due to placental insufficiency, is identified in the current pregnancy, women are referred to the high risk clinic for management of their care by the specialist team. The clinic referral criteria are outlined in Appendix 2.

### The Placental Profile

Women are invited to attend their first clinic appointment at 23 weeks of pregnancy, as this is the optimal gestation to conduct the placental profile (Toal et al., 2007). The placental profile combines; MSS markers, if available, second trimester uterine artery Doppler imaging and assessment of placental morphologic condition. The relevance of maternal serum screening markers in the identification of risk of FGR has already been explained. Second trimester uterine artery Doppler imaging assesses the resistance in the uterine arteries, increased resistance from 23 weeks of pregnancy represents abnormal placentation and increased risk of FGR (Albaiges, 2000). Assessment of placental morphology includes the examination of the placental shape, texture and site of umbilical cord insertion; this is also associated with abnormal placentation and an increased risk of FGR (Hafner et al., 2006).

A positive screen at 23 weeks of pregnancy indicates increased risk of fetal growth restriction due to abnormal placentation. An abnormal placental profile identifies the subset of women at highest risk of fetal growth restriction. The sample for this study was taken from the population of women with a positive placental screen. Women with a negative screen at 23 weeks of pregnancy are discharged from the clinic and referred back to their usual care pathway; this group of women were not eligible to take part in this study.

### Management of care

Women with a positive screen are required to attend the clinic on a regular basis (usually weekly or every two weeks) for assessment of fetal growth and well-being by ultrasound imaging. Women attending the clinic are cared for by a team of specialist clinicians; a Consultant Obstetrician and two midwives with expertise in the field of placental dysfunction. The clinic has established links with the neonatology team in order to facilitate holistic care for women and their families.

An estimated fetal weight of less than 500 grams is not compatible with life, where a fetus is unlikely to achieve this benchmark the options of care are discussed with the woman and her family. Unfortunately the options are limited; a termination of pregnancy is offered or continued surveillance, which frequently results in fetal death in utero (FDIU). Once an estimated fetal weight of 500 grams is achieved, the pregnancy is closely monitored to assess the optimised timing of delivery; this is based on an assessment of gestational age, the amniotic fluid surrounding the fetus and fetal well being as represented by Doppler ultrasound assessment. This is combined with identifying the most appropriate timing of corticosteroid administration. Parents' wishes play an essential role in the planning and timing of delivery and the clinic team discuss and review options at every appointment.

#### **1.2.8 Motivation for the study**

The high risk obstetric clinic at the focus of this research is one of many specialist clinics within the hospital setting. The clinic was selected as the setting for this study as I have a particular clinical interest in pregnancy complications associated with abnormal placentation. I am currently the joint midwifery lead for this service.

During my career as a midwife I have cared for many women with pregnancy complications, particularly those with pre-eclampsia and severe FGR. I have frequently observed the difficulties that women and their families face when experiencing a high risk pregnancy. I aim to provide appropriate psychological and



emotional support for this group of women, however, the first step to providing effective care is to understand the experience. I believe that I provide high quality care that addresses women's needs, however as a woman of childbearing age without any children I have questioned what it is like for women to experience a high risk pregnancy. My contact with these women is often only within the confines of a busy obstetric clinic. I began to inquire whether or not I fully understood their experiences. I also questioned whether closer insight into their world would alter the care I provide.

There has not been any qualitative evaluation exploring the experiences of the high risk population at this particular hospital. I therefore believe that it is especially important and relevant to understand these experiences with the aim of developing care. This perspective has informed the design of this research.

## **1.3 A Review of the Literature**

### **1.3.1 Introduction to the literature review**

A review of the literature and the strategy employed to search the literature are presented in this chapter. A synthesis of the findings retrieved from the searches is provided to describe the current literature in the field of high risk pregnancy. A conclusion from the evidence is also provided. The information collated from the literature informed the design of this research.

### **1.3.2 Search Strategy**

A narrative review of the literature was conducted for the purpose of this research. A narrative overview was selected as it is the most relevant method to cover a broad range of literature, selected from many sources in order to provide a comprehensive narrative synthesis of previously published data (Green et al., 2001). The process was guided by the principles of the systematic review process to ensure rigour and quality.

The aim of the search was to:

- Identify literature regarding women's experiences of high risk pregnancy
- Identify literature surrounding women's experiences of pregnancy complicated by placental dysfunction

The fulfilment of this aim allowed synthesis of the literature which led to an understanding of what is already known in relation to women's experiences of high risk pregnancy with particular relevance to placental dysfunction. The literature selected for the search was accessed by searching the following electronic databases; CINAHL Plus, Cochrane, PubMed, Medline, Midirs, Web of Science and PsychInfo. Due to the breadth of disciplines this subject covers, papers were included from midwifery, nursing, psychology, biomedical science and neonatal nursing. Relevant key terms were selected as described in Table 1.

**Table 1: Key terms used to search the literature**

High risk pregnancy, Women's experiences of high risk pregnancy, FGR, SGA, Complicated pregnancy, Placental dysfunction, Abnormal placentation, Specialist antenatal clinics, Perception of risk, Attachment
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In early 2008 a preliminary search of the literature was conducted to identify published work in the arena of women's experiences of high risk pregnancy, as recommended by Lang and Heiss (1998). The results of this search identified publications which examined different aspects of pregnancy risk; obstetric, maternal disease, fetal complications and psychosocial risk in pregnancy. However, to meet the research aim, the publications which focused on socially or psychologically high risk women were not included in the review. The findings of the preliminary search established the terms used for searching the literature, the initial assessment of the literature in this area revealed that most work was published post 1991, with the vast majority published subsequent to 2000. This is possibly due to advances in the ability to identify and manage high risk pregnancy in the past two decades and also the recognition of the importance of the patient experience in healthcare. From September 2008 to September 2010 the electronic databases listed in Table 2 were searched at three monthly intervals.

**Table 2: Sources used for the review conducted 2008-2010**

<b>Source</b>	<b>Date</b>
<b>Databases</b>	CINAHL Plus Cochrane PubMed Medline Midirs Web of Science Psychinfo Embase
<b>References</b>	Article references of key papers 1948 to 2010
<b>Expert contact</b>	Consultation with an expert in the field of placental dysfunction 2010

No restrictions were placed on the stage of research at which the literature was searched, therefore searches and retrievals continued throughout the data

collection and analysis stages of the research. Searches were also conducted through the reference lists of the articles retrieved and personal contact was made with an expert in the field of placental dysfunction. The grey literature and hand searching of key journals was not performed due to the time constraints of the MPhil programme. Similarly, relevant authors in the field were not contacted and only English language papers were included due to the length of time associated with accurate translation. Some literature relating to low risk or complicated pregnancies was consulted to provide a baseline understanding of the differences, if any, between the two classifications of risk.

### **1.3.3 Appraisal of the literature**

Greenhalgh (2010) acknowledges that all publications are not equal and therefore appropriate consideration should be given to the quality of a paper before it is used to inform practice and research design. Therefore, the literature retrieved from the searches was subjected to critical appraisal. There are a number of tools available to aid critical appraisal. The method offered by Greenhalgh (1997) was selected as it provides a simple but effective guide to appraising publications that have been informed by a variety of methodologies (an example of the tool used to appraise qualitative research is provided in Table 3). The criteria offered by Greenhalgh were used as a guide to select publications for inclusion in this review.

### **1.3.4 A review of the Literature**

This section provides a narrative overview of the retrieved literature. The collated information is synthesised into comprehensive sections arranged according to topic areas;

- I. Perception of risk
- II. The effects of risk classification
- III. Responses to models of care
- IV. Maternal-fetal attachment
- V. Managing relationships

**Table 3: How to read a paper: Papers that go beyond numbers (qualitative research).**

(Greenhalgh, 1997)

<p><b>Question 1:</b> <i>Did the paper describe an important clinical problem addressed via a clearly formulated question?</i></p> <p><b>Question 2:</b> <i>Was a qualitative approach appropriate?</i></p> <p><b>Question 3:</b> <i>How were the setting and the subjects selected?</i></p> <p><b>Question 4:</b> <i>What was the researcher's perspective, and has this been taken into account?</i></p> <p><b>Question 5:</b> <i>What methods did the researcher use for collecting data – and are these described in enough details?</i></p> <p><b>Question 6:</b> <i>What methods did the researcher use to analyse the data – and what quality control measures were implemented?</i></p> <p><b>Question 7:</b> <i>Are the results credible, and if so, are they clinically important?</i></p> <p><b>Question 8:</b> <i>What conclusions were drawn, and are they justified by the results?</i></p> <p><b>Question 9:</b> <i>Are the findings of the study transferable to other clinical settings?</i></p>
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**I. Perception of risk**

Biomedical science seeks to establish accurate methods of determining a pregnant woman's risk status. In addition, a number of researchers, for example; Corbin, Gupton and Heaman, have sought to explore women's self perceptions of their risk status. The current literature relating to perception of risk is inclusive of three main themes; disparity of appraisal, calculation of risk and the relationship between risk and behaviour.

Disparity of appraisal

Women appraise their level of risk differently to their medically determined risk, women employ subjectivity, based on self assessment and experience as opposed to the statistical calculations offered by health professionals (Heaman et al., 1992; Carolan, 2008; White et al., 2008). Midwives play an important role in providing a 'middle ground' between these two dichotomies of risk appraisal (Carolan, 2008).

As expected, women with complicated pregnancies perceive their risks as higher than women with uncomplicated pregnancies (Gupton et al., 2000). The inconsistency between a woman's assessment of risk and her level of risk as determined by her doctors is not exclusive to women with complicated pregnancies (White et al., 2008). A Canadian descriptive correlation study (Heaman et al., 1992) found no comparison between women's perception of pregnancy risk and the biomedical risk score determined by doctors. The study sought to compare the childbirth expectations in high risk and low risk pregnant women. Heaman and colleagues (1992) highlighted that the results should be treated with caution as the tool used to measure self-rating of pregnancy risk was unvalidated. Furthermore, the sample only included primigravid women; therefore, the views of multiparous women are not expressed. In addition the sample contained only women who had been hospitalised due to a pregnancy complication. However, women who have been hospitalised due to a pregnancy complication may appraise their risk differently to those who are high risk but are not admitted to hospital.

Women's appraisal of their risk is not always negatively correlated against their medically determined risk; women sometimes perceive their risk at lower level (Jackson et al., 2006). The qualitative methodology employed in the study by Jackson and colleagues (2006) highlights some of the factors contributing to women's perceptions of risk, such as the relationship between physical well-being and assessment of risk. However, all of these studies were conducted at a single time point during pregnancy and call for further longitudinal, qualitative work to enhance understanding of risk perception and the factors that influence it.

#### Calculation of risk

The differences in risk appraisal between a woman and her care provider are well documented (Heaman et al., 1992; Carolan, 2008; White et al., 2008). It is useful to understand the processes that women use to calculate their risk as this can

provide insight into their rationale for acceptance or rejection of a particular plan of care and associated health behaviours.

“Self assessed risk during pregnancy is a highly individualised and multi-dimensional concept” (Gupton et al., 2000: 199). Women use a multi-factorial approach to calculating risk, aspects influencing perception of risk included self-image, history, healthcare and ‘the unknown’ (Heaman et al., 2004). Women consider their personal experiences and use self-awareness to assess their risk as opposed to biomedical risk calculation (Corbin, 1987).

Studies by Heaman et al. (2004) and Corbin (1987) both describe the use of qualitative methodologies, however purist qualitative researchers would dispute whether the descriptive questionnaire based study used by Heaman is in keeping with the qualitative paradigm (Kearney, 2007). Furthermore, Corbin used serial, in-depth, one to one interviews compared to Heaman’s single time point, descriptive questionnaire based study. The differences in the two methodologies could account for the contrast in the depth of findings between the two studies. Both studies concluded that women’s assessment of risk is multi-factorial; however, Corbin’s longitudinal work provides a more in-depth account of women’s experiences which offers insight into the construct of risk appraisal. This is in contrast to the superficial descriptions offered by Heaman and colleagues. The sample in the study by Corbin contained only women with a pregnancy complicated by chronic illness such as pre-existing diabetes or hypertension, whereas, Heaman et al. included women with complicated pregnancies but did not include women with chronic illness in their sample. Despite both groups being defined as high risk, they can report contrasting experiences of pregnancy (Thomas, 2003).

Research conducted into the use of ultrasound as a screening tool for fetal anomalies revealed important insights into women’s calculations of risk and the effects it has on their pregnancies. A particularly high quality study sought to

explore women's reactions to false positive results when undergoing ultrasound screening for a chromosomal abnormality (Baillie, 2000). The study conducted by Baillie (2000) explored the perceptions of statistical calculations of risk following ultrasound screening for fetal abnormality. This British qualitative study used phenomenological enquiry to conduct and analyse semi-structured interviews with 24 women following 'false-positive' ultrasound results. The study recognised that "whilst health professionals and epidemiologists are concerned with population-based statistics, the population relevant to an individual pregnant woman worried about Down syndrome is a population base of one; herself" (Baillie et al., 2000: 388). For example; the study suggests that if the clinician gave the risk of an abnormality at 100:1, the individual pregnant woman would see herself as the one in 'one in 100' and she feels that she cannot go through the rest of her pregnancy not knowing if she is the one and therefore embarks on invasive testing which introduces an increased risk of losing a healthy baby (Baillie et al., 2000).

I have observed an opposing perspective, in my clinical practice, to that described by Baillie (2000); a woman with a 1:5 risk of Down syndrome from a second trimester serum screening test interpreted the result as having a higher chance of not having a baby with a complication, therefore she may not be 'the one'. This led to her decision not to undergo invasive testing and risk losing a healthy baby. Baillie's findings may have benefitted from serial interviews to explore the experiences of women later in their pregnancies. Through the use of interpretative phenomenology, the study by Baillie et al (2000) provides valuable insight into women's experiences of calculating risk and the processes she may experience when her risk status shifts from low to high.

#### The relationship between risk and behaviour

A woman's perception of her risk may be related to the health behaviours she displays in coping with a high risk pregnancy and the degree to which she complies with treatments and programmes (Corbin, 1987; Gupton et al., 2000).



In addition to influencing health behaviours, a woman's perception of her risk and appraisal of threat to her pregnancy has been found to inform a woman's coping strategy. White et al. (2008) identified a relationship between the perception of risk, the coping strategy utilised and maternal-fetal attachment. These findings add strength to the claim that a women's perception of risk is frequently opposed to her biomedical risk.

## **II. The effect of risk classification**

With the advancement of ultrasound there comes a delay in the practitioner's ability to determine the outcome of particular markers which in turn increases the number of women labelled 'at risk' (Filly, 2000). Labelling women to be 'at risk' may negatively affect their psychosocial status (Stahl and Hundley, 2003). However, the German prospective, cross-sectional, case-control study conducted by Stahl and Hundley (2003) is limited due to the use of a classification system of risk that is not reflective of maternity care across the rest of Europe. The system used in Germany results in a considerably high number of women being labelled as 'high risk'. However, subsequent British research, exploring an alternative approach to risk appraisal has also shown that referral to a high risk clinic increases anxiety and distress (Jackson et al., 2006). The qualitative interview study by Jackson and colleagues (2006) of 21 women used semi-structured interviews to explore the views of women referred to a pregnancy hypertension clinic in the UK. Jackson's study provokes important discussion about women's perceptions of risk, seeking reassurance and understanding of the reasons for referral to a high risk clinic. However, findings of this study (Jackson et al., 2006) are limited due to the single interview design of the study as women's experiences may change and evolve at different stages of their pregnancy. To gain an in-depth account of an experience, three or more contacts with the individual are required (Kearney, 2007).

Work by Stahl and Hundley (2003) suggest that "referral to specialist care should not be a 'one-way street'; there should be an option that would allow referral back

into midwifery care when the problem is solved” (Stahl and Hundley, 2003: 306). The study by Jackson and colleagues (2006) builds on Stahl and Hundley’s findings (2003) and highlights the effect of change in status from being referred to a high risk clinic and then subsequently discharged. They suggest that recognising the impact of being discharged from the clinic is important in addressing the needs of women who are advised that they no longer need to attend.

The sudden perceptual shift from a ‘normal’ pregnancy to a ‘high risk’ state of pregnancy can result in the normal pregnancy and the associated behaviours being put ‘on hold’ (Baillie et al., 2000). Furthermore, Baillie and colleagues (2000) reported that two thirds of the women in the study expressed the experience of uncertainty and were regularly predisposed to long lasting distress even after a chromosomal abnormality had been excluded. However they were only interviewed on one occasion; up to four weeks following notification of a normal diagnostic result, therefore their feelings in the third trimester of pregnancy were not explored.

Women who have been hospitalised earlier in their pregnancy due to a complication continue to appraise increased risk to themselves and their baby following discharge from hospital (Gray, 2006). The study by Gray (2006) fails to acknowledge the time interval between discharge from hospital and the woman’s assessment of her risk, therefore it is not clear how long the women continued to feel ‘at risk’ following discharge from hospital. In contrast to the findings presented by Baillie (2000) and Gray (2006) in a study conducted in the Netherlands only 30% of women with an abnormal serum screening result reported continued anxiety later in pregnancy after receiving a normal result from invasive, diagnostic testing (Weinans et al., 2004). However, the study by Weinans and colleagues (2004) used a ‘semi-quantitative’ questionnaire which limits participant response. Whereas, the use of in-depth interviewing allows the interviewer to probe further resulting in a more insightful, in-depth response. Baillie and colleagues (2000)

used this method of data collection in her data driven, interpretive phenomenological approach. Furthermore, the quantitative study by Weinans (2000) used a sample of 40 women which was not adequately powered to reveal statistically significant findings. In addition, data was collected at a single time point between 20 to 32 weeks of gestation. The results do not indicate the gestational ages at which women reported continued anxiety and longitudinal enquiry is required to assess responses in the third trimester.

### **III. Responses to models of care**

Advancements in obstetric screening and technology have brought about a change in the treatment and management of complicated pregnancies. Women's responses to the differing models of care have been examined using various methodologies. It is important to examine the treatments and regimes associated with high risk pregnancy as they form part of a woman's experience.

#### Bedrest: Hospital verses Home

Despite a growing body of evidence for the lack of benefit in improving outcomes, some obstetricians continue to prescribe a prolonged hospital stay or total bedrest at home as treatment for a high risk pregnancy. As a result many authors have studied the psychosocial effects.

Prescribing bedrest increases anxiety and depression (Dunn et al., 2007). However, this American, descriptive, correlational study conducted by Dunn and colleagues (2007) failed to identify whether the pregnancy complication or the bedrest contributes to the increased anxiety and depression reported by the women in this study. Whereas, earlier qualitative work by Gupton et al. (1997) identified that "the stressors and manifestations of stress reported in high-risk pregnancy are exacerbated and altered by the experience of bedrest" (Gupton et al., 1997: 428). The Canadian focused ethnographic study (Gupton et al., 1997) identified

components of the experience, providing valuable insights into the perspective of the high risk pregnant women assigned to bedrest.

The core characteristic of the experience of being hospitalised due to a high risk pregnancy is ambivalence (Leichtentritt et al., 2005). Women feel caught in the lonely mid-ground between the emotions of love for their unborn child and the feelings of resentment towards the pregnancy complication (Leichtentritt et al., 2005). The use of phenomenological enquiry in this study draws out the essence of the experience and provides a vivid insight into the experience of high risk pregnancy and hospitalisation. The sample contained only Jewish women; therefore the findings are grounded in the religious and cultural beliefs of this particular community. However, the findings resonate with the outcome of other qualitative work in the field of high risk pregnancy (Gupton et al., 1997; Dunn et al., 2007; O'Brien et al., 2010).

Receiving bedrest at home, as opposed to in hospital, relieves some of the associated stressors, stress outcomes and manifestations (Heaman and Gupton, 1988). However, the findings of the study by Heaman and Gupton (1988) are in contrast to the results of a study by Hatmaker and Kemp (1998) which examined perception of threat and well-being in low-risk and high risk pregnant women. The high risk women were at risk of pre-term birth and were enrolled in a home uterine activity monitoring program. The women in the program received daily contact with a health care professional and increased monitoring at home, however, women reported feeling a high degree of threat and negative feelings of fear and irritability (Hatmaker and Kemp, 1998). This American study of women at risk of pre-term labour had several limitations; the tools used to measure threat and well-being were not validated for use in pregnancy. Furthermore the effects of the monitoring system were not considered in the findings and the study only included multiparous women, therefore excluding the perceptions of women having their first baby.

A longitudinal quantitative study by Stainton and colleagues (2006) compared two models of high risk antenatal care in Australia; day stay and hospital stay. The study used validated tools at two week intervals from admission to birth and again at three to six weeks postpartum. Both groups reported disruption to their own lives and to family relationships. The findings are consistent with previous research (Leichtentritt et al., 2005) of women hospitalised due to a pregnancy complication. Daily admission to a Pregnancy Day Stay Unit (PDSU) does not eliminate the anxiety and stress associated with a complicated pregnancy; however, women on the PDSU reported lower levels of stress. The longitudinal design of this study exposed the fluctuations in the emotional trends experienced; this is helpful in the creation of programmes to support this group of women. The study identified the importance of recognising and acknowledging anxiety and uncertainty as legitimate responses to the need for special care during pregnancy. Furthermore, debriefing and interest in the outcome from all care providers is critical in helping these women and their families with the extended emotional and physiological recovery required after a complicated pregnancy (Stainton et al., 2006).

Numerous studies exploring the experience of high risk pregnancy include only women who have been hospitalised as a result of a pregnancy complication (McCain and Deatruck, 1994; Leichtentritt et al., 2005). However, not all women who have complicated pregnancies are hospitalised during their pregnancy. It is therefore important that sampling reflects the population under study and is inclusive of hospitalised and non-hospitalised women. Gray (2006) attempted to establish women's perceptions of maternal and fetal risk in relation to their hospitalisation history, she sampled three groups; currently hospitalised, history of hospitalisation and never been hospitalised. Gray's study (2006) shows an interesting correlation between being hospitalised and risk appraisal; women hospitalised due to a pregnancy complication appraised the risk to their unborn child higher than the risk to themselves, whereas, women who had never been hospitalised reported the opposite assessment of risk (Gray, 2006). However, 76% of the sample were

hospitalised at the time of data collection, 10% had a history of hospitalisation during the current pregnancy and 14% had no history of being hospitalised due to a pregnancy complication, therefore the two thirds of the sample contained hospitalised women and the views of the other two groups were under-represented.

#### Continuity of care

The provision of continuity of care for women with risk associated pregnancies, resulted in lower levels of worry and anxiety compared to women with 'normal' pregnancies also receiving continued care by a dedicated team (Homer et al., 2002). Homer and colleagues hypothesise that acknowledging worries and listening to women are strategies that may contribute to reducing a woman's worry during pregnancy. The study by Homer et al. (2002) measured women's responses at two time points; a mean gestational age of 36 weeks and at eight weeks postpartum. The results revealed that women with risk associated pregnancies did not report higher levels of anxiety than women with normal pregnancies at eight weeks postpartum (Homer et al., 2002). However, women with complicated pregnancies were unrepresented in this study, furthermore, the inclusion of qualitative inquiry may have provided greater insight into the experience, as opposed to the limitations of a pre-defined, quantitative questionnaire.

#### **IV. Maternal-fetal attachment**

Maternal-fetal attachment; "the extent to which women engage in behaviours that represent an affiliation and interaction with their unborn child" (Cranley, 1981:282) starts at birth or during pregnancy (Taylor et al., 2005). The technical and medicalised culture of both obstetric and neonatal care may influence women's experiences of high risk pregnancy and subsequent mothering (Black et al., 2009).

A recent meta-analysis of predictors of maternal-fetal attachment (MFA) identified that high risk pregnancy had a trivial effect in relation to MFA (Yarcheski et al., 2009). However, sufficient detail about the studies included in the meta-analysis is

not provided, hence the study falls short of identifying factors that facilitate or impede maternal-fetal attachment. In-depth qualitative inquiry would be an appropriate methodology to explore factors relating to MFA, as it allows the researcher to probe deeper, as opposed to the superficial responses gained by quantitative data collection methods. Qualitative inquiry is particularly relevant when exploring an emotive and complex topic such as maternal-fetal attachment. The research goals should inform the methods of data collection (Kearney, 2007).

#### Becoming a mother in a high risk environment

A frequent outcome of a high risk pregnancy is the admittance of a baby to a Neonatal Intensive Care Unit (NICU). There is a wealth of valuable and informative literature describing the experiences of mothers with hospitalised infants. In particular the literature examines attachment and the influence of technology upon the parenting experience. There appears to be a dearth of research reporting the experience of those mothers who had a complicated pregnancy which did not result in their baby being admitted to NICU.

The mothers of babies who are admitted to NICU immediately following birth are forced to practice motherhood in a setting, which places significant constraints upon how they can interact with their baby (Flacking et al., 2007). A mother often seeks permission to touch her baby and quickly conforms to the customs of the unit, as opposed to having the freedom to develop her own routine. Furthermore, their infant's hospitalisation has major implications for how women see themselves as mothers and how they construct and relate to the notions of the 'good mother' (Lupton & Fenwick, 2001). Mothers cannot initially experience the sensation of being physically close, of cuddling and privately getting to know their infant (Flacking et al., 2007). This experience is not unique to mothers of babies admitted to NICU. Women at risk of pre-eclampsia, who delivered healthy babies, reported feeling uneasy when handling their baby in the hospital and described a "sensation of relief at being able to go home where they would have more privacy

to interact with their baby" (Fleury, Parpinally and Makuch, 2010: 303). However, they felt that they had developed a good relationship with their baby despite the effects of their pregnancy complication. The sample contained only primiparous women who delivered healthy babies which remained with their mothers in the immediate postpartum period. Including the experiences of multiparous women and women whose babies were admitted to NICU may have strengthened the findings in relation to the exploration of the mother-child relationship following a complicated pregnancy.

Mothers acknowledge a lack of depth or significant attachment to the baby after birth which functioned to spare their feelings if the baby died (Black et al., 2009). Mothers of babies admitted to NICU express the notion of 'not feeling like a mother' and recall the first few days of motherhood as highly traumatic and feeling 'distanced' from their baby (Lupton and Fenwick, 2001). For some women this is a stark contrast to their original perception of motherhood. This Australian qualitative study used taped cot-side interactions and one to one interviews with the 31 mothers and 20 neonatal nurses (Lupton and Fenwick, 2001). Whilst the methodology informing the study is unclear, the research gives valuable insight into the experience of constructing and practising motherhood in a NICU. Furthermore, the study is limited in that it does not differentiate between the experiences of women with complicated pregnancies and those with low risk pregnancies.

Neonatal technology has created a culture that includes a language of laboratory values, ventilator settings and feeding volumes that replace conversations typical of parents, relatives and friends after the birth of a full term infant (Black et al., 2009). Seeing their tiny infants connected to wires and surrounded by machines causes distress to the mothers (Lupton and Fenwick, 2001).

The feeling of being denied the norm resonates with many mothers in terms of; a premature end to pregnancy, never pushing their baby in pram or taking their baby



home if the baby dies (Black et al., 2009). Black and colleagues (2009) used life course theory, a sociological framework, to examine becoming a mother of a medically fragile preterm infant. This postnatal longitudinal work analysed the narrative data from 34 women who gave birth prematurely after a high risk pregnancy. Not only does the study show the usefulness of the application of life course theory to health care research but it also illuminates the experience of early motherhood in this group of women through longitudinal enquiry.

Maternal recollection of a mother's initial feelings towards her baby, even after one year, have been found to be very close to those that had been expressed at the time (Robson and Kumar, 1980). This suggests that the powerful emotions experienced in early motherhood are never forgotten.

## **V. Managing Relationships**

A common finding to emerge from the work conducted around high risk pregnancy is the effect the experience has on a woman's partner, her children and the wider family. Women bear the physical endurance of a high risk pregnancy, but the emotional strain affects the whole family (O'Brien et al., 2010). Women with complicated pregnancies often endure a period of hospitalisation either during their pregnancy, in the postpartum period or due to neonatal morbidity. Infants requiring high level intensive care may be transferred to regional units some distance from the family home. Enforced hospitalisation results in separation from a woman's partner, her children and her support network at a time when the support infrastructure is most crucial.

There is the expectation that the partner will assume the additional pressures in the home and family (Richter et al., 2007; O'Brien et al., 2010). Concerns about family life and 'role reversal' create additional stress for the hospitalised high risk women (Gupton et al., 1997). Conversely, the diagnosis of a pregnancy complication has been found to strengthen the relationship between a woman and her partner, as

she felt he was dedicating more time to her (Fleury et al., 2010). However, the women in Fleury's sample were all primiparous, therefore existing children may not have been part of the family dynamic.

Positive social support has been found to be helpful in supporting a woman's adaptation to a state of increased risk during pregnancy (Ford and Hodnett, 1990). Support networks are important in overcoming the difficulties relating to a complicated pregnancy (Fleury et al., 2010; Gupton et al., 1997). However, hospitalisation can cause disruption and add pressure to the usual social interactions from which women find support. Conversely, health care professionals can provide or refer women to alternative sources of support whilst she is hospitalised (Ford and Hodnett, 1990; Gupton et al., 1997). Social support provided in a Day Assessment Unit or ward setting may contribute to less worry and anxiety in a high risk group (Homer et al., 2002).

### **Summary of the literature review**

The body of literature examining the physiology and management of high risk pregnancies far outweighs the studies that have explored women's experiences of high risk pregnancies.

The literature examines how women calculate their risk and suggests that there is a dichotomy between a woman's perception of risk and that of her care provider. Maternal calculation of risk is complex and multifaceted; women draw on previous experiences, expectations and self awareness when appraising their risk. Perception of risk has a causal effect on associated health behaviours, therefore it is important that a woman and her care provider share a mutual understanding of the associated risk in order to gain commitment and compliance to required treatments and care plans.

A large proportion of the research examining the experience of high risk pregnancy has been conducted in Canada and North America; there is little British research contributing to the body of evidence. A woman's experience is likely to be influenced by specific cultural practices or by treatments and regimes which differ from the care provided in the United Kingdom. Therefore, there is a need to examine the experience of high risk pregnancy in this country. This current review included only papers published in the English language. All, except one, of the studies reviewed included women who had a good understanding of the English language, non-English speakers are poorly represented.

Few papers focus on a single specific pathology, the majority of papers reviewed took their sample from a general high risk population. A breadth of complications are examined; hypertension, pre-term labour, diabetes. Women diagnosed with placental dysfunction and severe IUGR are included in several studies however, no studies were identified which focused on women's experiences of a pregnancy complicated by placental disease.

Much of the literature examined in this review which explored the experience of high risk pregnancy included hospitalised women, yet many women who have risk associated pregnancies do not require hospitalisation. This has created a gap in the knowledge around the experience of high risk pregnancy.

This review revealed that much of the literature seeks to measure perception of risk or related stress and anxiety. This work contributes to understanding the experience of high risk pregnancy however, there is little iterative work that actually seeks to explore the experience by producing data driven findings rather than using pre-defined categories.

The thematic narrative review revealed that there is a lack of longitudinal, qualitative research. The literature examined in the review comprised largely of

single time point studies that did not examine women's evolving, needs, experiences and outcomes. Furthermore previous research was principally confined to quantitative methodologies, in addition the studies were frequently limited by sampling criteria; samples mainly comprised of hospitalised women. A lack of British research was also evident from the review undertaken. Longitudinal, qualitative research is required to contribute to the body of knowledge regarding the experience of high risk pregnancy within the UK.

The aim of this research was to address this gap in the literature by using a longitudinal design to explore women's experiences of attending a high risk obstetric clinic.

## Chapter 2 Methodology

*"The research approach will depend on the research question and more importantly, on the researcher's perspective of the human condition"*

(Walters, 1995:794)

### 2.1 Introduction to methodological approach

The rationale for the methodology that underpins this research will be explained in this chapter. The justification of the methodological and ethical considerations that inform the study, including research methods, design and analysis are also provided in this chapter.

Qualitative inquiry was used in this study to explore women's experiences of attending a high risk obstetric clinic. Qualitative research methods are used in a wide range of fields and disciplines but they largely originate from the social sciences. "Qualitative research is concerned with the quality or nature of human experiences and what these phenomena mean to individuals" (Draper, 2004:642). Furthermore, qualitative research is particularly relevant to health care research; it provides insight into care and treatment from those receiving care (Pope and Mays, 2006). In qualitative research, findings are produced from using participants' own themes as opposed to the generation of a hypothesis determined by the researcher's own categories (Kingdon, 2004).

Qualitative research is broadly rooted in philosophical assumptions of interpretive and naturalistic enquiry. "The social world is seen as fundamentally different from the physical world and not reducible to it" (Draper, 2004:643). Whereas quantitative research is grounded in the materialist and positivist tradition, concerned with hypothesis testing, numerical data and deductive analysis. The nature of qualitative research requires that people are studied in their natural

settings. "Qualitative inquiry means going into the field – into the real world of programs, organisations, street corners – and getting close enough to the people and circumstances there to capture what is happening" (Patton, 2002:48). This holds its own practical and methodological considerations which are discussed in the course of this chapter.

The aim of this study was to explore the experiences of women attending a high risk obstetric clinic using a series of semi-structured qualitative interviews based on an interpretive phenomenological framework.

## **2.2 Theoretical perspective**

An interpretivist stance informs the theoretical and methodological approach. Interpretivism offers a contrasting perspective to the positivist approach; it questions the application of the same principles and procedures as the natural sciences apply to the study of the social world. Positivism seeks to generate hypotheses that can be tested and affirms that science must be conducted in a value free manor (Bryman, 2001). Interpretative research is concerned with the meanings people attach to their experiences of the social world and how they make sense of that world, it therefore tries to interpret social phenomena in terms of the meanings people bring to them (Pope and Mays, 2006).

The aims of interpretive research have been reflected by the employment of methods which attempt to capture the participants' views and actions in the context of their everyday lives (Snape and Spencer, 2003). Many authors have contributed to the development of interpretivism and its associations with qualitative research (Weber, 1948; Dilthey, 1989; Kant, 1938). Denzin and Lincoln (2008:31) state that "all research is interpretive; it is guided by the researcher's set of beliefs and feelings about the world and how it should be understood and studied". They go further to suggest that "every researcher speaks from within a distinct interpretive community that configures, in its special way, the multicultural,

gendered components of the research act" (Denzin and Lincoln, 2008:31). With this in mind it is imperative to acknowledge that as a white, married, female, professional midwife I bring my own interpretation to every stage of the research process, from the initial research question to the methods which were selected to explore the question and to interpret the narratives. This includes reference to my ontological and epistemological stance. Babbie (2004:7) suggests that "knowledge is constructed in part through personal inquiry or experience and through second hand knowledge; tradition and authority". Adopting a constructionist stance allowed me to interpret the data from the perspective of the individual. Each woman told her own story in relation to how her world was constructed, the data was collected and analysed according to my perspective of social reality.

I assert that reality is known through human interaction and through socially constructed meanings. "Social phenomena and categories are not only produced through social interaction but they are in a constant state of revision, the phenomena and their meanings are continually being accomplished by social actors" (Bryman, 2001:18). Generalisations cannot be drawn from the data; rather an individual truth is represented via my interpretation which adds to the growing body of evidence in this field. A constructionist's ontological position is that "people's knowledge, views, understandings, interpretations, experiences are meaningful properties of the social reality which the research questions are designed to explore" (Mason, 1996:39). In this respect I adopted a constructionist's lens.

A positivist epistemology seeks to study the world through deductive inquiry. "In the natural science model, phenomena are seen as independent of and unaffected by the behaviour of the researcher, consequently the researcher can be objective in his or her approach and the investigation can be viewed as value free" (Snape and Spencer, 2003:13). Conversely, in the social world the researcher seeks the discovery of reality through personal experience and through acquiring access to

people's 'common-sense thinking' and hence interprets their actions and their social world from their point of view (Bryman, 2001; Babbie, 2004). In this respect the research cannot be value free and the researcher's own interpretation and assumptions are brought to the process. Throughout this thesis I acknowledge my pre-conceptions and assumptions and remain transparent in my approach to this research. This epistemological position directly informed the methodological approach; hermeneutic phenomenology.

*"In order to grasp the meanings of a person's behaviour, the phenomenologist attempts to see things from that person's point of view"*

(Bogdan and Taylor, 1975:13)

There are a range of intellectual influences available to the interpretivist to understand the phenomena being explored, these include; symbolic interactionism, phenomenology, feminism and critical theory. "One of the main intellectual traditions that has been responsible for the anti-positivist position has been phenomenology, a philosophy that is concerned with the question of how individuals make sense of the world around them" (Bryman, 2001:14).

## **2.3 Phenomenology**

Phenomenology is the most appropriate methodology to inform this research as it asks 'What is this or that kind of experience like?' van Manen states that: "It differs from every other science in that it attempts to gain insightful descriptions of the way we experience the world pre-reflectively, without taxonomising, classifying or abstracting it" (van Manen, 1990:9). Phenomenology originated as a philosophy and provides a framework for a method of research (Mapp, 2008). Its origins are in the discipline of psychology, the philosophy was developed into an approach that could be used to study the 'lived experience' of human beings. Phenomenology is a qualitative method of inquiry in which researchers attempt to discover the meaning



of 'the lived experiences' by human beings as they exist in the world (Morse and Field, 1995). Phenomenology is an influential philosophic tradition that has led to various related philosophical movements such as existentialism, poststructuralism, postmodernism, feminism, culture critique, and various forms of analytical and new theory (van Manen, 2002). The phenomenological movement has a complex history and Patton (2002) suggests that its meaning has become "confused and diluted". It has been asserted that healthcare researchers commonly appear to skim over the methodological applications of their research and are unclear about how phenomenology informs their research (Draucker, 1999). To safeguard against this I am explicit about my phenomenological informed decisions throughout. This research focuses on phenomenology as a research methodology; however it is important to acknowledge the origins of phenomenology in order to understand its relevance to research.

### **2.3.1 The origins of phenomenology**

German philosopher Edmond Husserl (1859-1938), originally educated as a mathematician, is regarded as the founder of phenomenology, other philosophers; Heidegger and Gadamer in particular, have shaped the philosophical writings that underpin the phenomenological movement. Early phenomenologists such as Brentano offered important insights into the human condition, but these were not developed as 'methodologies'. Husserl's philosophy emphasised descriptions of the meaning of human experience.

*"Phenomenology, lays bare the 'sources' from which the basic concepts and ideal laws of pure logic 'flow', and back to which they must once be traced, as to give them all the 'clearness and distinctness' needed for an understanding, and for an epistemological critique of pure logic"*

(Husserl, 1970: 66)

For Husserl the aim of phenomenology was a description of how the world is constituted and experienced through consciousness (van Manen, 1990). Concerned with the experiential underpinnings of knowledge, Husserl argues that the relationship between perception and its objects is not passive (Holstein and Gubrium, 2008); in broad terms "it is said to be concerned with an individual's personal perception or account of an object or event as opposed to an attempt to produce an objective statement of the object or event itself" (Smith, 1996:263).

One of the notions essential to Husserlian phenomenology is to 'bracket' preconceptions and beliefs, in doing this Husserl argued that that 'essence' of the human experience could be understood. Husserl applied mathematical technique to the study of the social world. 'Bracketing' is modelled on the mathematical strategy of placing in brackets that part of the equation to be treated differently from the remainder of the equation resulting in a more objective approach (Walters, 1995). This process of phenomenological reduction (bracketing) is used to answer the research question (Koch, 1995). Schutz (1970: 58) states that the first step in Husserl's method is the 'elimination of all preconceived notions'. This particular technique could prove difficult within a healthcare setting. Practitioners are immersed in their field; they cannot erase what they already know or similarly suspend one's prejudices about the world, especially when the practitioner is part of that world. As a midwife involved in the care of the women under study and as the researcher it would be naive and methodologically unsound to attempt to eliminate my pre-conceptions of this world. Furthermore, my ontological perception of what it means to exist in the world rejects Husserl's approach. In addition, the Husserlian model of descriptive phenomenology is not relevant to the research aim as the purpose of this research sought to explore and interpret women's experiences in an attempt make sense of the phenomena. Heidegger, on the other hand, argues that it is only possible to interpret something according to one's own lived experience (Walters, 1995).

Martin Heidegger, Husserl's student, developed another phenomenological approach; his ideas have come to be seen as fundamental to Hermeneutic phenomenology. The founders and developers of the hermeneutic philosophy focused on the problem of interpretation. The term hermeneutics derives from the Greek word *hermeneuein*, meaning to understand or interpret (Patton, 2002). Heidegger's ontological approach replaced Husserl's epistemological focus, as Annells (1996) describes:

*"He moved from the epistemological emphasis of Husserl to an emphasis on the ontological foundations of the understanding that is reached through being-in-the-world, and thus to what is postulated as the pivotal notion of human everyday existence"*

(Annells, 1996:706)

Through the study of ordinary human everyday existence Heidegger's reaches an understanding of 'Being' (Walters, 1995). He recognised that without doubt the interpreter conveys particular background expectations and frames of meaning to abide in the act of understanding, these cannot be ignored, forgotten or 'bracketed' (Koch, 1995). The phenomenology of Martin Heidegger is based on this existential perspective which considers that an understanding of the person cannot be separate from the person's world (Walters, 1995). He goes as far as to suggest that interpretation is dependent on the researcher's background and assumptions, Heidegger calls this 'fore-structures' and in this respect interpretive research is never free of judgement or influence of the researcher (McConnell-Henry et al., 2009).

In his seminal work 'Being and Time' (Heidegger, 1962) Heidegger suggests that the real question "is not what way 'being' can be understood but in what way understanding is 'being'" (Koch, 1995:831). This notion of 'being' is essential to Heidegger's theory of interpretation; *Dasein*, translates from German as 'being

there', but is often referred to by English speaking scholars as 'being-in-the-world'. It is the idea that we cannot detach ourselves from our world, and can only study it from our own perspective which is firmly grounded in our culture, prejudices, societal expectations and pre-suppositions. Heidegger argued that it was not possible to bracket one's 'being-in-the-world' in the process of philosophical enquiry (Walters, 1995).

Consistent with this approach (Heidegger, 1962) I did not 'bracket' my preconceived ideas of high risk pregnancy. I actively reflected on my contribution to the research process and acknowledged my interpretive lens. Husserl condemned Heidegger's existential hermeneutics as he was of the opinion that life-world research was not 'to "lay out" our own experiences but that of others' (Dahlberg and Dahlberg, 2004). Heidegger seeks to interpret the experiences of others but affirms that this cannot be achieved without making explicit our own interpretive lens. Heidegger rejected a step by step epistemological approach; he postulated that understanding is not the result of a correct procedure, rather it is found in the hermeneutic circle (Koch, 1995). Heidegger does not separate the act of interpretation from understanding, he acknowledges that "everyone exists hermeneutically, deriving significance in whatever is experienced or sensed in the world" (McConnell-Henry et al., 2009: 11).

*"But if interpretation must in any case already operate in that which is understood, and if it must draw its nurture from this, how is it to bring any scientific results to maturity without moving in a circle, especially if, moreover, the understandings which is presupposed still operates within our common information about man and the world?"*

(Heidegger, 1962: 152)

Heidegger postulates that understanding exists within a circularity of background, fore-structure, co-constitution and interpretation, none of which can be excluded to

achieve the understanding of 'being' (Koch, 1995). Heidegger describes the elements of the circle in Being and Time:

*"In the circle is hidden a positive possibility of the most primordial kind of knowing, and we genuinely grasp this possibility only when we have understood that our first, last and constant task in interpreting is never to allow our fore-having, fore-sight and fore-conception to be presented to us by fancies and popular conceptions, but rather to make the scientific theme secure by working out the fore-structures in terms of the things themselves"*

(Heidegger, 1962:153)

McConnell-Henry and colleagues (2009:11) state that "by utilizing the hermeneutic circle the researcher attempts to read between the lines and uncover the true essence of the experience". This research acknowledges the connectivity of these elements to achieve understanding of what it is like to exist in the world under study.

Having given due consideration to the various phenomenological perspectives and in line with my ontological stance and epistemological position; Heideggerian, hermeneutic phenomenological informed this research and was applied to the methodological considerations throughout. The following section provides background to phenomenology as a methodology and gives a rationale for the methodological decisions.

### **2.3.2 Phenomenology as a methodology**

In the mid to late twentieth century, a number of authors (Colaizzi, 1978; van Manen, 1990 and Giorgi, 1985) adopted the phenomenological philosophy and developed it into a research method. The authors retained the fundamental philosophical tenets of phenomenology and developed these into methods for the

collection and interpretation of qualitative data. As a result they developed a means by which 'the lived experience' of human beings might be studied in a rigorous way. Colaizzi developed a step by step method by which qualitative data may be collected and interpreted. Hallett (1995) explains how Colaizzi's approach is an over simplification of phenomenology and is more aligned to a Husserlian rationalist perspective, this approach was therefore rejected. Giorgi's phenomenological method also provides a clear cut process; it aims to identify essential themes (Koivisto et al., 2002). However, as with Colaizzi's method its focus is descriptive rather than interpretive. Both methodological approaches were rejected in favour of van Manen's approach. Canadian educationalist Max van Manen has developed Heidegger's work. In his theory of hermeneutic reduction he calls for openness and the requirement to make explicit ones pre-understanding in an attempt to let the phenomena speak for itself.

*"Practically, the hermeneutic reduction consists of reflectively examining and turning over in ones textual labor the various pre-understandings that seem to impinge on the reflective gaze. This does not mean that one must hope to arrive at some kind of pure vantage point, as if such a pure gaze were possible. But it requires that the various dimensions of lived meaning of a particular human experience are investigated for their various sources and layers of meaning, rather than being overlaid with a particular frame of meaning. Phenomenological inquiry continually is open to questioning assumptions and pre-understanding"*  
(van Manen, 2002: phenomenology online)

For van Manen the reflective experiences of language and writing "bring about an intensified awareness of the phenomena that sometimes seem profound and sometimes trivial" (van Manen, 2002: 8). There is no prescriptive path according to van Manen's methodology, he does not disregard 'bracketing' completely but rather suggests an 'openness' and honesty in consulting one's own pre-

understandings to develop a closer understanding of the phenomena. The methodology informing this research is not a stage of inquiry that was merely acknowledged at the start of the research process, it was the basis of every decision. Therefore throughout the remainder of this chapter I make explicit my phenomenological informed decisions in relation to design, sample, data collection methods, ethical considerations, rigour and analysis. In particular I draw on van Manen's methods of reflection which assisted the interpretation of the data and in turn led to the understanding of the phenomena.

## **2.4 Design**

It is essential that the research study design enables the generation of rich data which meets the research aim. A qualitative interpretive approach was adopted, utilising one-to-one, face-to-face, in-depth interviews with a sample of five women. Serial interviews were used; two antenatal interviews following referral to the clinic and one postnatal interview. The interview schedule focused on women's experiences of high risk pregnancy but evolved as the interviews and pregnancy progressed.

### **2.4.1 Longitudinal design**

Previous research in this area has focused on women's experiences at one particular time point; for example, at referral to the clinic or following admission to hospital (Heaman et al., 1992; Homer et al., 2002; Gray, 2006). One such study reports that women may feel differently at different stages in their pregnancy (Jackson et al., 2006). The high risk pregnancy experience is not confined to a particular time point in pregnancy; it can begin prior to referral to specialist care and continue into the postnatal period. Studies which have sought to identify the factors contributing to the experience of high risk pregnancy have been limited by the selection of an inappropriate methodology or the collection of data at a single time point (Heaman et al., 1992; Baillie et al., 2000; Weinans et al., 2004). The

limitations of previous research, the research aim and the phenomenological underpinnings of the research led to the design of a longitudinal study.

“Longitudinal studies – involving more than one episode of data collection, are long established in quantitative research and in ethnographic research traditions, but have become prominent only relatively recently in other forms of qualitative research” (Lewis, 2003; 54). A longitudinal design provides a broad insight into the experience, providing data that will capture developments, consequences and outcomes (Saldana, 2003). Serial interviewing allows stories and experiences to unfold, the intricacy of individual situations is revealed and experiences since the last interview can be shared (Kearney, 2007). The use of repeat interviews enables reflection on earlier findings and the development of an ‘evolving, participant-researcher relationship’ (Murray et al., 2009). This is in line with van Manen’s multi layer philosophy that we require several reflections on the same point to achieve understanding of the phenomena. Therefore a longitudinal design was deemed relevant to explore the experiences of women attending a high risk clinic. Similarly, in-depth interviewing is appropriate to a phenomenological approach and was selected as the method of data collection; a more extensive rationale for the selection of this method is given later in the chapter. Furthermore, in keeping with van Manen’s methodological approach, the hermeneutic phenomenological interview has a collaborative element that allows participants to reflect on their experiences and the researcher’s interpretation of their experience. This was achieved through serial interviewing. Each interview was transcribed contemporaneously enabling the reflection on preliminary themes at subsequent interviews; these were discussed as the participant-researcher relationship evolved.

Several practical and methodological considerations were incorporated into the study design, to aid compliance and therefore encouraging the collection of rich data relevant to the research aim. Such considerations were the frequency, duration and timing of the interviews. Women experiencing a high risk pregnancy



are often required to attend additional appointments during their pregnancy, the increase in anxiety is well reported (Stahl and Hundley, 2003; Jackson et al., 2006) and therefore I did not want the requirements of the research to create an additional burden for participants. High risk pregnancy can increase the incidence of pre-mature birth, this was a consideration when creating the interview schedule, hence, I aimed to conduct just two interviews in the antenatal period, as it may have been unrealistic to attempt more than two since the pregnancy may have ended before all interviews could have been conducted. The first interview took place shortly following referral to high risk care, the majority of women referred to the clinic receive their first consultation by 23 weeks of pregnancy. A second interview was scheduled to take place at least four weeks following the first interview. It was felt that this timing would allow reflection on experiences and identify any developments of issues or feelings. As a care provider I am aware that the child bearing experience does not end as a woman gives birth, therefore a postnatal interview was scheduled for four to six weeks following the birth of the baby. Although women were no longer attending the clinic in the postnatal period I felt it was important to speak to women in the postnatal period to follow them through to the outcome of their pregnancy and to hear their reflections on their experiences of attending a high risk clinic. The optimum interview schedule is outlined in Table 4.

**Table 4: Interview Schedule**

Proposed gestation	
1 <sup>st</sup> Interview	24 weeks (At least one week following referral to the clinic)
2 <sup>nd</sup> Interview	32 weeks (Ideally > 4 weeks after the 1 <sup>st</sup> interview)
Postnatal Interview	4 to 6 weeks following the birth of the baby

Synonymous with the longitudinal approach, only women who attended the clinic for on-going care, that is regular care to the point of delivery, were approached to participate in the study. The women in receipt of on-going care were those who

had been identified as 'high risk' as they had already developed a pregnancy complication or their placental profile suggested that their risk of complications was considerably increased. As explained in chapter 1, the markers for the identification of placental insufficiency are not accurate predictors of Fetal Growth Restriction (FGR) therefore a proportion of women referred to the clinic are discharged back to their original care pathway at their first clinic appointment, following a normal placental profile. This group of women were not invited to participate in the study as they did not receive on-going care by the high risk clinic.

## **2.5 Sample**

"Qualitative inquiry typically focuses in depth on relatively small samples, even single cases (N=1), selected purposefully" (Patton, 2002: 230). A purposive sample was used to include those likely to experience the phenomena. Women attending the high risk clinic at the focus of this research were invited to participate in the study. Purposive sampling is appropriate when using a phenomenological approach as it allows the researcher to select the people who have the experience or knowledge of the topic (Clifford, 1997; Morgan, 2004). LeCompte and Preissle (1993) suggest that the term 'criterion based' is a more appropriate description of the sampling method than 'purposive sampling', as they propose that all sampling is purposive. However, 'purposive sampling' is the description most commonly used in the literature and is the term I use throughout this thesis.

From the population of pregnant women attending the hospital the sample was obtained from those women with experience of attending a high risk clinic. In light of the researcher's interest in women with placental insufficiency the dedicated clinic was selected as the high risk clinic from which to obtain the sample. Eligibility was assessed on the following criteria:

### Inclusion Criteria

To illuminate the research aim those women who had experienced the phenomena of being labelled as having a high risk pregnancy, were included in the research if they met the following criteria:

- Women who had been referred to the high risk clinic at a large tertiary referral unit in the North West of England and are in receipt of continuing care
- Women aged 18 or over

### Exclusion Criteria

- Pregnancies where a fetal structural abnormality had been diagnosed or suspected
- Women under the age of 18
- Women who were unable to provide informed consent
- Women whose babies were going to be adopted
- Women who did not have good use of the English language

### Sample size

Marshall and Rossman (2006) identify that recent qualitative research in healthcare averaged one to four informants, however, while funding and time constraints can affect sample size, the more pressing concern focus on the questions of research purpose. In keeping with a phenomenological approach: the number of participants is usually small but large enough to obtain rich data, and they are not randomly selected (Chamberlain, 2009). Polit and Beck (2004) state that phenomenological research may rely on a sample size of ten or less. Therefore, I expected that a sample of five to eight participants, interviewed at three time points would generate rich data which would address the research aim.

### Access to the sample

The familiarity of the research setting posed considerable advantages in setting up the study and gaining access to the sample. However, the close familiarity with the setting equally presented many practical, ethical and methodological considerations which are discussed throughout this chapter. The greatest consideration being the dual role of the researcher; I am both a specialist midwife and researcher. I have been employed at the Trust for a number of years as a clinical midwife and research project midwife, therefore I already had entry to the site and good knowledge of clinical operations. In addition, this position was advantageous in the practicalities of establishing field relations. Gatekeepers and stakeholders were involved from the original conception of the research idea and were wholly supportive of the research aims. This was particularly relevant to recruitment as the other midwives and doctors working in the clinic were required to ask eligible women if I could approach them to discuss participation in the research.

## **2.6 Data Collections Methods**

Patton (2002:104) describes that "undertaking phenomenological research requires methodologically, carefully and thoroughly capturing and describing how people experience some phenomenon – how they perceive it, describe it, feel about it, judge it, remember it, make sense of it and talk about it with others". He goes further to explain that the only way for us to really know what another person experiences is to experience the phenomena as directly as possible for ourselves, that is through participant observation or in-depth interviewing. van Manen (2002) offers two avenues of method when following a phenomenological line of inquiry; reflective methods and empirical methods, both avenues were present in my research. The purpose of phenomenological reflection is to try and understand the meaning of the phenomena (van Manen, 2002). The main purpose of the empirical methods is to explore examples and varieties of lived experiences; the object of phenomenological research is to 'borrow' other people's experiences (van Manen, 2002). A clear dichotomy does not exist between these two avenues and some

overlap is present. The traditional methods of qualitative data collection are available to the phenomenology researcher; interviewing, participant observation, written text. According to Hallet (1995) it is more usual, when undertaking phenomenological research, to interview research participants and interpret the recorded data using a phenomenological approach. I therefore selected to use in-depth interviewing as the method of data collection, using a phenomenological approach to inform my interview schedule and interpretation of the data.

### **2.6.1 Qualitative Interviewing**

*"Interviewing is one of the most common and most powerful ways we use to try to understand our fellow human beings"*

(Fontana & Frey, 1994: 361).

Historically, interviews have been a principal method of data collection in qualitative research. Whilst other methods are used, face to face interviewing is a common research technique applied by midwives (van Teijlingen and Ireland, 2003). This could be due in part to the numerous advantages of face to face interviewing, listed below (Walsh and Baker, 2004). In addition, face to face interviewing reflects a natural interaction between a woman and her midwife. Britten (1995) highlights the difference in purpose and technique between the clinical and qualitative research interviews. Phenomenology seeks to gain insight into the experience; this can be achieved through the use of interviews which allow the interviewee to create a graphic picture of the experience, leading to understanding of shared meanings (Sorrell and Redmond, 1995). Further advantages of face to face, semi-structured and in-depth interviews are:

- Enables the exploration of complex areas of health care
- Enables a comprehensive and in-depth coverage of research area
- Gives voice to patients priorities and concerns
- Enables 'on the spot' clarification of responses

- Provides flexibility around research areas
- Achieves a high response rate

(Marchant and Kenny, 2000: 56)

- Enables the meanings and interpretations of experience of patients to influence care provision
- Gives expression to an egalitarian and partnership model of doing research between patients and healthcare professionals

(Walsh and Baker, 2004: 68)

The face to face interview has become increasingly popular and it could be argued that this is in-line with the wider acceptance of qualitative research methods in health services research. The decline of other qualitative methods, such as participant observation, due to increased practical constraints, has encouraged the cheaper and quicker use of interview methods (Dingwall, 1997). The perception that one can "send a team of less experienced researchers out with a topic guide and a tape recorder and they will usually come back with usable data if they have been briefed properly" (Pope and Mays, 2009:3) has encouraged the use of face to face interviews. However, this should not be the motivation for the selection of a data collection method, the research question should determine what kind of method is most appropriate for its direction (van Manen, 2002).

Individual face-to-face interviews were used to collect data as they offered the most appropriate means to uncover the essence of the phenomena, this decision was reached through the exploration of other relevant methods of data collection. Focus groups were considered as a method of data collection due to the relevance to the chosen methodology; focus groups are useful in discovering what people think but also uncover why they think as they do (Morgan, 1988). Other authors share the belief that focus groups provide an insight into the attitudes that underlie the behaviour of a specific population, examining not just what they think but how and why they think it (Carey, 1994; Ashbury, 1995). However, focus groups were

discounted in favour of individual interviews due to ethical, practical and methodological considerations. It is crucial for the researcher to consider the probable impact on pre-existing groups of sharing their views on particular topics and on exposing vulnerable individuals to others (Barbour, 2005). Practical considerations include; being able to bring all participants together at a convenient time and location. Due to the small sample size it was unlikely that more than two women would be at a similar gestation at the same time, a focus group is generally understood to be a group of 6-12 participants, (Smithson, 2008). Ritchie and Lewis (2003) suggest that if groups are smaller than four they can lose some of the qualities of being a group. Bringing women of different gestations together to facilitate a larger group size would impact on the longitudinal design of the study aimed at exploring women's changing needs and experiences over time as participants may have looked for a consensus of opinion and this would not always reflect the individual experience at that time point. This would have increased the complexity of analysis. It was considered that focus groups would not produce the most appropriate data to explore the research aim.

The main purpose of the qualitative interview is to explore the meanings and interpretations that individuals assign to their experiences (Walsh and Baker, 2004). Marchant and Kenny (2000) suggest that additional purposes are to:

- Research sensitive topics, for example; Childbirth experience, that are less suited to the more impersonal and prescriptive questionnaires
- Generate theory around complex areas of care, for example; Maternity care where there may be considerable variation in packages of care
- Test existing theory
- Clarify terms and issues as a precursor to a quantitative study.

There are three main types of interview: structured, semi-structured and in-depth (sometimes referred to as unstructured) (Britten, 1995). In keeping with a phenomenological approach, data were collected longitudinally through in-depth

interviews. In phenomenological human science the interview serves the very specific purpose of exploring and gathering experiential narrative material that serves as a resource for developing a richer and deeper understanding of a human phenomenon (van Manen, 2002). "Phenomenology requires in-depth interviewing with those who have direct experience of the phenomena of interest; that is, they have 'lived experience' as opposed to second hand experience" (Patton, 2002; 104). A purist phenomenological approach would involve the collection of data by unstructured, one to one interviews, with a single inquiring question. However, as a novice interviewer, a semi-structured approach was used.

Semi-structured interviews are conducted on the basis of a loose structure consisting of open-ended questions that define the area to be explored, at least initially, and from which the interviewer or interviewee may diverge in order to pursue an idea in more detail (Walsh and Baker, 2004). van Manen (2002) draws attention to the potential for the novice interviewer to collect unmanageable and insufficient data as a result of the choice of method leading the research question. He therefore suggests that before embarking on a busy interview schedule one needs to be oriented to one's question or notion in such a strong manner that one does not get easily carried away with interviews that 'go everywhere and nowhere'. Themes are explored using open-ended questions to achieve a response from the interviewee in their own words (Patton, 1990). The loose structure of the interview allows the interviewer to pursue an idea or a comment made by the interviewee in more detail (Britten, 1995).

### **2.6.2 Conducting Interviews**

The semi-structured interview is differentiated from the free conversation and structured questionnaire by the use of an interview guide; which rather than containing exact questions focuses on certain themes (Kvale, 1983). As familiarity with the topic develops through the course of a qualitative study, the interviewer may introduce further questions or explore certain themes (Britten, 1995). The




skills and manner of the researcher can influence the type of response the participant gives and the amount of discussion they are willing to enter into, it is therefore important to adopt an open and accepting interviewing style which encouraged and allows participants to voice their genuine views, opinions and feelings without constraint (Hallett, 1995). Marshall and Rossman (2006) suggest that the qualitative researcher should possess certain qualities, such as being an 'active, patient and thoughtful listener.' Furthermore, the researcher should not embark on qualitative research if she cannot converse easily with others and have an empathetic understanding of and a profound respect for the perspectives of others. The qualities described by Marshall and Rossman (2006) are innate to my character; however, research interviewing requires additional skills, technique and methodological considerations. As encouraged by van Manen (2002), and in-line with a semi-structured interview approach, an interview guide was created (Appendix 3). A review of the literature informed the design of the interview guide, as did my interpretation of the phenomena at that time, the guide was orientated to the research aim. As a novice qualitative researcher I sought to develop my interview technique. Whyte (1982) devised a six point directiveness scale to help novice researchers analyse their own interviewing technique (Table 5). This is a useful tool as it takes time to develop interview skill and technique.

**Table 5: Whyte's directiveness scale for analysing interviewing technique**

(Whyte, 1982)

1	Making encouraging noises
2	Reflecting on remarks made by the informant
3	Probing on the last remark by the informant
4	Probing an idea preceding the last remark by the informant
5	Probing an idea expressed earlier in the interview
6	Introducing a new topic
(1 = least directive, 6 = most directive)	



It can be tempting for the novice researcher to ask a series of questions which resembles a structured, questionnaire based interview. This approach can result in irrelevant data as it is not consistent with the ontological stance informing this research. It is essential to ask probing questions to elicit detail and depth from the interviewee (Walsh and Baker, 2004). Maykut and Morehouse (1994) classify these probes as illustrated in Table 6.

**Table 6: Classification of Interview Probes**

(Maykut and Morehouse, 1994: 68)

<p><b>Detailed orientated probes:</b> who, what, where, when and how questions</p> <p><b>Elaboration probes:</b> nodding, silence, softly, voicing 'uh-huh' or 'tell me more about....' Or 'can you give me an example'</p> <p><b>Clarification probes:</b> to increase understanding, for example; 'I am not sure I understand what you mean', repeating back the interviewer's perception to check for accuracy.</p>
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Reflection and the ability to critically appraise one's own technique are essential. As a result, the research team met frequently to analyse my interview technique. The methodological implications of this are discussed in chapter 4. It became apparent through these reflections that the skill of listening and allowing space for the participant to think or expand was most pertinent to the success of the interview. "Qualitative interviewing requires listening carefully enough to hear the meanings, interpretations and understandings that give shape to the worlds of the interviewee" (Rubin and Rubin, 1995: 7).

**2.7 Ethical Considerations**

This research underwent rigorous ethical screening through the Local Research Ethics Committee (LREC) and both the University and Trust research and development departments. This is in keeping with the ethical codes of practice that govern research, such as the Declaration of Helsinki and the Nuremberg Code, that

came about due to the unethical conduct of research on prisoners of war in concentration camps during World War II. Ethical practice in qualitative research is a multi-dimensional process involving negotiations with participants; it is not a single isolated stage of research (Goodwin, 2006). Ethical considerations were made at every stage of this research to uphold the principles of ethical research formulated by Beauchamp and Childress (2001) such as non-maleficence and beneficence.

### Beneficence

Beneficence (the obligation to do good to others) informed the motivation for the research, as I wished to aid the development of practice by adding to the growing body of evidence in this field. Recommendations for practice and for research must be made through the production of rigorous research therefore constructive method of rigour was applied. The issues of rigour are discussed later in this chapter.

### Non-maleficence

Non-maleficence prohibits doing harm. It is generally accepted (probably by those who do not fully understand qualitative research) that qualitative research is relatively risk free (Manning, 2004). However, by its in-depth nature, qualitative research can evoke strong emotion through the discussion of sensitive topics. Relationships, termination of pregnancy, loss of a child were some of the few subjects that were discussed during the course of qualitative interviewing for this research, the discussion of such emotive issues can induce distress that can remain after the interview has finished (Lewis, 2003).

It has been shown that qualitative interviewing can be beneficial to the participant rather than harmful (Gysels et al., 2008); in part this could be due to the reflective nature of interviewing and a process which participants may perceive as 'therapeutic'. "Researchers must be prepared to deal with the distress which may be elicited in these settings, and to have arrangements in place to offer expert

support for this eventuality” (Cribb, 2003: 45). Prior to commencing data collection, a ‘distress policy’ was developed through discussion with the supervision team; who are experienced qualitative interviewers and midwives (see Appendix 4).

Participants were informed of the sensitive nature of the interviews through verbal and written communication (Participant Information Leaflet; Appendix 5) at the first contact. At the beginning and end of each interview, participants were reminded that they could terminate the interview or withdraw from the research at anytime. Furthermore they were informed of the availability of professional counselling and directed to a Supervisor of Midwives, if they should need it. During the course of interviewing, information may be disclosed that suggests the participant or a third party (including the unborn child) may be at risk (Murphy et al., 1998). The Participant Information Leaflet (PIL) clearly stated the researcher’s professional accountability and the action that would be taken if the researcher felt that there was an issue of safe guarding.

### **2.7.1 Informed Consent**

Potential participants were provided with a Participant Information Leaflet, as approved by the LREC, and a verbal explanation of the research. The verbal and written information made clear the aims of the research, the background to the study, what was required of the participant and emphasised that taking part was voluntary. Potential risks, such as distress through the discussions of sensitive issues, were identified and alternative contact numbers were provided should the participant wish to speak to someone independent of the research.

Potential participants were given time (at least 24 hours) to consider taking part, to discuss the research with family and peers and to ask questions. Following verbal agreement to participate the participant was asked to sign a consent form. As qualitative research is an evolving process, consent should be checked periodically and not regarded as a ‘one-off’ (Ramcharan and Cutcliffe, 2001; Manning, 2004).

Therefore, consent was checked verbally over the phone when arranging subsequent interviews and again at the beginning of each interview. Particular consideration was given to ensure that participants were fully informed about their involvement and also that they felt free to decline participation. Where the researcher has a dual role; care provider and researcher, potential participants must be aware that they are not obliged to take part in the research and that their care will not be affected by their consent or refusal (Holloway and Wheeler, 1996). This was iterated to potential participants to ensure they gave their consent freely and that they were able to distinguish between their participation in a research study and their clinical care.

Due to the naturalistic approach of qualitative research, the researcher cannot always control the research environment, therefore there is the possibility that the participant's family or peers may be present and may contribute to the interview. Goodwin (2006: 60) suggests that "a single brief and honest introduction, outlining the research questions, the data collection strategy and the overall objectives is sufficient" for those who have a fleeting role. This guidance was adhered to when other individuals encountered the interview environment, they all gave verbal consent to be recorded and for their comments to be used in the research.

### **2.7.2 Confidentiality**

"It is essential that the researcher is clear at the outset as to what confidentiality means in the context of qualitative research" (Goodwin, 2006: 55). If this is not made explicit the researcher runs the risk of misleading the participant as in the most traditional sense to maintain confidentiality is to keep something private. The use of the information provided by the participant was made clear through the PIL and verbal explanation prior to participation in the research. Due consideration was given to the possibilities that may arise as a result of the dual role of the researcher; clinical midwife and researcher. One such possibility was that participants may not wish certain information to reach their clinical care team,

alternatively they may assume that because something was disclosed in an interview with whom they perceive as a care provider that the information would be communicated to the team and acted upon. It was made explicit from the start that I was present in a research capacity and specific information relating to their care needed to be communicated through the appropriate clinical channels.

Data and consent forms were stored separately in a locked filing cabinet in a locked office, in accordance with 'Good Clinical Practice' guidelines. Electronic data was password protected and only identifiable by pseudonym and individual participant identification number.

### **2.7.3 Anonymity**

There is much discussion regarding the extent to which anonymity can be ensured in qualitative research. The nature of qualitative research, in particular hermeneutic phenomenological interpretive research requires getting close to the experience and contextualising interpretation. This can be a situation where the methodological underpinnings conflict with the practicalities of producing ethically sound research. However, steps must be taken to ensure the anonymity of participants and those who participants may refer to in their narrative. The use of pseudonyms, particularly when using verbatim quotes, is necessary to protect the identity of the participant (Manning, 2004). Participants were asked at the start of the interview process to select their own pseudonym, the reason behind this was explained to the participants. Furthermore, attempts are made to anonymise the institute in which the research was conducted. The baseline data provided to add context to the research findings were carefully selected to aid anonymity.

### **2.7.4 Researcher Safety**

The safety and well-being of myself, the researcher, was also examined during the course of the research. A local lone working policy was created with the research team as an extension of the University's policy and I attended lone worker training.

Furthermore, debriefing took place amongst the research team as is important and beneficial in a healthcare research setting.

## **2.8 Ensuring Rigour**

“Without rigour, research is worthless, becomes fiction and loses utility” (Morse et al., 2002:14). It is argued that the failure to acknowledge rigour weakens the acceptance of qualitative research as a methodical process that contributes to the ‘advancement of knowledge’ (Tobin and Begley, 2004). The issue of rigour in qualitative research is hotly debated, discussions include; if it should exist at all, what it should be called and when it should be considered. The source of this debate originates from the contest of qualitative verses quantitative paradigms and the application of scientific methods and processes to qualitative work. The discussion regarding the ‘processes’ of quality in qualitative research is as varied and as intensely fuelled as the discussion regarding epistemological standpoints and choice of methodological approach, probably because both are inextricably linked. It is argued that existing guidelines cannot merely be shaped to fit a broad range of qualitative epistemological and methodological approaches (Howe and Eisenhart, 1990; Meyrick, 2006). Tobin and Begley (2004: 389) suggest that “quantitative research has become the language of research rather than the language of a particular paradigm”. The recommendations of a Health Technology Assessment (Murphy et al., 1998) were rejected as a measure to ensuring rigour as the assessment promotes the same criteria for both quantitative and qualitative research. Because Heideggerian scholars believe that knowledge is never independent of interpretation, research findings are not considered ‘true’ or ‘valid’ (Walters, 1995; Koch, 1996). It is argued that the transference of terms across paradigms is inappropriate (Tobin and Begley, 2004; Morse et al., 2002). The quality of qualitative research should be judged by the degree to which it provides insight into human action not by a set of prescribed formulas (Buchanan, 1992).

Due to the naturalistic essence of phenomenological work, it is appropriate to assume measures of rigour other than the 'scientific' criteria; objectivity, reliability and validity (Hallett, 1995). Guba and Lincoln (1981) offer alternative processes of rigour to ensure 'trustworthiness' in qualitative research; credibility, transferability, dependability and conformability. Morse et al. (2002) highlight that a number of authors followed this trend which resulted in an offering of confusing terms and concepts. Guba and Lincoln (1981) suggest specific methodological strategies for achieving rigour in qualitative research; audit trail, member checking and negative case reporting. Although there is a strong collaborative reflective element to this research, as per a hermeneutic phenomenological approach, member checking or respondent validation, as it is sometimes called, was not used in this research. Member checking involves verifying the interpreted narrative with the participant. Lincoln and Guba (1985) suggest this assesses the credibility of a study. However, there are limitations with this process, for example; the participant may not relate to the account provided by the researcher due to the incompatibility of style of presentation (Pope and Mays, 2006). Furthermore, the account given in the safety of an in-depth interview may not be the account the participant wishes to be reflected in the written word and may therefore wish to amend her narrative. In addition, it is important to acknowledge that the data collected was interpreted in accordance with a particular dialogue that took place through the flow of the interview. When 'taken out of context' of the interview, the data may be interpreted differently. Throughout the course of the interview I re-iterated points to check mutual understanding.

To ensure rigour within this research the application of method was made in-line with my epistemological perspective and methodological approach, this was a constructive process and was considered at each stage of the research. van Manen (1990) opposes the application of the positivist methods of rigor to interpretive research. Therefore a framework for assessing the quality of qualitative research evidence by Spencer et al. (2003) was used. The framework is designed to



appraise completed research; however I referred to the four principles throughout the research process:

- *Contributory* in advancing wider knowledge or understanding about policy, practice or theory;
- *Defensible* by providing a research strategy that can address the questions posed (i.e. the methods of enquiry should be appropriate to the objectives of the study)
- *Rigorous in conduct* through the systematic and transparent collection, analysis and interpretation of data qualitative data; and
- *Credible in claim* through offering well-founded and plausible arguments about the significance of the evidence generated.

(Pope and Mays, 2006: 93)

The concept of transparency is encouraged as it contributes to the 'trustworthiness' of the research; this is achieved by clearly outlining decisions made throughout analysis (Lincoln and Guba, 1985; Clayton and Thorne, 2000). Therefore I make explicit my analytical thought processes (see Appendix 6, 7 & 8) and the use of verbatim quotes and field notes illustrate my findings.

Pope and Mays (2006: 99) draw a reasonable comparison across all the research paradigms by suggesting that the "basic strategy to ensure rigour, and thus quality, in qualitative research, is systematic, self-conscious research design, data collection, interpretation and communication". However, for now it appears that "there are no definite conclusions, only a discussion to be sustained" (Buchanan, 1992; 133)

## **2.9 Analysis**

The social phenomenon is explained through the development of categories that emerge through qualitative analysis (Pope et al., 2006). "Analysis of qualitative data is iterative, it is not something that you do to your data, analysis is a cyclical,

reflective process that you do with your data" (Carter, 2004: 88). Neither is it an end stage of the research process, it involves a number of analytical actions. The analytic processes which influence the data include; the theoretical lens from which the researcher approaches the phenomenon, the choice of data collection methods and the perception of the researcher about what might count as relevant data (Thorne, 2000). Phenomenology seeks to understand 'what is this kind of experience like?' therefore throughout the analysis I asked 'what does it mean to be a woman with a high risk pregnancy attending the clinic?'

### **2.9.1 Analytical approach**

There is not one specific approach to the analysis of qualitative data (Saldana, 2003). The approach to analysis is influenced by basic epistemological assumptions and should relate to the aims of the research (Spencer et al., 2003). There are three broad approaches for taking the analysis forward: thematic analysis; grounded theory and the framework approach (Pope et al., 2006).

Thematic analysis was selected as the approach to analysis the data collected. Thematic analysis is often considered the simplistic analytical approach; however providing the selected framework is appropriate to the methodology it can be more satisfactory to apply a simple approach than achieve inadequate results with a more complex approach (Carter, 2004). It is not a quick method of analysis and requires equal intensity and reflection on participant's meanings (Saldana, 2009).

Thematic analysis is appropriate to a phenomenological methodology as it allows categories to emerge from the data, whereas content analysis begins with pre-defined categories (Ezzy, 2002). Heidegger's hermeneutic circle was applied to the analysis of the data, the participants' narratives were re-examined several times "searching beneath the words and at what is not immediately obvious" (McConnell-Henry et al., 2009: 11). The research process including data analysis was influenced by my perspective of high risk care; as a clinical care professional

involved in the care of high risk women, I seek to improve care and the experiences of women. "A good phenomenological researcher will recognise the influence of her own subjectivity on the work, the data collected will be an acknowledged reflection of the participant's experience, filtered through the perceptions of the researcher" (Hallett, 1995: 55). Therefore the data were analysed through this interpretive lens. In keeping with a hermeneutic phenomenological approach I acknowledged and challenged my pre-understandings and assumptions through the analysis of the data. I achieved this by recognising my interpretive perspective and through regular discussion with the research team.

### **2.9.2 Preparation of the data**

Digital recordings were transcribed verbatim; this was a lengthy process, usually taking several hours to transcribe one interview. Some qualitative researchers outsource transcriptions to commercial or secretarial services; I chose to transcribe the data myself due to methodological and practical considerations. Outsourcing transcriptions is costly and a lengthy process as each transcript must be carefully checked against the original recording. Self transcribing may be time consuming but it brings familiarity with the data and allows preliminary analysis. "At its most basic, transcription preserves data making it more permanent, retrievable, examinable and flexible" (Lapadat, 2000: 204). Each interview was transcribed as close to the interview as possible, this allowed the development of themes which were explored in subsequent interviews. Conversation analysis was not conducted, but the repeated listening of the data allowed me to note particular non-verbal communications which gave added depth to the narrative. Data were analysed manually without the use of a qualitative analysis software package. Microsoft Word and Excel were used to aid the organisation of the data (as illustrated in Appendix 7 & 8).

### 2.9.3 Coding

Following the initial process of becoming acquainted with the data I sought to code the data. "A code in qualitative inquiry is most often a word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data" (Saldana, 2009:3).

An example of coding from the data:

[ Marie 1 <sup>st</sup> Interview ]	"Well, I just think it's easier to think that she's not coming what it is to believe that she is coming" Code assigned: Denial
----------------------------------------	-----------------------------------------------------------------------------------------------------------------------------------

I interpreted this text as *denial*.

At times 'in vivo' codes were used to analyse the data:

[ Vicky 1 <sup>st</sup> Interview ]	"I think it's my way of coping so no-one asks questions, I don't talk to anyone about it" Code assigned: Coping
----------------------------------------	--------------------------------------------------------------------------------------------------------------------

Here the participant directly acknowledged that she is used a coping strategy and this section of text was therefore coded as *coping*.

This process was repeated several times through all the interviews resulting in the identification of individual codes. Codes were grouped together in related families to identify subthemes and main themes. The process of analysis was verified by the supervisory team.

### 2.9.4 Themes

"A theme is an implicit topic that organises a group of repeating ideas" (Auerbach and Silverstein, 2003: 38). Saldana (2009: 139) describes this as the formation of sub-themes which "leads to the development of higher-level theoretical constructs when similar themes are clustered together". van Manen notes that "Themes are interpretive, insightful discoveries – written attempts to get at the 'notions' of data to make sense of them and give them shape" (van Manen, 1990: 87). Using the

above example from *Marie's* narrative the code *denial* joined other relevant codes to form the subtheme of *protection*, which in turn contributed to the formation of a main theme; *coping strategy*. Likewise the example from *Vicky's* narrative of in-vivo coding contributed to the development of a main theme; my interpretation of her simple statement revealed much about Vicky's experience; she requires a way of coping with her pregnancy; a coping strategy, the strategy involves withdrawing from conversations about her pregnancy, either because talking about her pregnancy causes her distress or she does not feel equipped to answer questions or she just does not want people knowing her business. I interpreted this as a demonstration of self protection which contributes to a coping strategy.

Once individual codes had been assigned, the transcripts were closely examined in terms of chronological ordering to identify the emergence of themes longitudinally as well as cross-sectionally. Saldana (2003) suggests that by repeating this process one re-examines earlier work in light of the revelations of later work, this brings about a deeper understanding of the phenomena. The relationship between subthemes was examined to develop main themes; this offers a stronger analysis than just providing a description (Pope et al., 2006) and is in keeping with an interpretive phenomenological approach. The main themes were synthesised to offer an interpretive "over-arching theme" that explains the phenomena (Saldana, 2009).

## **Chapter 3 Findings**

### **3.1 Introduction**

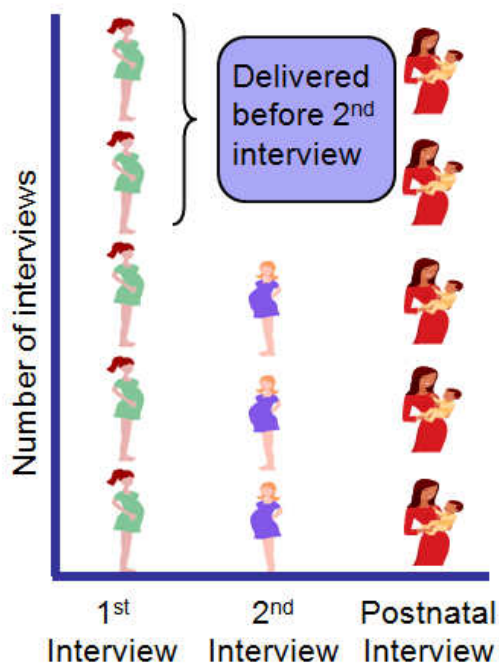
The findings of the study are presented in this chapter. Recruitment to this current study was conducted over a six month period (August 2009 to February 2010). A sample size of five women was obtained, in keeping with a phenomenological approach: the number of participants is usually small but large enough to obtain rich data and can rely on a sample size of less than ten (Chamberlain, 2009; Polit and Beck, 2004).

The interviews were arranged at a time and location convenient to the participant and were digitally recorded. Participants were offered a choice of location, either in their own home or in the research unit at the hospital. All of the women, apart from one, opted for an interview in their own home. One participant, wished to combine the second antenatal interview with a visit to the physiotherapist; therefore she was interviewed at the research unit at the hospital. It is important that the participant feels relaxed and comfortable to discuss their experiences. The location of the interview should encourage this and the participants own home should be considered if appropriate (Walsh and Baker, 2004). Partners were not encouraged to attend interviews, as their presence may have influenced the woman's narrative, however they were not excluded if women wanted them to be present. The majority of women were interviewed alone, although at times the woman's partner and children were in another room. One woman invited her mother to be with her at every interview; her partner was also in the house and contributed to the discussion at times. During one postnatal interview the participant's family arrived seven minutes into the interview, with the permission of all present I continued the interview.

It was anticipated that the interviews would last approximately one hour; interview length ranged from 19 minutes to 1 hour 21 minutes, the mean length was 47

minutes. Thirteen interviews were conducted in total; five first interviews, three second interviews and five postnatal interviews (see Figure 3). Two women did not receive a second interview as they gave birth before an interview could be conducted. Four interviews were conducted later than anticipated due to bad weather and participants' commitments.

**Figure 3: Data collection**



To add context to the findings I have provided brief individual introductions to the women who participated in this research. Specific baseline details are highlighted as this allows the reader to relate the personal details to the individual experience which is in keeping with a phenomenological approach. Heidegger asserts that the person's background is essential to understanding; he refers to this in his description of 'historicality' that our past becomes part of our 'being' (Heidegger, 1962). I have chosen to describe specific details that provide relevance to the data and to the women's experiences. Details of socio-economic factors such as age and employment status are described to illustrate the broad demographic profile of the sample. Participants' obstetric histories are summarised as this contextualises women's stories and the women frequently referred to their previous pregnancies in

the interviews. Following the description of the participants involved in the research, the main themes and subthemes are described, culminating with the synthesis of the themes which explains the overarching phenomena.

### **3.2 Descriptions of the participants**

Participants selected their own pseudonym at the first interview, to ensure anonymity.

#### **“Emer” Participant 001**

Emer was 29 years of age and a mother of a three year old child, she appeared to have a supportive husband and family, her first pregnancy was uncomplicated. Emer was employed as a hairdresser; this was a planned pregnancy following a miscarriage the previous year.

Emer was referred to the high risk clinic due to raised serum screening markers from Down syndrome screening conducted in the second trimester. She was 24 weeks pregnant at her first appointment

Emer’s initial assessment following referral revealed a normally grown baby and borderline placental profile; as a result Emer remained under the care of the clinic. A subsequent scan at 32 weeks of pregnancy revealed a fetal abdominal circumference of greater than the 90<sup>th</sup> percentile (an unexpected finding, opposite to the initial referral to the clinic) this prompted further investigations, all of which were negative. Emer’s final scan at 35 weeks of pregnancy revealed a normally grown baby.

Emer laboured spontaneously and gave birth to a healthy baby girl at term weighing 4 kilograms. Apart from a significant secondary post partum haemorrhage, mother and baby were both well and were discharged home soon after birth.



**“Olivia”      Participant 002**

Olivia was 26 years of age; in her second pregnancy following a termination of pregnancy a number of years ago. Olivia was employed as cabin crew for a large airline and she appeared to have a supportive husband and family.

Olivia was referred to the clinic due to raised serum screening markers from Down syndrome screening in the second trimester. Olivia was 23 weeks pregnant at the time of her first appointment, the initial assessment revealed a degree of growth restriction and an abnormal placental profile. Olivia was seen fortnightly until 33 weeks of pregnancy when she developed Haemolysis, Elevated Liver Enzymes and Low Platelets (HELLP) syndrome a serious pregnancy disease that threatens the well being of mother and baby.

In light of the complications she developed, Olivia had an emergency caesarean section at 34 weeks of pregnancy. Olivia gave birth to a baby girl who was born in a good condition weighing 1.6 kilograms, the baby was immediately transferred to NICU and remained an inpatient for three weeks until discharge home. Mother and baby were both doing well at home at the time of the final interview.

**“Sarah”      Participant 003**

Sarah, aged 37, was employed by a large recruitment company; she had a five year old son and appears to have a supportive husband and family. Sarah’s previous pregnancy was high risk due to the onset of pre-eclampsia. Sarah was referred to the specialist clinic following abnormal serum screening markers from private Down syndrome screening conducted in the first trimester.

Sarah attended her first clinic appointment at 17 weeks of pregnancy, the assessment revealed a normally grown baby but an abnormal placental profile, which indicated that Sarah could develop pre-eclampsia in this pregnancy. Sarah

was seen at three weekly intervals in the clinic and in-between her blood pressure was monitored by her community midwife and through self monitoring at home. At 35 weeks of pregnancy Sarah presented with a normally grown baby and a normal placental profile. As a result, from 35 weeks of pregnancy, Sarah attended the clinic for midwifery care only until she gave birth by planned caesarean section (Sarah's request) at 39 weeks of pregnancy. The baby weighed 2.7 kilograms at birth and apart from a few episodes of hypertension in the last two weeks of pregnancy neither Sarah nor the baby suffered any complications.

**"Vicky" Participant 004**

Vicky was 25 years of age; she is a mother of two small boys from a previous relationship, the pregnancies were uncomplicated. Vicky appeared to be in a stable relationship with a supportive family, she worked part-time as a school dinner lady. Vicky was referred to the specialist clinic by her local hospital due to oligohydramnios at 20 weeks of pregnancy. Vicky underwent invasive diagnostic testing (Amniocentesis) at the hospital's Fetal Medicine Unit (FMU) to identify a cause. The Amniocentesis provided a negative result, however it was explained to Vicky that the absence of amniotic fluid in early pregnancy could result in lung disease, which would only be confirmed by baby's condition at birth.

Vicky's first clinic appointment at 28 weeks of pregnancy revealed normal levels of amniotic fluid around baby, a normal placenta profile but a growth restricted baby. From 28 weeks of pregnancy until the birth of her baby at 35 weeks gestation Vicky attended the clinic weekly. At 32 weeks of pregnancy Vicky ceased to feel any fetal movements, as a result she was required to attend the hospital for monitoring at least twice a week. Vicky and her family did not have their own transport and relied on public transport to make the frequent visits to the hospital.

A scan at 35 weeks gestation revealed that the amniotic fluid surrounding baby had reduced, therefore it was decided that Vicky's labour should be induced. Two days

later Vicky gave birth to a healthy baby boy weighing 1.7 kilograms. The baby was born in good condition and did not require ventilator support at birth, he was later transferred to NICU due to complications of prematurity. Both mother and baby were doing well at home at the time of the final interview.

**“Marie” Participant 005**

Marie was 25 years of age; in her third pregnancy. She has a healthy six year old child from a previous relationship; she has had two pregnancy losses. Marie lives with her child, her partner and his child from a previous relationship. Marie and her partner were unemployed at the time of the interview; they appeared to have a supportive family network.

Marie was referred to the specialist clinic by her local hospital, as the baby was found to be severely growth restricted on the routine 20 week anatomy scan. The referring hospital was 31 miles away from the tertiary referral unit to which Marie was referred. Marie’s first clinic appointment was at 24 weeks gestation, the scan confirmed severe FGR with an estimated fetal weight of just over 300 grams. It was explained to her that she had suffered a large bleed in early pregnancy, which was a result of placental failure. The limited options of care were discussed including termination of pregnancy. Marie and her partner wished to continue with the pregnancy. Marie was seen two weeks later, again there had been little growth and the couple were informed that the “prognosis was bleak”. Marie continued to attend the clinic every two weeks until a scan at 32 weeks gestation revealed that baby required imminent delivery to achieve a live birth. Marie’s baby was born by emergency caesarean section a few hours later. The baby girl weighed just 536 grams at birth and was immediately transferred to NICU for intensive care. As the baby improved she was transferred to a large city centre NICU closer to her parents home, she was eventually transferred to the SCBU at the local hospital in preparation for discharge home. At the time of the postnatal interview the baby remained in hospital.

### **3.3 Main themes and subthemes**

Longitudinal data were collected to explore the high risk experience throughout the childbirth experience, the data were analysed cross-sectionally and longitudinally to identify emerging themes. The main themes and subthemes are described in this chapter and where relevant I have acknowledged the changes and differences in the experience over time. The themes are not mutually exclusive and some overlap exists between themes. In keeping with a Heideggerian phenomenological approach I have provided my interpretation of the experience throughout. Verbatim quotes are used throughout to illustrate the findings and excerpts from my field notes are provided to add context. Walters (1995) suggests that the provision of ample information about the research process allows the reader to make their own interpretations; this is achieved through the use of excerpts from the participants' narratives to illustrate interpretations. Finally, the main themes are drawn together to explain the overarching phenomenon of the experience.

Three main themes and several subthemes emerged from the data as displayed in Figure 4. These were;

#### **1. 'Evolving coping strategies'**

Protection

Seeking reassurance

Managing uncertainty

#### **2. 'Management of expectations'**

Expectations

The unexpected

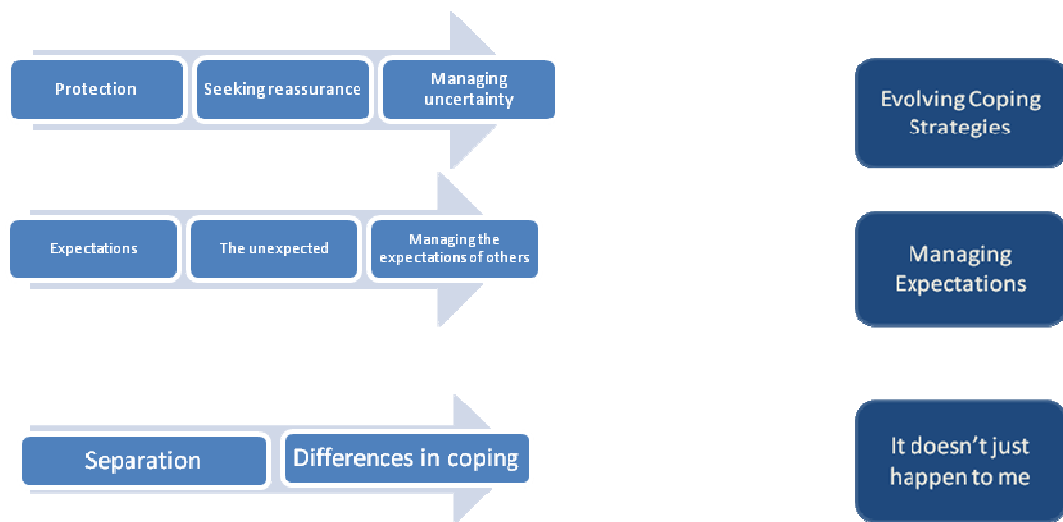
Managing the expectations of others

#### **3. 'It doesn't just happen to me'**

Separation

Differences in coping

**Figure 4: Main Themes and Subthemes**



### **3.3.1 Theme 1 – Evolving coping strategies**

The women in this study used coping strategies to survive their pregnancies, the longitudinal analysis of the data revealed that the coping strategies employed by the women evolved through the antenatal period into the postnatal period. Each category is discussed in turn and direct quotes from the data are provided to illustrate the findings.

#### **Protection**

Most pregnant women exhibit some form of coping strategy to alleviate fear during pregnancy (Melender, 2010). The demonstration of protective behaviour can be classified as a typical coping mechanism to manage stress or uncertainty (Kaira et al., 2010). Anecdotal evidence suggests that women frequently refrain from sharing news of their pregnancy to wider circles of family and friends until after the first trimester. Likewise, they may delay buying clothes for their baby until after the first scan, 'just in case something goes wrong'. However, the findings of this study suggest that demonstrations of self protection are exhibited for an extended period in a high risk pregnancy. The first interviews took place between 24 and 33 weeks of pregnancy. It became clear that the women would not allow themselves to get excited or buy items for the baby at a time when most women are enjoying

their pregnancy. It appeared that the women used protection as a coping strategy to deal with the uncertainty surrounding their pregnancy. This was explained by Vicky at 33 weeks gestation:

*"I've not planned anything or got anything ready because I don't know what the outcome's going to be. Whereas with my others I had my Moses basket up in the living room and everything, I was dead excited, but this one, I can't get excited because I don't know what's going to happen at the end"*

(Vicky, 1<sup>st</sup> interview, 33 weeks).

The women talked about their reluctance to get excited or acknowledge their pregnancy at a time when most pregnant women are able to accept and enjoy their pregnancy:

*"I've just been acting like I'm not pregnant to get used to when I'm not going to be pregnant because you're not going to have the baby to fuss around are you?"*

(Marie, 1<sup>st</sup> Interview, 27 weeks)

This reluctance to get excited came from a very real threat of losing a baby; both Marie and Vicky were offered a termination of pregnancy due to the severity of the complications relating to their pregnancy. As a result, the women explicitly tried to avoid others as a means of self protection. Three of the women in this study described how they felt unequipped to deal with conversations relating to their pregnancy. They could not contribute to 'normal' baby talk and a result would stay inside or avoid talking about the pregnancy. Marie describes how she actively avoided others:

*"I just feel like I don't even want to get out of bed some days...you have to see people if you get out of bed and then if people come I go upstairs and just sit upstairs"*

(Marie, 1<sup>st</sup> Interview, 27 weeks)

The women explained how avoiding others and avoiding discussing the pregnancy became a coping strategy:

*"I think it's my way of coping so no-one asks questions, I don't talk to anyone about it"*

(Vicky, 1<sup>st</sup> Interview, 33 weeks)

Olivia explained the difficulty in trying to explain her pregnancy to others; she felt that those who had not been through a similar experience could not understand. Alternatively, Emer describes how she used talking openly to others as a coping strategy. She found that sharing her experience and hearing the perspectives of others helped her to cope with her concerns. However, considering the various risk factors, Emer was identified as the most low risk of all the participants furthermore she expressed this view at 37 weeks of her pregnancy, when at 35 weeks gestation she had been reassured that her baby was growing normally.

It appears that the women's coping strategies evolved at different levels, this could be due to their exposure to previous difficult life events. For example, at Olivia's first interview (25 weeks of pregnancy), I felt that she had not developed a coping strategy. She was struggling to come to terms with her referral to a high risk clinic and the change in status from low risk to high risk:

*"I thought that everything was fine during the pregnancy, cos, I'd been for private scans as well and everyone told me I was fine"*

(Olivia, 1<sup>st</sup> Interview, 25 weeks)

Olivia cried throughout the first interview and I sensed that she felt completely overwhelmed and at a loss of how to cope. Olivia explained that her usual attitude to life had changed; she described herself prior to her pregnancy as a "get up and go girl". Olivia disclosed that she could not sleep and that she was too exhausted to go to work. My observations supported this, as documented in my field notes:

*"All around the house there were photos of Olivia looking very glamorous and happy; the photographs portrayed a very different person to the one I had met"*

(Field notes: O2 030909).

It appears that Olivia's coping strategy developed over time and she moved from passive to active coping, she referred to this in her postnatal interview when describing how she coped with the news that her baby needed to be delivered urgently:

*"and when they [Doctors] told me that, they said we've got to get the baby out, you just think I need this baby to be healthy, sod myself, I want this baby, I've tried hard enough for her, I'm not letting her go anywhere now"*

(Olivia, PN Interview, 6 weeks postnatal)

Olivia's mother was present at both interviews. Her observations are recorded in my field notes and they reinforced Olivia's comments and my interpretations:

*"but I knew my own daughter, my daughter's full of energy, constantly all the time, does her job then comes home and she's still bubbly and I knew it just floored her completely"*

(Field notes: OPN 171209)



Marie's coping strategy exhibited strong elements of self protection that included; denial, detachment and isolation. In her first interview Marie described how she avoided making contact with the baby clothes and equipment that she had bought for baby when she had anticipated a 'normal' pregnancy. At this stage of her pregnancy Marie used denial and making preparations for life without the baby as a coping strategy:

*"This sounds stupid, but I've already applied for a job.... if something happens to her then I can't sit round this house all day, I said it's doing me head in, and then I want to go back to college I don't want to sit around the house"*

(Marie, 1<sup>st</sup> interview, 27 weeks)

Four weeks later at 31 weeks of pregnancy, when Marie's baby had reached a viable weight and delivery was imminent, her thoughts turned to anticipation of the baby arriving rather than denial. However, she still exhibited self protection as part of her coping strategy;

*"I don't want to get excited cos she's still not here yet and him [Consultant Obstetrician] saying he wants me back on Monday scares me"*

(Marie, 2<sup>nd</sup> Interview, 31 weeks)

Marie talked about paying the deposit on a Moses basket for her baby, however she explained that they had delayed paying the balance 'just in case' something went wrong. This demonstrates a growing sense of hope, however, Marie continued to display feelings of doubt and uncertainty regarding the outcome of her pregnancy. When interviewed after the birth of her baby, Marie described the contrast in her coping mechanism from the antenatal period to the postnatal period; she described how she would stay at home and "hated the world" whereas when her baby was

seven weeks old she wants everyone to see her baby. Furthermore, she only allowed herself to buy clothes for the baby following its birth. In her postnatal interview I asked Marie why she had not bought anything for the baby until it was seven weeks old, she replied:

*"In case she died.... so I thought it would be easier just to deal with the baby dying rather than dealing with her dying and then coming home and seeing a pram and everything"*

(Marie, PN Interview, 7 weeks postnatal)

Elements of denial and self protection are present in the coping strategy that Marie demonstrated in the postnatal period with a premature baby on the NICU. Marie explained that she did not look forward to the future, she took "each day as it came" and she knew that was still a long way to go before she could feel at ease with the situation. Vicky employed a similar coping mechanism in the antenatal period, both Vicky and Marie explained that they "take each day as it comes".

In the second interview Marie talked about how her children had tried to protect her from the possibility that the baby may not have been born alive. During this interview it became apparent that Marie and her partner had used the children's excitement to display feelings of hope and optimism once the baby had reached a viable weight:

*"It was just harder then because the kids would come in and going 'don't go in the baby's wardrobe Mum' when we thought we weren't having her but now since we know she's coming the kids have got us dead excited really"*

(Marie, 2<sup>nd</sup> Interview, 31 weeks)

The findings suggest that the women in this study used protection as a coping mechanism to enable them to deal with a difficult pregnancy; denial, detachment and avoidance are strong contributors to this mechanism. Protection as a coping strategy can be demonstrated in a low risk pregnancy but the data from this current study suggests that it is employed to a much greater extent and until a later gestation in a high risk pregnancy. Furthermore, 'protection' is multi-dimensional and evolves as the pregnancy progresses.

### **Seeking Reassurance**

The women in this study talked at length about the need for reassurance during their pregnancy, they discussed how they sought it and what provided it. Seeking reassurance formed part of their coping strategy and was present at every stage of the pregnancy. The women also reflected on it at the postnatal interviews.

Sarah had a complicated first pregnancy and she had expected to receive specialist care in her current pregnancy, in addition she had abnormal serum screening markers on first trimester Down syndrome screening. Sarah explained that she used various methods to provide reassurance during her pregnancy. Sarah had been alarmed by the information she had read on the internet about the markers; she immediately contacted one of the clinic's specialist midwives to discuss her concerns and found the encounter reassuring. Sarah described the reassurance provided by the specialist clinic:

*"It's reassured me I think, I am one of those people who tends to worry, I need to understand what's going on. I need to understand that this will happen, then this will happen I need to know that kind of structure"*

(Sarah, 1<sup>st</sup> Interview, 24 weeks)

In contrast, Emer received an unexpected referral to the clinic; she sought reassurance through self assessment and her previous pregnancy experience:

*"she [Midwife] said that it meant that you could possibly have a small baby weight and I joked about it as I looked down and said not from where I'm looking and I said well what's small because I gave birth to an 8lb 14 and I'm thinking that's alright"*

(Emer, 1<sup>st</sup> Interview, 27 weeks)

Sarah also sought reassurance through self assessment and used this as part of her coping strategy. Sarah, who had pre-eclampsia in her previous pregnancy, found reassurance from monitoring her blood pressure at home with a personal electronic sphygmomanometer. This allowed her some control over her care; the readings provided Sarah and her husband with reassurance when they needed it. Vicky also self assessed her own risk in relation to her continuing pregnancy, she found it reassuring that her pregnancy had progressed further than her Doctor had anticipated:

*"Because it's got to nearly eight months, cos I'm not even a month off, well about six weeks, and my other Dr at Wythenshawe he kept saying it was 50/50 for ages, so it's just as if it's fighting and it's going to be alright"*

(Vicky, 1<sup>st</sup> Interview, 33 weeks)

A scan at 32 weeks of pregnancy revealed that Emer's baby had an abdominal circumference of greater than the 90<sup>th</sup> percentile, this was an unexpected finding, opposite to the initial referral to the clinic. This alarmed Emer and prompted further investigations for gestational diabetes. The investigations were negative but this planted a seed of doubt in Emer's mind and she requested an additional scan for reassurance later in her pregnancy. Emer explained that the model of care delivered by the specialist clinic provided reassurance to help her to cope with her

pregnancy complications, in particular being able to access the specialist team and negotiate individualised care as she needed it:

*"Because I've been able to have more scans, and see you a lot more often than I would have done in Antenatal Clinic (ANC), it's given more reassurance and it's been fine"*

(Emer, 2<sup>nd</sup> Interview, 37 weeks)

In keeping with Emer's and Sarah's experiences, Olivia explained that the clinic's flexible delivery of care provided her with reassurance and helped her to cope with the fear and uncertainty surrounding her pregnancy:

*"It's reassuring me that everything's ok, well the Dr yesterday said that we'll review you in three weeks and I wanted to come back earlier and he's let me come back at two weeks instead so I do feel that I'm getting more care because obviously I know that everything's ok then because I'm coming back more regular"*

(Olivia, 1<sup>st</sup> Interview, 25 weeks)

The findings suggest that model of care provided by the clinic played an important role in all of the women's experiences; all women discussed the importance of continuity of carers, knowing the team and being able to access the team. All the women in this study reported that they felt reassured by the individualised care provided by the clinic; they felt that this had established a relationship of trust between themselves and their care providers.

Emer described that the care she had received had provided the reassurance she needed at the end of her pregnancy. As she approached labour she did not have any concerns relating to the complications that had been highlighted in her pregnancy. However, an element of uncertainty appears to have remained with

Emer as she described how she assessed her baby at birth for any signs of abnormality:

*"I know when she came out I did look to see if her tummy was big, I thought 'has she got a big abdomen, what was all that about?' but it kind of looked normal to me, and then with her feeding so much I wasn't worried about her not growing or anything"*

(Emer, PN interview, 12 weeks postnatal)

Emer's case raises important concerns about the clinic's referral criteria, as described in chapter one, serum screening markers alone are not an accurate predictor of fetal growth restriction. Emer's referral to a high risk clinic and the label she subsequently received could have caused her unnecessary anxiety. It could also be argued that the additional surveillance she received revealed false positive results which could have heightened feelings of distress.

The additional monitoring necessary to manage a high risk pregnancy requires additional visits to the hospital which can result in additional anxiety but can also provide reassurance. From 32 weeks of pregnancy Vicky ceased to feel any fetal movements, as such she was required to attend the hospital for monitoring at least twice a week. Vicky and her family did not have their own transport and relied on public transport to make the frequent visits to the hospital, she explained that it was difficult travelling the distance to the hospital. Marie's experience of the burden of frequent hospital visits resonates with Vicky's, she explained that she was required to attend appointments both at her local hospital and the hospital to which she has been referred for specialist care. However, Vicky and her family were willing to make the journey because it provided the necessary reassurance:

*V: "When I come up for that machine [CTG], I know it's not a waste of time because it puts me at ease and I know baby's alright, going on the heart machine.... well I don't know what it's called"*

*R: "yes, the heart machine [CTG]"*

*V: "cos I know it's still alive, I know it sounds dead awful that"*

(Vicky, 1<sup>st</sup> Interview, 33 weeks)

Marie set milestones as her markers of reassurance. Marie's coping strategy did not include seeking reassurance from fetal movements or frequent discussion with the specialist team because Marie knew that unless the baby reached a viable weight (500g) then the baby would either demise in utero or she would terminate the pregnancy. The usual markers of reassurance such as fetal movements provided mixed emotions for Marie:

*"I don't know whether or not to feel happy she's kicking or guilty, because if we go back and she's not made it 400g I know it's not that I'm killing her but in a way I am because I'm choosing not to go on with it because I can't live my life where I'm stuck not knowing"*

(Marie, 1<sup>st</sup> Interview, 27 weeks)

Marie was forced to consider her course of action should her baby not reach this crucial milestone. Managing the uncertainty surrounding her pregnancy became part of Marie's coping strategy; I shall develop this category later in the chapter.

*"I was coming back in to tell him [Obstetrician] I was giving up, cos I said to him, if she hadn't got past 400g then I was giving up, cos that's what he wanted her to be, she was 440 and now she's 560"*

(Marie, 2<sup>nd</sup> Interview, 31 weeks)

I recorded my interpretation of Marie's change of attitude in my field notes:

*"Talks with excitement, looks brighter than previous interview"*

(Field notes: M2 110310)

Sarah also set milestones in her pregnancy as markers of reassurance. Sarah's previous pregnancy was complicated by pre-eclampsia and a growth restricted baby, she had developed complications at 30 weeks of pregnancy. In her second interview at 35 weeks, Sarah explained that 30 weeks of pregnancy was a significant gestation for her and that she had found reassurance in reaching this gestation and not developing complications:

*"I suppose getting to 30 weeks, because I'd worked out when 30 weeks was and it was the beginning of December so I sort of knew that that's when things could start going a bit awry"*

(Sarah, 2<sup>nd</sup> Interview, 35 weeks)

In addition to milestones relating to her health, Sarah also described pregnancy 'hurdles' in her career. It was important to Sarah that she could finish work at her scheduled date and complete her work commitments before any complications developed. Women may need to feel that they have completed a certain area of their life, usually work, or a milestone in their pregnancy. Failure to do this can result in women feeling cheated and unprepared for motherhood as they have not made the necessary psychological transition from one role to another. Sarah talked about feeling unprepared and disorganised in her previous pregnancy because she had not anticipated that she would develop complications. Being able to complete her work commitments and to progress passed 30 weeks of pregnancy without developing complications was very important for Sarah. Achieving this milestone was part of Sarah's coping strategy, she reflected that due to the complications of her previous pregnancy she felt disorganised which created additional pressure.



## **Managing uncertainty**

All the women in this study referred to the uncertainty that surrounded their pregnancies. In the trajectories for both Vicky and Marie these uncertainties were focussed on whether or not their babies would survive. Vicky explained her baby's chances of survival and her frustrations surrounding the uncertainty of her pregnancy:

*"They just said about it being 50/50 if it lives or if it doesn't....[I want] to know whether it's going to be alright, to know if it's going to survive, that's all I want to know and when am I going in to have it"*

(Vicky, 1<sup>st</sup> Interview, 33 weeks)

Vicky tried to manage with the uncertainty regarding her baby's survival by asking her Obstetrician questions about her pregnancy in order to gain more information. Vicky expressed that she felt frustrated when she did not get answers to her questions, which created further uncertainty:

*"It's just we get nowhere, we come all the time and then there's no answers at the end, getting scanned all the time and then it's no answers at the end"*

(Vicky, 1<sup>st</sup> Interview, 33 weeks)

The lack of information provided by her clinical care team added to the uncertainty surrounding her pregnancy, Vicky questioned if she was the first woman to ever experience this particular complication.

Sarah did not know if the complications of her previous pregnancy would be repeated in this pregnancy, she felt that she needed structure and a plan to cope with the uncertainties of her pregnancy:

*"I would rather know and think right this is how I'm going to deal with it now. Sort of put a plan of action together kind of thing and you feel that you're kind of doing something"*

(Sarah, 1<sup>st</sup> Interview, 24 weeks)

Sarah identified areas of her pregnancy in which she could have control such as self monitoring her blood pressure at home and making choices in relation to her mode of delivery. Having some feeling of control was important to Sarah; she reflected that she felt that her first pregnancy was "a bit out of control". Sarah gave birth to her first baby by emergency caesarean section and she explained that this had been a difficult and traumatic experience for her. Sarah made the decision very early in her pregnancy that she wanted to deliver this baby by planned caesarean section at 39 weeks of pregnancy and she discussed this with her obstetrician who agreed. Sarah explained that this provided her with some reassurance that she had some control over her care. This appears to be of particular importance in high risk pregnancy as many women with complicated pregnancies are faced with reduced choices and lack of control:

*"At least now I know what's going to happen so it's put my mind at rest, which is probably one of the reasons why I do feel more relaxed sort of at this point I think. I know what the outcome will be and what will happen"*

(Sarah, 1<sup>st</sup> Interview, 24 weeks)

Vicky also wanted to know when she would be having her baby; she described the frustration of not being provided with a delivery date. It appears that being able to gain some control and to know when the uncertainty surrounding her pregnancy may end may have been part of Vicky's coping strategy.

Marie described the spectrum of emotions she experienced when faced with a very uncertain outcome:

*"Because I feel dead happy when she [the baby] kicks and sometimes I think 'ha ha' you're still here and the Doctors are wrong, they thought you'd be dead by now and you're not and then sometimes I think 'oh god, if you've not grown then I'm going to have to do something to you that's cruel'"*

(Marie, 1<sup>st</sup> Interview, 27 weeks)

Marie explained the agony of living with the uncertainty of her baby's survival, she described this as "there's no good news for me". She explained that she needed a conclusion to her pregnancy:

*"I think I'm just over it now, I just want it to be one way or another"*

(Marie, 1<sup>st</sup> interview, 27 weeks)

I interviewed Marie for a second time just days before her baby was born, her baby had reached a viable weight and delivery was imminent as the baby's well-being was threatened, when I asked her how she felt about the pregnancy coming to an end she simply replied:

*"Relief"*

(Marie, 2<sup>nd</sup> Interview, 31 weeks)

I feel this simple statement expresses the agony that this group of women experience everyday of their pregnancy. However, Marie understood that giving birth to a live baby was just one of many hurdles they had to face, she didn't allow herself to plan too far ahead as the future remained uncertain.

A benefit of conducting longitudinal research is that one can observe the evolving experience over time. According to the clinic protocol Vicky and Marie were each offered a termination of pregnancy (TOP) when it was evident that their babies were growth restricted and may suffer long term morbidity or death. Marie and her partner seriously considered terminating the pregnancy, both women reflected on the process in the postnatal period:

*"But now it plays on your mind that imagine if we [Marie and her partner] did [have a TOP] because look how good she's doing"*

(Marie, PN Interview, 7 weeks postnatal)

Both women recalled their anger and shock at being offered a TOP. However, in her postnatal interview Marie recalled that she was pleased that she was given the option of ending her pregnancy. I sensed, however, that she now had feelings of guilt regarding her consideration of a TOP. She explained that one of the factors that influenced her decision not to have a termination was the procedure of having to give birth. Due to her advanced gestation, she may have had a TOP if she could have gone to sleep and not been aware of giving birth.

Marie was the only smoker of the women interviewed and she explained that she continued to smoke throughout her pregnancy, despite advice. This was one way of coping:

*"It [smoking] keeps me sane"*

(Marie, 2<sup>nd</sup> Interview, 31 weeks)

However, Marie talked at length about her smoking; she tried to provide a rationale for why she continued to smoke and acknowledged her feelings of guilt and what it would take to make her stop:

*"If they [Doctors and Midwives] told me 'if you have one more ciggie she'll die' I wouldn't smoke, I don't think I would smoke, it's bad that I still do smoke cos the placenta is, and she's still getting it, it is bad, I know it's bad that I do still smoke, but I think it's more stressful to try and quit"*

(Marie, 2<sup>nd</sup> Interview, 31 weeks)

Sarah used her previous experience as part of her coping strategy:

*"I am feeling a lot calmer this time, I don't know if it's hormones or what but last time I was like I'm having a terrible time but this time I'm like whatever will happen will happen and that's the best way to look at it this time. But if my blood pressure goes up, it goes up, there's nothing I can do about, I'll try and relax and all that kind of stuff"*

(Sarah, 1<sup>st</sup> Interview, 24 weeks)

The findings suggest that the high risk pregnancy experience forces women to see themselves as different from women with less complicated pregnancies, as a result they can lose confidence in their body and their ability as a mother.

*"I was just wondering why I was being scanned and I know that they [Doctors and Midwives] were telling me it was for growth scans, but I just thought 'what's wrong with me, why's my baby not growing, not normal'"*

(Olivia, PN Interview, 6 weeks postnatal)

Vicky and Marie both asked if they were the only women to develop such complications of pregnancy as they had not met any other pregnant women who had experienced the same complications as them. Marie carried her feelings of inadequacy into the postnatal period:

*"She [the baby] was only three days old [when the NICU nurses offered donor milk] and I was like 'give me a chance' and they made me cry then.....and I said I couldn't even grow her properly and now I can't even feed her. It felt like cos I hadn't done it right when I was pregnant and I couldn't do it right then"*

(Marie, PN Interview, 7 weeks postnatal)

The women's experiences of complications prior to conceiving, during pregnancy and in caring for their babies encouraged the women in this study to doubt their abilities and heighten their feelings of inadequacy.

*"Will I have complications like this in further pregnancies? Cos, we were trying for two years to get pregnant anyway, I just feel like everything seems to be harder for us [Olivia and her partner]"*

(Olivia, 1<sup>st</sup> Interview, 25 weeks)

### **3.3.2 Theme 2 – Managing expectations**

The second theme to emerge from the data is 'managing expectations' this includes the subthemes:

Expectations

The unexpected

Managing the expectations of others

At all stages of their pregnancies women indirectly referred to their expectations. They disclosed what they perceived to be expected of them, what was unexpected and how they managed the expectations of others. A notion essential to Heideggerian phenomenology is the hermeneutic circle. This directly refers to our understanding of 'being'. One of the elements of Heidegger's hermeneutic circle is 'pre-understanding'. He describes 'pre-understanding' as the organisation of the world that exists prior to our understanding. "Human Beings always come to a

situation with a story or pre-understanding" (Koch, 1995:831). I think this notion of pre-understanding contributes to the formation of expectations. Only one out of the five women interviewed had previous personal experience of high risk pregnancy, however the findings suggest that they all had expectations relating to their complicated pregnancy. Their expectations and the expectations of others appeared to have a direct impact on their experience.

I think this is an important theme to emerge from the data as it gives direct insight into the experience of high risk pregnancy. Furthermore it illuminates how care providers can seek to manage women's expectations and the unexpected.

### **Expectations**

Vicky's two previous pregnancies had been low risk, however, as described in theme 1, Vicky expected that her specialist doctor would provide the answers to her questions and to remove the uncertainty surrounding her pregnancy:

*"Because he's a Dr you think he's going to be able to say 'this is going to happen' .... It's just that he doesn't give me any answers, I know he can't but he doesn't, when we ask he says 'I don't know'"*

(Vicky 1<sup>st</sup> Interview, 33 weeks)

Vicky had expected to be given a date for induction of labour. When the obstetrician did not provide this date Vicky became frustrated with her care. Marie also talked about her expectations and how it influenced her experience; following a discussion with the NICU nursing staff Marie had expected that she would be able to see her baby at birth. However, the baby was transferred immediately without Marie seeing her daughter, this unmet expectation caused anxiety.

*"I was more worried that she [the baby] was going to come out and she was going to die as soon as she came out, cos' at first when we went*

*looking round [NICU], they [NICU Nurses] said they'd show me her and they'd hold her up over the screen [when she was born] so I could see her dead quick and when I had her they didn't"*

(Marie, PN Interview, 7 weeks postnatal)

Marie thought there was something wrong with her baby when she did not see her at birth; she attempted to seek reassurance from the midwives and doctors:

*"I said 'is she alright' and all they [Theatre Team] kept saying was 'she's tiny' 'oh my god, she is so small' and I was thinking she can't be that small they said she was over 500g, cos' even the nurses and the doctors looked shocked by how small she was"*

(Marie, PN Interview, 7 weeks postnatal)

The findings illustrate that feelings of distress can ensue if expectations are not appropriately managed, for example; Marie expected to see her baby at birth, she described feeling distressed when the baby was taken away without explanation.

In the postnatal period Vicky reflected on the care she received in her pregnancy; she had specific expectations from a specialist high risk clinic and she appeared to feel let down when her expectations were not met:

*"Yeah but when we were there asking questions, he [Consultant Obstetrician] couldn't give us the answer, cos we kept asking about his lungs and he said 'we don't know until he comes out' but couldn't he see them on the scan?"*

(Vicky, PN Interview, 18 weeks postnatal)

Vicky's baby was growth restricted and required care on NICU, however, her baby was born in a better condition than she had anticipated. In the postnatal period



she reflected on her perception of whether or not high risk care was necessary, she questioned if she needed to attend the hospital as much as she had done and believed that the doctors got it "completely wrong". I think this example provides an important insight into Vicky's experience as she felt that the level of care she received and the associated feelings of raised anxiety were unnecessary. Vicky's experience could have been more positive had her expectations of her care been different; this could possibly have been achieved through careful and timely communication.

In her postnatal interview Marie discussed the expectations that were placed on her by the routines of the NICU and the pressure which this created:

*"You feel under more pressure to be there at the same time, you have to be there when her cares are due and they [NICU Nurses] say 'we'll save it for you' and then it's not fair on her because she has to lie there in a dirty nappy"*

(Marie, PN Interview, 7 weeks postnatal)

Olivia's experience resonates with Marie's feelings of being under pressure to always be present at her baby's cot side. Olivia explained that as a result of a 'nurse lottery' she felt under pressure to be with her baby at every feed:

*"She'd [The baby] been fed at 10am and we got there at 4pm and she'd not been fed all day. The girl [Nurse] that was looking after her said 'well she's been asleep' I said 'it doesn't matter she's small, you wake her up, you know surely that's your job to wake her up' she said 'well do you want to feed her now?'"*

(Olivia, PN Interview, 6 weeks postnatal)

Vicky's baby was also admitted to NICU; Vicky explained how the unit's rules and expectations created pressure and added to their feelings of anxiety. Vicky was trying to juggle spending time with her new baby in hospital with time with her two other sons, she felt she could achieve this by asking the baby's grandparents to visit the baby daily, so her baby always had someone with him. Vicky explained that she found the separation from her baby difficult, therefore it was important to her that a family member was with her baby when she needed to be with her other children. Vicky also explained that she was 'told off' for allowing the baby's grandparents to visit without Vicky or her partner being present. I asked Vicky to describe her experience of having her baby on NICU:

*"It was horrible, cos I didn't stay [at the hospital] and I had to keep going up and cos I've got [my sons] it was hard and it was Christmas, so I had to get me brother next door to watch them, cos it was only two at a bed on special care, so I couldn't take them up"*

(Vicky PN Interview, 18 weeks postnatal)

Marie and Vicky both described the experience of juggling spending time with a sick baby on NICU with family life; they talked about this at length. This experience contributes to theme 3 – "it doesn't just happen to me".

A common thread throughout the themes is the buying of baby clothes and equipment, this is an expected ritual of pregnancy, being unable to participate in this activity highlights abnormality as women and their families are denied these rites of passage. Marie emphasised this in her second interview:

*"Because that's what makes you realise how abnormal it is when you can't go out and you can't buy your stuff"*

(Marie, 2<sup>nd</sup> Interview, 31 weeks)

### **The unexpected**

Three women were referred to the clinic due to abnormal serum screening results in the second trimester; this is the main route of referral for the majority of women. Emer only expected to be contacted in the case of a high risk result for Down syndrome. Emer referred to the distress she experienced when the specialist screening midwife tried to contact her to inform her of a high risk result in relation to markers for growth restriction from her serum screening, as she had not expected this result:

*"I got this phone call and because I knew it was about the test they [Midwives] said to me that I'd have a phone call if there was something wrong and if nothing was wrong I'd have a letter so because I had a voicemail I thought something was wrong so that did kind of get me a bit worried and I was trying all day to get back to them and I couldn't get back in contact with this lady [Screening Midwife] and then when I did and she eventually explained it"*

(Emer, 1<sup>st</sup> Interview, 27 weeks)

This confirms anecdotal evidence from my clinical experience that women are not being fully informed of all the information the test will provide. Women are well informed that the screening test will provide information relating to their risk of having a baby with Down syndrome. However, women are not always aware that the test can provide information relating to their risk of placental insufficiency. Therefore if they receive a positive screen for placental insufficiency they are not expecting it. Olivia also referred to the expectations that she had from the Down syndrome screening she had in the second trimester of her pregnancy. She had not been expecting that the result would provide information relating to placental function and fetal growth restriction. Conversely Sarah, who had private screening, felt well informed about the test and her referral to a specialist clinic:

*"Obviously because of my past history and when the results came back from the nuchal fold scan [First trimester Down syndrome screening] I knew exactly why [I had been referred], it had been well explained"*

(Sarah, 1<sup>st</sup> Interview, 24 weeks)

Vicky developed the expectation that she would need to have an epidural for the delivery of her baby, she stressed that she was "dreading it". I am unsure how she has reached this assumption, but she discussed her fear for a number of minutes during the interview, she explained that:

*"I don't know what to expect"*

(Vicky, 1<sup>st</sup> Interview, 33 weeks)

This highlights that despite the added complications, this group of women, or at least this woman, had some of the same concerns and fears as a low risk woman. I think this can often be overlooked as care providers try to prepare women for complicated childbirth. It is important to be aware of their spectrum of needs. Furthermore, it is important to acknowledge that women may fear the unexpected.

### **Managing the expectations of others**

As previously stated, themes and subthemes are not mutually exclusive; this particular category has links with 'evolving coping strategies' and 'it doesn't just happen to me'.

#### **3.3.3 Theme 3 – 'It doesn't just happen to me'**

The participants frequently discussed their experience in relation to their family, friends, peers and colleagues; the interaction between the women and these groups undoubtedly formed part of their experience. In attempting to understand the high risk experience, it is therefore important to understand the wider context of participants' individual lives. The subthemes that form this theme are:

Separation

Differences in coping

Interaction with others

Each subtheme is discussed in turn and direct quotes from the data are used to illustrate the findings.

### **Separation**

Marie frequently discussed her concerns about being separated from her children whilst she was away from home giving birth to her baby. Marie acknowledged the differences in this high risk pregnancy compared to a previous low risk pregnancy and how this would affect her existing children. This situation appeared to compound concerns that may exist in a low risk pregnancy, but adds another dimension and can cause additional pressure and stress:

*"I don't want her [daughter] to feel like I've left her for another baby, cos normally you go away have your baby and come back the next day, but I think I feel like she's going to think I'm going to abandon her for another baby"*

(Marie, 2<sup>nd</sup> Interview, 31 weeks)

Marie's concerns became reality in the postnatal period; she described the stress and worry of splitting her time between the hospital and home life. This resonates with Vicky's experience of trying to juggle time with her new baby and time with her other children:

*"I didn't like leaving him [baby] there and just coping with going up there and coming home to see to the kids as well, it was just hard"*

(Vicky, PN Interview, 18 weeks postnatal)

The effects of separation had an influence on Olivia's experience also. Olivia did not have any other children but she explained that found the separation from her new baby very difficult:

*"You're on a ward that's not close to them [baby] it's quite hard because there are other people on that ward who have got their babies there and that was hard. Because of a night their baby was crying and some nights I'd get upset thinking my baby's not with me and my baby's two weeks old and I'm still not with her and I'm having to go upstairs"*

(Olivia, PN Interview, 6 weeks postnatal)

Olivia's comments regarding the distance between her and her baby are very interesting. During the postnatal interview Olivia referred to the location of the NICU in relation to the postnatal ward, she describes that it is 'upstairs', whereas the postnatal ward and NICU are on the same floor and only a short distance apart. However, Olivia felt this distance was further than it is; this could represent the distance she felt between herself and her baby whilst her baby was on the NICU.

As with a large proportion of complicated pregnancies, care (including specialist neonatal care) is often delivered at a large tertiary referral hospital rather than at a woman's local district general hospital, this can create additional pressure:

*"It's hard trying to get there and back, especially with the transport ... when she [baby] was in [NICU at another unit] we had to leave at 7am to get the kids to school, get to the bus stop and make sure you were in time to get the train and so you were there for at least two hours before you had to come home"*

(Marie, PN Interview, 7 weeks postnatal)

In her second interview, Emer expressed her fears of being separated from her child if she died in childbirth:

*"I'm scared of labour this time round and I wasn't last time and I think it's the fear of if something goes wrong and I leave my child, not necessarily this one (points to pregnant abdomen) 'cos I don't know this one, it's the fear of leaving my little one and that kind of really upset me, because last time I was like what will be will be, I'll be fine"*

(Emer, 2<sup>nd</sup> Interview, 37 weeks)

I find this interesting as Emer was considered to be the lowest risk of all the participants; however, she was the only woman to discuss dying in childbirth. This highlights that it is important to discuss fears individually and not to generalise or to make assumptions according to risk status.

### **Differences in coping**

Olivia described how her partner could not understand her change of approach to life. She described that he remained supportive and was concerned about the outcome of the pregnancy but he was still able to continue with his normal daily routines, whereas everything had changed for Olivia. Marie and her partner also demonstrated alternative ways of coping with the complications of Marie's pregnancy, particularly in the postnatal period, these differences led to tensions in the relationship:

*"In my own head, I have to be a single parent to know that I can do it, cos, I need to know that I can do it without you [her partner], I said..... I don't want to get where I have to rely on him I need to know that I can do it on my own if I have to, and I think 'sod yous, I'll just do it myself, it's quicker and it's easier"*

(Marie, PN Interview, 7 weeks postnatal)

Marie had raised her first child by herself until meeting her current partner and, at times, she appeared to want to revert to a way of coping that is familiar to her. She explained that shortly after her baby was born she planned to leave her partner. Marie described that she felt that she needed to get away from "anyone and everyone" and she thought it would be easier to do it on her own.

Two women talked about trying to protect others, namely their children and partners. The women in this study acknowledged that the experience of high risk pregnancy affected their family and in turn their families' response became part of the woman's experience.

In her first interview Vicky discussed the avoidance of talking about the pregnancy complications; I sensed this was part of a shared coping strategy:

*"We [Vicky & her partner] don't talk about the pregnancy, well we do but not as much as we should, I don't think we've talked as much as we should ... erm they are excited [kids] but we don't really tell them much about what the complications are"*

(Vicky, 1<sup>st</sup> Interview, 33 weeks)

In both antenatal interviews Marie talked at length about her family's coping strategy and how this evolved during the pregnancy. Until 20 weeks of pregnancy Marie perceived her pregnancy to low risk, as a result she had taken her children to the routine anatomy scan to involve them in the pregnancy. It was at this scan that Marie was informed that her baby was growth restricted, but the cause was unclear. Marie talked about the difficulties of dealing with her children's attachment to her unborn child and trying to protect them from an adverse outcome:



*"and then to get pregnant again and for it to go so good for a little bit and go so wrong again, but I think it's just more hard work, especially with the kids, because the kids kiss your belly goodnight and they talk to her [the baby], I think it's just hard work ... the longer I'm pregnant the harder it is and for the kids as well, because the longer I'm pregnant the more they expect the baby to be coming soon"*

(Marie, 1<sup>st</sup> Interview, 27 weeks)

Equally Marie found it difficult to balance her own fears with those of her partner and tried to protect his feelings:

*"I don't like talking to [my partner] about it because he gets upset ... he gets upset because I say 'I feel guilty that she's kicking' I don't know whether to feel happy that she's kicking because she's hung on for so long ... when I'm on my own I sit on the bed and I still like to feel her moving, I just lie on me own and then I can feel the baby kicking and I don't have to feel guilty about saying 'oh, she's just kicked"*

(Marie, 1<sup>st</sup> Interview, 27 weeks)

Emer reiterated the differences in her and her husband's coping strategy and emphasised her child's attachment to her pregnancy:

*"It feels like he's [husband] got no emotion because he doesn't show it, and beforehand [previous pregnancy] he will have talked to the bump and there's been hardly any of that if any, my child talks to it more than he does.....my son comes and cuddles it and feeds it"*

(Emer, 2<sup>nd</sup> Interview, 37 weeks)

Marie talked about her mother and father's attachment to her unborn baby, her mother's comments influenced her decision making in her pregnancy. Marie

described that her mother encouraged her to continue with the pregnancy at a time when she considering ending it.

### **Interaction with others**

Some of the women described the effect their pregnancy complications had on their relationships with others. Marie described how she felt judged and peers would treat her with pity. She also wanted to avoid other pregnant women:

*"I hate being around pregnant people, I do, I don't like going round near anyone else that's pregnant ... because their baby's alright and mine's not"* (Marie, 1<sup>st</sup> Interview, 27 weeks)

I asked Marie why she felt that way and she explained that it was a reminder that her baby was sick. In the postnatal period Olivia was able to reflect on her pregnancy and the impact it had on her and her relationships:

*"I was just very tired and I didn't want to go out anywhere, I'd arrange things with me friends and then I'd ring them up and let them down straight away, I nearly lost all me friends"*  
(Olivia, PN Interview, 6 weeks postnatal)

Olivia explained that she did not want to tell her friends that she was depressed and anxious about the complications of her pregnancy because she did not feel that they would understand:

*"I didn't want them [friends] to know that because I wanted a baby for so long I don't think they would have understood 'well you've been trying for nearly three years why are you depressed now you're having a baby?'"*  
(Olivia, PN Interview, 6 weeks postnatal)

### **3.3.4 Conclusion**

Several themes and subthemes are drawn together to provide the essence of the overarching phenomena which is that **women utilise multiple internal and external factors to negotiate their pregnancies, drawing upon experiences, relationships and evolving coping strategies.** In keeping with Heidegger's epistemological approach women's experiences are formed through their pre-understandings and reflections. They bring their assumptions and expectations to the experience and their interactions and relationships inform their experience. I would suggest that this can be a lonely journey as women seek to protect those closest to them.

## **Chapter 4 Discussion of the thesis**

This chapter presents a discussion of the study findings; each theme is examined in relation to the available literature and current clinical practice. The appropriateness of the methodological approach used to conduct this research is discussed, including my reflections on the methodology. In addition, an in-depth examination of the strengths and limitations of the research is provided. The chapter concludes with recommendations for practice, policy and future research in the arena of high risk pregnancy. Reflective practice has been a constant and essential tool throughout the research process, in part because it complements my style of learning. Furthermore, reflexivity is a key characteristic of hermeneutic phenomenology (van Manen, 2002) therefore my reflections are made explicit throughout this chapter.

This is the first study to focus on women's experiences of attending a novel high risk clinic dedicated to the improvement of care of women whose pregnancies are at risk of, or affected by Fetal Growth Restriction (FGR). The findings of this study have contributed to the development of a unique phenomenon; that women utilise multiple internal and external factors to negotiate their pregnancies, drawing upon experiences, relationships and evolving coping strategies.

### **4.1 Discussion of the findings**

A thematic analysis revealed three main themes and several subthemes, the main themes are; evolving coping strategies, managing expectations and 'It doesn't just happen to me'. Each theme and its contributing subthemes are examined in turn, culminating with a discussion of the overarching phenomenon that was achieved through synthesis of the main themes. As previously described, themes and subthemes are not mutually exclusive and some overlap occurs throughout.

#### **4.1.1 Theme 1 - Evolving Coping Strategies**

The findings demonstrate that women use a variety of coping strategies to survive their pregnancy; this concurs with previous work in the field of high risk pregnancy (O'Brien et al., 2010). The strategies employed by the women in this current study were a combination of different key behaviours which helped them to negotiate their pregnancies; these included: protection, seeking reassurance and managing uncertainty.

The women in this study appeared to engage in 'protective' behaviours. This was displayed on three levels; the protection of their unborn child, self protection against a possible negative outcome, such as the loss of their baby, and the protection of their family. The women who participated in this study demonstrated protective behaviour towards their unborn baby, adopting measures in an attempt to ensure its survival. These measures included attending the hospital for additional monitoring, taking rest and searching for possible treatments. This can be attributed to instinctive maternal behaviour however it also forms part of the coping strategy. The women stated that they wanted to feel that their actions actively contributed to their baby's survival; however, ironically their behaviour was sometimes contradictory, for example; continuing to smoke or take a poor diet. These women ascribed this to the stress they were enduring as a result of a complicated pregnancy.

It should be noted that although stress was not measured quantitatively in this research, many women frequently described feelings of 'stress' and/or 'anxiety'. They perceived the pregnancy complication and the associated management to be stressful life events. There is an association between heightened anxiety in the antenatal period and increased maternal and fetal cortisol levels (Glover et al., 2009). Glover (2009) suggests that increased cortisol levels as result of maternal anxiety can affect placental function. Furthermore, longitudinal examination of the relationship between maternal antenatal anxiety and the behavioural development

of the child, identifies a possible link between increased anxiety and behavioural problems at four years of age (O'Connor et al., 2002). Stress has also been shown to influence health behaviours which may have an adverse impact on birth outcomes (Griffin et al., 1993) and eating and sleeping patterns (Krantz et al., 1985). Two of the women in this study recount altered health behaviours due to stress; they describe a cyclical process, whereby feelings of anxiety and stress increased maladaptive behaviours. For example; one participant reported that when she felt 'stressed' because her baby was small (FGR), she described that she increased her smoking habit during periods of 'stress', she felt guilty about doing this in pregnancy as she knew that smoking directly affected the growth of her baby. The women in this study showed awareness of their altered health behaviours and the effect that these may have had on their pregnancies. Many expressed feelings of guilt as a result, although they felt powerless to change their behaviour.

Denial or avoidance also formed part of the protective coping strategy for some of the women in this study. In some cases the women explained that by denying the pregnancy they believed that they would experience less hurt in the case of a poor outcome. It could be considered that the demonstration of such behaviour exhibits a negative coping strategy. However, denial can be a positive short term coping strategy as it offers a form of 'self-deception' which reinforces the norm and therefore promotes a sense of control, thus reducing anxiety and aiding decision making (Russell, 1993). The concept described by Russell (1993) is a well recognised psychological concept; "denial is motivated by the need to protect the ego from the overwhelming power of the stressor" (Roth and Cohen, 1986: 815). Therefore, an avoidance coping strategy is a demonstration of self-protection, women may use denial or avoidance as a means to protect themselves from the possible enormity of a traumatic experience. Some individuals utilise a non-avoidant coping strategy, often referred to as 'attention,' in place of an avoidance strategy. A meta-analysis of the literature on coping strategies revealed that denial

or avoidance indicated improved short term outcomes, however, in the long term the use of a non-avoidance strategy was associated with more positive outcomes (Suls and Fletcher, 1985). This current study did not examine the types of coping strategy employed by women with complicated pregnancies or the outcome of the strategy used. However, the findings of this research suggested that women utilised an avoidance mechanism as opposed to a non-avoidance strategy. It could be argued that a contributing factor to the sub-conscious selection of a short-term coping strategy is pregnancy is viewed as temporary state. Further longitudinal work is required to explore the consequences of the coping strategies used in high risk pregnancy.

Another form of self protection that the women used was to delay the planning and preparation for their baby's arrival. This is in line with research that explored mothers' experiences of caring for a sick baby on NICU. Black and colleagues (2009) reported that mothers attempt to avoid developing a deep attachment to their baby to spare their feelings if the baby died. The findings from the current study concur with this; women demonstrated this type of protective behaviour as a means of coping with an uncertain pregnancy trajectory. Previous research has also described how women talk about 'putting their pregnancy on hold' while waiting for the outcome of antenatal diagnostic testing (Baillie et al., 2000). Baillie and colleagues also note how this behaviour represents the change from the expectation of a normal low risk pregnancy to a high risk pregnancy which may not result in the birth of a healthy live baby. They refer to Rothman (1988) who describes a 'tentative' state of pregnancy, which involves withholding attachment to the fetus (Baillie et al., 2000). Women in this current study and in previous research describe 'closing the baby's bedroom door' during periods of uncertainty; I interpret this as a metaphor for their perception of altered risk status and an expression of their coping strategy. The findings of this current study suggest that demonstrations of 'protective' behaviour can originate and develop in the antenatal

period, and are not just confined to the postnatal period, as previously described by Black and colleagues (2009).

Interaction with social networks can also be affected when women enter into an unexpected state of pregnancy. The altered state of pregnancy can result in difficulties with social interaction. Three of the women in this current study explicitly avoided entering into conversation with those outside their immediate family, as they could not contribute into 'normal' baby talk, and did not feel that they could explain their situation to others. One woman described how her experience almost led to the loss of friendships. This resonates with the experiences of those who suffer from long term health conditions such as cancer; the person with the illness no longer shares the same social world as his / her friends, resulting in social isolation (Charmaz, 1983). Charmaz (1983) describes how those experiencing chronic illness report a 'loss of self' and a blurred identity; some of the women in this study also reported this phenomenon. However, longitudinal analysis of the data revealed that, in this cohort of women, difficulty with social interaction was a temporary state that did not continue into the postnatal period. Yet, it should be considered that all of the women in this study gave birth to live babies and at the time of the final interview the babies were developing well. A less successful outcome for the women in this study may have altered their ability to comfortably interact with their peers in the postnatal period.

An awareness of the 'tentative' state of pregnancy by midwives and doctors can assist in the provision of care by providing individualised support to women. Such support may positively address women's fears and attempt to contextualise the pregnancy complications. A study by Berg et al. (2003) considered if the use of an individualised birth plan could positively influence the childbirth experiences of high risk women. However, the use of a birth plan did not appear to improve the overall experience of childbirth, in turn it intensified negative feelings (Berg et al., 2003). The authors suggest that this was as a result of the birth plan forcing women to



consider their risk more closely. The findings of this current study, and my own clinical experience, suggests that high risk pregnancy compels women to examine every aspect of their pregnancy and associated risks, therefore, alternative support mechanisms should be considered to aid women's coping.

This research sought to explore women's experiences of high risk pregnancy; the underpinning methodology did not facilitate the use of pre-defined structured questioning (van Manen, 2002). Therefore the women in this study were not consistently asked about developing practice and particular support mechanisms, unless it was raised by the participant, this could be perceived as a limitation of the study and a suggestion for future research. Further mixed methods research is required to identify the appropriate delivery of support for women experiencing a high risk pregnancy.

Research by Carolan (2008) has suggested that being able to relate to someone who had had a similar experience that ended with a good outcome was important for women and encouraged positivity. The findings of this current study build on Carolan's work as three women explained that they worried because they did not know of any other women who had experienced a pregnancy with severe fetal growth restriction. A consequence of this appears to be that the women compared themselves to 'normal' women who did not seem to have any problems. The comparison was largely based on women's expectations of the pregnancy experience and outcome. I believe that this comparison and the failure to meet pre-existing expectations re-enforced feelings of abnormality which, in turn, became a source of distress and isolation.

The women in this study talked at length about their need for reassurance during their pregnancy; they discussed how they sought it and identified the sources which provided it. Seeking reassurance formed part of their coping strategy, and was present at every stage of the pregnancy. This concurs with other qualitative

research exploring high risk pregnancy (O'Brien et al., 2010). The women who participated in this current study also describe similar experiences, the women found comfort in their ability to access a specialist team and that they were involved in the planning of their own care. This suggests that women want to be drivers in their care as opposed to taking a submissive role in which their thoughts and concerns are not considered. The benefits of receiving care from a specialist team have been examined in other disciplines; a systematic review of the literature by Hearne and Higginson (1998) revealed evidence to suggest that specialist teams in palliative care improve patient satisfaction and support the delivery of holistic care (Hearne and Higginson, 1998).

#### **4.1.2 Theme 2 - Managing Expectations**

Each individual brings expectations to a new experience or situation and this is applicable to the experience of childbirth (Beaton and Gupton, 1990). Lupton (1999) describes that women's perceptions of pregnancy are constructed through the media, technology and expert and lay advice. It is therefore possible that the same influences will act upon the construct of women's expectations of pregnancy. Heideggerian phenomenology sees the world as constructed through 'fore-conception', that is that we bring our pre-understandings of a phenomena to any situation (Koch, 1995). The women in this study reported a range of expectations from how they thought their pregnancy would proceed to the role of the Consultant in the high risk clinic. The findings suggest that previous experience also influenced the construct of expectations. Women used their expectations as a measure of how to appraise their experience of childbirth (Hauck et al., 2007). If the experience does not meet with the expectations then women may feel that they have failed (O'Hare and Fallon, 2011). The findings of this study suggest that unmet expectations can be source of distress to women. The longitudinal analysis revealed that the associated distress and the experience of an unmet expectation in pregnancy continue to be present in the postnatal period.

Observations from my clinical practice suggest that clinicians do not routinely ask women about their expectations of pregnancy and their care. The findings of this current study suggest that knowing a woman's expectations and discussing the related issues can be an effective method of communication which may reduce associated distress and anxiety. Understanding a woman's expectations of pregnancy is an important tool which can aid the achievement of realistic assumptions that can be fulfilled (Gibbins and Thomson, 2001). Hauck and colleagues (2007) suggest that knowing a woman's expectations in pregnancy can assist the midwife in her advocacy role. Acting as an advocate for a woman is a core responsibility of the midwife and a key principle of providing individualised care (NMC, 2008). Midwives commonly explore women's needs and wishes when delivering care, however, the exploration of a woman's expectations may be less familiar. It is hoped that the dissemination of this research may prompt midwives to review and develop their own practice to include an exploration of women's expectations as a tool to enable the delivery of effective care.

All of the women in this study referred to the uncertainty which encompassed their pregnancy. The findings of this study indicate that women with complicated pregnancies learn to manage the uncertainty through management of their expectations. The women would set small milestones and came to expect disappointment, which had a cumulative effect on their outlook. Two of the women became despondent that they would always have 'bad luck'. As previously described in this section, the experience of high risk pregnancy displays parallels with the experience of living with a chronic illness. Living with uncertainty is a common concept in long term health conditions and patients seek to manage it through 'cognitive coping' (Small and Graydon, 1993). A cognitive approach to coping has been observed in a number of populations; cancer patients, individuals with HIV/AIDS, parents of children on NICU and parents of children with disabilities (Scott et al., 2002). The cognitive approach to coping involves an appraisal of the event and the individual's assessment of how she feels that she can cope with the

event (Folkman et al., 1986). Heideggerian phenomenology concurs with this approach as it declares that coping skills are constructed through socialisation and that "every encounter entails an interpretation based on the person's background" (Koch, 1995: 831). Therefore a woman's appraisal of the risk and the required coping skills are constructed as a result of her previous experiences and understandings. It is possible that by attempting to understand a woman's appraisal of an event / risk, health professionals may be able to offer support to aid her perception of the risk and her coping strategy.

#### **4.1.3 Theme 3 - 'It doesn't just happen to me'**

The women, in this study, referred to the impact of the experience on their family, children and social network. It became clear that the experience of high risk pregnancy, in this cohort of women, is not confined just to the pregnant woman. Through listening to the narratives of the women in this study I interpreted that these interactions became part of the woman's experience. Three subthemes emerged from the data; separation, differences in coping and interaction with others.

The women in this study who already had children explained that they were required to 'juggle' their time between commitments at home and the hospital. The women spent less time than they had hoped with their baby on NICU as they still felt they needed to be available for their older children. Work by Black and colleagues (2009) support this finding; Black found that previous children took priority over the hospitalised infant. The women in the current study expressed that this was a source of guilt, however, I believe they rationalised their actions by knowing that a neonatal nurse would provide constant care for their baby.

Lupton and Fenwick (2001: 1012) suggest that "the mothers of hospitalised newborns are forced to practice motherhood in a public arena over a period of days, weeks or even months under the watchful eyes of nursing staff in the

nurseries to which their infants are admitted". In contrast, one of the participants, "Olivia," found this beneficial as during this time she got to know her baby and learnt skills and techniques from the nursing staff, this gave her confidence to care for her baby following discharge from NICU.

As described earlier, themes and subthemes are not mutually exclusive and some overlap exists. Two of the subthemes; 'Differences in coping' and 'Interaction with others' which form this theme have been discussed earlier in the chapter.

#### **4.1.4 Overarching Phenomenon**

Synthesis of the themes led to the emergence of the overarching phenomenon which underpins women's experiences of attending this particular high risk clinic. The unique phenomenon portrays the essence of the stories told by women experiencing high risk pregnancy. This study found that women utilise multiple internal and external factors to negotiate their pregnancies, drawing upon experiences, relationships and evolving coping strategies. These unique experiences provide a powerful tool from which practical recommendations can be explored (as discussed in 4.3 Recommendations for practice and policy). The achievement of an overarching phenomenon is an important objective of phenomenology as it reveals the essence of the lived experience of the participants (van Manen, 2002). The synthesis of participant-generated-data aids understanding of the phenomenon under study (Draucker, 1999).

## **4.2 Discussion of methodological approach**

An exploration of women's experiences of attending a high risk obstetric clinic was undertaken by applying hermeneutic phenomenology and using in-depth one to one interviews. The findings of this study present the narratives of, what could be considered, a relatively small group of women. However, the longitudinal design of this study combined with an effective participant-researcher relationship resulted in the generation of rich, in-depth data which offered important insight into women's

experiences. The findings of qualitative research are not expected to represent the views of an entire population, rather it adds to the body of evidence from which conclusions can be drawn to aid understanding (Kearney, 2007). This current study successfully achieved the aim described by Kearney (2007), as the findings provide a deeper understanding of women's experiences of attending a dedicated high risk clinic.

The use of individual interviews as the choice of data collection method was effective in producing rich data. The interview technique employed developed rapidly, as a result of individual and group (the research team) reflection. This process acknowledged strengths and weaknesses in my own interview technique, for example, one area for development was that I would frequently interrupt a participant rather than leaving a silent pause for them to elaborate. The production of rich data relied on developing the art of listening. It was important that I provided the opportunity for women to tell their stories rather than impose my own pre-defined perception of the experience.

The use of an interview schedule provided some structure and security in the early interviews; however I soon developed the confidence to refer to it less frequently. Instead I would pursue developing themes and comments made by the participants whilst trying to maintain the focus of the research aim. The interview schedule was developed through a review of the literature relating to women's experiences of high risk pregnancy. If undertaking future qualitative work I would consult service users to aid the development of an interview schedule.

Previous research had focused on the findings from data collected at single time points. The longitudinal design of this research allowed immersion in data collection and an opportunity to build relationships with participants. Familiarity with the participants encouraged my development as a researcher; I became absorbed in their narratives and developed the confidence to probe deeper and to

pursue themes. The longitudinal design of the study aided the development of themes as I was able to listen to an interview several times prior to conducting a subsequent interview. This enabled me to analyse my interview technique and gain familiarity with the data.

As a confident, experienced midwife and competent communicator I expected that conducting interviews would be the simplest part of the research process and I looked forward to the activity. However, I quickly realised that conducting a research interview is a challenge for the novice researcher and requires the development of specific skills that are different from everyday or clinical interaction. During the immediate post-interview reflection (usually driving home) I could sense if an interview had gone well or not.

The interviews did not disappoint, as I enjoyed the interaction with women and their families in their own homes, it was a joy and a privilege to be entrusted with their narratives. I was pleased to observe that my interview technique quickly developed by making small adjustments; this gave me confidence as I proceeded to conduct subsequent interviews. It appeared that the women were very forgiving of my inexperience as a researcher and spoke very openly and honestly. The women talked about issues which they had discussed with few others. Some women talked for longer and with less prompting than others; as a result I adjusted my technique. Repeat interviewing was particularly beneficial as it allowed me to develop an understanding of the participant's conversational style and I therefore accepted that some women expressed themselves more succinctly than others. At times I would attempt to keep the interview going when, on reflection, it was clear that the woman had nothing else to add. An awareness of this was helpful during subsequent interviews and allowed me to be confident of when it was appropriate to close the interview.

Reflection and the ability to critically appraise one's own technique are essential (Gibbs, 1988), as a result the research team met frequently to analyse my interview technique.

#### **4.2.1 Strengths, Limitations and Reflexivity**

The strengths and limitations of the research are discussed in this section, both are discussed in parallel and are accompanied by my reflections on the research. Reflexivity was an integral process throughout this research.

The application of phenomenological qualitative inquiry and the use of in-depth interviewing were appropriate as they resulted in the production of rich data. The longitudinal design also contributed to the production of rich data as serial interviewing illustrated the evolving experience. The research design employed in this study allowed women to reflect upon their experience and also revealed the consequences of an action, decision or procedure. This is particularly relevant to clinicians involved in the delivery of care as it is valuable to understand the implications of practice. Such insight aids the avoidance of blindly implementing services which may have negative long-term psychosocial consequences for women and their families.

The rich data obtained through longitudinal hermeneutic enquiry, produced findings that are grounded in the women's narratives and relate to their experience as described and interpreted at the time.

This study only captured the views of a limited number of women and this excluded non-English speaking women. Furthermore, the study was conducted at a single site in the North West of England; therefore the findings may not represent the experiences of women in other areas of the United Kingdom. As acknowledged this was the author's first undertaking of qualitative research and the use of phenomenology. I was well supported by an experienced team of researchers;



however, in the use of qualitative methodologies the researcher is the data collection tool therefore a more experienced researcher may have obtained and analysed the data differently.

The high risk clinic at the focus of this research is only the second of its kind in the world. Assessing fetal growth is common place in every UK obstetric unit; however, the use of combined screening to assess risk of FGR as a result of placental dysfunction is limited to two centres Worldwide; Toronto Canada and the UK hospital where this study took place. No qualitative work has been undertaken to explore the experiences of women attending these clinics, therefore this research was relevant and timely. The findings of this study are specific to a particular pathology but they add to the body of knowledge relating to high risk pregnancy and therefore have implications for research and practice in other high risk clinics.

Since the start of this research the clinic protocol has developed following the analysis of clinical data, as a result one of the five women eligible for this study would not currently meet the eligibility criteria if the study were to be conducted again. Data collection commenced just five months following the launch of this novel high risk clinic therefore the clinic has evolved; adjustments have been made to the clinic protocol and delivery of care. Furthermore the number of women seen at the clinic has increased and the experience and skills of the team have developed during the two years since the study commenced, this should be taken into account when considering the findings of this study.

A particular challenge was my dual role as a researcher and a clinical midwife involved in the care of the women participating in this research. A number of authors have explored this phenomena (Asselin, 2003; Hodkinson, 2005) as it is has several practical and methodological considerations.

In qualitative research studies, the researcher is the instrument. The presence of the researcher in the lives of the participants in the study is fundamental to the methodology (Marshall and Rossman, 2006). All qualitative researchers need to consider how they are perceived by interviewees and the effects of characteristics such as class, race, sex and social distance on the interview (Britten, 1995). All of the women I interviewed asked me if I had any children, it was important to consider the impact of my circumstances upon the interview. Furthermore, the researcher's profession can also be relevant, especially if the research associates them with the institution as the participants are less likely to be critical (Walsh and Baker, 2004). All of the women I interviewed associated me with their clinical care as I had regular contact with them during their pregnancy. During the research process I asked them to describe their experiences of attending a clinic, for which I am joint midwifery lead. Approximately seventy-five percent of a woman's interaction with her care provider in the clinic is with a midwife; therefore, midwifery input could form a significant part of the experience. As a result of my involvement in their clinical care and my close association with the other members of the clinical team the women may have abstained from truthfully recounting their experience, as they may have thought that any negative comments may affect their care. The women in this study did report negative and positive aspects of their care which informed their experience; however, one cannot be certain that my dual role did not influence their responses.

My dual capacity also had a positive influence upon the research; the women appeared to be very open in the interviews sometimes discussing issues and concerns that they had not disclosed to their partners, family or friends. I believe that my professional capacity as a clinical midwife assisted the relationship of trust which was present throughout all the interviews. The women who took part in this research appeared to welcome the opportunity to recount their experience to an interested party and also ask questions and seek reassurance about their care from the comfort and security of their own homes. However, it must be acknowledged

that women's knowledge of my clinical role and affiliation to the specialist clinic may have prevented the women from divulging the less positive aspects of their care. The findings do not support this as the women who participated in this study appeared to be very open about every aspect of their care, including medical management of their care and the other health professionals they encountered. However, they did not disclose any negative concerns about their interaction with me in my clinical capacity, the women who participated in this study may have included this aspect of their experience in their narrative to a non-clinical researcher, yet such a relationship may have imposed other limitations on data collection.

Undoubtedly the researcher, if known to the participant as a midwife, will be asked questions during the interview. From my experience this can often happen before the interview begins or whilst trying to arrange an interview over the telephone. van Teijlingen and Ireland (2003) suggest that it is a weakness if the midwife switches roles from researcher to care provider and offers advice or counselling during the interview. I challenge this suggestion as, on occasions additional contact with the midwife can be the participant's motivation for taking part in the research. However, the nature of the research visits were made explicit and my agenda was outlined at the start of each interview, as I wanted the participants to understand the purpose of the interview. Failing to answer a participant's questions may reduce the interviewee's willingness to answer the interviewer's subsequent questions (Britten, 1995). Oakley (1981) offers a possible solution of stating in the introduction that questions can be answered at the end of the interview, although this is not always a satisfactory response. On occasions the questions asked can relate to the experience, for example; "is this something you would have liked explained in more detail in the clinic?" Furthermore, a woman may feel undervalued if you are not prepared to answer her questions until she has answered yours. Therefore, I would try to answer questions or queries throughout the interview process, the women soon realised that I would answer their questions

and began to ask them at the end of the interview. I attribute this to the effective participant-researcher relationship which developed as a result of serial interviewing. I was, however, concerned that women may feel that the disclosure of information relating to their clinical care would be acted upon and that they would not have to take any further action. As a result, I summarised the dialogue at the end of each interview and re-iterated that I was present in a research capacity; however, I outlined which aspects of their care they should pursue with their care providers and what action I would take to assist this. If appropriate, this was documented in the women's personal maternity record. Throughout the thirteen interviews the women did not present with any clinical symptoms or concerns which required urgent action on my behalf.

#### **4.2.2 Personal reflections on the research experience**

The research experience has been a journey of personal and professional learning and discovery. In addition to the development of specific research skills the methods that I employed to overcome particular challenges have provided me with new knowledge and new approaches to learning. The research process has provided the opportunity for an exploration of self awareness and a greater understanding of the concept of knowledge. The process has developed my ability to analyse, question, interpret and to reflect upon knowledge and experiences. The experience has stimulated continued interest in the field of high risk pregnancy and generated many other research ideas. I intend to build upon these and the skills that I have acquired through this experience.

### **4.3 Recommendations for practice and policy**

Women's expectations of pregnancy influence their perception of the experience; as a result, care providers need to be aware of a woman's expectations relating to her pregnancy and work together to manage the expectations. This could be done through discussion at regular intervals throughout pregnancy, particularly following

the results of investigations or when revising the care plan. Furthermore, the information which informs a woman's expectations needs to be addressed; this is particularly relevant when counselling for screening or diagnostic testing.

The women in this study who were referred to the clinic as a result of abnormal serum screening markers were not aware that screening for Down syndrome can provide information relating to their risk of FGR. Anecdotal evidence collected through my clinical observations to date supports this. This suggests that the health care professionals who are responsible for counselling women for such screening tests are omitting to inform women of the results which can be obtained from the test and the implications of those results. This could be attributed to a gap in their knowledge and understanding and therefore indicates a training need. I suggest the delivery of training to all maternity staff through the hospital mandatory training programme and additional targeted training for the Antenatal Clinic staff who provide the counselling for such screening. This should accompany the production of specific written information to accompany the verbal counselling provided by the midwife.

The women in this study reported the benefits of receiving care from a specialist team. The findings suggest that care should be provided by a team known to the woman and her family. Furthermore, women should be able to access the team with ease. Methods of providing effective access to health professional should be examined further. Women should be involved in the planning and delivery of care, particularly at important time points in their pregnancy, for example; the provision for additional monitoring at the gestation when a previous fetal loss occurred.

Understanding a woman's expectations and coping strategy can aid the delivery of individualised parent education. This should be offered at timely intervals based on the woman's desire to receive information. Families experiencing a high risk pregnancy and facing the prospect of having their baby admitted to NICU should be

offered an introductory visit to the Neo-natal Unit. During this visit women's assumptions of the postnatal period should be explored.

The high risk pregnancy should be viewed within the wider context of a woman's life, this involves health professional exploring the impact the pregnancy has on her professional and family life and social interactions. It is important to note that the women who participated in this study did not describe themselves as high risk. Previous research exploring women's appraisal of risk (Heaman et al., 1992; Carolan, 2008; White et al., 2008) confirmed that women appraise their risk differently than their care providers. The findings of this current study suggest that the labels provided by health professionals to describe a woman's risk status are not used by women. However, this research did not explore why women chose to label or not label their assessment of their risk. Lupton (1999) describes that the societal concept of high risk refers to high levels of danger; women may not perceive their pregnancy as dangerous. Understanding how women exist in this world provides greater insight into the context of the care needs. The effects of high risk pregnancy on a woman's psychological state were not measured quantitatively in this study. However, the inclusion of allied health disciplines may be appropriate in caring for women with a high risk pregnancy as the women in this study reported increase stress and anxiety during their pregnancy. Additionally, none of the women in this study reported a diagnosis of postnatal depression; however, the provision on postnatal debriefing may be appropriate due to the additional stress experienced as a result of high risk pregnancy.

#### **4.4 Recommendations for future research**

It is important to acknowledge that the five women who participated in this research all had high risk pregnancies; however, two women did not develop the anticipated complications of pregnancy. Whilst it is important to hear the stories and experiences of all women, I would recommend that future research in this field

should aim to stratify the sample further, according to the level of risk. Subsets of risk exist within a high risk population and it could be useful to distinguish the experiences in order to identify particular needs. This will aid the development of appropriate care pathways and the targeting of resources and appropriate care.

The five women who participated in this research were all English speaking and described their ethnicity as 'White British'. This study does not therefore represent the culturally diverse population of the high risk clinic as only 45% of the clinic population is White British. This is a limitation of this research and many other studies. I suggest that future work involves collaboration with translators and leaders of ethnic groups to gain access to other cultural groups to enable the exploration of the experiences of a culturally diverse population.

Further mixed methods research is required to identify the appropriate delivery of support for women experiencing a high risk pregnancy.

Only one of the five women who took part in this research expected a referral to the high risk clinic due to complications in her previous pregnancy. The other four women had assumed, as a result of previous experiences and reassurances, a low risk status and expected their pregnancy to continue with minimal intervention. The findings from this current study and anecdotal evidence observed through my clinical practice indicate that a group of women are caught in the transition between low risk and high risk. This includes women who are waiting for the results of further screening or diagnostic investigation or who have been referred to high risk care and are then subsequently discharged. The experiences of these women are important and of particular concern to me and I believe they should be pursued through longitudinal enquiry as the evidence to date is conflicting. Stahl and Hundley (2003) argue that a woman's risk status should be reversible if the risk no longer exists, whereas Jackson and colleagues (2006) suggest that recognising the impact of being discharged from a high risk clinic is important in addressing a

woman's needs. This concurs with Baillie's work (2000) that women experience long lasting distress even after returning to a 'low risk' status.

When embarking on this journey to explore women's experiences of high risk pregnancy, I expected to become absorbed in the experiences of women with high risk, tentative pregnancies; however I did not expect to identify this group of women experiencing 'transitional' risk status. Further research is recommended to explore the experiences of this group of women.



## Conclusion

This research aimed to explore the experiences of women attending a high risk obstetric clinic. The inspiration for this research was prompted by my clinical interest in this population of high risk women. In addition, there was a dearth of British qualitative research exploring women's experiences of high risk pregnancy. The timing of this research was also relevant as, at the onset of the study, the clinic was newly established and only the second clinic of its kind in the world. Therefore, it was particularly important to conduct rigorous research at the onset, involving service users, which aimed to inform the care provided through the clinic.

My clinical practice and development as a researcher have been equally influenced by both the research process and the findings of this research. At the time of writing this thesis the findings are being implemented into the clinic care pathway. However, my clinical and research interest in this group of women has not concluded with the end of this degree programme. Undertaking this piece of research has inspired further research questions that I had not been aware of prior to embarking on this process. I intend to use the skills, knowledge and insight that I have gained through this process to undertake further research. Based on the findings of this study future collaborative work is planned to examine the delivery of care and support in high risk pregnancy.

The findings of this study provide information that should be of relevance and interest to any clinician who is involved in the delivery of care to women with high risk pregnancies and it may inform their own practice or research agenda. In addition, the methodology and design employed in this study are appropriate to research which aims to explore experiences and seeks to understand a particular phenomenon. Therefore the methodology and design should be considered to

inform other such research. Following the submission of this thesis, papers (including a methodology paper), will be submitted to peer reviewed journals.

In conclusion, this journey provided an opportunity for women to voice their experiences within the context of a high risk obstetric clinic. This has provided a unique phenomenon which adds to the body of knowledge surrounding high risk pregnancies and has informed the future care of other women in the high risk obstetric clinic.

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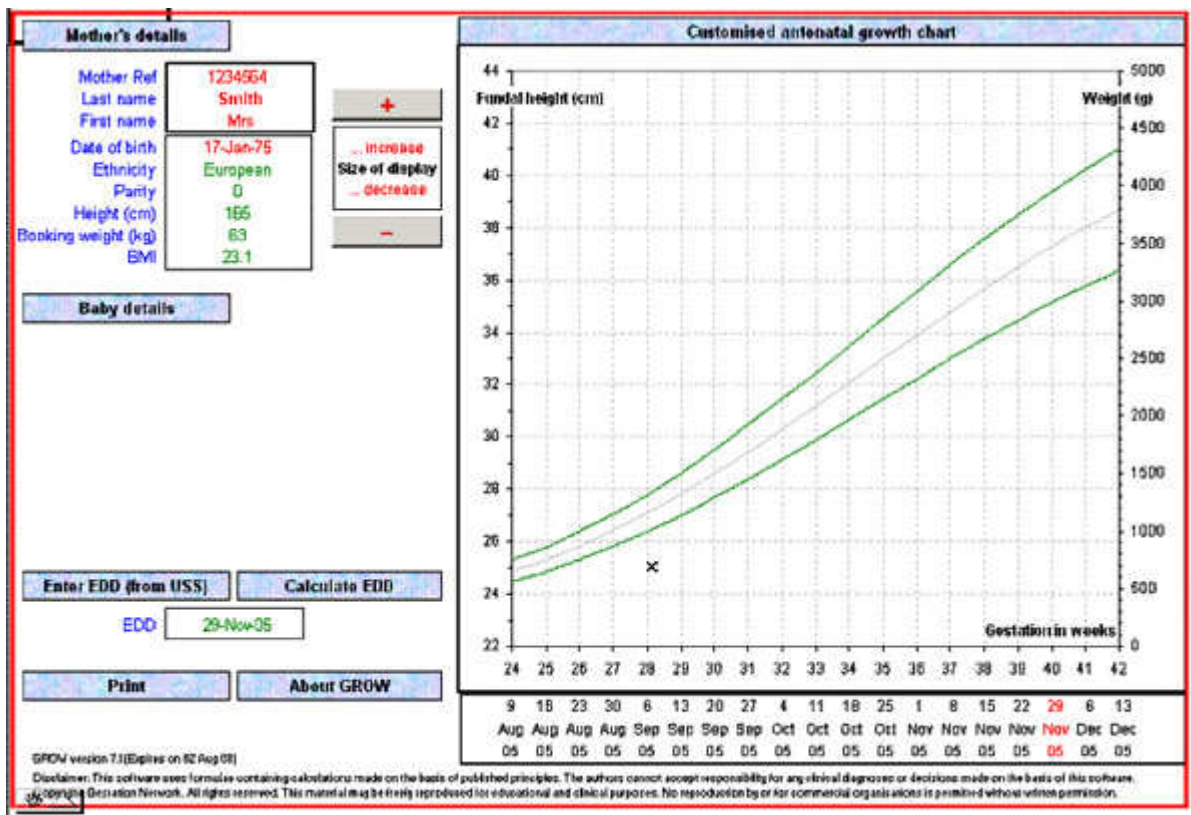
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# Appendix 1 – Customised growth chart

Measuring fundal height:



The fundal height measurement is plotted on the customised growth chart:



Perinatal Institute, 2011  
[www.perinatal.nhs.uk/growth/image006.jpg](http://www.perinatal.nhs.uk/growth/image006.jpg)



## Appendix 2 – Clinic Referral Criteria

<b>Referral Criteria</b>
<b>Maternal Serum Screening (MSS):</b>
<u>1<sup>st</sup> Trimester</u>
Papp A (Pregnancy Associated Plasma Protein A) <0.35 Corrected MoM
<u>2<sup>nd</sup> Trimester</u>
AFP (Alpha-fetoprotein) > 2 Corrected MoM
hCGb (Human Chorionic Gonadotropin) > 4 Corrected MoM
Inhibin-A > 2 Corrected MoM
<b>History of:</b>
<ul style="list-style-type: none"><li>• Previous baby under 2.5kg / 5lb 8oz (Live born or Stillborn)</li><li>• History of placental abruption</li></ul>
<b>Identified in the current pregnancy:</b>
<ul style="list-style-type: none"><li>• Abdominal Circumference &lt; 3<sup>rd</sup> centile</li><li>• Abnormal placental morphology</li></ul>

# **Appendix 3 – Interview Schedule (Version 1)**

## **An exploration of women's experiences of attending a high risk obstetric clinic**

### **Interview Schedule**

(Version 1, 07/04/09)

#### **INTRODUCTIONS**

The interviewer will thank the participant for attending and will attempt to make them feel as relaxed as possible. The interviews will be held in a place chosen by the participant wherever she feels is most convenient, comfortable and non-threatening.

#### **SETTING OF GROUND RULES**

- Explain Study
- Explain that matters disclosed will not affect level of care in any way
- Explain tape recording & transcription
- Explain study numbers/confidentiality
- Explain names will not be used or changed if appropriate
- Explain can stop at any time
- Explain that the interview is intended to take no longer than 1 hour
- Explain can refuse to answer question
- Opportunity to ask questions
- Consent
- Check tape
- Opportunity for referral to specialist services if required

#### **INTERVIEW PROMPTS**

In line with a phenomenological approach the interviews will be semi structured and respondent led. However, the following areas will be explored, the questions will guide the interview.

Participants will be invited to attend three interviews, at the following time points; at referral to the Placenta Clinic, in the third trimester of pregnancy at approximately 32 weeks of pregnancy and finally at approximately 4 to 6 weeks after delivery. Different areas will be explored at each interview in an attempt to explore a woman's journey through her pregnancy and into the postnatal period.

#### Interview 1: Soon after referral to the Placenta Clinic

- Do you understand why you have been referred to this clinic?
- What does that mean to you?
- How do you feel about going through a pregnancy labelled as high risk?
- How do you perceive the risk?

#### Interview 2: Third trimester

- What are the negative and positive aspects of care through the Placenta Clinic?
- What triggers positive and negative feelings?
- Have you had any thoughts about the birth of your baby?
- How would describe your pregnancy?

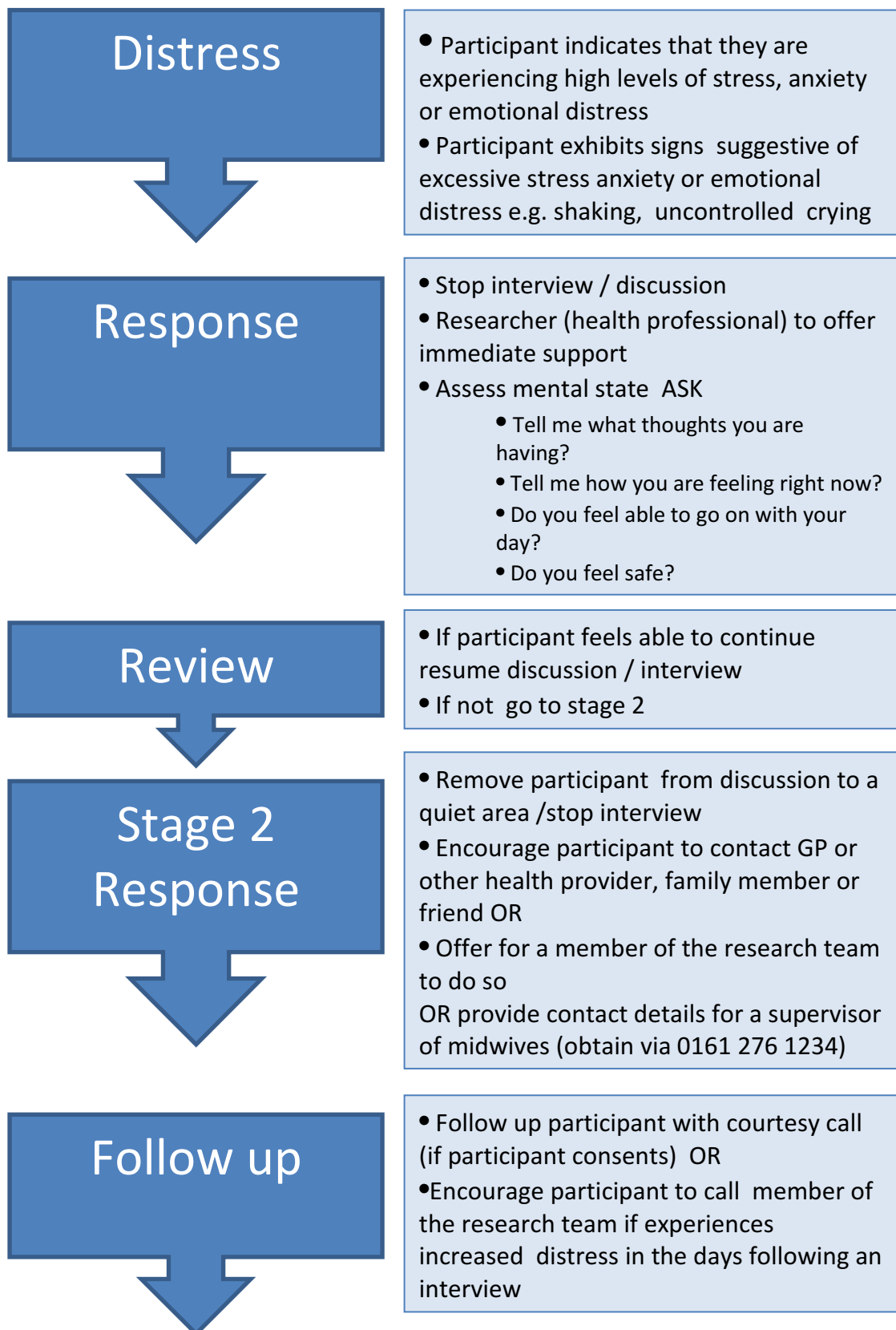
#### Interview 3: 4 to 6 weeks postnatal

- Do you think that events in your pregnancy had an effect on your experience of labour and the time following the birth of your baby?
- Did your experience meet with your expectations?

#### FOLLOWING THE INTERVIEW

- At the end of the interview the researcher will discuss referral to specialist services if required.
- The researcher will complete a reflexive diary
- The researcher will contact the participant to arrange the next interview and confirm continued participation in the research (before any contact is made the researcher will confirm that the pregnancy is on-going)

## Appendix 4 – Distress Policy



Adapted from Haigh and Witham (2009)

# **Appendix 5 – Participant Information Leaflet (Version 2)**

## **An exploration of women’s experiences of attending a high risk obstetric clinic**

(Version 2, 15/06/09)

### **Participant Information Leaflet**

#### **Introduction**

You are being invited to take part in a research study. Before you decided whether to take part it is important for you to understand why we are doing this research and what is involved. Please take time to read this leaflet, and, if you want to, discuss it with your doctor, midwives, family or friends. Please feel free to ask us if anything is not clear, or if you would like more information. Thank you for taking the time to read this.

#### **What are we trying to find out?**

Because of your medical / obstetric history you have been referred to The Placenta Clinic at St Mary’s Hospital; here specialist Doctors and Midwives will care for you during your pregnancy. Through additional blood tests and scans the clinic will identify your risk of developing a pregnancy complication.

This research wishes to understand the experiences of women attending this clinic. We aim to do this by obtaining the views of women like yourself.

#### **Why have I been chosen?**

You have been chosen because you are attending the Placenta Clinic.

#### **Do I have to take part?**

It is entirely your choice. If you agree to join the study you will be asked to sign a consent form, and you will be given a copy to keep. You are free to change your mind and withdraw from the study at any time, without giving a reason. The care you receive, now or in the future, will not be affected in any way by your decision whether or not to take part.

#### **What will happen to me if I take part?**

You will be asked to attend 3 interviews. The first interview will be around the time you are referred to the Placenta Clinic, the second interview will be when you’re about 32 weeks pregnant and the final interview will be four to six weeks after the birth of your baby. The interviews are expected to last no longer than one hour, the interviews will take place at a time and location convenient to you. This can be within the clinic area, in your own home, or at the research facility.

You will be interviewed by a Midwifery researcher (Suzanne Moody), to discuss your experience of your pregnancy and the postnatal period. The interviews are intended to be relaxed and conversational. There are no right or wrong answers we just want to try and understand your experience of pregnancy. Any data collected from you will be kept strictly confidential.

Discussing your pregnancy experience may at times cause upset, we believe that it is important that we hear your experience. If you feel that you don't want to carry on with the research or the interviews you can stop at any time. The researcher is an experienced Midwife who can listen and refer you to other professionals who may be able to help should you need this.

### **What happens to the information we collect?**

Any identifiable data such as name & address will be removed to protect your anonymity. If you agree the interviews will be tape recorded where possible, so we can remember exactly what was said. These recordings will be transferred word for word into a written format for analysis by the researcher and research team. Following transcription tape recordings will be destroyed. The data will be analysed by the researcher and the research team.

### **What are the benefits of taking part?**

There is no direct benefit to you of taking part, however the study may benefit future generations of pregnant women.

### **What if new information becomes available?**

Should any relevant new information come to light your Research Midwife will tell you about it and discuss whether or not you want to continue in the study. Your doctor may decide it's in your best interest to stop. He / she will explain why and make arrangements for your continuing care.

### **What if something goes wrong?**

In the unlikely event you are harmed by taking part in the research, there are no special compensation arrangements. If you are harmed due to someone's negligence you may have grounds for legal action, but you may have to pay for it. Regardless of this, should you wish to complain about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms will be available to you.

### **What happens if there is a problem?**

If you have a concern about any aspect of the study, you can speak with the researcher or the researchers supervisor (contact details listed below), who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the Hospital Complaints Procedure. Details can be obtained from Patient Advice and Liaison Services (PALS) on 0161 276 4261. The researcher is a qualified Midwife who adheres to rules and regulations of the Nursing & Midwifery Council (NMC), whilst information collected is kept confidential the researcher as a Midwife has a responsibility for the safe guarding of others. Therefore if the researcher felt that you or members of your family (including your unborn child) were at risk of harm then she would be obliged to disclose this information to an appropriate professional.

### **Will my taking part in this study be kept confidential?**

All information collected about you during the course of this study will be kept strictly confidential and all procedures for handling, processing, storage and destruction of the data will be compliant with the Data Protection Act 1998.

Any information about you that leaves the hospital will have your name and address deleted, so that you cannot be recognised by it. This includes data that are transmitted electronically. Details about the study and your participation will be kept in your handheld maternity notes, so that clinicians caring for you (GP, Midwife, Obstetrician) will be aware of your involvement. Information kept by the NHS and records maintained by the General Register Office may be used to follow

up the health status of you and your baby. All information will remain confidential at all times. Should further studies be planned related to you and your involvement in this study, we will contact you to seek your permission.

### **What will happen to the results of the research study?**

The study results and findings will be written up as a dissertation for a Masters degree. The study results may also be published in professional journals and presented at conferences. Your individual results will not be available. Please contact [suzanne.moody@manchester.ac.uk](mailto:suzanne.moody@manchester.ac.uk) for a copy of the results.

### **Who is organising this research?**

This research study is being undertaken as part of an education programme through The School of Nursing, Midwifery & Social Work at The University of Manchester. The research is closely monitored by a supervisory & advisory team. The hospital and other clinicians do not receive any payment if you take part in this project.

### **Who has reviewed this study?**

The local Research Ethics Committee has approved this research.

**Thank you for your time**

#### **Contact for further information:**

**Researcher / Research Midwife: Suzanne Moody**

**0161 701 6980**

**University of Manchester, Reception, 5<sup>th</sup> Floor (Research),**

**St Mary's Hospital, Oxford Road, Manchester, M13 9WL**

**[suzanne.moody@manchester.ac.uk](mailto:suzanne.moody@manchester.ac.uk)**

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## Appendix 6 - An interview transcription

04/05/10

14.39

'Marie' PN Interview 005 (3 of 3)

Marie had already started talking about her experience before I started the tape, she was saying that it was stressful at the moment, I quickly interrupted and asked if I could start the tape. Marie agreed.

TAPE STARTED

SM (Researcher): so it's stressful?

M: very stressful, very, very stressful.

SM: in what way?

M: splitting yourself between the 2 kids and being at the hospital, because while you're at the hospital you're thinking 'oh, I've got to get home to the 2 kids and while you're at the hospital you're thinking, oh I should be at the hospital with the baby' so stressful

SM: so how does that make you feel when you're here and not there?

M: if T's not with me and he's at home with the kids then it doesn't bother me, and I think it's the same with T if he's there and I'm here with the kids then it doesn't bother him but if we've got people minding them, it's hard trying to get there and back, especially with the transport, when we were getting the train because it was taking us 2 hours to get to L as well.

SM: so it wasn't that much better at L?

M: no, I think she should have stayed at M

T shouts: 'yes, it was better at M'

We all laugh

M: because when we got there (to M) we were staying so it didn't matter what time we got there, but when she was in L we had to leave at 7 to get the kids to school, get to the bus stop and make sure you were in time to get the train and so you were there for at least 2 hours before you had to come home.

SM: that's hard isn't it?

M: yeah.

SM: so did she come to O at the weekend?

M: on Friday

SM: so she's not been there that long has she?

M: no, she's had her first bottle now. She drank 6mls

SM: wow

M: they said she's only drink 2, but our greedy guts had 6, so she's doing good, she's not bad, if she's been iller or sicker it would have been worse than what it is now.

SM: and how are you feeling?

M: I'm alright, but I wasn't the other week. I said that I'd just painted this face on like I was alright and everything was ok and I was fine but I was being a little bitch to T.

SM: you take it out on those closer to you

M: yes, I was going I packed my bags and nearly lefty

SM: where were you going?

M: anywhere, away from anyone and everyone I was going away from everyone

SM: is that just how it got you?

M: yeah, I thought it was just easier to do it on my own, but then we talked and it was alright, we decided that we had to do it together

T: where are his footie socks?

M: in the airing cupboard, we were going through a bad patch after she was born

SM: you and T?

M: yes, I hated him, I hated everyone



SM: why do you think that was?

M: because after I had L me brother had C, then T's cousin had JP, they throw them at you and you think 'I don't want your baby I want my one' and in M we weren't allowed to do anything except change her nappy but in L, we were allowed to feed her and change her nappy but in O I'm allowed to feed her, give her vitamins, change her nappies, do her temperature do all her cares I'm allowed to do anything I want to because they said it's the next step to home anyway, so they want you to do as much as you want.

SM: and how's that made you feel?

M: it's better, but then you feel under more pressure to be there at the same time, you have to be there when her cares are due and they say 'we'll save it for you' and then it's fair on her because she has to lie there in a dirty nappy.

SM: so do you feel that puts you under pressure?

M: yes, to get there on time, and I'm like stop, cos' he dawdles, because I get there dead early if I go on my own but if I go with T he dawdles, he's like 'let me just do this first, let me just do that first'

SM: and you're like 'get a move on'?

M: yeah, and 'will you frigging get a move on and get out of the door?' I stand at the front with the keys going 'come on'

SM: and how long does it take you to get there now?

M: to O? 25 minutes on the bus

SM: is it one bus?

M: yeah, it stops right outside the hospital

SM: that's good

M: so it's not that bad now

SM: so last time we spoke on the tape you were....

M: it's when they thought she weren't going to make it

SM: I've spoken to you after that

M: have you?

SM: yes, this is the 3<sup>rd</sup> interview now, so we had the 1<sup>st</sup> interview when we didn't know if she was going to get to the

M: 500g

SM: yes, and then I think she was putting on weight and since then you've obviously had her

M: she's 7 weeks old now

SM: so take me back to when he told you that you were going to have L.

M: say's something I can't understand

SM: so you came into clinic on the Monday

M: yeah, on Monday, he done a scan and he said she's coming out today, she's coming out now, but then he turned round and said you don't have to have her, and I was thinking 'you cheeky get, you just made me do all this and now you're telling me that I don't have to have her' (laughing). He said 'you've got a chance to pull out' and then he said to me 'we'll only deliver her, if we've got a heartbeat just before we go into theatre' so she still could have died between being in the clinic and sitting on the bed and waiting for them to get a move on and take me to theatre, and it was scary when he said 'we'll only deliver her if she's got a heartbeat'. But she was dead hard to find a heartbeat because she was so small the monitors didn't really fit.

SM: so how was the waiting?

M: the waiting was worse because everyone was ringing me and 'oh, we wish you both luck' and then I wish I'd waited longer because when they told me I was going into theatre I thought I was going to throw up.

SM: so you felt sick and worried and anxious?

M: I was more worried that she was going to come out and she was going to die as soon as she came out, cos' at first when we went looking round, they said they'd show me her and they'd hold her up over the screen so I could see her dead quick and when I had her they didn't.

SM: so how did that make you feel?

M: like something was wrong with her, no but then it was ok because I heard her cry, she cried, but the worse was when I was sat in the waiting room to go into theatre I could see T across, through the windows, because you were there forever, and then they stuck that big needle in my back, never, ever, ever, ever have one of them.

SM: what was that like?

M: they stick it and you feel like your stomach's being pushed forward. Instead of saying I'm scared I kept saying I feel sick so they kept throwing all these bowls under me face, cos' instead of saying I'm scared I kept saying I feel sick , I was saying I feel sick you know. But then they stuck that horrible needle in me hand and I sat and watched them do that, I'm alright if I can see them doing it, I watch but if I can't see what they're doing then it petrifies me.

SM: so when they were doing the one in your back, you didn't know what was going on behind you?

M: no, because they say to you 'arch your back' and I said 'how are you meant to arch your back when you've got a big stomach?' 'Drop your shoulder, do this' and they hit me nerve so I kicked one of the Dr's (laughing) I kicked one of the Dr's because they hit a nerve in me back. It weren't as painful as what I thought because they done the other needle first.

SM: The local

M: yeah, so it wasn't as bad as what I thought, but then when you go numb, I started shaking and me mum went as white as a ghost because me mum came in with me didn't she? And she was as white as a sheet and I kept saying 'you alright mum?' And she said 'you're the one that's lying there, are you ok?' and I was shaking I couldn't stop me jaw from shaking and they said I was going to bit my tongue if I weren't careful, so that made me mum panic.

SM: and did you think you were well looked after in that time?

M: yeah, because I was just sat talking to my mum, then he stuck this big blanket over me, so the blanket was up to here and it was horrible when she got this (a word I can't understand, a lot of background noise) then they didn't say nothing and I said 'is she alright' and all they kept saying was 'she's tiny' 'oh my god, she is so small' and I was thinking she can't be that small they said she was over 500g, cos' even the nurses and the doctors about the anaesthetic looked shocked by how small she was and the T said he went in and she was just lying there with a ventilator in her mouth on that scale thing

SM: on the resusitaire

M: but he thought he was coming to see me didn't he?

SM: I know I took him into see L and I didn't realise that he thought that he was coming to see you

T comes into the room

M: you didn't like it when I was in theatre did you babe?

T shakes his head, mobile rings, M answers and has a conversation about O.

T offers a cup of tea, photo frame falls over, some discussion about the frame

M: they keep calling O, L and she really doesn't like, she's not happy, especially me Nan, cos' she's got cancer hasn't she?

SM: yeah, how's she doing?

M: they're not doing anything for her they're just making her comfortable, she's skinnier than me, she's skinnier than me little sister as well, our M, you've seen her haven't you?

SM: yeah

M: she's skinnier than our M but her hips are wider where the cancer is so you can see where the cancer is.

SM: oh dear

M: but she can't wait to see L, she calls our L; L ### who can fit in my pocket.

SM: well, she can can't she?

T brings in some photo's of baby

M: the rabbit got them (referring to the photos)

T: yeah, they fell off the top of the fridge and he got them

SM: she looks so tiny there

M: she looks freaky there, they're the ones me mum took when she was born so some are very blurred and everyone's robbed some. Did you think she was small Suzanne? Because everyone kept saying that she was tiny, that's all they kept saying to me when I was in theatre 'oh, my god, she is very small'

SM: and how did that make you feel when everyone kept saying she's just really small

M: that she's going to die, because they kept saying 'we haven't seen one that small, we haven't seen one that small' and I was like... (T interrupts)

T: ... the nurse said it yesterday in O, she said 'the smallest I've seen is 700g'

M: and I said L went down to 475 didn't she?

T: 486

M: 475

SM: and was she 520 when she was born?

M: 536 and she went down to 475

T: very small, very, very small, they think that she's very interesting don't they?

M: they say, even though she's premature she's got a lot of character in her face, cos' she pulls some mad faces

SM: I wonder where she gets them from!

Still looking at photos

SM: aww, look

M: I don't like those pictures, she looks scary

SM: but just look at how much she's come on

M: I know, she looks very red and horrible, I like this one, she looks like a normal baby on that one

The rabbit starts playing with the curtains

M: Benji I'm gonna kill you

SM: why does he do that with the curtains?

M: because he's trying to did

T: he thinks there's something there for him

SM: oh

T: he's not very bright, bless him

SM: well, she has had loads of spirit right from the start

T: I think they said she was interesting because she's doing so good, because she's so little, they were saying 'she's got good genes'

M: oh yeah the woman in L?

T: yeah the matron or whoever she was

SM: look at J (still looking at the photos)

M: they're were not very nice in L

SM: weren't they?

M: they were a bit snotty

SM: why were they snotty?

M: I don't know well, when you ring up, when you ring up M, because I got to know everyone in M and they tell you everything what they've done, like all the tests and what the results of the blood tests was, and all you get in O is 'yeah, she's fine'

T: I'm going for J, I'm off, (shouts) I'll see you later Suz

SM: see you later T

M: so that's all they said 'yes, she's fine and put the phone down' and then I was sat there on me own because T couldn't go because his hands went bad and they said 'so how old are you then?' and I went 'what do you mean?' and she went 'well how old are you?' and I said 'well how old do you think I am?' and she said 'you're about 17 aren't you?' and I was like 'no, I'm nearly 25' and she said 'well, how come your baby's so small?' and I was like 'well I don't know, you tell me'

SM: how ignorant, and where was this? O? No that was at L

M: yep, I think they just thought that because I look young that I was too young to have a baby and it all went wrong.

SM: that's really ignorant isn't it?

M: yeah and their faces dropped when I said I was 24, I was like 'I don't look that young'

SM: well you do look young but you look young in the sense of you look good.

M: I don't look like an old foggie

SM: no you don't you just look really well.

M: just normal, not bad for having 2 kids (laughing) it didn't hit me that I'd had her, 3 days I was lying the bed and I just turned round to terry and I said 'I'm a mum of 2 now aren't I?' and he went 'yeah, and it's only just hot you now?' and I was like 'I've 2 kids now haven't I' and he was like 'yeah, you have' and I was like 'oh, ok'.

SM: how did you feel, you know when we did the first interview on the tape and you expressed that it was difficult to bond with her then because you didn't know whether she was going to come or not so how did you feel towards the end of your pregnancy and when she arrived?

M: I still thought she weren't going to come at the end cos erm, E, the Dr scared me to death and I hated him then, (laughing) cos' I go through phases of liking him and hating him and I hated him

SM: I know

M: cos' he kept asking me, 'do you wanna do it?' and I'm thinking I've already told you I want to so there's no need to ask me again, so you don't have to ask me again. I was lying in the bed and said 'babe he keeps asking me if I want this baby, I'm sure they think I don't want it' (Laughing) and he's going 'no, it's cos she's so small' and I was like she's done it all and she did everything that she was meant to do. And you look at our #### who's baby died and you think just look at our L because he was nearly 800g and I was thinking it's mad the way they can be born so big but because she was 32 she had a better chance.

SM: well she did and you had the steroids

M: yeah, cos they said to me eventhough everything's small it's mature, that's why her bowel wasn't messed up and she's still taking the milk well, cos she's on like 19mls of milk every 2 hours, so they said it's too much

SM: she needs to be on a little bit less just to let ... (interrupts)

M: yeah, cos she's not on breastmilk anymore. I gave that up as a bad job

SM: you did really well

M: I know but it was hard because I was travelling and it was defrosting and erm J and O were like 'mum, why have you got milk in your boobs, I've I got it in mine?' and I was like 'no, leave me alone' and she'd sit with me while I do it and she wouldn't move and I was like 'O, just go away, leave me alone'.

SM: so why do you think it was a bad job?

M: I think it's cos I didn't want to do it in the first place, cos I'd never planned to breastfeed I was thinking, but I did it while she needed it

SM: yeah

M: so she had it while she needed it, and then she went on donor milk then, I was a bit put off by that, it made me cry when they offered donor milk in M.

SM: did it?

M: yes, because she was only 3 days old and I was like 'give me a chance' and they made me cry then

SM: oh I bet it did

M: and T said 'what are you crying for its only milk it's not as if it's a big thing?' and I said I couldn't even grow her properly and now I can't even feed her

Rabbit comes in to the room, M tells it to get out

SM: so is that how it made you feel?

M: yeah, it felt like cos I hadn't done it right when I was pregnancy and I couldn't do it right then.

SM: it's not that (almost whispers it, as I wanted to give reassurance but didn't want to interrupt the flow of the interview)

M: I know, but it's put me off having another baby though

SM: has it?

M: T wants another one, he wants a boy, but I say we've used all our luck with Lucy, cos you don't know if it'll happen again though do you?

SM: I know, but the chances are that it won't do, you've had a healthy pregnancy before and ....

M: but then I had miscarriage after miscarriage, I had about 2 or 3 miscarriages before I had L. So I'm saying, give it up as a bad job.

SM: If you've decided you've decided but it could be too early to say

M: well, T said to me 3 days after she was born 'we'll have a boy next time eh, love?' and I said 'we've only just had her, give me a chance' I said 'she's only 3 days old, stop talking about another baby already'

SM: and give you chance to recover

M: I know J said to me 'now you've had the baby you can have 6 weeks and then you'll feel better won't you? Cos that's when the nurse said you're allowed to do stuff again' and I said 'yeah' so he said 'does that mean I'm going to get a brother in 6 weeks then?'

Both laugh

M: 'no way, no way' and he said 'why?' so I told him that if I got pregnant within 2 years that it would kill me so he stopped asking and T said 'if M gets pregnant now and the baby grows her cut will open and she'll die' he said 'ok, wait 2 years'

SM: and how have the kids been?

M: J's alright, he got shouted at, cos he just thinks he can grab her and stick his hands in the incubator whenever he wants and it's ok now because she's bigger but when she was in M he used to try and grab her and O is just disgusted with the whole thing.

SM: is she?

M: yes, because I'm her mum and no one else's mum and I've always only been her mum, she say's 'oh, I love L' but I say 'do you want to come the hospital?' and she say's 'do I have to?' but she's dead good with me brothers baby, but if I've got hold of him, she's on me, sat right next to me 'I love you mum, I love you' and she cries when she goes to school now because she thinks I'm not coming home, she thinks that once I drop her off at school that she's going somewhere else.

SM: so it's been tough hasn't it?

M: I think it has on our O because she's only 5 but it's not been as bad as what I thought because she is 5 so I did leave a good age gap between them

SM: yeah

M: cos if she'd have been younger it would have been a hell of a lot worse, but I don't know how J feels because he doesn't really talk to me because I'm not his mum, so It's weird trying to ask J how he feels..

Shouts at the rabbit for chewing the curtains

M: it annoyed me when they wouldn't let me see her, I had her at half four and then I was in theatre until 5 and I knew T would have been panicking about me , so I said to them 'can T come now?' and then they took me out and they said 'no, only your mum' and me mum said 'I'll go and let T in' and I said 'no, you're alright mum' and when I came round the corner, he's sat in the room and he went 'where have you been?' like I'd been shopping or something and I was like 'I've been in here why?' and he said 'no one came to tell me that you were out of theatre or nothing or that you were alright' no one came to tell him that I was alright or out of theatre and that everything had gone ok. So he said 'where've you been?' and I said 'I've been shopping love I went to buy some new furniture and that'. But what scared me as well is that I could move my toes when I got out of theatre just as soon as I got wheeled out of theatre I could feel my toes, and I thought 'that's freaky, what if it wore off?' *some words I can't understand* and I was saying 'can you hurry up?' and me mum was a bit disheartened that she didn't get to see her when she came out, we thought that they might have let her go in and see her, but then she'd have had to walk past my open stomach wouldn't she?

SM: yes, she would. Probably because she was so small they just wanted to get her to the paediatricians, baby doctors and get her hooked up to anything that she might need

M: cos I thought that Dr X, would do my caesarean, cos he hasn't seen L in the flesh has he?

SM: has he not been down to see her?

M: I don't know, he didn't go while I was there

SM: I thought he'd seen her on special care.

M: I don't know, he might have done, I used to hide in special care, away from them nurses, I wish I'd hid when they took my stitches out

SM: they had to take them out, they'd have found you wherever.

M: They said to me 'don't leave the room, I'll be back in a minute' and I kept saying 'can you not do it tomorrow?'

SM: they'd still be in if it was up to you.

M: I know they would, but it doesn't hurt anymore, it feels weird though cos it's numb.

SM: are we seeing you next week for your postnatal appointment?

M: yes, the 13<sup>th</sup> and then you're going to stab me with another needle aren't you? And what would that one be for?

SM: Blood, we'll probably just take some blood.

M: Is that all you're going to do just take some blood?

SM: we'll have a look at your tummy and talk through everything that happened.

M: yeah, cos he did come down and tell me about my placenta, he said it was bad, very, very bad.

SM: erm and how did that make you feel?

M: that we were lucky that she was ok, because when we found out that she was very small, and they were saying well if you have her she could be severely brain damaged, she'll be on a ventilator for a while and she was only on it for 17 hours weren't she?

SM: mmm (agreeing)

M: and then in M she was doing like 8 hours off her cpap but now she's only doing 5

SM: but she's still coming off it

M: yes, cos she was doing 8 hours on 8 hours off in M but now she does 5 off and 3 on, but she did do 24 hours off it.

SM: Did she?

M: yeah, but then it knocked her for 6, it pushed her too much.

SM: it exhausted her

M: yeah, so she had a bad few days then, she had an infection in M, she had a bleed on her brain in M, but that's all cleared up now, they said it won't affect her because it weren't in her brain, she's got a heart murmur, she's got one of her valves that leads from her heart to her lungs which is too small they said, but that should hopefully grow with her, so she doesn't need open heart surgery they think, so we've been quite lucky when you think, I don't half pick some people to talk to, I really don't know how I manage to pick these people to talk to (laughing) B's mum drew me up the wall I wanted to kill her, and then I got talking to someone; P's dad, and then P died

SM: oh goodness

M: and then he asked me if I wanted to go and see him, I was like 'no thank you, bye bye' but he still rings up now to check up on the kids that were in the room, cos there was one baby there (points) and then there was P and then L and he still rings up and checks on L and that other baby, but I don't know what that other baby's name is. I said he should have just cut himself off.

SM: It's hard isn't it, when you've been that close to it all, it's hard isn't it?

M: yeah, cos he was only a few days old and he never even got to talk to him or nothing when he was alive. First of all I used to feel dead sorry for A because she used to compare the babies, because everyone was saying that it's weird to have 2 babies similar in size because he was, I think he was about 20 / 30g heavier than L weren't he? So she used to compare and she used to say 'oh, they won't let me hold B' and she discharged herself early which made me wanna punch her in the face and then she booked in to stay in the rooms and didn't stay, when it's not fair on the other mums.

SM: it's not is it?

M: no, cos she never stayed in them, she'd book them but not stay and then you'd have to wait for a place to stay because they were all booked up.

SM: I haven't seen much of her.

M: I like S though, cos S was there when she was born and then she got her ready to move to L, so I said 'do you want to move to L hospital with her?' But the journey from M to L really knocked her she had a blood transfusion that night, so I think travelling doesn't agree with her.

SM: how you've felt about her moving from hospital to hospital?

M: I think it's funny, I say to her 'you've seen the world already and you've not even been out of your incubator' cos' this is her third hospital isn't it? But I wish she'd stayed in M now because it was a lot easier, even though I was away from O it was a lot easier cos' she'd know that I was going and then I'd be home and then I'd be home just for her for those 2 or 3 days that I was at home and the attention would be on her, but now, when she got moved to L it was like 'I'll drop you off at school, but such and such is picking you up and mummy will be home at such and such a time' and by the time I get home she'd be going to bed and I'd be dropping her off at school again and someone else would be picking her up, so it was hard.

SM: yeah, it was a bit messy wasn't it?

M: yeah, cos she'll come in now and go; why don't you pick me up mum?

SM: so who's getting her today?

M: A, me mate, C's mum!

SM: oh yeah

M: she's going to get her today, but it won't be too bad, she doesn't like coming to the hospital with me though and her and J fight when they're at the hospital and fall out, lie on the floor and touch the things and if the baby's there then J's face is there (very close) and I'm like 'don't breathe on her!' and I do it to T as well, I'm like 'don't touch her and don't touch that' (laughing) and he goes 'she's my baby as well you know?' and I go 'and don't touch that (laughing) cos it might go off and don't open the gate thingies because her SATS have gone down, shut that door now'

SM: so you said it was a difficult for you and T when you first had her?

M: yeah, I nearly left him twice, I hated him.

SM: Why do you think that was?

M: (paused to think) I think it was cos the way he spoke to me, cos he used to sit there and he used to talk, and say if me friend was round and all day he'd ask me, this one day he asked me all day 'what's up with you?' I was like 'nothing' it was the first day I'd stayed at home and not gone to the hospital I just wanted to sit down and relax and plus the fact I was cooking a roast dinner. I said 'leave me alone' and then all day he kept asking me what was up with me and then me mate came round for a cup of tea, we were chatting and he goes 'something's not right with her is it?' and I said 'I am sat right here, you know, don't speak to me like I'm not in the room' and I was going to me mum's twice I was, I was packing up and going and then he made me feel dead bad because he was going 'even if you go I'll still love you and I'll still love the baby and I'll always love you and me baby' and I was like 'aw, I'm dead cruel' but in my head I weren't and it felt that he was trying to make me think that I was going by saying things that I knew I hadn't said, he say I said something when I knew I hadn't and saying I'd got the baby blues and I've got this and I've got that and I was like stop putting things in me head when I know I'm not, I said to him 'you make me feel like I'm going crazy you'

SM: so how did it get resolved?

M: (pause) he said to me that I have to stop speaking to him like a bag of crap and not loose me rag so much and I told him what he had to do; stop annoying me, stop grabbing, cos I had just had a baby and leave me alone and when I say I'm ok I am ok, he doesn't need to ask me 20 million times a day cos he says that I paint on this face and make everyone think I'm fine. Cos I haven't seen anyone since I had her, the community midwives been and everything and I just leave T to sort her out (laughing) I was sat in the hospital while T was sat in here with the community midwife (laughing)

SM: checking out T's scar

M: why is that what she's meant to do?

SM: yes

M: no way (laughing) I thought she was just coming to talk to me

SM: if you'd have been worried you could have seen a midwife at the hospital  
M: and she was asking him 'is M depressed?' and he was going 'I don't think so why?' and she told him that people who have baby's in special care are more prone to getting depressed. So that was it then he was on this thing about cos the baby was in there I was depressed and I had to go to the hospital, the Dr's for loony tablets.

SM: and did you think you were depressed?

M: no I thought he was making me feel like I was going crazy because he kept telling me I was and I said to him 'it's hard to share L with T because I never had to share o with her dad' from the day she was born she was always mine and cos her dad was only 17 when I had her he weren't very interested anyway so he didn't want to do nothin so you just go into single parent mode and I said to him, so I said to T 'it's hard to switch on and say she's ours because I'm like I think she's mine, she's mine, leave her alone, get off her she's mine'

SM: and do you find it easier to think oh it's just me sorting everything out, is it easier that way?

M: yeah, that's what I said to him, in my own head, I have to be a single parent to know that I can do it, cos, I need to know that I can do it without you, I said 'cos I don't want to sit here and be all whingy and going oh my god my poor baby and da da da and then there's nothing wrong with her' yes she's in intensive care and in the incubator because it's the best place for her but I don't want to get where I have to rely on him I need to know that I can do it on my own if I have to, and I think 'sod yous, I'll just do it myself, it's quicker and it's easier'

SM: it is and I think sometimes you end up

M: (*interrupts*) cos I find myself saying 'ahh me baby' not 'our baby'

SM: well it's what you've been used to isn't it?

M: yeah cos O's never been for her Dad and her Dad's only just started now, but she's always been mine and I've always had the final say and I've always done this, but it's hard cod T's such a hands on dad and we're both so used to doing everything on our own cos even when he was with J's mum J's mum was depressed but she still won't admit it now, she went on the tablets and everything and she just lay on the couch and did nothing, so he come in from work and did all the bottles and everything and I'm used to doing everything

SM: yeah

M: so it's hard, I said we're going to fight over her, we are, I can see it when she comes home, we're going to fight over her 'I'll do it', 'no, I'll do it'. But he thinks it's great now that I'm not pregnant because I get up and do everything.

SM: but you didn't sit that still before did you? Apart from the bedrest?

M: when I was on the, I used to go, I never used to go out, I used to sit in my room and lock myself in me room, I hated the world and I hated people asking me and touching me belly and I hated it

SM: so has that changed now?

M: Yeah I'm like (shouting) 'do you want to come and see the baby?'. Yesterday I went and bought everything, we didn't even have a babygrow or anything in this house and now I've got everything, I've got a pram and everything now, I didn't have anything.

SM: and why didn't you buy it before?

M: in case she died, I thought it's easier to deal with the baby dying instead of homing home and .... I made that mistake just before I got pregnant with L I was already 3 months pregnant so I had a scan at 7 weeks cos I had a bleed and they said everything was alright so we went out and we bought loads instead of waiting the 3 month scan and we came home after the 3 month scan after it had stopped growing and I had all the stuff there in a box, so I thought it would be easier just to deal with the baby dying rather than dealing with her dying and then coming home and seeing a pram and everything.

SM: so how have you coped with making that transition from thinking she's going to die to, do you believe she's going to be alright and come home?

M: I'm still iffy about it when she has bad days and I think 'oh my god' because they can turn so, cos they can look like they're fine and then turn dead quick one



minute, like you can in and see her one day and she looks good and she's having a bottle and she's doing everything and then you go and see her the next day and she's dead tired and she's dead white and dead pale.

SM: and how does that make you feel when you go in and she's like that?

M: I hate it. *Rushes off to the toilet saying* 'I've just got to go to the loo, I've been holding it in for ages'

SM: oh, you should have said

TAPE PAUSED

M: I forgot what I was saying

SM: about going in and having hard days when you see her and she's not doing so well

M: and it makes me feel bad when, everyone always say's, like me sister rings me up when she's drunk and she's going 'I don't know how you feel because I've always took my babies home, don't you feel bad for leaving her' and then I took me mate's into to see her she said 'I don't wanna leave her' I said 'come on let's go' and she said 'so you not feel bad for leaving her' and then I'm thinking 'should I feel bad for leaving her?' but as me and T say it's the best place for her, so why feel bad when you're leaving her somewhere where she's getting better?

SM: and she's well looked after

M: cos it done me head in as well when I go up the school they're like 'ah, don't you look dead good? ' cos they see K, T's cousin who had her baby and she looks like a bag of [whispers] shite (laughs) and I'm like, well I'm not getting up with my baby and I'm not getting up and I'm not doing night feeds.

SM: I know but I think you'd still look like this

M: and I said 'when she comes home you won't see me like this I'll be coming up to the school in me pyjamas' I said 'wait till she comes home' cos she'll have to get fed like every 2 hours won't she? 2-3 hours.

SM: so we talked about this before, do you still agree that it's hard what other people say?

M: yeah, cos they look at you like you've not had a baby, they say 'have you really had a baby?' and you're like 'yeah, why?' you know cos they don't see you pushing a pram and doing all the normal stuff. Like our K comes and he just throws our C (baby nephew) at me, he goes 'here you are go and see you Auntie M' and when I was breastfeeding he kept trying to eat me and I was like 'get him off me' cos as soon as he came, cos K came round the day I come home from hospital as well, which made me feel really peeved off, cos I'd just got in, cos I was in there for 10 days weren't I? I'd just got in and they threw this baby at me and I was like, and he was biting me top I and I was like K get him off me.

SM: that's tough isn't it? When you've just come out of hospital?

M: I was made up to see him cos he is me nephew but I was like 'uff, get off me, stop trying to bite me, stop trying to eat me'

SM: yeah, so have you had to develop a way of coping of not having L here?

M: I think it's easier, I'm dreading her coming home, I'm really petrified of her coming home. I'm really, really dreading her coming home.

SM: in what way?

M: because she'll come home on oxygen and she will, because he said that because she's not breathing on her own by now she will come home on oxygen and what if she, cos she cries so little what if you don't hear her? Because when you've had a baby your instincts kick in because she's right there, so your body tells you 'you have to get up' but if I've had 7 weeks already, alright I've had a baby but me body's not telling me to wake up, so it all goes, so I go to sleep and I'm gone.

Noise at the door

SM: is it O?

M: [Shouts] 'Hello'

O comes in, introductions, O in the room, playing

M: I'm dreading that she stops breathing or something, you know they can send them home with erm, a mattress (apnoea alarm) but you'd be petrified wouldn't you? I don't know.

Child in the background throughout then asks 'can I wear a dress'

M: you can wear whatever you want  
O: yeah, runs upstairs  
Discussion about the child, child shouting from upstairs, then comes down with dresses. She wants me to come to the hospital with them that evening.  
SM: I can't imagine what it's like, can you look forward?  
M: You don't look forward.  
SM: you get through each day?  
M: Yeah, but T does. Like I say to me mum, when it's our O's birthday will you babysit our L for me and then I'm thinking 'will she even be home by then?' cos like  
SM: when's her birthday?  
M: July, cos I'm thinking, will she be even home by then? Cos I was due on Friday.  
5 mins: Child come back into the room, conversation stops and turns to the child.  
T and J come into the house. Further discussion about the children, lots of noise.  
M: babe (M asking T) do you look forward to make plans for when L comes home?  
T: do I looking forward to making plans?  
M: yeah, do like look into the future and think 'oh, when L comes home'? Or while she's in hospital it is just day by day?  
T: I don't know, I mean she's coming home isn't she?  
M: well, yeah, we know she's coming home eventually  
More discussion with the children, they're running in and out of the room.  
Lots of background noise, tape difficult to hear  
T: day by day  
M: I've got a moses basket with lots of net round it  
Lots more noise and chat with the children about the new Sky channels.  
50 MINUTES  
Children leave the room to play, but still shout in  
SM: so how would you describe the whole thing if you could, can you sum up the whole experience?  
M: [shouts back to the children, through the window] One word?  
SM: no just whatever  
M: hard work but worth it, it was really hardwork but when you look at her now she really was worth it. Me mum's got ill (has MS) because she was worried about me, cos she was scared that she might loose me, you know in case me placenta abrupted or something, so she had an MS attack after I had L.  
SM: did she?  
M: yeah, so she's really bad now, me Nan said that to me, I went to see me Nan on Sunday, because I've not seen her for a year and she said 'you look so good you know, you look so good' and I said 'I've only had a baby Nan' and she said ' no I can't believe how good you look, she said by the sound of it you went through the mills' and I said 'Nan, I didn't go through anything worse than what you've been through, I it's not that bad I had me mum with me all the way' I said 'the only thing that really, really hurt was the needles, like the ones that were in me stomach and stuff'  
SM: you've both had a good perspective  
T: cup of tea?  
M: yes please [chats about the children for a minute]  
SM: you're very good together  
M: we weren't the other week, we walked round the house for 2 days like we didn't know each other  
SM: do you think it was the stress of the whole situation?  
M: I think so yes, and them 2 (children) didn't make it any easier because them 2 fight like cat and dog, they hate each other, cos she's so pig headed and she's so 'mummy, mummy, mummy' and there's the age range clash, but she is worth it, cos she has done better than what anyone would have thought. It was the way Dr J was going it was like she was just going to lay there like a vegetable for the rest of her life, which she could.  
SM: yeas, she has done really, really well.

M: she is loads better than what anyone would have thought, but it's like T said 'betting your life on red or black and it coming up' cos she did do really well. I didn't get to see her until like 1 in the morning.

SM: yeah, you just got up didn't you?

M: yeah, I got up and went for a ciggie, I said to them 'you either give me something to eat, I can go and see the baby or I'm going for a ciggie' she got me buttie, I said 'you really got to let me go for a ciggie now', she said 'no' I said 'can I go and see the baby then?' she said 'yeah' I said 'alright then, go and get us a wheelchair' she said 'you said you can't go until 1 O'clock' I said 'it's ok, we'll go for a walk round' I made T drag me all the way round to the front of the hospital for a smoke.

SM: those ladies with baby's on special care always get up quicker

T: [enters the room] do you want a cold drink or a hot drink?

M: yes, I was up and out of that bed, because I cried, because they said, you have to sign to give permission for along line don't you?

SM: mmm (agreeing)

M: and t had gone down for a ciggie which had really peeved me off even more as well and I said 'oh, I'll do it, look I can move me legs, I'll go and do it' she (midwife) said 'no you can't' I started crying and told her to get out me of me room she was no good (laughs) I told her to go away, I said you're no good are you? I said to her 'she's my baby why can't I go and sign for it?'

SM: yeah that must have made you feel terrible

M: I know, but then T went down. I think I whinged that much she wanted to shut me up and stop me from using that buzzer, they let me go and she her. But I was only there for 20 minutes and the next day I got up about 8 and marched there, I walked and then in the afternoon I said 'can I have a wheelchair?' and they were like 'no, you got up and walked, so you'll have to carry on walking' and then T was making me laugh

SM: which doesn't help?

M: no, me mum said 'you better stop making her laugh or you'll make her split open'

SM: and do you think

M: and I think I used to cry in hospital because t used to come home a lot, I felt like he'd left me, cos I knew he had to go and see J but I was thinking 'I'm away from O as well'

SM: yeah

M: but, I used to say to him 'you're always leaving me you'

SM: do you think it's put a lot of strain on your relationship with T and the kids?

M: it did at first but not so much now, I think we're back to normal now, it's like I've never been pregnant and I said to T 'do you prefer me when I'm not pregnant?' and he said 'yeah' because I've been pregnant for almost a year, so it's just starting to get back to normal now, we're getting into a routine sort of thing

SM: and do you think, dead honestly, do you think anything could have been done any differently or would you have liked anything to have been done differently in the antenatal period or during your pregnancy?

M: no, even though I hated him when he told me horrible things he was doing the right thing weren't he?

SM: do you think he did the right thing?

M: sometimes when he was sat there saying things I wanted to say 'I don't like you' but now as me mum says, if it weren't for Dr X she would never have made it, because O were going to take her out at 28 weeks and she would never have survived so he timed it right to the last day because if I hadn't gone in on the Monday and gone in on the Wednesday she would have died.

SM: so you think he knew what he was doing?

M: yeah, cos erm, I knew something had changed over the weekend because she weren't moving as much as she was, she weren't moving as much so he did time it right to the last day didn't he, Dr X? (talking to T who has just walked into the room)

T: timed what?

M: Our L  
T: yes, he's very good isn't he?  
SM: we won't tell him (laughing)  
M: he's got a big headed, you should've seen him when we told him that the nurses on the ward liked him, he was skipping out of the room  
T: ahh, you should've seen him (some laughter and everyone talking at the same time about Dr X)  
M: he was laughing when we called her L  
SM: because he's got a L?  
M: yeah, he's got his own little L hasn't he?  
SM: yeah  
M: but he said she's not so little she's big, not tiny like our one is she?  
T: nope  
O shouting from the garden for me to watch her  
[Discussion about the children]  
SM: and do you think anything could have been differently in the postnatal period, since you had, around your delivery and on special care  
M: I wish I'd kept her where she was, I wish I didn't move her I wish I'd kept her in M because I was adamant that she needed to go because the day she was born I was like 'when can she go to L?' She was only for 3 weeks so if she'd just stayed in M, because she doesn't like change, when she gets moved she doesn't like it  
SM: *agreeing*  
M: she really, really doesn't like it and I suppose the baby gets used to the nurses as well doesn't she because as soon as you walk in and talk she opens her eyes, so she knows when we're in the room and stuff and she freaked me out in L I nearly dropped dead, she was lying there on her front because she likes being on her belly and I was talking to her through the glass being like 'L' and banged on the glass to wake her up, in M we used to call it a tank, we used to bang on it and they'd say 'she's not a fish' and she lifted her head up and turned it round  
[shouts at one of the children]  
M: and she liked freaked me out because she lifted her head up and turned it round and I said 'why has she done that?' and they said 'well, she is a 6 week old baby' and I was like 'I didn't think she'd be able to lift her own head up', her head's dead big, I'm dead scared about her head, it's huge  
SM: she'll grow into it, they always have big heads  
M: she has got a really big head, it feels like she's never going to come home cos in Omskirk they said give her at least 2 months  
SM: so she's 2lbs...?  
M: 6, 2lb 6.5 on Sunday she was, but then if they gave her this thing with x-ray and she's got fluid she'll be weeing her weight out won't she? Cos that'll make her wee more won't it?  
SM: At the same time she'll be putting on weight as well.  
M: so they might reduce her feed if they reduce her feed then she'll stay in  
M: [shouts at O] she's gone really bad she won't even speak to T anymore, in the morning, she won't go near him, she's dead lovin she'll give him hugs kisses and everything and 'I love you' but when I'm here she won't, she won't go near him  
SM: will she not, she's all for you?  
M: yeah, she'll lie in her bed and she'll say 'mum, I love you you know?' and I say 'I love you, now go to sleep' she does it till about 10 o'clock at night, cos she got used to sleeping in a bed.. cos that was hard as well because her routine changed, she got used to sleeping in a bed with me sister  
SM: yeah, cos she stayed a lot at your mums didn't she?  
M: yeah, for almost 3 weeks straight, she only came home for a couple of nights, cos me sister's got a double bed she stayed in the double bed with me sister, so she come back in a different routine, demanding an ipod a laptop and that she should be allowed to do more cos she's a big girl and she's not my baby any more I've got a new baby  
SM: so she thinks she's all grown up

M: that's what she said to me 'I'm not your baby anymore mum, you've got a new one'

SM: so it's changed the dynamics of the family then hasn't it?

M: yes, I suppose it would have been easier for O if I'd the baby and brought it straight home and then she'd have got over it but cos she's so used to being with me on her own she just thinks that L is taking me away from her all the time, cos I've got to be at the hospital, cos I keep saying to her 'I've got to go and see your sister, I can't not go and see her'

SM: so it's hard for her to understand just how, well when I say poorly, she is doing really really well but

M: she's still ill, they still class her as disabled, they say that because she's severely underweight then she is disabled

SM: they could use a better term couldn't they?

M: cause they said severe LUG, or something like that and I said 'what the hell does that mean?'

SM: severe?

M: LUGR, it means she's dead small or something

SM: IUGR

M: yes, and I said 'what the hell is that?' and she said 'it means she's really small but her head is in proportion with everything else' and I was like 'what the hell does that mean?' cos everyone (staff) keeps asking me why... and I was like 'don't you read notes?' when she went to L I had to explain why she was so small, I even had to explain something at M and I was like I was upstairs, but they didn't read it because I didn't have the green notes, they didn't know how to read them and because O hadn't written nothing in my notes had they?

SM: so did you find that quite frustrating having to say the same things to people all the time?

M: yes and this Dr came in to see me in O and he just stood there staring at me and I was thinking 'what you looking at?' he was asking stupid questions that I didn't even know the answer to and then he said 'do you smoke?' and I said 'yes' and he said 'did you smoke when you were pregnant?' I said 'yeah' and he went 'well maybe that's why she's small' and I went 'nope' and he said 'have you had this in pregnancy, have you had that...' and I was thinking; read the notes, you don't have to stand there and read all these stupid questions and I thought that with O's dad as well, cos his girlfriend was walking up to the school with me just before I had our L and I was having a ciggie and she said 'you need to stop fucking smoking and then maybe your baby will grow' and I went 'what?' and she said 'you need to stop smoking and then maybe your baby will grow' and I was like 'you don't know what the fuck you're talking about' and I said 'don't even go there, wait till I've had this baby and I'll knock your fucking head off'

SM: so do you think that, that's something that went all the way through your pregnancy?

M: yes, everyone just assumes that because I smoke that's why she was so small

SM: and not understanding

M: yeah and everyone who knows me day to day, say's 'I can't believe how much you don't smoke anymore, I can't believe how much you've give up' I used to smoke about 40 ciggies a day, so I really don't smoke that much, and I still haven't gone back to that, now we smoke about 20 ciggies a day and that's with T smoking what he normally does and me just having a little bit off the ciggies, I didn't really smoke that much anyway

SM: no and it was that bleed that did most of the damage wasn't it?

M: yes and it was cos it was at 14 weeks

SM: the timing of it, yeah, do you think you could have been better supported in your pregnancy?

M: I did at O, because at O they didn't have a clue what they were doing, that Dr D didn't have a clue what he was doing and he was my consultant with O and I didn't see him once through my whole pregnancy and through my labour, after I had her, he was down as my consultant but I never seen him once.

SM: probably because you were so normal the first time.

M: no cos when you're meant to go in and meet your consultant, you know at your 20 week scan, he weren't there he had someone else doing it for him, so I don't see the point in him, I said to me mum 'he always looks like he's got a cob on' and she said 'he's thinking love' and I said 'he's not, he's snotty'

SM: do you think if there was a patient support group or something like that, other couple or mums who have been going through the same thing in M would you like to have spoken to them?

M: no, I thought I would till I met O's mum cos they were so similar, but when we were on the ward and T had gone home we used to go down for a ciggie together, but then you'd find yourself feeling bad when your baby was having a bad day and your wasn't

[the kids come into the room, but told to leave]

M: you'd find yourself having bad days when it weren't even your baby that was sick, when O got put back on the ventilator and I was feeling dead sorry and I was saying 'I'm sorry' if L was having a good day you'd be like 'oh yeah' but then you spoke to A and O had had a bad day then it could put you in a bad mood

SM: you mentioned when you were pregnant that you thought there might only be you going through it, did it reassure you to know that other women are going through that?

M: That made you feel bad when you your own baby was doing good, because she was devastated when he got put back on the ventilator because she couldn't touch him because his skin weren't as good as L's and then, when you find yourself getting used to speaking to someone you find yourself having more bad days, cos you talk to them when they're having a bad day it makes you go in a bad day, but she got moved to high dependency unit it's different because all the babies there are getting ready to go home.

SM: do you think that you would have liked some support from other mums when you were pregnant rather than in the postnatal period?

M: no, cos I hated everyone didn't I?

SM: yeah

M: cos me sister in law was pregnant and T's cousin...

SM: what about other women going through the same thing with small babies?

M: no cos I think it would have broke me heart if one of them would have died or something, I don't know.

SM: do you think that eventhough there were other women in the same position

M: eventhough it happens to loads and loads of other people it's an individual experience and no one can predict the outcome so no one knows, you can't say well such and such had a baby which survived

[O interrupts]

SM: I'm nearly done now

M: I think it's cos even though loads and loads of people go through it no one goes through it the same

SM: yes

M: no one has the same experience and you can't say 'oh well such and such had it and their baby was ok, and she had a bleed at so many weeks and look at her baby'

SM: yes, because your baby is smaller than some of the babies we've had but they've not done as well as L.

M: yes, cos is L the smallest one you've done

SM: mmm (agreeing)

M: she is a bloody pain in the bum isn't she?

SM: she's not she's gorgeous

M: I didn't think she was the smallest I thought you'd delivered one smaller than L

SM: I think she's our smallest

M: because even Dr X was shocked that she only weighed 536 and on the scan it was saying she was over 600

SM: I can't remember if we've had one at 520

M: I said to them in L 'what's the smallest baby you've ever seen?' thinking they'd say 200g or something and they said 'the smallest we've ever seen that survived

was 1lb 4oz' and I was like [shows her face dropping in amazement] and she said 'what are you looking like that for?' and I said 'cos she was only 1lb 3' and she went down to 1lb, didn't she and I was like 'I don't like that, don't tell me that I wish I'd never asked'

[discussion about the rabbit]

M: but erm, bad, but I don't know it could have been a hell of a lot worse, she could have died, cos it still plays on me mind dead bad cos (pause) me and T were going to give in it was me mum that convinced us not to

SM: I know but

M: we were so close to saying 'if she hasn't put any weight on then that's it we're done' and it was me mum that talked us into carrying it on weren't it? (talking to T)

T: yes, cos she weren't growing so I just thought, she'd be completely broken if she were born

SM: and I don't think that was a silly thing to, I think it was a really sensible way to think for the sake of you and your family

T: but you were saying it doesn't matter what happens, it doesn't matter what happens (talking to M)

M: yes, cos at first we thought she had downs syndrome and T was like 'oh my god, if she's got down syndrome we can't do it' and I was like 'it's ok it's just the same as a normal baby we'll be alright we'll do it' and T was like 'no it's not, cos she'll look up at the other kids and think, why am I like this and then the kids will get, cos the kids round here they're horrible, the kids will get picked on for having a brother or sister the way she is'

T: plus I thought if it comes back positive off the amnio and she was tiny as well I just thought she had no chance.

SM: so it was all those things?

T: yes, and it was still early when he was doing it and he said we could still have an abortion

M: the only thing was that if they told me that if I could go in and have the operation like when I had me miscarriage, I would have done it, me mum was the only one who told us how they'd do it weren't she? Me mum said 'give her another chance' me mum said right from the start she'll be alright

T: yeah but she was only doing that 'oh you'll be fine' it's all very well and good for someone else to say that but when the Dr says to us quite blatantly 'right I won't think less of you if you said you wanted an abortion' that's a bit...

SM: are you pleased he gave you that option?

M: yeah, but now it plays on your mind that imagine if we did because look how good she's doing

SM: I know but...

M: but I'd have regretted not having her if she'd have come out and there'd been something seriously wrong with her

SM: you always said

M: we'll give it to...

SM: yeah if she's not grown by then, then we'll

M: no the only reason I said that is because I had to give birth to her, if they'd have said to me 'you can come in tomorrow and you can have the operation and you can go to sleep and it's done' I would have done it. I think it was the thought of going into labour and then me mum says 'oh you can still see her and they'll show you her and you can have your own funeral' and I was like 'oh no I can't'

SM: cos then that attaches too much reality to it

M: yeah, cos I'd only had one in the July hadn't I and if they told me that I could go to hospital and get knocked out and it would have all been over and done with I would have, I would have gone right then 'right come on she's not growing let's grow'

T: is was only the last week or 2 when we thought she wasn't going to make it to 500g. One fortnight we went and she'd put on 40g and then the next fortnight it was about 11 and he was going 'she's only put on about 11g'

M: and he was going 'no way'

T: he said we'll do it another couple of times and then

M: he said your pregnancy's going to run out before she gets chance to  
SM: she'd never make it up  
M: because I'm shocked I stayed carrying L till 32 weeks because O's mum only carried him to 26 or something like that  
SM: yeah  
M: and he weighs more than her, the only reason she got delivered was because she started having contractions and his heartrate started dipping  
T: that's when the blood flow goes isn't it  
M: because they kept saying to me 'you had no bloodflow through your cord did you?' because sometimes they'd write on that they could hear it and sometimes they'd say they couldn't  
SM: he writes on 'absent' or 'present'  
M: yeah  
SM: the worst is reversed, so when it's reversed that's the worst  
M: why? What's reversed?  
SM: it means it's going in to opposite direction  
M: yeah cos with mine I think there was only one time he did it and it was present, cos when I started taking the aspirin and stuff it was there for a bit and then it went again, cos he said to me 'I've I got this right?'  
T: I think if she's taken aspirin from the beginning then she would have had a bigger baby  
M: but if I had taken it from the beginning and I had had a bleed it would have been worse because my blood would have been thinner  
T: oh I didn't think about that  
SM: also you would have needed to be taken the aspirin from earlier in your pregnancy but you didn't know anything was wrong then  
M: so I didn't really need to take the aspirin that I took all the time I was pregnant?  
SM: Dr X doesn't really think it does anything?  
M: so I didn't really need to take it, he said they were stupid putting on aspirin and then on bedrest because I could have got blood clots.  
SM: well it's supposed to stop you getting a blood clot  
M: yeah and he said he's prefer you to be walking around, cos Dr D told us that if you divert all your blood, you're not exerting yourself so the blood goes to the baby, but Dr X said that's crap  
SM: it is  
M: because no matter what I'd done no more blood would go to the baby  
SM: yeah because it's an old fashioned treatment, so to speak, not many places do it  
M: they stick you in bed away from everyone else  
SM: and how did you feel about the bedrest?  
M: I hated it because they put me on bedrest the day before my 24<sup>th</sup> and Christmas, I was cooking Christmas dinner for me brother and his girlfriend and the kids and it was our first Christmas together and I was stuck in bed, and it was worse because O stayed at her dad's, so I got up to no baby, nothing, cos it was the first time I'd ever let her go, cos I was thinking; oh, next year I've got her when I've got the baby, I'll have both of them together and then they put me on bloody bedrest because of my 20 week scan  
SM: because she was so small  
M: she was in a ball, she couldn't move, she was rolled in a dead tight ball, it was horrible, you could see her head was huge on that one, and then she straightened out but even if she'd lie flat, cos you could see on the scan that she'd lie flat and you still couldn't feel it, cos not the last scan but the one before that, some woman was scanning me and she said, well Dr X was saying 'what's going on' and she was saying 'you'll have to wait a minute because she keeps kicking the thing' and you can't feel it because she's so small, you can only feel it when she does big movements.  
SM: you've done so well (trying to wrap up the interview as have now been there 1 hour 20 mins)



M: I knew she was coming out when she did though, I knew. I said 'I'm going in now and I'm having her' because she stopped kicking. I knew she was coming but I still hated him when he said 'right she's coming out now'

SM: it's hard isn't it? Do you feel you need any counselling or support?

M: no I just want me baby now, I'll be alright once she comes home

SM: if there's anything that comes up after we've talked, because I know it's hard talking about all this, just ring me and I can sort out some support for you, or we can talk through it more if you want?

Child enters the room wanting her mum

SM: I'm going now, because we've been going for an hour and 20 minutes

TAPE STOPPED 1 Hour 20 Minutes

## Appendix 7 - Analysis: Level 1 codes (Excerpt from an Interview)

1.		<b>4/05/10</b> <b>14.39</b> <b>'Marie' PN Interview 005</b> <b>Location: Participant's home</b>
2.		Marie had already started talking about her experience before I started the tape, she was saying that it was stressful at the moment, I quickly interrupted and asked if I could start the tape. Marie agreed.
3.		TAPE STARTED
4.		SM: so it's stressful?
5.	Very stressful	M: <b>very stressful</b> , very, very stressful.
6.		SM: in what way?
7.	Juggling the family and NICU	M: <b>splitting yourself between the 2 kids and being at the hospital</b> , because while you're at the hospital you're thinking 'oh, I've got to get home to the 2 kids and while you're at the hospital you're thinking, oh I should be at the hospital with the baby' so stressful
8.		SM: so how does that make you feel when you're here and not there?
9.	Partner support is important  Difficulties travelling between home and NICU	M: <b>if T's not with me and he's at home with the kids then it doesn't both me, and I think it's the same with T if he's there and I'm here with the kids then it doesn't bother him but if we've got people minding them, it's hard trying to get there and back, especially with the transport, when we were getting the train because it was taking us 2 hours to get to L as well.</b>
10.		SM: so it wasn't that much better at L?
11.	Expectations - should have stayed in M	M: no, <b>I think she should have stayed at M</b>
12.		T shouts: 'yes, it was better at M'
13.		We all laugh
14.	It was easier to stay over	M: <b>because when we got there (to M) we were staying so it didn't matter what time we got there</b> , but when she was in L we had to leave at 7 to get the kids to school, get to the bus stop and make sure you were in time to get the train and so you were there for at least 2 hours before you had to come home.
15.		SM: that's hard isn't it?
16.		M: yeah.
17.		SM: so did she come to O at the weekend?
18.		M: on Friday

## Appendix 8 - Analysis: Table of codes (Excerpt from an Interview)

“Marie”

A	B
5.	Very stressful
7.	Juggling the family and NICU
9.	Partner support is important
9.	Difficulties travelling between home and NICU
11.	Expectations – should have stayed in M
14.	It was easier to stay over
20.	She drank 6mls from the bottle - milestone
22.	Baby exceeded expectations
22.	She’s not bad
22.	It could have been worse
24.	Painted a face
24.	I was a bitch
26.	I was going to leave
28.	I wanted to get away from everyone
30.	I thought it was easier to do it on my own
30.	We talked
30.	We need to do it together
32.	We went through a bad patch after she was born
34.	I hated everyone
36.	Everyone else having babies
36.	I don’t want your baby I want mine
36.	Differences in parents contribution to care
36.	We weren’t allowed to do anything for her
36.	Now I’m allowed to do everything
38.	It’s better to do more
38.	It puts you under pressure to be there when the cares are due
38.	They say ‘we’ll save it for you’
38.	It’s not fair on her because she has to lie there in a dirty nappy
40.	Getting there on time creates tension in the relationship
46.	O – we can get a bus straight there
56.	She’s 7 weeks old now