

**The University of Hull**

**Women's experience of pregnancy when post-birth surgery is indicated: A phenomenological study**

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By

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## **Abstract**

**Background:** Pregnant women who are told their unborn babies require postnatal surgery following the 20 week scan are likely to be distressed. There is a small body of research in this area that suggests pregnancy experience is fundamentally changed and that pregnancy expectations may play a part in that process but it is unclear how women come to terms with their news. **Objectives:** This study aimed to gain a detailed understanding of what pregnant women experienced when faced with this news by applying Lazarus and Folkman's (1984) transactional model of stress and coping (TMSC) and expectancy theory against a backdrop of disruptions to the normal stages of pregnancy as identified by Raphael-Leff (2005).

**Method:** Seven in-depth interviews were conducted with pregnant women whose unborn babies had been diagnosed with a surgical nonlethal structural abnormality following the 20 week anomaly scan.

**Results:** Pregnant women's experiences had four super-ordinate themes: *'living with a changed pregnancy'*, which represented living with the unknown and pre and post news pregnancy expectations; *'an emotional journey'*, which represented post news emotions experienced and concerns about the future; *'coping'* which represented how women mediated their distress; *'relationships with self, their baby and others'* which involved questioning ideas around motherhood and their baby's identity and how others influenced pregnancy experience.

**Discussion:** Themes were discussed in relation to the TMSC and expectancy theory and explored emotions and appraisals and the interplay an uncertain prognosis had on pregnancy expectations alongside interactional influences from the environment.

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## CHAPTER 1

*“To live is to change” (Sugarman, 2001)*

### **Overview**

This study aimed to explore how the detection of a surgical abnormality at the 20 week anomaly scan affected pregnancy experiences. This was important because relatively little was known about what this particular group of women might experience. Pregnancy is likely to come with a set of expectations. News that may challenge expectations (that the newborn baby requires surgery) could potentially be very distressing. The National Service Framework (NSF. UK Department of Health DH, 2004) refers to this particular group of women needing support and recommends tertiary led care. However recommendations regarding pregnant women with their own health needs are the focus, rather than pregnancy-related problems located in the unborn baby. This suggests a gap in knowledge and understanding of how to best support these women.

Previous research identified themes for this particular group of women around prenatal attachment, uncertainty and loss (Jones, Statham and Solomou, 2005; Hedrick 2005) which was negatively affected. Psychological models and theory have not been applied to explore pregnancy experience in this particular group of pregnant women. This research highlights the need for descriptive research to examine this process and provide health professionals with a framework from which to work to provide support and care during a challenging time. This study specifically looks at how pregnancy experience may be mediated by Lazarus and Folkman's (1984) transactional model of stress and coping and expectancies (expectancy theory in Olson, Roese and Zanna, 1996) enabling a framework for understanding the process of disruption of normal pregnancy. Qualitative methodology (Interpretive Phenomenological Analysis - IPA)

was used to as a tool to explore pregnancy experience when faced with news that the unborn requires postnatal surgery.

## **INTRODUCTION**

Pregnancy experience is influenced by a range of factors some of which are around individual expectations, level of available social support (including the quality of relationships with others, which may or may not include a partner), the number of previous pregnancies or children and the cultural norms and expectations of society alongside the intra-personal characteristics of the ‘mother-to-be’. There are of course likely many other psychosocial and situational variables that can affect pregnancy experience (for example, sexuality), however, for the purpose of this study the factors noted above will be considered and described within the context of a ‘complex pregnancy’.

### **Clinical utility**

The Office for National Statistics (ONS, 2008) for England and Wales recorded 4,254 live and stillborn babies with anomalies in 2008, which equates to approximately 1% of all births. However even these figures, which are comparable to past figures are likely to be a conservative estimate according to Boyd, Armstrong, Dolk, Botting, Pattenden, Abramsky, Rankin, Vrijheid and Wellesley (2005). Women giving birth to babies who require post-natal surgery would be in need of specialist medical care and are likely to have far greater contact with health care professionals both during the antenatal and postnatal periods of pregnancy and birth and early infancy. Therefore women faced with post-natal surgery in their unborn are likely to have very specific needs that require

specialist support. The National Service Framework (NSF, UK Department of Health DH, 2004) for children, young people and maternity services state women with more complex pregnancies need access to tertiary services from multidisciplinary teams. However the psychological needs of this group are not addressed specifically and relatively little is known about the factors that influence their experience of pregnancy. Whilst Maternity Matters: choice, access and continuity of care in a safe service (Department of Health, Maternity Matters, 2007) recognises that healthy pregnancies are vital to long-term outcomes as well as recognising the importance of care for vulnerable groups of women, no attention is given to women with complex pregnancies. The National Institute of Clinical Excellence (NICE, 2010, CG62 p. 134) states the mid-pregnancy anomaly scan<sup>1</sup> can cause great anxiety throughout pregnancy due to adverse results affecting the foetus yet it is unclear how anxiety may be moderated. This suggests that little is known about this particular group of pregnant women. Therefore this research aimed to explore and shed more light on these factors and the experiences of this specific group of women.

### **What is ‘complex pregnancy’?**

There have been a range of words used to describe complex pregnancies, which can make an exact definition difficult. An anomaly can "...include the full range and variety of conditions that might be detected prenatally..." (Statham, Solomou and Green, 2003, p. 164). When a surgical anomaly has been diagnosed the following terms have been used: 'surgical malformation' (Kemp, Davenport and Pernet, 1998 p. 1376) or

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<sup>1</sup> "**Anomaly scan.** A detailed ultrasound scan done for the purpose of looking at foetal anatomy to enable identification of foetal malformations. Such scans are routinely carried out at most antenatal clinics in the UK at about 19 weeks of pregnancy." (Abramsky and Chapple, 2003 p. 237). *NB: fetal has been replaced with foetal.*

'foetal malformations' (Hunfeld, Wladimiroff, Passchier, Vanema-Van Uden, Frets and Verhage, 1993 p. 603) or 'congenital abnormality' (Hedrick, 2005 p. 732) and 'fetal abnormality' (Jones, Statham and Solomou, 2005 p. 195). Women whose babies require postnatal surgery and have been diagnosed as having congenital structural abnormalities following the 20 week anomaly scan fall within the definition of 'complex pregnancy'. For the purposes of this study a complex pregnancy involves a non-lethal structural surgical abnormality that can vary in severity and has been detected in the 20 week anomaly scan.

### **What is 'pregnancy'?**

Pregnancy is typically referred to as an event where there are definitive phases and stages that affect changes to the physical and mental health of women (Collins, Dunkel-Schetter, Lobel, and Scrimshaw, 1993 p. 1243). Yet pregnancy may be better understood when using a wider framework of motherhood that has its roots firmly located in early development as suggested by Philipp and Carr (2001 p. 15). Women therefore, may have long-term expectations deeply embedded in their sense of self around what pregnancy will mean to them stemming from childhood. However, women with complex pregnancies may be different from the norm, which may mean that their experiences are now in conflict with preconceived ideas of being a 'mother-to-be'. If so, women in this position may find their pregnancy experience distressing.

According to Raphael-Leff (2005, chap. 5) pregnancy is conceptualised into three distinct maturational phases which coincide with the three trimesters<sup>2</sup>. Moreover, Philipp and Carr (2001, p. 15) suggest these phases are influenced by the biological

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<sup>2</sup> According to Greer (2003). The first trimester is between "0-13 weeks." The second trimester last "14-28 weeks" and the third trimester is between "28-40 weeks".

status of the woman, her psychological state and influences from her environment, which proposes pregnancy experience, is a biopsychosocial phenomenon. The biopsychosocial model assumes a "...person's health was the result of an interaction of biological...psychological and social factors." (Curtis, 2000 p. 5-6). Therefore it could be argued that pregnancy is a health event that incorporates all of these factors.

### **Factors Influencing Pregnancy**

#### **Psychological Sequelae of pregnancy and complex pregnancies**

##### *Psychological sequelae of the 1<sup>st</sup> Trimester*

According to Philipp and Carr (2001) the first trimester begins when a woman realises she is pregnant. During the first trimester is often a time when ambivalence is experienced (Philipp and Carr, 2001). This phase of pregnancy is associated with the potential for miscarriage and loss, whereby approximately 1 in 5 (14-18%) of pregnancies result in miscarriage (DeFrain, Millspaugh and Xie, 1996 p. 331). Furthermore a third of all women experience miscarriage (DeFrain et al., 1996 p. 331).

Ambivalence in the first trimester is understandable if it is linked to potential loss. Indeed research has found that one of the overriding concerns of pregnant women is the possibility of miscarriage (Georgsson Öhman, Grunewald and Waldenström, 2003 p. 148; Statham, Green and Kafetsios, 1997, p. 223). Another key concern identified in research was worry around finding a foetal abnormality, termed 'something might be wrong' (Statham, et al., 1997, p. 223). Moreover a longitudinal study of 1207 pregnant women found that women were most worried about something being wrong when they had experienced previous unsuccessful pregnancies (Green, Kafetsios, Statham and

Snowdon, 2003, p. 760), which suggests prior experience may help shape expectations. Therefore, research suggests that concerns about the potential loss of the baby and/or that 'something might be wrong' is widely experienced during pregnancy. For women who find out that something is indeed 'wrong with the baby' during a routine scan, it could be that their greatest concerns have been realised and that these may or may not be in conflict with prior pregnancy expectations, which may then affect appraisals.

Furthermore (Robinson and Wisner, 2001, p. 44) cite further research highlighting the impact of receiving adverse news during pregnancy. Whereupon concerns about the viability of survival of the unborn baby negatively affects postnatal attachment, irrespective of reassurances otherwise. (Drotar, Baskiewicz, Irvin, Kennell and Klaus, 1975). This suggests that coming to terms with this adverse news is very difficult and that disruption to the bonding and attachment process may have long-term consequences for women with complex pregnancies.

#### *Psychological sequelae of the 2<sup>nd</sup> Trimester*

According to Raphael-Leff (2005, p. 71) the second trimester is a time when the pregnant woman and her unborn child coexist somewhat separately, although the mother is acutely aware of her unborn. Raphael-Leff (2005, p. 71) asserts that this is also a time when fantasies about their unborn are fostered and the 'baby-to-be' is imagined as a real baby with particular traits and characteristics. This suggests women may have clear ideas and expectations about their baby and being given adverse news at the 20 week anomaly scan is likely to challenge these. Research has shown that this phase of pregnancy (2<sup>nd</sup> trimester) is the lowest point of worry for pregnant women (Georgsson Öhman et al., 2003, p. 151; Statham et al., 1997, p. 229). For women who receive unexpected adverse news their greatest worry may have been realised and they

may find their pregnancies are then overshadowed by an unknown prognosis, which may consequently lead to experiencing distress throughout their pregnancy and into the future.

### *Psychological sequelae of the 3<sup>rd</sup> Trimester*

The 3<sup>rd</sup> trimester is characterised by a psychological shift where the mother begins to see the identity of her baby as a separate person from her, which shifts from a fantasy baby to a baby that is real (Raphael-Leff, 2005, p. 75). According to Philipp and Carr (2001, p. 18) this point of pregnancy is associated with the highest level of maternal-foetal attachment. Therefore the logical presumption could be that if there is an absence of nesting behaviour this may reflect psychological problems located within the pregnant woman, as suggested by Philipp and Carr (2001, p. 18, who cites research Cohen 1979; Leifer 1977).

Research also found worry regarding the birth and the identification of a foetal abnormality was also high during the 3<sup>rd</sup> trimester respectively (Georgsson Öhman et al. 2003; Statham et al. 1997). In addition to this, other concerns pregnant women had related to hospital care; citing specific issues of concern were staff work-load and concerns about medical safety (Georgsson Öhman et al. 2003 p.151). Women who are told their unborn baby is in need of surgery are likely to have this phase of pregnancy 'transition' disrupted, which may then make their pregnancy-experience very distressing when faced with the fast approaching birth, alongside uncertainty of their baby's prognosis and may magnify 'typical' pregnancy related concerns.

Robinson and Wisner (2001, p. 44) cite research whereby couples giving birth to malformed babies are placed in a position where they "...must also grieve the loss of their expected infant and accept the malformed child...they may experience severe

guilt..." (Solnit and Stark, 1961). Additionally defence mechanisms to protect against guilt such as lack of emotional response may occur (Robinson and Wisner, 2001). Robinson and Wisner (2001) also suggest anticipating disapproval from others is when shame is experienced. Women when faced with adverse news may experience negative emotions also, which may arise from perceptions of being judged by others alongside grieving the loss of their hoped for baby, which as suggested above may be in contrast to long-term fantasies embedded in childhood.

### **Summary**

Research has identified one of the greatest worries pregnant women have is that 'something might be wrong' (Statham et al. 1997) with their baby. For women whose unborn babies have been diagnosed with surgical anomalies this 'worry' has been realised at a time when this pregnancy related worry is typically at its lowest (during the 2<sup>nd</sup> trimester). This could cast these women's pregnancies under a veil of uncertainty and distress, with the likelihood of longer-term consequences. Any preset expectations may be challenged and this may also be distressing depending on how this news is appraised. Also research highlights the powerful role negative emotions may play in complex pregnancy experience. Perhaps women with complex pregnancies may experience negative emotions also, causing them to retreat and experience their pregnancy in isolation? What is of interest what emotions are experienced in complex pregnancies and whether they affect appraisals and expectancies?

## **The cultural context of pregnancy**

When considering the impact of receiving adverse news during pregnancy, images projected from the media may also serve to enhance awareness of a pregnancy no longer being 'normal'. For instance:

"The media both shape and reflect society's views. For many pregnant women the media are their main source of information about prenatal screening which is usually presented in a positive and simplistic way." (Green, Statham and Snowdon 1992, p. 66).

Women who are given unexpected news at their 20 week anomaly scan may find that their own pregnancy expectations are challenged and are now in conflict with those of wider society. Indeed research has found women perceive scans to be a positive experience (Ekelin, Crang-Svalenius, Dykes 2004; Eurenus, Axelsson, Gällstedt-Fransson and Sjöden, 1997). A systematic review of women's views of pregnancy ultrasound (Garcia, Bricker, Henderson, Martin, Mugford, Neilson and Roberts, 2002) found evidence that having a scan is a positive experience because of the visual certainty that her pregnancy is viable and healthy alongside creating an opportunity to establish their maternal-foetal relationship early on in the pregnancy process. Therefore, any suggestion that a foetal surgical abnormality diagnosed during scanning may be in conflict with individual and societal ideas that are counterintuitive to an expectation that scans are a positive experience. Having an understanding about complex pregnancies placed within a cultural context such as this may be fundamental in understanding the impact of adverse news during scanning.

### **Personhood and the environment (social support)**

It is worth noting how interactions between people and the world they cohabit may affect each other. Lazarus (1995) refers to this as a process where people "...are locked into mutually influenced and constantly changing relationships with person A affecting person B and B affecting A...the central point is that the person-environment relationship is not static but is ongoing and changing" (Lazarus, 1995 p. 191). This process may be conceptually important because it exposes the underlying appraisal mechanism that affects interpersonal interactions between the self and others. A woman managing a complex pregnancy will undoubtedly be affected by the reactions of those she tells. Conversely others' reactions may affect her appraisals of her situation, which suggests communication about pregnancy experience may be multi dimensional and dynamic and are also factors to consider when exploring complex pregnancy experience.

### **The role of social support and pregnancy**

The definition of social support is summarised as '...information leading the subject to believe that he [sic] is cared for and loved...esteemed and valued...and a member of a network of mutual obligations' (Cobb, 1976, p. 300). Evidence of the effectiveness of psychosocial support in normal pregnancies has been documented (Collins et al. 1993; Oakley, 1992) and shows that social support has positive benefits for pregnant women. In a systematic review of 35 published and unpublished randomized controlled trials of psychosocial interventions in pregnancy the conclusion was that:

"During pregnancy, supported women are less likely than others to feel unhappy, nervous, and worried, and are less likely to have negative feelings about the impending birth." (Oakley, 1992, p. 136).

However not all psychosocial support in pregnancy has been found to be beneficial. Wheatley (1998, p. 48, cites research Oakley, 1992), states psychological health is modified by the quality of social support, which may have either positive or negative effects upon an individual. Also Collins et al. (1993, cite research p. 1254 Antonucci & Jackson, 1990; Rook, 1984) comment that the negative effects of social support can lower self-esteem, which can also then affect coping.

Therefore when attempting to understand how women come to terms with adverse news about their unborn babies it may be the value or kind of social support available that is important. Research into group support for women who terminated their pregnancies after receiving a diagnosis of prenatal abnormality found benefits from sharing their experiences with others who were in similar situations to them (Gordon, Thornton, Lewis, Wake and Sahhar, 2007). This could suggest women with complex pregnancies find that their usual networks of support no longer fit and that this could potentially isolate them, suggesting they too may need to be offered group support to address this potential gap.

When exploring complex pregnancy experience it may be important to consider familial social support. In a literature review examining the role of marriage on social support and adaptation it was found being married was beneficial psychologically and socially compared to unmarried people (Coyne and DeLongis, 1986), although this was related to successful, happy marriages (Coyne and DeLongis, 1986). Furthermore DeFrain et al. (1996, p. 332) cite research investigating the role of the family when

miscarriages or sudden infant death syndrome<sup>3</sup> (SIDS) occurs. The authors comment that:

"No individual family member lives in a vacuum unaffected by other family members. Each member's coping mechanisms are supported by others." (Rando, 1986).

Research such as this implies that family members could contribute to pregnancy experience and that this could be either positive or negative depending on the quality of these relationships.

### **Role of the health professional providing support during complex pregnancies**

Women faced with adverse news during their pregnancy are likely to have their pregnancy managed by a specialist team; a necessity to assure high levels of care are met. Therefore the role health professionals play in complex pregnancies is likely to be significant.

However it may be important to understand pregnant women's potential vulnerability when receiving adverse news during pregnancy, especially as the professional is in a privileged position. Raphael-Leff (2005, p. 138) comments that health professionals are in this privileged position because they are equipped with the knowledge of the state of her pregnancy, and therefore her foetus rather than the pregnant women being more knowledgeable about her pregnancy, hence the health professional is in a unique position to aid the pregnancy process and as such the relationship between the two may intensify for women with complex pregnancies. Furthermore, they may find that their role or status as the 'mother-to-be' is challenged

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<sup>3</sup> "SIDS the sudden death of an infant younger than one year of age that remains unexplained after a thorough investigation, including a complete autopsy, examination of the death scene, and review of the clinical history." Vanes, D. (2005).

as their dependency increases on 'expert-others' to significantly aid their pregnancy process in a way that exceeds prior expectations about pregnancy.

### **Power of the scan**

The 20 week anomaly scan may have cultural significance if, as previous research suggests that the majority of women have an expectation of normality rather than the detection of an abnormality despite this being the function of this scan (Ahman et al. 2010). Indeed Lalor and Begley (2006 p. 12, cite research Hyde 1986; Green, Stathem and Snowden 1992; Rapp 1999; Lalor 2000; Stephens 2000) suggest women view scans as a positive experience. Women who find that they are on the receiving end of adverse news may find this event becomes potentially threatening as scans may then have a very different meaning.

Research that highlights the value placed upon ultrasound examinations during pregnancy may be critical when understanding how adverse news identified at the 20 week anomaly scan may affect pregnant women. A Swedish study evaluated women and their partner's perception of information, expectations and experiences of attending a second-trimester routine ultrasound scan and found that 89% were concerned about the detection of a foetal abnormality despite the purpose of the scan was to ascertain the age of the foetus, viability and detection of multiple gestations (Eurenius et al., 1997). Moreover anxiety of men and women was only elevated if problems had been identified earlier on in the pregnancy process (Eurenius et al. 1997), findings also echoed by more recent research (Lalor and Begley, 2006), which also showed that previous positive ultrasound experiences were equated with expectations of foetal good health following the scan (Lalor and Begley, 2006). Both of these studies used a qualitative

methodology and as such their findings cannot be generalised. However, these studies illuminate the powerful effects scans have on pregnancy experience, which suggests many questions still need answering as to why scans are important to pregnant women. Moreover the significance of this inherently social event (20 week anomaly scan) may be even more relevant to explore when pregnancies are complex.

Marteau and Mansfield (1998, p.187 cite research, Stathem, 1987; Brown 1989), identified women experienced shock and distress when receiving adverse news during screening and that this shock and distress was not related to the severity or type of abnormality found. Furthermore the uncertainty that arose following this event had long lasting effects on the pregnancy if the pregnancy continued (Statham et al. 2003). Thus the interactions between the ultrasonographer and pregnant women when imparting adverse news during scanning may be an important aspect of understanding women's complex pregnancy experiences. For example when a surgical anomaly is detected, especially as it is suggested that this is the time when women will feel most vulnerable (Abramsky and Chapple 2003, p. 106). How this news is delivered and the subsequent relationship that develops between ultrasonographer and pregnant woman may be of interest. Furthermore it may be important to consider the value women may place upon their relationship with the ultrasonographer when faced with adverse news about their pregnancy. An increase in appointments alone may give those with knowledge great status as they disclose much desired information about the health of the unborn as suggested by Raphael-Leff (2005, p. 136).

## **Summary**

Literature on the socio-cultural aspects of pregnancy shows that factors from the environment can affect pregnancy experience. The quality of relationships within the

social support literature has been highlighted as a possible important factor and suggests there are positive and negative effects to consider. Additionally research has highlighted the cultural significance of the 20 week anomaly scan; an event that is usually viewed positively, however negative news creates 'worry', hence understanding how or why they occur in complex pregnancies may be important. The role of the ultrasonographer in these cases may profoundly affect women's pregnancy experiences because of the intimacy of an internal world that the scan provides.

### **Theoretical Considerations**

When foetal post-birth surgery is indicated pregnancy care is delivered by a specialist team (which includes obstetricians and paediatricians and other highly skilled professionals) in addition to the community midwifery team, who typically deliver routine antenatal care. Therefore the experience of being pregnant may shift conceptually for women, from normal to complex, and as such this deviation from the norm may result in pregnancy experience being equated to an illness as the pregnancy automatically requires medical attention. Hence the literature on illness representations may be appropriate in understanding this complex pregnancy experience. If deemed 'ill' then pregnancy is potentially threatening. For instance Leventhal's self-regulatory model (SRM) of illness cognition and behaviour could be used to explore complex pregnancy experience because "...of its emphasis on personal, common-sense beliefs about illnesses" (Cameron and Moss-Morris, 2010, p. 150). Ogden (2012, p. 217) cites research by Leventhal and colleagues who defined illness-related beliefs as important constructs in understanding illness cognitions because of the conceptual framework,

which may help people cope and understand their illnesses (Leventhal, Meyer and Nerenz 1980, 2007a, 2007b; Leventhal and Nerenz 1985). The SRM represents illness-related cognitions along 5 dimensions (see Appendix). It could be argued therefore that elements of Leventhal's SRM are applicable to women faced with foetal post-natal surgery. For example, according to Ogden (2010, p. 218) the first dimension '*identity*' refers to receiving a medical diagnosis And women faced with adverse news about their unborn baby requiring postnatal surgery will have received a diagnosis.

However, this model represents illness cognitions, and although women faced with adverse news about their unborn are likely to evoke thoughts of emotional responses about the consequences of their news these are in relation to their unborn babies and not directly themselves. Therefore the 'illness' is not located in the 'self' (the mother-to-be) but the 'other' (their unborn baby). It could equally be argued then that when problems in pregnancy are associated with the unborn baby and not the 'mother-to-be'; despite the deviation from the norm, these complex pregnancies do not represent illness either. Perhaps more appropriate psychological models would be those that conceptualise stress. Stress appraisal (SA) models could be better placed to explore complex pregnancies because they enable the interpretation of thoughts and emotions that occur when stress is experienced, as already suggested in this chapter.

### **What Is Stress?**

According to Lazarus (2006) stress can be understood when there is an imbalance between the demands placed upon them and the psychological resources they have to cope with the situation. Furthermore psychological stress occurs when "A persons mind

is at work evaluating the significance of what is happening and it struggles effectively to cope with the stress." (Lazarus, 2006, p. 60). Women whose unborn babies are under threat of post-natal surgery may at times feel overwhelmed, consequently they may experience stress. Therefore, how women come to terms with a potentially stressful event is of interest when exploring complex pregnancy experience.

### **The Transactional Model of Stress and Coping (TMSC)**

Lazarus and Folkman's (1984) TMSC allows for emotions to be scrutinised in relation to stress appraisal and coping. For instance:

*"Cognitive appraisal is a process through which the person evaluates whether a particular encounter with the environment is relevant to his or her well-being..."* (Folkman, Lazarus, Dunkel-Schetter, DeLongis and Gruen 1986, p. 992)

It could be argued that adverse news during pregnancy is likely to activate cognitive appraisal around this event. Additionally coping is relevant to women receiving adverse news during pregnancy for a number of reasons. Firstly, coping is linked to appraisals and secondly it relates to an event (Folkman et al. 1986), hence stress is specific versus being representative of the intrapersonal characteristics of an individual. Folkman et al. (1986, p. 993) cites research stating coping arises when a:

*"...person is constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the person's resources." (Lazarus & Folkman, 1984).*

Cognitive appraisal therefore has a role in moderating stress because it provides a situation for a person to examine whether an event is likely to have an effect on his or her well-being, this process of evaluation allows for a person to explore in what ways this may be so (Folkman et al. 1986). Hence cognitive appraisal is a way of understanding how potentially stressful events impact upon an individual. Cognitive

appraisals are defined as 'primary' and 'secondary' (Lazarus and Folkman, 1984 p. 993).

### *Primary appraisal*

*Primary appraisal* arises out of an evaluative process that defines whether the event is either "...stressful, positive, controllable, challenging, benign, or irrelevant." (Wenzel, Glanz and Lerman, 2002, p. 213). 'Primary appraisal' therefore involves an assessment of the seriousness of a stressful situation and the associated potential for harm. For example, this means judging "is the health or well-being of a loved one at risk?" (Folkman et al. 1986, p. 993), hence an evaluation of the likelihood of this happening is associated with the primary appraisal of threat. Women with complex pregnancies may experience stress if a diagnosed foetal surgical structural abnormality is deemed 'serious' and thus appraised as threatening. However it is possible that women with complex pregnancies may view their experience as a challenge, which according to Lazarus and Folkman (1984) is closely related to threat although different. For example challenge:

“...has much in common with threat in that it to calls for the mobilisation of coping efforts. The main difference is that challenge appraisals focus on the potential for gain and growth inherent in an encounter and...characterised by pleasurable emotions...threat...is characterised by negative emotions...” (Lazarus and Folkman, 1984 p. 33).

Also, according to Wenzel et al. (2002) primary appraisals can be used to reduce the importance of a threat when ambiguity or uncertainty is introduced into the process. Pregnant women who received adverse news may find that they can minimise the importance of this threat because their pregnancies have an unknown prognosis, therefore making them less threatening. Wenzel et al. (2002, p. 213) refers to this as '*appraisal bias*'. Additionally primary appraisals can be broken down further into "*goal*

*relevance, goal congruence or incongruence, and goal content...type of ego-involvement.*" (Lazarus, 1991 p. 827) where:

"goal relevance has to do with what...is at stake...goal congruence or incongruence concerns whether the encounter is appraised as harmful (threatening if it is future harm) or beneficial...goal content...is necessary to distinguish among several emotions, for example, anger, guilt, and shame. It is concerned with preservation or enhancement of one's ego identity, a moral value, or living up to an ego ideal..." (Lazarus 1991 p. 827).

These three facets of primary appraisals indicate the complexity of primary appraisals that goes beyond not just assessing whether something is at stake but links this intricate analytical process with different levels of thinking and individual emotions, which may be an important tool for fully understanding the experience of complex pregnancies.

### *Secondary appraisal*

According to Folkman et al. (1986) secondary appraisal is, where an individual examines what they can do to prevent harm or overcome a difficult situation, this process of evaluation then initiates a coping response. For example, secondary appraisals occur to manage primary appraisals of "*harm/loss, threat, and challenge*" (Lazarus and Folkman, 1984 p. 32). Therefore:

"Secondary appraising refers to a cognitive-evaluative process that is focused on what can be done about a stressful person-environment relationship, especially when there has been a primary appraisal of harm, threat or challenge...it is part of an active search for information and meaning on which to predict action..." (Lazarus, 2006, p. 76).

Women may feel threatened in the face of receiving adverse news about their unborn baby because they may evaluate (primary appraisals) that surgery could be harmful. Indeed women whose babies may need surgery may perceive loss (primary appraisals),

which in this instance would be defined as the loss of their 'ideal baby' (loss of loved one) (Lazarus and Folkman, 1984). When appraising surgical anomalies pregnant women could see this event as a challenge and/or threat as they may perceive 'harm' to their newborn (and therefore also feel threatened), which they may respond to by thinking about how they will manage, thus evoking secondary appraisals that involve an evaluation of coping options. Secondary appraisal, as already stated, is activated not just with the perception of threat but also challenge, for instance, "...when we are in jeopardy, whether it is threat or challenge, something must be done to manage the situation." (Lazarus and Folkman, 1984 p. 35).

Consequently, complex pregnancies may evoke responses to threat and/or challenge. Furthermore these appraisals (primary and secondary) may interact with each other, thereby creating their very own stress that is also then modified by their emotional reactions to their situation, which implies the dynamic potential of these appraisals that interact with each other in shaping experience (Lazarus and Folkman, 1984 p. 35), as secondary appraisals are then likely to be activated, this process can then also lead to coping options (Lazarus, 2006).

However, Lazarus (2006) states emotions have a key role to play in this process too, where principally the choice of emotion is governed by an evaluation of:

"three basic issues...namely, blame or credit for an outcome, coping potential, and future expectations...blame and credit require a judgement about who or what is responsible for harm, threat, challenge, or benefit" (Lazarus, 2006 p. 93).

### ***The role emotions play in stress appraisals and coping***

According to Lazarus (2006) stress, emotion, and coping coalesce in a system that is controlled by emotions. Lazarus (1991b) talks at length about the importance of emotions in their role in the stress appraisal process:

"...emotion cannot be divorced from cognition, motivation, adaptation, and physiological activity...the reaction tells us that an important value or goal has been engaged and is being harmed, placed at risk, or advanced. From an emotional reaction we can learn...how that person interprets self and world, and how harms, threats, and challenges are coped with." (Lazarus, 1991b p. 6-7).

Furthermore Lazarus (1991b) explains emotions follow a set of rules and in doing so emotions are critical in informing people about the seriousness of something, situations or events that people do not hold any value for are unlikely to evoke an emotional reaction. Also the way a person appraises their situation and the emotions that arise can inform us about what is important to that person in terms of their beliefs about themselves and the world (Lazarus, 1991b).

Lazarus (1991b) advances the importance of emotion by describing the cognitive-motivational-relational theory, which is a "...working classification of the emotions..." (Lazarus, 1991b, p. 81). According to Lazarus (1991b) this consists of:

"...a common *core relational theme*, which in turn is comprised of a particular primary and secondary appraisal pattern. Each emotion family is also characterised by an action tendency or impulse..." (Lazarus, 1991b p. 81).

Therefore understanding emotions can inform in far greater detail the significance of an event than a simpler analysis of stress (Lazarus, 1995). Consequently exploring and identifying emotions may lead to a far broader and richer understanding of what women may experience when faced with adverse news during pregnancy.

### ***Role of reappraisal in moderating emotions and the effects of threat***

However according to Lazarus (1995, p. 191) reappraising is also purposeful in coping with distress. Thus, it would appear that reappraisal could be a cognitive mechanism to diffuse threat. Also, the process of reappraisal is influenced by "...knowledge and appraisal and emotion..." (Wells and Matthews, 1999 p. 166). Wells and Matthews

(1999, p. 166) cite research whose findings showed that this process is about how a situation changes when new information comes to the fore that changes appraisals (Lazarus and Folkman 1984). This suggests that this process is dynamic and it may therefore have a role to play in understanding complex pregnancies. Furthermore according to Lazarus (2006) there is another layer of complexity to consider, which relates to reappraisals which are unconscious appraisals (Lazarus, 2006), however:

"Defensive reappraisals...should be more difficult to make conscious because of the strong motivation not to confront them. Because the person does not wish to be exposed to the threatening ideas, the exclusion is deliberate...it is employed as a means of coping with the threat...Thus, the statements: "I am not angry," or "I am not scared" must have unconscious counterparts, such as "I am angry," or "I am scared,"..." (Lazarus, 2006, p. 83).

### *Commitments*

Commitments may also be important because they highlight the relevance something has to a person and in doing so reveal its meaning and so establish what is at stake (Lazarus and Folkman, 1984). In addition, Lazarus and Folkman (1984, p. 56) cite research stating commitments underpin the "...values, and/or goals, we do not wish to abandon..." (cf. Lazarus, Coyne & Folkman, 1982) and that this is moderated by how strongly an individual is committed to something. Moreover, if there is strong commitment then this increases vulnerability to psychological stress. (Lazarus and Folkman, 1984, p. 58). For these reasons pregnancy experience will be influenced by the values placed upon it and how important the expectation of an uncomplicated pregnancy was as a life goal. Any suggestion of anything different from this may be devastating and associated with negative emotions and therefore primary appraisals of threat.

### *Beliefs*

Beliefs are used to gauge an individual's sense their place within the world, their beliefs may shape expectations about the future, which includes hopes and fears (Lazarus, 2006 p. 71). Thus beliefs are "...pre-existing notions about reality...in appraisal, beliefs determine what fact...is and they shape the understanding of its meaning..." (Lazarus and Folkman, 1984 p. 63). This implies beliefs and stress appraisal are closely intertwined, where one could influence the other whilst defining meaning. For instance, the beliefs women hold about pregnancy generally may affect appraisals of the seriousness of their situation and, as such, a complex pregnancy may then have a different type of 'meaning'. For example, if a woman has a strong belief regarding motherhood or a strong sense of family, then adverse news challenging her belief may cause a great deal of distress, therefore affecting appraisals as her pregnancy meaning would then change.

Thus individual beliefs about 'self' and 'world' would be important constructs to consider in furthering our understanding of complex pregnancy experiences as they elicit a sense of who a person is (self) in a particular context (world). Subsequently, understanding beliefs around pregnancy expectations (and the possible effects of these expectations being disconfirmed) after receiving adverse news will be important, especially when considering future goals within changed expectations and how these may be appraised and reappraised.

### **Summary**

Women who experience complex pregnancies are likely to ask themselves a number of questions as they attempt to come to terms with the news that there is something wrong. Conceptual accounts of stress, appraisal, coping and emotion appear potentially relevant

to making full sense of this process. Primary appraisals evaluate the importance or significance of the 'news' to the individual and secondary appraisal (where the news is seen as a threat and/or challenge) precipitates coping options and application of a particular set of coping strategies. Wells and Matthews (1999, chap. 8) state that the process of appraisal and re-appraisal is important in determining emotional experience, which may then play a role in governing more general expectancies and beliefs which may in turn affect cognitive appraisal.

Hence cognitive appraisal of the news of foetal post-natal surgery could be dynamic and may interact with expectancies and beliefs, each influencing each other. In addition to this the role emotions play in appraisals and expectations may be seminal in capturing the essence of what women experience living with complex pregnancies especially as Lazarus (2006, chap. 2) states that emotions play a super-ordinate role in influencing primary and secondary appraisals which are also inherently linked to future expectancies and beliefs.

### **What are the functions of expectancies and how are they used?**

#### *Expectancies*

Expectancies may be important when understanding complex pregnancy experience because they are "...beliefs about a future state of affairs." (Olson, Roese and Zanna 1996, p. 211) hence they connect "...the future with an outcome at some level of probability..." (Olson, et al. 1996, p. 211). Therefore, they are helpful because they generate some level of certainty about the future. Furthermore expectancies are acquired directly or through communication with others (indirectly) (Olson et al., 1996). Pregnancy expectations could be questioned in the event of adverse news as this may

challenge expectations directly or indirectly. This may be relevant for women with complex pregnancies if living with an unknown prognosis means certainty about the future is questioned, especially as past experience may no longer be useful in guiding the pregnancy process.

#### *The role of certainty in expectancies*

Clearly one of the functions that 'expectancies' have is allowing people to assess the level of certainty of something happening (Olson et al 1996, p. 214). However, according to Olson et al. (1996) there are a number of factors that affect expectancies and Olson et al. (1996, p. 215) cites research stating "expectancies...based on direct experience...will produce more certain expectancies" (Fazio and Zanna, 1981), hence experience facilitates the expectation of a certain outcome because prior experience confirms expectancies, which then increases the certainty of expectancies (Olson et al. 1996). According to Fazio and Zanna (1981, p. 180) this is because attitudes based on direct experience may be perceived with increased certainty in comparison to an attitude based on indirect experience. If women with complex surgical pregnancies experience uncertainty, as previous research suggests (Jones et al. 2005; Rempel, Cender, Lynam, Sandor, and Farquharson, 2003) then any prior knowledge about pregnancy may become redundant when faced with living with a pregnancy beyond the norm. Consequently women in this position may be deprived of normal pregnancy strategies that would previously have helped them through their experiences.

#### *The role Consensus Information plays in expectancies*

There are a number of other factors that are related to certainty of expectancy. One of these is consensus information (Olson et al. 1996), which is where others who have the

same expectancy will "...serve to make the expectancy more certain in the perceiver's mind" (Olson et al. 1996, p. 215). Hence what may be also important in shaping expectancies are not just individual beliefs about the self and world but the beliefs and expectancies others hold about the self and world. As such, those who are close to a pregnant woman, such as immediate family and friends (constituting social support) may also play a part in shaping complex pregnancy experience because of their expectancies about pregnancy.

*Accessibility & the role Disconfirmed Expectancies play in shaping experience.*

According to Olson et al. (1996) expectancies are also explicit (conscious) when they have a level of uncertainty. Olson et al. (1996) refers to this particular state as disconfirmation and argues that this is a potentially aversive. Hence, if expectancies do not turn out as expected, women with complex pregnancies may become aware of challenges to their previous expectations, where their expectancies according to Olson et al. (1996) now become explicit (or more so) and may lead pregnant women to be much more aware of their pregnancies than they previously would have been. It may be that on a psychological level the experience of being informed about post-natal surgery is comparable to having fundamental expectations of 'normal' pregnancy disconfirmed and this is potentially emotionally aversive for women in these circumstances.

**Summary**

The Transactional Model of Stress and Appraisal alongside Expectancy Theory may help to explain elements of complex pregnancy experience. This is because this model of stress appraisal may reveal the underlying cognitive processes women use to help them come to terms with their unusual pregnancy experience. For instance,

expectancies may become disconfirmed, perhaps challenging existing values or beliefs, and this may then affect appraisals especially if experienced with a range of negative emotions. How women then come to terms with their news would be evaluated through a process of re-appraisal which may include whether the pregnancy is deemed to be threatening, experienced as a sense of loss or challenge or a mixture of all three appraisals. This process of appraisal and reappraisal may also be influenced by features of expectancies, thus the relationship between expectancies and appraisals may be cyclical and dynamic and therefore open to change.

### **Current Research into women with complex pregnancies**

#### *Anxiety & Mood*

A quantitative pilot study designed to investigate levels of anxiety and mood and their possible interactions between medical, socio-demographic and psychological aspects of women with a prenatal diagnosis in the foetus reported their participants had mood scores commensurate with people with a major depressive episode (Leithner, Maar, Fischer-Kern, Hilger, Löffler-Statka and Ponocny-Seliger, 2004). However given the small sample size, as noted by the authors (Leithner et al. 2004) findings may not be representative of pregnant women with a prenatal diagnosis. Furthermore whilst primarily investigating ‘anxiety’ and ‘mood’, questions about how women mediate coping and experience negative emotions when faced with a prenatal diagnosis remain unanswered.

### *Coping*

A descriptive longitudinal study of 42 women who received an antenatal diagnosis of lethal and nonlethal foetal abnormalities, using grounded theory methodology explored coping styles and information preferences in response to their news. Miller's 1980 concept of information preference and threatening medical information as cited by Lalor et al. (2008, p. 186) was used to understand decision-making in this group of pregnant women. This study identified two information-seeking preferences 'monitors' and 'blunters' (Lalor et al. 2008, p. 185). The results of this study indicate pregnant women may fall into two different styles of coping following adverse news. This suggests possible interpersonal characteristics influence decision making in relation to particular styles of coping with adverse pregnancy news, although results cannot be generalised. However questions remain about how this complex process occurs and warrant further investigation. The application of SA models and expectancy theory may be useful in answering these questions regarding complex pregnancies.

### *Coping and foetal Attachment*

A quantitative study was designed to measure appraisal of risk, coping and prenatal attachment in 87 hospitalised pregnant women. This study used Lazarus and Folkman's (1984) model of stress as a theoretical framework to investigate potential relationships between coping, social support and prenatal attachment (White, McCorry, Scott-Heyes, Dempster and Manderson 2008). Findings reported correlations between how intense prenatal attachment was and positive appraisal coping (White et al., 2008). Moreover further correlations were found between complications arising during pregnancy and threat appraisals that also had an influential effect on choosing particular coping strategies (White et al., 2008). Results therefore suggest that perception of threat and

how threat appraisals are mediated could have an influence on level of distress experienced when women have complex pregnancies. However 7% of participants in this study had complications due to a foetal anomaly versus problems with maternal health and therefore results may not be representative of pregnant women with foetal anomalies. For this reason possible correlations between appraisals and attachment may be inconclusive for women who receive adverse news regarding their unborn during pregnancy.

### *Research investigating adverse pregnancy results and expectations*

There have been a number of descriptive studies investigating women's reactions to adverse news during pregnancy (Ahman, Runestam and Sarkadi 2010; Baillie, Smith, Hewison and Mason, 2000; Lalor and Begley 2006, O'Brien, Quenby and Lavender 2010; Smith, Hewison and Mason 2000). Ahman et al. (2010) study of Swedish primiparous and multiparous women used a naturalistic inquiry methodology and explored women's expectations of a routine ultrasound scan at 18 weeks of gestation when soft markers were discovered. Conclusions suggest women experienced shock and that the news was unexpected.

Baillie et al. (2000) study used IPA methodology to explore the impact of pregnant women having routine ultrasound screening for chromosomal abnormalities when given false positive results of either 'low-risk' or 'high-risk' groups. Conclusions were that women were also unprepared for their results and two-thirds of participants were left with continuing anxiety despite further tests that established there were no foetal problems (Baillie et al. 2000). One of the key themes identified was 'putting pregnancy on hold', for instance, which negatively affected prenatal attachment (Baillie et al. 2000 p. 390). Furthermore, this study found that adverse news during pregnancy

also interrupted prenatal attachment and raised fears of further adverse news (Baillie et al. 2000); which indicates adverse news can have a powerful effect on pregnant women throughout the rest of their pregnancy. However these two studies findings (Ahman et al. 2010; Baillie et al. 2000) cannot be elucidated upon as psychological theories and/or models have yet to be applied to this specific field of pregnancy research, hence findings are limited because how women come to terms with unexpected news has yet to be explored.

Lalor and Begley (2006) study used grounded theory methodology to explore women's experiences of an adverse diagnosis following a routine second trimester ultrasound examination and found that participants also experienced shock and had expected a healthy baby; an expectation which was based on good maternal health and a lack of experience of an abnormality in previous children (Lalor and Begley, 2006). As this study explored the impact of receiving adverse news from a routine pregnancy event rather than questions designed to explore how women interpreted their news and made sense of their subsequent pregnancy experience, these remain unanswered. This research underlies the seminal role prior pregnancy experience may have in forming current pregnancy experience. It is possible therefore to suggest that if women's past pregnancies were uncomplicated the expectation of a straightforward pregnancy may even be stronger for women.

A study by O'Brien et al. (2010) explored the content of focus groups and individual interviews of pregnant women at risk of having a preterm birth using a qualitative interpretative methodology and found 3 main themes. These were:

"...'balancing the risks' associated with the threat of preterm birth, they developed 'personal coping strategies to survive the pregnancy' and they watched as the strain made their 'whole family crumble'." (O'Brien et al. 2010 p. 79).

This group of women with high risk pregnancies reported living with threat however as previously stated, what is unknown is how women came to terms with their news, understanding their appraisals regarding risk may lead to a greater understanding of the affects of living with high-risk pregnancies. This research also suggests that the context (environment) is important in shaping complex pregnancy experience.

*Research investigating surgical abnormalities during pregnancy*

In a quantitative study, Kemp et al. (1998) investigated parent's trait (STAI-T) and state (STAI-S) anxiety and the effects of counselling shortly after receiving a diagnosis of a surgical anomaly in their unborn. Their findings showed that there were "no significant differences in STAI-T scores between subjects and controls" (Kemp et al., 1998 p. 1376) and that STAI-S scores were significantly reduced following paediatric surgical consultation (Kemp et al., 1998, p. 1376). This study provides evidence that suggests anxiety is reduced following counselling. However questions regarding how parent's anxiety was reduced or how their personal coping style may have mediated their level of distress remains unanswered.

To date only three qualitative studies have attempted to look specifically at the experiences of women whose babies may require surgical interventions post-partum, during pregnancy. Analysis of thoughts and feelings therefore are not retrospective but current. Hedrick (2005) explored pregnant women's experiences of carrying a child with a known, non-lethal congenital abnormality using a qualitative phenomenological methodology. Participants in this study experienced both positive and negative consequences around themes of coming to terms with the news, grief and acceptance of their changed babies. Importantly the pregnancy-experience was irrevocably changed when women were told adverse news about their unborn baby, although how this

occurred has not yet been explored. Jones et al. (2005) also used a qualitative methodology (data mining) to explore pregnancy experiences of expectant mothers with a pre or post natal diagnosis of foetal abnormalities. A re-analysis of data from a previous longitudinal study into "the views, attitudes, emotions, and experiences" (Statham, Solomou and Green, 2001) of these women revealed that "...the loss of the natural order of things can overwhelm a woman who may feel distanced and diminished..." (Jones et al. 2005 p. 203). Three key themes related to the pregnancy experience were identified in this study: ambivalence, uncertainty and loss.

A qualitative study (using symbolic interaction) was designed to gain parents' perspectives on decision-making following an antenatal diagnosis of congenital heart disease<sup>4</sup> (CHD). Findings showed that "uncertainty characterised the experience and compounded the parents' difficulty in incorporating a profoundly changed image of a previously envisaged healthy child..." (Rempel et al. 2003, p. 66). Furthermore, it was suggested that deciding to continue with the pregnancy was an initial parenting decision that may have conflicted with the views of others who were pro-termination. This research suggests not only living with uncertainty is difficult, but also pregnancy experience can be influenced by expectations from wider society.

## **Summary**

There are a number of key issues identified in current complex pregnancy research suggesting negative emotions, expectations, coping, prenatal attachment and socially constructed ideas around mothering all have a role to play in pregnancy experience. Receiving adverse news therefore indicates pregnancies were at the very least stressful as these factors affected pregnancy experiences. Other affects of adverse news suggests

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<sup>4</sup> CHD: "Congenital disease. A disease that is present at birth, it may be due to hereditary factors, prenatal infection, injury or the effect of a drug the mother took during pregnancy". Vanes, D. (2005).

women put their pregnancy on hold and that this affected commitment to the foetus, or that news affected the whole family. Research also suggests women experience loss and become uncertain when they receive adverse news during pregnancy regarding their unborn baby. Furthermore adverse news can have a profound effect on women's pregnancy experiences, that also affects others who cohabite her world.

In terms of research into pregnancy experience of a diagnosis of a structural surgical abnormality affecting their foetus during pregnancy there were a number of key themes identified (Hedrick 2005; Jones et al. 2005) suggesting that commitment to the pregnancy is altered alongside loss. There is the possibility that stress appraisals around loss and possible harm may occur and that values held by women around pregnancy may also be challenged. Finally, research has clearly identified that living with an unknown outcome profoundly changes pregnancy experience, although how this may be so is currently unknown.

## **Chapter Conclusion**

National policy suggests a gap in literature. Perhaps this is because there are difficulties defining what complex pregnancies actually are; implying a number of biopsychosocial issues are related to this process that warrants further investigation. The broad range of classifications reflects the array of medical and surgical abnormalities that can affect pregnancies. The range of definitions emphasises pregnancies are medically and socially constructed, however what is clear is that an 'anomaly' is a deviation from the norm. The literature around 'complex pregnancies' has revealed that 'deviating from this norm' has shown that pregnant women are distressed. Furthermore complex pregnancies present challenges to a woman and those who are emotionally close to her.

Research identifying the very normal but typical ‘worry that something may be wrong with the baby’ highlights anxiety exists around pregnancy generally. Those who go on to find out their unborn babies have an anomaly may consequently experience adverse psychological effects as delineated in Chapter 1.

Research of pregnancy experiences of surgical structural abnormalities suggest the natural phases and stages of pregnancy are disrupted perhaps because perception of pregnancy and therefore meaning has deeply altered. Or that adverse news raises awareness of expectations that now conflict with typical pregnancy expectations rendering complex pregnancies distressing. The possible challenge to expectations also has implications for interactions with others whose own expectations may also affect pregnancy experience. However what is not yet known is how women come to terms with their news with the application of psychological models and theories. Exploring this process from the social-cognitive paradigms may be useful. Therefore to recap ‘complex pregnancy’ experience is likely to be a biopsychosocial phenomenon that has yet to be explored through the application of psychological theories and models.

## **CHAPTER 2**

### **Research Aims**

This current study aims to produce an account of the lived experience of women’s pregnancy after receiving news that their unborn child has a medical problem requiring surgery following the 20 week anomaly scan. This may help address any potential gaps in knowledge, as discussed in Chapter 1. Research into the experience and needs of

women with complex pregnancies could inform the development of specialist support services.

This topic of research was initiated by a consultant paediatrician working in a hospital in the North of England who expressed concern that little was known about the needs of this particular group of pregnant women. A phenomenological approach was chosen because 'little was known' therefore research questions would need to be exploratory and a literature search supported this view. A constructionist approach to this study was chosen because this would allow for a phenomenon, such as this to be explored. IPA was chosen over other qualitative methodologies because within its philosophical underpinnings IPA is concerned with "...first-hand experiences..." (Giorgi and Giorgi, 2008, p. 28).

IPA is therefore aimed at understanding perceptions (and therefore meaning of a phenomenon), general claims are not made (Smith and Osborn, 2008, chap. 4). Smith and Eatough (2008, p. 326) cite research, which states "IPA is resolutely idiographic, focusing on the particular rather than the universal." (Smith, Harré and Van Langenhove, 1995b). Thus IPA is an ideographic (individual), rather than a nomothetic (norms and general principles) mode of enquiry, which according to Smith and Osborne (2008, chap. 4) is hypotheses driven.

### **Rationale for the current study**

The rationale for this study is that it is possible that complex pregnancies such as those referred to would be distressing experiences (as already delineated in current research in Chapter 1) and that they could potentially adversely affect the mental health and well being of mothers and their children in the long term. Research suggests that "women with 'foetal abnormality' are likely to have immediate and long-term psychological

morbidity” (Pelly 2003, p. 158). Understanding complex pregnancies such as these could have implications for the way news is delivered by health professionals.

### **Rationale for using a Phenomenological approach**

There have been a number of studies investigating the effects of foetal anomalies during pregnancy (see Chapter 1). Although some research has focused on how this distress may be expressed through the analysis of cognitive processes or the changes in expectations, none describe how distressing thoughts and feelings may be appraised alongside the challenges to any preset expectations around pregnancy and importantly how these two psychological paradigms may interface with each other. One of the overarching issues that appear repeatedly in complex pregnancy research is that uncertainty becomes part of the process of pregnancy. Therefore this study is suitable for the use of IPA because of a number of issues, which are: (1) The research question is exploratory. (2) Little is known about women's pregnancy experiences when faced with postnatal surgery of their babies. (3) ‘Uncertainty’ plays a part in expectancies and therefore by default, expectancy theory and therefore any prior expectations are likely to be challenged. (4) When pregnant women are then faced with uncertainty, as is the case with adverse news during pregnancies then pregnancy experience is likely to be complex; all of these facets warrant exploration. For these reasons IPA was chosen to explore pregnancy experience after being informed of a surgical abnormality following the 20 week anomaly scan. Furthermore "the inductive nature of IPA allows authors to discuss their analysis in light of varied existing psychological theories, models or approaches." (Brocken and Wearden, 2006, p. 96) and as such IPA was chosen over other qualitative approaches. For instance any predetermined categorisation, based upon key themes already identified in literature, namely: ambivalence, uncertainty, loss

and timing may have constrained exploration if using qualitative approaches such as: thematic analysis or content analysis (Brocki and Wearden, 2006 p.89).

### **Overview of Interpretative Phenomenological Analysis (IPA)**

According to Smith and Osborn (2008, chap. 4) IPA is based within philosophical paradigms of (1) *phenomenology*, (2) *hermeneutics* and (3) *symbolic interactionism* where phenomenological enquiry explores "...the structure and essence of the experience..." (Patton, 1990 p. 69). The phenomenon is understood by attending to an individual's perception and therefore meaning of an event. Thus a participant's lived experience is examined in detail rather than "an attempt to produce an objective statement of the object or event itself" (Smith and Osborn, 2008 p. 53). Ashworth (2008) comments upon Heidegger's (the founder of hermeneutics) interpretation of hermeneutics and states hermeneutics is about being "...interpreters, understanders...the hermeneutic approach provides a new view of the meaning of data." (Ashworth, 2008, p. 19). Also *hermeneutics* is "...concerned with trying to understand what it is like, from the point of view of a participant, to take their side" (Smith and Osborn, 2008 p. 53). According to Smith and Osborn (2008, chap. 4) a detailed IPA analysis also involves asking critical questions of the text from participants such as: what is the person trying to achieve here?" (Smith and Osborn, 2008, p. 53) and as such hermeneutics' *a priori* position is both empathic and questioning. Also IPA research is an active process, Smith and Osborn (2008) refer to this as *double hermeneutics* where "the participants are trying to make sense of their world; the researcher is trying to make sense of the participant making sense of their world." (Smith and Osborn, 2008 p. 53). However, unravelling this is as not straightforward as people may have difficulty expressing themselves, which the researcher then has to interpret the meaning of.

Hence the researcher has to have a firm understanding of not only what is being explored, but also its context and as such the researcher "...has to know the rules, the conditions, the mores, the local myths and popular expectations." (Solomon, 1997 p. 301). Furthermore this is a dynamic process where "people create shared meanings through their interactions, and those meanings become a reality." (Patton, 1990, p. 75). Smith and Osborn (2008) refer to this as *symbolic interactionism*. Hence this study is able to address these 3 philosophical underpinnings of IPA from a clinical health psychology stance. Furthermore, this study fits Brocki and Wearden's (2006) literature review findings that most IPA studies within the health psychology domain are designed using semi-structured interviews, which are recorded and transcribed verbatim.

### **Shortcomings and discrepancies to be described – limitations of the study**

Smith and Osborn (2008, chap. 4) state IPA places the participant as the expert and interviews are done using open-ended questions to enable participants' to express the meaning of their experiences, thus IPA is flexible. Hence, there is opportunity to obtain a deep and rich understanding of the phenomenon that may enlighten further understanding of complex processes. IPA focuses on what the words people say as IPA "...recognises the importance of language in influencing how individuals make sense of the lived experiences..." (Smith and Eatough, 2007, p. 326) and ignores other elements of communication, such as how words are said or omitted, including pauses, unlike conversation analysis that takes these aspects of language into account (Drew, 2008, chap. 7). There may be a question of validity in IPA studies when considering whether a finding can be generalised, Smith and Osborn (2008) argues validity is inherent within the analytical process. Barker, Pistrang and Elliott (2002, p. 145) cite research that

refers to this as 'external validity', which is implicit in assessing whether findings can be generalised (Cook and Campbell, 1979).

Barker et al. (2003 p. 237) cites further research that refers to this stating this issue remains contentious (Bryman, 1988; Willig, 2001). IPA uses purposive sampling consequently the aim is for the group to be closely defined and attempts therefore should be made for homogeneity within participants (Smith and Osborn, 2008). However, homogeneity can also lower studies external validity (Barker et al., 2003) because "...this will make the sample less representative and thus lower the studies external validity" (Barker et al., 2003 p 237). Participants within this study are bound together by their complex pregnancies and gender rather than an age cohort and/or socio-demographic factors. Therefore participants' homogeneity in this study is around pregnancy alone which may or may not represent the issue of external validity if findings are generalised. Alternatively differences within the cohort could potentially weaken findings if generalized.

### **The factors to consider (setting the scene)**

This study has been conducted to understand pregnancy experience and as such there is a relationship with feminist research. Webb (1993, p. 417) cites literature on feminist research stating "the enquirer her/himself...must be placed in the same critical plane as the overt subjective matter, thereby recovering the entire research process for scrutiny" (Harding, 1987). This study is about women's pregnancy experiences when faced with adverse news. Therefore this study is implicitly aimed at women. Webb (1993, p. 416) refers to research for women "...that tries to take women's needs, interests and experiences into account and aims at being instrumental in improving women's lives in one way or another." (Klein, 1983). Thus one of the aims of this research would be to

enlighten the issues for women after being told that their unborn baby requires surgery, which may be empowering.

### **Research Questions**

IPA means that IPA projects "...are usually framed broadly and openly...the aim is to explore...an area of concern." (Smith and Osborn, 2008 p. 55). In order to do this a primary question was proposed followed by four secondary questions.

Primary research question: What are women's experiences of pregnancy after being told their unborn baby requires surgery?

Secondary research questions:

1. How do women's expectations of pregnancy change in response to learning about their baby needing surgery?
2. What are pregnant women's thoughts and feelings (stress-appraisals) about their pregnancy after being told their unborn baby is in need of surgery?
3. How do women view their stage of pregnancy in response to learning about their baby needing surgery?
4. What are women's experiences of support during their pregnancy in this situation?

## CHAPTER 3

### METHOD

#### Design

This was a qualitative cross-sectional interview study with women who experienced complex pregnancies. Research questions were designed to explore pregnancy experiences, expectations and appraisals against the backdrop of pregnancy transition. The interview transcripts were analysed using the qualitative method of Interpretative Phenomenological Analysis (IPA Smith and Osborn, 2008, chap. 4).

#### Settings

Women were recruited at 2 ultrasound departments at hospitals in the north of England. These departments provide a service for a broad geographical area with urban and rural populations. Clinics screened 19,018 total pregnancies and births during two phases of recruitment (over 19 months, see below). This resulted in a total of 19,018 pregnant women during recruitment, which equates to 12,011 pregnancies and births per year. This resulted in 9,434 deliveries in the two hospitals and 9,584 pregnancies booked in for screening in the two ultrasound departments. The prevalence rate of foetal surgical abnormalities nationally is estimated to be 1%, although Boyd et al. (2005) state the true figure is more likely to be between 2-3%. Locally there were 15 women whose babies were diagnosed with a surgical abnormality during the recruitment phase. When compared against the total number of pregnancies booked in for screening the number of surgical abnormalities detected equates to 0.002% of the national average and when compared to the number of deliveries the number of surgical abnormalities equates to 0.002% of the national average also. The 20 week anomaly scans were carried out at the two different hospitals where participants were recruited from. If a foetal surgical

structural abnormality was detected women were referred (within 24-hours for another diagnostic scan, apart from 1 participant that waited 1 week due to annual leave) to the consultant ultrasonographer either at the main maternity hospital in the region or at the hospital they were first scanned at. The total number of women who were told their unborn baby was likely to require postnatal surgery during the recruitment phase of the study was 15. The total number approached and invited to participate was 15.

### **Participants**

All pregnant women over the age of 16 who attended the ultrasound departments for their 20 week anomaly scan diagnosed with a foetal surgical structural abnormality were eligible to participate in the study. Women were recruited and interviewed over a period of 19 months. Recruitment was in 2 phases due to the main researcher being pregnant and being away from the study during maternity leave. Therefore participants were approached to be recruited into the study between 29 August 2008 to 31 December 2008 (4 months) and then from 14 February 2010 to 31 May 2011 (15 months). Research and Development (R&D) approval was initially with the local trust (29 June 2008, see Appendix), approval was further required for the local National Health Service (NHS) hospital, which resulted in a change in sponsor for the study as the main researcher was then working voluntarily. A substantial amendment was sought with NRES and approval gained (29 January 2010, see Appendix) and recruitment did not commence again until 1 year following the birth of the main researcher's baby when R&D approval was gained (14 February 2010, see Appendix).

Sampling was purposive in that women had been told their babies needed surgery following birth were sought to talk about their pregnancy. Women invited into the study were initially 27-32 weeks gestation. However recruitment was altered from

32 weeks gestation to 42 weeks gestation (or up to the point of birth). This extension was deemed necessary due to recruitment difficulties and was a substantial amendment. Approval was sought by the National Research and Ethics Committee (NRES, 13 November 2008, see Appendix). All participants had all had their 20 week anomaly scan and had met the consultant ultrasonographer. 2 participants were informed of the possibility of a foetal structural surgical abnormality during prior routine scans (12 weeks), which were also confirmed at the 20 week anomaly scan by the consultant ultrasonographer. All women who had fit the research criteria were invited to participate by the consultant ultrasonographer (15 participants).

The exclusion criteria were: no pregnant women under the age of 16 (due to needing parental consent); the baby's condition was known to be fatal<sup>5</sup>; women with current serious mental health difficulties e.g. psychotic depression, psychosis etc.; women who are unable to give informed consent to participating in the study and pregnancies with chromosomal abnormalities that resulted in chronic disability, as identified by consultant obstetricians. All interviews were conducted in English, only women who understood English were invited into the study. Recruitment ceased when data saturation was deemed to have occurred. This was apparent when similar emergent and no new themes appeared in subsequent transcripts, recruitment stopped at the ninth interview.

In total 15 women were approached and 15 agreed to participate (100% response rate). One woman initially expressed interest in the study but then declined to participate stating that she did not think that she fit the research criteria because she was

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<sup>5</sup> The probability of a baby's survival rested with consultant radiologist, paediatricians, paediatric surgeons and obstetricians. The decision is usually a combined one but personal discussion is necessary in each case, women whose pregnancies with those prognoses were excluded from the study.

very positive about her pregnancy. This potential participant reported that her two previous pregnancies had miscarried; hence her baby's abnormality (cleft lip and or palate) did not affect her adversely. However, these comments were noted and the patient information sheet (summary version, see Appendix) wording was subsequently changed to reflect a more neutral stance. This was also a substantial amendment and again ethical approval was sought with the NRES (13 November 2008, see Appendix). The rationale for these amendments is discussed in 'assuring validity' section in this chapter (see below). 3 further women agreed to participate but when contacted by telephone after being sent the full patient information sheet (see Appendix) declined. All of these women were carrying babies with cleft lip and or palate. A further woman consented and arranged to be interviewed but further declined. Reasons given were that she could not face an interview at that time and needed time to come to terms with her news. This participant had been given a diagnosis of a brain tumour in her unborn and was contemplating termination of pregnancy and did not wish to proceed any further with the study.

Another patient initially agreed to participate after meeting the main researcher and gave written consent but when contacted with a follow up telephone call 1 week later withdrew consent stating that she was too upset to talk about her pregnancy. This potential participant expressed that she did not wish for any further action but was told that she could contact the main researcher if she wanted to in the future (see Patient Information Sheet – full version in Appendix), which reflected ethical standards for the study. Therefore a total of 6 participants agreed then declined to continue for reasons stated above (40%).

In total 9 women were recruited into the study. Participants given diagnoses were a mix of primiparous (4) and multiparous (5) women. There was range of

abnormalities, which were: talipes\* ( $n=3$ , including a double amniotic sac  $n=1$ ), gastroschisis\*\* ( $n=3$ ), congenital diaphragmatic hernia\*\*\* ( $n=1$ ) congenital pulmonary airway malformation (CPAM)\*\*\*\* ( $n=1$ ), omphalocele\*\*\*\*\* ( $n=1$ ). 7 women's interviews were included in the analysis of the study (47% of those approached). For full information regarding all structural surgical abnormalities included in the inclusion criteria please refer to Appendix. 2 participants (with talipes and CPAM) were excluded from the analysis.

One participant's interview was removed from the study because it was felt that this participant did not meet the research criteria due to the seriousness of her baby's anomaly (3<sup>rd</sup> interview). The first participant interview (pilot interview) was also removed from analysis because the interview was of poor quality and accuracy was an issue, resulting in poor data for analysis. Also this participant was interviewed when the main researcher was visibly pregnant. In order to clarify any potential conflict of interest regarding the study's aims that pregnant women with complex pregnancies would be interviewed by a pregnant woman, advice was sought from a range of professionals and is discussed under 'ethical considerations' in this chapter (see below). However the potential effects of being interviewed would be difficult to partial out from the data from other interviews. Therefore this interview was removed from analysis for this reason also. No further interviews were conducted whilst the main researcher was pregnant. Analysis is therefore not confounded in any way by this potential artefact to the data.

Women were given a choice of venue to be interviewed, either in their own homes, at the ultrasound department at the main maternity hospital or at the university. The choice of location was clarified as it had previously been deemed 'to vague'; changes to the patient information sheet reflected this, an amendment which was sought

by NRES (13 November 2008 see Appendix). Over half the women interviewed chose to participate at the first meeting (N = 6, 67%). The total number of women interviewed in their own homes was 5 (56%), none chose to be interviewed at the university.

## **Measures**

### *Information about participants and their pregnancy history*

Participants were asked details about their physical health, age, and pregnancy history. This was to contextualise the data. Pregnancy interviews could be understood in terms of physical health, maternal age, stage of pregnancy and pregnancy history (see Appendix).

### *Semi-structured interview*

A semi-structured interview schedule was designed by the primary researcher. Smith and Osborn's (2008) guidelines were used to help develop questions. The interview schedule covered the following issues: pregnancy experience, expectations of pregnancy, stress appraisal and social support within the particular transitional stage/phase of pregnancy. Questions were designed to be neutral and open, in a language familiar to the participants. The interview schedule was used as to guide so that women had the opportunity to tell their stories and define their own experiences.

The interviews were non-directive and the interviewer responded to participants' views and concerns following what women wished to discuss, within the theoretical framework that would be used to explore individual differences. The interviewer was not constrained by the order of questions. The primary researcher was the only interviewer. Initially questions were asked specifically about pregnancy experience.

The questions addressed present circumstances and were chosen because this was deemed less threatening for women. Only the last question asked women about pregnancy prior to their news. This question served as a platform to explore any changes around pregnancy expectations (see Appendix).

### *Expectancies*

*Expectancies* as delineated in Chapter 1 (Olson et al. 1996) were explored. Questions were therefore asked about expectations of pregnancy prior to the news to bring forth an understanding of the past, followed by questions eliciting current expectations (present) and what future expectations may be. Thus the order of questions was designed to draw out any possible changes and explore why these possible changes occurred.

### *Stress Appraisal*

*Stress Appraisal* was broken down by a series of questions to represent different theoretical areas of Lazarus and Folkman's (1984) Transactional Model of Stress Appraisal, cited in Wells and Matthews (1999, chap. 8). Firstly questions were designed to discover women's thoughts and feelings about their pregnancy (i.e. emotions and associated primary and secondary appraisals). Subsequent questions tapped into coping strategies used by women (emotional focused versus problem solving focused) and were also used to explore emotions about the past, present and future. Women were also asked about how their emotions and thoughts may have changed. This was to explore if appraisals of pregnancy were affected, thereby affecting expectations about the pregnancy and vice versa. Finally there were questions about social support, used to explore whether experiences of stress were influenced by the level of support.

### *Transitional phases of pregnancy*

Understanding the impact of postnatal surgical news in pregnancy was considered against the backdrop of the transitional phases and stages of pregnancy and mothering orientation as described in Chapter 1 (Raphael Leff, 2005; Philipp and Carr, 2001) and research by Sharp and Bramwell (2004).

### *The Hospital Anxiety and Depression Scale*

The Hospital Anxiety and Depression Scale (HADS) is a 14 item questionnaire designed to measure depression and anxiety in medical patients and is easy to administer (Herrmann 1997, p. 32). According to Herrmann (1997) the HADS is both reliable and valid. The HADS has an internal consistency 0.80-0.93, (Chronbach alphas) and 0.81-0.90 (Chronbach alphas) respectively. The re-test reliability is  $r > 0.80$ . The HADS has factorial, discriminant and concurrently validity (Herrmann 1997). This measure was not used to include or exclude participants. The purpose was to obtain a baseline for mood and anxiety, where the outcome can be used as a backdrop from which to analyse and interpret the data, therefore helping to contextualise the data (see Appendix).

### **Reflexivity**

Pregnancy is a state encountered by many women, it commonly binds women and there are expectations about pregnancy that affect women's perception of this event. The researcher believes understanding complex pregnancies such as these are important because being in a pregnant state is experienced by the woman alone hence pregnancy is fundamentally a women's issue. Therefore to understand complex pregnancies it is

important to get women's views about this process. According to Ashworth (2008) *hermeneutics*, asks "what processes of construction have the researchers themselves employed in coming up with the findings they have presented?" (Ashworth, 2008 p. 18). IPA is therefore reflexive thus researchers' findings may be influenced by their values and beliefs, gender, socio-economic status and level of education, which may influence their interpretations.

The main researcher is an older female who was also pregnant during some of the recruitment phase of this study (phase 1, interviewing participant 1), which brought an element of complexity into the research process also and could explain possible recruitment difficulties at the time. Perhaps potential participants felt inhibited by being interviewed by a pregnant woman? It is difficult to assess the effects of pregnancy because only one interview was conducted when pregnant, which was the pilot study, which was removed from the data as stated above. Fundamental changes to interview style were made following this initial interview where questions were curious and therefore more searching, inviting participants to reflect and expand upon their pregnancy experiences. It is worth noting also that during the second interview (participant 1) there was a number of occasions that this participant reflected upon meeting the main researcher and how that experience positively changed her pregnancy experience (see Appendix for an example of this from the interview). This underlines reflexivity as a process and can be considered in the context of how an interaction can affect experience.

Some participants 3/7 (43%) did not return feedback forms regarding the accuracy of the themes. It could be argued that participants may not have wanted to be reminded about how they felt during their pregnancies and may have avoided replying. Women had given birth by the time they were sent feedback forms and were coping

with surgery with their babies; it is unlikely that replying was a priority. Also, living with a baby is very different to being pregnant. Alternatively commenting on an interview during pregnancy may have long been forgotten, women may not have been able to comment on the accuracy of the themes. It is possible also that the role of the interviewer represented a health professional; participants may not have wished to challenge those perceived as more knowledgeable (findings that will be elucidated upon in Chapter 4).

Also intensely rereading and reworking transcripts of this particular group of women was sometimes distressing. Thus a certain level of awareness was needed in order to remain objective and true to the data. However, there was an element of nervousness about other academics finding ‘something wrong’ with the thesis. This suggests an emotional response may have occurred that possibly mimicked participants being given adverse news about their unborn baby. Further suggesting that complete objectivity may not have been fully achieved; perhaps this is unrealistic in research with an IPA methodology, which requires a double hermeneutics to occur in order to get as close to the data as possible? It would appear that writing up has been an emotional journey that may have mirrored some of what participants experienced with their complex pregnancies; participants whom I had the utmost respect for. Therefore the issue of transference and counter transference also came to the fore during the writing up of this research.

## **Procedure**

Women were invited into the study by the main field supervisor at their follow up appointment (see flow chart of the procedure, Figure 1). However, it had become evident that the consultant ultrasonographer required a degree of flexibility when

introducing the study to potential participants. Although initially this was thought to be when women attended their follow-up appointment (1-2 weeks after their 20 week anomaly scan) discussions with the field supervisor (consultant ultrasonographer) revealed that for some potential participants, it would not have been appropriate to introduce the study then. Therefore changes were made to allow the consultant ultrasonographer the flexibility to choose when to contact women, either at their follow-up appointment (in keeping with the original research proposal) or at further follow-up appointments or via the telephone. Hence substantial changes to the research protocol were made, which NRES approved (13 November 2008, see Appendix).

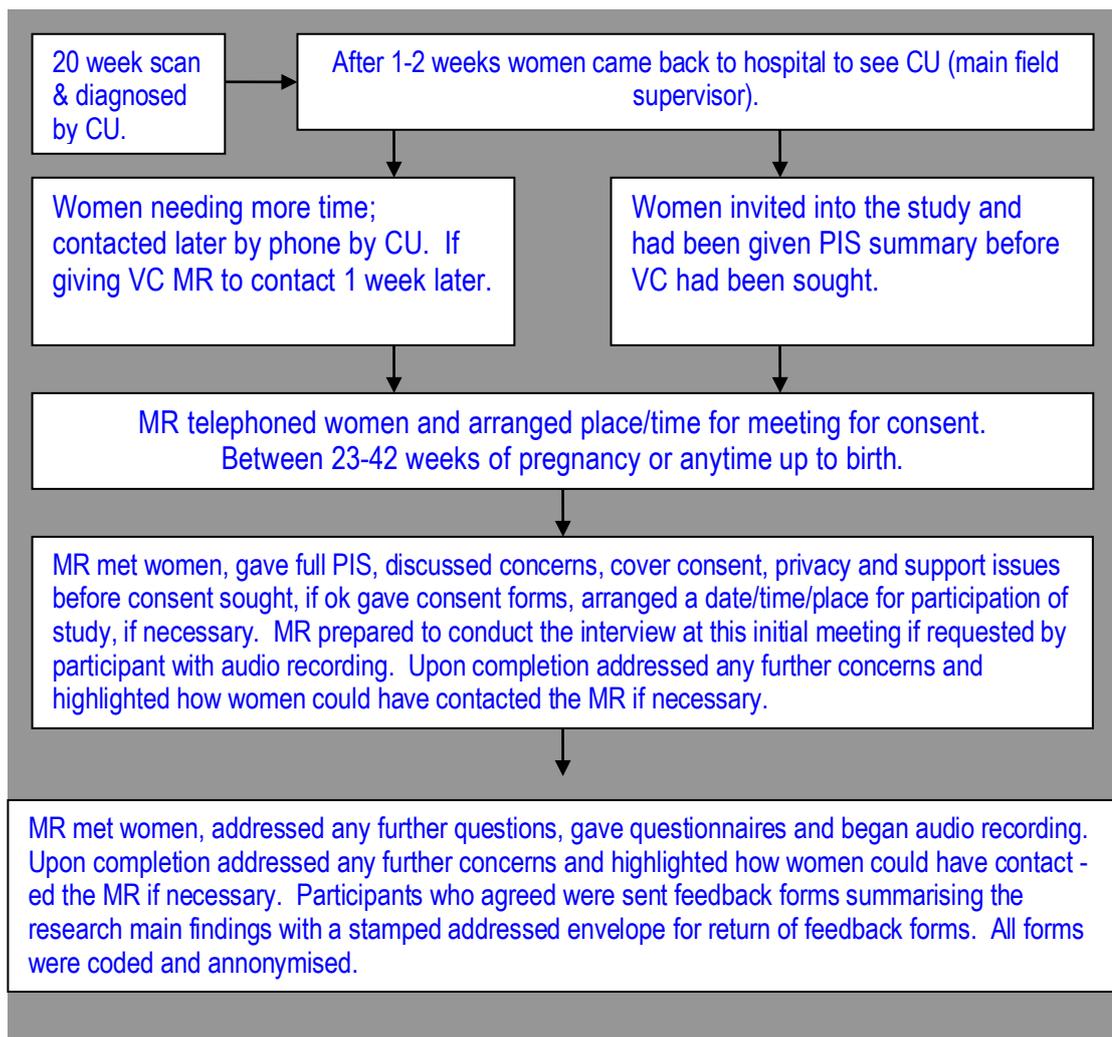
Women who expressed an interest in the study and gave verbal permission to be contacted by the main researcher to the consultant ultrasonographer were contacted 1 week later, following their appointment with the consultant ultrasonographer. Participants were informed by the consultant ultrasonographer that they would be contacted in 1 week; this was supported in the summary patient information sheet, a change to the previous summary patient information sheet which was approved by NRES (13 November, 2008, see Appendix). The ethical issues raised by this change are discussed below in 'ethical considerations' section. The main researcher contacted the participants via telephone and the study was explained briefly, but the emphasis was on arranging a meeting at a suitable venue decided by the participant as discussed above.

Written consent was sought after meeting with participants and answering any queries or concerns when the main researcher met potential participants for the first time, this was to ensure confidentiality and to maintain informed consent. Women were told they could contact the main researcher at any time after their interview if they felt it necessary or had any queries. Therefore, therapeutic boundaries for the interview were established before gaining written consent and before the research took place, this was

in line with achieving informed consent and maintaining confidentiality as described under the ethical considerations section. The interviews were audio recorded and transcribed verbatim, which participants were informed about in this initial meeting. Women were told all identifying information would be removed and that their transcriptions would be kept with the academic supervisor at the University for 5 years, again in line with data protection. This was to establish confidentiality and comply with data protection.

Upon commencement participants were issued with two questionnaires (background pregnancy health history information questionnaire and HADS - see Appendix). The purpose of this had been explained to contextualise the data. The HADS was chosen as an objective measure to screen for potential difficulties not necessarily obvious when meeting the participants. If HADS scores were high then these would be discussed with participants, as was the case with a participant, which after talking these scores through the participant acknowledged she was anxious but did not feel unduly so as she described herself as an 'anxious person' and more importantly, did not wish to discuss things further with any other health professional, which was her choice. However, if participants wanted or needed to be referred to psychological services or to have further appointments with their obstetrician's or midwives, they could request the help of the main researcher during, after or at any time after the interview. Participants were given the main researcher's contact details to do so if they wished. The consultant obstetrician (field researcher) was informed, who had agreed to inform participants' respective consultant obstetricians, whom they were referred to that they had agreed to the study by letter. This was deemed a substantial amendment and approval was given by the NRES (13 November 2008, see Appendix).

Participants who agreed to be contacted when rudimentary findings had been identified (9, 100%) were sent feedback forms to comment on rudimentary themes apart from 1 participant as stated above. It was deemed unethical to send this form to this particular participant whose interview had been removed from the study (3<sup>rd</sup> interview) due to the seriousness of health of the baby at the time of the interview.



**Figure 1: Flowchart of the procedure**

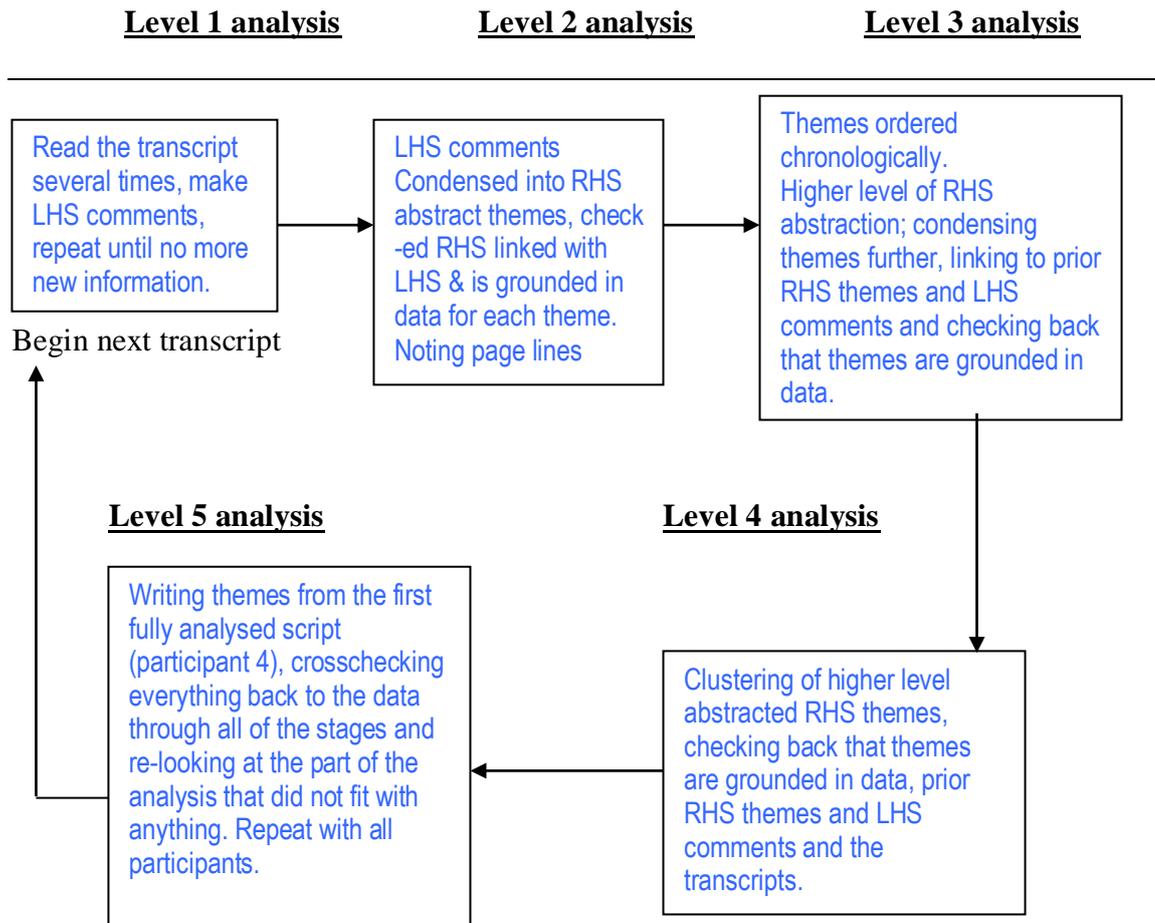
Key: CU = consultant ultrasonographer (the main field supervisor); VC = verbal consent; MR = main researcher; PIS = patient information sheet

## **Data analysis**

All of the analysis followed Smith and Osborn's (2008, chap. 4) guidelines. All interviews were recorded in full and transcribed verbatim. The first interview was used as a pilot study and, although no changes were made to any of the semi-structured interview questions (see Appendix) issues regarding interviewing technique was reflected upon and used to improve subsequent interviewing method as discussed above (see Assuring Validity section below). All of the transcripts had line numbers, which was used as an aid to link left-hand side (LHS) and right-hand side (RHS) and eventual super-ordinate themes together. This made for easier referencing when moving through several transcripts and for checking backwards to ensure that all levels of analysis were grounded in the data. The flowchart below (Figure 2) shows the analytical process, where initial LHS comments became linked to RHS themes and finally rudimentary super-ordinate themes were reached. Most analysis was done using Microsoft word, developing tables to contain LHS columns and RHS columns. New tables were then designed that listed all of the RHS themes, grouped together in chronological order, section by section with the semi-structured interview questions at the top of each bracketed group. This placed the data in chronological order.

The next stage of analysis led to making sense of these initial themes and clustering them together. Some were unable to be placed, but were not removed at this stage of analysis. The clustering process led to the initial development of preliminary super-ordinate themes. The clustered themes were also connected back to the data and rechecked for validity (see Figure 2). This process was repeated for all transcripts with the addition of using the generation of RHS clustered themes in one transcript as a guide for future analyses of all of the other transcripts only when all LHS comments and RHS

higher level abstractions had been completed as described in Smith and Osborne (2008, chap. 4). This resulted in RHS themes being clustered under the same headings, developing these headings further or extending them or developing new headings whilst paying attention to convergence and divergence. This process was repeated several times for each transcript until rudimentary super-ordinate themes were developed.



**Figure 2: Flow chart showing Analysis of the Data to Rudimentary Super-ordinate themes**

Each quote was cut out by hand and then placed on a large sheet of paper that had headings representing the emerging super-ordinate and sub-ordinate themes. The quotes were then moved around to fit the themes. This process created further divergence; themes were expanded before being converged. Some themes were disregarded because they were not common across all participants. The components of

sub-ordinate themes were then further broken down into micro-sections so that only those components that represented all participants were kept, which represented higher level abstraction. These were placed into tables using micro-soft word (see Appendix), which had the quote, participant and line-number in one column (Level 1: Higher level abstraction). The second column had the RHS analysis and the final column had the word that contained the ‘essence’ of the quote. Analysis then focused on the second column where the interpretations about what the quotes represented were then written down. Analysis then led to a synthesis of super-ordinate themes and subsequent sub-ordinate themes (Level 2: Higher level abstraction), where the strongest quote was chosen to represent the synthesis of that theme. This process was repeated throughout all themes; the sub-ordinate themes that were broken down into sections that represented the key points within the sub-ordinate themes were highlighted through this process in preparation for writing the results section (see Figure 3 below).

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**Level 1: Higher level abstraction**

All quotes were cut out by hand and placed under emerging super-ordinate themes. Tables developed with 3 columns containing quotes; RHS interpretation; single word essence of theme. Themes diverged and then converged. Quotes that did not fit were disregarded from the study.

**Level 2: Higher level abstraction**

Themes broken down into key points for synthesis, most representative quotes were chosen for writing up

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**Figure 3: Flow chart showing Higher level abstraction Analysis of the Data to synthesise themes for writing up**

### **Assuring validity of the study**

The issue of validity in qualitative research is debated as to whether the same criteria should be used to assess as quantitative studies (Mays and Pope, 2000). Yardley (2000) explores the benefits of using qualitative research and comments that qualitative researchers are closely aligned to clinicians. The purpose of this study was to address a potential gap in knowledge, highlighted by a Consultant Paediatrician working in the field. Hence this qualitative research is likely to be meaningful because it represents real world clinical issues and dilemmas highlighted by a specialist working in this field. Yardley (2000) proposes the problem of diversity of quantitative studies versus novel qualitative studies is an issue of quality control. In order to maintain quality control and quality assurance the researcher utilised a paediatrician's concerns about the need to know more information about this particular group of women and set up a number of meetings with key professionals in the field to corroborate this potential clinical need. The main researcher also took time to evaluate the importance of investigating this particular group of pregnant women by building relationships with key professionals and discussing their needs. Further discussions with the main field supervisor led to changes to the summary patient information sheet to convey a more neutral tone that reflected the research aims as discussed above. These changes were approved by the NRES as were changes to the research protocol, (full version patient information sheet and flow diagram; Figure 1 (13 November 2008, see Appendix). Thus the changing of the wording of the patient information sheets was to allow women to control how they defined their experiences. The potential participant who declined the study highlighted the potential bias in the study. This was not only a possible barrier to recruitment, but may have questioned the validity of this study. Thus the likelihood of influencing participants' recounts of their pregnancy experiences was removed, and the main

researcher was mindful of this potential bias and construed interviews to reflect a neutral stance as discussed above.

The main researcher also attended an IPA peer support group to check the analytic process; of LHS and RHS interpretations. The main researcher also interpreted other peer IPA studies and gave feedback. This gave the main researcher insight into potential own analytical biases, as awareness was raised of common words or ways of interpretation through analysing peers studies. Hence the main researcher endeavoured to, in terms of Smith, Jarman and Osborn (1999, p. 223) maintain ‘a close interaction’ with the text so to remain close to this particular group of women's pregnancy experiences through engaging in the analytical process and by analysing peer studies and receiving feedback on this study. The researcher also kept a diary making notes about participants after interviewing, thereby ensuring the exploration was rigorous and that findings were grounded in the data. The main researcher also periodically utilised yahoo support IPA groups for advice regarding conceptual difficulties of data analysis.

### **Ethical considerations**

Consideration was given to the possibility of participants' distress in this study. The consultant ultrasonographer chose who and when to approach women. Important changes to the research protocol were made and approval by NRES was sought and given on a number of issues (13 November 2008, see Appendix). Firstly, instead of women waiting 2 weeks to be contacted this was changed to 1 week because it was deemed that 2 weeks was too long for women to wait to be contacted as discussed above. Hence participants, after agreeing to be contacted may be expecting to be contacted sooner rather than later. The issue of informed consent was not thought to be

compromised as women still had a substantial period of time to reflect whether they wished to participate in the study and as already stated they were able to decline from the study at any given point. Participants who wanted to be interviewed during the first meeting with the main researcher were asked to consider their decision and were also informed that they may experience becoming upset during the interview before the interview began. Other ethical considerations were around informed consent; women who were approached were made aware that they could withdraw from the study at any point up to publication and that this decision would not affect their care in any way. Before research began confidentiality was covered, women were made aware that their questionnaires and transcriptions would be treated confidentially.

Women were also informed about the longer-term implications of storing information and how this would be done securely (transcripts would be stored with the academic supervisor within the University for five years), which also helped build trust between the main researcher and participant. This issue of informed consent and privacy in creating therapeutic boundaries for the participant was to enable participants to have control over their information, to feel respected and not coerced into participating. The main researcher, also during the interviews summarised participant accounts to achieve clarity for both participant and researcher, thereby attempting to create an alliance based upon mutual respect and trust. It was hoped that creating therapeutic boundaries in this way may have led to a safe environment for participants to open up and explore their pregnancy experiences without concerning themselves with potential adverse repercussions. This all served to enhance a feeling of safety and trust to aid the ethical psychological exploration of their complex pregnancies.

Other potential ethical dilemmas challenged the study when the main researcher became pregnant. The question raised was whether recruitment should carry on or be

postponed until after the birth had occurred. Opinion was sought from several key professionals to address this ethical dilemma. People approached were: members of the university research committee in the Department of Clinical Psychology and Psychological Therapies; professionals from the local hospitals which included the head of maternity services, 2 lead midwives, and the consultant ultrasonographer (main field supervisor). Opinions were mixed, although the head of maternity services approved recruitment. However, the research supervisor raised concerns about how to partial out the effects of interviews by a pregnant researcher versus a non-pregnant researcher, which was discussed above (see reflexivity). It was decided, after the pilot study to cease recruitment into the study temporarily.

## **CHAPTER 4**

### **Results**

This chapter presents analyses of data collected from seven women. Demographic and clinical characteristics of the women are presented to describe the sample of participants interviewed and contextualise the qualitative data (see Tables 1 and 2). The main super-ordinate and subordinate themes are summarised and presented in Table 3. Super-ordinate and subordinate themes are then described in detail with examples from quotes.

#### Participant Characteristics

**Table 1: Pregnancy History of the participants**

<b>Characteristics</b>		<b>Percentages</b>
<b>Current Pregnancy History</b>	First pregnancies	28%

	Planned pregnancy Length of time conceiving	86% 57% < 6 months
<b>Prior Pregnancy History</b>	Previous Pregnancies Previous Miscarriages Terminations	71% 57% 43%

**Table 2: Demographic and clinical characteristics of the participants**

Characteristics	Participants						
	1	2	3	4	5	6	7
<b>Health</b>							
Physical Disability							
<b>Age</b>	16-20	31-35	20-25	25-30	31-35	20-25	31-35
<b>Current pregnancy history</b>							
First pregnancy		√	√				
Planned pregnancy		√	√	√	√	√	√
Length of time conceiving		6 mths	2 mths	1 mth	2 mths	2 mths	1 yr
Fertility treatment							
<b>Previous pregnancy history</b>							
No of previous pregnancies	2	0	0	3	1	5	5
Miscarriages	1			1		2	1
Terminations				1	1	1	
Abortions							
Anxiety	1	2	8	4	10	4	9
Depression	5	2	3	4	5	2	3

## Themes

Participants described their pregnancy experiences when post-birth surgery was indicated in their unborn baby. The results followed a narrative, starting with individual experiences (super-ordinate themes 1-3), which then connected with the social worlds of the participants (super-ordinate theme 4). Results are therefore presented as following a biopsychosocial model, as delineated in Chapter 1. These themes (summarised in Table 3), although differing on some levels contained elements that were shared between all participants. The first 3 super-ordinate themes relate to thoughts, emotions and behaviours linked with individual experiences and are representative of the biological and psychological aspects of the biopsychosocial model. The final super-ordinate theme was the largest and most powerful and explored the ‘social’ connotations of complex pregnancy experiences.

Hence complex pregnancy experience was explored through interactions with others and this then had an impact on individual complex pregnancy experience. The super-ordinate overarching themes were: *living with the changed pregnancy; an emotional journey; coping and relationships with ‘self’, their baby and others*. Direct quotes are taken from the interviews to represent participant’s experiences. At the end of each quote is the interview number and page line from which the quote was taken.

**Table 3: Summary of super-ordinate and subordinate themes**

**1. Living with the changed pregnancy**

- 1.1 Not knowing - "*...we think, well what's going to happen...*" (Part. 2, line 112)
- 1.2 Changed expectations - "*...just very happy and I didn't think anything was going to be wrong...*" (Part. 1, line 1078)

**2. An emotional journey**

- 2.1 The initial response - "*Devastated*" (Part. 4, line 1068)
- 2.2 I'm confused and have mixed emotions - "*I can't explain how I feel to be honest.*" (Part. 6, line 656)
- 2.3 Reaching acceptance - "*I mean now, I feel fine.*" (Part. 3, line 665)
- 2.4 There's always something to be worrying about - "*...it probably kept me awake on a night as well worrying about it.*" (Part. 6, line 1192)

**3. Coping**

- 3.1 Belief, Hope and achievements - "*And I always make a positive thing about it.*" (Part. 3, line 892)
- 3.2 Detachment - "*You can't get excited.*" (Part. 4, line 275)
- 3.3 Making sense in different ways "*Yeah, I've tried to look for things on the internet and...*" (Part. 4, line 1350)

**4. Relationships with 'self', their baby and others**

- 4.1 Sense of motherhood and baby identity – "*just feeling as though I loved this little person and I needed to, to look after her*" (Part. 4, line 1101)
- 4.2. The way things are communicated - "*my two friends, girlfriends are just really supportive.*" (Part. 2, lines 746-747)
- 4.3 Isolating self - "*I think it's quite a private thing anyway.*" (Part. 7, line 489)
- 4.4 Needs not being met, "*they're not giving you any answers*" (Part. 7, line 832)
- 4.5 In safe hands, "*I'm getting a, a fantastic, fantastic service.*" (Part. 5, line 1615)

Themes will now be described in more detail.

**Super-ordinate Theme One: Living with the changed pregnancy**

*Overview of super-ordinate theme*

Participants in this study found that living with adverse news about their unborn babies lead to a profoundly altered pregnancy experience that was unforeseen. Participants' sense of living with the changed pregnancy developed out of exploring the impact of

receiving bad news about their babies. Participants no longer defined their pregnancies as normal, as their news meant that their pregnancies no longer fitted typical developmental milestones and therefore became uncertain. They expressed this uncertainty as 'not knowing'. This uncertainty meant participants had difficulties understanding what their pregnancies were and that lack of understanding inhibited preparation and planning. This in turn meant pregnancy experience prior to receiving adverse news was incompatible with the reality of their new pregnancy experience, which then led to new expectations that then had to be assimilated into their new pregnancy experience.

### **1.1 Subordinate theme one - Not knowing**

When receiving a diagnosis for their unborn baby's condition this did not mean participants lived with certainty throughout the rest of their pregnancy, on the contrary the seriousness of post birth surgery meant they had to live with an unknown prognosis until the baby was born. Thus living with 'not knowing' generated many questions that could not be answered and forced participants to live in a perpetual state of uncertainty throughout the rest of their pregnancy:

*"We know that she's got, em, we know she's got a problem but the nature of the, of gastroschisis is they can't tell to what extent and what treatment she's gonna need when she's born. So, nobody can say, 'well, this is what's going to happen, this could happen, or we might need to do this, and we might need to do this, and it depends what condition the bowel is in as to how long it will take the baby to recover'. So it's all these unanswered questions that no-one can answer at this stage." (Part. 5, lines 45-56)*

However, living with an unknown prognosis meant many questions about their forthcoming birth also could not be answered and this therefore disrupted their ability to clearly plan ahead because they did not know what the future held for them:

*"But I'd rather know what, if that happened, what would happen if she comes through the amnion? Have I got, have I got two bags of water? Do I have to*

*have, like, if I got induced, would they have to break two lots of water? Just silly things like that. Would I have to go into labour early? Would I have to have a section to deliver her? Just me being over-organised and you can't be, which I don't like. (laughs) I like to know where I am and what I'm doing and you can't do it so." (Part. 4, lines 374-381)*

The uncertainty created from not knowing also interfered with planning in other ways, such as buying clothes for the new baby. This suggests planning may intrinsically be very important to pregnant women and having news that interferes with this fundamentally disrupts normal pregnancy experiences (such as buying items for the baby) that may be necessary for the psychological adjustment in preparation for the future arrival of a new born:

*"But yeah, it has, it's been totally, thrown us out because I don't know what to get for her. And I think that's one of the reasons why I don't feel so prepared." (Part. 6, lines 636-639)*

## **1.2 Subordinate Theme two - Changed expectations**

When participants recalled their experience of pregnancy before receiving their news it was largely devoid of worry and the focus was on typical development, which was enhanced by receiving pregnancy information about gestational milestones. Participants described generalised expectations that were largely around experiencing positive emotions, citing excitement at enjoying their pregnancy by understanding developmental and gestational milestones reached by their unborn baby:

*"...every week I'd get an email saying 22 weeks, 3 weeks and your baby's this size and it was just all kind of like wrapped up in that and then you think ooh it's, the baby's got hair now and they're mov [pause]. you know, and so, kind of it was all..." (Part. 2, 507-513)*

However despite this overall positive view they also had difficulty recalling specific aspects of pregnancy experienced prior to their news that post-natal surgery was required in their unborn, which suggests there were generalised expectations of a happy

pregnancy that matched typical gestational milestones. This indicated the generalised sense of enjoyment cited previously no longer matched their new reality. The impact of their adverse news was so great that prior and post pregnancy experiences could not be assimilated as a cohesive unit as it was completely disrupted by their adverse news. This was echoed by the acknowledgement of displeasure, which contrasted against previous pleasure experienced and lead to the difficulties around accessing early pregnancy memories:

*“Just, erm can’t really think that far back. I was all right. I was just really, I was really happy. I just thought I was going to be a like a really pleasurable and enjoying pregnancy kind of thing but then its like it’s gone to the opposite way to that...” (Part. 1, lines 1081-1084)*

Given that the news changed pregnancy experience in an elemental way participants were aware of certain expectations they had harboured about their pregnancy prior to their news that post-natal surgery was required in the unborn and how these conflicted with the reality of their situation. Therefore specific expectations about ‘bad news’ were not only unexpected but a straightforward pregnancy had been expected. Importantly these post-news pregnancy expectations was not based on memory recall of prior generalised pregnancy expectations as above, rather they were representative of being ‘surprised’ by adverse news about their unborn. In this way their news was likely to be unexpected and something that they had not considered possible. This suggests participants only became aware of their expectations around normality until they were contradicted by receiving adverse news:

*“I thought it was going to be like, fly through everything is going to be okay and like I didn’t imagine anything like.” (Part. 1, lines 657-658)*

It was apparent that there had been very strong expectations about family life and babyhood also, which almost became idealised in perfectionist terms, especially as they were no longer going to be met. Pre-scan expectations were assimilated into the new pregnancy experience to accommodate the realisation about having an imperfect baby. This caused conflict because an ideal baby and family life was desired and expected despite the news about their baby. Any prior expectations around family life were described as something that would be very different to how it had been imagined:

*“Umm, my expectation at first was this perfect little world, em and I kind of had to get myself out of that a bit, like, I don’t know, I guess it was, I imagined it to be all rosy and he wouldn’t cry and he, do you know, he’d be this perfect, happy little thing and he’d just look at me and smile, I guess.” (Part. 3, lines 36-40)*

In contrast, however, participants were also able to assimilate their prior expectations around perfectionism making perfection fit with their new baby, which also suggests that these prior expectations were difficult to let go of:

*“Well I am yeah, I’ve that old expectation of ‘perfect’ changed and now I’ve just made this new one ‘perfect’. (laugh) Like no matter what it’ll be perfect.” (Part. 3, lines 838-840)*

Furthermore the impact of the news challenged participants’ generalised expectations around pregnancy that normal developmental and gestational milestones could no longer be used as a tool to predict the longer-term outcome of their babies. Hence expectations either ceased to exist or were foreshortened:

*“I just feel that it’s now a case of we’re just taking each day at a time.” (Part. 2, lines 547-548)*

The impact of the news was in some ways traumatic as participants’ beliefs or expectations about pregnancy were shaken to such an extent that the survival of their infant was questioned or death was expected:

*"I expected that I would miscarry or that I would go into labour and that she would die. Em..." (Part. 7, lines 879-880)*

## **Super-ordinate theme Two: An emotional journey**

### *Overview of super-ordinate theme*

Participants experienced an emotional journey as they tried to come to terms with their news of post-natal surgery being indicated in the unborn, experiencing many emotions comparable to grief, where letting go of the old pregnancy was necessary before embracing the new pregnancy was possible. There was a clear start point where participants were overwhelmed in certain ways by their unexpected news. Participants then moved on to a place where emotions could not be easily defined as they worked through this complex process until they reached resolution of their distress as they accepted their news. However, participants, whilst living with their news of post-natal surgery being indicated in the unborn experienced continuous high levels of anxiety (described as worry), which was also an integral part of living with their new pregnancy alongside reaching acceptance.

### **2.1 Subordinate theme one - The initial response**

In response to news of the likelihood of post-natal surgery being required for their unborn participants experienced a mixture of negative emotions including sadness and shock, which also created a sense of hopelessness for the future; an indication of how devastating it was for them:

*"It was just, awful. It was, I didn't feel that I could be happy or I just wanted to cry all the time. Em, I just didn't feel that I had anything to look forward to and that I shouldn't be enjoying myself, in a sense. But I think that's just you coming to terms with things at the time. Bizarre. I don't really know why I felt like that." (Part. 7, 887-892)*

Participants also talked about not being aware of their emotional state, yet having an emotional reaction, such as ‘crying’, which also indicated their news was overwhelming and unexpected:

*“I can remember tears just running down my face but ever so slightly, like I didn’t get all emotionally upset, do you know, in the room or anything like that.” (Part. 3, lines 776-777)*

## **2.2 Subordinate theme two – I’m confused and I have mixed emotions**

Participants described going through an emotional process where they could not articulate their emotional state as they appeared to be processing emotions that were changing as they struggled to make sense of their pregnancy experience. Hence participants appeared to be trying to work through their emotional state as they processed their news. It was during these times that participants described a mixture of positive and negative emotions as well as being confused:

*“I’m always thinking a lot I think about it like cause I just I just think I don’t. Some days I’ll be like numb about it and other the days I’ll like I’ll like like be really happy about pregnant and other day’s I’ll be like really I’m confused about it.” (Part. 1, lines 202-205)*

Furthermore as they went through this process they were unable to define any individual emotions and could articulate anything other than their state of confusion:

*“You just, I don’t know, you’re just constantly confused.” (Part. 4, line 1044)*

### 2.3 Subordinate theme three – Reaching acceptance

Participants also described how they came through an emotional process, where they were able to understand their news (about post-natal surgery being indicated in the unborn) and had reached a stage of acceptance. They had let go of their old ideas around their pregnancy whilst coming to terms with their news by eventually embracing their new pregnancy:

*“Em, I think it’s, I think it’s become, become something else now. I think, I think it was a sort of grief for the, sort of the pregnancy that, the pregnancy that I wanted. Em, and, and now this has become, this has become my pregnancy. This is normal for me at this time, em, so I’ve just, yeah, we’ve just, [pause]I haven’t, you know, I can’t say that it wasn’t a, didn’t go through all the stages that you would expect to go through, through grieving, but we certainly did, you know, similar, the shock and the anger and the, sort of coming to terms and then, em, accepting it for something completely, something completely different now and, like I say, this is my pregnancy individual to me, not the pregnancy that everyone else has.” (Part. 5, lines 1410-1426)*

In doing so participants became increasingly positive about their pregnancies as they reached this stage of acceptance:

*“Yeah, I’ve slowly built up to being a lot happier.” (Part. 4, Line 1030)*

They also described reaching acceptance by talking about how they had clearly moved on by being in a different emotional place, which was much more positive to where they had originally been when they had first heard their news:

*“I guess I almost forgot how distressed I felt, until you have to kind of think about it. Because I honestly don’t feel that way now.” (Part. 6, lines 726-727)*

## **2.4 Subordinate theme four - There's always something to be worrying about**

Although there was acceptance of their new pregnancy this was not reached without concurrently living with continuous worry. Living with the anxiety associated with this worry seemed linked to having to live with an uncertain prognosis. Furthermore participants would not only talk about their concern for the future in relation to treatment for their on-going pregnancy but also around what may happen during and after the birth, where again being anxious was still evident:

*“...I worry about her ability to, to sort of tolerate em, the treatment that she’s gonna have. Em, I worry about things that aren’t directly related to the bowel problem. I think well if she’s born a little bit early and she has any breathing problems. I worry about sort of things associated with that. Em...” (Part. 5, lines 836-842)*

Living with uncertainty and worry may have precipitated a situation where normal pregnancy bodily sensations were given undue attention, which then perpetuated worrying thoughts:

*“It’s like, normally you wouldn’t think at 32/33 weeks, you’d be having a couple pains and you wouldn’t think anything of it and I think it’s just ‘oh, what’s that now? I’m having a pain, oh, God I’d better start’ and it just, it’s like never-ending, there’s always something to be worrying about.” (Part. 7, lines 733-737)*

## **Super-ordinate Theme Three: Coping**

### *Overview of super-ordinate theme*

Coping with the news of the likelihood of post-natal surgery in the unborn was expressed in different ways as participants seemed to employ a range of methods to manage uncertainty, which were occurring simultaneously. Participants therefore used a range of coping methods to manage their distress. These included a belief in their

ability to cope, being hopeful when there was no further adverse news, breaking down their pregnancy in smaller weekly stages, (which made living with the unknown less daunting) and by dampening their emotional reactions or by halting them to manage distress alongside being occupied in every day events as a form of distraction. Participants also searched for explanations as to why this event had happened to them by reading around or looking for connections with their own past behaviour.

### **3.1 Subordinate theme one – Belief, Hope and achievements**

Participants had a strong belief that they would cope, even when facing adversity. They were able to deal with the outcome of their news alongside having confidence in their own ability to manage their situation:

*“Yeah, yeah I do I know I’d cope because you’ve got to cope anyway, so anybody you know in the world has to cope, even if they feel that they can’t they always.” (Part. 1, lines 1111-1113)*

*“...so I mean, you can either sit there and dwell on it and get upset and, you know. Or think, no I’m, you know, I’m going to deal with it. Throw it at me...” (Part. 6, lines 1609-1613)*

Participants were also able to be hopeful when their babies continued to develop as expected and there were no more unexpected difficulties and therefore pregnancy perhaps reflected prior expectations around gestational development, fostering certainty rather than living with the unknown:

*“...she’s not seen any other complications, she’s growing, she’s putting weight on. And all those things are encouragement, so I think it’s more the fact of I can feel more positive than I did to start with. So that makes it easier to deal with.” (Part. 7, lines 578-582)*

However, pregnancy was not thought about in the long term. Participants set their own short-term goals, such as reaching the next appointment, and this was perceived as an

achievement and acknowledged as such, which made living with the unknown less overwhelming and therefore more manageable:

*“‘we’ve made it to the Dr X<sup>6</sup> appointment’, ‘oh, we’ve made it to the next appointment’. It was always something to aim at.” (Part. 4, lines 876-877)*

### **3.2 Subordinate theme two - Detachment**

Detailed analysis revealed that participants also coped by employing detachment as a coping mechanism. Hence participants experienced a lack of emotion whilst simultaneously being aware of being pregnant and as such participants appeared emotionally disconnected from their own pregnancies. For instance, some participants described ‘detachment’ when buying items for their forthcoming babies and cited going through the ritual of buying items as if it was for another pregnant women rather than for their own baby. Here pregnancy was almost an intellectual experience as this was acknowledged as happening to ‘her’, yet experienced without emotion:

*"To be honest, I don't really feel like I am pregnant. I am pregnant but it doesn't feel like a pregnancy, if you see what I mean, because it's just, it's like it's happening to somebody else, not me. Obviously I'm, I feel her moving about and I know that I'm getting bigger, but even just the basics of preparing for her to arrive, it's like it's happening to somebody else and I'm buying stuff for a friend's baby,[pause] or it doesn't feel like it's my pregnancy this time." (Part. 7, lines 70-77)*

Furthermore, participants avoided any maternal arousal by not looking at babies and focused on practical aspects of babyhood, such as prams. This suggests they detached from their own baby and even other babies as they chose to cope by distancing themselves from their own pregnancies:

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<sup>6</sup> X = replaces name of health professional

*"Well, yes, you know, it [pause] I still look at all the buggies when I'm down at the infirmary. I look at all, I don't look at the babies (laugh). I look at, I think which pram do I want because I can't decide. So there's that, but..." (Part. 2, lines 825-827)*

Participants also detached from their pregnancies by carrying on as normal by socialising with family, friends, going to work, or by focusing on tasks they wanted to achieve. It is of note that this form of detachment worked and gave temporary relief from continuous worry about their pregnancies and therefore participants experienced respite from their concerns:

*"...sometimes I forget, you know, when I'm carried away at work and that I forget all this, you know, the fact that, you know, we've got these worries ..." (Part. 2, lines 539-541)*

### **3.3 Subordinate theme three – Making sense in different ways**

Living with an unknown aetiology led to searching for answers about causation and they did this by reading around the subject. However, anger was experienced as they considered their own behaviour being a causal factor of their unborn babies' anomaly:

*"I was reading up, so like when I was reading up. You know what could have caused it, that's when I thought, that's why I got angry with myself and I thought 'if you didn't do this'. Like I was is more like thinking what I should not have done, what I should have done." (Part. 1, Lines 976-970)*

Participants also searched the internet to gain a greater perspective on their unborn baby's condition. They were prepared to do this, despite facing negative as well as positive reports that they found, suggesting the need to know 'why' was paramount to them:

*"I've been on the internet and obviously (laughs) that can work two ways in that it can be reassuring but then you can also see, you can also read about em, not so good experiences." (Part. 5, lines 843-847).*

In conjunction with the above coping strategies other ways participants managed their distress was to blame themselves independent of reading around the subject before apportioning self-blame. Here participants thought they had caused their unborn babies' anomaly because of an unknown aetiology and as such they searched for answers to this by looking at their own behaviour directly. This strategy therefore appropriated a fundamental understanding that would answer 'why' and helped to manage an uncontrollable stressor (living with the unknown):

*"I was convinced I'd done something wrong. Eh, I couldn't understand why it happened to me and I guess this was irrational thinking as well 'cos it, like I said, I didn't have the chance to process it and that kind of, yeah, I thought it was my fault." (Part. 3, lines 607-610)*

#### **Super-ordinate Theme Four: Relationships with 'self', their baby and others**

##### *Overview of super-ordinate theme*

The super-ordinate theme of relationships is complex because participants' sense of motherhood was challenged and intertwined with creating a strong identity for their unborn. Concurrently, there was a heightened need to care alongside a sense of inadequacy and failure around motherhood. Participants struggled with being a nurturer or protector as they considered the demands placed upon them to mother their sick baby as well as mothering others. Participants' choices around rejection and acceptance of their pregnancy were also challenged by themselves and their close family members were influential in affecting complex pregnancy experience.

Participants therefore came to terms with their news in isolation and / or through conversations with others. Hence this theme relates to how important other people were perceived to be as either ameliorating or exacerbating participants' distress and whether others increased a sense of isolation. These 'others' included partners, close family members, health professionals and people from wider society. Participants were the

gate keepers to information about their pregnancy, choosing who to tell and when to remain private and alone. Their relationships with the specialist surgical team and associated health professionals exposed their vulnerability and the quality of these relationships gave rise to either positive or negative experiences.

#### **4.1 Subordinate theme one – Motherhood and baby identity**

Participants focused on the needs of their unborn babies rather than attending to their own emotional state and therefore took responsibility for their infant, irrespective of their own personal emotions. In doing so they displayed a great capacity for love and protection and prioritised their baby's needs over anything else. Thus their emotions towards their unborn babies were intensified because of the anomaly. They did this by imagining their future with their baby and how they would care for them. Participants therefore had a strong sense of motherhood which almost was enhanced by their news:

*"he's the bigger picture isn't he, he's who I have to look after and he's the most important thing so, I guess I might have a little cry and I might have little breakdown (laugh) but I would pull myself together and I think 'no', do you know, 'this is what I need to do'. And it'll be done and I guess I love him so much..." (Part. 3, lines 454-459)*

They also thought about the future impact of the medical and surgical setting upon their relationship with their baby and in doing so experienced a sense of failure or inadequacy as they thought about how this may affect them both. These challenges to motherhood were considered when the artificiality of the incubator was cited as a physical barrier to be able to hold and therefore nurture and care for their babies:

*"I know that she's in safe hands in the ICU but all the feeding and stuff, I'm worried that I might feel a bit incapable 'cos she's getting fed through a tube and it's not me feeding her, or being able to pick her up, 'cos I looked in the rooms of where they go after the operation and it's not an incubator you can put your hand in and touch her. It's covered right the way round. And really you just have to look at your baby and I'm worried about how that'll affect us both, I suppose." (Part. 6, lines 423-433)*

Other feelings about inadequacy around motherhood arose when considering other children that they either had from another partner that their partner had prior to them being together, which indicated their mother identity was somewhat not fulfilled and that there was a sense of failure about what it meant to be a 'mother':

*"I just thought I don't know why I can't give (partner) a kid. What's wrong with me?" (Part. 4, lines 775-776)*

Participants also experienced a sense of being judged as mothers and this further represented a generalised sense of failure to mother:

*"Whereas now, it's just a little thing on her ankle, or her leg, so it's not going to be as noticeable, so people can't talk, or you can feel a bit happier taking her out without people staring and commenting. She is just a normal child [pause]. so, I don't know. (laughs)." (Part. 4, lines 857-861)*

However participants also had a clear sense of responsibility when considering their other children and were in conflict about how they would manage the demands and constraints of a newborn needing care alongside the demands of mothering their other children, which challenged their mother identity as they wanted to mother in a particular way to all:

*"I just try to want to keep everybody's life and routine as easy as possible and not disturb it or upset anybody. And I know that I'm not going to be able to do that. There's going to be casualties along the way." (Part. 7, lines 268-271)*

Yet participants also created an identity for their unborn baby and they did this by a number of means, which included noticing characteristics, focusing on physical features when being scanned, or talking about their gender, which helped them see beyond their

babies' anomaly and focus on their baby as a person, which may have helped normalise their pregnancy:

*"we've had to have a lot of laughs and jokes around the problems that she's got and her being a little monkey already and and it's sort of, it's shaped who she, who she is and her character already in some ways and how we think about it. Em..." (Part. 5, lines 1230-1236)*

However, through creating a baby identity participants were able to imagine how their baby's anomaly may affect them and were therefore concerned about the life their baby may lead because of the anomaly:

*"Oh I just want him to be okay but then I think if he's not he's still my baby, you know (sobs)." (Part. 5, lines 596-598)*

Thoughts arose about what the future may hold for their child in wider society also, as the desire to protect their children from harm from others was prominent:

*"It does worry me what she's gonna look like because I don't want people judging her or her being bullied or because she's different, but (sigh). I suppose it's the stigma that goes with it, that's why they don't call it club foot anymore ..." (Part. 4, lines 1241-1243)*

In addition to this participants talked about a mixture of intense love and protection for their own baby alongside having strong feelings of rejection and wanting to abandon their baby:

*"The thought of her being there with this problem, em, I just wanted ever [pause], I just wanted her to be out of me, fixed and put right. Em, yes, I just did [pause], at that moment, for the first week after, I didn't want to be pregnant." (Part. 5, lines 1032-1037)*

However participants also talked about how their sense of motherhood was undermined when they experienced pressure from family members to terminate their pregnancy,

which was in contrast to how they felt about their unborn baby when they had clearly formed a strong attachment and were protective:

*“I mean I can’t understand why she’d think that I’d terminate my pregnancy, you know. It’s still my child and I mean, yeah, maybe, I found out at fourteen weeks, but by the time I’d realised what gastroschisis was I was nineteen weeks. She was a baby, fully formed baby that was just growing now. So it’s not, I mean, at fourteen weeks they are, so I don’t get, really why, I mean obviously you don’t want your children to be in pain but you can’t help what they’re going through and I don’t think my mum should have said anything like that.” (Part. 6, lines 1459-1471).*

#### **4.2 Subordinate theme two - The way things are communicated**

Participants disclosed information about how they felt about their unborn baby’s health to their partners, close family members and close friends. This gave participants the opportunity to tell a selected group about the health of their unborn baby and therefore share their greatest concerns. Thus, the burden of their distress was shared in a safe way. In doing so a sense of togetherness was created where distress was contained:

*“...I feel safe talking about it with my mum. So I don’t feel like I’ve em, I don’t feel as though I’m holding it all into myself and I’m not discussing it.” (Part. 5, lines 875-876)*

By communicating with people they had close relationships with participants were able to access a great deal of support that helped maintain a positive outlook, which also created a sense of togetherness and a sense of shared distress:

*“...they took their cue from us because we’re being positive. You know, we talk about it and say ‘well, so far so good’ because I mean there’s no fluid so it’s all, it’s good, I mean it could have been a hell of a lot worse, it might be tomorrow, I don’t know, but, so we’re kind of all the same.” (Part. 2, lines 719-727).*

However, if participants talked about their concerns and their emotions were not reflected back by people close to them then this made things more difficult. Or if other

people missed the opportunity to reflect participants fears and concerns and tried to ‘fix things’ then this increased distress and led to anger:

*“Umm, it upsets me. I feel like just shouting, ‘just listen to me and stop making out that everything’s going to be all fine’. Well it is going to be fine and I know that, but I mean, that it’s not going to happen and they keep saying ‘well the doctors are not always right’ and I think, ‘well, most of them are’ (laugh) ‘that’s what their job is, so stop saying that, you’re just making it worse’.” (Part. 3, lines 650-655)*

### **4.3 Subordinate theme three – Being isolated**

Relationships with close family members were difficult when interactions were not supportive; discussions with others were then experienced as deconstructive, thereby leading to avoidance of sharing information, which increased isolation in participants:

*“...Em, but I don’t really speak about mum, I don’t really speak about it to my mum anymore. I aren’t that close to my mum anymore anyway so [pause]” (Part.6, lines 1303-1306)*

Some participants found that reactions from others were extreme that they experienced a sense of betrayal:

*“Because I always think ‘what are they saying about me behind my back?’ because it like a lot of my family are like that. They say things behind people’s backs...” (Part. 1, lines 815-817)*

Participants talked about being responsible for their significant others, including partners and close family members, which led participants to withholding information about their unborn baby. This protection of others’ feelings isolated participants from potential sources of support:

*“My dad’s, my dad worries a lot about me (laughs); more me than the baby, I think. So he’s em, I think he’s probably been the most affected by (laughs) it all. So I’m constantly having to try and em, to try and reassure him.” (Part. 5, lines 1578-1582)*

Participants talked about choosing how much they let other people know about their unborn baby's health and as such presented with a public face, which isolated them from potential other types of social support:

*“But I didn’t tell her there was a problem. I just said that we were pregnant and we only had about nine weeks left.” (Part. 4, lines 402-404)*

Participants also chose carefully when telling others and shared their news about the likelihood of post-natal surgery in their unborn with a select few; the need to be private appeared to be fundamental in maintaining isolation and also further prevented participants being asked questions that could not be answered. In doing so they controlled who was informed and avoided talking about their distress. Thus their distress may have been moderated by their choice of confidant:

*“I say not everybody in the group know. Actually only [name<sup>7</sup>] knows, you know my friend, who’s also very close friend with (partner)’s sister so, and I get on with [name] as well, so [name] knows and she wouldn’t tell anybody. But it is a private thing, it’s yeah, and I think, as I say I think we just, because we don’t know much about it ourselves, we just don’t” (Part. 2, lines 292-297).*

Furthermore participants may have experienced shame or embarrassment and therefore chose not to tell others whom they did not completely trust thereby avoiding potential disapproval by others but also depriving themselves of potential sources of support:

*“Maybe, I just tend to think, I’ve only told people who em, I really trust em, and I would say immediate family or friends rather than just general, anybody I’m just talking to in the street, or neighbours or, I’ve just sort of kept it to myself or [pause]. Just for them it’s not really, I don’t know, I think maybe it’s just nobody’s business. (laughs)” (Part.7, 475-480).*

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<sup>7</sup> Name = in place of original name, line 293 participant 2.

#### 4.4 Subordinate theme four - Needs not being met

Participants were concerned that care may not be good enough for their unborn babies and in particular found that health professionals providing routine ante-natal care contradicted information given by the specialist medical and surgical team who had told them what to expect. This not only caused distress but caused further uncertainty, alongside eroding trust in the people who they looked to for support and care, namely the specialist medical and surgical team. This seeming lack of belief in appropriate care also gave rise to further questions that needed answering and maintained uncertainty:

*“Because I feel like they’re not looking at my case properly and they’re not looking at my notes [pause] to be able to just say out ‘oh, well, do you know, that’s not going to be right’. And I don’t think that’s fair. So, that makes me doubt what’s going to happen when he comes. Is the hospital gonna deal with it the way, do you know, that the doctors are saying this is what’s gonna be needed and what’s gonna happen. I’m thinking ‘is that gonna happen, are they gonna know what they need to do?’ I guess that’s probably what’s bothering me more than anything.” (Part. 3, lines 187-195)*

Although relationships with particular members of the surgical and medical team were vitally important to participants there were concerns about whether care would be ‘good enough’ if these individuals were not available in their time of need and this appeared to undermine trust that participants had about care being delivered. Furthermore, thoughts about the possibility of this happening were further facets of uncertainty. What is of interest is the emotional investment participants placed in certain members of the medical team:

*“Yeah, I just worry that if it’s in the middle that, you know, it happens in the middle of the night and it, I’m sure it won’t, but if it did happen very quickly, that, that the key people who we’re putting so much faith in, won’t be around.” (Part. 5, lines 735-740)*

Participant's dependency on the surgical and medical team for expert care and advice was so high that when it was removed (due to their pregnancies progressing more as expected) there was a sense of abandonment if they were left to continue alone for the rest of their pregnancy:

*"...it's just, it's like as if you've been cared for all this time and really cuddled and then all of a sudden you're just dropped in the middle and you don't know. Nothing's going on, you've gone from having an appointment all the time, be it midwife, consultant, scan, to nothing." (Part. 4, lines 132-135)*

Participants were sometimes placed in a position where they felt the need to question health professionals because they had doubts about their unborn babies care needs being met. However challenging people with medical knowledge raised difficulties because participants did not feel comfortable. This exposed participants' vulnerability and suggests a power differential exists where participants were subordinate to medical professionals:

*"And I don't ever, I don't feel like I want to question what they're saying or, because, I don't know, I feel like they're gonna look at me stupid as if to say 'well, you're not in this profession so don't comment'. Do you know like they know better, kind of thing. If that makes sense." (Part 3, lines 686-690)*

Moreover when accessing routine antenatal care with midwives, participants found they were placed in a position where they had to inform midwives about their unborn babies' anomaly. This was uncomfortable for participants because they needed the support from the antenatal services and consequently were being prevented from accessing the routine care available to other pregnant women, which may have also isolated them further:

*“When I go and see my midwives at Z<sup>8</sup> Centre, on and off, I feel a bit silly with them asking it because they didn’t have a clue what gastroschisis was, you know. They wanted me to fill in them with the information, you know, tell them about it if they had any dealings with anybody with it later. Which is fine, but I suppose I feel as if I can’t ask them questions ‘cos they won’t really know how to answer them.” (Part. 6, lines 236-244)*

Sometimes when participants raised questions about their babies needs their concerns were also minimised by health professionals providing routine antenatal care. Participants talked about not being treated properly or listened to; there was a sense of being disregarded or unacknowledged:

*“Do you know, ‘I was thinking of the little things like bath time’, do you know, and I think, do you know, ‘how could you help me with advising’ do you know, going about different things. And they are just like ‘oh, it doesn’t matter’...” (Part. 3, lines 133-136)*

#### **4.5 Subordinate theme five – In safe hands**

When receiving good quality care participants felt secure because their complex pregnancy needs were being completely understood when they attended appointments. This fostered an atmosphere of ‘trust’ that the team could care for them throughout their pregnancy:

*“I feel fine. When I’m seeing Dr X<sup>9</sup> or Mr Y I feel absolutely fine. I feel in safe hands and I know that, you know, I don’t know, yeah. I know that they’ve seen it and they understand sort of really. I think that’s what it is.” (Part. 6, lines 294-298)*

The manner to which the team delivered their high quality of care was greatly important to participants. Their ability to communicate complex care easily and openly was vital in lessening participant’s anxiety especially as responsibility was shared, which meant the pregnancy was less overwhelming for participants and may have decreased their isolation:

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<sup>8</sup> Z = change to the original name of the centre providing antenatal care.

<sup>9</sup> X, Y = replaces name of professional

*“but when they’re actually normal, nice friendly people and they make you feel at ease and they let you know what’s going on and they give you confidence, then you can sort of think, you can relax and let them take a bit of the strain as well, rather than have to deal with all yourself, in that way.” (Part. 7, lines 940-944)*

However, not all participants were comfortable with all members of the specialist team and made comparisons between them on how care was delivered. For instance appointments with a particular physician were the only time that they relaxed throughout their pregnancies. This was because of the way their babies’ development and health was reported continuously to them when being scanned:

*“When I go to see the consultant, he hasn’t, he just checked where the baby is laid, my urine, the baby’s head position, and then sort of says come back in two weeks and we’ll look at a date. And that’s it, you get no reassurance, no, nothing to make you feel better and the only time that you do is when Dr X does the scan and she says ‘she’s putting weight on, she’s got bigger, everything seems fine, her heart looks fine, her lungs are fine, this is fine’ and that’s the only time that you actually think (sigh), and you sort of feel yourself coming down and you can relax, but then, within a few days, it starts again.” (Part. 7, lines 746-755)*

This physician had the ability to ameliorate participants’ distress by tailoring information to the individual in a way that demystified medical jargon. This lowered anxiety whilst at the same time being informative. This was also effective as this decreased uncertainty, which was reassuring to participants that everything was developing as expected. Therefore they trusted and valued this doctor’s opinion:

*“Yeah, she always knew how to word it, that you didn’t panic but you knew there was an issue to be aware, made aware of, you were always made aware that there was something that you’d know, she’d tell you if it was that bad or...” (Part. 4, lines 1099-1102)*

The relationship between participants and this specialist was so special that sometimes it was perceived in ‘ideal carer’ terms and that this was based on interpersonal skills that

fostered trust with expertise. Therefore this specialist was able to exactly meet their needs of requiring expert care with good communication skills:

*“But I’ve always felt this like she does tell us the truth and she always has told us the truth and always like she’s never, I don’t feel that she’s ever, while I don’t think she has ever held out back. She’s always told us, like see if anything like is wrong she has to and she has to inform the other, all the other people that are going to like that are involved with my pregnancy as well. So obviously there going to like obviously is going to tell us. I just felt this bond with her right from like the beginning and I felt that nice because.” (Part. 1, lines 866-873)*

Furthermore scans also appeared to allow for the development of an intimate and special relationship and indicated how vulnerable participants were especially when being compared favourably to other health professionals:

*"I go and have the scan and she makes me feel more positive really, that I can deal with it and it's [pause] and I think even if there was a problem, she would still be able to tell me in a way that would make me feel that it wasn't as dramatic as, or as tragic as it could be. So I think that just shows how good she is really with her em, with her people skills. Because you get some who are just quite blunt and make it worse. " (Part. 7, lines 650-656)*

## **CHAPTER 5**

### **Discussion**

This chapter summarises the findings of this study in relation to its aims and presents an integration of the findings with the current literature and theoretical constructs outlined in Chapter 1. Strengths and limitations of the study are discussed alongside suggestions for future research and clinical implications.

## **Overview**

The study set out to explore and understand the lived experience of a particular group of pregnant women who had been told that their babies had health risks that were likely to require surgical interventions post-birth following the 20 week anomaly scan. These pregnancies were framed as ‘complex’ in terms of the potential medical, psychological and social ramifications of this ‘news’ and the fact that women’s experiences of these pregnancies is probably altered to varying degrees. The qualitative methodology IPA was chosen as this allows for a detailed exploration of participants complex pregnancy experiences. Existing research delineated in Chapter 1 informs that complex pregnancies such as these are significantly and permanently altered, moreover news is unexpected, creating aversive uncertainty into the pregnancy process that suggests pregnancy becomes threatening. How women came to terms with their news had not been explored using models of stress appraisals and expectancy theory. The objectives of this study therefore were to explore this complex pregnancy experience from this social and cognitive paradigm. This study was deemed clinically relevant because little was known about what women experience, as a ‘need to know more’ was raised by a local consultant paediatrician and a literature review revealed a gap in understanding. Participants were interviewed ( $n=7$ ) about what their complex pregnancies meant to them, with a range of surgical diagnoses, that differed in severity. Thus the focus of the study was on the psychological impact that adverse news about the foetus had upon pregnancy experience following this event. An exploration of pre-news pregnancy experience was also undertaken as this offered a richer understanding of possible fundamental changes in perceptions and appraisals of pregnancy before and after the news. The themes that arose from this study may enhance understanding of what

appears to be a complex set of issues for women experiencing pregnancies such as these.

### **Summary of findings**

Four super-ordinate themes emerged from an Interpretative Phenomenological Analysis of women's accounts of the experience of pregnancy pre and post receiving the news that their baby had an abnormality that may require surgery. These were: *living with the changed pregnancy*; *an emotional journey*; *coping* and *relationships with self, their baby and others*. The adverse news women received meant that their pregnancy experiences may have deviated from 'normal' pregnancy experiences. Living with the 'changed pregnancy' appeared to revolve around uncertainty about living with an unknown prognosis and also how this uncertainty overshadowed the rest of their pregnancy, which may have been associated with primary appraisals of threat. This state of the 'unknown' could have challenged what may have been typical pregnancy-related expectations about a straight-forward pregnancy. Their adverse news appeared to inhibit preparation and planning and may have interfered with fundamental nesting behaviour when disruptions to planning occurred. Receiving adverse news therefore seemed linked to elemental changes to pregnancy expectations. Participants may not have expected their news because all were less than 35 years of age, often a demarcation line where foetal abnormalities are known to be lower risk. As the majority of pregnancies were planned this may have increased commitments to the pregnancies, which may also have contributed to more distress when being faced with news of post-natal surgery, and, in some ways, this became an experience of loss as well as threat. Thus the experience of receiving adverse news could have produced an emotional response that in many ways seemed akin to a grief process but if so, this was also

complicated by continuous worry about the health of their unborn baby throughout pregnancy.

Participants employed a range of problem and emotional focused coping methods to help them manage their distress. Within this, participants appeared to be searching for an understanding of why this ‘event’ had happened to them and they did this in a number of ways. Coping strategies appeared to occur simultaneously rather than in sequence or exclusively and secondary appraisals seem likely to play a part in this process.

Receiving adverse news about their unborn set this particular group of pregnant women apart from other pregnant women to an extent that they were not able to easily find common ground with other pregnant women; possibly challenging their sense of motherhood, which may have been linked to their sense of self. Furthermore, this deviation from the norm appeared to impede this particular group talking openly about their pregnancies to others potentially leaving them without a clear place to address their experiences, which has implications for the role of social support in complex pregnancies such as these. Despite this, this particular group of pregnant women were actually able to create a strong identity for their babies alongside experiencing their possible distress and ambivalence.

Receiving adverse news about their unborn also had social ramifications as participants may have felt judged by others, which possibly caused isolation as they retreated from sharing their news with others generally. Therefore, their pregnancy experience was very much at times a private concern. Pregnancy experience was also connected to relationships with health professionals and, depending on who the health professional was, affected the quality of their interactions with others, good or bad. Thus women’s experiences were complex, distressing and at times conflicting.

## **Integration with Previous Pregnancy Research**

### **1. Super-ordinate theme one: Living with the changed pregnancy**

Changed and disconfirmed expectations about pregnancy seemed to underpin a sense of uncertainty that was aversive for women in this study and may also have been linked to threat appraisals and worry. The adverse news received by women generated many questions related to the health of their unborn baby but these did not easily find answers, a finding supported in previous research (Jones et al. 2005, p. 199) as discussed in Chapter 1. The finding that participants' pregnancy experiences were altered in a fundamental way and disrupted norms around expected gestational phases and stages of pregnancy echoes previous work in this area (Hedrick, 2005; Jones et al. 2005; Lalor, Begley and Galavan, 2009).

The findings of the present study share some specific similarities with those reported by Lalor et al. (2009), which identified expectations of normality and the shock of foetal adverse news as key issues for women in these circumstances. Lalor et al. (2009) reports that their participants had high expectations that specialists could give medical certainty or provided barriers to termination of pregnancy. This was interpreted as 'gaining meaning' and framed as a phase of loss within a temporal model of adjustment. In doing so Lalor et al. (2009) appear to place changes to expectations within the conceptual domain of loss. Thus their study merges possible changes to expectations rather than independently exploring how changes occur pre- to post-receiving adverse news about the foetus. In contrast, the findings of the present study suggest that post-news pregnancy experience was so different to pre-news pregnancy experience that the two were unable to be consolidated as one pregnancy, creating a

sense that, in the lived experiences of these women, pregnancy cohesion was shattered by the adverse ‘news’ they received. Whilst similar to the findings of Lalor et al. (2009) the current study offers a further understanding of this fundamental change in pregnancy experience by relating it in relation to appraisals of threat as well as possible disconfirmed expectations, in addition to the broader experience of loss. For women in this study, when future expectations became foreshortened or death was expected (in stark contrast to previous positive longer-term expectations), thoughts and feelings seemed to become focused on key threats with ensuing emotional distress (see below). A detailed analysis of the potential role played by expectations in the process of adjusting to a fundamentally ‘changed’ pregnancy was not put forward by Lalor et al. (2009) but the findings of the current study allow for this possibility (see below).

#### *Not Knowing*

Uncertainty has been documented as a key feature of so called ‘surgical pregnancies’ (Hedrick, 2005; Jones et al. 2005; Rempel et al. 2003). Other studies (e.g. Ahman et al. 2010; Leithner et al. 2004; Statham, Solomou and Green 2001) have found that receiving adverse news during pregnancy has long lasting effects on pregnancy experience where typical phases and stages are disrupted, leading women to think about a series of questions regarding the baby’s physical and mental health (Jones et al. 2005) yet what was not known was how uncertainty affected questions regarding pregnancies. This study suggests aversive uncertainty appeared to raise questions that were future threat focused because they were unanswerable. Furthermore it appears that the objective seriousness of the diagnosed foetal condition is less important than the perceived impact of adverse news, a finding that concurs with Lalor et al. (2009) and Statham et al. (2003). The apparent lack of preparation for the forth-coming baby, such

as not buying clothes or preparing a nursery in this study could be what Philipp and Carr (2001, p. 18) refer to as a 'lack of nesting behaviour', which appears to suggest that uncertainty interfered with this process in a fundamental way, which may have implications for mental health if antenatal attachment is disrupted.

### *Changed Expectations*

The element of 'surprise', cited by participants and the possibility of disbelief coincides with findings from previous research (Lalor and Begley, 2006; Mitchell, 2004) and suggests expectations were not only unexpected but disconfirmed, which concurs with previous research (Lalor et al. 2009) findings. However Baillie et al. (2000) raises questions about the psychological meta-cognitive and emotions systems that may occur in complex pregnancies affecting expectations, such as the role of emotions and their possible links with appraisals and expectancies but these have not yet been explored, which this study aims to address.

The potential for participants to be without a cohort when faced with adverse news may exist alongside potential negative effects on mental health, as suggested by Hunfeld et al.'s (1993) research into lethal foetal malformations.

Participants' possible expectations about family life may be indicative of long-term expectations stemming from childhood as suggested by Philipp and Carr (2001). News that contradicts these may question pregnancy expectations around a family 'ideal'. The notion of a 'perfect' baby was identified in Hedrick's (2005) study. Clearly, there are similarities between Hedrick's (2005) study and this current study. However, there are important differences, 'being perfect' was aligned to prior expectations rather than a feature of prenatal attachment or a feature of grief as suggested by Hedrick (2005, p. 737), which allows for a detailed exploration of findings

to be linked to expectancy theory. Lalor et al. (2009) comments on the loss of expectations, suggesting similarities with this current study but locates expectations as an adjunct to loss, rather than a theme that stands alone, which highlights key conceptual differences between their study and the present one.

### **Super-ordinate theme two - An emotional journey**

Loss in response to receiving news of a foetal anomaly has been described in other studies (Hedrick, 2005; Lalor et al. 2009), which may be linked to the symbolic loss of a 'perfect' baby and family alongside identifying shock as a finding (Ahman et al. 2010; Lalor and Begley, 2006; Lalor et al. 2009; Pelly 2003).

This study suggests emotional reactions were experienced that could parallel a grief process; as identified by Kübler-Ross (1997, p. 34) that involved the lived experience of shock and the mental state 'confusion' before reaching eventual acceptance and adjustment. In particular, stages of grief may be conceptualised by '*the initial response*' and '*reaching acceptance*'. Lalor et al.'s (2009) study suggest that participants also moved back and forth through a grief process before reaching some level of acceptance, a finding which concurs with '*I'm confused and have mixed emotions*', which may also in some ways reflect this process.

However findings from this study suggests it is possible that appraisals of loss may have occurred in response to the news because of the potential for real and symbolic loss regarding their unborn baby, alongside considerations of the likelihood of harm occurring because of the continuous worry regarding their unborn leading also to appraisals of threat (Lazarus and Folkman, 1984).

For women in this study this common pregnancy related concern 'worry' identified in prior research (Georgsson Öhman et al. 2003; Statham et al. 1997), was

realised. Results appeared to suggest that there was a continuous state of high anxiety experienced that was accompanied with worrying thoughts, which may have generated a state of hypervigilance, where checking and interpreting bodily sensations occurred. Mental health issues in reaction to complex pregnancy have not been thoroughly examined in previous studies and therefore this study stands apart in its suggestions of this. Hunfeld et al's (1993, p. 610) research into a diagnosis of severe lethal foetal malformation found 45% of the women involved had negative emotions of anger and sadness, common reactions of loss according to Kubler-Ross (1997), an increase of 35% compared to the prevalence rates for depression in women who deliver healthy infants during the first year. Therefore the findings of the current study add to a small body of literature suggesting that adverse news about the foetus is a potential trigger for emotional distress and mental health problems in pregnant women.

#### *The initial response*

Disbelief has been cited in a previous study following adverse news of foetal anomaly screening (Lalor and Begley, 2006), a finding that concurs with this study, and may be indicative of a state of shock, which according to Kübler-Ross (1997, p. 34) is often an initial reaction to news that is calamitous. Previous studies have attempted to broadly explain early stages of grief in psychodynamic and loss frameworks (Jones et al. 2005; Lalor et al. 2009). A new model ('Recasting Hope') was developed to explore loss of an ideal child (Lalor et al. 2009) and suggests 'shock' relates to an early part of this process.

Furthermore, when describing 'shock' within this framework of adaptation to loss this emotional state is aligned with avoidance (termed 'lack of engagement') alongside the use of distraction. Hence 'shock' has been contextualised within levels

of avoidance rather than solely an emotional reaction of a grief process. However this current study not only separates ideas of loss of an 'ideal' child into the subordinate theme '*changed expectations*' but explores emotions associated with loss independently from other constructs and in doing so is able to suggest how participants experienced loss through stress appraisals and disconfirmed expectations.

*I'm confused and have mixed emotions*

The idea that participants' state of confusion appears to represent a process of coming to terms with their news, which is dynamic accords with previous research (Lalor et al. 2008; Lalor et al. 2009). However, Lalor et al. (2009) study identifies loss within a social context, and therefore comments upon this process in relation to psychosocial issues regarding terminations of pregnancy. Although the wider context of pregnancy may indeed be relevant when understanding the meaning of loss this aspect may not necessarily reflect the psychological state, and therefore grief process women may experience. Hedrick's (2005) study also merged conceptual representations of grief, placing emotions within super-ordinate themes whereas this study differentiates these two processes. Hence independently separating 'emotions' allows for a fundamental exploration of the psychological state when to coming to terms with adverse pregnancy news, which has not been addressed yet in any previous research.

In terms of experiencing positive emotions, such as happiness this does not relate easily to models of grief as stated by Kubler-Ross (1997) as moving through to acceptance is described as a time where emotions are not necessarily positive (Kubler-Ross, 1997), indeed prior research in this area, as stated above focuses on loss rather than the potential for positive emotions, which as far as the author is aware is a unique interpretation of coming to terms with news and will be discussed in detail below.

### *Reaching acceptance*

Pregnancy research has identified the negative psychological outcomes for women following prenatal diagnosis of abnormality (Leithner, et al. 2004) and previous studies found elevated levels of anxiety following adverse news (Ahman et al. 2010; Leithner, et al. 2004). Lalor et al. (2009) study suggests that their participants eventually reached a stage where participants can rebuild their pregnancies, only after the decision to continue or terminate their pregnancy, therefore socially constructing this stage of 'acceptance' rather than exploring emotions within it. In contrast, this study explored this possible stage of grief 'acceptance' by identifying positive emotions (such as happiness) and a positive mental state, which allows for a thorough examination of a grief process because emotions and psychological state can be accounted for within the individual experience. Hence appraisals of loss and / or challenge can be applied to explore this process at a deeper psychological level than prior research to date.

### *There's always something to be worrying about*

Previous research identified worry about the health of the unborn baby was a major concern for pregnant women (Georgsson Öhman et al. 2003; Glazer, 1980; Homer et al. 2002; Statham et al. 1997), suggesting anxiety typically occurs in pregnancy. Anxiety was also found in previous complex research (Ahman et al., 2010; Kemp et al. 1998; Leithner et al., 2004; Madarikan, Tew and Lari, 1990; White et al., 2008), and was related to appraisals and coping when health of the unborn was perceived as good (White et al. 2008), whereas Kemp et al. (1998) found that anxiety reduced when post-news counselling was given, which suggest that the lived experience of anxiety is linked to appraisals. Participants in this study may have experienced significant anxiety

because appraisals were future-threat focused as adverse news related to the future baby. Therefore the continuous rumination, cited in the results would support this interpretation.

This ruminative process driven by the continuous worry regarding the health of their unborn baby alongside the loss experienced, indicated in '*an initial reaction*' and '*reaching acceptance*' also suggests that when 'letting go' of their prior positive pregnancy expectations, participants were simultaneously having to carry on with their current pregnancy. Hence complex pregnancy experience in this study may be a state of conflict that possibly led to high levels of anxiety because these two processes were being experienced simultaneously. Furthermore this has not been explored in complex pregnancy research, the application of stress appraisal models and the potential for disconfirmed expectations may help understand this challenging process.

### **Super-ordinate theme three – Coping**

Previous complex pregnancy research identified hope diminished when there was greater aversive certainty (Lalor et al. 2009; Redlinger-Grosse, et al. 2002). In this study hope appeared to be linked to certainty around gestational development when pregnancy experience began to match previously held positive pregnancy expectations, which suggests positive certainty allows hope to grow, which may be an inverse relationship between hope and certainty identified in previous research, suggesting there may be similarities between the studies when considering the role of uncertainty in hope.

It appears also that hope manifested alongside high self-efficacy<sup>10</sup>, as participants believed they could cope, thus emotions and beliefs appear closely linked. This may be why participants were able to break their pregnancy experience into small manageable steps, if firstly they believed they could cope, they then chose a manageable strategy that successfully reinforced their problem-focused coping strategy, thereby further encouraging success and creating hope? Furthermore in contrast to previous research, hope was experienced in the 'here and now' and was consequently related to current pregnancy experience rather than a system for processing adaptation in the future.

Previous complex pregnancy research reported equivocal results on the use of emotion and problem focused coping strategies (Lalor et al. 2008; Philipps and Zinn, 1986 as cited by Marteau and Mansfield, 1988, p. 186-187), however participants were cited either as 'monitors' or 'blunters' in response to information preferences regarding their aversive pregnancy news (Lalor et al. 2008, p. 185). Yet, within the subordinate themes of '*making sense of things*' and '*detachment*' suggests both strategies were used simultaneously, which may account for equivocal results in previous research. Also this study explored pregnancy experience in relation to changed expectations rather than within information preferences, which may be why both coping strategies were revealed as pregnancy experience was explored within a broad framework of expectancies.

### *Belief, Hope and Achievements*

It appears that participants in this current study managed their aversive uncertainty by breaking down their pregnancies into small achievable goals. These strategies may be akin to the 'baby steps' cited in O'Brien et al. (2010, p. 82) qualitative study, which

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<sup>10</sup> Ogden (2012, p.43) cites research stating Self-efficacy is "the belief in one's capabilities to organise and execute the sources of action required to manage prospective situations" (Bandura, 1986)

suggests that participants employed a similar problem-focused approach to managing their distress.

It could be argued that participants who engaged in this problem-focused coping strategy may have done so to experience mastery or to increase their perceived control over the uncertainty of their pregnancies. However, what is not known is the potential for stress appraisals to play a key role in managing uncertainty in this way. Participants utilising their own belief in their ability to cope (self-efficacy) as a coping strategy has to the author's knowledge not yet been addressed in previous complex pregnancy research beyond this current study.

When considering the role of hope in complex pregnancy experiences research showed participants reconstructed hope around the likelihood or certainty of survival of their unborn, where a quick death was hoped for when there was a greater likelihood of death versus hope for survival when survival was deemed likely even if for only a few weeks (Lalor et al. 2009). Qualitative research into parents who received a prenatal diagnosis of Holoprosencephaly<sup>11</sup> (HPE), also suggests hope was experienced because of the uncertainty around survival (Redlinger-Grosse, et al. 2002).

However, it appears that hope grew when pregnancies became more predictable and therefore less uncertain but participants were not faced with such poor foetal health outcomes, which suggests the meaning of hope may be different for participants in this current study because of the differences in aversive uncertainty, which also suggests uncertainty may be the mediator in generating hope in complex pregnancies. Furthermore, Lalor et al. (2009) revealed new information that challenges the current health status of the unborn causes a re-evaluation of this process. This suggests that the

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<sup>11</sup> "Holoprosencephaly (HPE) is a condition characterised by a defect of the midline embryonic forebrain when detected prenatally, a diagnosis of HPE offers...a poor but uncertain prognosis." (Redlinger-Grosse, Berndhart, Muenke & Biesecker, 2002 p. 269)

role of stress appraisals, particularly reappraisal may have a role to play in the manifestation of hope also, which has not yet been addressed in previous complex pregnancy research.

### *Detachment*

Previous research identified women resist bonding during pregnancy following perinatal loss (Côté-Arsenault and Mahlangu, 1999; Côté-Arsenault and Donato, 2007) or from prior foetal adverse news (Ahman et al. 2010) and that this may be because of a need to self-protect against possible future loss or further adverse news regarding the unborn baby (Côté-Arsenault and Mahlangu, 1999; Côté-Arsenault and Donato, 2007; Lalor et al. 2009), which supports findings in this current study that detachment may be a protective factor against the possible loss of their baby, especially as participants cited expectations of death.

The use of denial as a defence mechanism from overwhelming emotions has also been cited in previous research as a coping mechanism to enhance perceived control (Redlinger-Grosse, et al. 2002). Therefore participants in this study may have done precisely this to achieve these aims. However it could be argued that emotionally detaching from their unborn baby could equally be a way of diffusing threat appraisals activated by uncertainty, to enable increased perceived control, a rationale that has not yet been considered in previous complex pregnancy research.

White et al. (2008) identified causal links between positive appraisal coping and foetal attachment; thus attachment was strong when perception of risk (related to the foetus) was low and the perception of foetal health was good; demonstrating a link between coping and appraisals. It is possible that a reverse relationship in this study

occurred, as foetal health-related fears were likely to be threat focused, which may have negatively affected attachment possibly leading on to a process of detachment?

*Making sense in different ways*

Previous research found participants questioned health professionals in an attempt to come to terms with their news (Hedrick, 2005; Lalor et al. 2009; O'Brien, et al. 2010), which may be akin to findings in this study where participants appeared to want to know as much as possible about their pregnancies and searched for answers in a number of ways; namely reading around the subject, searching the Internet and engaging in self-blame. Moreover, this need to understand is an active coping response referred to as 'monitoring style' as described by Lalor et al. (2008) in Chapter 1. Thus it could be argued that the participants in this study were actively trying to problem solve their complex pregnancies in a similar way.

Although these findings concur with previous research what is not yet known is why this occurs. Lalor et al. (2009) suggest this is a process of adaptation but what has not been considered so far is whether this is a mechanism for possible cause and effect explanations to possibly increase perceived control over aversive uncertainty. It is possible also that reappraisals, as delineated in Chapter 1 may play a role in this part-ruminative process (see below) as this may be an attempt to understand 'why'.

The potential for 'self-blame' within this current study also suggests guilt was experienced, a finding which concurs with previous complex pregnancy (Jones et al. 2005; O'Brien et al. 2010). O'Brien et al. (2010) suggests guilt may be a response to participants' perceived missed opportunities to read their signs of pre-term birth. It is therefore possible that participants in this current study may have experienced guilt that

manifested itself as ‘self-blame’; how and why guilt may arise will be discussed in detail below through cognitive and emotional models.

#### **Super-ordinate theme four - Relationships with ‘Self’, their Baby and Others**

Key concepts of this theme suggest participants’ relationship with the ‘self’ was questioned through challenges to motherhood as participants appeared to experience a sense of failure from not being able to carry out this role. This sense of failure manifested itself on an individual level and with interactions with others, such as thoughts about not being able to provide care when their babies were born and when perceiving others were judging them. Previous research has commented upon the possible loss to motherhood as being a diminished role, (Jones et al. 2005) but aligned this loss to how women may be socially excluded rather than a possible sense of failure. Previous research found participants’ negative experiences with significant others were undermining (Redlinger-Grosse, et al. 2002), which suggest similarities with this study. However these interactions were not explored either as a sense of failure and therefore the potential for this to impact on participants’ sense of self were not explored, which is a key difference with this study.

It appears that participants also created an identity for their unborn baby and therefore viewed their unborn as a separate being from them, a process that was aided by regular scans, a finding which concurs with previous research that scans help normalise pregnancy (Lalor et al., 2009; Redlinger-Grosse, et al. 2002). Hedrick (2005) identified participants considered the long-term implications of their unborn baby, suggesting similarities with this study regarding baby identity also.

Results suggest the quality of social support contained or exacerbated participants’ distress, which accords with literature on social support (Collins et al.,

1993; Oakley 1992) as delineated in Chapter 1. Moreover the suggestion that participants in this study were without a cohort due to their atypical pregnancy process, supports research that poor social support can have deleterious effects on individuals (Collins et al., 1993); which highlights participants' potential vulnerability of being isolated in complex pregnancies.

Results suggest similarities with previous research (O'Brien et al. 2010; Redlinger-Grosse, et al. 2002) that positive and negative interactions with health professionals appeared to be around how participants felt listened to and taken seriously. However this study explored how interactions were either successful or failed in their support of participants; key features around establishing trust and working collegiately have not been covered in prior research.

#### *A sense of motherhood and baby identity*

The uncertainty regarding the future health of their unborn baby may have caused participants to question their role as a mother, especially as participants considered how their relationship with their baby may be different shortly after birth. The conflicting state participants appeared to be in was expressed by intense feelings of love; suggesting prenatal attachment occurred alongside living with a sense of inadequacy. However the desire to provide a high level of care and no longer wanting to be pregnant suggests participants in this study experienced ambivalence. There are clearly similarities with Jones et al. (2005, p. 202) findings of 'heightened ambivalence', although Jones et al. (2005) conceptualises this construct within loss whereas this study suggests ambivalence is representative of the failure to mother, hence the potential for a sense of inadequacy to arise.

The medical setting in this current study may also have given rise to a sense of inadequacy or sense of failure to fulfil the role of a 'mother' as participants may have been acutely aware of their inability to provide care because of appraisals around the artificial surroundings their babies will begin their life in. Suggesting threat appraisals may have occurred here, which also could account for potential disruptions to prenatal attachment for participants in this particular study. It is possible also that the potential sense of failure and the potential loss to motherhood may have occurred because expectancies were disconfirmed regarding the role of motherhood, which have not yet been explored in complex pregnancy research.

Other possible conflicts arose when thinking about how they would mother their sick baby and their other children, which suggests similarities with O'Brien et al. (2010). This implies that participants had a strong mother identity to care for all children in their care. Facing multiple demands, such as these could mean the unborn baby could be resented and perceived as a burden.

However despite the potential intrapersonal difficulties that their complex pregnancies may have placed upon participants in terms of their ability to 'mother', a strong identity for their baby was developed. Clearly participants prioritised their baby's needs above anything else and their sense of fighting for their babies was steadfast in the face of pressure from others to terminate, indicating others may also feel ambivalent, which accords with previous complex pregnancy research (Redlinger-Grosse, et al. 2002). O'Brien et al. (2010) found that distress extended beyond their participants, affecting the whole family, suggesting similarities with this study.

Suggestions of terminations of pregnancy by close family members indicates further conflict lived with from the influence of others, which may also increase a sense of isolation, a finding that concurs with Redlinger-Grosse, et al. (2002).

Previous research states the loss of an ‘ideal’ child can evoke the negative emotions shame and guilt (Jones et al. 2005, p. 203; Redlinger-Grosse et al. 2002, p. 376), suggesting similarities with this study. However there are key differences in this study in that it is possible that these negative emotions are similarly linked to a sense of failure or inadequacy rather than loss of an ‘ideal’ child. This suggests a sense of failure or inadequacy is threatening, thus threat based appraisals could lead to shame and guilt (Lazarus, 1991b), which will be discussed in detail below. Furthermore, the suggestion of a complex interplay between emotions, appraisals and expectations have not yet been explored in complex pregnancy research.

*The way things are communicated*

When interactions between participants and significant others were supportive, distress appeared to be shared and non-judgemental between trusted others, perhaps relieving the overall burden of the pregnancy, which may have helped diffuse threat, suggesting participants’ distress was held and contained by others. Hence positive experiences of support appeared to be derived from significant others. However when others were unsupportive this appeared to be around participants not being properly listened to, therefore increasing distress; findings that are similar to Redlinger-Grosse, et al. (2002) study.

O’Brien et al. (2010) identified difficulties with partners coming to terms with their adverse news, which put a strain on the family. Difficulties with coping as a family-system were related to increased anxiety in their participants, which suggests that the participants in this study, if unsupported would not only have to cope with their own distress, but possibly the distress of significant others, which may have implications for their mental health.

### *Isolated self*

There were similarities with this study and previous research when participants were not supported by close family members (Redlinger-Grosse et al. 2002). Redlinger-Grosse et al. (2002) findings of family members wanting to override parents' decision to continue with their pregnancy may be akin to a sense of betrayal in this study. However previous research has not addressed other areas that appeared to increase isolation, such as fearing judgement by others.

Furthermore the role this may play in avoidance of sharing news has not been addressed either. In addition to this, the aversive uncertainty in complex pregnancy research has not been explored as to how this may prevent participants from talking openly about their pregnancies either, which are key findings in this study.

### *Needs not being met*

Key concerns regarding care by the specialist obstetric and paediatric teams appeared to be around whether their baby's complex needs would be met. Results suggest there was a high level of emotional investment in the specialist teams that when questioned by other health professionals appeared to undermine this relationship and perhaps had caused greater uncertainty for participants.

Previous complex pregnancy research found inconsistencies with care and a lack of knowledge in staff caused distress (Chitty, Barnes & Berry, 1996), which accords with results in this study. O'Brien et al. (2010) reported both positive and negative interactions with health professionals, which was attributed to regular appointments and reassurances from obstetricians, who displayed empathy in contrast to health professionals not within the specialised clinic, who exacerbated distress when concerns

were not taken seriously; suggesting similar findings with this current study. However, this study by presenting uncertainty as a construct can explore participants' perceptions and therefore meaning of this health event beyond O'Brien et al. (2010) study whose findings were explored within a broad concept of risk.

It could also be suggested that as the specialist team are the providers of essential postnatal care, they may, in some ways be viewed as 'primary carers'; a term synonymous with attachment theory and may explain why participants cited being abandoned when care was removed. Raphael-Leff (2005) asserts that health care professionals may be perceived as having an elevated status because of their unique ability to assess the unborn baby's health, this elevated status may in some ways replace women's sense of motherhood as professional carers become the main 'carers' during appointments. However living with aversive uncertainty may increase participants' perceived vulnerability to such an extent that removal of support means that this uncertainty becomes overwhelming, creating a sense of abandonment.

### *In safe hands*

Thus the combination of expertise and empathy already suggested may explain why positive interactions with health professionals occurred in this current study, findings that concur with previous complex pregnancy research (Hedrick, 2005; Redlinger-Grosse et al. 2002; Rempel et al. 2003) and literature discussed in Chapter 1 (Abramsky and Chapple, 2003). However previous research suggests women with high-risk pregnancies acquiesce to a medical regime because responsibility is ultimately transferred from the patient to the health professional (O'Brien et al. 2010), thereby sharing responsibility and possibly relieving any sense of possible future guilt if further deterioration occurred. Key health professionals within the specialist team may be

highly regarded because of the delivery of complex care with empathy; findings which also concur with previous research on complex pregnancies as suggested above (O'Brien, et al. 2010; Redlinger-Grosse et al. 2002). What appeared to be a fundamental to good care and positive interactions with health professionals from the specialist team was that this level of care was always accessible to participants, never alienating them.

With regard to asking health professionals questions it appeared that some comfort was derived here as participants' questions appeared to be answered with as much certainty as possible. Miller (1979) study found that participants chose certainty of an electric shock rather than the uncertain state that shock may not occur. Thus regular hospital appointments with key health professional may have decreased perceived uncertainty, thereby reducing the potential for threat appraisals, which could account for the safety cited by participants. However there is a lack of psychological theory and models currently to explore why interactions may be positive or negative in complex pregnancies. This is addressed below in an exploration of uncertainty and its effects upon expectations, stress appraisals and emotions, which have set this study apart from previous research.

The suggestion that a particular health professional provided the role of surrogate mother implies participants had a deep need to be cared and this 'need' was fulfilled. Furthermore the level of consistency in care provided by this health professional may be why trust was so readily established, which may be experienced alongside reductions in uncertainty, suggested above.

## **Conceptual Integration**

Several psychological theories and models appear relevant to understanding the emergence of the super-ordinate and subordinate themes identified in this study and could help elucidate what this particular group of pregnant women experienced when faced with postnatal surgical news. This could advance our understanding of the impact of receiving news such as this during pregnancy, accompanying and adding to a body of literature currently available.

## **Uncertainty and its relationship with stress**

Results suggest that participants in this particular study may have been distressed because they were exposed to high levels of uncertainty at a critical point in their pregnancies, which, as delineated Chapter 1, is often a cause of distress. Lazarus and Folkman (1984) state there are a number of situational factors that influence appraisals that can lead a person to experience stress, these are: (1) novelty of a situation; (2) ambiguity; and (3) event uncertainty. Novelty can lead to appraisals of threat or challenge if the unusualness of the situation is interpreted as harmful. If a situation has ambiguity, in that individuals are not clear about the significance or meaning of an event (Lazarus and Folkman, 1984), they are also likely to experience stress. However, if individuals have an awareness of their ambiguity then they may experience greater uncertainty and therefore greater threat, which in itself has implications for coping, which may or may not tax an individual. In terms of understanding participants' complex pregnancy experiences it could be argued that their adverse news, by being uncertain was novel and ambiguous, indicated by the super-ordinate theme of '*living with the changed pregnancy*'. Furthermore, results suggesting participants experienced shock in the subordinate theme of '*an initial response*' are likely to indicate heightened stress in participants because of a perceived and / or real lack of control and

predictability, as suggested by Lazarus and Folkman (1984, citing research, p. 86 Weinberg and Levine, 1980).

Lazarus and Folkman (1984) assert stress can also be increased when established expectancies are challenged and this can then perpetuate being in a stressful state, until new expectancies are created. This relates closely to how participants modified their view of their baby (being perfect) in the subordinate theme of '*changed expectations*'. Initial positive expectations were challenged and disconfirmed, leading to stress and a need to form new expectations about the experience of pregnancy that offered more of a sense of predictability and control for the women involved.

In terms of understanding *event uncertainty* and the relationship with stress Lazarus and Folkman (1984 p. 89) cites research stating that uncertainty of an event can be a source of anxiety and tension (e.g. Epstein and Roupelian, 1970) and that naturalistic circumstances, which complex pregnancy experience could be an example of are likely to create greater conditions of uncertainty and are therefore greatly stressful (Lazarus and Folkman, 1984 p. 90). Lazarus and Folkman (1984) also suggest that having hope may be paradoxically stressful because it has the capacity to prevent an individual grieving and therefore moving on from their distress. With regard to health-related matters, Lazarus and Folkman (1984, p. 92 citing research cf. Breznitz, 1971) suggest that hope is difficult to manage because it elicits preparing for permanent loss alongside hope that functioning will be restored and that this confusing state leads to mental confusion, accompanied by unavailable closure, fear, increased worry and rumination and eventual anxiety. These concepts relate closely to the subordinate themes '*there's always something to be worrying about*' and '*I'm confused and have mixed emotions*', which describe how the processes of managing uncertainty, anxiety and hope actually seemed to manifest in women's experiences.

According to Lazarus and Folkman (1984) uncertainty can also be stressful because of temporal factors, which are around timing, namely; imminence and duration. Firstly, the imminence of an event is likely to lead to thoughts regarding greater harm or danger or, conversely, mastery. Hence the anticipated distress regarding the birth of participants' babies may be representative of this process. Moreover, when threat cannot be abated, as in the case of the unalterable duration of the pregnancy, stress is likely to remain high, resulting in hypervigilance. This helps explain the hypervigilance participants experienced in the subordinate theme of *'there's always something to worry about'*.

### **The role of appraisal and expectancy in complex pregnancy**

#### *Primary Appraisals of threat*

Living with *not knowing* (uncertainty) could have produced primary appraisals of threat because of the uncertainty this adverse news brought to the pregnancy process that concerned their loved one (unborn baby) and their unborn baby's future. When participants talked about morbidity and mortality of their infant or the possibility of further damage during birth in the super-ordinate themes of *'living with the changed pregnancy'* and *'relationships with self, their baby and others'* primary appraisals of 'threat' appear to have been activated as a response to these potential uncertain negative outcomes.

Wenzel et al. (2002) asserts that primary appraisals of threat also occur if perceptions of susceptibility and severity of the threat are present; catastrophic expectations of death within the subordinate theme of *'changed expectations'* and the possible shock and disbelief experienced within the subordinate theme of *'an initial response'* may suggest this occurred for this group of women. Furthermore, as

pregnancy is an experience, related to the individual woman, adverse news may have been appraised as threatening because it could be argued that participants regarded their pregnancies as meaningful to them and in doing so their pregnancies were likely to have high '*goal relevance*'. Alongside this the adverse news they received could therefore be seen as '*goal incongruent*' (Lazarus, 1991b, p. 133), because goal incongruence involves an assessment that the event is appraised as harmful and the uncertain news may have been appraised as harmful and therefore threatening (Lazarus, 1991b).

Health professionals' interactions with participants, when viewed positively, may have diffused primary threat appraisals because of the potential for an increase in perceived certainty or predictability. Such positively-perceived support seemed to have the potential to help women build revised expectations that were compatible with previously held pregnancy-related expectations but assimilated the uncertainty and threat generated initially by the adverse news they received. This also implies that a reversal of this process could occur; greater uncertainty and stress might be linked to support that is perceived to be negative, as suggested in the accounts of some women (indicated within sub-themes of '*the way things are communicated*'; '*isolating self*'; and '*needs not being met*').

#### *Primary Appraisals of loss*

When considering the super-ordinate theme of '*an emotional journey*' participants may have experienced primary appraisals of loss. The potential for sadness and a sense of hopelessness in the subordinate theme '*the initial response*' could be examples of primary appraisals of loss, activated because of a failure to actualise a life-goal (Lazarus, 1991b). The role that sadness plays may be a necessary part of the process of loss because it allows movement through a grief process towards acceptance and in

doing so there is a disengagement from the prior but now lost commitment, which Lazarus (1991b) suggests is necessary for this process to occur.

It is possible therefore that ‘sadness’ threatened or at least questioned possible long-term goals or expectations regarding pregnancy, indicating participants pregnancy-related expectations were not met, which again suggests the relationship between expectations and appraisals is dynamic, where one may affect the other. In more general terms the potential loss of an ‘ideal’ baby, may have been experienced as primary appraisals of loss. Letting go of prior held beliefs or long-term expectations regarding their unborn may have required a process of detachment for this to occur, which may be part of the process of loss associated with grieving.

#### *Primary appraisals of challenge*

However, primary appraisals of challenge may also have occurred when participants talked about detachment, if detachment is conceptualised as a form of avoidance (which includes the distractions participants engaged in) then it could be argued that detachment was a mechanism to diffuse threat as suggested by Lazarus and Folkman (1984). The suggestion that hope occurred may also have been a mechanism to possibly reduce primary appraisals of threat, thereby turning ‘threat’ into primary appraisals of challenge (which will be explained in greater detail below).

#### *Secondary appraisals*

According to Lazarus (1991a) secondary appraisals relate to decisions about blame/credit, which involves an evaluation of whether harm, threat or benefit may occur leading to an evaluation of whether an individual can influence their environment (coping potential) and in doing so, future expectations are considered regarding:

"...what we think will happen in the way of change, that is, whether things will work out favourably or will get worse for any reason, including effective or ineffective coping" (Lazarus, 1991a p. 827-8).

This suggests the likelihood of future expectations is considered whether to achieve or abandon them and in doing so what coping methods need to be employed to facilitate this process. Therefore secondary appraisals involve activating the coping potential of people to enable them to better respond to environmental demands (Lazarus, 1991a). Within the super-ordinate theme of  *coping*  there are some signs that pregnancy experience became a challenge through the activation of such secondary appraisals and also that self-efficacy (belief in ability to cope) played a role in this, seen within the subordinate theme  *'belief, hope and achievements'* , when participants appeared to believe in their ability to cope. Thus secondary appraisals may have occurred to reduce the threat of harm and to enhance challenge, which suggests the potential for resilience within participants.

In addition, participants may have also experienced other elements of resilience, such as 'comprehensibility', which relates to making sense, thus the subordinate theme of  *'making sense in different ways'*  could be a positive ruminative process rather than a negative one. Also 'meaningfulness', which according to Hefferon and Boniwell (2011 p. 119) is part of the motivational system that utilises a common sense understanding that it is in people's best interests to cope, may be similar to a belief in 'having to cope' that was cited by participants in the subordinate theme  *'belief, hope and achievements'* .

Attempts to gain control or mastery over uncertainty may explain why participants chose to break their pregnancies down into small, manageable steps, as suggested by foreshortened expectations, cited in  *'changed expectations'* . This mechanism of coping may have been activated to reduce the uncertainty and exert an element of control over perceived 'threat'. Also the effects of uncertainty appeared to

have an influence on appraisals of challenge because when there was no further adverse news, hence results suggest confidence may have increased.

The subordinate theme of '*detachment*' could be explained in relation to secondary appraisals because this particular group of women were likely to be living with an uncontrollable stressor due to the uncertainty of their pregnancies and therefore may have chosen this form of avoidance as an emotional coping strategy. According to Lazarus (2006, p. 114) avoidance based coping occurs when the stressful situation cannot be changed, which involves:

“...mainly thinking rather than acting to change the person-environment relationship. They are by no means passive, but have to do with internal restructuring, sometimes even to the point of changing a commitment pattern that cannot be actualised.” (Lazarus 1991, p. 112).

Coping options may also have been activated during the subordinate theme of '*an emotional journey*', with secondary appraisals being involved in moving through a process of loss in order to reach acceptance.

Also the possible generation of hope may have led participants to conceptualise their pregnancies as a challenge to be met rather than a situation that is ridden with loss. According to Lazarus (1991b), this is because hope may arise when there is uncertainty. However hope appeared to arise when certainty increased, hence results suggest the opposite occurred in this study, that uncertainty decreased and this gave rise to hope. Lazarus (1991b) suggests hope occurs when uncertainty exists regarding expectations, which suggest that is why hope arose and not necessarily because certainty increased. It is also possible that being hopeful and holding on to prior pregnancy-related expectations was more meaningful to participants in this study, thus giving rise to hope.

However ‘*appraisal bias*’ as suggested by Wenzel et al. (2002) may also occur for hope to exist, as appraising the possibility of a favourable outcome may be what generates the emotion hope. Positive emotions, such as happiness, as cited within the super-ordinate themes of *an emotional journey* and *coping*, when hope may have also manifested suggests this may be possible and applicable to this group of women.

It is also possible that primary appraisals of threat may have been changed into primary appraisals of challenge when dividing pregnancy experience into small achievable goals because this re-appraisal process may have raised the likelihood that these goals would be met, thereby potentially increasing a sense of predictability back into the pregnancy process. Therefore it is possible that during this process of reappraising, uncertainty may have been diffused. Therefore this process of reappraisals may be what Lazarus (1991b) refers to as constant change of primary and secondary appraisals in response to feedback received from one’s actions from the environment.

### **The Role of Emotion**

Results suggest participants may have experienced a range of emotions, namely; anxiety, anger, shame, guilt, sadness, love (attachment), joy and happiness and hope. Lazarus’ (1991b,) C-M-R-T of emotions may give a framework for understanding why the above emotions may have occurred in this particular group of women because of the links this theory makes between emotions and primary and secondary appraisals. Alternative theories of emotion, such as the Differential Emotions Theory, suggested by Izard (1991) concurs with Lazarus (1991b) that emotions are unique but deviates in that each emotions have different motivational processes that influence thoughts and behaviour differently, furthermore these motivational processes culminating in different motivational pathways then feedback affecting emotions differently. The key aspects to

this theory appear to be around the role emotions play in motivation, rather than the role emotions exert on appraisals.

Anxiety was represented most clearly in the subordinate theme *'there's always something to be worrying about'* and seemed clearly associated with appraisals of threat and hypervigilance, as well as the broader experience of uncertainty. Wells and Matthews (2000) suggests anxiety may be a facet of vigilant attention where preparing for possible greater danger (threat), may involve monitoring bodily sensations. In doing so, it is possible that participants perceived greater threat, as awareness may have increased causing more searching that may have led to ruminative thoughts (re-appraisals of the primary appraisal of threat), as a feedback loop, especially as the future was unknown for this particular group of pregnant women and answers to questions had no clear cause and effect explanations, thereby creating continuous aversive uncertainty into the pregnancy process.

With regard to the subordinate theme *'sense of motherhood and baby identity'*, participants' potential heightened need to care and therefore their subsequent potential heightened antenatal attachment (and therefore love) may have been activated by primary appraisals of threat. Thus in doing so, were likely to involve goal relevance and goal congruence because the meaningfulness of their pregnancies, which were highly relevant to them but also under threat.

According to Lazarus (1991b) guilt arises out of a complex process involving primary appraisals of threat. This then includes assessments of whether goal relevance, goal incongruence and ego-involvement occurred. Thus if all are activated this can then lead on to a potential attack on the ego, leading an individual to conclude a moral transgression had occurred, and therefore experiencing the emotion guilt (Lazarus, 1991b). Hence the negative emotion guilt occurs when a person's core relational theme

*'having transgressed a moral imperative'* is experienced (Lazarus, 1991b p. 242), a view that is also supported by Izard (1991, p. 363). Therefore it is also possible to suggest within super-ordinate theme *'relationships with 'self', their baby and others'* participants may have experienced incongruence because their uncertainty associated with their pregnancies were likely to be appraised as harmful, further suggesting causal pathways between emotions felt (guilt and shame) occurred, especially if participants' held a belief that they had caused harm or hurt an innocent person (Lazarus 1991b). Similarly when participants avoided telling some close family members their adverse news they may have also been burdened with a fear of causing emotional distress in others, which could have evoked guilt.

Within the subordinate theme of *'needs are being met'* there was the potential for participants to experience shame. According to Lazarus (1991b) shame occurs when an individual concludes there has been a failure to live up to an ego-ideal (within the primary appraisal process of ego-involvement), a view that is supported by Izard (1991), who comments that shame arises when individuals experience helplessness and inadequacy, which lead to diminished conscious awareness (1991, p. 333) and that shame to occurs when interactions with others views are valued. Therefore when participants talked about *'feeling silly'* in relation to questioning health professionals, this indicates participants may have experienced shame because of awareness of their lack of medical knowledge, in the presence of knowledgeable others that may have been akin to a failure to live up to an ego-ideal, which suggests these interactions could have been threatening.

According to Lazarus (1991b) for joy or happiness to occur secondary appraisals of blame and coping potential are irrelevant. However, future expectations are expected to be positive. This suggests participants were positive about their pregnancies before

their adverse news and mourning the possible loss of their ideal baby, as suggested in *'reaching acceptance'*.

Lazarus (1991b) asserts hope is problematic because of its association with yearning and therefore may to some extent be a negative emotion rather than being strictly a positive emotion. However, according to Lazarus (1991b) for hope to arise future expectations must be able to sustain hope (discussed above), which indicates that participants may have used hope to maintain a positive future outlook that helped them manage their distress. Although Lazarus (1999) states that hope is a belief in something positive happening that distinguishes it from 'motivation', which represents desire.

However, other definitions of hope contest the view that hope can only be understood as an emotion. Snyder (2002), for example, asserts that hope is an expression of human action that is goal directed and can include specific goals; in these terms, giving birth to a healthy baby could be a specific goal that participants in this study held. In contrast to Lazarus' (1999) Snyder (2002) proposes hope arises when there is dissatisfaction with current life circumstances and is therefore related to 'threat', which means hope acts as a form of *repair* hope. In addition Snyder (2002) states that hope is dependent on two prerequisites which are that (1) goal directed thoughts or agendas are useful in maintaining goals and (2) antecedents that promote hopeful thoughts, such as previous successful life experiences, then create hope and in doing so hope has already proved to be satisfactory, thus generating more hope and therefore enhancing goals.

Hence thinking is directly involved in the role of hope, a term referred to as 'agency thinking' (Snyder, 2002 p. 252), which according to Snyder (2002) attunes individuals' perceptions, based on experience to reach goals. Moreover, this is a motivating force in hope-related thought. Therefore Snyder's (2002) theory of hope

involves emotional effects of hope and responses to perceptions (therefore meaning) in the pursuit of desired (motivation) activities.

Participants in this study, perhaps in their pursuit of the highly valued goal of a healthy baby, may have been galvanised to remain hopeful about the future, particularly if they used their prior positive life experiences as a mechanism to remain goal directed, which allowed them to maintain their hope. Suggestions of positive life experiences that may give rise to hope may be seen in the subordinate theme '*The way things are communicated*' when participants talked about how positive social support helped maintain a positive outlook, or when participants talked about being able to cope in the subordinate theme '*belief, hope and achievements*', again suggesting high self-efficacy was enabled, which may have been based on previous hopeful and positive life experiences.

#### *Unconscious appraisals*

According to Lazarus (1995) part of 'appraising' and therefore 'coping' is unconscious and can serve as a defence mechanism:

"The unconscious feature is the result of the blocking of a threat from consciousness, and a threat that is warded off often constitutes the basis of emotions, such as anxiety and anger." (Lazarus, 1995 p. 185).

It is possible that unconscious appraisals protect against other negative emotions, such as guilt and shame. For instance avoidance could be employed as a defence against guilt as this process tends to view distress from a rational perspective that dampens emotional reactions as suggested by Robinson and Wisner (2001). Hence the lack of emotions displayed during the subordinate theme '*detachment*' could be a representation of a rational process that does not involve emotional affect and therefore may create psychological distance from emotions such as guilt, which may be

overwhelming. This could be why participants were able to talk about buying items of clothing for their babies whilst talking in the third person, which may have been precipitated by suggestions of death expectations in the subordinate theme of '*changed expectations*'. According to Lazarus (2006) exploring the possibility of unconscious appraisals may be important in understanding avoidance because:

"From the standpoint of an appraisal, the mental contents produced by ego-defence distorts what a person can tell us about the meaning of the transaction with the environment. This makes the task of assessing how the person is appraising the transaction very difficult because what is reported cannot be accepted at face value." (Lazarus, 2006 p. 83-84).

Therefore without some ways of exploring the unconscious then the true meaning of this particular group of pregnant women's experience could be misinterpreted. Within the subordinate theme of '*an emotional journey*' it is possible that conscious acceptance (moving on) may equate to unconscious rejection. Or concerns regarding the need to maintain a routine in the subordinate theme of '*a sense of motherhood and baby identity*' may equate to resentment that their unborn baby will bring to their world chaos.

Participants may have also unconsciously experienced shame hence when concerned about the potential negative attitudes from others views regarding disability may represent their own negative attitudes and therefore difficulties accepting their unborn baby.

#### *Transactions and emotions*

Transactions between people are likely to evoke different meanings about what is happening (Lazarus, 1995), as suggested in Chapter 1 therefore the meaning of emotions are likely also to be interpreted differently between people. The super-ordinate theme of '*relationship with 'self', their baby and others*' involved exploring interactions

between this particular group of pregnant women and others. Variability in interactions and therefore pregnancy experience may be understood in terms of who the person was, whether this was a close family member or a health professional. Therefore, differences in the types and quality of interactions in relation to emotions and appraisals of situations can be more clearly understood. For instance, in this super-ordinate theme the proposed lack of empathy from certain health professionals to participants could have led to being disappointed and being let down, suggesting primary appraisals of loss occurred, which could have been associated with negative emotions such as sadness, indicating an ultimate fear of being rejected or abandoned.

### **Expectancy theory**

As expectancies are acquired from direct experience or from communication with others as delineated in Chapter 1 (Olson et al. 1996) pregnancy expectations could be threatened in the event of adverse news as these may challenge prior expectations directly or indirectly. The subordinate theme of '*not knowing*' (uncertainty) is interesting, especially as this relates in a key way to expectancy theory. Olson et al. (2006) states that certainty is an integral part of expectancies, which are based upon beliefs, derived from direct or vicarious experience, however the perceived probability of an expectancy occurring is linked to subjective interpretations of future outcome. Therefore, uncertainty could challenge beliefs, especially if these beliefs are disconfirmed. For instance if participants had expectations of pregnancy of everything going to plan, news that challenged this could have been so shocking that participants were no longer able to predict the course of their pregnancy.

Additionally, when pregnancy is further complicated by an unclear prognosis, certainty about the future may indeed lessen. Consequently adverse news during

pregnancy could result in pregnancy-expectations no longer being a useful guide to aid the pregnancy process especially as the future may be questioned. Questioning the certainty of an expectation may indeed be stressful, and suggests expectations may have become threat focused. Furthermore living with uncertainty may also tap into appraisals about personal control. Lazarus and Folkman (1984, p. 70) cite research stating this is important because appraisals influence emotion and coping because this process involves secondary appraisals, which also involves appraising efficacy expectancies, which involves an evaluation of how capable people believe they are at coping with threat (Bandura, 1977a). This suggests perceived self-efficacy suggested in the subordinate theme of *'belief, hope and achievements'* may also affect pregnancy experience and reiterates previous comments that these paradigms (stress appraisals and expectations) are closely linked and affect each other.

The possible distress caused by being placed in a knowledgeable position by health professionals suggests that expectations concerning the role of health professionals exist and are very powerful because if challenged they could cause distress. Expectancy theory suggests that if there is value attached to ideas about expectations of health professionals being knowledgeable, then a situation that runs counter to these values may be very distressing.

Also the possible emergence of attachment and fantasies about the baby in the subordinate theme *'changed expectations'* could be due to pre-set expectations about pregnancy experience. Furthermore, suggestions of these prior news positive expectations being in conflict with knowledge about the baby may also provide evidence that expectations of pregnancy or the baby existed prior to the news.

### *Disconfirmation of Expectancies, Accessibility and Uncertainty*

The suggestion that participants had preset expectations around pregnancies implies that if these were challenged participants could have experienced disbelief, which can account for '*changed expectations*' and also aspects of shock. Expectancy theory suggests that when expectations are disconfirmed they become explicit rather than implicit, thus raising awareness. Awareness itself may evoke stronger stress appraisals of threat and therefore increase anxiety. Moreover, disconfirmed expectancies are likely to be aversive themselves as suggested by Olson et al. (1996; see Chapter 1), which again could help explain this theme and its significance. Hence disconfirmation of expectancies could play a role in the super-ordinate theme of '*an emotional journey*' and the subordinate theme '*changed expectations*' because reality (now explicit) is likely to challenge an idealised version of pregnancy that no longer serves a purpose because it is so far removed from reality. Olson et al. (2006, p. 215) state that disconfirmation of expectancies is a determinant of accessibility and cites research stating that "the accessibility of a category refers to activation potential and predicts the likelihood that it will be used to interpret reality" (Bruner, 1975). Hence accessibility and therefore by default disconfirmation of expectancies are integral to interpreting reality.

### *Beliefs, Goals and Commitments*

The belief in an ability to cope and the setting of short-term goals may also have aided self-efficacy in this particular group of pregnant women at times despite living with uncertainty within their pregnancies, and if so participants could have ameliorated (at least temporarily) their own distress, which could account for their appraisals of their appointments as milestones and achievements. Therefore Bandura's (1977) Self-

Efficacy theory may be relevant to understanding how participants managed anxiety as results appeared to suggest in the subordinate theme of *'belief, hope and achievements'* participants may have had an inner belief in their ability to cope, thus being prepared to face anything the future held for them. All of the pregnancies were planned (see Table 1), which may have led to stronger commitments and this may have meant that participants may have had even greater investment in their pregnancies and therefore may have been highly motivated to cope but this also suggests greater vulnerability because planning for the baby could represent values or goals that are heavily sought after as cited by Lazarus et al. (1982) in Chapter 1 therefore the thought of failure in a successful outcome for their unborn babies may have been unbearable.

The subordinate theme of *'needs not being met'* suggests that participants are vulnerable, which also further suggests that commitment to the pregnancy could be extremely high. Therefore what is at stake may be appraised as very alarming because of fears around loss or serious disability. Furthermore Lazarus and Folkman (1984 p. 64) cite research stating the impact beliefs have on appraisals is "...evident when there is a sudden loss of belief or a conversion to a dramatically different belief system." (cf. Paloutzian, 1981) and it is only when this happens that there is an awareness of "...their influence on appraisal." (Lazarus and Folkman, 1984 p. 64).

#### *Consensus information*

Expectations regarding pregnancy generally may have developed over the life course, hence if life experience regarding sharing news is received with empathy then this could lead to positive expectations of emotional congruence with the reverse also being true, which could explain why avoidance of sharing news with others may be a chosen coping option for some. Consensus information as suggested by Olson et al. (1996) in

Chapter 1 suggests that perceptions about pregnancy can also be influenced by others' opinions. When interactions are congruent this may indicate that participants share common beliefs about being pregnant whereas incongruence may represent beliefs that conflict with each other.

### **Interplay between stress appraisals and expectancy theory**

It is possible that disconfirmed expectancies could have triggered primary appraisals of threat/harm which then had an effect on interactions and emotions for these women, as outlined above. Therefore these two conceptual areas could interact with each other, one affecting the other, which could help explain findings in the super-ordinate theme of *'living with the changed pregnancy'* and *'relationship with 'self', their baby and others'*, where uncertainty may have been experienced as stress, as suggested above.

Furthermore this suggests that expectations could also have a role to play in coping with this adverse news. For example, whether hope drives future hopeful expectations or hope is the consequence of uncertainty around future expectancies is to the author's knowledge yet unclear although Snyder's (2002) Theory of Hope suggests motivation may be critical in this process. However it would appear that hope and future expectations are linked together suggesting there may be overlap between cognitive-motivational-relational theory and expectancy theory in this instance. Further suggestions of overlap between these two psychological domains can be seen in the development of beliefs and coping options. According to Olson et al. (1996) prior experience is influential in expectancies because past experience develops beliefs. Therefore an individual's life experience could influence anxiety if people, through negative life-events become predisposed to threat appraisals. Therefore, coping options are likely to be activated partly at least by prior experience. Lazarus (2006) suggests

stress appraisal models may now need to include systemic elements of wider society (see Figure 4) as a comprehensive way of understanding how other forces interact to produce stress appraisals and coping options, etc. Lazarus (2006) proposes that a systems theory approach to understanding psychological stress and coping systems could be useful because there is an interaction that would "...produce the state of mind and adaptation patterns that characterise a stressful transaction." (Lazarus, 2006 p.196).

The subordinate theme of '*belief, hope and achievements*' indicate participants may have had high self-efficacy in their ability to cope, (Bandura, 1977). Thus participants were able to utilise personal beliefs that they could cope, despite their adverse news. When no further adverse news arose participants became more hopeful. Participants may have also managed their distress by not being so long-term future focused, setting small goals will have matched foreshortened expectations and allowed for a sense of achievement to grow. This may have also allowed participants to experience greater control in their pregnancies thus possibly increasing self-efficacy possibly allowing hope to grow also. Therefore it is possible that hope is connected to coping options; which could imply stress appraisals of challenge began to emerge and had a role to play in self-efficacy related expectancies. Therefore, hope may have arisen from primary appraisals of challenge because uncertainty was not about the potential of death but related to the prognosis of a non-lethal condition surgical 'fixable' condition, with an expectation of survival.

#### *Interpersonal factors that may affect appraisals, emotions and expectations*

Results indicate there was a high level of emotional investment in the specialist obstetric and paediatric teams and also a belief/expectation that care would meet the complex needs of their unborn baby. Therefore, if other health professionals, outside of

the specialist team questioned care plans then this could account for high distress experienced, which suggests appraisals of threat were activated. Especially as questions posed by health professionals outside of the specialist teams appeared to destabilise and undermine trust in designated care-plans, which could also account for why greater uncertainty was experienced. Furthermore, expectations around future care may have also been questioned, also possibly leading to appraisals of threat.

Care providers may also represent participants' internal expectations and societal expectations. When placed in the position of being asked to explain their unborn baby's condition, providing knowledge may have conflicted with their own expectations regarding the role of health professionals; namely, advice and expert care, which for them may have resulted in increased distress and served to isolate them further, which also suggests appraisals of threat may have been activated here.

This model has been presented (see below, Figure 4) and extended to theoretically incorporate elements of expectancy theory.

**Antecedents**

**Processes**

**Outcomes**

*Person:*

- goals & goal hierarchies
- beliefs about self and world
- expectations & expectancies
- personal resources
- consensus information

*Environment:*

- Harms/loses
- Threats
- Challenges
- Benefits
- Disconfirmation of expectancies
- Accessibility
- Uncertainty

The person-environment relationship

→ Appraisal

→ Relational meaning, as core relational themes

→ Coping

→ Revised relational meaning

→ One or more of 15 emotions & their effects; sometimes combined in the same transaction. Also, morale, social-functioning, and health

**Figure 4: Adapted from Lazarus (2006, p. 198: Figure 8.1b A revised model of stress and coping)** Key = Black print Lazarus' model  
Blue print adaptation to model by author

## Summary

Stress appraisal models, theories of emotion and expectancy theory have been applied to help explore this study's results and suggests the relationship between all three conceptual domains are connected, possibly where one affects the other. For instance, "...cognition of the emotions involves goals, plans, and beliefs and is about the stakes (active goals) and (coping) options a person has to managing the person-environment relationship." (Lazarus, 1991b, p. 13). It appears also that different parts of stress appraisals, emotions and expectancies interact with each other in different ways, suggesting the relationship is dynamic and open to change depending upon the environment of context that the pregnancy is in.

Furthermore Lazarus (2006) suggests that models of stress appraisals need to incorporate interactional factors from the environment because these can also influence stress appraisals. Lazarus (2006) proposes that a systems theory approach to understanding psychological stress and coping systems could be useful because an interaction would "...produce the state of mind and adaptation patterns that characterise a stressful transaction." (Lazarus, 2006 p. 196).

This relates to findings from this study because of the likely interplay between all three domains in response to a stressful event suggested in *'living with the changed pregnancy'*. The primary appraisals of threat and loss suggested in the *'living with the changed pregnancy'*, *'relationships with self, their baby and others'* and *'an emotional journey'* may well have precipitated secondary appraisals of challenge suggested in *'coping'*, possibly leading to reappraisals, suggested in the subordinate theme of *'belief, hope and achievements'*. The emotions in this process appeared to be fundamental and a range of negative and positive emotions appeared possible, whether these drive appraisals or vice versa is beyond this research however results suggest they may be

linked to appraisals and expectancies and may have a role to play in motivation. Given that the news was likely to be unexpected, results suggest challenges were made to expectations; hence disconfirmed expectations may have occurred within the subordinate theme of *'changed expectations'* and *'the initial response'*. What is important perhaps is the interplay of all of these conceptual domains as they appear to be multi-faceted and interactional between all domains that includes an interplay between societal expectations suggested within the super-ordinate theme of *'relationships with 'self', their baby and others'* suggesting complex pregnancy experience goes beyond the individual.

## **Other Key Concepts and Relevant Theoretical Frameworks**

### **Attachment and interactions with others**

Although the above models and theories can offer frameworks for understanding what this particular group of women experienced there is still a substantial part of pregnancy experience not covered by the above. Trust has not been accounted for yet trust appears to be a vital element in understanding women's interactions with others in the context of complex pregnancy. Participants' distress may therefore have been contained if there was trust in their relationships. Using this basic premise of trust as a necessary component in interactions, attachment theory alongside transactional lifespan development theories may also help further explain what this particular group of women experienced when faced with adverse pregnancy news.

How trust forms a component of positive interactions for women with complex pregnancies may be explained by Bowlby's Attachment Theory. Securely attached

individuals are likely to have an internal representation of trust that has been established from birth and continued throughout life if life experiences regarding relationships with others continued to be positive; based on the premise that emotional distress during infancy was contained by their primary carer (often the mother). Bowlby (1969) classified attachment behaviour into three broad areas: *Pattern A* refers to approximately 20% of infants that are anxiously attached to their mother and avoidant, and during reunion will avoid her. *Pattern C* refers to 10% of infants that are anxiously attached to their mother; key features are resisting contact and interaction. *Pattern B* refers to the majority of infants, who are securely attached to their mother, defined as inactively enjoying play and seeking contact after short separations, or when distressed, where they are readily comforted and soon resume their play. (Bowlby, 1997 p. 337-8).

Importantly when the infant's distress is acknowledged and contained by a mother who is emotionally in tune with her infants, this allows for a secure relationship to grow. Individuals who are securely attached are therefore likely to develop beliefs that others will comfort them in times of distress. Therefore participants who spoke about positive interactions with others may well have beliefs that someone will comfort them in times of distress, i.e. hold secure attachment styles.

Conversely participants who talked about avoiding interactions with others could have an insecure attachment style of either *Pattern A* or *C*, where life experience from infancy has taught them that others do not recognise or contain their distress. This could partly explain why participants avoided talking about their news to significant others Beliefs and therefore expectancies may be based upon an acute sense of loneliness that cannot be satisfied when reaching out to others. This could partly account for avoidance strategies experienced when talking to others about their news.

### **Sociocultural factors and pregnancy experience**

It appears the environment has a role to play in stress as situations can disaccord with goals and beliefs that causes such disharmony that stress is experienced (Lazarus, 2006 p. 62). The findings in this study suggest that the environment (context) plays a part in pregnancy experience and could have been linked to reported experiences of isolation. If complex pregnancy is perceived as a 'crisis' because it causes a major life transition, as suggested by Gerson (1995 p. 91) then the possible impact of not completing this developmental task successfully could lead to a sense of failure. For instance Sugarman (2001, p. 67) cites literature stating a failed task "...leads to unhappiness in the individual, disapproval by society, and difficulty with later tasks" (Havighurst, 1972). This particular group of women avoided interactions with their partners, close family members and acquaintances which may be because of perceived disapproval by others, based upon a sense that they were failing to achieve a salient life task successfully.

Pregnancy is experienced by women, thus the notion of 'the Private is the public' (Galveston, 1992) as a philosophical stance may be appropriate to help explain why the socialisation of women is important when understanding the social repercussions from a complex pregnancy. This philosophical viewpoint suggests that women's identity of the self and therefore mother identity is constructed through mechanisms within society that oppresses women (Galveston, 1992). The notions of what is public and what is private are therefore central to this concept.

By extension expectations are important constructs in understanding how women interpret their complex pregnancies. Women with complex pregnancies may have expected their pregnancies to be a largely private experience, whereas in reality their pregnancies became a public experience because of their foetal diagnosis; the idea

that something private, such as a woman's pregnant body may become something public, which in this instance would be around the need to have extensive investigations throughout the pregnancy process.

The potential for experiencing shame, possibly created (from experiencing a sense of failure, experienced either from an internalised idea of inadequacy as expectations may have not been met, including disapproval from others') may represent psychological and social elements of complex pregnancy experience that is connected to how these pregnancies were no longer perceived as special and part of the 'self' but how this complex pregnancy experience then became the property of 'others'.

Conflict imposed by the pregnancy (a private experience imbued with societal norms) becoming a medical event, questions whether the privacy of the individual is therefore invaded and may compound a sense of loss of role, which also implies stress appraisals of loss may have occurred. Pregnancy being visually obvious may already be a public event? A deviation from the norm could extend this potential loss of privacy further.

It is of interest, therefore, that the notion of public and private may be related to a sense of womanhood as suggested by Galveston (1992) and this philosophical stance may be worthy of consideration when attempting to explore complex pregnancies.

### **Strengths**

The aim of this study was to explore pregnant women's experiences when faced with postnatal surgery following the 20 week anomaly scan. Using IPA to analyse data meant that a "commitment to an idiopathic, case study level of analysis." (Smith and Eatough et al. 2007, p. 326); hence the 'essence' of women's experiences were captured and in this way this study makes a unique contribution to pregnancy research in this

field in two ways.

The phenomenology of lived experiences in complex and high risk pregnancies has not previously been explored within the conceptual domains of psychology (stress appraisal and expectancy theory), which were applied to explore the results; this has not been done before in descriptive studies examining the effects of receiving adverse news during pregnancy. This study can therefore offer a psychological framework for understanding how pregnancy experience changes following adverse postnatal news about the baby when surgery is indicated, which up until has not been attempted before.

Also this study explored pregnancy experience before adverse news as well as pregnancy experiences after this adverse news. The advantages of this were that talking about expectations prior to the adverse news could be contrasted with post adverse news expectations. Therefore pregnancy experience gave a context for examining how the news (challenging previous expectations) affected pregnancy experience thereafter. Also the systematic way that the themes were constructed and analysed, with feedback by the main researcher, the research supervisor, peer reviews and by feedback from participants reveals that this study has been rigorously scientifically evaluated and that measures were taken to validate findings. One participant in providing questionnaire feedback questioned an emerging theme around being overwhelmed, which further analysis no longer supported, which was extremely useful in assuring validity of the study.

### **Limitations of the study**

Findings from this study cannot be generalised due to the small n size. It was also difficult recruiting participants for this study because foetal anomalies where surgery is indicated are rare and there was a small pool to recruit from. However over the period

of data collation, those who agreed to take part in the study may have wanted to do so because they felt the need to talk to someone, especially as there was no counselling service available specifically dedicated to complex pregnancies. Therefore other potential participants' views may not have come forward. Hence, there is the potential for bias in the findings. Participants were from the north of England and all were Caucasian, hence findings may be culturally specific.

All of the participants also continued with their pregnancies. No women were recruited into the study who then decided to terminate their pregnancies. The findings suggest pregnancy experience is dynamic, recruiting participants who terminated their pregnancies may have revealed very different findings. Also only 4/7 (57%) participants returned feedback forms validating themes. Those that did were largely positive (apart from one participant discussed above) and were participants recruited in the later stages of the study. This could suggest convergence of themes could have occurred in the later interviews. Looking for commonalities between participants could have been at the possible cost of dismissing information that did not fit. Hence the analytical process could have then led future interviews, with questions that led participants to respond to themes that were thought to be relevant based on analysis of previous transcripts. Therefore there is the potential for these themes not being as relevant to initial interviews because they may have reflected less divergence; issues that may have been just as important to women in the initial stages of the study.

### **Clinical implications**

The findings of this study suggest some women faced with news about postnatal surgery during pregnancy may experience stress and could also experience loss, akin to a grief process. The consequences may mean that women could be vulnerable to isolation,

which could also impact negatively on their mental health. It is therefore important for health professionals to be aware of these findings in an area where little is known about what women faced with adverse postnatal surgical news may experience. NICE (National Institute for Health and Clinical Excellence CG45) guidelines for the clinical management of antenatal and postnatal mental health highlight the importance of building trust with pregnant women who could be vulnerable to distress.

Working collegiately could help diffuse isolation and help establish a safe environment for women to explore their distress regarding their unborn. Health professionals could be curious in asking women about the many possible negative emotions and thoughts that they may experience as a consequence of their distressing news. Having a place to talk openly with positive regard could buffer women against the possible negative experiences as suggested in the results. Furthermore, being curious about women's experiences could empower women in this position by raising awareness of their own strengths to manage their distressing news. This alone may reduce isolation and normalise emotional and cognitive reactions to their adverse news.

Also gently probing about the quality of women's relationships may serve to enhance women's perceptions that they can cope or highlight potential vulnerability in them. Being curious and spending time could also help inform part of coming to terms with the news, which may involve a range of problem and emotional solving coping strategies in response to uncertainty, which may enlighten women and potentially lessen their distress. Also talking to women may enhance perceived self-control if they are given the opportunity to talk about their deepest fears and in doing so this strategy whilst being empathic could also mean that distress is shared.

## **Future research**

This study answered some important questions about what women experienced when faced with adverse postnatal surgical news. The women in this particular study have provided vivid accounts of a number of areas that could benefit from future research.

The role of emotions, according to Lazarus (1991) plays a key role in stress appraisals. Hence future research warrants investigations into how specific emotions interact with stress appraisals, coping options and expectancies in complex and high-risk pregnancies. For example, understanding how shame or guilt relates to complex grief in pregnancies could be necessary to understand the exact conditions that give rise to isolation. A mixture of descriptive and hypothesis-based studies could be used to investigate this. Also an understanding of possible resilience may be better explored in future research. Other research for instance could explore the role shame, guilt, anger and hope may play in pregnancies such as these, suggesting a further need for descriptive studies.

The possible interaction between stress appraisal models and expectancy theory warrants further investigation. This novel approach to understanding complex pregnancies such as these suggests that there is a need of further descriptive and hypothesis-based studies to examine this potential overlap further. However hypothesis driven research is also warranted to establish further validity that these two psychological domains interact with each other.

This research has revealed the dynamic influences that uncertainty has on pregnancy experience and this is an area of further research, especially in relation to primary appraisals of threat and loss and the effect on coping options. However a model that includes environmental factors (see above, Figure 4) highlights the importance of including interactional factors from wider society (see Figure 4) in order

to fully explore or explain why and how stress is appraised. A model such as this could help explain other elements of pregnancy experience that were not covered in Lazarus and Folkman's (1984) TMSC or the Lazarus (1991b) C-R-M-T of emotion or indeed by elements of expectancy theory. Therefore future research perhaps should focus on exploring complex pregnancy experiences via a systems model approach.

However not all aspects of pregnancy experience were explained by the above models and theories. Other areas such as relationships with others and attachment style may offer further insight into how relationships also affect pregnancy experience.

## **Conclusion**

Scientific evidence has shown that women when faced with a surgical diagnosis and an unknown prognosis following the 20 week anomaly scan may experience negative thoughts and feelings about their pregnancies and that their experiences are starkly changed. Women may experience high levels of distress, akin to grief. It appears that the women in this particular study had to manage the shock of their news, the grief of their lost expected pregnancy whilst enduring uncertainty for the duration of their pregnancy alongside living with an uncertain prognosis beyond birth. This appeared to place them under a huge amount of stress, which findings suggest were underpinned by threat appraisals and disconfirmation of expectations.

This stress was managed in a number of ways, revealing the complexity of coping with adverse news and is a testament to the resilience of these women and their capacity for different coping options and reappraisals especially following their adverse news.

Findings suggest women in this study were isolated and this was partly explained by the quality of relationships with others; when interactions with others appeared negative the need for specialist social support is apparent because of the capacity to cause further distress and potentially increase isolation. The uncertainty generated by the news meant that pregnancies no longer fitted typical phases and stages of pregnancy and this may have left a void about how to define pregnancy experience; being without a cohort also added to this potential void. Emotions possibly played a key part in what appears to be a cyclical relationship between beliefs and stress appraisals. Women's pregnancy experience appeared to be at times a difficult and complex process that women manage through a range of coping strategies.

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## **APPENDIX**

Appendix

**NRES Summary of changes (13 November 2008)**

**NRES Summary of changes (29 January 2010)**

Both copies have been removed for hard binding

Appendix

**Patient Information Sheet (summary version)**

*Letter Headed Paper*

**PATIENT INFORMATION SUMMARY SHEET**

Title of Project

**Pregnant Women's Thoughts and Feelings about their Baby possibly  
needing Surgery:**

Researchers: Titles and qualifications of main researcher and field and academic supervisors.

**Invitation:** *We invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.*

*If you find out at your 20 week anatomy scan that your unborn baby may need surgery you may have a range of thoughts and feelings about this that are positive, negative or have a mixture of both. This study aims to explore how women think and feel about their pregnancies. You may wish to comment on the results of what others have said about their pregnancies in a group if this has happened to you. If you are interested in participating the researcher will contact you in one week to discuss this. This time delay is to allow you to consider whether you wish to participate.*

**What is the purpose of the study?**

This is in an area where little is known about women's experiences. We are interested in your experience of your pregnancy, whatever this actually is to see if it is similar to other women. Your experiences are important because they could help us understand better what women might go through in these circumstances. The findings may also help doctors and nurses provide better ante-natal care in the future.

**If you are interested in participating and wish to have further information please contact:** Contact details of main researcher

Appendix

**Patient Information Sheet (full version)**

Letter Headed Paper

**PATIENT INFORMATION SHEET**

Title of Project

**Pregnant Women's Thoughts and Feelings about their Baby possibly needing  
Surgery:  
Research Project.**

Researchers: Titles and qualifications of main researcher and field and academic supervisors.

**Invitation:** *We invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.*

*Some women at the 20 week anatomy scan are told their unborn baby may need surgery. This study aims to explore how women think and feel about their pregnancy if this has happened to them.*

**What is the purpose of the study?**

This study is being undertaken as part of an educational qualification (Doctorate in Clinical Psychology). However it is hoped that it will enhance knowledge in an area where little is known about women's experiences. The findings may help doctors and nurses provide better ante-natal care in the future.

**Why have I been invited?**

You have been invited to participate in this study because you learned at your 20 week anatomy scan that your unborn baby may need surgery.

**Do I have to take part?**

It is up to you to decide if you want to take part. We will describe the study and go through this information sheet, which we will then give to you. Participation in this study is voluntary. You will be able to withdraw from the study at any time. There are no penalties for withdrawing; no one else will be informed of your decision. Withdrawing will not affect the standard of your care.

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

You would be invited to meet with the researcher on 1 or 2 occasions. The research will be conducted at a suitable venue of your choice either in your own home or at the antenatal department, **X** Hospital, or in the Department **B** at the University of **Z**<sup>12</sup>.

The doctor who did your scan will explain the study to you. If you express an interest in participating this doctor will ask you for your written and/or verbal permission for

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<sup>12</sup> Z & B = The name of the university and department has been removed to ensure confidentiality of participants.

your contact details to be forwarded onto the main researcher. When contacted you can ask questions about the study and confirm whether you still wish to participate.

If you still express an interest in the study a convenient time and place will be arranged so that you can meet the main researcher and give your written consent. At this meeting you will be given this long patient information sheet to read. You can ask questions about this with the researcher if you wish. Here you will have a further opportunity to raise any questions about the study before you agree to participate. If you need more time to decide, you can request that the main researcher contacts you at a later date, which you can agree upon then. If you wish to participate you will be asked for your written consent. If you decide that you wish to take part in the study a convenient time, date and location will be arranged. This second meeting is where the research interview will take place. This interview would last about an hour and a half. Alternatively, you may wish to meet the researcher only once where you can give your written consent immediately before participating in the study.

The interview will be typed up by the researcher. The researcher and the educational supervisor will then listen to the interview to ensure accuracy of the typed interview. When the researcher and the educational supervisor are satisfied that this has been achieved the recording will be wiped clean.

#### **What will I have to do?**

You will be asked to fill in 2 questionnaires, one will be to gather some background information and the other will be about your mood and feelings. This will last approximately 20 minutes. Then the interview will begin and will be tape-recorded. Here you will be invited to talk about your experience and the researcher will ask you questions to help you do this; this is likely to last approximately 1 hour. Your consent will be sought about this on the consent form. Your treatment will continue as usual throughout your participation in this study.

#### **What are the possible benefits of taking part in this research?**

By taking part you will help to provide valuable information that will contribute to the understanding of women's antenatal experience. This may help improve support for other pregnant women in the future. This information can also be used to facilitate further studies. Participating in such studies is an interesting and helpful experience for many people.

#### **What are the possible disadvantages of taking part in this research?**

Your thoughts and feelings are important whatever they actually are. You may find that some questions asked may evoke upsetting thoughts or feelings for a short time. Should you find the interview upsetting, the main researcher of the study is a trainee clinical psychologist who would be able to address this. Also, the main researcher will have contact details of other agencies that can offer support. Alternatively, with your agreement your GP, midwife and/or hospital specialist could be informed. The main researcher can provide a letter for your GP (if you wish) explaining that you wish to seek further emotional support.

#### **What will happen if I don't want to carry on with the study?**

If you do not want to carry on with the study then you have withdrawn your consent. Withdrawing consent means that your data will be removed from the study and destroyed securely.

**What if there is a problem?**

If you have a concern about any aspect of this study, you should ask to speak to the main researcher who will try to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the NHS complaints procedure. Details can be obtained from the hospital. This study has been given a favourable ethical opinion by the Local Research Ethics Committee. The Y Hospital is the sponsor of this research and the normal National Health Service complaints mechanisms will still be available to you.

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

We will follow ethical and legal practice. No one will have access to personal information. Your identity will be protected because your personal details will be coded and kept separate from the data. This will be stored confidentially for 5 years in accordance with ethical and data protection protocols, with Dr A<sup>13</sup> (the custodian of the data), in the Department of B, University of Z. After which the data will be disposed of securely. The data will be used for this research only. Only the main researcher will have access to view any identifiable data. Your hospital specialist will be informed of your involvement in the study by one of the field supervisors but you will be asked for your consent for your hospital specialist to be notified before you start the study. Your midwife will also be notified but you will also be asked for your consent for your midwife to be contacted if you agree to participate. Participation will not affect your care. Your hospital specialist will not have access to any of the research data.

**Will my family doctor (GP) be informed that I am participating in this research?**

All the information that is collected about you during the course of the research will be kept strictly confidential. Your GP will be notified of your participation in the study if you consent to this. Should the information you give raise serious concerns either about you or your baby, it is our professional duty to discuss this with you and share this information with your GP where appropriate and necessary.

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

The results of this research will then be reported to the Obstetrics Department, X Hospital and will be written up and published in professional journals. In such publications no identifiable names will be included, always ensuring your confidentiality. You will be given the option of receiving feedback about the findings of the study.

**Should you require further information about the research please contact:**

[Contact Details of Main Researcher]

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<sup>13</sup> Dr A = removal of the name of the custodian of the data to ensure confidentiality of participants

Appendix

**Semi-Structured Interview Guide**

**Title: Pregnant Women's Thought and Feelings about their Baby's Surgery.**

*Questions to settle someone in*

- How are you today?
- Perhaps we could start with you telling me a bit about your pregnancy at the moment?

*Questions about Pregnancy experience*

- Could you tell me what it is like being pregnant at the moment?
- I am wondering what it means to you being pregnant right now?
- *[Prompts]* I am wondering what your experience of being pregnant is like right now?
- Tell me a bit about your experience of being pregnant before you had your scan and were told this news about your baby?

*Questions about pregnancy expectations*

- What were your expectations before you were told this news?
- What are your expectations of your pregnancy now?
- What are your expectations for the rest of your pregnancy?
- *[Prompts]* have they changed in any way since you were told this news about your baby?
- Could you tell me a bit more about what you mean?

*Stress appraisal - feelings*

- What were your feelings about your pregnancy before your 20 week anatomy scan?
- What are your feelings about your pregnancy now?
- What did you feel about your pregnancy when you were told this news?
- What changes have there been to the way you feel about your pregnancy, since hearing this news?
- *[Prompt]* Could you tell me a bit more about the ways your feelings have changed?
- *[prompt]* In what ways might they have changed?

*Stress appraisal - thoughts*

- What were your thoughts about your pregnancy before your 20 week anatomy scan?
- What are your thoughts about your pregnancy now?
- What did you think about your pregnancy when you were told this news?
- What changes have there been to the way you think about your pregnancy, since hearing this news?
- *[Prompts]* Could you tell me in what ways your thoughts have changed?

- Can you tell me a bit more about that?

## **Semi-Structured Interview Schedule page 2**

### ***Stress appraisal - threat***

When you heard this news about your baby, could you tell me if you felt threatened in anyway?

[Prompt] Could you say a bit more about what do you mean by that?

### ***Stress appraisal – loss***

When you heard this news about your baby, could you tell me if you felt any loss?

[Prompt] Could you say a bit more about what do you mean by that?

### ***Stress appraisal – challenge***

When you heard this news about your baby, could you tell me if you were challenged in anyway?

[Prompt] Could you say a bit more about what do you mean by that?

### ***Social support***

- Have you told family and friends?
- How have you found things have been between any of your family or friends after you told them about this news about your baby?
- In what ways have you coped?
- [Prompt] Can you tell me a bit more about what you mean about that?

## Appendix

### **Participant background information questionnaire**

Code:

Page 1

*Before the interview begins I would like to ask some background questions about you that will help put the interview in context. However, you are not obliged to answer these questions and if you do provide answers you are free to withdraw the information at any point during the research. Withdrawing from the study will not affect your treatment in any way.*

Place a cross in boxes that apply to you and write information in the spaces provided.

1) The following question is about your physical health:

Can you list any physical disability health problem you are currently encountering?

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

2.) Please state your age in Years Months

3) The following questions are related to your pregnancy history.

With your current pregnancy how long were you trying to conceive?

.....

Was your current pregnancy planned?

.....

Did you receive fertility treatment for this pregnancy?

Yes  No

Is this your first pregnancy?

Yes  No

**PLEASE TURN OVER THE PAGE**

Code:

Page 2

If not, please write how many times you have been pregnant?.....

Have you ever had a miscarriage?      Yes       No

If yes, how many times?.....

Have you ever terminated a pregnancy?      Yes      

If yes, how many times?.....

Have you aborted a pregnancy in the past?

Yes       No

If yes, how many times?.....

## Appendix

### **Participant feedback forms**

## Experiences in Pregnancy – Questionnaire

This questionnaire is designed to represent the study's main findings so far. There were 4 main areas that seemed to characterise the experiences of the women who were interviewed.

We would like to know how well these broad areas sum up the experiences you had. Please read the brief description of what each main theme is describing and then fill in the questionnaire by ticking which box applies to you. Please also use the boxes below to write comments in if you wish to. All information remains anonymous.

When ticking the boxes below please note that 'agree' means that you think this was an important aspect of your experience, similarly 'disagree' would mean that this was not an important part of your experience. If you thought that any of the themes were a very important aspect of your experience please tick the 'strongly agree' or if they were not please take the 'strongly disagree' boxes. If however none of these apply please tick the 'don't know' box.

\*\*\*\*\*

**Theme 1: The news felt overwhelming.** This meant that talking about that particular time in my pregnancy was difficult because I was in shock, I felt numb and it left me feeling very uncertain about the rest of my pregnancy.

<b>Strongly Agree</b>	<b>Agree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>	<b>Don't Know</b>
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**Comments:**

**Theme 2: I coped in different ways.** Being positive, daring to hope, being matter of fact, trying to understand, such as searching the internet or thinking about what may have caused this.

<b>Strongly Agree</b>	<b>Agree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>	<b>Don't Know</b>
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**Comments:**

**Theme 3: Relationships with other people.** This included how other people responded when I shared my news, how I kept the news to myself, my relationship with the doctors & nurses, my relationships with close family, friends and others.

<b>Strongly Agree</b>	<b>Agree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>	<b>Don't Know</b>
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**Comments:**

**Theme 4: Pregnancy.** This included old expectations and finding new expectations, a pregnancy that was different from any other pregnancy, unfairness, grieving and how I viewed myself as being a mother.

<b>Strongly Agree</b>	<b>Agree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>	<b>Don't Know</b>
-----------------------	--------------	-----------------	--------------------------	-------------------

**Comments:**

**Please return this questionnaire in the envelope provided**

Thank you for your time.

## Appendix

### **Participants feedback letter**

Letter Headed Paper

Dear participant

Title of study

Some time ago you were interviewed about your pregnancy experience and your thoughts and feelings when faced with unexpected news during your pregnancy. At the time you consented to be contacted about the results as you wish to know what the findings were. The results are preliminary and are very interesting.

By now you will be undoubtedly in the throes of new motherhood, which I appreciate can at times be very demanding. Also how you thought and felt about yourself and your baby is not necessarily how you feel now.

However I wondered if you could possibly spend a moment or two casting your mind back to that time so that you could fill in this questionnaire, which summarises the main findings. There is also spaces to write comments if you also wish to.

Although the results are at a preliminary stage It is important to get feedback about how accurate they are. Feedback such as this will help tailor the results further thereby creating greater confidence in their accuracy.

Yours sincerely



## Appendix

### **Study Consent Forms**

*Letter Headed Paper*

Patient identification number:

date:

**Consent Form**

**Title of Research Study:** Pregnant Women's Thoughts and Feelings about their Baby's Surgery.

**Name of Researchers:** Titles and qualifications of main researcher, field supervisors and academic supervisors.

**Please tick all relevant boxes to which you agree:**

1. I confirm that I have read and understood the information sheet for the above study and I have had the opportunity to ask questions.
2. I confirm that I understand that I may need to ensure privacy in my own home if I chose this as a venue to participate in the study as I wish to discuss private information .
3. I understand that my participation is voluntary and I am free to withdraw at any time, without giving any reason, without my medical care and legal rights being affected.
4. I agree to take part in the study. I understand this includes an audio recording, of my interview, which I give consent for.
5. I have agreed to give my contact details to the researcher. This is necessary to enable me to give feedback on **the results** and to receive a summary of the results if I request this.
6. I understand that all identifying information will be coded and anonymous.
- 7a. I agree to my GP being informed of my involvement in the study.
- 7b. I agree to my Hospital specialist being informed of my involvement in the study

**PLEASE TURN OVER THE PAGE**

*If you would like your midwife to also be informed of your involvement in this study please sign below.*

- 7c. I agree to my midwife being informed of my involvement in the study.
8. I would like to be informed of the results of the study.

**Please print clearly using capital letters**

Name of Patient: \_\_\_\_\_ Date: \_\_\_\_\_

Signature: \_\_\_\_\_

Name of Researcher: \_\_\_\_\_ Date: \_\_\_\_\_

Signature: \_\_\_\_\_ DOB: \_\_\_\_\_

**Please complete your contact details below.**

Address: \_\_\_\_\_

Post Code: \_\_\_\_\_

Date of Birth: \_\_\_\_\_

Telephone Number: \_\_\_\_\_

**GP and Practice and Hospital Specialist Contact Details (to be completed if you agree to your GP and your Hospital Specialist being informed of your involvement in the study). Additionally please provide telephone contact details of your community midwife if you wish.**

<p><b><u>G. P.'s Name:</u></b></p> <p>.....</p> <p><u>Hospital Specialist's name:</u></p> <p><u>Midwife's name:</u></p>
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<p><b><u>G.P. Practice or Surgery Name:</u></b></p>
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<p><b><u>G.P.Address (if Known):</u></b></p>	<p><b><u>Midwife's contact details: Tel:</u></b></p>
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## Appendix

### **Explanations of surgical abnormalities & psychological theory**

#### **Definition of Surgical Abnormalities**

1. Talipes: a non-traumatic deviation of the foot in the direction of one or two of the four lines of movement (Vanes, 2005 p. 2141).
2. Gastroschisis: a congenital fissure that remains open in the wall of the abdomen (Vanes, 2005 p.861)
3. Congenital Diaphragmatic Hernia: protrusion of any part of the abdominal organs through the diaphragm and into the thoracic cavity (Baillière's Midwives' Dictionary).
4. Congenital Pulmonary Airway Malformation: a multi-cystic mass of segmental lung tissue with abnormal bronchial proliferation (Baillière's Midwives' Dictionary).
5. Omphaloceol: congenital hernia of the umbilicus (Vanes, 2005 p. 1518)

#### **Leventhal's self regulation model (SRM)**

According to Ogden (2012, p. 218) Leventhal and colleagues identified 5 dimensions of illness cognitions. These were:

- *'Identity'* which refers to receiving a medical diagnosis.
- *'The perceived cause of the Illness'* pertains to searching for why an illness occurred.
- *'Timeline'*, represents how long someone may think an illness may last.
- *'Consequences'* refers to how an illness may impact on someone's life.
- *'Durability and controllability'* refers to questioning whether health can be cured.

## Appendix

### **Hospital Anxiety and Depression Scale (HADS)**

Participants were asked to choose one response from the four options and to give an immediate response and were encouraged from thinking too long about their answers, as directed by the rubric for the HADS

## Hospital Anxiety and Depression Scale (HADS)

I feel tense or 'wound up':

Most of the time 3  
A lot of the time 2  
From time to time,  
occasionally 1  
Not at all 0

I still enjoy the things I used to enjoy:

Definitely as much 0  
Not quite so much 1  
Only a little 2  
Hardly at all 3

I get a sort of frightened feeling as if something awful is about to happen:

Very definitely and quite badly 3  
Yes, but not too badly 2  
A little, but it doesn't worry me 1  
Not at all 0

I can laugh and see the funny side of things:

As much as I always could 0  
Not quite so much now 1  
Definitely not so much now 2  
Not at all 3

Worrying thoughts go through my mind:

A great deal of the time 3  
A lot of the time 2  
From time to time, but not  
too often 1  
Only occasionally 0

I feel cheerful:

Not at all 3  
Not often 2  
Sometimes 1  
Most of the time 0

I can sit at ease and feel relaxed:

Definitely 0  
Usually 1  
Not Often 2  
Not at all 3

I feel as if I am slowed down:

Nearly all the time 3  
Very often 2  
Sometimes 1  
Not at all 0

I get a sort of frightened feeling like 'butterflies' in the stomach:

Not at all 0  
Occasionally 1  
Quite Often 2  
Very Often 3

I have lost interest in my appearance:

Definitely 3  
I don't take as much care as I  
should 2  
I may not take quite as much  
care 1  
I take just as much care as  
ever 0

I feel restless as I have to be on the move:

Very much indeed 3  
Quite a lot 2  
Not very much 1  
Not at all 0

I look forward with enjoyment to things:

As much as I ever did 0  
Rather less than I used to 1  
Definitely less than I used to 2  
Hardly at all 3

I get sudden feelings of panic:

Very often indeed 3

Quite often 2  
Not very often 1  
Not at all 0

I can enjoy a good book or radio or TV program:

Often 0  
Sometimes 1  
Not often 2  
Very seldom 3

## Appendix

### Example of reflexivity

Using a part of an interview Participant 1 (2<sup>nd</sup> interview) to expose the potential effects of interactions between the participant and the main researcher, which underlines the reflective aspects of using IPA:

*I:* Okay so how are you today?

*Participant 1:* I'm feeling fine, I've had a few pains walking down but I always do anyway

Yeah

*Participant 1:* but in myself I feel fine,

*I:* okay

*Participant 1:* very happy.

*I:* Good

*Participant 1:* I'm at the stage where I'm excited now,

*I:* yeah

*Participant 1:* I just can't wait

*I:* but your looking forward to it

*Participant 1:* I can't wait, I really am looking forward to it. I've had doubts all the way like quite a lot way through like, just thinking can I do this can I put myself through it like what if he's going to have to go through but till like I'm at this stage where I'm so glad I've gone through with it [slight pause] I really am like really happy and I love [slight pause] I'm in a stage in my relationship at the moment like I said before we have been really tough but like seen as I saw you on erm Friday I spoke to him at like have got my feelings out to him because I've held a lot back of my pregnancy and like I've held it all to myself and now I've finally told him how I feel n that I'm feeling really happy in myself and I'm just looking really forward to it now because I've opened up more because I was quite closed, quite close to the time so I'm feeling fine

## **Appendix**

### **Worked example of IPA**

To highlight the analytical process a worked example is shown of an excerpt from a transcript of participant 7, followed by level 1, 2, 3 analyses as identified in figure 2.

(key I = main researcher; P7 = participant)

#### **Lines 23**

**I** That's what you think about. Do you want to tell me a little bit more about that?

**Lines 25-43 P7** Well, I mean, mainly they just said it was chromosome things and em, when the paediatric surgeon, she sent a letter to all the em, to the other consultant basically, when I'd had a meeting with her. And we were discussing the chromosome things that she could have wrong with her. And obviously I came home and I Googled them all and then that panicked me because it, obviously some of the pictures are a lot worse than even your imagination and you think, oh, it's not just the fact of she's got a liver growing outside her body, she could have this wrong with her, or she could have that wrong with her. And because of my decision not to have the amnio, I'm having to wait 'til she's born to then deal with it. Whereas I think with most things, it's easier if you know up-front. So part of me thinks maybe I should have had it done because at least I would know now. And I would have longer to deal with it rather than I'll wait until she's born and then panic and think, 'Oh, no it's this as well, and it's that then', and it's even more to deal with than the just the birth itself and actually seeing the omphalocele when I see it. So I think that's what panics me as well, is the unknown.

#### **Lines 44**

**I** So you've gone and got some information and ...

#### **Lines 45**

**P7** Yes, which I think was the wrong thing to do.

#### **Lines 46**

**I** In what way?

#### **Lines 47-61**

**P7** Because I think, nowadays, when you've got things like Google, there's such extreme cases that you can see and images of such extreme that it just makes things

worse really. I know when, when I first had my twenty weeks scan and they said there was a problem, they said 'Don't go and Google it, just don't look. Wait 'til you've seen Dr X and then she will be able to discuss it with you properly'. And luckily enough, my computer was broken 'cos otherwise I would have gone and done it. But because it was broke and I couldn't, and then when I heard her explanation of it all and what was going to happen and everything, I felt a lot better to then be able to look at the information that was on computer, rather than if I'd done it the other way round. And I think it would have just made it worse and I would have been more stressed and I would have thought the worst. So I think sometimes, too much information from the wrong sources...

<b>Participant 7 – Level 1 analysis</b>	<b>Level 2 analysis</b>	<b>Level 3 analysis</b>
<p><b>Question exploring pregnancy experience 23-65</b></p> <p>Out of control, fear other 25  In this system, being part of something else 25-28  Large team involved, pregnancy no longer belongs to mum- others26-27  Discussing other possible abnormalities, further worry29  Panic30  Shocking images, worth an imagination 31  Petrifying thoughts, gruesome &amp; alien, unexpected32-33  Cascade of other possible problems associated with initial diagnosis, anxiety &amp; worry, uncertainty and out-of-control, unexpected33  ‘my decision’ alone-babies mine pain not shared, not together, taking control 34  In the hands of others, having no control, waiting for time, distancing, anger ‘if’ mum is unimportant, sense of being pulled out, Glory of pregnancy removed, uncertainty, better to know in advance unlike my pregnancy 36  Hard on self-all my doing, I’ve done wrong, on own- not shared, expected certainty if done things differently 37-38  Over and done with, dealt with versus uncertainty, hanging around39  Panic, (fear?), fearful thoughts, catastrophic scenarios-dread of seeing ompholocene-overwhelming situation, highly distressing, other bad possibilities40  More stress and more difficulties as a result of choosing no further investigations, regrets, up to her limit 41-42  Panic, uncertainty 43  Extreme cases, petrifying and overwhelming images, makes much words, terror, horrible Internet information 48-49  ‘they, them’, distanced and power of the Internet, childlike state, don’t do anything wrong ‘just don’t look’, others (medics), not me50-51  Powerful others, waiting for advice and guidance, childlike place, told not to but compelled to do – natural curiosity, wanting to understand, get handle, theatre baby’s health 52  Compelled to do so 54  ‘her’ distanced, angry somewhat disrespectful 55  Contained, anxiety lower, could face things, fear reduced, everything explained- demystified 57  Could face things on own, alone, her, me 58  Distanced, worsened, perceive is called being worse if not saying doctor first (timing is important because people/women at going to</p>	<p>Distancing 25</p> <p>being part of something else pregnancy taken Panic 30</p> <p>Shocking images 31</p> <p>Unexpected and petrifying thoughts 32-33</p> <p>babies mine pain not shared34</p> <p>uncertainty is worse 36  my fault</p> <p>Anger uncertainty is worse 39</p> <p>Fearful and overwhelming thoughts 40</p> <p>Uncertainty and regret panic &amp; unknown 41-43</p> <p>Passivity power of the Internet 50-51</p> <p>Searching for understanding 52  Compelled</p> <p>Everything explained contained 57  empowering</p>	<p>Distancing 25</p> <p>Pregnancy taken over  Panic</p> <p>Scan and shocking images</p> <p>petrifying thoughts 32-33, 40</p> <p>private pain</p> <p>uncertainty  anger  regret 36, 39, 40</p> <p>search for understanding  sense of being compelled (internet)</p> <p>sense of being contained  empowered</p>

Google) 59 Could have been worsened and more stressful60 Too much information, uncontrolled heightens distress 61		
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## Appendix

### Worked example of Level 1 Higher level abstraction

Quotes post viva coping mother identity	Interpretation	Keywords
<p><b>Participant 5:</b> That did, it <b>kicked in</b> around, around that time, yeah. (Lines 1082-1083)</p>	Maternal protection	Kicked in
<p><b>Participant 5:</b> Yes, because you've never, never felt feelings like that before really, it's, you know, it's, you know, I think for as much as, as much as (husband)'s going through exactly the same thing, I think it's em, when, you know, when she's inside you and you're, I don't know, I can't really explain it, but yeah, it was a very new and very <b>intense</b> sort of feeling of love really; for somebody that I've (laughs) never really met, yeah. (Lines 1168-1177)</p>	Intense attachment (mother ID?or baby id)	Intense
<p><b>Participant 5:</b> It happened after, after my news when I <b>felt her move</b>. (Lines 1185-1186)</p>	<u>Check overlap with baby ID</u> emotional connection	Felt her move
<p><b>Participant 6:</b> That bothers me a bit. I don't know, I think, it maybe is for myself and for the baby might wanting to bring her home. I came home the next day with my first. It's sort of like, but this time I don't, I think it's probably because it's out of my hands as well. I know that she's in safe hands in the ICU but all the feeding and stuff, I'm worried that I might feel a <b>bit incapable</b> 'cos she's getting fed through a tube and it's not me feeding her, or being able to pick her up, 'cos I looked in the rooms of where they go after the operation and it's not an incubator you can put your hand in and touch her. It's covered right the way round. And really you just have to look at your baby and I'm worried about how that'll affect us both, I suppose. (Lines 418-433)</p>	Questioning ability to mother, disempowered mothering	Bit incapable
<p><b>Participant 1:</b> I aren't. I don't feel like that now I'm just thinking like when he comes along. Cause where at like, like whe when a baby hasn't got anything you can bond with it straight away cause you can pick it up, you can feed em like like when they need to change napp but then this baby's gonna be like in like an <b>incubator</b> so I aren't going to be able to see so much of ... (Lines 186-191)</p>	Motherhood removed concerns around disruption to relationship Awareness of fearful future but wanting to protect underconfident motherhood	Incubator

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## Appendix

### Worked example of Level 2 Higher level abstraction

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#### Mother identity

**Intense attachment/maternal protection/wanting to protect**

**Strong positive attachment (mother identity?)**

#### Participants displayed a great capacity for love for their unborn babies

But I don't know, as soon as I knew obviously we was having a baby, **this unconditional** love just comes out of nowhere I guess. I don't know how that happened but it did (laugh). (Part. 6, Lines 468-475)

when she's inside you and you're, I don't know, I can't really explain it, but yeah, it was a very new and very **intense** sort of feeling of love really; for somebody that I've (laughs) never really met, yeah. (Part. 8, Lines 1168-1177)

*P8* It happened after, after my news when I **felt her move**. (Lines 1185-1186)

*P6* "I just, it sounds really stupid but I just know it in my heart, I just know that I love him that much that **I would do anything for him...**"(Lines 436-438)

And because I'd got, I'd suddenly got all these feelings around loving my baby and **wanting to protect her**, and then reading the, you know, the worst case scenarios about what could happen, it was, it was very sort of intense that I had these feelings but that, you know, ... (Part. 8, Lines 1135-1145)

he's the bigger picture isn't he, he's who I have to look after and he's the most important thing so, I guess I might have a little cry and I might have little breakdown (laugh) but I would **pull myself together** and I think 'no', do you know, 'this is what I need to do'. And it'll be done and I guess I love him so much I just think, whatever comes I just know that that feel of him on me, that little cuddle or, do you know, just knowing that he's there, I guess that makes everything okay. The sound of his breathing (laugh). I don't know, I guess it's the only way I can explain it. (Part. 6, Lines 453-463)

**So, although I think I probably had felt the odd movement, I hadn't recognised as being such. So, I hadn't really, sort of, I hadn't had that experience and when I got told the news at the twenty week scan, a couple of days after that I started**

**noticing movement for the first, for the first time. Which helped because I, when I had these feelings of not wanting, not wanting to be pregnant any more, and then suddenly I started feeling her move, which is a wonderful feeling, and it just, em, it just, it just made me, I don't know, it just made it all very real as to what was going on. (Part. 8, Lines 1040-1078)**

## Appendix

### *Ethics and Research and Development approval*

Both of these letters have been removed for hard binding.