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RECASTING HOPE

A Longitudinal study of women's experiences of carrying a baby with a fetal abnormality up to and beyond the birth

RECASTING HOPE

A Longitudinal study of women's experiences of carrying a baby with a fetal abnormality up to and beyond the birth.

A thesis presented to the University of Dublin, Trinity college
for the degree of Ph.D in Midwifery

by

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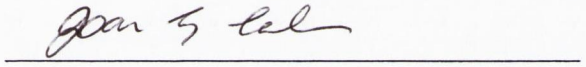

Joan Gabrielle Lalor.

RECASTING HOPE

A LONGITUDINAL STUDY OF WOMEN'S EXPERIENCES OF CARRYING A BABY WITH A FETAL ABNORMALITY UP TO AND BEYOND THE BIRTH.

Abstract

Aim: The overall aim of this study is to explore and understand women's experiences of carrying a baby with a fetal abnormality up to and beyond the birth of the baby, from which recommendations can be made to optimise provision of care.

Background: Routine ultrasound in pregnancy has received uncritical acceptance in pregnancy from both women and clinicians alike. However, due consideration has not been given to the psychosocial consequences of mass screening resulting in fetal anomaly detection in low risk populations.

Methodology: A constructivist grounded theory (n=38) was carried out in 2004-2005 using repeated in-depth interviews before and after the birth. Thirty women chose to continue the pregnancy and eight women accessed termination of pregnancy services outside the state. Data were analysed using constant comparative analysis. The usual tenets of written informed consent were obtained.

Findings: The conceptual framework of Recasting Hope emerged and represents the process of adaptation after fetal anomaly diagnosis. Recasting Hope is a theory of traumatic loss, and is idiosyncratic to the area of prenatal diagnosis. The process of adaptation is represented temporally in four phases 'Assume Normal', 'Shock', 'Gaining Meaning' and 'Rebuilding', whereby women are concerned with reconstructing meaning in the aftermath of an ostensibly negative event in order to resolve the inconsistency between the experience and previously held views of pregnancy and beliefs in the world in general.

Conclusion: The process of adaptation after fetal anomaly diagnosis is complex. The framework of Recasting Hope is intended for use as a tool to assist health professionals through offering simple yet effective interventions in order to support women during this time. The data have shown that women need particular support during this crisis. Therefore consideration of the impact of a midwife practitioner role on the process of meaning reconstruction is recommended.

DEDICATION

To Adam Lalor,

The most perfect person I know,

Without you this thesis would never have been written.

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RECASTING HOPE

A LONGITUDINAL STUDY OF WOMEN'S EXPERIENCES OF CARRYING A BABY WITH A FETAL ABNORMALITY UP TO AND BEYOND THE BIRTH.

SUMMARY

Background: Ultrasound screening for fetal anomalies was first introduced into practice more than thirty years ago, and rapid technological developments have meant that women's experience of pregnancy has changed irrevocably. While science endeavours to come to terms with constantly evolving diagnostic techniques, mass screening of fetal health in pregnancy is blurring the traditional boundaries between health and illness, as normal populations are being screened for an illness that has not manifested itself through the identification of risk factors. Routine ultrasound in low risk pregnancy has led to the modality developing a social meaning, one that for many women has come to dominate its medical use. The paucity of information concerning the experiences of women who continue the pregnancy following an adverse diagnosis is alarming, and is reflected in women's accounts of unsupportive interactions with caregivers. However, women's experience of care and decision-making after prenatal diagnosis in the Irish context is unknown.

Statement of purpose: This study was designed to establish a scientific base to underpin the practice of caring for women after diagnosis, irrespective of the type of anomaly detected, likely prognosis or outcome of the pregnancy. Identification and conceptualisation of the patterns of behaviour that manifest in response to such a diagnosis would assist in moving the evidence from individual interactions to those based on a more collective representation of the experience.

Aim: The overall aim of this study is to explore and understand women's experiences of carrying a baby with a fetal abnormality up to and beyond the birth of the baby, from which recommendations can be made to optimise the provision of care.

Methodology: A constructivist grounded theory study (n=38) was carried out in 2004 and 2005. Data were gathered using in-depth interviews on three occasions; 1) within

four weeks of diagnosis, 2) pre-birth and 3) up to twelve weeks postnatally. Thirty women chose to continue the pregnancy and eight women accessed termination of pregnancy services outside of the state. The fetal medicine unit of a major Dublin maternity hospital was chosen as the study site as it provides a tertiary referral service for much of the country. Consequently, the experiences of women receiving care in regional centres referred to the unit for a second opinion could also be explored. Initial sampling was purposive, in that women with no previously known risk factors and a diagnosis of fetal abnormality in the current pregnancy were invited to take part. As data collection proceeded, women were theoretically sampled[1] on the basis of the diagnosis and outcome for the pregnancy in order to ensure that women carrying fetuses with a range of anomalies were sampled. Ethical approval was obtained from the study site, the School of Nursing and Midwifery and the Faculty of Health Sciences, Trinity College Dublin. Women gave written consent before and after each interview, and women who chose to participate were offered access to support services should they feel this would be helpful in the circumstances. Pseudonyms were used to protect the identity of participating women. Data were analysed using the constant comparative method, and concurrent data collection and analysis led to the emergence of the basic psychosocial process that is associated with living with and beyond the diagnosis of a fetal abnormality.

Findings: The process of adaptation after fetal anomaly diagnosis is represented and can be understood through the conceptual framework of Recasting Hope. Recasting Hope is a theory of traumatic loss, and is idiosyncratic to the area of prenatal diagnosis. Adaptation after fetal anomaly diagnosis is achieved through reconstructing meaning from the event in order to rebuild life assumptions. The four theoretical codes of 'Assume Normal', 'Shock', 'Gaining Meaning' and 'Rebuilding' represent each phase of this process. When the expectation of normality is devastated through an adverse diagnosis, some mother's expressed a sense of incredulity when informed of their baby's

---

[1]Theoretical sampling within this context goes beyond categorical sampling of women on the basis of the type of anomaly diagnosed as it extends to an exploration of women's experiences of that diagnosis, and is controlled by the emerging theory (Glaser 1978). For example, women receiving a diagnosis of chromosomal anomaly responded very differently to the news - some women hoped the anomaly would be lethal obviating them from the need to care for a baby with complex needs, whilst others hoped that the anomaly would be non-lethal, in order to have a baby to take home at the end of the pregnancy.

anomaly. 'Assume Normal' provides an improved understanding as to why women remain unprepared for an adverse diagnosis. Transition from this phase to 'Shock' is characterised by receiving an adverse diagnosis at the ultrasound examination as women struggle to cope with the information they have received. Once the diagnosis is made transition to 'Gaining Meaning' begins, as the process of searching for meaning in this ostensibly negative event begins. 'Rebuilding', the final stage in the process is concerned with the extent to which women make sense of the loss and resolve the inconsistency between their experience and their previous expectations of pregnancy in particular and beliefs in the world in general.

Conclusion: This theory contributes to the theoretical field of thanatology as applied to the process of grieving associated with the loss of an ideal child. The framework of Recasting Hope is intended for use as a tool to assist health professionals through offering simple yet effective interventions based on women's experiences of this event. Consideration of the impact of a midwife practitioner role on the process of recovery is recommended to ensure that all women have continued access to support irrespective of the pregnancy outcome.

1 Literature review: A contextual overview of pertinent issues in prenatal diagnosis

1.1 A description of the literature search:

When using the grounded theory method to generate theory, it is recommended that a literature review is not performed until data collection and primary analysis are complete, in order to minimise the risk of extant data influencing the direction of the study. Consequently, a systematic literature search was undertaken in September 2005 and finally reviewed in August 2006. A vast amount of evidence on a multitude of factors connected with prenatal screening is available; consequently, the search was limited to studies relating to the use of ultrasound in pregnancy to screen or diagnose fetal anomalies, with an emphasis on routine provision for unselected women. Initial scoping strategies to identify the evidence were performed through searching Health Technology Assessment (HTA) reports and the Cochrane Database of Systematic Reviews, with subsequent searches of the databases CINAHL, Psychology and Behavioral Sciences Collection and PsycINFO. Pubmed (the US National Library of Medicine online database) was searched via the World Wide Web, initially limiting studies to randomised controlled trials. Date restrictions were not applied, but languages were limited to English, German and Norwegian, as translation was available for these languages only, through friends and family. The search was refined to address two of the main areas associated with ultrasound in pregnancy; measurement of the clinical effectiveness of ultrasound as a screening tool for fetal anomaly, and issues for women in relation to the examination.

A detailed analysis of the sensitivity of ultrasound for specific anomalies to include false positive rates and the use of soft markers is beyond the scope of this review, but overall sensitivity rates associated with the modality are addressed. As much of the research in this area is observational, additional strategies were employed to achieve a more comprehensive overview of the topic. The database search was widened to include additional concepts such as: pregnancy, ultrasound, scanning, gestation, prenatal diagnosis, anomaly, abnormality, malformation, specific anomaly types e.g. chromosomal/structural, psychological, reactions, bonding, grief, and coping. Scientific

journals were hand searched on the basis of the articles retrieved through the electronic search, and reference lists provided additional sources of material. The literature was then sorted into two categories for inclusion: direct research addressing views of the examination and associated psychosocial impact, and background studies on early work on the effects of prenatal diagnosis and invasive testing in high risk populations. In order to include ongoing or unpublished research, prominent authors in the field were contacted and databases such as index to thesis and dissertation abstracts were searched; however, the yield from this method was poor. Studies that address the utility of ultrasound in facilitating pregnancy management for indications other than fetal anomaly i.e. assessment of fetal wellbeing, placental function and pregnancy complications, are excluded. As the study sample have received an adverse diagnosis at a routine second trimester ultrasound, other methods of prenatal screening such as pre-implantation diagnosis, biochemical screening (first and second trimester) and the utility of combinations of the aforementioned biochemical markers with ultrasound in the first trimester have been excluded.

1.2 Introduction

Routine ultrasound examinations in pregnancy have become available to most women worldwide (Garcia et al. 2002, Vankayalapati and Hollis 2004), and Ireland is no exception (Lalor et al. 2006a). Recent decades have seen ultrasound revolutionise the management of pregnancy and its possible complications (Hemmingway 1991, Goldberg 2000) and its contribution in this regard is well documented (Campbell and Smith 1983, Eik-Nes et al. 1984, Bucher and Schmidt 1993, Backe and Nackling 1994, Vankayalapati and Hollis 2004). Immediate availability of results, combined with the visibility of the fetus, has led to near universal acceptance of routine ultrasound by clinicians and parents alike (Hyde 1986, Green 1990, Green et al. 1992, Green 1994, Rapp 1999, Lalor 2000, Stephens 2000). However, its role in fetal anomaly screening raises contentious ethical dilemmas associated with subsequent management of the pregnancy after an adverse diagnosis (Lalor and Begley 2006).

Although most babies are born healthy and do not have abnormalities, women's need for reassurance of this may only be required because antenatal testing has raised doubts

in the first instance (Campbell and Smith 1983, Katz Rothman 1988, Kolker 1989). Although few women have specific grounds to worry that something might be wrong with their baby, Statham et al (1997) found this to be one of the highest scoring worries for women, and may explain the high uptake of routine ultrasound in low risk pregnancy. Previous studies have demonstrated that when ultrasound scans (USS) reveal normal findings, women's views of screening are extremely positive (Hyde 1986, Green 1994, Statham et al. 1997, Lalor and Devane 2007). Positive responses include parents' overjoyed reactions to seeing the moving image of the fetus on the screen (Eurenius et al. 1997, Baillie and Hewison 1999, Larsen et al. 2000) and the identification of their baby's features, such as a hand or facial profile (Lalor 2000). As ultrasound screening becomes increasingly available to all women, it is inevitable that more women and their families will be faced with discovering that their baby has an abnormality during pregnancy, rather than in the neonatal period. Despite the availability of routine ultrasound, relatively little is known about women's experiences of receiving an adverse diagnosis in pregnancy i.e. one of a fetal abnormality or variant. This chapter will provide a contextual overview of ultrasound as a screening tool, and introduces pertinent issues that require consideration by those involved when an antenatal diagnosis of abnormality is made.

1.3 The introduction of routine ultrasound into antenatal care

The origins of many midwifery and medical specialities are obscured by controversy, but ultrasound in obstetrics and gynaecology has a precise birth date. Ultrasound in obstetrics and gynaecology was pioneered in Glasgow in the mid 1950s. Ian Donald, the 'Father' of obstetrical ultrasound published his seminal paper in the Lancet in 1958, which for the first time showed ultrasound images of obstetrical and gynaecological conditions. Donald in 1974 speculated that: "The day may come shortly when a routine ultrasound examination will be offered to every pregnant patient". Ultrasound in pregnancy has three discrete functions; facilitating pregnancy management, screening for fetal anomaly and diagnosis of fetal anomaly. As with any imaging technique employed in pregnancy, the risk of side effects to the mother and developing fetus must be investigated. The Royal College of Obstetricians and Gynaecologists was sufficiently convinced about the safety of ultrasound in pregnancy that it supported offering this examination routinely (RCOG 1984), with the caveat that large scale studies be performed to examine the benefits of routine versus selective ultrasound. Subsequently, additional issues requiring further investigation were identified such as: population impact of screening, psychological impact of receiving an adverse diagnosis and the effects of prenatal invasive procedures (RCOG 1997).

1.4 Clinical effectiveness of the second trimester examination

Routine ultrasound in pregnancy has become increasingly topical as it begins to affect more women. The RGOG report of ultrasound screening for fetal abnormality (RCOG 1997) updated in 2000 (RCOG 2000) concluded that two ultrasounds should be offered to all women, the second to be a screen for anomalies around 20 weeks' gestation. This guideline soon became policy in many units even though there were many aspects associated with providing such a service that remain to be evaluated. Marsal (1992) suggests that since the widespread introduction of ultrasound, it has become an indispensable tool in obstetric practice, and that there have been very few techniques to make such an impact on pregnancy management. Advantages of pregnancy ultrasound include increased accuracy in assessment of gestational age, identification of multiple pregnancies and improvements in the management of complicated pregnancies (Neilson

2006). However, controversies regarding the routine use of ultrasound in pregnancy remain (Proud 1994), and are further complicated by the targeted use of ultrasound for fetal anomaly detection.

Ultrasound screening for fetal anomalies was introduced into practice almost 20 years after the first demonstration of its ability to identify deviations from normal anatomy (Hobbins et al. 1979). As the diagnostic capability of ultrasound to detect structural anomalies became apparent (Donald and Brown 1961, Sunden 1964, Campbell et al. 1972), advances in the area of obstetric imaging have led to developments in the assessment of fetal anatomy and physiology with a concurrent increase in the identification of fetal anomalies in utero. In the absence of prenatal screening, 2% of babies will be born with a structural anomaly and a further 1:700 will be born with a chromosomal or serious genetic disorder such as Down syndrome. As most abnormalities occur in healthy low-risk women the Royal College of Obstetricians and Gynaecologists (RCOG 1997) has recommended that screening for fetal anomalies should be offered routinely rather than selectively, hence the growth in the provision of ultrasound as a routine aspect of antenatal care. Despite a relatively low prevalence (2-4%), fetal anomalies are responsible for approximately 30% of perinatal deaths in developed countries (Grandjean et al. 1999) and intervention to improve perinatal outcome is to be welcomed. Although antenatal detection provides information for decision making during pregnancy, and an opportunity to plan treatment at birth including transfer to specialised paediatric units in the neonatal period, the assumption that ultrasound diagnosis of fetal anomalies can contribute to a meaningful reduction in perinatal mortality rates and improvements in neonatal outcome has been challenged (Ewigman et al. 1993, Bahado-Singh et al. 2006, Neilson 2006).

Ultrasound screening for fetal anomaly has been the subject of much debate, (Levi 2002) due, in part, to the broad range in sensitivity rates quoted in the literature and the accompanying concerns as to the consequent benefits in maternal and perinatal outcomes (Baillie et al. 2000, Bricker et al. 2000). A wide range in ultrasound detection rates (5.8-90%) for fetal anomalies has been reported (Ewigman et al. 1990, Chitty et al. 1991, Levi et al. 1991, Goncalves et al. 1994, Carrera et al. 1995, Boyd et al. 1998, Hagenfeldt et al. 1998, Boyd et al. 2004). Most of the studies have been retrospective, with limited series of malformations, and studies in low-risk populations have suffered

from a lack of standardisation of both the structures examined and the definition of the anomaly, making an overall estimation of the reliability of ultrasound as a screening tool difficult. The variation in sensitivity rates for ultrasound performance is also due to the fact that the ability to detect an anomaly is dependent upon many factors (Dillon and Walton 1997) such as the gestation at examination, the purpose of the examination and the type of anomaly detected, with the level of expertise of the operator being of paramount importance (Levi 2003, Garne et al. 2005). This variation implies that the quality of an ultrasound examination can vary at both a micro (between individuals) and macro level (between units and countries). Although an opinion from an expert operator is requested when concerns arise, experts are not available in sufficient numbers to provide a mass screening programme for all women. Developing an argument to support the need for the availability of large scale expertise could be difficult when only 2% of pregnancies will be affected, and many of the anomalies detected will not be compatible with life. The most recent assessment of the efficacy of ultrasound (sensitivity studies) in detecting fetal malformations through mass screening of large populations for European nations is reported in the Eurofetus (Grandjean et al. 1999) and Euroscan (Clementi and Stoll 2001) studies respectively. Both studies were designed to evaluate the effectiveness of routine anomaly screening in unselected populations; however, there are fundamental differences between them. The Eurofetus study (Grandjean et al. 1999) was a prospective design and included all personnel (non-experts) involved in performing fetal anomaly screening on a regular basis to unselected women from 61 units over a 3 year period. The participating centres were considered to have good facilities to offer screening, and the study was designed to overcome the shortcomings of the retrospective nature and sample size of previous studies. The Euroscan study was a retrospective population based study that collected data from 20 malformation registries in 12 European countries (Clementi and Stoll 2001). However, there are some methodological differences between both studies that warrant consideration when interpreting the sensitivity levels reported.

Estimates from the Eurofetus study may be subject to bias through the inclusion of tertiary and regional centres as heterogeneity of expertise between examiners is likely, as tertiary referral centres usually have a higher throughput of problem pregnancies than district/regional centres affecting the level of expertise available. The centres participating in this study have a routine screening policy of offering at least one

ultrasound around 20 weeks gestation to all women attending, reporting an overall sensitivity rate of 61.4%, an overall detection rate was 56.2%, decreasing to 44% before 24 weeks. However, data from women having a routine examination after 24 weeks were included. This uniform approach to screening may have contributed to an increased sensitivity rate for this study, as it is considerably higher than the sensitivity rates (24-38%) reported in other studies (Gillerot 1995, Papp et al. 1995, Stoll et al. 1995). In addition, ultrasound examinations are not exclusively performed by trained personnel (Whittle and Honest 2005, Lalor et al. 2006b) and are at times carried out by personnel outside of ultrasound departments with little or no training to do so. Consequently, the Eurofetus sensitivity rate may not be achievable in other centres where ultrasound provision is not as circumscribed. However, the Eurofetus study is useful in that it has identified the prevalence of structural anomalies across a range of European countries, and highlighted that detection rates for different anatomical systems varied considerably, with high detection rates for central nervous system anomalies and low rates in the detection of cardiac anomalies. The proportion of anomalies identifiable by ultrasound alone before 24 weeks is not provided.

The retrospective design of the Euroscan study (Clementi and Stoll 2001) did not allow for the calculation of a sensitivity rate for the overall detection of anomalies but only for specific classes of anomalies. Evaluation of the sensitivity of ultrasound in fetal anomaly detection is dependent upon postnatal ascertainment, which may not always be complete. The background anomaly rate of 1.15% in Euroscan is considerably lower than the frequency in Eurofetus (2%), thus an under ascertainment of the detection rate in newborns cannot be excluded. It is also important to note, when considering ultrasound alone as opposed to in combination with serum screening, the detection of chromosomal anomalies depends on the presence of associated structural defects, and can be as low as 18% (Bricker et al. 2000). Within this context, Nackling and Backe (2005) have suggested the contribution of routine second trimester ultrasound to pregnancy outcome in a low-risk population remains to be proven. The development of uniform and reproducible guidelines and standards for the content of the examination (Lalor et al. 2006a) with concurrent improvements in training for those performing USS are likely to be important factors in optimising the accuracy of the examination (Lalor et al. 2006b).

Whilst this issue remains unresolved, women are taking part in routine ultrasound screening programmes predominantly with the expectation that their babies are healthy and view ultrasound screening as a means of confirming normality and viability (Lalor 2000, Ekelin et al. 2004, Lalor and Devane 2007). Medical and technical advances in prenatal diagnosis have made it possible to detect many fetal anomalies with targeted screening moving rapidly into the first trimester. However, technological progress can have human consequences. With such widespread availability of ultrasound in pregnancy it is unavoidable that some women taking part in screening programmes will be faced with the USS uncovering a fetal anomaly. An exploration of the impact and utility of fetal anomaly diagnosis before the birth and the factors that influence subsequent decision making within the specific cultural, social and legal contexts that prevail in Ireland is required.

1.5 The polemics of screening

Traditionally people attend hospital when an illness is observed; however, when it comes to pregnancy a newer paradigm of surveillance medicine is developing (Armstrong 1995). Armstrong describes this concept in terms of screening normal populations for an illness that has not manifested itself through the identification of risk factors. Consequently, mass screening in low risk pregnancy is blurring the traditional boundaries between health and illness. Some authors have suggested that routine screening has resulted in pregnancy being treated as a risk factor (Davis-Floyd 1992), only being viewed as a state of health in retrospect (Katz Rothman 1988). Sociologist John McKinlay has highlighted several stages in the process of the acceptance of medical interventions as standard of care. These stages seem to explain how a perceived need to introduce said interventions routinely materialises prior to a systematic evaluation of their usefulness and effectiveness (McKinlay 1981). McKinlay outlines how the process is often initiated through the appearance of a promising report in a journal leading to a pilot study intended to investigate the innovation's potential. McKinlay goes on to suggest that pilot testing of the new technology has the paradoxical effect of exposing clinicians to the apparent usefulness of the innovation, whereby it becomes too valuable to withhold from patients not enrolled in the evaluation. Institutions respond by

committing resources to providing the technology, and finally consumer enthusiasm follows. Although this model is useful in explaining how prenatal testing techniques become absorbed within the context of non-controversial routine antenatal care without prior evaluation of their utility or acceptability to women (Bricker et al. 2000), it does not explain the mechanism whereby support for an intervention is 'transformed into actual patient choice' (Press and Browner 1997 p987). Most women appear to want an ultrasound examination of their fetus and the offer of a routine ultrasound seems to be popular, with high uptakes in screening programmes internationally (Hyde 1986, Crang-Svalenius et al. 1996, Eurenius et al. 1997, Lalor 2000, Ritchie et al. 2004). Others have suggested women defer to medical control (Oakley 1981) seeking reassurance from clinicians they are doing all that they can to guarantee the wellbeing of the pregnancy (Browner and Press 1995). Perhaps the non-invasive nature of ultrasound (Mitchell 2004) contributes to the social meaning associated with the examination, where couples may even see it as an important landmark in pregnancy (Ekelin et al. 2004). Meanwhile the availability of a range of prenatal diagnostic technologies is increasing in Ireland without any concurrent investigation of the issues pertinent to those involved in the process.

The issues surrounding prenatal screening and diagnosis are convoluted, not least because of the myriad of people involved, i.e. extended families, communities, midwives and obstetricians to mention but a few. Whilst trends in the public perception of the merits or difficulties of prenatal screening materialise, individual encounters between families and health professionals involving complex decisions regarding pregnancy outcomes are ongoing. Therefore, professionals' attitudes to screening, and subsequent pregnancy management after an adverse diagnosis, are undoubtedly influential in women's experiences of this situation.

1.6 Professional and lay persons' attitudes to prenatal screening

Scientific developments are increasing the range of congenital malformations and genetic disorders that can be detected antenatally. Just as individual and societal held views influence behaviours seen to be acceptable, professionals' views of prenatal diagnosis are without question influential in the subsequent pregnancy management available to women. Health professionals and members of the public resident outside of

Ireland may question the value of offering prenatal screening in a country that does not allow termination of pregnancy if an anomaly is detected. However, Farrant's (1985) landmark study of attitudes to prenatal screening and termination for fetal abnormality in 1980 drew attention to the fundamental differences in agendas between caregivers and women participating in screening programmes. Health professionals, in general, viewed the goal of a screening programme as being "to detect fetal anomalies", whereas women participated to seek reassurance of normality. This fundamental difference in the perception of the purpose of screening goes some way towards explaining why women who would not consider abortion may still take part in testing (Green 1993). Differences in attitudes between professionals and lay persons was reaffirmed by Drake et al (1996), with an acknowledgement that attitudes are also influenced by culture (Drake et al. 1996, Ettorre 2002). The authors have suggested that further investigation of the extent of the difference and whether such differences result in a discordant presentation of the perception of disability with patients' value systems is warranted.

While science endeavours to come to terms with evolving diagnostic techniques, it also needs to learn to respect the culture of those affected by the utilisation of such diagnostic procedures (Ettorre 2002). With time, the influence on practice of obstetricians' personal attitudes towards specific anomalies began to emerge (Green 1995), with the introduction of the clinician's assessment of the severity of the condition into pregnancy management decisions, resulting in a variation in outcomes and options for women. Although clinicians may strive to provide non-directive counselling, the question as to whether any information can be value free has been questioned (Kessler and Levine 1987, Marteau 1989a). However, others have suggested that some parents may readily seek professional guidance, and provision of information in order to inform parents of their options could be misconstrued as a recommendation towards discontinuing the pregnancy (Remple et al. 2004). There is evidence that varying approaches to counselling between professions exists, with obstetricians self reporting a more directive approach than genetic counsellors (Marteau et al. 1994). Others have suggested that many factors impinge on the decision, including pressure from family and from differing perspectives within the couple themselves towards continuing a pregnancy or not (Statham and Solomou 1998).

In Europe, although the structure and provision of maternity care varies between member states, midwives fulfil a pivotal role, in particular in the care of low risk women. Kooij et al (2002) surveyed midwives from four European countries and discovered that some midwives appear to offer prenatal screening tests to women despite feeling that they are unlikely to avail of those tests themselves if pregnant, leading one to question the value they place on the test being offered. Although this may be the largest data set addressing this particular issue (n=1,220), there are many weaknesses with the study such as; small sample sizes per country (175-571), an unknown response rate, and a poorly described instrument. In the context of prenatal diagnosis, with the exception of the aforementioned study, little is known about midwives' views and concerns internationally. Conceivably, the most pertinent point is that when women are being cared for by midwives, their opinions and attitudes to prenatal screening tests are very relevant as they may influence women's participation in and experiences of screening programmes.

There are many personal factors that may influence a woman's decision to take part in antenatal screening programmes such as age, education, reproductive history, religiosity, and individual risk assessment (Green et al. 1993) with as many arguments as to the intrinsic worth of participation to be considered. Three recurrent themes dominate the literature in relation to the positive aspects of ultrasound scanning for women: visualisation of the fetus and sharing this with significant others, receiving confirmation of fetal life pre-quickening and gaining reassurance about fetal health. Although women may worry that there is something wrong with the baby (Statham et al. 1997), that does not actually mean that they prepare themselves for receiving bad news. However, given the fact that ultrasound has been shown to detect fetal anomalies, few would argue that women should be given enough information in order to make an informed decision when considering whether to opt-in or opt-out of screening. It seems unlikely that prenatal screening of healthy pregnancies will go away, consequently, it has been recommended that detailed information be given to women before the examination (Field et al. 1985, Abramsky and Chapple 2003) to ensure that women are aware of the diagnostic capability and limitations of the ultrasound (Green 1994, Seeds 1996, Larsen et al. 2000).

1.7 Communicating the purpose of the second trimester ultrasound

Communication of risk in screening programmes in health care is, in general, poorly investigated. Service users may be led to take part in screening because they perceive that clinicians desire them to do so and, indeed, calculation of an individual risk factor may influence some. However, assessment of risk alone cannot be construed as evidence of informed decision making when measuring the uptake of a programme (Edwards et al. 2003) as the lure of seeing the baby may be a key factor (Ekelin et al. 2004). Concerns have been raised in relation to the unsatisfactory availability of accurate information for women who choose to participate in ultrasound screening programmes (Tunon 1998). The antenatal USS has been shown to have psychological sequelae (Seeds 1996) from providing reassurance about fetal wellbeing to shattering hopes of a healthy pregnancy, and it has been speculated that provision of detailed information will reduce the likelihood of any misunderstanding of the capabilities and limitations of the examination leading to expectations that may exceed that which the technology is capable of delivering (Proud 1995, Eurenius et al. 1997).

Information leaflets are a common strategy used in health care to disseminate information to large numbers of people; however, the inherent value of these decision aids is unclear. While a systematic review by O'Connor et al (1999) concluded that decision aids had a positive role to play in facilitating women to make more informed choices, Lalor and Devane (2007) found that women's knowledge regarding USS did not necessarily improve through disseminating information using this format, highlighting that issues such as distribution (Stapleton et al. 2002), readability (Sherr and Hedge 1990) and information content rather than presentation alone are important considerations. Others have highlighted that time pressures in busy antenatal clinics can be a confounding factor in successfully disseminating information to women (Stapleton et al. 2002, Smith et al. 2004) and that the optimal time to discuss the USS is with the midwife/sonographer just prior to the ultrasound (Smith et al. 2004, 2006). Providing women with sufficient information to make informed decisions about their care and their participation in screening (Santalahti et al. 1998), without worrying them unnecessarily is problematic. However, the reality is that many women receive limited information from health professionals on which they can make informed decisions

about their pregnancy (Smith and Marteau. 1995, Eurenius et al. 1997, Lalor and Devane 2007), leaving women to access the information they require from other sources. Unfortunately, an ideal method of providing adequate information has yet to be achieved (Marteau 1989b, Green 1990, Graham et al. 2000), and the extent to which women in Ireland feel prepared for the possibility of an adverse diagnosis at the routine antenatal ultrasound remains to be established.

1.8 The psychological effects of antenatal ultrasound

Maternal-fetal attachment is described as a natural phenomenon that grows over the duration of the pregnancy and is regarded as an essential step towards developing loving motherly behaviour (Siddiqui and Hagglof 2000). Historically, attachment in pregnancy has been associated with quickening (Lerum and LoBiondo-Wood 1989), intensifying in the third trimester as the birth becomes imminent. Currently, the debate in the literature regarding the risk/benefit equation of ultrasound screening is focused almost completely from the perspective of measuring clinical impact (Ewigman et al. 1993, Baillie and Hewison 1999, Bricker et al. 2000). The psychological impact of the ultrasound examination has been far less well appraised and is seldom considered when discussing the relative merits of screening pregnant women. Qualitative analysis of small numbers of women's experiences of USS have resulted in a number of claims being made regarding the psychological impact of the examination (Hyde 1986, Pershutte 1995, Bricker et al. 2000). It has been suggested that bonding is now initiated prior to the perception of fetal movements through the visualisation of the moving fetus on the screen (Milne and Rich 1981, Campbell et al. 1982, Villeneuve et al. 1988, Dykes and Stjernqvist 2001). Although early studies of the psychological impact have been limited by small sample sizes (Hyde 1986), the exclusion of low-risk women and manipulation of the level of feedback regarding the ultrasound affecting the experience of the examination (Reading et al. 1982, Fletcher and Evans 1983, Cox et al. 1987a), the positive response from parents to seeing the fetal image on the screen is undeniable (Lalor 2000, Ekelin et al. 2004). With the development of 3d and 4d ultrasound, the visible humanity of the fetus is likely to influence this process even further (Sedgmen et al. 2006). Whilst visualising the fetus may encourage antenatal bonding and positively influence a mother's health behaviours such as reducing alcohol or nicotine intake in pregnancy, Pershutte (1995) maintains that "a clear association seems to exist between

the psychological benefits of prenatal ultrasonography and reduced stress" (p.795) when the examination does not reveal adverse findings.

The consequences of technologically mediated bonding when a fetal anomaly is discovered have not been investigated, and data on the psychological consequences for women and their families resulting from the identification of malformations/variants at the USS remains relatively sparse. A social dimension to antenatal ultrasound scanning has been identified previously, as women come for examination to get a photo of the baby and seek reassurance of fetal wellbeing (Eurenius et al. 1997, Chudleigh 1999, Lalor 2000, Ekelin et al. 2004). The pleasure women experience through seeing the fetal image on the screen makes USS distinctive. It is regarded as non-threatening when compared with other forms of prenatal testing, increasing expectations of delivering a healthy child (Hunfeld 1995). However, if the psychosocial aspect of the examination distracts women from considering the potential ramifications of screening, then it is imperative that women's preparedness for an adverse diagnosis is explored. Although this is a global issue, it is situated within a particular context in Ireland; when the use of screening as a way of offering real alternatives to women is limited within the state. Given the likelihood of cultural influences and the unique legal situation in relation to termination of pregnancy in Ireland, an exploration of women's experience of an adverse diagnosis of fetal abnormality and the possible consequences of having this information for the remainder of the pregnancy is imperative. Some women will likely choose to terminate the pregnancy (Byrne and Morrison 1999), and issues regarding the impact of having to travel outside the jurisdiction to access this service requires further study if responsive and supportive care is to be provided.

1.9 Receiving an adverse diagnosis

It has been established that receiving a diagnosis of fetal anomaly on ultrasound is a traumatic experience (Green et al. 1992, Marteau and Mansfield 1998, Pelly 2003, Statham 2003) ending parental expectations of normality (Sandelowski and Corson Jones 1996a). Statham et al (2001) have highlighted that internationally there is a dearth of research on the psychological effects of prenatal diagnosis. The literature in the area is composed primarily of comparisons between the psychological outcomes of women who chose to continue with those who have chosen to terminate the pregnancy. It is

undeniable that investigating the psychological effects of this experience is difficult due to the sensitive nature of the subject, and trying to understand the impact on women is further complicated by the influence of family, religious and cultural factors and the varying prognosis for the fetus in subsequent decision making (Statham et al. 2000). When exploring the impact of the diagnosis cognisance must be given to the likely outcome for the fetus. Whilst some fetal anomalies are lethal the majority are not, and instead may carry a significant risk of mental/physical disability. Alternatively, some may benefit from antenatal diagnosis (Carvalho et al. 2002) through the availability of in-utero intervention or immediate specialised treatment in the neonatal period (Kumar and O'Brien 2004). However, only a minority are amenable to such specialised intervention, leading some authors to question the value of antenatal identification of anomalies for parents when such a therapeutic vacuum persists (Sandelowski and Corson Jones 1996a) and the psychological cost of knowing is significant (Zeanah 1989, Hunfeld et al. 1993, Statham 2003).

The psychological effects of receiving an unexpected diagnosis of fetal anomaly have been predominantly explored through either qualitative analysis of women's experiences or alternatively through empirical measurements of level of trauma at various junctures. The latter have primarily sought to gauge if a pattern exists in the level of emotional distress experienced through the use of a multitude of standardised instruments to measure concepts such as grief, despair, coping, anxiety and depression. Most studies to date have focussed on second trimester diagnosis; however, with the development of first trimester screening, research studies of parental experiences of an adverse diagnosis at earlier gestations are emerging. Much of the investigation in this area began as a result of the recognition of stillbirth as a perinatal bereavement (Kennell et al. 1970). This attention to loss and bereavement has created a situation whereby researchers have focussed on women's experience of termination after prenatal diagnosis, with relatively few considering the issues pertinent to women who choose to continue the pregnancy. Statham et al (2000) have suggested that predicting an individual response is difficult as personal coping styles, family/social support and options available such as access to termination and neonatal intervention affecting the eventual neonatal outcome will influence initial reactions to the diagnosis. Although attitudes to the visibility of disability in society and the acceptability of termination for abnormality (Shakespeare 1998, Savulescu 2001) will vary between cultures and over

time, the impact of societal held views on individual decision making is largely unknown (Statham et al. 2000), yet it is likely a perceived consensus view will have a bearing to some extent.

1.10 Terminating a pregnancy after diagnosis of fetal abnormality

Parental decision making after an adverse diagnosis is a complex process and when termination of the pregnancy is an option there are many factors to be considered. Particular attention has been given to exploring predictive factors surrounding the decision to terminate the pregnancy (Verp et al. 1988, Zeanah 1989, Drugen et al. 1990, Pryde et al. 1992, Hunfeld et al. 1993, Marteau and Mansfield 1998, Zlotogora 2002), such as the severity of the disorder and gestational age at diagnosis (Evans et al. 1996), and their effects on the outcome. With substantial variation between qualitative studies with regard to the characteristics of the populations being studied, sample size and the type of anomaly diagnosed, it is unsurprising that conflicting findings regarding key variables and their relationship with pregnancy outcome are seen. A strong association with cognitive impairment in the fetus and termination of pregnancy rates has, however, been identified (Mansfield et al. 1999). Many of the studies describe the emotions parents felt, their concerns regarding the termination procedure and worries around seeing or creating momentoes of the baby. Through the emergence of recurrent themes and observations, valuable research perspectives to inform practice are provided (Statham et al. 2000). However, the process of how parents make decisions has been largely overlooked (Broadstock and Michie 2000). Recognising the risk of psychological trauma to parents on hearing their baby has a congenital defect; a number of studies have focussed on statistically measuring women's psychological responses to termination after fetal anomaly (TAFA). Thirty years ago when invasive testing was relatively new, and only offered to women on the basis of age or family history, Blumberg et al (1975) performed psychometric testing on 13 families after amniocentesis had identified a genetic defect. The intention of the authors was to minimise the trauma of the procedure and improve the counselling available to women with high risk pregnancies. The study findings demonstrated that while preparation was targeted towards the technical aspects of the procedure and the risk of an abnormal result, families needed to be made cognisant of the emotional sequelae that can result after selective abortion. The authors suggested that personnel should be available to help

parents to clarify issues in the decision making process (Lippman-Hand and Fraser 1979), and provide ongoing emotional support post abortion (Kenyon 1988, Langer and Ringler 1989) as neglecting to do so may compound the psychological trauma experienced by some (Dyer 2002).

The last twenty years have seen much research into measuring parental grief in a formal way (Black 1989, Zeanah 1989, Iles and Gath 1993, Lilford et al. 1994, Hunfeld 1995, Salveson et al. 1997, Burgoine et al. 2005, Davies et al. 2005, Kersting et al. 2005, Korenromp et al. 2005), intended to develop an understanding of the short and long term psychological consequences for women after selective termination of pregnancy. Many authors have concluded that psychological distress is high in the immediate period after the diagnosis, with a tendency to fall over time, suggesting that psychological responses are similar to those following perinatal loss (Zeanah 1989, Black 1992, 1993, Hunfeld et al. 1993, Salveson et al. 1997). However, in spite of the use of standardised instruments, wide variations in the results between studies exist. This is largely due to stated differences in study design leading to heterogeneity in the population being studied, sample size, gestations at measurement and myriad of instruments used. However, when studies used comparable instruments, results remained inconsistent as the circumstances around the termination, support available, interaction with caregivers, time of administration of the instrument related to the index pregnancy and drop out rates differed. When such contradictory findings exist, extrapolation of data to underpin practice is difficult. This is further compounded by the lack of clinically meaningful guidance for practitioners on how to respond when abnormal scores are obtained.

Previous studies have highlighted the influence of factors such as gestational age, severity of the malformation, the procedure performed at termination, demographic and social factors, the care provided by health professionals (Verp et al. 1988, Black 1989, Zeanah 1989, Pryde et al. 1992, Iles and Gath 1993, Redlinger-Grosse et al. 2002), who counsels the parents and cultural differences (Mitchie et al. 1997, Marteau and Dormandy 2001) on pregnancy outcome. Although psychological distress in the immediate period around the diagnosis is normal, some women continue to exhibit high levels of distress (Black 1989, Iles and Gath 1993, Hunfeld 1995, Korenromp et al. 2005) as time passes. Even though empirical measurements of levels of distress are available,

inconsistencies between studies mean that there is insufficient evidence to develop a scientific base to underpin practice. A tool to derive a composite measure of clinically relevant determinants with the intention of predicting those women likely to develop a pathological grief response in the short or long term has yet to be developed. Making a decision to interrupt a pregnancy is such a significant event that the RCOG (2001) have stated that professionals involved in counselling couples should provide information on the possible psychological sequelae; however, a framework to monitor the effectiveness of the information given is not proposed. More research is required in identifying therapeutic interventions that would support individuals at risk, including specific actions/interactions that might be useful in monitoring the grieving process (Suslak et al. 1995).

1.11 Continuing a pregnancy after diagnosis of fetal abnormality

When reproductive choices are limited, presumptions are made that being forewarned of the presence of a genetic disorder provides the opportunity for emotional preparation for the birth, and time to gain an understanding of the possible difficulties that lie ahead. Although there are many studies describing parental responses and decision making following abnormal results after serum screening or invasive testing, there is little information available on the specific role of ultrasound in parental experiences of receiving a negative test result (Jorgensen et al. 1985, Hunfeld et al. 1993, Salveson et al. 1997). Issues such as breaking the news and the impact of seeing the anomaly on the screen have not been systematically investigated. Black's (1992) qualitative analysis with women undergoing early ultrasound prior to invasive testing indicated that for 40% of the participants (n = 132), seeing the baby on the screen added to the difficulty of coping with the loss, suggesting that visualisation of the fetus is an added dimension that may lead to a more pronounced emotional reaction to the diagnosis (Dallaire et al. 1995). This may also be compounded by the sonographer's reaction to the fetal image, as subtle changes in facial expressions or body language may be interpreted by women as markers of fetal wellbeing (Green 1994, Rapp 1999, Mitchell 2004).

Little consideration has been given to parents experience of continuing a pregnancy (Statham et al. 2001, 2003) and perhaps this is because developments in prenatal diagnostic techniques over the last twenty years have led to an increase in selective

termination of pregnancy (Peller et al. 2004) in particular following the diagnosis of anomalies that are lethal or associated with risk of handicap (Mansfield et al. 1999, Tymstra et al. 2004). For women who continue the pregnancy, evaluation of the psychological risks and benefits of knowing is essential as routine screening means there is a real potential for large numbers to be affected. An early small scale study (n = 14) has suggested that if an abnormality is detected parents want to be informed, even though women remained "emotionally unbalanced" for the remainder of the pregnancy (Jorgensen et al. 1985 p78). There are isolated reports of women expressing regret at having foreknowledge (Armstrong 1996, Tymstra et al. 2004) as they were placed in a position of having to choose, and moreover were angry at being commended for their bravery if they continued the pregnancy. Any discussion in relation to prenatal diagnosis must take cognisance of the possible range of outcomes for the pregnancy, as there is evidence that parents define the condition in terms of seriousness when choosing to terminate the pregnancy (Statham et al. 2003). Although there are some accounts in the scientific literature of parents' experiences of continuing the pregnancy after an adverse diagnosis, they are limited on the basis of the severity of the anomaly i.e. to those known to be lethal (e.g. anencephaly, Edwards Syndrome), carry a significant of risk of handicap (Down Syndrome, Neural tube defect) or varying degrees of risk associated with treatment (Diaphragmatic hernia, cardiac anomalies). Statham et al (2003) have urged caution in relation to defining anomalies as 'serious/severe' and 'less serious/severe' (Statham et al. 2003 p164), and continuing to examine parents' experiences of prenatal diagnosis on the basis of the implications for the baby will result in an under representation of women with uncertain prognoses or treatable anomalies in the literature. Assumptions that parental reactions are based on objective measures of fetal outcome such as mortality and risk of impairment and extrapolation of data from this group of anomalies to others may result in insensitive encounters with caregivers, and may culminate in women receiving an inappropriate level of care (Green et al. 1992).

Chitty et al's (1996) analysis of the experiences of five couples who chose to continue the pregnancy after a diagnosis of a lethal anomaly re-enforces concerns regarding the inappropriateness of care provided by some health professionals. Women described the unsuitability of routine antenatal clinics for ongoing care, and a lack of continuity of carer led to some women being treated insensitively as staff did not seem to be aware of

the situation and interacted with the woman as if a normal outcome was expected. In spite of the difficulties, parents in this study reported that having an antenatal diagnosis helped them to be prepared for the birth. However, the authors expressed concern that as staff experience of couples continuing the pregnancy is limited and they seem ill prepared to provide appropriate care, concerns that remain unresolved. Edwins (2000), a midwife, describes how her rationale for interviewing five women who continued the pregnancy after a diagnosis of Down Syndrome was due to the fact that she had no first hand experience of this in her practice. This combined with little published data for reference left a feeling of insecurity regarding the lack of guidance to underpin practice. In this study, the women's children were between one and five years of age, and although time had passed since the pregnancy, Edwins (2000) found that although foreknowledge was valued, women remained critical of the care they had received. Their accounts describe incidents of feeling let down as both the system and staff appeared to have no frame of reference to assist in delivering appropriate care once their assumption that one would terminate was not met. Watkins (1989) provided anecdotal evidence of reduced levels of emotional distress in one woman who continued her pregnancy after a lethal anomaly was diagnosed when compared to others that had interrupted the pregnancy, and it has been hypothesised subsequently that this may be due to the fact that such women are spared the guilt associated with arbitrating on the outcome of their pregnancy. It could be argued that the provision of postnatal care after a birth not afforded to women after termination is influential in ameliorating the distress; however, evidence to support that supposition is not currently available (Statham et al. 2003).

Ralston et al (2001) conducted a retrospective cohort survey of 38 mothers of children with aneuploidy. The study included two groups of women, 17 who received a diagnosis at birth and 21 in pregnancy, to explore if there were benefits to antenatal diagnosis when compared with postnatal diagnosis. Although the authors suggest that antenatal diagnosis is beneficial as mothers had the opportunity to access information on their child's condition, several women in each cohort commented on their dissatisfaction with the way the news was conveyed, re-iterating previous study findings that communication with caregivers is problematic (Abramsky and Chapple 1994, Chitty et al. 1996, Edwins 2000, Redlinger-Grosse et al. 2002, Statham et al. 2003). Women expressed discontent that caregivers seemed to display little understanding of

their decision, re-iterating the fact that personally held views that termination is more appropriate can have a negative impact on parents (Tymstra et al. 2004), leaving them to feel abandoned by the system (Finnemore 2000). When choosing to continue the pregnancy following the diagnosis of a potentially treatable abnormality, certainty regarding the eventual outcome is not always available. It has been shown that parents have increased anxiety levels when such diagnoses are made (Madarikan et al. 1990, Kemp et al. 1998). The anxiety is exacerbated further by the time it takes to reach a comprehensive diagnosis, as on occasion parents have to wait for results from chromosomal analysis or referral to tertiary centres before an accurate prediction of outcome can be reached. Anxiety levels measured using the State-Trait Anxiety Inventory (Spielberger et al. 1970) have been shown to fall after consultation with paediatric surgeons, irrespective of the mortality rate associated with the condition (Kemp et al. 1998). The authors speculate that initial anxiety levels may have been precipitated by inaccurate or insufficient information given at the time of detection, which is allayed, in part, by the consultation. However, when ambiguity regarding the diagnosis and or eventual outcome existed, anxiety levels remained high (Madarikan et al. 1990). Others have suggested that when the neonatal outcome remains uncertain, the decision to continue the pregnancy is not always clear cut and may evolve over time. This is usually followed by a process of revisiting the decision throughout the remainder of the pregnancy in order to cope (Redlinger-Grosse et al. 2002). In some cases women will continue the pregnancy due to late diagnosis, where termination at a advanced stage of pregnancy is unacceptable to them or legal gestational limits apply (Hunfeld et al. 1993, Redlinger-Grosse et al. 2002). These women did not feel that a decision was made, as an alternative to continuing the pregnancy was not available. Irrespective of whether the decision to continue the pregnancy is passive or active, Statham et al (2001) have identified a number of themes from parents' accounts (n=72) of their experience. Parents commented on how optimistic friends or professional's emphasis on the future denied them the opportunity to express feelings of sadness or loss. Healthcare professionals did not appear to provide planned emotional support leaving parents to access the service offered by voluntary groups, which was evaluated favourably. Parents also highlighted that caregivers' focus for the remainder of the pregnancy was towards the outcome for the neonate. Whereas they were trying to negotiate travelling to antenatal visits in specialist centres, disruption to home life and uncertainty as to what to do if labour began unexpectedly without professional support

or recognition of the personal costs involved. Although there may be many individual difficulties that parents experience, Statham et al (2001) have reaffirmed that supporting families in this situation is challenging for health professionals, as they may have little opportunity to develop their practice if working in a jurisdiction where termination of pregnancy is available. Further research in this area is vital if practice is to become responsive to parents' needs at this difficult time.

1.12 Summary

Whether the consequences of medicalisation of a healthy pregnancy through mass screening in order to enhance reproductive choices for a small proportion of women is seen as acceptable is a question open to debate. However, the reality is that prenatal screening is now offered routinely to most women in the western world. The positive experiences associated with visualisation of the fetus undoubtedly add to the attractiveness of the examination to parents, as is evidenced by the high uptake of ultrasound programmes; however, information regarding the impact of seeing the fetus in the context of an adverse diagnosis is scarce. Concerns have been raised in relation to the availability and framing of information for women accessing ultrasound services. It is acknowledged that receiving an adverse diagnosis is devastating for parents; yet their preparedness for an unexpected result in the context of routine screening has not been explored. The medicalisation of childbirth is of concern to many (Murphy Lawless 1998, Cahill 2001), and although mass screening of unselected women can be viewed in this context, the scientific literature presents ultrasound as a tool capable of increasing the reproductive choices available to women. However, having foreknowledge of an anomaly can been seen as a double edged sword, as it places women in the unenviable position of arbitrating on the relative value of their unborn child (Katz Rothman 1988, Rapp 1999). Qualitative studies have provided individual stories of choosing, but have all been conducted in countries where termination of pregnancy is available, although gestational limits apply. Results from empirical studies measuring psychological responses to termination after fetal anomaly have been varied. However, neither guidelines on therapeutic interventions in response to abnormal scores nor an instrument to predict pathological grief has emerged. Decision making after prenatal diagnosis is complex and is influenced by a myriad of factors such as; the severity of the abnormality, gestation at diagnosis, reproductive history, caregiver attitudes, personal

and religious beliefs, social support and the views of society towards disability and termination in general. The paucity of information concerning the experiences of women who continue the pregnancy is alarming, and is reflected in women's accounts of unsupportive interactions with caregivers. However, women's experience of care after receiving an adverse diagnosis in the Irish maternity services is unknown.

Published findings are limited to descriptions of a multitude of factors related to parental responses culminating in insufficient evidence to develop a scientific base to underpin practice. Future research should explore the process of adaptation after an adverse diagnosis in order to develop a theoretical framework that can be used to guide the health professional when responding to individual needs, irrespective of whether the woman continues or terminates the pregnancy. Currently, Ireland appears to be unique when compared with our neighbours in that continuing the pregnancy is the dominant course of action. Whether women feel that prenatal diagnosis provides them with meaningful choices when termination of pregnancy is not available within the state is unknown. Consequently the value of foreknowledge and issues around leaving the state to interrupt the pregnancy remain unexplored. It has been suggested that there are some members in society that seem astounded by the emotional response exhibited by couples after experiencing fetal loss (van Mourik 2003), and this may be due, in part, to the many perspectives that exist in relation to the moral status of the unborn (Dunstan 1988). The following chapter will explore ethical issues in screening from the perspective of the rights of the mother versus the rights of the unborn, with an emphasis on the legal situation that prevails in Ireland.

2 Literature review: Maternal-fetal conflict: the moral significance of the fetus and the reproductive integrity of women

A literature review in relation to ethical issues in screening was undertaken between September 2005 and February 2006. The search was refined to address two of the main areas associated with adverse diagnosis in pregnancy; the relationship between the fetus and the pregnant woman and the social and legal status of abortion in Ireland. Key search terms such as; ethical issues, maternal-fetal rights, maternal-fetal conflict, moral status of the fetus, personhood, fetal imagery, abortion, legal abortion, termination, disability, disability rights, eugenics, psychological, motherhood and reproductive decision making were entered into the databases previously mentioned, yielding vast amounts of literature. Electronic searches proved unwieldy and difficult to limit, so key texts on the subject were accessed through the university online catalogue combining broad search terms such as abortion, ethical, moral, fetus and Ireland. Frequently used terms from these texts and references sourced from within the texts were then re-entered into the electronic databases and this assisted in focussing the search to ethical issues pertinent to prenatal screening. Studies were limited to those published in English. The search was refined to include research or scholarly inquiry directly related to the ethical and social aspects of choosing the pregnancy outcome after mid-trimester diagnosis of fetal anomaly. Research evidence or scholarly inquiry that addresses issues such as new reproductive technologies in In-vitro fertilisation/cloning, compliance with treatment in the third trimester, the prolongation of life or withdrawal of treatment for handicapped neonates, although relevant to women participating in screening are excluded as they are beyond the scope of the review. The search for unpublished research was limited to work that directly referred to the legal situation in relation to termination of pregnancy that exists in Ireland. Finally, the Government of Ireland, and International Court of Human Rights and relevant linked websites were searched for reports, cases and any relevant legislative amendments pertaining to the right to life in the Irish Constitution (Government of Ireland 1999). Irish and UK national newspaper archives were searched to capture the essence of the public debate around the issue of termination for fetal abnormality whilst they were happening.

2.1 Introduction

I approached this section of the literature review from a perspective of seeking to provide an overview for the reader of the impact that technology has made on the reproductive choices available to women, when it became apparent that the controversies that surround Irish abortion politics required analysis if one is to understand the cultural context in which women are making decisions after an adverse diagnosis. Arguments as to whether the mother has a right to control her body or whether the fetus has a right to life are deeply rooted in the abortion debate, an issue that the scientific literature seems to all but ignore. Mainstream scientific journals accessed by clinicians have reduced the debate around reproductive technologies to measuring fetal outcome in biological terms, and discussions of the ethical aspects of clinical decision making in the context of prenatal diagnosis are conspicuous by their absence. Whilst there are calls to evaluate the clinical effectiveness of technology and the psychosocial impact of screening, assumptions are made that because women participate in screening it is in either their own best interest or that of the fetus to do so. When instances occur where the mother arbitrates on the wellbeing of her fetus in relation to her own circumstances or interests, the emerging situation has come to be referred to as "maternal-fetal conflict" (Scott 2002). Scott (2002) suggests that this term is regrettable, as women are renowned for protecting the interests of their fetus and for doing all they can to ensure fetal wellbeing (Corbin 1987). The debate around the mother's choice is typically driven by two views; the rights and reproductive choices of the mother versus the right to life of the fetus. This juxtaposition between the mother's legal right to choose versus her legal duty to her fetus is commonly addressed in state law of the jurisdiction in question. Although there are relatively few circumstances of a woman choosing to refuse treatment in the fetal interest, in certain circumstances, a woman may make a treatment choice that will harm her unborn baby.

The purpose of this chapter is not to debate the rights and wrongs of termination of pregnancy, or even to arrive at what might constitute an acceptable abortion policy for Ireland. However, an overview of Irish abortion politics in relation to the cultural, legal and moral position of the fetus is presented with the intention of describing the social

context in which women in Ireland are placed when choosing whether to continue or terminate the pregnancy after an anomaly is discovered.

2.2 The maternal-fetal relationship and the emergence of the fetal patient

The relationship between mother and fetus is unique, in that there are no other circumstances when one life is so completely reliant on the actions of another. Ultrasound has irrevocably altered the mystery of that relationship through increasing the visibility of the fetus, permitting fetal diagnoses to be made with the consequent emergence of the concept of the fetal patient (Chervenak et al. 2002). Historically, images and samples of fetuses were drawn and preserved to describe the fetus through a range of observations aimed at understanding as opposed to treating (the fetus being considered a monster due to its abnormal proportions compared with an infant, and as abnormal outcomes could occur, mole etc). The advent of pregnancy testing, ultrasound screening and prenatal diagnosis have contributed to exposing women and the public to the facts of intrauterine life (Duden 1999), where previously pregnancy was a somatic experience for the woman only, confirmed with the birth of a child. Historically, the fetus was represented in art as a portrait of a child to be rather than an actual image appropriate for gestation. Eighteenth century medical interest in intrauterine life began to show the fetus in anatomical terms, and Sommerring's (1799) series of fetal images served to represent the linear evolution of fetal development, epigenesis of the fetus, with a focus on understanding fetal development. The erosion of the mystery and wonder of pregnancy as it had been began, and an alternative perception of the fetus as an individual emerged. Fifty years later, Storer (1860) cited in (Addelson 1999), as head of the then fledgling American Medical Association, began to argue that science had demonstrated continuous development from conception therefore attributing the fetus as inalienably human, and deserving of protection. Scientific knowledge influenced the epistemological emergence of the fetus, and the introduction of the concepts of rights, choices and personhood in the public procreation debate has been seen to influence law and the judiciary ever since. Beginning in the eighteenth century, ongoing medical developments have attempted to use professional authority and scientific knowledge to shape a single objective reality, referred to by some as the imperialism of western science (Addelson 1999).

As technology developed, Ian Donald (1950s) and William Liley (father of fetal surgery 1960s), both staunchly pro-life, have used technology to back their argument, changing fetal ontology through the introduction of the fetal patient. Sherwin (1992) suggests that fetal humanity is determined by fetal relations with pregnant women and others; however, this has become increasingly complex as fetal imaging and the real prospect of in-utero fetal treatment develops. Technological developments have increased the social significance of the fetus as 3 and 4 dimension images influence our view of the fetus, moving it from an incomprehensible shape in the 1950s to a stage where prospective parents are invited to embrace their baby on the screen (Boucher 2004). Fetal surgery has emerged as a biomedical sub-speciality whereby medicine has moved from seeking to understand fetal physiology to treating an individual with medical problems to ensure infant survival (Casper 1999). Media coverage of the heroic acts of fetal surgeons have brought fetal treatment into the social domain, with women acquiescing to all that is asked of them to save their baby (Casper 1999), actively engaging with the promise of what technology may offer. Petchesky (1987) contends this construction of the fetus as a patient and splitting of the mother-fetus dyad has resulted in the intensification of care away from the mother, causing her to fade from the scene with a consequent loss of personhood. Whether interventions such as fetal surgery, invasive testing and intensive monitoring with ultrasound are actually performed in the maternal-fetal interest or are more to do with developing science warrants debate. Beyond the fact that women participate in and seek the availability of treatment (however experimental) to save the fetus, little is known of the psychosocial consequences of interventions that are performed in the fetal interest. There are many circumstances where therapeutic interventions are not available to improve neonatal outcome, and termination of pregnancy has been offered as a therapeutic option. Over the last twenty years there has been some effort to explore the factors taken into consideration when the decision to terminate a pregnancy after prenatal diagnosis is made (Drugen et al. 1990, Pryde et al. 1992, Evans et al. 1996, Mansfield et al. 1999). However, the authors have omitted to describe the context within which such decisions are taken. The focus continues to be limited to factors that form the most proximate context to the index pregnancy, such as the actual diagnosis, maternal age, reproductive history, presence of other children, gestation of diagnosis, to mention but a few.

Whilst insightful analyses of the social impact of amniocentesis in America have challenged our beliefs regarding the relative benefits/risks of regularising particular forms of prenatal diagnosis (Katz Rothman 1988, Rapp 1999), it is difficult to disentangle the experiences of the women in these studies from the setting. The social conditions where women are making these decisions may be very different, making comparisons of women's experience across national boundaries difficult. For at least two decades, women in the United States and United Kingdom have been referred for genetic counselling and prenatal testing on the basis of maternal age, which may have little to do with individual choice. Unlike the aforementioned, there is no such uniformity in the approach to prenatal diagnosis in Ireland, and both the level of screening offered and available vary between maternity centres (Lalor et al. 2006a). One could suggest that perhaps women in Ireland are protected from the dilemmas that their counterparts in the USA and UK have experienced in this regard, but unfortunately it is never that simple. The absence of a uniform approach to prenatal diagnosis is problematic for many reasons; geographical location will limit a woman's access to services, standardised guidelines for training those providing services are not in place, audit of the accuracy of diagnosis, pregnancy management and outcome are not available, support structures for women taking part in screening programmes are not in place and evaluative studies of acceptability and experiences of screening by women who partake are not performed.

Murphy Lawless (1998) provides an extraordinary account of women's struggle for personal agency within the Irish maternity system and details the dominance obstetric science maintains over childbirth in Ireland. Given the propensity of obstetrics to intervene in childbirth in Irish maternity units, is it perhaps an anomaly that the emergence of prenatal diagnosis is a relatively new phenomenon, and its role in women's experience of maternity care is yet to emerge. Although the introduction of prenatal diagnosis and ultrasound in particular could not be traced accurately, its delayed appearance compared to other western nations may be due to the restrictive abortion laws that exist within the state, and accompanying professional recommendations that wherever screening for fetal abnormality is offered, termination of pregnancy should be an option available to parents (RCOG 1997). As discourse relating to women's encounters with the obstetric profession continues, the social impact of mass screening of unselected pregnancies needs to enter the debate. It is timely

that the extent to which women welcome obstetric care/interventions in the context of fetal anomaly diagnosis or, conversely, experience it as an expression of medical power is investigated. An exploration of the extent to which carrying a baby with a fetal abnormality problematises a pregnancy for the purposes of providing care, or whether the pregnancy remains within the construct of normality is beyond the scope of this review, but requires analysis. Ireland is situated on a frontier between a routine (for almost all) ultrasound examination being part of antenatal care and the introduction of rapidly developing technological advances in first trimester screening. Seldom are accounts available from women affected by prenatal diagnosis. The sensitive intersection of disability and reproductive rights combined with the intensity of the abortion debate in Ireland may have silenced women once again.

2.3 The social and legal context of abortion in Ireland

Abortion practices and services have been part of life for millennia, amidst varying degrees of approbation. However, women faced with pregnancies they no longer feel they can continue have chosen to access abortion services in the context of religious and legal sanction, and often at considerable risk (David 1981). Historically, the Catholic Church had a relatively tolerant approach to abortion; with Pope Gregory XIV stating in 1591 that termination of fetal life was not abortion if carried out prior to quickening (at approximately 116 days), and was not grounds for excommunication. This was church policy until 1869 until Pope Pius IX eliminated the distinction between quickening and non-quickening and required excommunications for abortion performed at any stage of pregnancy (Hurst 1989). It is surmised that this change in policy resulted due to a fall in the Catholic population in France and Italy and was motivated by a desire to control its followers in the context of its declining political power (Hurst 1989). However, church influence in state affairs appears to be ongoing even in 2006 as demonstrated by the European Commission's challenge of the legality of a draft treaty between Slovakia and the Vatican (Watt 2006). This draft treaty is designed to restrict medical treatments such as abortions and IVF and, according to the commission, suggests that Slovakia as a member of the EU may be violating its obligations in relation to fundamental rights. Although the Vatican has signed similar treaties with Italy, Latvia and Portugal on the grounds of religious conscientious

objection, these have been more limited. Smyth (2005) suggests that our political and national identity is constructed in traditional, patriarchal, familial and conservatively catholic terms. In Ireland, Church and State have been intertwined for many decades and the integration of catholic philosophy and state policy is well documented (Smyth 1992, Oaks 1999, 2003, Smyth 2005). The decision to have an abortion is complex and no less so after the diagnosis of fetal abnormality. Political and legal perspectives in Ireland add to the complexity of the debate. Access to services are complicated by legal mandates, financial costs that must be borne by the individual, travel concerns, gestation of the pregnancy, lack of support (professional and social), fear of the procedure ahead and, in addition, fear of harassment and or judgement. As termination of pregnancy remains unlawful in Ireland unless the life of the mother is threatened, conclusions could be drawn that its unavailability in the State is because it is inherently wrong. Yet morally a woman's choice to exercise these rights are often the subject of criticism (Mahon et al. 1998), leaving women to face difficult decisions in a context of secrets and lies.

There are many other elements that form the context within which decisions are made that require examination. Others have found that the structure and quality of family relationships in which women find themselves when making the decision are indisputably influential (Skjelstad et al. 1994, Tornbom et al. 1996). It has been previously identified that religiosity is also significant (Statham et al. 2001), and the centrality of religious and ethical beliefs to one's life carries greater weight than affiliation to a particular faith. However, influences of religious and ethical beliefs of the community/State on decision making after fetal anomaly diagnosis are relatively unexplored. The value attributed to persons in the community with disabilities may vary, and integration of personal and societal perspectives to decision making in this area poses a challenge to researchers to design studies that can take account of the complexity of our lives (Nardi 1983, Petchesky 1987). There are many arguments to support both sides of the abortion debate and the complexity within. For example the pro-choice position does not necessarily advocate a carte blanche approach to abortion, and the pro-life lobby may accept some circumstances where termination of pregnancy is acceptable. Some are of the view that abortion may be justified as self defence, if the harm by being pregnant is so great that the fetus may be aborted (Thompson 1971) whilst others contend the fetus is a person, with the rights attached to persons, and

afforded protection from the time of conception (Finnis 1973). Arguments in this sensitive public debate have often been advanced using emotive language and graphic representations of fetuses in the form of protest rallies or public demonstrations. Ireland is divided with the pro-choice and pro-life proponents polarised on either side of the abortion argument, with adversaries having an almost evangelical approach to portraying their views. The status of the unborn and legal position on termination of pregnancy in Ireland

2.4 The status of the unborn and legal position on termination of pregnancy in Ireland

Although abortion has been a fact of women's lives for centuries, control of women's reproductive rights in Ireland has been exercised with some austerity. In Ireland, these rights are governed by four legal frameworks- Irish Constitutional law (The Constitution), Criminal law in Ireland, European Community Law and the International Human Rights law. This is complicated further by the unique and individual approach of each system and the variation this allows for interpretation of issues in different courts (Reid 1992). This section will primarily discuss the lawfulness of abortion in Ireland under Criminal law and the Constitution in particular with reference to the relevance of European Community law and International Human Rights law on Article 40.3.3 (the right to life of the unborn) of the Constitution.

2.4.1. Abortion and Criminal law

The Offences Against the Person Act (OAPA) 1861 s.58 and s.59[2], enacted under British rule and passed into Irish law following independence in 1922, had the effect of making abortion a criminal offence in Ireland. This statute criminalises the provision of abortion by a medical practitioner and procurement of the procedure by the woman. The Act also includes the right to bodily integrity, and this right has been interpreted as incorporating a more specific right not to have one's health exposed to risk or danger by any unjustified act or omission of the State i.e. the absence of abortion services. Prior to the Act, abortion was a misdemeanour, and only if performed after "quickening", the time when fetal movements are felt by the mother. It is not known if the Act was aimed at protecting pregnant women or the unborn. The 1937 OAPA Act removed the distinction between quickening and non-quickening, and from that point s.58 and s.59 made it unlawful to procure or perform an abortion at any gestation, whether it is by the woman herself or any other person, and doing so became a criminal offence, liable to a life sentence. It is of interest to note it was rarely cited to criminalise women who had abortions, but was rigoursly enforced against those involved in procurement

[2] Offences Against the Person Act 1861.

(Kingston et al. 1997). The law in Northern Ireland will be discussed briefly for two reasons; some may perceive incorrectly that the British Abortion Act 1967 applies in this jurisdiction. Northern Ireland is also of particular interest as the assembly seems to have a similar unwillingness to the Oireachtas to clarify the uncertain ambit of the law in regard to abortion. The common law does not actually require an individual to intervene to save the life (or health) of the mother, unless a special relationship exists between both parties, such as the duty of care that arises in the doctor/patient relationship. One could then argue that an obligation to perform an abortion exists when the life of the mother is at risk, and such a possibility was indicated, obiter, by Macnaghten J. in R v Bourne[3] in Northern Ireland. The Bourne judgement found abortion to be lawful where the life or mental/physical health of the mother was at risk resulting in a situation whereby if a doctor did not intervene to save the life of the mother by performing an abortion (resulting in her death) could leave him/her self open to the charge of manslaughter. The Infant Life (Preservation Act) 1929 was extended from Britain to Northern Ireland in 1945, and introduced an exception to the law, permitting abortion if the mother's life was at risk. In Northern Ireland the 1861 OAPA Act has been clarified to a certain extent as regards time limits in section 25 of the Criminal Justice (Northern Ireland) Act 1945, and prohibits the killing of a child capable of being born alive. Ireland on the other hand has no such clarification. In 1984 the Northern Ireland Assembly voted against the introduction of the British Abortion Act 1967 and abortion remains a criminal offence under sections 58 and 59 in all cases except as above. This means that women in Northern Ireland are required to travel to access abortion services outside of the jurisdiction; however, this right to travel has never been challenged.

The timing of when the right to life is afforded to the unborn is not defined in Irish law, but rather assumed to be at the point of conception rather than implantation, as independent viability of the fetus was not dealt with in the *X Case* (Kingston et al. 1997). The use of certain methods of birth control aimed at preventing implantation rather than fertilization i.e. the morning after pill, intra-uterine contraceptive device, may therefore be considered a criminal offence under section 58. Under Irish law

[3] [1939] K.B. 687; [1938] 3 All E.R. 615.

(despite the right to freedom of religious belief guaranteed in Article 40.3) one would suppose that a right to conscientious objection is also guaranteed; however, this right does not prevail where the life of the mother is at risk as action must be taken to preserve the woman's constitutional right to life. Referral to a third party would only be available in the absence of an emergency situation. It remains a fact that in limited circumstances, abortions take place in hospitals in Ireland, although they are not characterised as such. Furthermore there does not appear to be national data available relating to abortion practice within the State (Kingston et al. 1997), although many have commented on the number of women travelling to the UK to access legal termination under the liberalised 1967 Abortion Act (O'Regan 2001). Guidelines issued by medical and nursing/midwifery professional bodies are vague and do not provide satisfactory guidance for professional practice. The theory of "double effect", supported by Catholicism also warrants consideration in relation to section 58 as it has practice implications for health professionals. The doctrine of double effect, although not exclusively Catholic in origin, refers to the justification of termination of fetal life "indirectly", for example an unavoidable secondary effect of salpingectomy or hysterectomy, whereby the procedure is performed to save the life of the woman i.e. in cases of ectopic pregnancy or uterine cancer. Under this doctrine the termination does not constitute a "direct" abortion and could probably be justified under section 58 and/or Article 40.3.3. The lawfulness of abortion in circumstances other than those outlined remains unclear, as the lawfulness of a particular abortion or contraceptive method has not, to date, come before the courts.

2.4.2. Abortion and the Constitution

Prior to the Eighth Amendment to the Constitution and insertion of Article 40.3.3 in 1983, the Irish Constitution did not contain any specific reference to abortion, and prior to 1983 no Irish court was directly called upon to decide this matter. However, the Irish Constitution and legislation continued to be influenced by Catholic doctrine. The Censorship of Publications Act 1946 introduced by the Catholic and socially conservative politicians that had emerged from the 1916 rising (Oaks 1999), which banned the circulation of information about and the sale of contraceptives, remained in force. One could question as to how the State can interfere in personal matters when

the right to privacy is enumerated as a personal right under Article 40.3 and as a right of the family in Article 41. Nonetheless, in a number of cases individual members of the Supreme Court indicated that abortion was constitutionally prohibited and the right to privacy (within marriage) did not encompass a right to an abortion (Kingston et al. 1997). Perhaps the most significant case to test the right to privacy is *Mc Gee v. Attorney General* (1974)[4]. In *Mc Gee*, the plaintiff, a married woman, sought access to contraception on the grounds that another pregnancy could be life threatening. This is particularly significant as in the USA the landmark *Roe v. Wade*[5] case recognised a full constitutional right to abortion on the grounds of constitutional privacy – protection of individuals from State intrusion into private decisions. In contrast to *Roe v. Wade*, Walsh J., in *Mc Gee* held that the right to (marital) privacy in Article 41 was held by her, irrespective of any threat to health. However, he pointed out that his judgement was in relation to contraception and held that:

"any action on the part of either the husband or the wife or of the State to limit family sizes by endangering or destroying human life must necessarily not only be an offence against the common good but also against the guaranteed rights of the human life in question."[6]

If it is assumed that fetal life is human life it could be interpreted that this judgement rejected the possibility of a constitutional right to abortion. However, Griffin J. in his judgement of *Mc Gee* held that the plaintiff's claim primarily rested on Article 40.3 and the provision of contraceptives did not extend to the right to access to abortifacients,[7] extending the right to married couples to import and use contraceptives only. The criminal prohibition of abortion was re-affirmed subsequently in several other cases, *G v. An Bord Uchtála*[8] and *Norris v. Attorney General.*[9] During the 1970s various groups established a network of services for women supplying information on contraception, pregnancy counselling and abortion services available legally outside of Ireland

[4] Mc Gee v. Attorney General [1974] I.R. 284
[5] Roe v. Wade 410 U.S. 113 (1973)
[6] Above, n.3 at 312.
[7] *ibid.* at 335.
[8] G v. An Bord Uchtála [1980] I.R. 32.
[9] Norris v. Attorney General [1984] I.R. 36.

(Kingston et al. 1997). Despite the maxima reiterated by the Courts, the anti-abortion lobby in Ireland wished to ensure against any possibility of an introduction into Irish law, as had happened in the U.S in *Roe v. Wade*.[10] In addition to the aforementioned dicta, the anti-abortion pressure group "Pro-Life Amendment Campaign" (PLAC), successfully lobbied for constitutional change. Graphic fetal images were used to bolster the concept of fetal personhood, calling for the fetus to be awarded legal protection from the State. Oaks (1999 p180) contends that the pro-life use of fetal images created a "natural association between an anti-abortion stance and an Irish national identity". In September 1983 the Constitution (Government of Ireland 1999) and the Eighth Amendment was passed adding the following clause as Article 40.3.3:

"The State acknowledges the right to life of the unborn and, with due regard to the equal right to life of the mother, guarantees in it's laws to respect and as far as is practicable, by it's laws to defend and vindicate that right."

This amendment created the circumstance where women seeking to terminate their pregnancy would have to do so abroad, uncertain of their legal position in doing so and without relevant information, financial or social support (Smyth 1992). It is also worth noting that Eighth Amendment does not define the term 'unborn', yet the date from which Article 40.3.3 provides protection is of extreme importance. Hamilton P[11] indicated that in criminal law the right to life of the unborn is protected from conception, however it cannot be assumed that the Supreme Court share this assumption. Following insertion of the Eighth Amendment several cases came before the courts challenging its interpretation. From 1986-1991 the Society for the Protection of the Unborn Child (SPUC) took a series of cases to the High Court *Attorney General (SPUC, (Ireland) Ltd.) v. Open Door Counselling Ltd and Dublin Well Woman Clinic Ltd,*[12] *S.P.U.C. v. Coogan*[13] and *S.P.U.C. v. Grogan*[14] that largely dealt with the provision of information on where and how to access abortion services outside the jurisdiction.

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[10] Above n.4
[11] Above n.8.
[12] Attorney General (SPUC, (Ireland) Ltd.) v. Open Door Counselling Ltd and Dublin Well Woman Clinic Ltd. [1988] I.R. 593. hereinafter referred to as SPUC
[13] S.P.U.C. v. Coogan [1989] I.R. 734.
[14] S.P.U.C. v. Grogan [1989] I.R. 753. hereinafter referred to as Grogan No. 1.

Hamilton P.[15] declared that the provision of such information was in breach of Article 40.3.3, as it undermined the right to life of the 'unborn.' The Supreme Court appeal confirmed his decision in 1988, and held the rights to privacy, freedom of expression and travel to be inferior to the constitutional protection afforded to the fetus, expressing concern that the terms of Article 40.3.3 amounted to an absolute ban not just on abortion but on information regarding services available in other jurisdictions.

In 1992 the case of the *Attorney General v. X*[16] came within the public domain, and caused unprecedented public outrage. The abortion debate repositioned itself from an interest in fetal rights to concern for the wellbeing of a survivor of sexual assault. *X* was a 14 year old girl, pregnant as a result of unlawful carnal knowledge, one of a series of sexual offences of which she was a victim, who was planning to travel to the UK to procure an abortion. Her parents contacted the Gardaí within the context of the criminal proceedings against the assailant, notifying them of their intention to travel and enquiring if forensic testing of the fetal material determining paternity was possible in England. In seeking to ascertain if such evidence would be admissible a legal opinion was sought from the Director of Public Prosecutions (DPP), who advised such evidence was inadmissible and informed the Attorney General (AG) of the matter. The AG applied for a High Court order restraining the child and her parents from leaving the jurisdiction for nine months and from procuring/arranging an abortion outside the State. In the High Court Costello J. granted an injunction preventing *X* from leaving Ireland to have an abortion in England, effectively ensuring that all women could be interned within the State on the basis that they might go abroad to seek an abortion. The family, already in England, returned and sought to defend their right to travel to access that which is lawful elsewhere, as they were uncertain of the legal retribution that might await them if they stayed and proceeded as planned. There was significant public dissent on what appeared to be a judgement favouring the right to life of the fetus over the right to life of the mother. *X* had stated her intention to commit suicide if the pregnancy continued, and was examined by an experienced clinical psychologist who formed the opinion that the psychological damage that could occur if she continued the

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[15] Above, n.1, at 597 and 617.
[16] ibid

pregnancy would be "considerable" and the damage to her mental health would be "devastating".[17]

The Supreme Court overturned the ruling two weeks later to allow her to go, ruling that:

"if it is established that there is a real and substantial risk to the life, as distinct from the health, of the mother, which can only be avoided by the termination of her pregnancy, such termination is permissible."[18]

Having decided that although the right to life in relation to the mother and the fetus are deemed equal, "the mother's right may be superior to the right to life of the unborn because of her other constitutional rights and duties."[19] Here, Finlay CJ held that there was a real and substantial risk of suicide if the pregnancy continued; thus the termination was permissible, even in Ireland. However, where no such risk existed, both information and possibly travel could be prevented in the interest of safeguarding the right to life of the unborn. Post appeal, she was subsequently granted right to leave the country, in part, because of the Irish Government's internationally tainted image (Murphy Lawless 1993) as it hosted the presidency of the EU. It has been suggested by Binchy that a consequence of the *X* case is that Irish law permits termination up to the completion of childbirth, and it would appear that at present the Supreme Court would have the say in when the right to life begins, which was the antithesis to the intent of the pro-life movement. This subsequently led to lobby groups seeking an additional amendment to the constitution that would clarify the eighth amendment post *X*. The Oireachtas passed three bills to amend the Constitution, the aim of the first being to reverse the Supreme Court's decision that suicide posed a risk to the life of the mother, the other two to address the right to travel and information regarding services lawfully available in other states. This resulted in three referenda being put to the people:

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[17] *ibid* at 8.
[18] *ibid* at 8.
[19] *ibid* at 35.

1. The 12th Amendment proposed that it would be lawful to perform a termination of pregnancy if it was necessary to save the life, as distinct from the health, of the mother (excluding cases of suicide):

Rejected, meaning the *X* case ruling regarding suicide remains valid.

2. The 13th Amendment proposed the travel between the State and another State would not be limited:

Approved.

3. The 14th Amendment proposed the freedom to provide information regarding services available in another jurisdiction:

Approved.

The Twelfth Amendment was opposed by pro-choice groups who wished at a minimum to retain the lawfulness of abortion in circumstances as those addressed in *X*. It was also opposed by Pro-Life groups, who felt it did not go far enough to ensure that abortion would not be lawful in any circumstance unless it was "an unsought side-effect of medical treatment necessary to save the life of the mother". Without the enactment of the Thirteenth Amendment, it would have been unlawful for women to leave the State in order to procure an abortion unless their life was at risk. To implement the Fourteenth Amendment The Regulation of Information (Services outside the State for Termination of Pregnancies) Act 1995[20] was enacted by the Supreme Court. The Act sets out the circumstances in which information can be provided by a doctor or appropriate agency and decrees that such information regarding abortion services outside the State can only be given in the context of full and unbiased counselling, without any advocacy of abortion, whereby direct referral to any such service is absolutely prohibited; however, during consideration by the Supreme Court several issues were raised. Denham J. referred to the fact that abortion is lawful to protect the life of the mother with a concurrent need to provide such women with information. Keane J. raised the issue of whether abortion would remain legal to protect the life (a right now established in *X*) of the mother if the pregnancy was at such an advanced stage as to be independently viable, and in addition brought up the possibility that

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[20] Article 26 and The Regulation of Information (Services Outside the State for the Termination of Pregnancy) Bill 1995 [1995] 1 I.R. 1 (The Information Bill).

abortion could also be lawful in cases of rape and incest, indicating that the law in this area is not wholly developed, leaving health professionals in a difficult position when dealing with women whose lives may be put at risk by continuing the pregnancy. This is further complicated by the presence of both Medical Council guidelines for medical staff and An Bord Altranais guidelines for nursing and midwifery staff. The Medical Council guidelines are ambiguous in relation to whether a medical practitioner would be subject to a fitness to practice hearing if they either gave or with-held beneficial treatment to a woman on the basis of her being pregnant at the time. Whereas An Bord Altranais guidelines focus on the nurse/midwife's responsibility to preserve life, born and unborn, and are unclear as to how this is to be interpreted in practice. However, it would seem to be the case (as interpreted by Mc Dowell S.C. in *A Ward* case) that professional bodies cannot apply punitive sanctions to its members who have operated within the framework of constitutional law (O'Morain 1995). The law in Ireland in relation to abortion remains uncertain and the Constitution does not lay down criteria as to when termination of pregnancy is lawful, with a concurrent absence of legislation to clarify the situation. This lack of clarity in the law may mean that Ireland is in breach of international obligations to ensure respect for private life and family life under the European Convention on Human Rights, Article 8. It could be interpreted that any interference with a woman's private life in Ireland is in 'occurrence with the law' of the state for the purposes of the Convention (Kingston et al. 1997 p 28). However, the Convention also requires that domestic law be sufficiently clear to allow an individual to ascertain if his/her conduct is in agreement with same, allowing for a case to be made in respect of this jurisdiction.

As a result of the *X Case*, and after ratification of the Information Bill 1995, the Constitutional Review Group (1996) in their report suggested that legislation should be enacted to define specific circumstances whereby abortion would be lawful (to include determining when the right to life is afforded to the unborn), redressing the current legislative void. This recommendation was rejected by the anti-abortion campaign, who continued to seek a referendum on the outlawing of abortion absolutely. In 1998 the *C Case* entered the public domain. Similar to the *X Case*, *C*, a 13 year old girl, pregnant as a result of rape and in the care of the Eastern Health Board was the subject of

proceedings in the District Court as she sought permission to leave the state for the purposes of availing of a lawful abortion in England. The original proceedings related not to the abortion itself but to her leaving the jurisdiction while subject to a care order. That matter became more complex when her father, originally supportive of her decision, reversed his decision after the influence of a pro-life lobby group. Youth Defence (a pro-life group) established a fund to provide financial support for legal counsel for the parents, and material support for mother and baby after delivery (Brennock, 1997). However the case proceeded and *C* was represented by two lawyers, one for her body and one to represent her fetus. The separation of the fetus from the pregnant mother was taken to the extreme and considered to be "outrageous" (Bacik in Humphreys, 1997). In the High Court, Geoghegan J. ruled that as Miss 'C' was likely to take her own life if forced to continue with the pregnancy, and that she was entitled to an abortion in Ireland by virtue of the Supreme Court judgement in the 1992 *X Case*. However, as an abortion in this case would not be unconstitutional within this State then she could not leave the State in order to have it. This raised a new issue from *X*, in that a person subject to a care order, not at risk of suicide, may be prevented from leaving the jurisdiction to access abortion services outside the State. This judgement highlighted the difficulty left by the *X Case* and subsequent failure to enact legislation determining the circumstances in which abortion would be lawful within the State. At this point the government responded to the *C Case* by establishing an 'Inter-Departmental Working Group on Abortion' supervised by a cabinet sub-committee resulting in a Green paper on abortion published in September 1999.

Seven possible options were outlined as follows (Department of An Taoiseach 1999):

1. Absolute Constitutional Ban on Abortion.
2. Amendment of the Constitutional Provisions so as to restrict the Application of the X Case.
3. Retention of the Status quo.
4. Retention of the Constitutional Status quo with Legislative Restatement of the Prohibition on Abortion.
5. Legislation to regulate Abortion in circumstances defined in the *X Case*.

6. Reversion to the pre-1983 position.

7. Permitting Abortion on grounds beyond those specified in the *X Case*:

a) Risk to Physical/Mental Health of Mother

b) Abortion for Women Pregnant as a result of Rape or Incest

c) Congenital Malformations

d) Abortion for Economic or Social Reasons

e) Abortion on Request.

The masters of the Dublin maternity hospitals spoke of their perceived lack of legal protection for current medical intervention and gave their support to the referendum in particular the inclusion of the situation of lethal fetal anomaly as a criterion for direct termination of pregnancy (McCafferty 2002). The Twenty-Fifth Amendment of the Constitution (Protection of Human Life in Pregnancy Bill) 2002 was proposed and defeated. The consequences are that the *X Case* judgment remains, and the precise conditions within which a pregnancy can be terminated within the law remain undefined, leaving health professionals in the unenviable position of providing care in the absence of a legislative framework. In Ireland, the conflict lies between the moral and legal right of the woman to make reproductive choices as protected within the European Convention for the Protection of Human Rights[21] and Fundamental Freedoms [European Convention] (and ratified by Ireland) and the right to life of the unborn enshrined in the Article 40.3.3 of the Constitution (Government of Ireland 1999). Although, in general, Ireland has ratified the European Convention, Article 29.3 of the Constitution states that "Ireland accepts the generally recognised principles of international law as its rule of conduct in its relations with other States" (Government of Ireland 1999). Ireland's legal system, derived from the period of British rule prior to independence in 1921, is a system of common law. Like other common-law countries, Ireland has a dualist system under which international agreements to which Ireland becomes a party are not automatically incorporated into domestic law. Article 29.6 of the Constitution of Ireland provides that "No international agreement shall be part of the domestic law of the State save as may be determined by the Oireachtas"

[21] For full text see: http://www.hrcr.org/docs/Eur_Convention/euroconv.html.

(Government of Ireland 1999). This provision has been interpreted as precluding the Irish courts from giving effect to an international agreement, such as the European Convention, if it is contrary to domestic law or grants rights or imposes obligations additional to those of domestic law. This position was strenuously maintained in relation to dissolution of marriage until a referendum to the Constitution in 1997. At present, Ireland's restrictive policy on abortion in the case of fetal abnormality is inconsistent with almost all other member states, as the *X Case* did not allow for areas such as rape, incest, fetal anomaly or serious threat to the wellbeing of the mother to be considered. This position has resulted in incongruence between a citizen's rights within the Irish constitution and their human rights within the European Union.

2.4.3. Abortion and European Community law

The purpose of this section is to provide an overview of the provision and case-laws on abortion in the European Community that may be of relevance to the right to life of the unborn within Ireland as an aspect of the Constitution. Specific reference however will be made to the situation in the United Kingdom (to exclude Northern Ireland), as due to the geographical proximity of our islands, England and Wales are predominantly where women domiciled in Ireland access abortion services.[22] Between January 1980 and December 2004, at least 117,673 women travelled from Ireland for abortion services in Britain. Although the statistics are stratified by age, there are no data on the indication for termination. Therefore the number of women terminating a pregnancy due to fetal anomaly is unknown. Abortion law varies amongst European Union member states with Ireland only permitting termination of pregnancy to save the woman's life (including risk from suicide). Abortion on demand in the first trimester or later is permitted in Austria, Belgium, Czech Republic, Denmark, Estonia, France, Germany, Greece, Hungary, Italy, Latvia, Lithuania, Netherlands, Slovakia, Slovenia, and Sweden. Abortion is allowed for health, economic and social reasons in Finland and the United Kingdom, and for health reasons or in cases of rape, incest or fetal impairment in Cyprus, Luxembourg, Poland, Portugal and Spain. Abortion is banned in all circumstances in Malta. The British Abortion Act 1967 (not applicable in Northern

[22] For further detail see: http://www.ifpa.ie/abortion/iabst.html.

Ireland) was introduced to ensure women's safety and to reduce deaths from back street abortions. The act exempts abortionists from prosecution if carried out for a specific health reason. This Act permits abortion up to 24 weeks gestation (reduced from 28 weeks in 1990 by the Human Fertilization and Embryology Act) once two doctors confirm/certify that a risk exists to the women's life or mental or physical health, or to her existing children, and that this risk is greater that that posed by an abortion. Where substantial risk to the woman's life exists or there is a fetal abnormality that would result in the child being born with such physical/mental abnormalities as to be seriously handicapped the restriction on a gestational time limit does not apply. The definition of "seriously handicapped" has been challenged in the British courts but as yet is open to interpretation. Prior to the *X Case* the Irish Government entered Protocol No 17 into the Maastricht Treaty in 1991 ensuring that that treaty or any treaties involving the European Communities (EC) will not affect Article 40.3.3, removing the issue from the jurisdiction of EC law. The purpose was to ensure that abortion could not become available within the State through membership of the European Community, effectively maintaining the current status on the prohibition of abortion services in Ireland. Although attempts to bring the laws of E.C Member States into line have never been made, concern was expressed that a move for such harmonisation might occur in the future (Binchy 1992), which could give priority to the rights of the mother. The Commission has taken the view that abortion has no influence on the development of an internal market and as such regulation is the remit of individual States. Nevertheless, this does not apply to the free movement of persons, labour and goods (which could include the RU486 abortion pill). Both the Eighth Amendment and insertion of this Protocol has effectively denied Irish women recourse to European Community law to overrule the Irish Constitution on abortion.

2.4.4. *Abortion and European Human Rights law*

The law in Ireland relating to abortion is vague and previous judgments in the *X Case* and *Grogan No. 4* specifically indicate that the boundaries of the law are uncertain. This lack of clarity may mean that Ireland is in breach of its international obligations, *inter alia*, under the European Convention for Human Rights. Article 8 of the convention guarantees the right to respect for private and family life free from interference by a

public authority (with some exceptions) except as in accordance with the law. However, it could be argued that the law in relation to abortion in Ireland currently lacks the quality of "law" within the meaning of the convention. Domestic law should be sufficiently clear for a citizen to interpret if their conduct is in accordance therewith (Kingston et al. 1997 p28), and to meet this requirement, clarification for citizens and health professionals on the grounds under which abortion is permissible, the means of establishing those grounds have been met and time limits are at the very least in need of a legislative framework. Abortion was last on the political agenda in 2003 when the Twenty Fifth Amendment was defeated. However, 2006 appears to be seeing the re-emergence of public debate as four high profile applications have been lodged in the European Court (ECHR) in the past year. Currently *Cases A, B, C* and *D* are suing the government on the basis of human rights violations at having to travel to the UK for abortion services. However, the most relevant case in the context of this thesis is that of the *D Case*. *D*, an Irish woman, took her case on the basis of being "forced" to carry a baby with a lethal fetal anomaly to term (2005). At issue is whether the European Convention on Human Rights requires states to legalize abortion in cases of fetal impairment and permit providers to give their patients full information and referrals relating to abortion., who decided in 2002 to have an abortion after receiving a diagnosis of lethal fetal anomaly, argued that restrictive abortion laws—especially those that prohibit abortion in cases of fetal impairment—and barriers to abortion-related referrals (absolutely prohibited in the Information Bill 1995), violate women's human rights. The woman was pregnant with twins, but her doctors told her that one fetus had stopped developing entirely and that the other had developed Edwards' Syndrome. As *D's* life was not threatened, she was forced to travel to Britain and make her own arrangements to have the procedure.[23]

To synopsize, prior to the Eighth Amendment, abortion was criminalised under common law in s58 and s59 of the OAPA 1861. In 1983 the Constitution was amended to give an equal right to life to the mother and the unborn in Article 40.3.3. This right became somewhat blurred in 1992 by the *X Case*, in which a 14 year old girl became

[23] In August 2006, a decision to hear the case was rejected. The repercussions resulting from this decision will be discussed in section 10.1.3.

pregnant as a result of rape and was refused leave to travel to the UK for an abortion by High Court, in a judgement stating that when balancing the equal right to life of the mother and the fetus, the risk of loss of life to the mother through suicide is less than the certainty that the fetus would lose its life if the mother was permitted to travel to access abortion services outside of the state. The Supreme Court judgement allowed the appeal which changed the legal situation, and stated that abortion is currently legal in Ireland if there is a real and substantial threat to the life of the mother including the case of suicide, concluding that the mother's life is more important. However, legislation to define the circumstances in which abortion is legal in Ireland in yet to be drafted or enacted, consequently the country's position in this regard remains unclear. Anti-abortion groups in 1992 and 2002 tried and failed to have suicide precluded as a justification for abortion in two separate referenda, and there appears to be a distinct lack of political will to tackle the issue again.[24]-[25] With that said, public debate has re-ignited as reports of four cases against the State are being brought to the ECHR, and the claimants, *A,B,C* and *D* were awaiting a response to their applications.[26] It has been reported that legal experts are of the opinion that the women are unlikely to succeed in Europe (McDonald 2005), as their cases have not been heard in Irish courts, and based on past maxima the ECHR has referred issues of abortion back to national governments to decide.[27] The Irish Human Rights Commission, when asked even if *D* was successful in her challenge would Irish law change, suggested that Ireland can take years to address any concerns that might arise from the European court, in effect allowing the status quo to remain (Personal communication). In addition to these cases in ECHR, it has also been revealed that the State has funded a teenage girl's expenses to travel abroad for a termination in 2005 (Connolly 2006). Although details of the case remain sketchy the Health Service Executive (HSE) has confirmed the teenager had an abortion in Britain, suggesting that there remains an urgent need to legislate for the legal situation

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[24] Rory Brady (AG) Speaking with Eamonn Dunphy on the 20th June 2002 on "The Last Word", Today FM. Radio, stating there is no public appetite for the area to be re-visited for quite some time.

[25] Dearbhail McDonald reports that Bertie Aherne (Taoiseach) confirmed that the government had no intention of tackling the issue before the next general election on 14th August 2005, The Sunday Times.

[26] *ibid* Neville Cox a barrister, says "They (A,B,C, and D) haven't a hope...The European Court will not touch this stuff" p13.

[27] *A,B and C* are still pending, *D* was refused a hearing as predicted.

surrounding abortion as a result of the *X Case*, whether there is a political appetite to do so or not.

2.5 The concepts of autonomy and bodily integrity within pregnancy

The value of autonomy is prevalent in medical law and ethics literature as it underpins the patient's[28] moral interests in self-determination and bodily integrity (Scott 2002). The literature on autonomy is vast and its many interpretations are wide and varied. Clarification of the term autonomy within this thesis will be made to elucidate what is meant when the pregnant woman is referred to as acting autonomously. The concept of bodily integrity is introduced as an aspect of self-determination rather than in its legal sense. Autonomy has been described by many philosophers, with many varied interpretations. Kant associated autonomy with the concept of will, attributed to humans due to their rationality (Rawls 1980), whereas Dworkin sees autonomy as an equivalent of liberty to self-rule, and identifies it with the qualities of self assertion, critical reflection and freedom from obligation (Swift and Mulhall 1996). Philosophers such as Rawls and Dworkin also acknowledge the role of society in our capacity for self-determination; however, society is required to provide meaningful choices so that we can exercise our ability to choose between them. Autonomy has also been described in terms of being rights-based. Raz (1986), who does not hold with this perspective, conceives autonomy as an ultimate value central to wellbeing. He suggests that in order to be able to lead an autonomous life one must be able to choose from an "adequate" range of options (Raz 1986 p373).

Feminist work describes autonomy in a way that acknowledges the social situation of individuals and in particular provides a more detailed critique of the notion of agency, demonstrating autonomy as a feature of "agents who are emotional, embodied, desiring, creative, and feeling as well as rational, creatures" (Mackenzie and Stoljar 2000). In the medical context, this implies that a woman is capable of determining to reject or accept care, seek a second medical opinion etc., and the combination of self-determination and

[28] Patient is defined as a recipient of healthcare, hereinafter referred to as "woman", engaging with maternity services.

autonomy capture the importance of making decisions for oneself (Scott 2002). Within the context of this thesis, what is important is that to act autonomously, a woman must be able to choose to accept or reject treatment "with an absence of undue coercion or manipulation by others" (Friedman 2000 p40). However, the data show that a combination of Irish law, societal attitudes and factors regarding the provision of maternity care can militate against this. In the context of medical care, and associated with autonomy, is the concept of bodily integrity (legally protected in the OAPA 1861). This is broadly described as being able to decide what happens in or to one's body (Scott 2002). In matters of pregnancy, Cohen (1997) introduces the concept of privacy and suggests that bodily integrity is central to one's identity. Mackenzie develops this notion further saying that although pregnancy is a passive biological process, it is judged by social meanings and by the manner in which the woman's decision-making fits this social context. Decision-making needs to be done in a way that is compatible with her future moral relationship with her fetus, as the physical relationship between the two if the pregnancy continues, results in a separate being for whom the woman becomes morally responsible (Mackenzie 1992). This implies that the concept is richer than its legal term of being free from bodily invasions, and in pregnancy, extends to include the emotional aspect associated with decision-making with regard to the pregnancy. Within the context of the Constitution (Government of Ireland 1999) if the fetus has the right to life, then perhaps the pregnant woman has a duty to protect that life. Alternatively if the woman has a right to self-determination, then that right should not be interfered with. Bentham's theory of legal rights is a useful structure for defining rights and duties in pregnancy, as according to the theory X[29] has a right if Y[30] has a duty to protect that right which is in X's interest (Waldron 1984). However, this legal theory based on interest means that identification of the interest forms the basis of the content of the duty. It does not explicitly address if X is a fetus with an anomaly, whether it is it in X's best interest to be born, and if Y has a duty to guarantee this, and consequently does little to elucidate the moral concept of duty. Hart's Choice Theory approaches rights and duties from an alternative perspective (Hart 1984). Hart suggests that if Y has a duty to X, then X can determine how Y

[29] X will represent the fetus for the purpose of illustration
[30] Y will represent the mother for the purpose of illustration

should act, therefore limiting Y's freedom of choice and perhaps with benefit only to X and possibly negative consequences for the woman. In Hart's theory he suggests that one can only have rights if one has the power to choose i.e. autonomous persons, and therefore rights could not be held by a fetus, the antithesis to the Constitution (Government of Ireland 1999). While Bentham's theory of interest could be said to serve to benefit the fetus, Hart's theory of choice could be said to favour self-determination for the woman. Such contrasting views highlight the opposing values attached to rights and duties within moral theories, leading to the classification of theories on the basis of whether they are rights, duty or goal based (Dworkin 1978). However the pertinent question seems to be: what is morally required of a woman who is pregnant with regard to her fetus?

2.6 The moral status of the fetus

The concept of a pregnant woman representing two "patients" is not new and the point at which a fetus in moral rather than legal terms is considered a future child or indeed is attributed with personhood is widely debated and highly relevant within a rights versus duties debate. As abortion relates to fetal death, the fetus's moral status is of significant concern, as after a predetermined period of time a human being will be born, and "the weight of that future child's interests need to be determined" (Scott 2002 p25). Although the concept of maternal-fetal conflict implies that there are two patients with competing interests, this is predominantly manifested in two ways; refusing treatment in the fetal interest or causing harm to the fetus. There are five key opinions regarding the moral status of the fetus, each arising from the abortion debate (Scott 2002), and concentrating predominantly on whether the fetus is a person (with rights). One could suggest that no single theory is sufficiently comprehensive to underpin all aspects of the debate. An overview of these arguments is fundamental to understanding the positions taken by those on both sides of the debate, as it often influences aspects of abortion law. These arguments will be presented briefly; however, a detailed critique of these positions can be found in Scott (2002).

2.6.1 Human species argument

There are two fundamentally different positions within this argument. Noonan (1970) contends that a human being exists from the moment of conception because at that point the genetic code for a new human being is established. Being a member of the human species does not require the possession of characteristics such as consciousness, reasoning and the ability to communicate. However, others present a more moderate view, suggesting that third trimester fetuses should be afforded moral and legal status as persons because of their participation in social interaction with others (Strong and Anderson 1989). Gillon (1989) disagrees with both perspectives, suggesting that the point at which a fetus can become independent from the mother's body i.e. viability, is the point at which the fetus should be awarded higher moral weight. This is not to say the fetus would not require medical or technological support, but would rather no longer require support from the mother's body exclusively. With these theories either the fetus has rights from conception or gradually acquires rights as gestation advances, implying a concurrent diminution of the interests of the mother.

2.6.2 Personhood argument

The original exponent of the personhood argument, Mary Ann Warren (1973) expressed the view that in order to resolve the issue of whether the fetus should have full and equal moral rights we must define the moral community and decide if the fetus is a member of that community. Warren would contend a moral community is made up of persons, the most obvious criteria of personhood being consciousness, rationality and agency, an ability to communicate and self-consciousness. Possession of all these characteristics is not required; however, she argues that the fetus is in possession of none, and consequently is not a person, consequently viability does not feature in this argument. In addition the fetus can have no moral claim to treatment which would imply the woman has no moral duty towards fetal wellbeing.

2.6.3 Interest view and relevance of sentience

The third argument distinguishes between two senses- the first being that what is good for one is said to be in one's interest. In relation to the fetus who cannot consciously act

or take an interest in its own wellbeing, the second sense of sentience is introduced i.e. it is arguable that the fetus has an interest in the context of whether it feels pleasure or pain (Steinbock 1992). With advances in technology, scientific evidence has emerged to show fetuses sucking their thumbs, presumably a pleasurable act for the infant. The complex issue of fetal pain has been explored, and although a reliable measurement scale is unavailable, anatomical and physiological evidence demonstrates fetal capacity to show distress from 15 weeks and to feel pain from 26 weeks (and possibly as early as 20 weeks) in response to intrauterine interventions (Glover and Fisk 1999). Practically, this raises the issue of administering analgesia in the fetal interest that may have adverse effects for the mother. Morally, Steinbock (1992) contends that the development of fetal sentience is accompanied by a moral duty in others to support its preservation. Whilst Warren (1973) concurs that sentience is relevant to the ascription of rights, she says the absence of fetal personhood does not mean the woman does not a have a duty to the developing fetus i.e. protection from pain, and would suggest that the development of sentience weakens the mother's right to self-determination, a factor applied to the legal regulation of abortion. However, as the fetus resides in its mother, this does not give licence to anyone to override the woman's rights to protect those of the fetus (Warren 1973).

2.6.4 Argument based on potential

The argument from potential typifies the traditional Catholic view of the fetus by combining the potential and human species arguments. Noonan (1970) and Finnis (1973) both emphasise that the fetus's rights are equal to that of a born individual with conception as the crucial moment marking the creation of a new individual. Both contend that it is not possible to look backwards from the point of maturity in order to ascribe fetal rights at a specific time, as the zygote is a potential person. Critiques of this position would say that a potential person does not have actual rights, however Feinberg (1979) suggests a potential person is of value, deserving of our consideration, suggesting that it may be owed duties.

2.6.5 Gradualist approach

This approach is a development of the potential argument, through ascribing rights as the fetus develops closer to its full potential. The argument develops with fetal maturity, stating that the fetus's personhood develops with maturity, increasing the necessity for a compelling countervailing reason for abortion as gestation advances.

Based on the positions outlined above, restrictions on abortion can range from total prohibition to being acceptable up the delivery of a live infant. The intersection of the moral status of the fetus and state law will ultimately control legal access to abortion services at a national level. Although the OAPA 1861 affords the right to bodily integrity to women, challenges to the constitution on varying grounds have confirmed the State's obligation to protect the right to life of the unborn as outlined in many *dicta*.

2.7 Summary

Many authors have expressed concern regarding the separation of mother and fetus in relation to the consequent impact this may have on women's reproductive rights. While women's groups and feminist scholars and authors address the controversial issues involved, the influence of the Church in domestic law and politics remains. The Church's traditional view of abortion can be traced through history, demonstrating a move from a relatively tolerant approach to abortion to outright condemnation, as a means to hold on to political power, an endeavour to which it remains committed. It has been suggested that considerable social and economic change is altering the "character" of Ireland, its distinctiveness as a "devoutly Roman Catholic country" is fading... [and] far fewer people are regular Church-goers" (Oaks 2003 p1975). Although religiosity rather than affiliation to a particular faith has been shown to influence decision making regarding termination, the extent to which a traditional pro-life culture impacts on that decision remains to be examined. One thing is clear, all attempts to date to liberalise abortion law in Ireland have failed, forcing women to seek abortion services outside the state, irrespective of their circumstances. Technology, and in particular ultrasound, has contributed to raising the moral status of the fetus to person, as images

display the fetus as a unique entity, separate from the pregnant woman. Hyde's (1996 p169) analysis of unmarried women's experiences of pregnancy in Ireland found that although these women viewed careers as important they were "unable to pursue the abortion option because they could not obviate their construction of the foetus as a person". Whether this perspective has been altered in the intervening years, or if the complication of fetal anomaly has a role to play in the construction of fetal identity by women who are affected remains to be seen. The moral status of the fetus seems relatively absent from clinician accounts of decision making in the context of prenatal diagnosis internationally. Although the masters of the Dublin maternity hospitals gave their support to the inclusion of lethal fetal anomaly as a criterion for direct termination of pregnancy, their primary concern related to a lack of legal protection for medical intervention, rather than an interest in the moral status of the fetus or the mother's right to choose. Prenatal screening in Ireland is neither policy nor prohibited on the grounds that it might benefit/injure the mother or the fetus. Although women have become consumers of prenatal screening technologies, an extensive literature search failed to identify the agency of women in its development. The limits of non-directive counselling have been addressed, with concerns that personal views may unduly influence a couple to choose to interrupt the pregnancy. However, women's experiences of counselling after an adverse diagnosis in the Irish maternity services are undocumented. Although information is available on the number of women leaving the State to access abortion services, predominantly in Britain, the data are not stratified in any way. Consequently, the number of women travelling to the UK after an adverse diagnosis is unrecorded. Although there is national and international scholarly inquiry into the nature of the maternal-fetal relationship, clinical research has been limited to identification of factors associated with decision making after an adverse diagnosis; however, the social impact of routine prenatal screening in an Irish context remains to be explored.

3 Epistemology, ontology and selecting a methodology

3.1 Introduction

This chapter explores a number of epistemological and methodological issues that were considered during the planning and conduct of the research and are intended to provide the context and process of undertaking the study. The ways in which we 'know' or how knowledge is generated are considered with reference to how they influenced the selection of the research method. The complex historical and political terrain of scientific research is characterised by tensions and contradictions in terms of research styles, with methods competing for the honour of having the greatest power to uncover the truth and provide solutions to problems. The emergence and divergence of two broad epistemological positions, positivist and interpretative, have resulted in the equivalent of 'paradigm wars' (Oakley 2000 p23) resulting in positivists' claims that naturalistic enquiry is unscientific, with counterclaims from social scientists that the experimental model is ill-suited to examining complex and dynamic contexts (Lincoln and Cannella 2004). At the root of the conflict between paradigms are contrasting beliefs of how it is we know what we know and the consequent judgement on the authenticity of the evidence each particular inquiry can produce.

An ongoing dialogue exists throughout the methodological literature regarding knowledge construction. Historical analysis of the development of research methods often refer to the astronomer Aristotle as a key point in the process. Aristotelian philosophy and logic were taught in most European universities from the 11th to 15th century. However, most critically this philosophy was concerned with the use of human reason to understand Christian teaching, using observation and experience to support theism. Aristotelian 'theories' were based entirely upon observation, he did not perform any experiments to confirm his contentions, and his arguments did not deviate from those put forward in Christian thought. Galileo Galelei in the 16th century advanced the use of empiricism, mathematics and the scientific experiment as methods to challenge traditional ways of constructing knowledge. However his downfall is likely due to the fact that his methods and discoveries confronted received doctrines, methods

traditionally seen as reliable ways to construct knowledge and perhaps most importantly countered Christian teaching. This subsequently led to his condemnation for heresy in 1633, and provides a classic example of the difficulties that exist in the "pursuit of knowledge and ways of knowing (however defined) from the constraints of strongly held beliefs" (Oakley 2000 p79). Oakley (2000) traces the methodological legacy we have inherited today along two paradigmatic lines, contrasting accounts of how we know what we know, providing the background as to the relative values and merits that have come to be ascribed to various forms of evidence. This divergence of epistemological positions between positivist and interpretative approaches, although theoretical, has had practical implications for this research, and consequently it is deemed useful to provide an overview of the debate as it applies to the present study. The multiplicity of philosophical and theoretical orientations described in the literature prompt us that issues of "quality and credibility intersect with audience and intended research purposes" (Patton 1999 p1189). According to Patton (1999) the credibility of qualitative inquiry depends on three exclusive yet related elements:

1. Careful collection and analysis of data, using rigorous techniques and methods concerned with paying attention to issues of validity, reliability and triangulation;
2. The credibility of the researcher; and
3. Philosophical belief in the value of qualitative inquiry.

This chapter provides an overview of the interplay between the context of the research and the process of selecting a methodology for the inquiry, and is cognisant of the credibility criteria described above. The position of the researcher (hereafter referred to as I) and the influence of the theoretical perspective on interpretation are explored.

3.2 Ways of knowing: the search for a conceptual framework

Although Galileo was isolated for threatening the validity of the canon of Christian teaching in relation to the natural world, the project to develop a systematic method of

observation and experimentation continued.[31] The new concept of science became a progressive force. The intellectual revolution that marked an end to unthinking acceptance of an oppressive ecclesiastical system emerged whereby the power of human reason and experience of the world became the only valid basis for knowledge (Oakley 2000). Bacon (1561-1626),[32] is one of the most important figures in the development of scientific methods, as his theory of knowledge played a central role in the advancement of scientific inquiry. Bacon speculated on the nature of reality, and contended that theory should be generated from facts rather than speculation, and is largely responsible for the development of the experimental method in science (Perez-Ramos 1996). He was anxious for knowledge to be empirically based, viewing emotion as a contaminant, and a potential source of error in the perceptions of reality. He regarded his purpose as leading the world toward progress out of a long period of doubtful tradition, laden with irrationality. However, this shift in the advancement of knowledge through rationality, basing knowledge on that which can be known reliably (observed rather than unobserved) was further developed by other 'like-minded' philosophers. Epistemology, in the writings of René Descartes, was based on a cynical view of the traditional ways of knowing and inquiry into the nature of knowledge, and in many ways, was influenced by the ideas of Galileo and other philosophers of the previous period. Cartesian philosophy is best known for the separation of the mind and body "I thereby concluded that I was a substance, of which the whole essence or nature consists in thinking... so that this 'I', that is to say, the mind, by which I am what I am, is entirely distinct from the body" (Oakley 2000 p75),[33] and has resulted in the introduction of the rules of method into natural sciences, whereby systematic procedures are to be followed in order to know the truth through reducing problems into their constituent, quantifiable parts in order to omit nothing. This historical intellectual movement advocated rationality as a means to establish an authoritative system of ethics, aesthetics, and knowledge, and receives contemporary application in the unity of science movement which includes logical positivism. The 18th century also saw the continued rise of empirical philosophical ideas, and their application to medicine and interventions

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[31] For a more detailed discussion of the history of methodology see Oakley (2000).
[32] For further detail: http://www.constitution.org/bacon/preparative.htm
[33] Above, n 27, Descartes, Discourse on the Method.

within. The Age of Enlightenment had emerged, where epistemology in both the natural and social domains based upon thinking autonomously, free of the dictates of external authority continued to advance.

The history of the empirical movement in science has been alluded to in this thesis in order to provide context as to why quantification has come to be so revered, and serves to elucidate the progressive cultural move towards an empirical, technological society, the pursuit of objectivity and subsequent claims to professional expertise (Illich 1975). However, limiting the debate to epistemology based on quantification is to ignore the concept of subjectivity and the consequent value and representation of non-numerical 'data'. The term 'positivism' has its roots in the work of Auguste Comte (1798-1857) which stated that the only authentic knowledge is scientific knowledge and developed the application of the scientific method to social issues. Comte placed his emphasis on a quantitative, mathematical basis for decision-making. He provided a framework for the development of sociology and his philosophy is the foundation of the modern notion of positivism and quantitative statistical analysis. In Comte's view, positivism is an approach to understanding the world based on science with a belief that social progress would necessarily be brought by scientific progress. However, Comte saw a limit in its ability to help explain social phenomena. The turn of the century witnessed the antipositivistic revolution, which stressed the difference between the social sciences and natural sciences, as the works of Max Weber (1864-1920), Émile Durkheim (1858-1917) and others began to take into account the actions and reactions of individuals in their work. Durkheim advanced the argument that the experiment as a methological tool was not suited to the study of all phenomena, in particular those beyond the control of the investigator: "... social phenomena evidently escape the control of the experimenter, the comparative method is the only one suited to sociology" (Durkheim (1938 p125) cited in Oakley 2000 p129). Therefore, alternative approaches to explain and predict human behaviour were required.

3.3 Historical 'moments' in qualitative inquiry

As the foundations of modern knowing progressed from theism/divine to experiential/real, scientific inquiry moved towards the incorporation of non-numerical data to produce knowledge about the world. The struggle to attain legitimacy for interpretative methods in the contribution to knowledge has a chequered history. Although qualitative research crosses many disciplines and subject areas, the importance of interpretive inquiry for social observation using systematic methods was founded in the work of the Chicago school in the 1920s and 1930s (Denzin and Lincoln 2005a). The Chicago school established the use of mapping as a technique to uncover patterned conduct and processes of social interaction. This technique pre-supposed that observation could be objective (Vidich and Lyman 2000), conforming to the received dictate of emphasising rationality and facts to the exclusion of emotion. However the work of notable American figures such as George Mead, John Dewey and the emergence of Herbert Blumer's (1969) distinctive methodological position, symbolic interactionism, established a unique tradition in qualitative inquiry, challenging more traditional ontological and epistemological positions (Hammersley 1989). Traditions of thought have continued to progress and change, however epistemological progress is characterised by the development of multiple theoretical paradigms, each with their own perspectives and methodologies designed to obtain the truth. Denzin and Lincoln (2005a)[34] define the timeline of this complex development within qualitative inquiry as follows: The traditional period (1900-1950) is associated with the positivist paradigm with an emphasis on objectivity, modernist (1950-1970) also known as the golden age and blurred genres (1970-1986) moments are associated with the emergence of postpositivist arguments as the line between text and context begins to blur, the crisis of representation (1986-1990) phase highlights the researchers' struggle to locate themselves reflexively in their texts, postmodern (1990-1995) witnesses the emergence of new and experimental ethnographies and is characterised by the refusal to privilege any method or theory (Richardson 1997), the methodologically contested present (2000-2004) and fractured future (2005-) "confronts the backlash associated with the evidence-based social movement" (Denzin and Lincoln 2005a p3). The authors suggest that qualitative

[34] For further detail please see Denzin and Lincoln (2000): Introduction.

research means different things in each of these moments, as the perspectives, methodologies and evaluative criteria employed to interpret problematic phenomena and meanings in individuals' lives are historically located.

However, Nelson et al (1992) contend that the "choice of research practices depends on the questions that are asked, and the questions depend on their context" (p2), therefore no methodology can be either privileged or dismissed out of hand.

3.4 Grounded Theory methodology: philosophical and ontological considerations

Qualitative approaches vary in terms of the ontological, epistemological and methodological assumptions upon which they are based. Although certain methodologies demonstrate labelled movement or affiliations with certain schools, their identities are not always described consistently. Grounded theory is a widely used inductive methodology that seeks to uncover the main concern for specific groups of people in relation to a particular phenomenon, and aims to provide an understanding of how individuals create meaning. Classic grounded theory was devised by Barney Glaser and Anselm Strauss and published in their seminal text The Discovery of Grounded Theory (1967). Their pioneering work provided research strategies on the modelling of theory based on their collaborative studies of dying (Glaser and Strauss 1965, 1970), challenging the hegemony of the positivist tradition in social sciences that dominated the modernist period. Grounded theory has been used extensively in women's health care research (Noerager Stern and Holland Pyles 1986, Levy 1999, McAllister 2001, Wuest et al. 2002, Maijala et al. 2003, Holtslander et al. 2005, Coyne and Cowley 2006, Nathaniel 2006) and is transdisciplinary in application. Glaser trained as a doctoral student with Paul Lazarsfeld in quantitative survey research design, where Lazarsfeld conducted qualitative studies in order to generate instruments for survey research. Glaser was later to collaborate with Anselm Strauss, receiving training in the social construction of realities by symbolic interaction, affording him the opportunity to apply quantitative techniques to the analysis of qualitative data (Glaser 1998 p32). Grounded theory was discovered using "Lazarsfeld's quantitative inductive data analysis techniques" (Glaser 2003 p83), based on methodological notes from the Awareness of

Dying study. Discovery provided a research strategy with explicit analytic procedures for systematic analysis of qualitative data. This innovative methodology effectively refuted the canons of sociology that contended the purpose of fieldwork was to verify rather than to generate concepts or theory. This new approach gave license to researchers to generate theory systematically from data and to depart from a logico-deductive model. Glaser and Strauss were later to diverge on the precise nature of grounded theory with the publication of Strauss and Corbin's co-authored book on grounded theory methodology (Strauss and Corbin 1990). The root of the Glaser-Strauss debate originates from an ontological divide between critical realist and relativistic ontologies, as evidenced through the irreconcilable differences in the process of data analysis and purpose of theory generation. Strauss and Corbin (1990) increasingly acknowledge the interaction between the participant and the data when compared to the original text (Glaser and Strauss 1967). However, the shift towards postmodernism seems limited. A combination of Strauss's growing assertion that verification is an explicit goal (Charmaz 2000b), and the authors proposal of increasingly rigid analytical framework, signals a return to the logico-deductive model, through forcing pre-conceived hypotheses on the data (Glaser 1992). This schism has contributed to confusion as to the key elements inherent within grounded theory, consequently, many studies have claimed to have used grounded theory when in fact aspects of the methodology were employed without adhering to the critical components of the approach (Becker 1993, Benoliel 1996, Cutcliffe 2000). The rigorous yet flexible strategies provided to generate theory, and the historical links of the original authors (Glaser and Strauss 1967) with particular theoretical perspectives has given rise to intellectual debate regarding the ontological and epistemological position underpinning the methodology. Classic (Glaser and Strauss 1967) grounded theory methodology is not defined by any particular discipline or any one theoretical perspective (Glaser 2005c), and claims that it is founded on the research aphorisms of positivism or symbolic interactionism (Chenitz and Swanson 1986, Morse and Field 1995, Annells 1996, Crooks 2001) have been vociferously refuted (Glaser 2005a p141-160). However, a combination of the strategies advanced to maintain objectivity and a positivistic reporting style that excludes the effect of the researcher could be regarded as an attempt to gain credibility with scientists who use quantitative methods by decreasing any

chance of personal bias (Charmaz and Mitchell 1996, Cutcliffe 2000), inviting criticism that it is and remains a product of modernist tradition. This criticism combined with Glaser's insistence that the method is not dominated by any particular philosophical position, has led authors to adapt the method for use within a variety of theoretical perspectives (Keddy et al. 1996, Charmaz 2000b).

3.4.1 Objectivist and constructivist approaches to grounded theory

The researcher's ontological and epistemological perspective will determine the form of grounded theory used (Annells 1996). Historically, grounded theorists have predominantly focussed on the procedures required to obtain data in an objective manner and have paid negligible attention to their relationship with their participants (Glaser and Strauss 1967, Glaser 1978). Many researchers have remodelled the methodology to fit with a variety of perspectives such as feminism (Hyde 1996, Keddy et al. 1996), postmodernism (MacDonald and Schreiber 2001) and constructivism (Charmaz 2006). Constructivist grounded theory explicitly alters the researcher-participant relationship, bringing the centrality of the researcher as author to the forefront (Mills et al. 2006). Striving to attain more credibility according to an objectivist standpoint ignores this aspect of theory formation, and some would challenge that the credibility of the research depends on the explicit positioning of the researcher (Ricoeur 1981, Greene 1996, Wolf 1996, Patton 1999, Denzin and Lincoln 2005b). That is not to say that the procedural steps intended to provide a rigorous approach limit the scope for theory generation (Mills et al. 2006), rather that there is a need for the grounded theory researcher to acknowledge personal ontological and epistemological positions and to discuss how it has affected theory development (Turner 1981). This philosophical shift acknowledges that interviews are not neutral, context-free tools for data collection (Fontana and Frey 2000, Hand 2003) and retaining positivist inclinations for the sake of parsimony is no longer tenable. Recognition of the diversity of experiences amongst individuals has raised questions as to the generalisability of theory beyond the context, leading to an escalation in calls for the presence of researcher to become more visible, allowing the reader to judge the findings without the necessity to repeat the study. Ontologically relativist and epistemologically subjectivist, constructivists contend that the researcher's interaction with the data

creates what will emerge from the inquiry (Guba and Lincoln 1989). A constructivist approach requires:

1. "The creation of a sense of reciprocity between participants and the researcher in the co-construction of meaning and, ultimately, a theory that is grounded in the participants' and researcher's experiences.
2. The establishment of relationships with participants that explicate power imbalances and attempts to modify these imbalances.
3. Clarification of the position the author takes in the text, the relevance of biography and "how one renders participants' stories into theory through writing" (Mills et al. 2006 p9).

After more than a decade of post-positivistic qualitative inquiry (Denzin and Lincoln 2005a) consideration of the situatedness of the researcher in the process remains largely absent from qualitative health research reports, segregated into journals whose focus is on interpretative methodology (Ellingson 2006). It seemed apparent that I could no longer maintain this tradition and remaining 'distant' from participants in this situation seemed unethical. Consequently the constructivist approach was selected for this study. The extent to which the tenets of constructivism are congruent with my personal epistemological and ontological position is explored.

3.5 The challenge of postmodernism: locating the Self in research

The study aimed to explore and understand women's experiences of carrying a baby with a fetal anomaly up to and beyond the birth to enable the provision of individualised, women-centred care by practitioners working in any care context, specialised fetal medicine units, maternity care settings, hospital or community based. Years of clinical practice in the substantive area emphasised the need to establish a sound theoretical basis for practice (Medical Research Council 2000). The diverse literature base illustrates the utility of grounded theory methodology in the development of a theoretical base for clinical practice (Elliott and Lazenbatt 2005), advancing its appropriateness for this study. Medical and midwifery practice in the

substantive area was frequently based upon a preference to measure biological outcomes in response to technological intervention, with less acknowledgement of the psychological burden that an adverse diagnosis can confer. In general, the care provided was based on the clinician's past experience with individual cases, a concern previously expressed almost two hundred years ago by William Farr when he advised caution as to the misleading character of evidence based solely on individual experience (Farr 1837 cited in Oakley 2000). Yet clinicians and women see the doctors as 'experts' re-enforcing the common impression that doctors' knowledge is based in fact when on many occasions it may come from largely unscientific foundations (Illich 1975).

Midwifery (to coin Kearns and Moon's (2002) idiom) is a 'Magpie Discipline', collecting theory that fits from a range of social science disciplines. Yet not unlike nursing, midwifery research is relatively new and fighting for legitimacy (Andrews 2002) within maternity care and academia, contexts laden with long-standing scientific traditions. Although obstetrics and midwifery have varying philosophical foundations, midwifery practice and research is associated with a biomedical model (based largely upon an epidemiological framework intended to map disease in large populations) and detachment from this model is an agonising and hard fought endeavour. Liaschenko (2001) has identified that where and how we work is controlled and influenced by different kinds of power, determining a person's agency within a particular place or environment. An obstetric orthodoxy prevails in maternity care in Ireland (Murphy Lawless 1998), and the value attributed to empirically-derived scientific knowledge guaranteed that extending beyond this traditional epistemology during the inquiry would not be without risk. My search for a methodology was heavily influenced by positivistic criticisms of the inherent 'weakness' of bias and subjectivity that pervade qualitative inquiry, 'reducing' the ability to produce rigorous and scientific results. Having identified the necessity to develop a theoretical framework to support practice, grounded theory methodology provided a systematic and rigorous approach to theory generation from data, and not from *apriori* assumptions. I had concerns regarding the remodelling of grounded theory to reflect a postmodern perspective, as any association with rejection of validity was unlikely to ingratiate practitioners to inculcate the theory into practice (Rolfe 2006), or advance the likelihood that midwifery knowledge could be

as authorative as any other knowledge. Yet I was acutely aware that I had a bias towards improving care for women in this situation. Epistemologically, my positivist tendencies draw me towards modernity, seeking guarantees of validity through the rigorous application of method. I find no solace in a postmodern ironists' argument that the same method employed in different situations, by different researchers will have a different outcome, yet the rationality of this position is overwhelming. Ontologically, I believe in the existence of an external reality, constructed by individuals in relation to self, others and context. Once again, I find consolation in a realist standpoint, seeking to generate data that closely resemble the truth, resorting to the use of method to neutralise the effect of position and place. However, I feel it necessary to concede to the resonance of the ironist's position, who "simply *believes* her project to be the best, at the same time knowing that there is no epistemological substance to her belief" (Rolfe 2000 p64). I continue to advance the project of social constructionism, uncovering patterns of human behaviour associated with social processes, seeking to understand the meanings people give to their actions, identifying connections between events, in the belief that they are as proximate to a common 'reality' of a particular phenomenon as I can hope to achieve, not predictable, not static. However, authoritative statements of the 'truth'are required in the context of practice based research,[35] as "research findings should be as trustworthy as possible and every research study must be evaluated in relation to the procedures used to generate the findings" (Graneheim and Lundman 2004 p109). I hold an attitude of *différence* (Rolfe 2006), struggling for legitimacy within a positivist hegemony, yet stopping short of a judgemental relativist position, that contends "collective agreement on validity is virtually meaningless" (Rolfe 2006 p6), risking the "romanticizing of narratives and the concomitant retreat from analysis" (Fine 1994 p80). Although the conflict between and within paradigms is evident in a number of academic and practice fields, positivism is perhaps most dominant in medicine, where the quantitative orientation of scientific inquiry in natural sciences has

[35] If qualitative techniques are to be used to inform practice, they must demonstrate credibility, rigour and relevance to use qualitative research evidence with confidence. Increasingly qualitative enquiry is being employed in social research. In order to ensure quality in health care provision and practice if it is to be effective, efficient and appropriate to those involved it must be informed by robust, valid and appropriate research evidence. SPENCER, L., RITCHIE, J., LEWIS, J. & DILLON, L. (2003) *Quality in Qualitative Evaluation: A framework for assessing research evidence,* London, Government Chief Social Researcher's Office.

laid the groundwork that consigned qualitative inquiry to the status of poor cousin for many years (Oakley 2000). Polemics in favour of a positivist approach to scientific inquiry remain dominant.

Findings from the initial stages of the study were submitted for consideration of publication in a medical journal and below are a synthesis of the spirit of the reviewers' comments:

"In particular, in order to avoid problems with regards to generalisability, I think it is important that you somehow find a way of presenting the currently rather anecdotal observations of the prospective mothers in a more structured and "digestible" way. Although the narratives quoted are effective, some discussion is required about the ability to draw recommendations from them and their external generalisability. The study extends over a 17 month period and had 38 participants. Is this enough, using the studies sociology methodology, to justify recommendations? Are there any other data, ordinal or otherwise, to give the reader a better sense of the study population? There are no percentages for the number of women with these kinds of specific themes in their interviews e.g. why not X% of women described ..."(December 2005).

This example re-enforces Fleck's (1979) argument about scientific systems, "that what is known appears to be systematic, proven, applicable and evaluated to the knower because it has been generated within a framework" (Murphy Lawless 1998 p256). Hopefully, it provides context to the reader as to why contradictions will be evident between the objective elements in the reporting style and its incongruence with the deep interconnectness that developed between the women and me during the study. It is hoped that the indeterminacy of giving priority to presenting patterns and connections as processural rather than linear and predictable will increase the scope and applicability of this grounded theory to other traumatic situations. However, this will be judged ultimately by the reader. In the context of such contradiction compromise is inevitable, and for the purpose of clarity and utility for end users the diagrammatic representation of the theory appears as though the process is simple and linear. Therefore detail

regarding the iterative process which has resulted in a rendering of these women's lives is more explicit in the text in chapters 5-8.

I planned to adopt a woman-centred approach (van Maanen 1988, Anderson 1991) through demonstrating respect with a deep-rooted desire to interact with women choosing to take part, therefore my participation in this study would inevitably influence the findings. Charmaz's (2006 p10) constructivist approach to theory generation used in this study assumes that any theoretical rendering offers an interpretative portrayal of the world, not an exact picture of it (Charmaz 2000b). This re-visioned approach incorporates systematic strategies to data collection and analysis yet sheds "positivistic proclivities by becoming increasingly interpretative" (Charmaz 2000b p523). I was also interested in the influence that the process of interaction between women and their caregivers may have on their experience of the phenomena. Clinical experience and a functional knowledge of the literature led me to believe that encounters with caregivers could be influential on the woman's experience and I wanted to identify specific behaviours that women regarded as supportive. Other authors (Halldorsdottir and Karlsdottir 1996a, 1996b, Halldorsdottir and Hamrin 1997, Maijala et al. 2003) have identified the impact of caring and uncaring encounters across a range of care situations. Their findings emphasise the often devastating effects of uncaring encounters on the recipient of health care therefore I sought clarification of women's direct experiences of care, exploring if any connections exist between these interactions and how they deal with the situation they find themselves in. Blumer's (1969 p1-60) symbolic interactionism is founded upon the following three premises; human beings act toward things on the basis of the meanings they attribute to them, meaning is derived from the social interaction one has with others and these meanings are interpreted by the person whilst dealing with the things he/she encounters. The theoretical perspective of symbolic interactionism was congruent with my ontological position and clinical experience and was therefore adopted for use in this study. As Strauss and Corbin's (1990, 1998) model was influenced by this perspective, it was tested in the early phases of data collection and analysis. The immutable rules and rigid procedural focus made it ill-suited to this study, and the use of a conditional matrix led to contrived comparisons, was diverting, and reduced sensitivity to the latent patterns in

the data, a difficulty also experienced by other researchers (Robrecht 1995). This also seemed incongruent with a constructivist approach as the matrix did not facilitate the positioning of the researcher or the flexibility required to pursue plausible, alternative explanations. Hence this prompted a return to the original Glaser and Strauss (1967) text and subsequent texts by Glaser (1978, 1992, 1998, 2001, 2003, 2005a). I also attended three workshops facilitated by Dr Glaser between 2004-2005 which involved a combination of group work and one-to-one mentoring to gain training in the use of the original methodology and fundamental principles of the method. The significant difference between the use of the Strauss and Corbin (1990, 1998) model when compared with Glaser's (1978, 1992, 1998, 2001, 2003, 2005a) view of theory generation is that the indicator concept framework offered by Glaser provided a flexible but rigorous means by which the data were interrogated for meaning and connections, and it was not antithetical to the creative, interpretative constructivist approach. This explicitly systematic approach to analysis addressed issues of credibility yet the emergent *theory* remains my interpretation of the studied phenomenon, with evidence of the influence of the pragmatist foundations of symbolic interactionism that incorporate the effect of a personal perspective on the process. The classic grounded theory methodology guided the construction of hypotheses regarding meanings, yet the reciprocity involved in a constructivist approach meant these tacit meanings were subsequently clarified with the women in order to approximate 'reality'.

Constructivist grounded theory, lying between a postmodernist and postpositivist approach was consistent with my personal epistemological and ontological positions. Throughout this study priority was placed on the experiences of and relationships with the women when compared with methodological considerations. Developing relationships (akin to friendship for some women) that included reciprocity and balancing power within the interview setting are a key component of this study and will be developed in chapter 4.[36]

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[36] Care in professional life involves recognition of the uniqueness of relationships, and ethical care involves giving priority to the particularity of that relationship. Within the context of this study, the relationship that developed contained some of the characteristics of a friendship, in that both the woman and I were equal, with a common interest in the experience of prenatal diagnosis. However, the relationship was limited to that of a 'professional' friendship i.e. certain boundaries

3.6 When gender and method intersect

It would seem reasonable for the reader to question the influence of gender in this study as it involves a woman interviewing women regarding a particular childbearing experience. However the issues of gender and power infuse a significantly broader context than that addressed in this research. The interplay between gender and the discourse on power in scientific thinking in the historical development of methodology in the natural and social sciences has been explored by many authors. These authors have demonstrated how gender dichotomies have been critical in the oppression of midwifery, rise of patriarchy, control of childbirth and the technologically mediated division of mother and fetus (Donnison 1977, Symonds and Hunt 1996, Murphy Lawless 1998, Morgan and Michaels 1999, Oaks 1999, Oakley 2000, Pilley Edwards 2001). Although many of the issues mentioned above are influential in the value placed on qualitative inquiry and midwifery knowledge in the context of scientific inquiry they are not central to the experience of concern i.e. women's experience of carrying a baby with a fetal abnormality. Hence the discussion around the issue of gender is limited to its role within the conduct of this study.

My aim was to use grounded theory methodology to obtain quality data for future action and practice by making explicit connections between theorised antecedents, current conditions and the processes that would develop during theory generation. As previously mentioned, my ontological position is more deeply rooted in symbolic interactionism when compared with other theoretical perspectives. In addition, adopting grounded theory strategies imply that any extant concept must earn its way into the analysis (Glaser 1978). Hence I chose to consider the available concepts of gender, agency, power, status, hierarchy etc as they became relevant to the study (Charmaz 2000c) and some are addressed in the following chapter in particular as they

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applied. For example women could make contact with me between interviews via email or by ringing the study mobile phone number for support or further explanation of the fetal condition/pregnancy-related issues, but they did not have access to my personal contact details, nor was I contactable at night. See sections 4.10.1 to 4.10.3 for further detail.

relate to the approach to and conduct of the interviews. However, a constructivist approach overlaps with many concepts from feminism, allowing for the development of an equitable rather than hierarchical relationship with the woman (Wolf 1996), using women's words to demonstrate how theoretical sensitivity was informed and theoretical questions asked and answered. However, this equitable relationship did not extend beyond the relationship with the researcher. Women's involvement in the co-construction of meaning was limited to clarification of issues raised within the interview and elucidation of the relevance of theoretical connections that emerged during the iterative process. Nine women were invited to test the abstracted process for fit once their participation in the study was complete. A sample rather than all women was selected as I was concerned that if I tested it on all women it may result in overstating the experiences of some who were particularly articulate, inhibiting the analytical process to a more descriptive level, minimising my sensitivity to the underlying patterns of human behaviour that may not be apparent at an individual level (Morse 1998). Therefore, ultimately the balance of power in relation to the analytical process and representation remained within my control. Many authors have challenged researchers to become increasingly explicit about their positioning (Greene 1996, Wolf 1996, Sword 1999, Ellingson 2006), hence the comments that follow.

Whilst I grapple with where I am positioned within modernity, postmodernism and the conceptual lenses through which the data are gathered and interpreted, I remain resolved in my adherence to certain principles and values:

"I want to do good, improve practice, influence caregivers and policy makers to provide support structures for women in this situation, a certain arrogance I feel gives me strength to fight. I want my work to be attributed legitimacy, considered sufficiently robust to underpin practice, hence my pragmatic approach and adherence to methodological rules of analysis. Most of all I wanted participation to be a positive experience for women. I wanted to protect them at all costs. I know these women are speaking to me, at times telling me more because they see me as a friend, someone who understands, someone just like them, a woman equally likely to be in their situation yet hoping no-one else has to go through this. Hence their wellbeing is of paramount importance, given priority over methodological decisions

(although not without causing anxiety) throughout the entire conduct of this study and beyond".

In the next chapter I explain how I approached this study and the methods I used to generate a grounded theory. In the interests of clarity, many of the nuances and complexities of individual's lives have been lost during the process of abstraction. However, I hope that through the use of direct quotations a picture of a proximate and collective 'reality' is possible for the reader to see.

3.7 Summary

This chapter presented the epistemological and methodological issues considered leading to the selection of a constructivist grounded theory methodology. Explication of my epistemological and ontological position as a researcher is intended to facilitate the reader to locate my situatedness within the research process and subsequent generation of the theoretical framework that is Recasting Hope.

4 Implementing the Research Strategy: Fieldwork and analysis

4.1 Initial proposal and preparation for fieldwork

My initial proposal was to follow approximately twenty women through their experiences of carrying a baby with a fetal abnormality up to and beyond the birth. In order to explore this experience in depth, I planned to interview each woman within four weeks of receiving the diagnosis, within four weeks of the likely birth and up to twelve weeks postnatally, irrespective of the outcome for the baby. I received research ethical approval from the university and study site. Following this I arranged a meeting with the staff in the fetal medicine unit in the study site seeking their help in informing women of the study and arranging for relevant study information and an invitation to participate to be posted to eligible women. I was known to most of the staff in the unit as three years previously I had worked there in a clinical capacity; consequently the support I received was overwhelming. The experiences of women carrying a baby with a fetal anomaly are, in general, under-represented in the literature and the focus is predominantly on those carrying a baby with a lethal condition. I was interested in including women carrying babies with conditions ranging from survival without deficit to certain demise. Drawing on the notions of theoretical saturation in grounded theory (Glaser and Strauss 1967, Glaser 1978, 1992, 1998, 2005a) sampling was also targeted to take account of the type of anomaly, to ensure that women at all stages of the spectrum were included. Due to the diversity of experience and richness of data collected recruitment continued until 30 women representing each category of anomaly had participated and data saturation had occurred. However, this all changed with Aoife's participation.[37] Aoife was recruited to the study after her ultrasound examination raised concerns regarding the presence of a chromosomal abnormality. During the time period between having an amniocentesis and receiving confirmation that a lethal abnormality was present Aoife contacted me wishing to take part. When I arrived at her home she informed me that she had decided to travel to the UK to access termination of pregnancy services. At the end of the interview I asked her if she would still consider taking part in a second interview after her return, and she agreed. Her experience raised unique issues regarding the decision

[37] For details regarding characteristics of the women please see Tables 1& 2 chapter 5.

making process of choosing not to continue the pregnancy in addition to the concerns that existed around having to leave the country to exercise that choice. Hence, seven additional women, all choosing to terminate the pregnancy, were recruited.

4.2 Research purpose

This study was designed to establish a scientific base to underpin the practice of caring for women after diagnosis, irrespective of the type of anomaly diagnosed, likely prognosis or outcome of the pregnancy. Identification and conceptualisation of patterns of behaviour that manifest in response to such a diagnosis would assist in moving the evidence from individual interactions to those based on a more collective representation of the experience.

4.3 Research aim

The overall aim of this study is to explore and understand women's experiences of carrying a baby with a fetal abnormality up to and beyond the birth of the baby, from which recommendations can be made to optimise provision of care for these women. In order to achieve this, women's experiences were explored in relation to the following landmarks in the process a) receiving the news that their baby has an abnormality, b) concerns that emerge as the pregnancy continues and the time for birth approaches, c) the key issues that emerged in relation to the birth and at approximately 12 weeks postnatally (with or without a live baby).[38]

4.4 Research question

The study is guided by the following question: Based on your experience, how can healthcare professionals provide responsive and supportive care to meet the needs of women in this situation?

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[38] Category 'c' also includes the experiences of women who chose to terminate the pregnancy (gestational age at birth 16-26 weeks). Most of these women experienced an induction of labour and birth in a hospital delivery suite, and chose to spend time with their baby once born. It is crucial that caregivers acknowledge that although women consented to an antenatal intervention to interrupt a 'wanted' pregnancy (e.g. intra-cardiac administration of KCL), that advanced gestation when combined with mode of delivery renders the experience analogous to giving birth to a stillborn infant. See Chapter 6-8 for these women's narratives.

4.5 Access and sampling of research sites within the study

The fetal medicine unit of a major Dublin maternity hospital was chosen as the study site. The study site was the only tertiary referral centre in Ireland with a Director of Fetal Medicine. Over the duration of the study the fetal medicine team expanded to include three fetal medicine specialists and specialist trainee registrar, all of whom informed women about the study. The site offers prenatal diagnosis, in-utero fetal surgery and rapid diagnostic procedures e.g. Chorionic Villous Sampling (CVS) and Polymerase Chain Reaction (PCR) and is a referral centre for many regional sites. During the study period women were referred to the unit from six regional centres for a second opinion or for invasive procedures. The experiences of women attending five of these sites are represented in the data. The sixth site is not represented as the women attended either with a particular classification of anomaly that was no longer being sampled or were at an advanced gestation at the time of referral.

4.6 Study population and eligibility criteria

Approximately 70 women are diagnosed with a fetal anomaly in the study site per annum. All low-risk, Irish women (or those who were domiciled for a long period in Ireland) booked at or referred to the study site with an ultrasound diagnosis of fetal anomaly in pregnancy were eligible to participate. Fetal anomalies were classified for the purpose of the study, using the following prognostic range:

1. Lethal and untreatable
2. Likely mental +/ physical deficit whereby, the extent may vary but complete resolution is unachievable
3. Uncertainty as to the long-term effects and eventual quality of life
4. Treatable, but with varying degrees of risk
5. Uncertain prognosis as improvements to or deterioration of the fetal condition were possible in utero. Therefore, for some women the diagnosis may remain uncertain throughout the pregnancy (Statham et al. 2003).

Classification of fetal anomaly has been performed to facilitate data description, comparison and analysis and to ensure that the sample is inclusive of a range of possible anomalies. Low-risk is defined as a woman with a background population risk of fetal anomaly of 2%. These women are offered routine ultrasound and frequently see the examination as non-threatening to the extent of perceiving it as a social event (Proud 1995). Non-Irish women were excluded on the basis of the following: a) to exclude influence of heterogeneity of culture (Statham et al. 2000) on women's experiences, b) high-risk women, as they receive more focussed screening information and more detailed fetal anatomical surveys than are routine, c) many women unable to give informed consent or complete self-administered questionnaires. Women with a known history of psychological morbidity were excluded to avoid any additional strain that might be associated with taking part. Women booked for birth at the tertiary centre received the initial diagnosis from either a midwife or radiographer in the routine ultrasound clinic, and those booked for birth elsewhere and were referred for specialist opinion received the initial information from midwives, radiographers or obstetricians.

4.7 Sample selection

Initially all consecutive eligible women were invited to participate. As sampling progressed the fetal medicine team were requested to inform only women carrying a baby with a particular classification of anomaly to ensure each category was represented.

4.8 Recruitment

Women were informed of the study by the fetal medicine specialist they attended in the tertiary referral site. The fetal medicine specialist (FMS) assessed the woman for eligibility and requested her permission to post the study information to her home. This ensured that women did not receive information in the post without forewarning. Some women requested the information at that point and this was provided. Postal recruitment was chosen to ensure women would not feel that their decision to participate, or not, could have any influence on their care as clinicians were unaware of the woman's decision. An information pack containing a letter of explanation from the consultant to verify the origin of the information, a letter of introduction explaining my professional background and interest in the area, an

explanation of the study and a consent form to participate, was posted by the unit staff within two weeks of the diagnosis. Women had two options to indicate their interest in taking part. They could contact me directly by phone or email: this facilitated further clarification if required and permitted interviews to be scheduled at short notice. Alternatively the woman could return the consent form in a prepaid envelope to Trinity College Dublin at which point I made contact to reaffirm consent and to make an arrangement to meet at her convenience. Two weeks following the initial invitation to participate if there had been no contact from the woman a reminder was posted. If there was no response to the reminder the woman was deemed to have chosen not to participate. A register of invitees was held in the fetal medicine unit. This allowed for a calculation of the participation rate and for follow up letters to be sent to women after two weeks. The register was a loose leaved binder and once the woman had chosen to participate or the reminder was sent her name was removed and destroyed by the researcher.

4.9 Data collection instruments

The core instrument in this project was the interview, and data were collected from April 2004 to August 2005. Women's case notes were accessed with the woman's consent in order to obtain demographic and obstetric data (see Appendix 8). This eliminated the need to access this information during the interview and risk altering the tone to that of a market survey. Access to the notes also ensured that I was aware of key information prior to contact to arrange follow up interviews such as; whether the baby had been born prematurely or died in utero as the circumstances of the pregnancy may change significantly between interviews. The 1st interviews generally took take place within, four weeks of diagnosis (Hunfeld 1995). However, when recruitment began initially the team were informing all women, and some were recruited closer to delivery. The 2nd interview was intended to be completed before delivery at approximately 36 weeks gestation, although the timing had to be flexible as delivery dates can alter significantly from the expected date of delivery depending on the fetal condition. For women who delivered preterm or experienced an intrauterine death (IUD), only one antenatal and one postnatal interview was conducted. For women who chose to terminate the pregnancy, all women with the exception of one were interviewed after they had returned from the UK. This was largely due to the fact that women, in general, travelled

within 48 hours of receiving a diagnosis. The rationale for the timing of the antenatal interviews is to understand and explain the experience prospectively, to follow women up to the birth and beyond. Not all women received a certain diagnosis at the beginning, and for some the diagnosis emerged over time (Redlinger-Grosse et al. 2002). For others the fetal condition seemed to swing between showing signs of improvement or deterioration. Hence, the longitudinal design employed, facilitated capture of the extent to which uncertainty regarding the fetal prognosis influenced the overall experience for women. The postnatal interview was scheduled for 12 weeks after the birth. However the timing also varied depending on the woman and the outcome for the pregnancy. In order to ensure maximum safety for participating women a referral pathway to psychiatric services within the site was established. This pathway was based on The Edinburgh Postnatal Depression Scale (EPDS) (Cox et al. 1987), a 10-item instrument with established antenatal and postnatal reliability and validity (Statham et al. 2001). The EPDS was used as a screening tool for psychological morbidity, and has a sensitivity of 79% and specificity of 85% for identifying women at risk of postnatal depression when administered antenatally, postnatally and after six weeks postpartum (Cox et al. 1996).[39]

4.10 Developing a constructivist approach to interviewing

The design and methods are influenced by the research question and the theoretical perspective of the researcher (Glaser and Strauss 1967, Glaser 1978, Charmaz 2000a, Charmaz 2006). Traditional approaches to interviewing influenced by positivist science have focussed on maintaining value-free, distant, objectivity in order to uncover facts about the truth (Wolf 1996). Conversely, a constructivist grounded theory approach openly addresses the interactive relationship between the researcher and participant (Mills et al. 2006) committing the researcher to reflect upon his/her underlying assumptions and the extent to which they influence the iterative process. The range of interviews from unstructured to highly structured survey tools (Weiss 1994, Seidman 1998, Holstein and Gubrium 2003) were reviewed for their suitability to the context and although some authors have referred to interviews with minimal structure as conversations, I felt this term was a little misleading. I was provided with the

[39] Aggregate results for these measurements are available in Appendix 1. Details regarding the referral pathway are provided in section 4.15.4 on ethical considerations and in appendix 2.

opportunity to talk with these women on the basis that they had chosen to participate in the study and I was interested in a particular part of their lives. On arrival I initiated casual conversation, re-affirming consent and clarifying the purpose of the study and what was involved in participation, re-affirming that the woman could choose to withdraw from the study at any point. I emphasised the importance of understanding the experience in order to improve care for other women who would inevitably find themselves in a similar situation. This soon changed to a conversation typical of how women talk to each other and expressions such as 'you know' and replies such as 'I don't know him/her' (Devault 1990, Pilley Edwards 2001, Slee 2001)[40] frequently featured in the interviews. The study information pack provided for women contained information on my clinical background which was re-iterated by clinical staff when they were informing women about the study. This did not ameliorate my concern as to how women would perceive me and I consistently experienced some level of anxiety when meeting a woman for the first time. I knew it was crucial to engage women from the outset (Shaffir 1991, Sword 1999) in particular due to the longitudinal nature of the study. A topic guide was formulated for the conduct of the first interview just in case the story did not spill out, but was never utilised, and minimal structure was maintained throughout. This was largely due to my own anxiety in my new role as 'researcher', and a perception that rigid adherence to methodological rules was required to ensure the main areas of interest as defined in the tentative objectives were addressed. For the first four months of data collection I was disturbed by what I perceived to be my requirements to adhere to the traditional/objectivist principles of interviewing i.e. remaining detached, generating sufficient rapport to obtain data, remaining neutral (Oakley 1993) and how I continued to fail in this endeavour. Talking in a way that felt 'natural' revealed much information about these women's lives (Finch 1984), the conversation was more spontaneous when combined with the element of reciprocity, and felt more like a collaborative endeavour than an investigation. After the first 3-4 interviews, subsequent data collection was heavily informed by the information that was gathered in each previous interview, keeping the focus close to the data and not theoretical hypotheses generated from the literature or personal practice/experience in the area. However, on return visits for the second or third time the tone in the initial stages changed from negotiating

40 When women used these phrases we were usually engrossed in conversation, often leaning forward towards each other. Silence was not uncommon, and gestures of support such as touch, supplying tissues and sometimes laughter were commonplace when particularly painful issues resulted in an outpouring of emotion.

consent, to one more closely resembling a conversation two people would likely have that had not met for a while, keen to share recent news, with the woman always leading. I felt at ease with all but two of the women. I cannot fully explain the root of this discomfort except to say that it seems likely that their intense difficulty in coping with the diagnosis and deep negativity towards almost everyone they mentioned were influencing factors. Interviews with these women inevitably became dominated by a focus on their suggestions for improvements to care. I feared that probing too deeply about their experience would either be too intrusive and unwelcome, or unravel the strategies they were using to cope. I was in the peculiar position of experiencing wonderful co-operation from health professionals in the study site secondary to my previous clinical experience in the area. Yet, not being a member of the clinical team gave women the freedom and security to be openly critical regarding aspects of care as they applied to themselves. Across the sample, women's views were sought on a range of issues that became pertinent to each phase of the study. For example phase one was dominated by women's reactions to the diagnosis and the interactions with caregivers and extended family/friends that ensued. The main concern was frequently related to decision making regarding further testing and understanding the consequences for pregnancy. In phase two, aspects related to how women coped with an ongoing pregnancy and concerns related to the impending birth and neonatal outcome were at the forefront. Some women expressed fear of how they might react when they saw the baby, in particular if a cranial abnormality was present or the baby had died before birth. Almost all women spoke of their desire for life to return to some kind of normality, and some focussed on building a future with or without the baby. In phase three women predominantly spoke of how they were trying to cope with their situation i.e. coming to terms with the loss of a healthy child, with the decision they had made regarding the pregnancy outcome, bearing the burden of care for a child with special or health care needs or grieving for their dead infant.

Glaser suggests that questions should concentrate on exploring the participant's main concern and be phrased in a way that will 'instil a spill'. In the first interview I moved the conversation from casual introductions to exploring the experience of interest by asking women to begin by taking me back to when they had discovered that they were pregnant. Although many of the pregnancies were unplanned none of the women said they were unwanted. Recounting the pleasure or surprise felt at that point usually led women seamlessly into describing their

feelings towards the pregnancy, arranging antenatal care, taking them up to the point of the ultrasound examination and the discovery of the problem. Although a conversational style was adopted within the interview probing questions were asked in a way that would encourage women to articulate the meaning they attributed to their experiences; however, I interrupted as little as possible (Whittaker 2002). Some women sought clarification about how deep to go, and were encouraged to reveal whatever they felt, to a depth at which they felt comfortable. In this circumstance women were reassured of confidentiality. For some women I was the first person to hear their unsanitised story. This was more common in interviews with women who had experienced a termination of pregnancy, possibly due to the fear of opprobrium from friends and family. The interview provided a safe place to speak freely and finally tell 'someone' what they had been through; demonstrating that the constructivist approach was well suited to this study. The flexibility of the grounded theory method merged well with a constructivist approach as it allows for open-ended questions and the directiveness required to test theoretical assumptions, which can be paced appropriate to the context (Charmaz 2006).

The open-ended questions were structured as follows:

1. Can you take me back to the day you discovered you were pregnant how did you feel?
2. Could you describe how you felt the day you went for the scan?
3. What contributed to your decision to have amniocentesis?
4. How have other people reacted to the diagnosis?

Each visit to the field gathered additional data filling conceptual gaps and allowing theoretical hypotheses to be tested. Specific questions regarding the issues raised by women during the interviews included:

1. Who was present for your scan?
2. How were they involved?
3. Could you describe what it feels like to have a 'good' day?
4. How does this compare to a 'bad' day?
5. Is there anything that influences which kind of day it will be?

As data saturation was achieved, the emergent process was tested for 'fit' with those women who were taking part in their final interview. However, each interview irrespective of where a woman was in relation to the diagnosis was ended with questions targeted at improving care. For example:

1. How do you think care can be improved in the future?
2. What information do you suggest should be provided for women taking part in a routine ultrasound programme?
3. What advice would you give to someone who has just discovered their baby has a problem?
4. Is there anything you would like to ask me?

As the interviews involved an exploration of a very emotive subject all interviews were closed by grounding women back into reality by asking women what they had planned for the rest of the day etc. This strategy aimed to increase participant safety and ensured the woman was debriefed following data collection.

A constructivist approach also advocates equity and reciprocity, and I remained conscious of trying to minimise any differences between the woman and I during the study.

4.10.1 Equity

Within the interview, I positioned myself as a learner, seeking to understand the woman's experience in order to improve clinical practice in the area. My midwifery experience and knowledge of the hospital system added to my credibility and undoubtedly contributed to the extent to which women freely disclosed information about their experience. This in itself highlighted the inequities that existed both socially and educationally between me and some of the women, a situation I could not rectify. My privileged status was further highlighted by the fact that I could leave once the interview was completed. In order to minimise any potential adverse effect associated with the development of a hierarchical relationship I dressed casually to minimise the woman's discomfort, changed my body language and altered the complexity of language within the interview based on the level of scientific literacy/articulacy I observed.

At times maintaining equity involved eating with a woman, on occasion accompanied by her partner, playing with children, looking at ultrasound images and reports and providing assistance with the interpretation of the images and the technical language that pervades such reports. One of the most distressing experiences for me was been shown a photo album of a deceased baby. When this recurred with other women I had less of an emotional reaction. It was not that the appearance of the baby shocked me although some had significantly disfiguring anomalies, but rather the fact that I was moved that women were offering me access to such deep and personal experiences. Many women gave me a photo of the baby to take away, to mark that this short life did exist and was very important. This sharing of photos seemed to represent that rather than being exploitative, the interview had resulted in the woman feeling that her experience had been understood. Consequently, methodological considerations were always secondary to ensuring the woman's wellbeing. For example, Glaser (1978, 1998) suggests that as more data are gathered and theoretical sensitivity is increased, interviews can become more semi-structured in nature, and describes how a smash and grab approach to data collection, if rigorous can be effective in discovering the basic social/psychosocial process in the data. Due to the emotive nature of this subject, a smash and grab approach would have been antithetical to exploring these women's experiences and potentially destructive to both the women and myself. Data collection was necessarily responsive to the context (van Manen 2006). Women were facilitated to tell their story in their own way and theoretical sampling for connections within the data or hypothesis testing was interwoven within the flow of conversation or deferred until the point where it appeared that the woman had completed what she had wanted to say. The use of recapitulation probes (Sorrell and Redmond 1995) was an effective strategy that permitted theoretical sampling yet supported the position I had taken of minimal interruption. Recapitulation probes allowed me to take the woman back to a particular incident to allow for a more in-depth understanding to be gained, compare incidents and add density to emergent categories. In practice this meant that each interview lasted from one to three and a half hours.

4.10.2 Reciprocity

Reciprocity in this study took place within the interview, between interviews and for some women continued after they had completed their participation in the study. Due to the

sensitive nature of the subject matter, women were advised at the end of each interview that they could contact me if they thought I could clarify any issues for them or if they felt contact would be supportive. Women chose the time and location of the interview. All interviews with the exception of three were conducted in the woman's home. They were scheduled during the day or evening and over weekends depending on the woman's circumstances. Of the three interviews not conducted in the home, two took place in the woman's local public house, and one was in an office made available in a maternity unit where the woman had been admitted as an antenatal inpatient. The timing of the latter was requested by the woman as she found participation to be therapeutic, and felt that talking with me would be a support to her during this stressful time. The change of venue from home to elsewhere does not appear to have affected the quality of data, as this seemed to be related to the level of comfort the woman felt with the chosen environment. Although the background noise on the audio file led to difficulties with transcription. Some women viewed the research relationship akin to friendship and sought contact between interviews and after participation in the study was complete. This contact was facilitated and had the effect of providing valuable insight into how women cope (Patton 1990, Shaffir 1991) and the highlighted level of support required from health professionals by some. Some women remain in contact, seeking updates on the study progress and copies of any publications arising from the research.

4.10.3 Revealing my persona

Although a 'friendship-like' rapport developed with many women, seldom did they request details regarding my personal life. As Reinharz and Chase (2003) have found rapport was established by strong listening skills rather than by promises of future friendship (p 81). Women seemed content to assume that some level of self identification existed and that as a woman of childbearing age I had the potential to empathise with their loss (Daly 1992). On occasion I was asked if I had experienced an adverse diagnosis myself, to which the answer was no. However, my brother's son was born with Down Syndrome, so I had experienced the devastation associated with the birth of a less than perfect child into the family. I seldom

revealed this fact unless I felt it was appropriate to do so or that revealing it had the potential to provide some form of comfort to the individual woman concerned.

4.11 Dilemmas in fieldwork

The blurring of boundaries between being a midwife, researcher and woman meant that I experienced a variety of emotions. In particular I was affected by negative accounts of women's interactions with their caregivers which ranged from insensitivity to withholding or providing inaccurate information. There is a tendency toward avoidance of any discussion of the emotional aspects that the research process may have on researcher(s) (Young and Lee 1996). Several authors (Rowling 1999, Eaves 2001, Gilbert 2001, Johnson and Clarke 2003, Beale et al. 2004) have looked at the impact of data collection in sensitive areas on the researcher/research assistant and have recognised that undertaking such research may cause emotional pain or trauma to those individuals involved, highlighting the need for support for the researcher. In particular, it has been noted that nurses undertaking such research express feelings of isolation and also verbalise the need to provide some service for the patients involved; to reciprocate for their participation (Johnson and Clarke 2003). There are many paradoxes confronting researchers in the field and Wolf (1996) refers to these dilemmas as the *secrets* of fieldwork. These *secrets* often remain hidden as disclosure makes us vulnerable. Rager (2005) recommends counselling, peer debriefing, and journal writing as a way of coping with what is termed "compassion stress". I chose to record my feelings in a diary where I also recorded field notes taken immediately after the interview, and memos relating to conceptualisation during analysis. This allowed me to see if my feelings were influencing my interpretation of that particular transcript. When the emotion had abated, I would return to the data again to see if there were alternative explanations to my original analysis. For me, the impact involved, on occasion, crying after an episode of fieldwork, as emotions were contained during the interview. This outpouring of emotion was a way of reacting to a human, humbling and heart-wrenching experience, yet containing it to when I exited the field served to prevent it from becoming entangled in my everyday life. Although I was not working with research assistants the data had an impact on my supervisor and the two women who were transcribing the audio recordings. One of the many questions that arose in the field was in relation to role boundaries i.e. being a researcher and a health professional without the

responsibility for the provision of direct care. Similar to others I wanted to take on a helper role, yet in the earlier interviews I felt constrained to remain in my negotiated role as researcher (Sword 1999). Within that context the following diary entry was written:

I'm not sure how close to get. I know my professional experience is encouraging women to talk as they don't have to explain the context. So how close do I get? How do I care for them? (Journal entry JGL, April 2004)

Maintaining a stance of detached objectiveness during the interview was unlikely to contribute to building a rapport and facilitate a sharing of deeply personal issues. Caring initially involved seeking and accessing written information from the primary caregivers (e.g. prescriptions, hospital appointments etc) on behalf of the women. This led to an uneasy tension in the role of the researcher and the effect that this role might have on the validity of the research:

She is distraught at the uncertain prognosis and is having difficulty getting information [from clinicians]. Her questions are basic, and I can answer them, but should I? (Journal entry JGL, April 2004).

Can I be human and still be a researcher? I gave so much information, could it have had an effect on the data? (Journal entry JGL, October 2004).

As previously mentioned, I found negative encounters with caregivers particularly shocking. The following entry is an example of one woman's difficulty negotiating access to information and test results and is given to provide an understanding as to the ongoing ambiguity and tension that accompanies trying to maintain realistic research role boundaries:

Caitlin has been given incorrect information and decided on a post mortem as a result. She can't visit her baby now [in the graveyard] as she feels she has let him down. Her distress is visible and palpable; her sobs came from the core of her being. Her grieving is being strangled by this block and there are times I feel my own heart is being squeezed too, in particular, in trying to determine the boundaries or remit of my role as a researcher, midwife, information source and not a member of

her health care team as her destruction is like a horror movie being played in real-time before my eyes (Journal entry JGL, July 2005).

This woman required access to a clinical geneticist and the consultant in the regional maternity centre was refusing to arrange a referral. I intervened through arranging an appointment in the tertiary maternity centre (seen as non-threatening to the regional centre) where the referral to genetic services was arranged subsequently. The second problem encountered was in relation to women expressing suicidal ideation. Due to the nature of the research this possibility had been addressed by the research ethics committee and study design; however the impact on the researcher was not considered meaningfully. In one interview a woman who had been informed ten weeks earlier that her baby had a serious anomaly with likely mental and physical disability, was becoming increasingly concerned for her baby's wellbeing in-utero and for how she would cope after the birth. She began to believe the best option for her husband and children was for her to take her own life whilst pregnant so they might, from her perspective, be afforded the opportunity of living their lives without hindrance by her and her unborn child. During the interview she described how she planned to end her life, and the pre-established mechanism of referral to psychiatric care was enacted.[41]

I know we [researcher and psychiatrist] talked this through but I can't believe it's happening, what if he [husband] goes out and leaves her? Should I have taken her with me? I know he [the psychiatrist] said I did the right thing but I won't rest until I hear she made it safely to hospital for assessment (Journal entry, JGL August 2004).

The above encounter resulted in marked anxiety until I heard that the woman was safely treated in hospital. The third area of difficulty stemmed from the fact that I was neither an insider nor an outsider in these women's lives. However, I did experience a level of difficulty 'letting go' when a woman's participation in the study was complete, as at this stage I had met with her at least two or three times over a nine month period. The following diary entry was

[41] The integrated care pathway established to maintain the safety of participating women is described in the section on ethical considerations, and the algorithm representing this process is represented in appendix 2.

written after a final interview with a woman whose participation had begun nine months earlier:

I felt such anxiety leaving, tachycardia, a rash, the works. She told me she had 'celebrity' status when in hospital and now there is no attention. I felt I was abandoning her like the others even though she described our meeting as closure. I felt she was looking for some kind of continued contact (Journal entry JGL, August 2004).

This woman like others remains in contact through email or phoning or texting the study phone number, providing updates on their infants' progress or requesting information and support for prenatal screening issues in a subsequent pregnancy.

Transcription for the study was provided by a company experienced in transcribing sensitive health related interview data. It had been identified at the proposal stage that the data transcribers might be affected by transcribing such heartrending stories of distress. Therefore, regular contact between the researcher and transcribers was established in order to provide a forum for discussion where any issue in relation to project planning or the affective component of the data could be discussed and support provided. This contact consisted largely of planning deadlines for transcription, forewarning of particularly distressing interviews and ensuring that the opportunity to talk about issues that might emerge was available. Transcription was predominantly provided by one woman with another covering leave. It was not until several months into data collection that the transcribers were formally asked, as part of the process of ensuring their wellbeing, to identify the effects (if any) on themselves of working on the project. I would suggest that these comments provide evidence to support the inappropriateness of maintaining distance and non-involvement in qualitative inquiry (Fine 1994, Ellingson 2006) and the suitability of the constructivist approach taken.

[when the interview] is handled so well by [the interviewer] and in such a sensitive manner that also helps the person typing it up as there is real empathy and concern. Often the interviewer [in other studies] can be cold towards the participant and just ask questions without showing any emotion or concern that is more difficult because it leaves you then feeling sorry/worried for the person. (Transcriber 2, Jan 2005).

Such comments highlight that transcribers, in addition to other members of the research team, may experience a feeling of vicarious responsibility for the participants' well-being. The principal transcriber identified several issues that had emerged for her personally as a result of the project, and acknowledged that much of these changes came from hearing the participants' stories and gaining an insight into experiences she has never had. At times she found the data distressing but also acknowledged a change in her own attitude towards the decisions some parents made after a fetal anomaly was diagnosed and described listening to women's experiences as educational:

While I find the situations that people are in quite upsetting and they often would bring me to tears as I am listening, they do on the other hand give me great respect for people who have to go through these very difficult times. I have become much less judgemental of people and the decisions they make as I now realise that you just never know what is behind those decisions. That has been quite an attitude shift ....and I admire the strength of the people involved (Transcriber 1, Feb 2005).

This transcriber also described the deep emotional impact the data had for her and how she coped with her responses to the data by spending more time with her family and realising the 'fragility of life'.

It makes me aware of how lucky I am and my family have been. It also makes me appreciate my own children and would make me take the extra time to just show them how much I appreciate them and thank God for my good fortune (Transcriber 1, Feb 2005).

'Letting go' also emerged as an issue for the transcribers, who appreciated completing the task of transcribing all interviews, to hear 'how the story ended'.

..... since the interviews are held on 3 occasions, ending with the final outcome of the whole experience, it helps to put closure to the issue. At first the story is very harrowing and disturbing, then it can improve or not on the 2nd interview but no matter what the outcome is at least you get closure on it in the final interview.

It was a very sad case and I could actually feel the woman's pain when I was doing the transcription. She had suffered terrible sadness, which was made worse by mistakes made by hospital personnel... I did not do the follow-on transcription but would like to have known how things turned out for this woman. She seemed to be so brave and I would like to imagine she coped quite well (Transcriber 2, Jan 2005).

The affective components of fieldwork involved at times significant emotional reactions; these were seldom displayed to the supervisor, although she asked on every supervisory occasion in the early stages how the researcher was coping with the undeniably emotional experience involved in interviewing these women. Reading transcripts was in itself an emotional experience for the supervisor:

Some of these stories are heart-rending. I just keep remembering my own miscarriage 21 years ago – you'd think it should have been forgotten about by now. Just shows, you never forget (Journal entry, CB June 2004).

In particular, reading examples of poor care given to grief-stricken women without the opportunity for reciprocity was distressing.

...[JL] felt that reciprocity...made it easier for her as she could give something back to the women. From the supervisor's point of view, I was reading the same transcripts and they would visibly bring to my mind what the interview was like, how the women had felt and what it had been like for them....And I didn't have the option of reciprocity....I had no way that I could do anything to help those women...or to redress the situation if I felt they hadn't received good care...and that's quite a weight on you [supervisor]...It's that helpless feeling when you want to help another human being and you can't (Interview with CB, March 2006).

Some of the greatest challenges in this project have been due to the inter-connectedness that necessarily develops during data collection, and the consequences of this are elaborated in a paper in press from this study (see appendix 3).

4.12 Managing the data

As someone who is very technology dependent I envisaged handling and analysing the data using the N6 Student (Non-numerical Unstructured Data Indexing Searching & Theorizing) qualitative data analysis program (QSR International 2002). I attended an eight hour module of practical instruction on how to use the package and purchased the student license for use on my personal computer. Given my positivistic tendencies I felt the empirical functions available within the package would enhance my awareness of the extent to which codes and incidents occurred, adding to the rigour of the analysis. Unlike others who have used this programme successfully I found that I spent more time entering the data and adding labels than actually interpreting 'what was going on'. At any one time only small sections of text are visible on the screen and as a visual learner I was very frustrated by this, as I need to see everything spread out in order to have an overview of the process. The tree structure was easy to construct, yet as it enlarged it could not be viewed in its entirety at any one time on the screen. The structure of creating a hierarchy of nodes gave undue weight to areas that perhaps were mentioned frequently but were of little consequence to the substantive experience. While technologically it was easy to use and the coding system easy to set up, due to this fragmentation I couldn't make connections between the same woman's experience over time or across several women's accounts. Hence the process was abandoned and I returned to the transcripts and began the system of writing the process pages for individual women and interviews as described previously.

4.13 Data analysis[42]

The overall purpose of this study was to explore women's experience of carrying a baby with a fetal anomaly up to the birth and beyond in order to develop a theoretical basis to underpin care. While the theoretical perspective of symbolic interactionism influenced my interpretation of the data and led to probing questions as to the impact of encounters with caregivers on the experience, the analytical strategies advocated in the grounded theory method (Glaser 1978, 1992, 1998, 2001, 2003, 2005a, 2005b) guided the process of analysis. The cornerstones of the method are constant comparative analysis and theoretical sampling. The

[42] Please refer to appendix 4 for a diagram of the process of data collection and analysis.

purpose of constant comparison is to verify if the data support and continue to support the emergent categories. Glaser (1998) contends that if researchers remain sensitive to the participants' main concern, constantly asking of the data 'what is going on here?' the basic social processes (BSP), basic social psychological processes (BSPP) and basic social structural processes (BSSP) that are grounded in the data will become evident. This certainly describes my experience of analysing the data for this study. Although the presentation of the data may reflect an objectivist stance, this belies the constructivist approach to data collection and the cyclical process involved in analysing transcripts, returning to the field, memoing thoughts regarding propositions and possible connections between incidents and revisiting the data many times as the conceptual framework became denser. All interviews were recorded and with the exception of the final 12, were transcribed verbatim. This was largely because at this stage the need for transcription had become redundant as saturation of most categories had occurred. Each woman's interview transcripts were placed in individual files and hand coded. Analysis began early and the first interview was coded line-by-line before the second interview took place. After four interviews I attended my first grounded theory workshop with Dr Glaser to ensure I had a sufficient grasp and understanding of the process. I realised at this stage how conceptualisation moved beyond description, later allowing me to see the BSPP in the data as it emerged. Coming from a practice based profession was advantageous at this stage, as I did not have a familiar list of sensitised concepts that I could unwittingly impose on the data. Therefore the line-by-line coding was an essential step in the production of concepts grounded in the data that were subsequently tested both in the field and during the process of constant comparative analysis (Glaser and Strauss 1967, Glaser 1978, 1992, 1998, 2001, 2003, 2005a, 2005b). However my perspectival proclivity towards symbolic interactionism meant that I actively sought information on women's interactions with caregivers and others, intending to explore the impact that this had on the overall experience. The initial codes were a starting point from which to build the analysis, and these formed the basis of the development of categories/selective codes. Selective coding is more conceptual than line-by-line coding and these categories are used to make explicit decisions about connections, highlight and refine the diversity of properties within and expose conceptual gaps requiring further theoretical sampling. On occasion, when women from each of the three phases were being interviewed simultaneously, the interview schedule overtook the pace of transcribing. When this happened the interview was re-played and notes made about relevant issues that

needed to be considered and tested immediately. This took two formats. On one side of an A4 page I recorded incidents that related to emergent categories and eventually the BSPP. On the reverse side I recorded significant statements, or behaviours that occurred as part of as interaction with a caregiver. I also recorded recommendations made in relation to the care that had been received. Notes were also written to remind me to ask women for more detail at the next interview, either to follow up on something that had been said previously or to theoretically sample for comparison or similarity with the views and experiences of other women or properties of the categories being developed (Glaser 1978, 1992, Charmaz 2000, 2006). This 'process page' as I named it was like a short story of the transcript, and was filed with each subsequently transcribed interview in the woman's individual file. This meant that changes in the woman's main concern as she progressed through the pregnancy and beyond were clearly visible at an individual level and on a collective basis. The previous interview was reviewed again usually the evening before the next interview was scheduled. In order to compare incident with incident between women and in relation to the phases of data collection, categories were developed that subsumed many of the line-by-line codes. As a visual learner, I transcribed these categories from the transcripts and accompanying process pages onto an A1 sheet where I colour coded the main categories, listing their respective properties underneath. This system also had the advantage of monitoring the frequency with which indicators occurred and allowed for the analysis of negative cases, avoiding the risk of lending too much weight to some issues when devising the composite model. For me this visual representation of the many categories and their properties allowed me to search the data for connections and eventually the BSPP became apparent. This continued comparison resulted in amendments and revisions to initial selective codes. As the data were revisited many times, new insights and perspectives regarding connections in the data emerged. Revised codes were added alongside the original codes in the margins of the transcripts. For example the theoretical code of 'gaining meaning' began as 'information receiving', 'seeking', and 'integration' and 'rebuilding' began as a two phase process of evolution, which involved 're-integration of a different future' combined with 'hope'. The original open and selective codes were recorded on the right hand margin of the transcripts for ease of retrieval; consequently developments in coding could be transferred with ease onto the transcripts and process pages. This process of induction, deduction, speculation and conjecture, falsification and verification necessary in theory generation (Morse and Field 1995) did not occur in a tidy linear order.

Hence the actual complexity of the process defies detailed description. The examples given below are an attempt to elucidate the complexity of this process. Codes that frequently emerged during the open coding phase of the 1st interviews were related to expectations that the pregnancy would culminate in the birth of a healthy child. For multigravidae, a previously successful pregnancy increased the belief that a similar outcome would occur. However, all women referred to a general lack of preparation in relation to and understanding of the capabilities and limitations of the examination.[43]

Aoife 23rd July 2004	
Excerpt from a 1st interview	Initial coding
JL: Aoife do you have any other children?	all normal
A: Yes a little boy, and he's perfect. It was an uneventful pregnancy...	previous experience
I had no problems at all and the 18 week scan was fine... so I was low risk	perception of risk
this time. We didn't think about an abnormality, everything felt so routine, ?	because scan routine
we were more curious about gender	gender
JL: did you feel you were prepared in any way for the scan?	
Aoife: No [this is] when you get your scan, when you get checked out	lack of pre-scan information

As more interviews were conducted, substantive codes/categories such as *maternal wellness* emerged. These categories then subsumed certain open codes such as previous experience, previous normal child, feeling nauseated, reassurance from health professionals and risk. As conceptualisation began the data were interrogated for links between women seeking reassurance from their own bodies that the pregnancy was progressing normally, as some women revealed they had a gut feeling that something was wrong.

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[43] Further detail on this aspect of women's experience is available in data published from this study in appendix 5.

Doireann 5th Dec 2004

Excerpt from a 1st interview	Initial coding
JL: So you were referred to the hospital by the GP for slight bleeding?	pregnancy threatened
A: Yes but I don't think people were actually taking it that serious...so he did	woman not believed
a really quick scan, about 20 seconds and he went ok the baby is there.. I thought	viability confirmed
it was a bit rushed but at the same time I was reassured that everything was	from assume normal
alright....	to hope normal

Doireann went on to explain that although she was reassured by the presence of a fetal heart, her body was telling her that something was wrong, and "everything wasn't alright as it turns out". Here she suspected that if careful scrutiny had been given to the fetus it would have been discovered that there was a problem. When the analysis advanced extant concepts from other theoretical perspectives such as patriarchy and mechanised care were brought to the analysis. As is demonstrated above, the concept of hope begins to emerge. This subsequently forms the core category to which all other categories relate. As the process of testing the data incident by incident continued, open codes such as gender and naming the baby were subsumed into categories developed from and informed by extant concepts such as assigning personhood as the process of accepting, rejecting and marking the baby's existence in this world developed. As extant literature was searched to clarify concepts and deepen understanding I attended my 2nd grounded theory workshop with Dr Glaser. As the categories continued to be developed I was utilising the visual map extensively in order to begin the process of conceptual integration and articulation of the emerging grounded theory. I sought direction from Dr Glaser as to whether I was adhering to the principles of the method as I had deviated somewhat from that which was outlined in the texts. My personalisation of the process remained close to and did not deviate from the fundamental tenets of the method i.e. constant comparison and theoretical sampling. I returned to data analysis again and at this stage the categories/selective codes became integrated into theoretical codes as theoretical saturation occurred. The process of theoretical sampling was informed by the extensive and systematic process of memoing that parallels data collection and analysis. During the study I filled two 120 page A4 diaries with field notes, conceptual memos and entries regarding the emotional impact of the data as it occurred. Conceptual memos could be written at any time, post data collection, during hand coding of transcripts, and even in the middle of dinner. During early attempts to conceptually integrate the theory by searching for 'what is going on' between the categories on the A1 map, many questions regarding the interchangeability of indices and assumptions being made about these connections were stimulated. These were later tested in subsequent interviews or by making revisions to preliminary codes. The following is an example of a conceptual memo, demonstrating that many questions about different aspects of the data and particular women's experiences emerged simultaneously.

Conceptual memo 31st May 2006

I have just tested the theory with Niamh. She cried and said make sure more people get to hear what I have been through. She has no time with her family as [baby] is always in hospital. She talked a lot about the final stage of rebuilding. She feels she is not as successful as others in this stage because of the burden of care required to care for [baby]. She is highlighting that although the scan detected a kidney abnormality it didn't detect the bowel problem, the one that is causing most concern now.

Why does she want people to know? Is it because she feels alone? Would she feel any better if she was in contact with other women with a similar experience? Is the role of the midwife enough? Is this the need for acknowledgement emerging again? Is this failure of screening re-enforcing the fact that she can never assume normal again, no matter how much reassurance she is given in a subsequent pregnancy?

It's six weeks since Molly's termination and her anger at having to leave the jurisdiction is palpable. She says the staff want to help but their hands are tied.

How can they help more and stay within the law? Is there a particular effect on grief due to having to leave? How can we provide a care pathway?

This reminds me of Kerrie's experience in the UK where she felt she wasn't given enough analgesia as a punishment. She said 'it's a medical situation not social' what does that say about the impact of the law and society in Ireland on these women. Her husband told her to tell people it's a miscarriage and not an abnormality... shame at the TOP or the fetal anomaly? This all leads back to the extent to which women will assume normal in the next pregnancy, there is a relationship here between trusting your body and carrying a genetic risk. There is a link between this trust and Niamh's concerns regarding the reassurance that screening can and can't give.

But what are the effects on grief and coping? Make sure to ask this question at the next interview.

Once I had achieved theoretical saturation of my core concept Recasting Hope I proceeded to review all the data, field notes and memos and then hand sort by category. The purpose of this was to integrate and relate each category and theoretical code to the core. The final phase involved refinement of the abstract model of the latent pattern (BSPP) that had emerged which integrated and explained the emergent theory. I attended my 3rd and final workshop with Dr Glaser to ensure that I had moved the analysis beyond description to conceptualisation, and the feedback was positive.

4.14 Reaching for quality

This study gathered rich, in-depth data from 38 women who had experienced the diagnosis of fetal abnormality in pregnancy. The concern to make certain that women with multiple possible experiences were sampled ensured that sufficient data were collected to saturate the core category. Women from many backgrounds and geographical locations, carrying babies with a wide range of possible outcomes chose to participate. Recruitment was also extended to include the experiences of women that chose to terminate the pregnancy, as delimiting eligibility to women who chose to continue the pregnancy would have ignored the reality of women who experience this outcome within the context of receiving an adverse antenatal diagnosis. The longitudinal design allowed for prolonged engagement with participating women, which supported the development of a trusting relationship between us. This relationship was the key element to providing women with the freedom to reveal intensely private and emotional experiences. The constant comparative method fundamental to the generation of a grounded theory provides a systematic approach to analysis, forcing the analyst repeatedly to review and test the interpretative assumptions being made during the process of moving the data from a descriptive to a conceptual level (Glaser and Strauss 1967, Glaser 1978, 1992, 2001, 2005a). Samples of interviews were coded (blindly) by my supervisor to explore if we would come up with a similar interpretation of the data or at the very least disparate explanations that were equally plausible. Although there were slight variations in the theoretical labels we had assigned (independently of each other), our interpretations were remarkably similar. Repeat interviews facilitated testing these assumptions with those experiencing the

phenomenon, rather than limiting interpretation to data already collected. Repeated access to women enhanced the depth of understanding as clarification and development of issues previously raised could be sought. Each follow up interview also incorporated a review of what had been discussed previously and my interpretation of same to ensure that women were being fairly represented. Also, changes in women's attitudes to the diagnosis could be gathered and developed over time. Some authors have suggested that a way to demonstrate the truth value of the findings is to return to participants to check the overall adequacy of the interpretation (Lincoln and Guba 1985, Holloway and Wheeler 1996, Begley 1997). As data collection was almost complete and the abstract model of the emergent theory was being saturated, nine women[44], selected at random, were invited to test the emergent theory for 'fit'.

These particular women were asked to comment in relation to the following aspects:

1. Do you recognise the stages in this process based on what you have been through?
2. Could this help others to understand what you have experienced?
3. Is there any particular part that rings true for you?
4. Is there any aspect that does not represent your experience? (with the exception of decision making regarding TOP)
5. Do you feel I have left anything out, or should emphasise particular aspects?

Each woman confirmed that it provided a composite representation of their experience, yet as one would expect with multiple realities they related more strongly to some aspects than others. None of the categories put forward were rejected out of hand and each had varying degrees of resonance with all of them. Seven women who had requested to be provided with updates regarding the study progress were emailed the first publication (see appendix 5) which related to the extent to which women feel prepared to receive an adverse diagnosis. All but one woman replied, and each woman was very supportive of the conclusions reached. Patton (1997) strenuously supports the

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[44] Using two separate random number tables generated in Microsoft excel seven of the thirty women that continued the pregnancy and two of the eight women that terminated the pregnancy were randomly selected to test the emergent theory for fit.

utilisation of end-users in order to enhance the utility of the derived theory for practice. Consequently, I asked a midwife colleague working in an ultrasound department not related to the study site to comment on the utility of the framework from a practice perspective. Her comments were reassuring in that she said she could recognise the behaviours represented in women she had come into contact with in practice, and felt that the interventions were logical and achievable within the current context of maternity care in Ireland. She also suggested that the diagrams should be laminated and made available in every prenatal diagnosis unit in the country to support staff in caring for these women, in particular in regional centres where contact with women in this situation is less frequent.

Ultimately the credibility of the findings will be judged by the reader, and the utility and modifiability of the process to other traumatic situations is there to be tested. The process of constant comparison in a relatively large study such as this is complex and difficult to portray neatly. Therefore, in the following chapter I have presented the grounded theory on one A4 page as a diagram, with expanded versions of each phase in order that the process is clearly auditable. Direct quotations to support the assumptions being advanced are interwoven throughout the supporting text.

4.15 Ethical considerations[45]

Although the ethical implications for the researcher and participants cannot always be foreseen (Seymour and Ingleton 1999), it remains the responsibility of researchers to ensure that their study is ethically rigorous. The ethical issues associated with minimising a hierarchical relationship within the interview setting have been previously addressed. However ethical dilemmas predicted or otherwise, can only be addressed as they occur. In the literature searched, although emotional aspects associated with data collection are addressed by some authors (Cowles 1988, Dunn 1991, Rosenblatt 1995, Kellehear 1996, Rowling 1999, Sword 1999, Weaver Moore and Miller 1999, Gilbert 2001, 2002, Beale et al. 2004) I could not find any comment regarding the ethical dilemmas that might be associated with including women carrying a baby with a fetal anomaly in research. My focus for guidance turned towards research literature in the area of loss and bereavement. During the planning phase, the focus was towards protecting participating women from harm by using mechanisms such as anonymity and confidentiality. However the extent to which participating women are considered vulnerable in their role as respondents was also considered.

4.15.1 Defining vulnerability

There are several definitions of vulnerability within the literature however, one author defines it in terms of 'individuals who experience diminished autonomy due to physiological/psychological factors or status inequalities' (Silva 1995 p15). Within the literature, several groups of individuals are considered vulnerable including but not limited to fetuses, pregnant women, children and older adults (Weaver Moore and Miller 1999 p1035). This begs the question as to whether these women would be considered doubly vulnerable due the additional emotional factors involved or whether they were in a position to make decisions and choices voluntarily. Regardless of the challenges involved, these women were the only individuals who could answer the

[45] All documents included in the study information pack and letters of research ethical approval are available in appendices 6-10.

research question (Pinyerd 1990), hence the following measures were taken to ensure their safety.

4.15.2 Consent

Women had up to four weeks from the initial invitation to choose if they would like to take part, and women who chose not to participate were not required to provide a reason for so choosing. As the staff in the unit were assessing women's eligibility to participate, informing women as to the nature of the study and seeking their permission to post further information to their homes, they were also in a position to decide, based on their clinical experience, to withhold this offer if it was felt it would cause undue distress. Staff did inform me that they had made this decision when the individual woman was particularly distressed. How often this occurred is unrecorded but based on staff feedback seems infrequent. This strategy ameliorated concerns that any woman could make a decision to take part when she was under undue stress and perhaps would not have made the same decision ordinarily. For those women who received the invitation to participate, written informed consent (ICM 1999) outlining the usual principles involved i.e. voluntary participation, risks-benefits, confidentiality, alternatives was obtained from women choosing to participate prior to, and on completion of, each interview.[46] Each woman was also asked for permission to contact her again. The consequences of this contact were discussed in particular with women who were likely or certain to have experienced the death of their baby in the intervening period. None of the women refused contact at this point.

4.15.3 Confidentiality

Principles and procedures under which the research was to be undertaken were discussed with participating women and these formed the basis for the conduct of the study. Pseudonyms were used for people and places in feedback throughout the study and subsequent public domain reporting. The interviews took place outside the study site at a venue of the woman's choosing. Care providers were not informed as to who had chosen to participate unless the woman chose to reveal this fact herself. Women

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[46] All study related information was reviewed by the National Adult Literacy Agency (NALA) for language appropriateness suitable for a general audience. http://www.nala.ie/

were advised that confidentiality would be broken if as a registered midwife I became concerned for her safety during the study. This happened on one occasion and the fact that this could occur was stated explicitly in the study information pack. In the case of this particular woman both herself and her husband were fully informed of my concern regarding her psychological well-being and that I would be contacting the psychiatrist to arrange an urgent assessment. Women were also informed that in addition to breaking confidentiality, although unlikely, I may need to withdraw their participation from the study if I thought it would be in her best interest. This also happened on one occasion. One of the women taking part seemed particularly vulnerable during the interview, and had a raised EPDS score of 22. She also informed me that she had been treated for depression in the past and was currently receiving counselling. This information was not available in her notes and she had not informed hospital staff of this fact. I did not see an immediate threat to her safety, but arranged between herself and her husband that he would seek an urgent appointment with the psychiatrist who had treated her previously. This was arranged within 24 hours and the woman was admitted to hospital for treatment. The supporting psychiatrist in the study site was also informed. With the exception of the cases outlined above, all information was kept confidential and, due to the sensitive nature of the data being held, I registered as a Data Controller with the Data Protection Commissioner and all data were held in accordance with the Data Protection Act (1998 & 2003).

4.15.4 Protection of participating women

All participating women were offered the option of an exploratory counselling session with a counselling psychologist external to each of the healthcare sites. No-one took up the offer. Each of the maternity units also had designated staff members who could offer support. These staff members were frequently working in departments of social work, bereavement or chaplaincy. Psychiatric services are also available within the healthcare structures of the study site and all women expressing suicidal ideation (n=1) or seen to be at risk of self harm (n=1) were referred immediately. A system of urgent referral for other participating women was established within the study site and was based on scores obtained on the EPDS (see appendix 2). A referral score of 19 or above was decided upon by the consultant psychiatrist. The initial pathway proposed that all women with

a score of 19 or above were to be referred. However, this became untenable as many scores could be explained by the process of coming to terms with the diagnosis. This process was subsequently amended to a system whereby I would phone the psychiatrist regarding all women (n=8) with this score, discuss the case with him and only refer on his advice. On all occasions he agreed with my assessment. There were some women with scores less than 19 (n=2) that gave me cause for concern. In these cases he advised particular interventions such as phoning the woman the following day and asking specific questions in particular relating to suicidal ideation, contacting the woman's partner or GP or advising the woman to contact her GP directly. All decisions in such cases were recorded and the psychiatrist was kept informed of all actions and progress until the concern had abated. None of the women in this category required psychiatric treatment but frequently received additional contact from me which they described as supportive. The psychological technique of grounding at the beginning and end of the interview was used to debrief women during data collection.

Some authors have suggested that there can be positive aspects for participants associated with taking part in research exploring sensitive issues (Cook and Bosley 1995, Coyle and Wright 1996). The impact of the research on a personal level for participating women in this study was predominantly positive[47] and for some it was profound. Although it was not my wish to intrude upon aspects of the experience that women wished to remain private, I was also prepared to terminate any interview if it seemed that my questions were causing unnecessary pain. Discussion of the events around the diagnosis and the women's reaction to them did cause pain for many. It was quite usual for women to breakdown and cry during the interview yet they did not regard this as harmful, and I felt no sense of intrusion after the first few minutes of the first interview. Conversely they seemed to find it therapeutic and seemed grateful for the opportunity to talk freely. Most expressed joy at my impending visit, as I was someone to talk to, someone with whom they did not have to protect or mind their words with. Women also reported that the process of using probes within the interview prompted them to clarify their thoughts about their experience or an issue that seemed to defy

[47] The term 'all' cannot be used as some women did not have a follow up interview and consequently the impact on these individuals is not known. However the drop-out rate was minimal.

explanation. Women often used expressions such as 'here is my friend back' or 'its great to see you again'. One of the more profound responses was '*we didn't even know we needed to talk about it, we didn't know we'd have questions, [but you came like] the guardian angel appearing, and I'm going to help you through this now*'. For other women the impact was less profound, but no-one expressed regret regarding their decision to participate.

4.15.5 Protection of the research team

As indicated earlier little is written about how a researcher establishes procedures for resolving the ethical dilemmas that arise from the interactive dynamics of the research. The intention to establish a collaborative non-exploitative approach within a constructivist paradigm created a major dilemma for me. I had to develop skills and management techniques to monitor the possible entanglement of the women's suffering in my own life and control my own emotions during the resurgence of women's feelings in the retelling of their stories. Oakley suggests empathic involvement is a key element in researching sensitive issues: "personal involvement is more than dangerous bias-it is the condition under which people come to know each other and to admit others into their lives" (Oakley 1981 p58). Cook and Bosley (1995) have suggested that one mechanism to address the impact of the emotionality of the research on the researcher is to schedule time in between interviews. This was not possible in this study as data were being collected from women in each phase concurrently, and the condition of the pregnancy could change with little warning. In relation to the transcriber, regular contact was established from the outset, to arrange timelines, to forewarn her of particularly difficult material that was forthcoming and to check, in as much as was possible, that the impact of the data was not harmful. This prompted asking the transcribers and subsequently my supervisor to describe their interaction with the data and arising from this a paper describing the experiences of the research team is in press (see appendix 3). The dilemmas and *secrets* of field work have raised the question as to the necessary characteristics required of researchers conducting research in a sensitive such as this. Until more *secrets* are recorded as part of the process, experience will remain limited to those directly involved in individual projects.

4.16 Summary

This chapter has presented an overview of the steps involved in implementing this study, and has raised many challenging issues regarding the conduct of research with women carrying a baby with a fetal abnormality. Addressing and engaging in these challenges will hopefully provide some insight for other researchers embarking upon similar projects. Engagement with the women in this study has provided a unique insight into what it is like to receive an adverse diagnosis in pregnancy. The following chapter begins the process of revealing that experience to provide carers and readers with new insights as to how quality care may be delivered.

5 Recasting Hope- a process of adaptation after fetal anomaly diagnosis

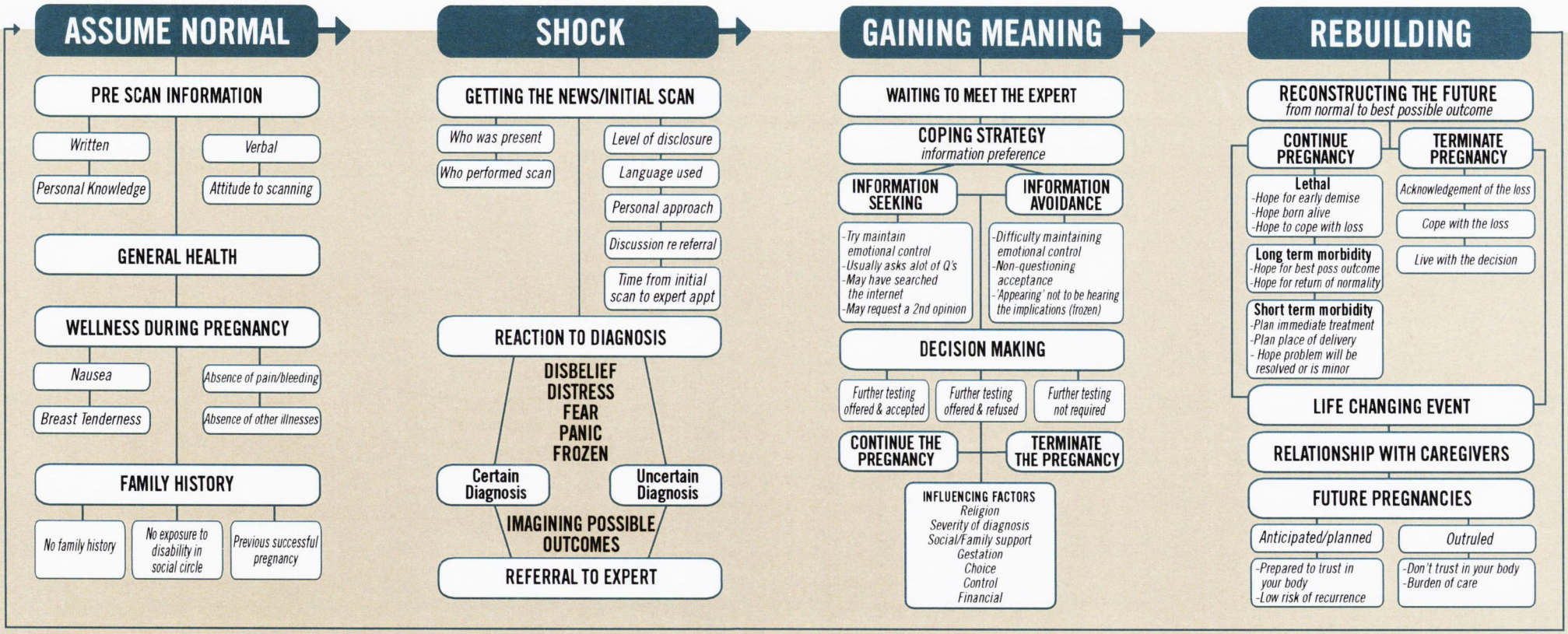
5.1 Introduction to and presentation of findings

Although much has been written regarding the nature and pursuit of knowledge, epistemological progress has resulted in some of the most fundamental features of our world being described by the natural sciences. Yet the existence of other phenomena that are not in any obvious way physical or chemical can give rise to perplexity (Searle 1995). Much of our world view depends on the degree to which we distinguish between objectivity and subjectivity, and the distinction between both concepts is often a matter of degree. Although confirmation of a fetal abnormality with ultrasound and invasive testing is epistemologically objective, the emotional pain experienced by women in response to a diagnosis has a subjective mode of existence. However, it is epistemologically true that women feel this pain, and hope for a particular outcome relative to themselves as individuals, and collectively as members of a couple, family etc. It is also not unreasonable to assume that receiving a diagnosis of fetal abnormality in pregnancy is a traumatic shock and that women will undoubtedly react to this alarming information.

Each woman made a unique contribution to this study, sharing their experience in such a way as to leave one humbled by their honesty and strength in the face of adversity. Although women's experiences are diverse, the context of the inquiry meant that many of the topics discussed were developed and integrated into a whole over the series of interviews conducted within the timeframe given to the research. This in-depth exploration and interpretation of women's experiences determined the basic psychosocial process that women faced was living with and living through a diagnosis of fetal abnormality. Recasting Hope represents the core variable that assisted women in processing this concern of coping with and surviving this traumatic event. The four theoretical codes that emerged as sub core variables are termed: Assume Normal, Shock, Gaining Meaning and Rebuilding. In keeping with Glaser's (2001, 2003, 2005a) view of grounded theory the four sub core variables have a linear and temporal construction;

there is a sense of stages or phases to the process and within these stages there is an underlying cyclical process. The data presented over the next four chapters explain this response, and like grief, it is a dynamic process not a state (Parkes 1998). This process differs from one person to another as regards both the duration and form of each of the four phases. Furthermore women can move back and forth through the phases. Nevertheless the process explains a common pattern whose features can be observed. The conceptual model of this integrated emerging theory is presented in Figure 1. This chapter presents data on the characteristics of participating women in order that the reader may link women's words with their individual circumstances and the particular nature of the diagnosis. The focus is predominantly on the first phase of the process 'Assume Normal' (Fig 2) and draws on material from the initial interviews where women reflect on the time proximate to the diagnosis. The findings will show that loss in the context of this study extends beyond the death of the fetus or neonate. This form of ambiguous loss is complex, at times irrevocable and without closure, as the dream of a perfect child is lost.

RECASTING HOPE - a process of adaptation after fetal anomaly diagnosis



WOMEN CENTRED SUPPORTIVE INTERVENTION

- Availability and content of scan information leaflet
- Focus on normality
- Option to access additional information ie websites
- Individual discussion re risk
- Space on reverse of leaflet to write questions for discussion at next appointment

- Written information on the specific condition for the parents and can be utilised to inform family members
- Set up link support person
- Honesty regarding the initial diagnosis
- Set ideal and maximum time frame from initial scan to referral
- Acknowledgment of personal impact of diagnosis/the loss of the healthy baby that was hoped for
- Contact number for health professional for support and opportunity to ask further questions before planned visit

- Continuity of caregiver
- Recognise and match information with preference

INFORMATION SEEKING
Guide and support with multiple information sources
ie discuss scientific literature, websites & referal to other experts
INFORMATION AVOIDANCE
Allow the woman to 'opt-in' to information ie provide written information that they can read when they are ready

- Midwife role (home visits)
- Planning antenatal visits
- Planning ahead (packing bag/info re birth/funeral)
- Planning place of birth

- Plan of care for remainder of pregnancy and birth
- Plan neonatal care if survival is likely
- Postnatal examination and consultation
  outstanding test results given
  appropriate risk assessment for future pregnancies
  referral for genetic counselling if appropriate
  pre pregnancy counselling
- Assessment of emotional wellbeing
- Acknowledgement of experience
- Support groups
- Ongoing access to designated 'link support' person and also to provide access to support in future pregnancies

5.2 Characteristics of participating women

Between April 2004 and August 2005, 62 women with a range of fetal anomalies were invited to participate of whom 38 (61%) women with 41 fetuses (39 anomalous) agreed to take part. Thirty women continued the pregnancy (nine primigravidae and twenty-one multigravidae). Eight women (one primigravida and seven multigravidae), each of whom were carrying a fetus with one of the following anomalies: anencephaly (n=3), hydrocephalus, Triploidy, Trisomy 18, Trisomy 21 and diaphragmatic hernia, chose to terminate their pregnancy outside the jurisdiction.

Characteristics of participating women in relation demographic data and obstetric history, and details regarding the index pregnancy were accessed predominantly from case notes and are presented in Table 1. Women's backgrounds were diverse and although all women were partnered at the time of recruitment, the quality of the relationship varied from married/living as married and unsupported to happily married/living as married and well supported. Women's financial circumstances also ranged from receiving financial assistance from the state to a household income in excess of €100,000 (based on combined earnings). All women had completed early or late secondary school education, and 14 women had completed third level education at diploma level or above. The majority of women (n=27, 71%) were aged between 30 and 39 years (mean 32.89 years, SD 5.535, range 18-44). Ten women were primigravidae, two of whom were pregnant with twins with each having one fetus with a lethal or likely lethal anomaly and one apparently normal fetus. One of the multigravidae women was also pregnant with twins, both with lethal or likely lethal anomalies. Twenty-eight women were multigravidae, of whom 20 were para 1, 3 were para 2, 4 were para 3 and 1 was para 10. The frequencies of anomaly by classification were as follows: Type 1 (n=15), Type 2a (n=2), Type 2b (n=4), Type 3 (n=5), Type 4a (n=5), Type 4b (n=7), Type 5 (n=1) (Table 1). Each category was represented, demonstrating that, in this sample, the actual diagnosis did not appear to influence women's choice to participate.

Table 1: Characteristics of participating women (N=38, 41 fetuses (39 anomalous, 2 normal)

o	Ref Site	Pseudonym	Age	Parity	Diagnosis	Type of anomaly	SEG	PRH	Religion	Religiosity	TOP/ Cont	Neonatal outcome	Gestation Phase 1	Gestation Phase 2	Postnatal Phase 3	Invasive testing
1	Tertiary	Dáire	23	1+0	Omphalocele	4a	F	Nil	RC	No	C	NND	NIP	35+ /40	14 /40	Amnio Normal
2	Tertiary	Fay	36	1+0	Gastroschisis	4a	C	Nil	RC	No	C	Repair, high Burden of care	27/40	E-Delivery 35/40	Too busy With care	Not offered
3	Tertiary	Eavan	37	2+0	Cloacal	4a	B	Nil	RC	No	C	Repair, high Burden of care	21/40	36+/40	Too busy With care	Bladder tap normal
4	Tertiary	Emma	34	1+0	OEIS complex, Twins, 2 Affected	1	G	Nil	RC	No	C	NND x2	23/40	33+/40	8/40 after 2nd NND	Not offered

o	Ref Site	Pseudonym	Age	Parity	Diagnosis	Type of anomaly	SEG	PRH	Religion	Religiosity	TOP/ Cont	Neonatal outcome	Gestation Phase 1	Gestation Phase 2	Postnatal Phase 3	Invasive testing
5	Tertiary	Maoliosa	36	1+0	Talipes	4b	B	Nil	COI/E	No	C	Repair	23/40	34/40	10/40	Not Offered
6	Tertiary	Lori	37	1+0	T 21	3	D	Nil	RC	No	C	Cardiac, high burden of of care	20/40	34/40	7/40	Amnio T 21
7	Tertiary	Shannon	18	0+0	? T 21	3	G	Nil	RC	No	C	T 21 NND	21/40	27/40	6/40	Refused due to 1:3 risk of T21
8	Tertiary	Emer	34	1+1	Diaphragmatic hernia	4a	H	Nil	RC	No	C	Repair	NIP	37/40	8/40	Not Offered
9	Tertiary	Hayley	28	1+0	Cardiac	4a	E	Nil	RC	No	C	NND	NIP	35/40	Too Distressed	Not Offered

o	Ref Site	Pseudonym	Age	Parity	Diagnosis	Type of anomaly	SEG	PRH	Religion	Religiosity	TOP/ Cont	Neonatal outcome	Gestation Phase 1	Gestation Phase 2	Postnatal Phase 3	Invasive testing
10	Regional	Alannah	34	1+0	Renal	4b	H	Nil	RC	No	C	Repair	Late referral	37/40	8/40	Not Offered
11	Tertiary	Trina	32	1+0	Talipes	4b	D	Nil	RC	No	C	Ongoing	23/40	36/40	11/40	Not Offered
12	Tertiary	Cliona	34	1+0	CCAML	4b risk 4a	D	Nil	RC	No	C	Repair	24/40	36/40	11/40	Not Offered
13	Tertiary	Keeley	29	3+8	Ventriculo-megaly	2b	G	Fetl loss	RC	No	C	High Burden of care	30/40*	36/40*	8/40*	Amnio Normal
14	Tertiary	Ciara	30	1+0	Suspicious	5	D	Nil	RC	No	C	High Burden of care	19/40	25/40	9/40	Amnio Normal
15	Tertiary	Aisling	34	0+0	Renal	4b	D	Nil	RC	No	C	Repair	24/40	37/40	8/40	Not Offered

o	Ref Site	Pseudonym	Age	Parity	Diagnosis	Type of anomaly	SEG	PRH	Religion	Religiosity	TOP/ Cont	Neonatal outcome	Gestation Phase 1	Gestation Phase 2	Postnatal Phase 3	Invasive testing
16	Tertiary	Aoife	35	1+0	Triploidy	1	B	Nil	COI/E	No	T	TOP/IUD	25/40	TOP	7/40	Amnio Triploid
17	Regional	Niamh	28	3+0	Ventriculo-megaly	2b	G	Nil	RC	No	C	High Burden of care	23/40*	32+/40	8/40	Amnio Normal
18	Tertiary	Laoise	30	0+0	Anencephaly, Twins, 1 normal	1	D	Nil	RC	No	C	NND x1 Normal	25/40*	34/40	10/40	Not offered
19	Regional	Maeve	39	1+2	Turners Syndrome	3	I	Fetl loss	RC	No	C	High Burden of care	21/40	29/40	10/40	Amnio Turners (XO
20	Tertiary	Erin	35	1+0	Renal	4b	C	Nil	RC	No	C	Repair	23/40	Premature Delivery	16/40	Refused due to risk of

o	Ref Site	Pseudonym	Age	Parity	Diagnosis	Type of anomaly	SEG	PRH	Religion	Religiosity	TOP/ Cont	Neonatal outcome	Gestation Phase 1	Gestation Phase 2	Postnatal Phase 3	Invasive testing
														33/40		fetal loss
21	Regional	Fiona	34	2+0	Ventriculo-megaly	2b	D	Nil	RC	No	C	High Burden of care	30/40*	Participation D/C by researcher		Refused due to risk of fetal loss
22	Tertiary	Blannad	38	3+0	Talipes	4b	C	Nil	COI/E	No	C	High Burden of care (ALTE)	26/40	35/40	12/40	Not offered
23	Tertiary	Sian	44		? T21	3	I	Nil	RC	Yes	C	Normal	31/40	38/40	8/40	Refused wanted to hope normal

o	Ref Site	Pseudonym	Age	Parity	Diagnosis	Type of anomaly	SEG	PRH	Religion	Religiosity	TOP/ Cont	Neonatal outcome	Gestation Phase 1	Gestation Phase 2	Postnatal Phase 3	Invasive testing
24	Tertiary	Orla	38	0+0	Bladder outlet obstruction Twins, 1 normal	4a	C	Nil	RC	No	C	NND x1 Normal	18/40	31/40*	15/40	Bladder tap Normal
25	Tertiary	Molly	34	0+0	Anencephaly	1	B	Nil	RC	No	T	TOP/IUD	NIP	TOP at 21/40	5/40	Not Offered
26	Tertiary	Tara	30	0+1	Triploidy	1	C	Nil	RC	No	C	IUD	21/40*	IUD at 25/40	4/40*	Failed x2
27	Tertiary	Kerrie	35	1+1	Ventriculomegaly	2b	B	Nil	RC	No	T	TOP/IUD	NIP	TOP at 20/40	6/40	Not Offered
28	Regional	Caitlin	31	3+0	Potters Syndrome	1	G	Nil	RC	No	C	IUD	23/40	34/40	12/40	Not offered

o	Ref Site	Pseudonym	Age	Parity	Diagnosis	Type of anomaly	SEG	PRH	Religion	Religiosity	TOP/ Cont	Neonatal outcome	Gestation Phase 1	Gestation Phase 2	Postnatal Phase 3	Invasive testing
29	Tertiary	Doireann	34	0+0	Triploidy	1	C	Nil	RC	No	C	IUD	16/40	IUD at 25/40	4/40	Amni Triploid
30	Tertiary	Muireann	40	1+0	T 18	1	C	Prev IVF	RC	No	T	TOP/IUD	NIP	TOP at 21/40	5/40	Amnio T 18
31	Regional	Ava	34	0+0	Limb body wall Complex	1	C	Nil	RC	No	C	IUD	25/40*	IUD at 32/40	8/40*	Amnio Normal
32	Regional	Breffni	22	1+1	Potters Syndrome	1	G	Nil	RC	No	C	NND	27/40	Premature Delivery at 32/40	Moved house couldn't locate	Not offered
33	Regional	Kasey	24	0+0	Limb body wall complex	1	E	Nil	RC	No	C	NND	24/40*	Del 30/40* Arrived for interview	16/40*	Amnio Normal

o	Ref Site	Pseudonym	Age	Parity	Diagnosis	Type of anomaly	SEG	PRH	Religion	Religiosity	TOP/ Cont	Neonatal outcome	Gestation Phase 1	Gestation Phase 2 D3	Postnatal Phase 3	Invasive testing
34	Tertiary	Regan	32	1+0	anencephaly	1	C	Nil	COI/E	No	T	TOP/IUD	TOP/IUD	NIP	TOP at 21/4	4/40
35	Regional	Heather	26	0+0	Cloacal	1	H	Nil	RC	No	C	NND	26/40*	33/40*	12/40*	Amnio Normal
36	Tertiary	Bethan	35	1+0	Anencephaly	1	C	Infert	RC	No	T	TOP/IUD	TOP/IUD	TOP at 15/40	6/40	Not Offered
37	Tertiary	Áine	35	2+0	Diaphrag-matic hernia	4a	D	Nil	RC	No	T	TOP/IUD	TOP/IUD	TOP at 20/40	4/40	Not offered

o	Ref Site	Pseudonym	Age	Parity	Diagnosis	Type of anomaly	SEG	PRH	Religion	Religiosity	TOP/ Cont	Neonatal outcome	Gestation Phase 1	Gestation Phase 2	Postnatal Phase 3	Invasive testing
3. 8	Terti ary	Laura	44	1+0	T 21	3	D	D C	RC	No	T	TOP/IU D	TOP/IU D	TOP at 15/40	20/40 Wasson holiday	Amnio T 21

Index to table abbreviations [48]

48 SEG: B: Higher professional, C: lower professional, D: non-manual, E: manual skilled, F: semi-skilled, G: unskilled, H: own account workers, I: Farmer. http://www.cso.ie.

TOP: termination of pregnancy IUD: intrauterine fetal death

DC: Delayed conception: pregnancy achieved after one year without intervention.

Infert: history of infertility not requiring IVF

NIP: not invited to participate either due to diagnosis made pre- study commencement or during initial phases of study when staff unfamiliar with recruitment procedures, or TOP planned within days of diagnosis

E-delivery: emergency delivery pre-interview.

Premature delivery: pre-interview.

ALTE: acute life threatening episodes, on apnoea monitor at home.

* Partner present for interview.

5.2.1 *Interviews in Phase 1*

Twenty seven women were interviewed within 4-6 weeks of receiving the diagnosis (ten primigravidae, seventeen multigravidae). Four women who took part in phase 2 had been diagnosed before recruitment to the study began or were referred late from a regional centre for a second opinion and were at an advanced gestation at their first interview. Although the time from diagnosis to interview exceeded four weeks, this did not negatively affect their ability to recall the event. Eighteen of twenty seven women also took part in phase two. Aoife who took part in phase one opted to terminate the pregnancy and consequently, was interviewed for a second time post the birth.

5.2.2 *Interviews in Phase 2*

Of the 30 women who continued the pregnancy, 22 were interviewed pre-birth. Eighteen of these were also interviewed in phase 1. Four were recruited at an advanced gestation and were interviewed for the first time in phase two. Seven of the women (23%, n=30) who had taken part in the initial interviews delivered unexpectedly shortly after the diagnosis, and consequently were not interviewed again until after the birth. One such woman, Fiona, developed a depressive illness and was receiving care from the psychiatric team. In order to ensure that she did not become increasingly vulnerable through taking part in the second interview, Fiona was excluded from further participation in the study from this point forward. Of the seven women who delivered prematurely, 5 were primigravidae and 2 were multigravidae. Three babies died in utero and two in the immediate neonatal period. This compares with one death in utero and six neonatal deaths in the pregnancies that continued to term (Table 2). During this phase of data collection, the second interview with Kasey was somewhat unusual. We had arranged on a Thursday evening to meet the following Monday for the pre-birth interview. I called to Kasey's house as arranged to discover that she had given birth on the Friday night. Her baby had died soon after the birth. I was about to leave on discovering what had happened but she insisted I come in and hear about her experience. After listening to her experience, and as I was about to leave, she asked if I would call back for the 'proper' postnatal interview as she wanted to see me again. I

agreed to return and we met sixteen weeks later. It was after this interview that I cried most of the way home.

Table 2: Characteristics of participants in Phase 2 (n=22).

Type	Description of premature deliveries (pre-interview)	N=8
1	Lethal (e.g. anencephaly, renal agenesis, Trisomy 13 & 18)	4
2	Non lethal with normal karyotype	1
	A: likely physical handicap only (e.g. limb abnormality, skeletal deformity)	
	B: likely physical and mental handicap(e.g. Neural tube defect, Dandy Walker malformation)	
3	Non lethal with abnormal karyotype (e.g. Trisomy 21, Turners Syndrome)	1
4	Structural abnormality with an option to repair	1
	A: with a significant risk of mortality (e.g. diaphragmatic hernia, abdominal wall defects, cardiac)	1
	B: without significant risk of mortality (e.g. talipes, some renal anomalies)	
5	Suspicious (e.g. multiple markers/anomalies with normal karyotype)	0

Type	Description of anomaly in those interviewed	N=22 (23 fetuses)
1	Lethal (e.g. anencephaly, renal agenesis, Trisomy 13 & 18)	7
2	Non lethal with normal karyotype	1
	A: likely physical handicap only (e.g. limb abnormality, skeletal deformity)	2
	B: likely physical and mental handicap(e.g. Neural tube defect, Dandy Walker malformation)	
3	Non lethal with abnormal karyotype (e.g. Trisomy 21, Turners Syndrome)	3
4	Structural abnormality with an option to repair	3
	A: with a significant risk of mortality (e.g. diaphragmatic hernia, abdominal wall defects, cardiac)	6
	B: without significant risk of mortality (e.g. talipes, some renal anomalies)	
5	Suspicious (e.g. multiple markers/anomalies with normal karyotype)	1

5.2.3 *Interviews in Phase 3*

Thirty seven of the thirty eight women recruited were eligible to take part in phase 3 interviews, and 33 interviews were conducted. Seven of the eight women who opted to terminate the pregnancy were interviewed between 5-7 weeks of the birth. Laura was interviewed 20 weeks following her termination as she had been on holiday for eight weeks. Of the thirty women who continued the pregnancy twenty nine women were eligible to participate in phase 3 interviews. Fay and Eavan were too busy caring for their baby with significant health care needs to take part. Each woman made several appointments to meet but all were cancelled due to hospital appointments or difficulty arranging childcare. Breffni moved house and could not be located. Hayley's baby had died at five days of age, and this crisis precipitated a relationship break up with her long-term partner and father of her young son. She decided that talking about it would be too distressing and she was given contact details to access psychological support to deal with both her grief and the breakdown of her relationship with her partner. Seven of the eight women who had given birth prematurely were interviewed again; suggesting that drop out from the study was minimal. Of the 30 women who had continued the pregnancy, four gave birth to stillborn babies. Ten babies born to nine women were liveborn and subsequently died in the neonatal period. Both of Emma's twins died 16 weeks apart, and Orla and Laoise both lost one of their twins and both also gave birth to a second healthy baby boy.

5.2.4 *Partner presence at interviews*

Although the information leaflet indicated that the purpose of the study was to explore women's experience of the phenomenon, nine women invited their husband/partner to be present at some or all interviews (Table 1). Women were not questioned directly on their choice therefore the reasons as to why some partners were present are based predominantly on my assessment of the context or passing comments made during the interviews. Keeley had three young children and as her husband was unemployed he played an active role in childminding. He was present predominantly to keep the children occupied, however, when in the room he did contribute to the conversation. Keeley's freedom to speak openly did not alter depending on his presence or absence over the course of the interview. At the second interview when Keeley expressed

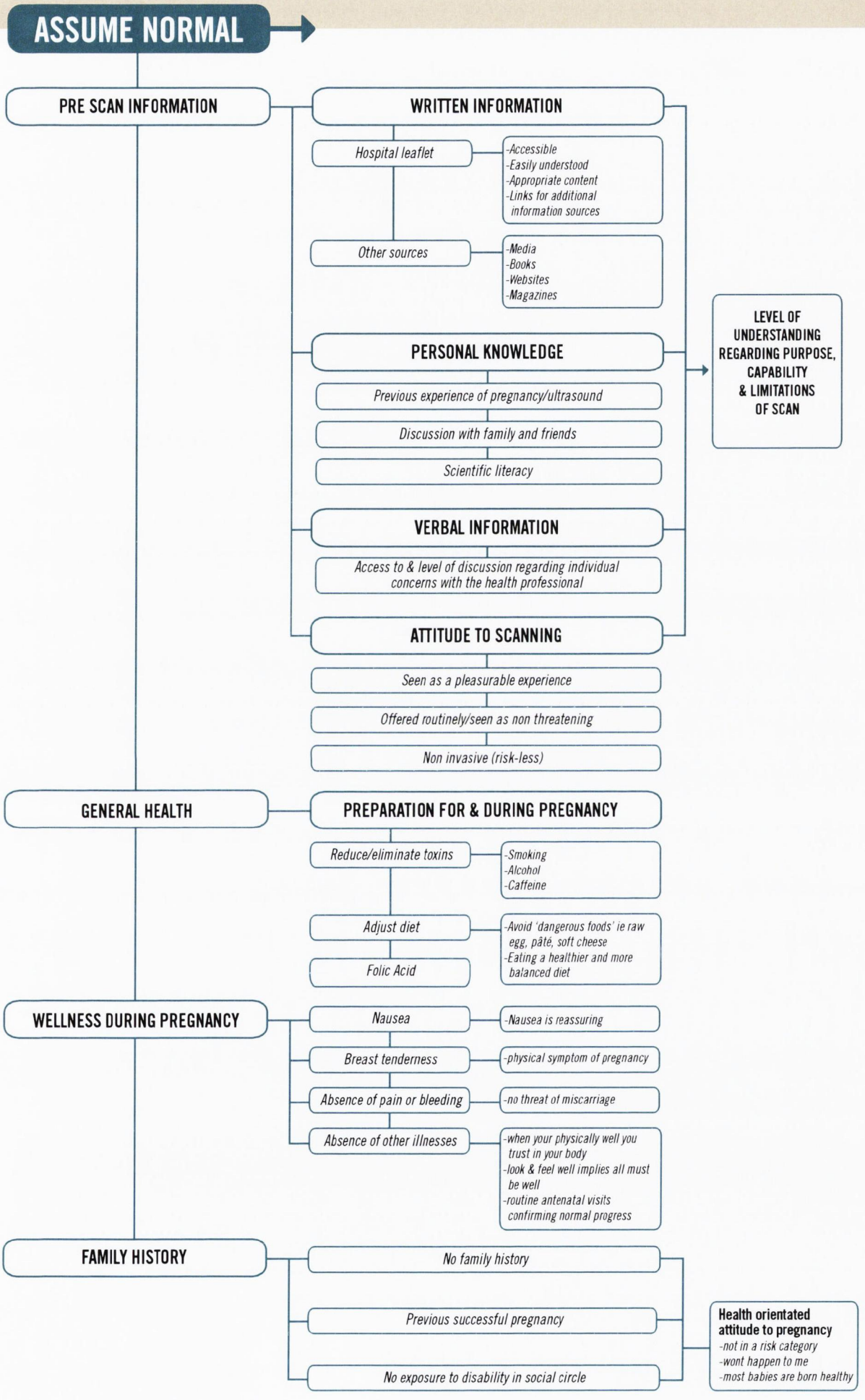
suicidal intention, his presence was vital in ensuring Keeley's safety before arrival at hospital. Both Niamh and Laoise's husbands were present at the first interview. My impression was that Niamh thought the interview would be more like a survey, asking factual questions regarding the diagnosis, and she felt her husband's presence would enhance the accuracy of recall. Once she realised this was not the case she chose to participate alone as she felt she derived therapeutic benefit from talking about her experience. Laoise felt more secure meeting me for the first time with her husband present, and once the first meeting was over he did not attend any further interviews. Fiona's husband was also present at the only interview conducted and once again recognised her need for psychiatric support and was extremely helpful in arranging same. Orla's fiancé was present at the second interview (they married eight weeks before the birth). He contributed very little; however, his presence did not alter the extent to which she spoke about the issue when compared with the first interview. Although I emphasised to Orla at the first interview that I was particularly interested in her experience and that his presence was not essential, I feel Orla wanted him to be present at least once to show she was in a supportive relationship, perhaps because it was not as yet regularised. Tara, Ava, Kasey and Heather had their husbands/partners present at all interviews. Each partner contributed freely during the interviews and at times displayed the depth of their emotional response to the situation. These couples presented themselves as a unit, representing both the collectiveness and individuality of how they reacted to this loss. This process of merging strengths has been identified as a coping strategy used by couples in other traumatic health care situations (Morgan et al. 2005). During the interviews where partners were present, at no time did I feel that partners were there with the express intention of controlling, monitoring or limiting what the woman had to say, and I never felt uncomfortable in their presence. My assessment of these couples was that they felt as parents or as parents in prospect (Redshaw and van den Akker 2006), that the loss was a significant blow to them both and therefore I would want to understand the impact on men as well as women, as individuals and as a couple. The data from these women did not differ noticeably in relation to their composite experience when compared with the composite experience of women whose partners were not present.

5.3 'Assume Normal': phase one of the process of Recasting Hope

How women cope with the diagnosis of fetal abnormality has received little research attention internationally and no reference could be found to any inquiry conducted within an Irish context. The grounded theory method used for this study specifies that it would be inappropriate to complete a detailed review of the literature prior to data collection (Glaser and Strauss 1967, Glaser 1978, 1992). However, as a midwife with clinical experience in the substantive area and having undertaken research that focussed on women's expectations of ultrasound I was already familiar with some of the technical literature. My background meant that I was also familiar with some grief models such as those proposed by Kubler-Ross (1970), Parkes (1972) and Bowlby (1980). However, these earlier grief models, based on the death experience, may be inappropriate to describe women's reaction to the diagnosis, as death grief is potentially terminable, whereas parental grief in the absence of death can be chronic (Kurtzer-White and Luterman 2003). As my knowledge of these models was relatively superficial, I did not employ my time testing the grief-related concepts that had been proposed previously. In addition, the historical location of the inception of these earlier models has led to problems with a view of bereavement as simplistic, linear, and unidirectional, alluding to a final stage where resolution is achieved for the bereaved individual. Although there has been a substantial amount of work within the area of bereavement, I had almost no *a priori* knowledge of more recent models or other potentially relevant psychological theories and therefore I proceeded to collect data with little more than an abstract wondering about how other forms of loss would be similar or unique when compared with loss involving the death of a loved one. In keeping with the methodology, earlier interviews were conducted using predominantly exploratory questions. As data were collected and analysed simultaneously, further comparison with additional data was used to help refinement of the emergent concepts and indicators. As a tentative conceptual framework was generated I returned to the literature for the specific purpose of seeking additional clarification or fine-tuning of the concepts or key psychosocial processes as they emerged. This is the essence of the practice of theoretical sampling. Combinations of exploratory and confirmatory questions were subsequently

used within the interviews in order to sample theoretically for additional data, to test hypotheses and to clarify the 'fit' of modifications made resulting from the literature search. Emergent concepts were compared with more highly developed concepts sampled from existing literature, and in turn these were woven back into the framework.

'Assume Normal' is the first phase in the process of Recasting Hope and represents the context in which women participate in ultrasound screening. This is the only phase in the process that relates to the time pre-diagnosis and explores women's assumptions about fetal well-being and the nature of ultrasound screening in pregnancy. This first stage in this pattern of adaptation highlights the baseline factors that influence a positive or negative outlook for the pregnancy in order to explore the extent to which women were prepared to receive an adverse diagnosis.


ASSUME NORMAL
PRE SCAN INFORMATION
WRITTEN INFORMATION
Hospital leaflet
-Accessible
-Easily understood
-Appropriate content
-Links for additional information sources
Other sources
-Media
-Books
-Websites
-Magazines
PERSONAL KNOWLEDGE
Previous experience of pregnancy/ultrasound
Discussion with family and friends
Scientific literacy
VERBAL INFORMATION
Access to & level of discussion regarding individual concerns with the health professional
ATTITUDE TO SCANNING
Seen as a pleasurable experience
Offered routinely/seen as non threatening
Non invasive (risk-less)
LEVEL OF UNDERSTANDING REGARDING PURPOSE, CAPABILITY & LIMITATIONS OF SCAN
GENERAL HEALTH
PREPARATION FOR & DURING PREGNANCY
Reduce/eliminate toxins
-Smoking
-Alcohol
-Caffeine
Adjust diet
-Avoid 'dangerous foods' ie raw egg, pâté, soft cheese
-Eating a healthier and more balanced diet
Folic Acid
WELLNESS DURING PREGNANCY
Nausea
-Nausea is reassuring
Breast tenderness
-physical symptom of pregnancy
Absence of pain or bleeding
-no threat of miscarriage
Absence of other illnesses
-when your physically well you trust in your body
-look & feel well implies all must be well
-routine antenatal visits confirming normal progress
FAMILY HISTORY
No family history
Previous successful pregnancy
No exposure to disability in social circle
Health orientated attitude to pregnancy
-not in a risk category
-wont happen to me
-most babies are born healthy

5.3.1 Pre-scan information

The literature on women's views of ultrasound scanning reports an overwhelmingly positive experience of the examination (Hyde 1986, Green et al. 1992, Green 1994, Rapp 1999, Lalor 2000, Stephens 2000) and, on occasion, inordinate expectations of technology (Eurenius et al. 1997, Lalor 2000). As some women participating in routine screening programmes will inevitably be faced with their scan uncovering an adverse finding, it is recommended that detailed information regarding ultrasound be given to women before examination (Field et al. 1985). The importance of provision of accurate information regarding the purpose, capability and limitations of the examination has been debated, yet there is difficulty in ensuring appropriate content and method. In order to ensure that a woman is fully informed Abramsky (2003) suggests that information should be provided on conditions being screened for, effects and prognosis of the condition, her prior risk for the condition, whether the test is for screening or diagnostic purposes, the sensitivity and specificity of the test and possible consequences of information that may be revealed. However, previous research in the study centre (Lalor and Devane 2007) and a national survey of ultrasound provision in Ireland (Lalor et al. 2006a, 2006b) have demonstrated that provision of both written and verbal information in relation to routine ultrasound in pregnancy is poor, yet uptake rates for ultrasound screening programmes are almost 100%. So why is routine ultrasound screening viewed as non-threatening?

Provision of information

The importance of provision of information to women before they are scanned has been debated (Eurenius et al. 1997) and women in this study referred to the effect of a lack of information on their preparedness for an adverse outcome.

J: Did you get any information about the scan from the clinic?

... he [the consultant] wasn't very informative, it was actually the midwife, [who provided information] they were great. I didn't get any written stuff; I didn't even know what they

were scanning for. I thought they were scanning to give you a more accurate date... I wasn't prepared really at the end of the day for what was involved. (Aisling)

..... they didn't say anything in the clinic as to what to expect or what the scan was about, it was just here is the number and ring up. (Emer)

The lack of information on the purpose of the examination reinforced the non-threatening aspect associated with ultrasound screening, leaving women to look forward to the examination with anticipation. This is in stark contrast to general experiences in relation to other forms of screening where concerns regarding the test are associated with the probability of an adverse outcome.

J: Did you get any information about the scan?

No just your scan is on such and such a date, such and such a time. No, no information on what it was for. We were excited [going for the USS] we'd never thought there would be anything wrong and we were excited at seeing him or her at the time and getting the picture. We were in the waiting room discussing whether we'd ask the sex of the baby... once I saw the heartbeat I thought everything is fine, then she asked me if there was a history of kidney disease...then she said there was a shadow on the kidney...I was in floods of tears. (Erin)

Yeah, to make sure it was growing, it [possibility of finding an anomaly] never crossed my mind, and this is my fourth...and I started crying because I knew it was serious if they wanted us to hang around to see a doctor. (Keeley)

Routine ultrasound screening in pregnancy represents an example of the newer paradigm of surveillance medicine previously described whereby normal populations are screened for an illness that has not manifested itself through the identification of risk factors (Armstrong 1995). This blurring of traditional boundaries between health and illness is evident in women's experiences whereby ultrasound in pregnancy has been 'normalised' to just another aspect of routine antenatal care. These accounts emphasise the transition that has occurred in maternity care from a time when ultrasound was

offered selectively, and women were to be sympathised with if offered the test (Hyde 1986). The feminist argument that routine scanning promoted medical over maternal expertise (Oakley 1979, 1980, 1984) that was evident in women's accounts of their attitudes to scanning twenty years ago (Hyde 1986) is no longer a feature. Screening has become an integral part of antenatal care and ultrasound is now seen as a necessary source of reassurance. As almost all women currently experience the procedure, and anxiety associated with ultrasound has moved from participating in screening into the arena of non-reassuring results.

Personal knowledge

All of the women in the study anticipated that their fetus would be healthy and did not perceive themselves to be in a risk category for the occurrence of a fetal anomaly. Given the paucity of information provided by health professionals in relation to ultrasound screening, multiparous women, all of whom had had an ultrasound in the previous pregnancy, spoke consistently of how their previous experience of ultrasound had influenced their participation in screening this time around.

J: How was your first pregnancy, did you have a scan?

Completely different, a brilliant pregnancy right through. I had a scan at 20 weeks, something like that... and everything was perfect. I had sort of heard about it [USS] from other people so it was something I was looking forward to. I probably think it was to check for dates and just to check everything was generally okay. This time she [community midwife] gave me a leaflet, I didn't even read it... I thought everything was going to be okay. I remember lying there trying not to cry. (Ciara)

J: Why were you offered a scan?

Just to check my dates, but I knew my dates, I used to write it down every month. I suppose I thought this [the USS] is routine like my first pregnancy, and that was fine so this one would be fine. I didn't even think that there was going to be anything wrong. You think everything is going to be fine. (Lori)

J: So you were offered a scan?

Yeah, I was coming from this really cocky confident place, I can make babies...there was no reason why I would have a problem. (Emer)

Maternal confidence was also influenced by the model of antenatal care being offered, as being considered suitable for midwifery-led care reinforced the absence of risk.

J: So you booked for antenatal care?
Yeah, I had my first visit, I was 13 weeks, and she made it in [X hospital], so she done the blood and the usual... and they [the midwives] were happy enough to take me on, especially since I had a good labour and birth the last time. I was the ideal candidate at the time [no problems]. (Ciara).

Primigravidae in particular may have their expectations of ultrasound formed or influenced by what they hear on the grapevine. Molly had several sisters, each of whom had experienced pregnancy previously. Most of the advice Molly received was in relation to booking early if she wished to increase the likelihood of access to her preferred consultant. When ultrasound was mentioned by her friends or family it was in a positive context, as she recalled how the proud parents exhibited the ultrasound photo with pride (Pershutte 1995).

J: What were your expectations of the scan?
A picture, kind of like we were going in to get a picture of the baby like. And eh just that was it. I knew they were checking for things but like really they are checking for things while I am lying there going look at the picture not that they are checking for things and they could possibly tell me something was wrong. (Molly)

Molly's account is not dissimilar to that of other women, and is reflective of the social aspect that routine ultrasound has acquired (Mitchell 2004). All of the women said they had informed friends and family of the pregnancy and the date scheduled for the ultrasound. The influence of ultrasound on parental emotional well-being is strong (Baillie et al. 1997) and many women have chosen to share this experience with family and friends (Proud 1995).

J: Did you bring anyone with you [for the scan]?
Yeah, mm.. [my partner] and [name] my son came with me. I was assuming everything was okay and I wanted him to see the baby. Of course, he is big enough now...and he was really excited. It was great now, when the baby first came on the screen, you could see it...but then [there was a problem]. (Ciara)

You expect to go in and like he [husband] was very excited, he even said to my mother-in-law it won't be long... you're in and out, not knowing what is ahead of you. I took it for granted [fetal wellbeing]. (Emma)

This was later to have consequences for informing those more remotely connected of the presence of the anomaly. Some authors have hypothesised that a reduction in anxiety levels post ultrasound are associated with increased anxiety in anticipation of the ultrasound (Green et al. 1992). This notion of anticipatory anxiety did not manifest in the data and some women described how their pre-ultrasound discussion in the waiting room was dominated more often by a debate as to whether to seek out the fetal gender rather than a heightened concern for fetal well-being.

We were sitting actually down in the waiting room, there was a couple before us and they went in and we were discussing whether we'd ask the sex of the baby and then I decided no we wouldn't and my husband was looking kind of, you know will you and I said no we're not going to find out. (Erin)

Cliona alternatively spoke of how they approached the midwife once the ultrasound began to identify fetal gender as part of the examination.

So first of all we said can we get some of the nice stuff out of the way, I said we were looking to find out the gender ...[then a problem was identified] I said Jesus if you had seen the baby it was like she was ready to be born, it was just like, you know, features and turning around and scratching her neck, God how could anything be wrong with this child. (Cliona)

Later the data will show that this technologically mediated image of the fetus often gave an impression of fetal maturity incongruent with gestational age, raising women's expectations of the treatment possibilities available and reinforcing the image of the child to be (Sherwin 1992). The data will demonstrate that the ultrasonic image of the fetus was to also result in an intensification of care towards the fetal patient (Petchesky 1987), however, this was not necessarily always incongruent with the mother's wishes. It is evident that women participating in ultrasound screening receive little information regarding the potential of a fetal anomaly being detected. Some women broadened their search beyond the health care staff and indicated that they searched the internet and pregnancy books for further information. However, they predominantly looked for information regarding fetal development in order to anticipate the extent to which fetal features would be visible at the examination rather than information regarding the efficacy of screening.

Attitude to scanning

In the absence of any perceived risk regarding fetal well-being, women and their partners, were excited and happy coming for the scan, and eagerly awaited the appearance of their baby on the screen.

Well I know the main reason for the scan is for dates she [clinic secretary] just booked me in for a scan with my first visit. I just assumed everything was going to be fine.. Mostly good things happen, the statistics are much more in favour of things going right... and you're looking forward to the scan. (Eavan)

It was just a routine scan [in this pregnancy], there was no discussion... you don't expect anything to be wrong...I was very blasé about it...then it was like someone burst your bubble. (Fay)

[I thought] if it's routine [USS] I'll have it...routine is best practice. (Maolíosa)

Women's attitudes and expectations of ultrasound were influenced by the non-threatening presentation of the examination by health professionals, previous personal

experience, and information gleaned from family members associated with ultrasound, all of which created the expectation that attending for the ultrasound scan more closely resembled a social event than that of a medical examination.

5.3.2 General health

Cognitive psychology research suggests that we seldom consider health screening in terms of probabilistic information, instead relying on reasoning heuristics such as 'representativeness' (West and Bramwell 2006 p61). The issues highlighted previously confirm that position as pregnancy is viewed as a normal physiological process. However, being in good health was an additional factor associated with the likelihood of a positive pregnancy outcome.

I was in great health... I felt brilliant. We wouldn't be the type to think of that [fetal anomaly]. (Hayley)

There was an element of I do all this [diet, exercise, no alcohol], I have a good diet going on here... and I mean where else would you get 98% odds [of a healthy baby], you would never get that in the lottery, you'd get that nowhere, your chances are really good so don't worry about it, try and enjoy it. (Doireann)

Other authors have shown that women with both low (Rubin 1975) and high (Corbin 1987) risk pregnancies take action to control their environment, diet and activity in order to increase their chances of having a healthy baby. Participating women who planned their pregnancy also used strategies to maximise their chances of a healthy outcome through restricting alcohol, improving dietary habits and taking folic acid pre-conceptually.

I was so covered on the folic acid because it was planned and I am that kind of a person. So it was very much I will take this because, you know...when I start something it's like a crusade...I have done what I have been told to do like, nothing can happen now. (Molly)

However, women who had taken folic acid and subsequently received a diagnosis of a neural tube defect, trying to understand why the anomaly had occurred was to pose a unique challenge. For those women who discovered they were pregnant unexpectedly, modifications to lifestyle began with a positive pregnancy test.

But I never thought I was pregnant because even though we done some pregnancy tests, I only got me periods back [after a recent birth]...we done what 3 pregnancy tests. When I found out I was pregnant now on this baby what happened was we were after being away in Lanzarote weren't we? But I was saying to him [husband], even eating out during the day there was certain things like I was avoiding, I was going no I can't eat that. (Fiona)

These alterations in lifestyle re-affirm women's commitment to the pregnancy once recognised and positive efforts to control alcohol and dietary intake were only abandoned when the outcome for the pregnancy seemed hopeless.

5.3.3 Wellness during pregnancy

In addition to feeling healthy, the absence of any threat to the pregnancy, such as pain or bleeding further supported the assumption that the pregnancy was progressing normally. Positive indicators included the absence of warning signs, such as vaginal bleeding associated with threatened miscarriage, previously successful pregnancies and the existence of normal symptoms of pregnancy such as nausea or vomiting.

J: How did you feel about the morning sickness?
It was driving me mad but you know at the same time I was so, so excited about being pregnant, and its good isn't it? (Molly)

I was sick, I was very sick. You know everyone says if you're sick... you will have a healthy baby...so I took it for granted. We were sitting there seeing other people coming out with their

little photos. She [midwife] said to us it was twins... well hold on don't get too excited. (Emma)

.....I think once you get past the 14 week mark and your risk of miscarriage is sort of gone, I don't think women realise how much of an assumption they put themselves under that it's going to be plain sailing. It's a bit of a knock back when you are told it's not. I thought they would have just scanned and said everything is okay. (Cliona)

For some women, experiencing pain or bleeding in the first trimester was not linked with the possibility of a congenital abnormality. Alannah had experienced recurrent bleeding in the first trimester both in a previous pregnancy and in the current pregnancy. She described her fifteen month old son as a "fighter with a strong personality like his parents" (Landsman 1998) and how she felt this baby would be the same.

I think I had seen so many pictures of the baby [from repeated viability scans] that I thought the baby looked very healthy and was kicking...I assumed the baby was going to be healthy. (Alannah)

Alannah was not alone in recounting how ultrasound provided reassurance even in the context of physical messages to the contrary. Doireann had also experienced recurrent first trimester bleeding and the combination of ultrasound and medical reassurance of fetal well-being influenced her outlook for the pregnancy.

The doctor had assured me the two weeks previously and there hadn't been much bleeding since then...I had taken a rest off work and had felt good, so I had been reassured by the doctor at that point that everything was ok. [Doireann attends the clinic with a second episode of bleeding] So I went in and I explained the situation. This was my first meeting with him at all, I haven't actually seen him since and I explained it to the first nurse, then I'd to go into the second nurse, I didn't think people actually were taking it that serious to be honest with you, because I don't, I don't know why but I kind of felt, ah sure she's in again or something, I don't know, maybe that's completely my paranoia but that's how I felt. And I

also heard them talking about it outside, when they brought me in I heard them explaining the situation again to the doctor. So he came in then and he said so what's the story and I said I've been bleeding a lot, and he said ok well lets look so he did a really quick scan [it took] about 20 seconds he looked and he went ok the baby is there, that's fine he said, em there's no problem, eh the baby is supposed to be where its at and he looked at it, that's grand, that's no problem, he said has anyone given you an internal examination, I said no, so he said ok I'll give you an internal examination, so he did that. And he did discover there was blood there so I knew I wasn't going mad, that I knew the source was that direction as opposed to the haemorrhoid as such. So he said ok that's fine, when is your scan and I said its in about two weeks time and he said okay keep that appointment and he walked off and that was it, so it was all very quick and to the point, he was looking for the blood and that was it and he didn't see say anything as such, that was fine. So then I went in for the scan two weeks later

J: How did you feel about that session?
I thought it was a bit rushed, yeah I thought it was all a bit quick and rushed and all that kind of carry on but at the same time I was reassured that everything was alright and everything wasn't alright as it turns out if he had looked, if I'd been sent to the fetal unit they would have looked at the size of the baby and then they would have known, that's where the problem lies, they would have known then....Then when I went in for the scan [to the fetal assessment unit]and anyway I knew then, really as soon as the midwife looked at it that she wasn't happy, she noticed the baby was tiny basically. So I wasn't, at that point I wasn't really that worried because I kind of felt God you know back in our mother's days they didn't have scans, maybe one of us was tiny, you know what I mean? (Doireann)

Doireann felt that her concerns were not been taken seriously and the combination of a patriarchal attitude armed with technology subsequently undermined her confidence in her own judgement regarding the pregnancy (Oakley 1979, 1980, 1984). Nevertheless, maintaining hope that the pregnancy would result in a positive outcome even within the context of negative feedback remains a strong force. Aoife experienced recurrent vaginal loss thought to be secondary to spontaneous rupture of membranes. However,

prior to the onset of these physical symptoms she described how she did not feel the same about this pregnancy when compared to being pregnant with her son.

That is the thing, from the ten weeks and when I had this leak, like I knew it was amniotic, like I had the feeling sometimes that people didn't think I knew what I was talking about or they thought I just pee'd my pants or something. But no, I knew. I remembered what amniotic fluid looks like and this is what it was. I just didn't feel as good about this pregnancy from early on and like I was looking forward to that feeling but it never came...and I can't remember if I felt that way even before the fluid leak or not. I don't think I was feeling that good even when we knew I was pregnant, when we did the test and found out I was pregnant. I think from the very start I found it weird that I didn't get the same uplifting feeling that I had the first time...and then we went for the 20 weeks scan and the bleeding had stopped and things were okay

J: Had you any additional concerns because of this?
We just took it as one of these things. It's just a different pregnancy, which is all; no pregnancy is the same is what they are always telling us so I just thought its just bad luck. I was just bleeding a bit, and a bit of a leak which was just weird or I was running around too much. No, no we were still very optimistic about it I think. (Aoife)

Only one woman in the study spoke of her concern regarding fetal loss in the absence of bleeding and how she sought reassurance of fetal well-being from ultrasound.

I know the main reason for the scan is for dates, I was dying to have them just to make sure everything was okay. The pregnancy was grand, it wasn't quite the same, for [two daughters] I was feeling nauseous morning noon and night but for this baby I was feeling nauseous in bouts, really nauseous for a couple of days and then it was okay. But I don't honestly know whether this is just... Well I was sure I was going to have a miscarriage this time whereas on the other two I probably had little worries but this time it was like every day. I was thinking I am hoping I am not going to have a miscarriage.

J: Did you have any pain or bleeding?

No, I didn't have anything, just all in my head. But they were very real, the worries. I was feeling a bit down, but my dad was suffering from depression at the time so things were just, a few things were on top of me...then when you go for your scan, I was a bit anxious but overall I suppose I was still assuming that everything is going to be right its like when you get to 13 weeks [and the risk of miscarriage passes]. Yeah, so you breathe a sigh and move on to the next phase, and then you are looking forward to the scan because you want to check the next phase of your pregnancy so when that didn't happen it was awful. (Eavan)

Although women expressed concern regarding fetal well-being either in the presence or absence of symptoms, the concern always related to fetal loss, and the connection with a potential fetal abnormality was never made.

I am starting to have a little bit of bleeding. So she [the community midwife] was saying like you know just because it's the start of the pregnancy and maybe its that...You hear of people like having miscarriages but never did I think I was going to have one because of the three girls and then I said to him [husband] I said this has to be a boy. Because in their [husband's] family, there is a bit of a problem with carrying some of the boys. Now after getting the all clear and everything mm it went on say about three weeks later and I was grand and then I had a tiny bit of discharge so I rang her [midwife] and she said come out [to the hospital]. [A scan was arranged] and she [radiographer] said I will check it then she said no, everything is still perfect. (Niamh)

Within the context of this study, this was the only reference (albeit tenuous) made to a perceived link between pregnancy outcome and inheritance pathways.

5.3.4 Family history

The absence of fetal anomaly or known genetic disease in their family and immediate social circle increased women's confidence in the health of their fetus.

There wasn't a bother on me I was grand... you assume everything is alright rather than all wrong. (Sian)

I only discovered [I was pregnant] when my husband said to me you are getting sick a lot...I mean the only thing we did think of was hopefully this is a girl, at least we will have one of each. It never crossed my mind [fetal abnormality], I was so sick; I think there was a confidence there. In my immediate circle of friends and family...everybody else had a positive experience, nothing wrong anywhere. (Alannah)

J: Was there any genetic indication from your own family?
No, no, no we'd no background of anything like that at all; we were very shocked because nobody had any knowledge of [hydrocephalus] at all. (Kerrie)

Many women re-iterated the absence of known genetic links within the family and how this added to the shock of receiving an adverse diagnosis. The data have shown many factors that are involved in supporting an assumption of fetal normality within an Irish context and regularising second trimester ultrasound has created an environment where women attend to seek reassurance of presumed fetal well-being rather than the exclusion or confirmation of fetal abnormality. This differs significantly with the American experience (Katz Rothman 1988, Rapp 1999) whereby women without known risk factors for an adverse outcome embark on a conveyor belt of prenatal tests shifting the view of presumed fetal health to one where health is only confirmed in retrospect.

5.3.5 Women's views of pre-ultrasound screening information

As previously stated women maintained a health orientated attitude to pregnancy and did not view ultrasound screening in terms of the probability of receiving an adverse result. Given the positive attitude to screening held by health professionals and the dearth of available information, women were asked given that they had been unprepared to receive an adverse diagnosis if they would comment on how information regarding screening should be provided in the future. A few women spoke of how they felt they should have been given information on reasons for the ultrasound and possible outcomes.

J: How would you talk to a woman about the scan?

You can't prepare everybody for problems ... 99% of women will not have problems. If you could explain it to them and say we are going to look for abnormalities, small ones, large, they could be anything. (Aisling)

J: How much detail do you feel women should receive before the scan?

How much information is helpful to receive? Mmm, clear information on the purpose. (Maolíosa)

The majority, however, believed that it would only upset women to be told of the possibility that abnormalities that might be discovered.

Well you hope everything is going to be alright and that's enough...you don't ever consider you'll get bad news but if you gave me a list [incidence of detectable anomalies] I would be fretting for a week before I'd go up and who wants that? (Sian)

Mmm I tend to think more information is better....but one of the things I really liked about pregnancy is it is not treated as a disease- it's the way it should be. Keep it normal because when there is something wrong you have plenty of time to get upset and freak out about it. I have friends who were constantly worried [pregnancies in the USA] for no reason, you have natural worries anyway. (Aoife)

You go through worries that something might be wrong with the baby but that's normal, but it would be worse knowing [about all the possible abnormalities that might be found]. (Fiona)

I wouldn't do anything to burst anybody's bubble. You don't have to know anything bad until you have to deal with it. Definitely 99% of the time everything is fine...and like why? You worry enough on your first pregnancy so what is the point of saying it to somebody. I don't think it would achieve anything; you deal with things when they are thrown at you. But for anybody I know going to have a scan its good luck, I wouldn't put a damper on it. I don't think you need to, you have enough to worry about and its such a happy time. You find

out your pregnant and for most of us it's a fantastic experience...for most people nothing ever goes wrong so I don't think it would benefit. (Fay)

[Finding the balance] between knowing nothing and frightening the living daylights out of people...there should be some way of maybe telling people we are going to take measurements and make sure everything is progressing normally. Most women don't want to be confronted with a big list of things that can go wrong. (Tara).

For reasons previously highlighted, most women voiced a desire to treat pregnancy as normal until proven otherwise and raised concerns expressed by others (Oliver et al. 1996) that providing extensive detail about what can go wrong as has been recommended by others (RCOG 2000), may create needless anxiety for the 98% of women who will not have adverse findings. Although women in this study received little pre-ultrasound information they are clearly articulating that they feel it is inappropriate to diverge away from the well documented situation where parents experience natural excitement and anticipation at seeing their baby on screen (Eurenius et al. 1997, Lalor 2000, Ekelin et al. 2004) toward providing explicit information on what might go wrong, when the majority never have to face this situation.

5.4 Summary

The data presented represent women's constructions of the normative constancy, experience of and belief that pregnancy almost always results in the birth of a healthy baby. Colin Murray Parkes (1971, 1988) developed the construct of the assumptive world, and suggests that this construct is the ordering principle for the psychological and psychosocial construction of the human world. He defines it in terms of "the only world we know and it includes everything we know or think we know. It includes our interpretation of the past and our own expectation of the future, our plans and our prejudices. Any or all of these may need to change as a result of changes in the life space" (Parkes 1971 p102). Undoubtedly, receiving an adverse prenatal diagnosis constitutes a change in one's expectations and plans for a pregnancy. Seldom are accounts available from those affected by prenatal diagnosis and the following chapter

begins the journey of how these women attempted to move through their pregnancies after the diagnosis in the hope of adapting to an unforeseen and at times unpredictable future, as women's previously unquestioned beliefs of normality are replaced with shattered assumptions (Janoff-Bulman 1992).

6 'Shock': phase two of the process of Recasting Hope

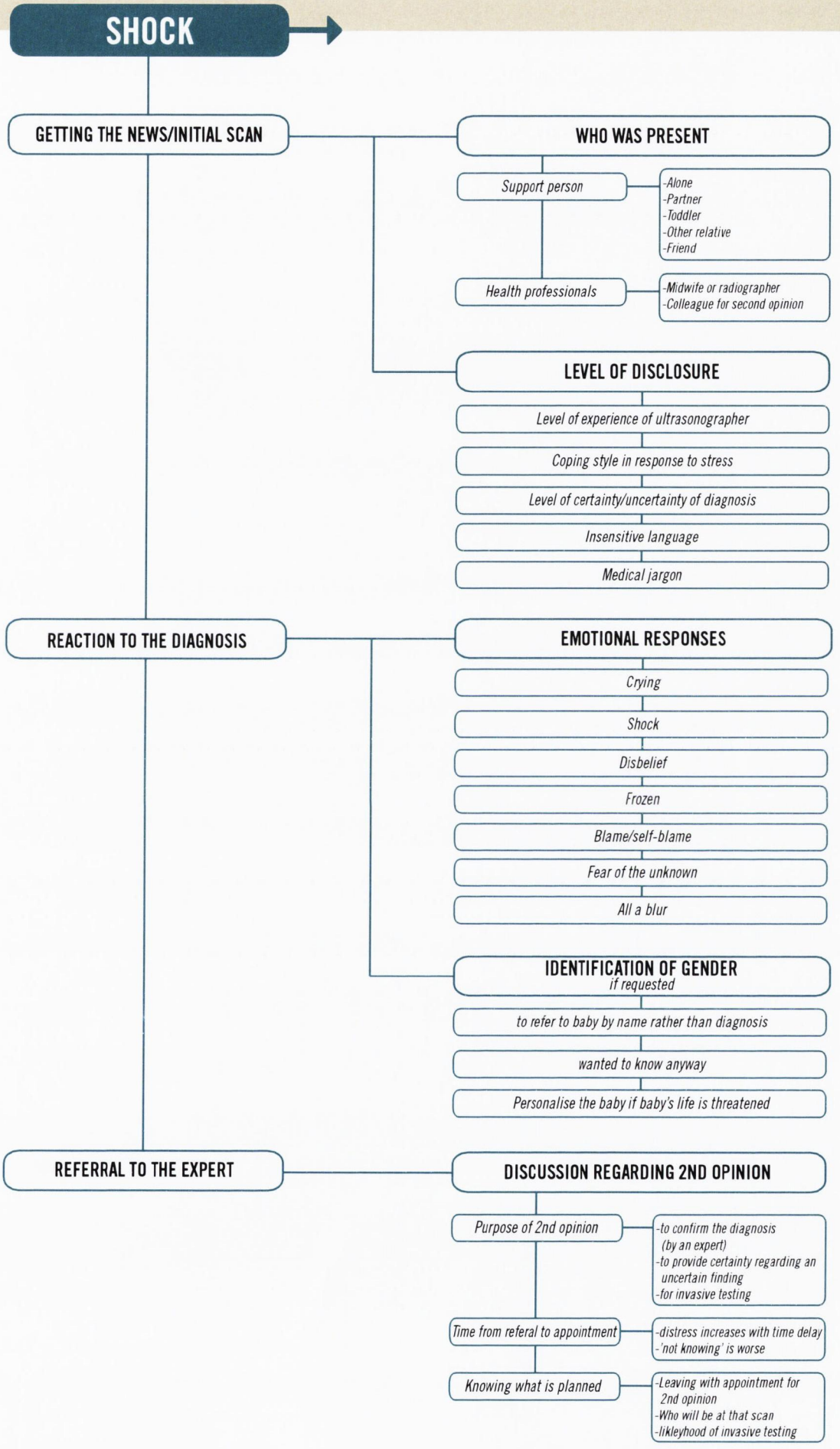
6.1 Introduction

How women cope with the diagnosis of fetal abnormality has received little research attention internationally and no reference could be found to any inquiry conducted within an Irish context. The following three chapters take a different format to chapter five for several reasons. Assume Normal, is the only phase in the process that refers to the time preceding the ultrasound and serves to provide an understanding as to why women are unprepared for an adverse diagnosis. However the cutting point in the analysis begins once a fetal anomaly is suspected or confirmed. Existing data are not as comprehensive as is necessary to understand what is actually occurring once women are given a diagnosis of fetal anomaly. Consequently I chose a constructivist approach to develop an understanding of this phenomenon, within the context of women's perspectives and experiences (Merriam 2002). In keeping with grounded theory methodology, I theoretically sampled the literature as data collection and analysis proceeded in order to develop emergent concepts. However, review and analysis are essentially divided across time and space, with the final level of analysis occurring as I co-constructed women's experiences. As I revised my understandings of theoretical debates in light of women's accounts, many relational theories were reviewed, but as I engaged in complex theoretical debates and extant frameworks within the wider area of thanatology and loss, I discovered many of these theories did not appear to be entirely satisfactory as a way to theorise women's experiences. Consequently, in the interest of time, clarity and a desire to ensure women's voices are represented with as little diversion as possible, issues regarding the re-integration of the emergent framework with extant literature are addressed in chapter 9.. During the final stages of the research process, the construct of the assumptive world was located within the field of grief and loss (Parkes 1971), and as what is known cannot be unknown, the construct has become inextricably interwoven into the fabric of this thesis.

When the expectation of normality is devastated through an adverse diagnosis, some mothers experienced a sense of incredulity when informed of their baby's anomaly, confirming the findings of others (Smith and Marteau. 1995, Baillie et al. 2000). Yet

understanding why women are unprepared for an adverse diagnosis, the impact of the manner in which abnormal findings are presented to women, and the ability to visualise the abnormality on screen have heretofore not been systematically studied (Mitchell 2004). However, the conceptualisation of the assumptive world as a set of fundamental assumptions that comprise the bedrock of our cognitive-emotional worlds provides clues as to our complete lack of psychological preparedness when faced with a traumatic event (Janoff-Bulman 2002), advancing our understanding of women's reactions to prenatal diagnosis. Transition from the first phase of 'Assume Normal' into this second phase of 'Shock' began once a suspicion of abnormality was raised at the ultrasound examination. This chapter focuses on the timeframe from receiving the initial news up to the point where referral to a fetal medicine specialist for confirmation or further clarification is made.

This stage of the process is characterised by women's responses to this stressor, how their reactions vary widely, depending on the individual's repertoire of coping techniques, previous experience, and the capacity to tolerate powerful emotions including the need to maintain self esteem (Parkes 1998). In keeping with Cannon's (1929) original descriptive summary of the effects of stress, the duality of the fight/flight response was also evident in women's reactions to the diagnosis. Some women experienced elements of autonomic disturbance (such as insomnia or loss of appetite) as the threat of the loss of a healthy child produced a high state of alarm. Other women avoided engaging with the issue until confirmation of the situation was received.


SHOCK
GETTING THE NEWS/INITIAL SCAN
WHO WAS PRESENT
Support person
-Alone
-Partner
-Toddler
-Other relative
-Friend
Health professionals
-Midwife or radiographer
-Colleague for second opinion
LEVEL OF DISCLOSURE
Level of experience of ultrasonographer
Coping style in response to stress
Level of certainty/uncertainty of diagnosis
Insensitive language
Medical jargon
REACTION TO THE DIAGNOSIS
EMOTIONAL RESPONSES
Crying
Shock
Disbelief
Frozen
Blame/self-blame
Fear of the unknown
All a blur
IDENTIFICATION OF GENDER
if requested
to refer to baby by name rather than diagnosis
wanted to know anyway
Personalise the baby if baby's life is threatened
REFERRAL TO THE EXPERT
DISCUSSION REGARDING 2ND OPINION
Purpose of 2nd opinion
-to confirm the diagnosis (by an expert)
-to provide certainty regarding an uncertain finding
-for invasive testing
Time from referal to appointment
-distress increases with time delay
-'not knowing' is worse
Knowing what is planned
-Leaving with appointment for 2nd opinion
-Who will be at that scan
-likleyhood of invasive testing

6.1.1 Getting the news

The data presented are women's reconstructions of their reactions to the initial diagnosis several weeks after the event. Considering the potential for emotional pain, women were in general very vivid in their recall of place, time, presence of others and the words used when the news of a problem was initially given. In this study, most abnormalities were detected in a routine midwifery led ultrasound clinic in a tertiary hospital; however, some were detected by radiographers operating in regional maternity units. Based on local birth rates in these regional centres, fetal anomaly diagnosis for an individual practitioner is likely to be an infrequent occurrence. In phase one, pre-ultrasound information was addressed in terms of availability and the difficulties that exist in designing information leaflets for a diverse population in terms of suitable content. The RCOG (2000) recommendation that specific details regarding the frequency of common abnormalities, accompanied with local detection rates be provided to all women presumes that women will use this information to either opt-in or opt-out of screening, and suggests that if women understand the potential for an adverse result it may ameliorate the impact when received. Whether women's immediate psychological response to a positive diagnosis is mediated by characteristics such as prior information about the possibility of an abnormal result (Marteau and Mansfield 1998) is unknown and untested. However, if we are to believe Parkes' (1971) definition of the assumptive world to be ontologically true, an information leaflet with statistical facts regarding the occurrence of anomalies in the population is unlikely to alter the extent to which one is prepared for an adverse diagnosis, as women continued to link the assumption of normality with their utter lack of preparedness for what they were about to hear.

Yeah, more babies are born normal than not, I would have a very positive approach. So we were a bit shocked. (Blannad)

But Joan in terms of how we felt and that, we were absolutely shell shocked. I was so excited and it had a huge effect on everything, all our plans changed. We didn't know [what lay ahead]. (Eavan)

I just would not have expected it to happen to me. It happens to someone else and you feel just so awful for them but it doesn't happen me like. I think you know, up to this point in my life I have been quite, you know up to now it has been quite lucky. Nothing really bad has happened to me, I have had a very, a very you know not easy but you know I haven't had, I haven't lost anyone really close to me or nothing like this really. So you just think that is someone else's life not mine like. (Molly)

Presence of others

As the interview progressed from confirmation of the pregnancy and completion of the first trimester, the story reached the point where the day had come to attend for the ultrasound examination. Many of the women began recalling this day by telling me who had accompanied them, who had performed the ultrasound and the cues that alerted them to the fact that something was wrong. Tara attended for her scan with her husband and describes how the midwife requesting a second opinion from a colleague raised alarm bells that all was not as it should be.

J: So have you a clear memory of the day you had the scan?
Oh I do yeah. Myself and [husband] went in, all excited. She [the midwife] scanned me and first she was kind of pointing out all the bits, you know, and then she went I am just going to get my colleague to have a look at this, and we knew from last year that that is not good as rule, you know [previous miscarriage]. She was getting more serious. She was measuring and measuring and measuring. She was kind of saying everything is okay, but she measured the same thing a number of times and it was still coming up, you could see on the screen it was going up whereas it should have been at 17 weeks but it was coming up as 13. Then she brought in [another midwife], and the two of them together were at it and then whatever way they had the screen we could see the dates popping up at 13, 14, 15, they were all over the place. And they were printing pictures. Yeah, so they just said at the end of that that we are not seeing the kind of things we would expect to see. The head looked a bit enlarged, the tummy looked very small and the hands were clenched shut, they didn't like the look of it but they couldn't actually tell us anymore than that, you know. So they left the room and I think the tears came then for the first time, I knew it was going wrong.

J: Could you take it in, did it make any sense?

It was just such a shock and it was, it was making sense only the questions didn't come then, just the knowledge that things were badly wrong and no questions, just taking that fact in, and then the [midwife] took us to the crying room as I call it, we have been there before. (Tara)

However, not all women confronted the problem at this initial stage. In Kubler-Ross' (1970) earlier model of grief, she used denial as the first of five stages in the psychology of a dying patient, and the idea has been extended to include the reactions of survivors to news of a death. Unlike some other defence mechanisms the general existence of denial is fairly easy to verify, even for non-specialists on the other hand, denial is one of the most controversial. Although outright cognitive avoidance of the reality that a problem could be present did not feature in these women's accounts, it was apparent that some women deferred engagement with the problem until it had been confirmed by a second party. This is likely to be a strategy employed to protect oneself from overwhelming emotions (Landsman 2002).

J: Can you remember what was said at that first scan?

Yeah, I can. Of course I can remember...she [midwife] scanned me and said there was a shadow on the heart. It was [name midwife] that scanned me and basically told me not to worry about it.

J: Okay.

And could I come back in the following week and see the doctor. I was told not to get upset.

J: and did you feel upset?

I was a bit whingy now but I just said look, because of the fact she had said it's probably the baby is laying a certain way. I went back to work and I convinced myself there was nothing wrong. (Hayley)

As Hayley initially sought reassurance from the uncertainty regarding the query over the diagnosis she returned for the second ultrasound unaccompanied when the Fetal Medicine Specialist informed her that her baby had a serious cardiac anomaly. This

initial minimisation of the problem was to cause her to direct her anger at the healthcare team as the level of mistrust that developed was never to be undone. Lori's description of her initial reaction is also reminiscent of the flight response to stress and serves as an exemplar of the character of this strategy of avoidance (Lazarus and Folkman 1984).

Yeah, so the appointment was for 6 o'clock in the evening. Everything was just so clear [the image of the fetus]. We could see everything, which is why we were so shocked; we were in there for an awful long time...for about 10 or 15 minutes. And she [radiographer] was there just like checking everything, and mm...you still don't think that she is going to say to you that something is there, I just thought they were being extra thorough. And then she just said to me eh....she saw a little abnormality with the heart and she asked me would I ring the hospital at 8.30 in the morning to get an appointment with [FMS]. But she didn't go into much detail either she just said she could see abnormalities and could I come in and get them to check again. I was very upset.

J: Did you ask what it was?
No, I think I just wanted to get out. I don't think it really hit [my partner]. I just started crying, she was saying its okay. But I was trying to like say it's just maybe something like a cloud is over the heart, something [not serious]. (Lori)

Aisling, like Lori used avoidance strategies to deal with the diagnosis initially seeking reassurance of fetal well-being from the fetal movements visible on the screen.

Yeah, we were getting organised to go in for the scan the next day and just making plans about how we were getting in there. It was a Thursday afternoon appointment 5 weeks ago today. She [midwife] scanned me and the baby came up immediately...and she goes there is his head and legs and oh there's his kidneys, and then as soon as she said kidneys she goes oh there is a problem with his kidneys, there is a bit of stagnant fluid or urine or whatever in the kidneys...so I said to myself whatever the problem is he is obviously moving around in there so he is not too bad. (Aisling)

For many women, the initial feedback that the scan result was non-reassuring caused a high degree of alarm (Green 1994, Statham et al. 2000, Statham et al. 2001), more similar to the fight response to stress.

She kept looking at the head, and eventually she said that eh there was a problem with the baby's head and yeah, just like you actually can feel the pain, like heartache, its like a stabbing pain in your heart and just like your mind is rushing, you are just like, you know, you have all these questions in your mind but you are not, you know, asking. (Molly)

J: Did you bring your husband with you that day?
Ah yeah, yeah. I couldn't see the monitor at all, because of where I was. I had the scan done and she [radiographer] was concentrating very heavily on one particular area and mm she said I have to go and get someone else. I want to ask them about something. But my straight away reaction would have been 'right, tell me what is going on'. (Caitlin)

Precisely because ultrasound is a technology of visualisation, some women recognised that the image on the screen seemed abnormal and this prompted them to ask if there was a problem.

I said [looking at the screen] that doesn't look right... she [midwife] didn't fudge around...it looks like some of the bowel has come out...but it's operable...at least we knew. (Fay)

I could see the black area [on the screen]. She [midwife] knew there was something wrong; she didn't take long to find it. I was asking her loads of questions. (Eavan)

J: Did she say where the fluid was?
Yeah, she said in the tummy and that there is a problem. I was just bawling and you know, then we had to go into another room, I already knew something was wrong but I didn't know how wrong or what the significance of it was, I still don't. (Eavan)

Level of disclosure

Women's perception of the sonographer's level of experience in diagnosis was viewed as important when it came to trusting the information that had been given. Statham et al (2003) have previously cautioned against making the assumption that parental reactions

will vary in accordance with the relative severity of the anomaly, and congruent with this concern, women who received a diagnosis of a potentially treatable anomaly from a health professional's perspective did not always view it in such simplistic terms.

J: Did your husband come with you for the scan?
No, I was on my own. Again maybe that might have made things different. Again personally I was very relieved when I realised I had, you know, an extremely experienced midwife doing the scan, who picked up the talipes. However as soon as they picked up the issue with the feet, and said there could be other abnormalities and to come back for another scan... I couldn't help my mind racing ahead in terms of if this, because there was only 2 outcomes, either everything else looks fine or there are some other issues as well. As soon as you get into the realm of possibility you need to be much more supportive, and take more time to explain issues. (Maolíosa)

These women commonly expressed concern that perhaps the diagnosis of a treatable anomaly was not quite so positive and may in fact resemble Pandora's Box, and that opening this box with the appearance of one treatable abnormality today could herald the discovery of increasingly serious anomalies at future ultrasound examinations, obliterating the hope of a healthy or 'near' healthy child.

It's not just the condition...it's is there anything else or is it worse than they think it is. (Trina)

Once a concern for fetal well-being was raised, most women described a need for prompt information regarding their baby's anomaly (Mitchell 2004).

We didn't have any reason to think there would be a problem, but the [midwife] picked it up straight away...she gave us quite a bit of information and then said look you know you'll have to come back and talk to an obstetrician [for confirmation]. (Muireann)

This is not good news.... They were quite clear, which was a good thing, they booked an appointment for the consultant later that day. (Doireann)

Any perceived difficulty in accessing information as quickly as they would have liked added to their distress.

I was trying to find out what about the other organs, was there something else [affected], where was this coming from, where was it originating from, but she [the midwife] couldn't answer all the questions...[referred to consultant], now I wasn't leaving there that day without seeing [the consultant]. (Erin)

She told us it was bad... things were not what she was expecting... but I would need more facts [than that] (Tara)

The woman's awareness of subtle changes in the sonographer's behaviour combined with the use of medical jargon (Green 1994, Sandelowski 1994, Rapp 1999, Mitchell 2004), contributed to the anxiety felt during the examination. Partial disclosure has also been shown previously to compound women's anguish (Rapp 1999, Mitchell 2004).

They [radiographers in regional centre] told us absolutely nothing...it left us a little bit more frightened, you know not knowing, saying nothing and standing scanning, looking very worried looking. I mean, you're there and you're thinking what is it, what's wrong? You're looking at someone's face and I remember looking at her and she looked so worried. It would be nice to know, to be clear because its, when the time comes you need to know what to do. It is because you're just thinking and worrying and wondering, maybe it will be alright, and maybe it won't like, its worse to think that. Yeah, I just really wanted to know what was wrong from a doctor, from the professional people [in the tertiary centre]. I don't know what I was hoping for...just an answer, just to know. (Heather)

Trina describes her experience of being informed that her baby appeared to have talipes.

So the midwife did the scan, she was very thorough. Then at the end she was just looking at the one foot or leg, obviously investigating what she thought was there but eh...she said it looks like there is talipes in the left foot.

J: Did that mean anything to you?

It didn't mean anything to me, that is what came out on the report I think[49]*, I remember that is what she said and that was what we read. We didn't understand what that meant so she said well you know it's like club foot. I didn't think that was great because to explain something by the worst possible case, like she said its not actually, it isn't' actually that, but you know, I suppose she said that to give me an idea of what it was. I could see that on the screen. Then I think she was just clarifying it in her own mind and then said I think there might be a problem there, or it might be the way he is lying. So she then went off, I don't know what she went off to do, I think to see if I needed another scan, and she came back with an appointment and said the procedure is if there is something [wrong] we need you to come back and see the consultant. (Trina).*

J: Okay. Can you remember how you felt?

I suppose you are a bit taken aback when you are not expecting anything. Then I suppose if it's something you are familiar with, the language is very difficult isn't it? She said like a club foot but we said what is a club foot? But she didn't have any more information in leaflet or oral form to give me on it. I didn't feel that she was definitely able to tell me. I felt she should have been able to explain to me what it was so that I knew what I was dealing with. We did ask [the midwife], I think we asked several questions and we got a bit of information but not much. I think we felt we would just go and find out ourselves. I think if I had been able to ask the questions and get the information, it's just not knowing what you are thinking about and that's the worst. (Trina)

Some women recalled how when the sonographer was hesitant regarding the diagnosis they hoped that a second opinion would disregard the sonographer's suspicions.

She [radiographer] didn't really say what was wrong I thought I would get to Dublin and they would say it's all a mistake; after all they have better machines up there so they can see more. (Breffni)

However, it appears more likely that sonographers are limited by institutional procedures or their personal level of confidence in breaking bad news rather than a level

[49] In the tertiary centre, women attending for routine ultrasound examinations are commonly provide a copy of the ultrasound report for their GP or referring consultant.

of uncertainty regarding the diagnosis, as local policies at healthcare sites are possibly a key factor in the perpetuation of this practice of non/partial disclosure (Mitchell 2004). All women who had their routine ultrasound in a regional centre, where the procedure was to have the examination performed by a radiographer and subsequently receive results from an obstetrician, were unhappy with this process. During the examination they felt frustrated and distraught when the suspicion of an anomaly was raised and they felt that the radiographer/radiologist was insensitive to their questions or need for information. Kasey, Caitlin and Niamh attended three regional centres in three different counties yet their experiences of the system are equally distressing.

So then she scanned me [radiographer], and then a doctor [radiologist] came in and he just basically pointed out the problem to her and then he walked back out again, there was no talking. I said is there something wrong? She said I can't read it. (Kasey)

The girl [radiographer] that did it for us first she was having a look and mm she wouldn't talk to us really at all. Ah well I just want to get a few measurements and then I will talk to you, I said 'come on can you not do both? Tell us what you are doing'. (Caitlin)

Discomfort at breaking bad news in Niamh's case appeared to be shrouded in a falsely positive prognosis. Similarly to Hayley's interaction presented previously, this initial encounter led to the development of a relationship with the regional centre that was characterised by feelings of mistrust, complicating future interactions with staff in this particular maternity unit.

She said [radiographer] here is a bit of fluid around the brain... you see kids with hydrocephalus and a lot of them have been coming back to us and the child is perfect. I'm going down to the doctor just to check, she just walked out. She [the obstetrician] didn't even come up to look at it, just yeah there's water on the brain and I'm sending you to Dublin and they will be in touch. We didn't understand what it meant. (Niamh)

Many of the women felt they didn't receive enough information at the initial ultrasound and accessed additional information resources. This was influenced by access to the internet and information seeking preferences i.e. some women expressed a high need for information while others commented on needing time to process what

information they had already been given. It was not unusual for women to search the internet with an uncertain diagnosis while awaiting an appointment for the fetal medicine specialist. However, information sources that were not subjected to critical appraisal by health professionals were not without consequence:

If I had been told even in passing don't be alarmed by what you read on it. I have seen some horrific stuff on the internet I actually feel now that the information should be available quicker. The internet is a very dangerous tool. (Blannad)

The diagnosis of polycystic was absolutely horrific on the net, it was like more or less death and you know, even though we had been told the other kidney looked okay. (Alannah)

All the information on multi cystic kidneys was actually positive. (Erin)

If I hadn't got internet access I think I would be still in the wilderness. (Cliona)

However not all women had either the means or the skills required to access additional sources of information outside of the maternity services. Niamh was left in a position by staff in the regional centre of waiting for a tertiary centre referral before further detail regarding her baby's condition would be provided.

It could take about a week like, you could be waiting for about a week for them to contact you and that was basically it, so we went off, walked out. I rang his [husband's] work to let them know what had just happened[50]*. He [husband] got back into the van and went back out to the doctor as we were left without any information whatsoever. Hydrocephalus, that is all we were told. He [husband] went back to work and asked the lads [staff in care of the elderly unit] in work what is hydrocephalus and they were more or less trying to explain a bit more. He [husband] rang me and said he would call up to the maternity unit and ask them do they have any leaflets on hydrocephalus. Just to let us know what we are dealing with. So with that who walks out only the doctor [obstetrician] and she said [to him] are you okay and he said I was with you this morning and she said yeah and he said I am just wondering do you have any literature on this hydrocephalus because we are in the dark as to what it is...Oh no she*

[50] Niamh's husband worked as a care attendant in one of the medical services in a regional centre.

[obstetrician] said we don't have anything like that. She said it is bad we don't have any. But she said I have faxed Dublin with all your details so they will be in touch with you in a week. (Niamh)

Niamh did receive a call from the tertiary centre later that day; however, as her initial scan was on a Thursday, she had five days to wait for the consultation with the FMS. Given that a same-day appointment with the fetal medicine specialist could not be guaranteed, women were asked if there were any alternative strategies that might provide support during this particularly difficult time of uncertainty.

Give us written information in the problem, it would sort out things, rather than have us looking at American sites, here we are in [tertiary hospital] which is the leading hospital and we can't get [written] information... just to be able to take it away. (Fay)

It would have been nice to know and then be given all the bumph straight away. (Blannad)

I just felt if you are going to tell people, whatever, I know there are a lot of different things that could be wrong but they should have leaflets available to explain to you. (Trina)

Others have suggested that clinic policies ought to ensure that, in so far as is practicable, women should be given a name and description of the diagnosis before leaving the unit (Mitchell 2004). This study supports that recommendation as participating women also explained that having a name for the condition meant that their search for information was more targeted and less likely to reveal unlikely associated diagnoses. Many suggested that having written information would have afforded them the opportunity to review what they had been told during the examination, and assist in formulating relevant questions for the fetal medicine specialist.

6.1.2 Reaction to the diagnosis

Many women described how they experienced physical symptoms in response to the shock, analogous to the emotional responses exhibited. Autonomic disturbances or disruption to previously normal function varied from individual to individual and alterations to sleep patterns were reported commonly.

I was still tossing at maybe three this morning, I still hadn't closed me eyes, and I know he [partner] only went to sleep at about one, but we weren't, we weren't talking about it. When [partner] went to sleep last night I probably cried for a little while all right. (Cliona)

The GP just gave me the sleeping tablets [no improvement in sleep pattern]. I haven't been back to my GP. I just don't want to go near any doctors. They are not going to give me anything so what is the point. (Keeley)

Many women spoke of how the responsibility to care for other children helped them to maintain some level of daily function. As the only literate parent, Keeley carried a lot of this responsibility as she had two children of school-going age.

It's all on me you see....[if this was my first pregnancy] I would say I would just sit here and be smoking and sleeping, but you have to get up and there has to be meals cooked and lunches made and there's homework to be done. (Keeley)

However, it was to turn out that Keeley was unable to maintain this in the long-term. Dáire described how worries about the final outcome were more intrusive at night as she could not avoid dealing with painful thoughts through keeping busy.

I think when I can't sleep at night, when I am lying awake thinking. Then I make myself worse. I feel sorry for myself. But I probably make things worse when I think of it. I try to think realistically as well, but you can't just think that way, you try to think it's going to be okay, it might not be but... you have to get up and do things. I would probably just feel sorry for myself all the time but I have to get up out of bed, you have to do things when you have other kids. You have to function, you have to do it. Whereas if I didn't have [son] I would just have myself to look after, it takes my mind off things having him. (Dáire)

Strategies to avoid becoming overwhelmed by painful emotions such as keeping busy or loosing interest in one's personal appearance have been previously reported in death-related grief studies (Parkes 1998). Even when the fetus was likely to be born alive, some women, overwhelmed by the emotions they experienced, could not maintain daily functioning, even when there were other children to be cared for, and sometimes stayed in bed for several days.

My appointment [for the tertiary centre] was 5 days later, but I would have gone up that day. I don't think I even got dressed until that Monday. There was nobody to talk to so everything was going through my mind. (Niamh)

I lost my child for about four days [after the diagnosis] and it was like a big black cloud and you wake up in the morning and you think I can't get out of this. (Sian)

Other death-related bereavement studies have shown that bereaved persons have a tendency to increase their consumption of alcohol, tobacco and frequency of attendance to general practitioners with physical symptoms. With the exception of one woman, this study did not show an increase in consultations with general practitioners for treatment of issues such as insomnia. However, two women volunteered that their alcohol and tobacco consumption had increased since the diagnosis. This difference is likely due to the fact that maternal responsibility for fetal well-being remained, irrespective of the eventual outcome, whilst the pregnancy continued. The challenges women faced in attempting to cope with the diagnosis seemed to be pervaded by a sense that even though there is an awareness that some babies are born with anomalies there was a feeling of 'it couldn't happen to me'.

It's a whole shock as I said, you know, you hear about poor people having problems but you never think it'll be at your own door...you feel all of these things happen to somebody else. (Maeve)

When we were telling [family members the baby had a problem] we went to bed that night and we kind of just couldn't believe it. (Heather)

We just couldn't believe what was happening...just devastation I suppose. (Kasey)

Although this period of disbelief was short-lived as it was frequently followed by referral to a fetal medicine specialist for clarification of the diagnosis, the process of reconciling this event with the assumption of fetal normality continues.

Identification of gender

As previously discussed in chapter 2 the relationship between mother and fetus is unique. However, perspectives on the nature of fetal personhood and consequent moral rights afforded to the fetus are complex. When a concern for the baby's well-being emerged, a desire to know the fetal gender in order to personalise the baby, and refer to him or her by name rather than by diagnosis was not uncommon. This desire to personalise the baby manifested irrespective of whether the woman chose to continue or terminate the pregnancy.

J: Did you ask if the baby was a boy or a girl?
Yes we did because when she [midwife] told us that there was a problem my husband said can we, we would like to know the sex, we'd like to know what we're having and she said it's a boy, she said I'm 95%, 99% sure it's a boy, it's a little boy. (Áine)

We decided back then to find out the sex of the baby so that we could mm ...bond with the baby now rather than, because we know we are not going to have much time in the delivery room. So we found out the sex of the baby and it's a girl which is great you know. (Emer)

I was going no I'm not going to find out [the gender], to me that is playing with nature...then the minute she said there is something wrong, I went is it a little girl or a boy, that is all I wanted to know. (Regan)

Other women were fearful that if gender was not established antenatally it may not be possible to do so at the birth, in particular if the baby was very immature or had died in utero prior to delivery. Lori requested that the baby's gender be checked when amniotic fluid was being sampled for cytogenetics purposes.

We just wanted to know if it was a boy or girl. I suppose if it was the Edward's syndrome and the baby didn't survive then we wouldn't know [at the birth]. That was one possibility. Then the other possibility was if there was a chance of miscarriage after having it [amniocentesis] then we wouldn't know then either [as the baby would be delivered at 20 weeks gestation]. (Lori)

Some women, in particular those diagnosed at earlier gestations did not anticipate that gender could be assigned and therefore did not ask during the examination.

No, and I don't know but I just named it myself. In hindsight I kind of would like to have known, yeah. (Bethan)

Doireann, on the other hand chose not to find out the baby's gender in the initial stages.

No, I never asked you see in one way I don't want to make this pregnancy too real because I don't want to have to associate with it. (Doireann)

However, Doireann was later to revise her decision when information on gender became available through karyotyping. Assigning personhood and creating a place for the babies who did not survive becomes more dominant for women as time passes and will be discussed in greater detail in chapter 9.

As previously shown, women exhibited a range of emotional reactions in response to the shock such as crying, disbelief, asking questions, fear of the unknown etc. These reactions are the first step in responding to this life crisis and represent the onset of emotional pain and disillusionment that accompanies the loss of the belief in the normalcy of fetal health. Other elements of the assumptive world such as 'I am a good person, things are meant to be a certain way, God is good, having a vision of the future' also emerged during women's reconstruction of the experience. Therefore I returned to the literature in order to develop an understanding of why we think this way, and this led to the discovery of Lerner's (1980) theory of 'belief in a just world'. Emma's account of the day she heard the news highlights the dialogue we may have with ourselves and others whilst attempting to come to terms with the apparent randomness of a very negative event, and contains many of the concepts from Lerner's (1980) theory such as 'bad things happen to bad people'.

It's like in a film; you know something is not right. I knew then. I thought something is definitely wrong here [during the scan]. We didn't really talk. They [the midwives] wanted [FMS] to look at it.

J: Can you remember what you were thinking?

Just mm...that you are on a high and you come down like. I was trying not to get – you know mm...What can I say....mm...Too upset about things, until I was told something. You know, [midwife 1] said while [husband] had gone out that things don't look too good. For the babies, and I said what is it, and she said well I have to get [FMS] to have a look, and [midwife 2] said to me she touched my leg and said you are very brave and you know you are great. And I was saying but like...you know... you are not giving me, I know they can't give you anything... too much information because they haven't got the doctor there but if you were told a bit more.. I am lying here but what am I being brave for? Tell me more. So I sat up. Nothing was pointed out to me and the two midwives were just getting on with it. Nothing was pointed out to me. I wasn't afraid; I was just in the unknown. They said just go out and get a bit of a breather, I got a bit angry then, you know. I know it's terrible, I am not a bad person but I was coming down the steps in the main building, coming down the steps and going out and watching all the girls either going off with their babies, husbands coming in, partners coming in with the carry cot to bring the baby home, and there was one girl parked outside. I always looked towards that day when I would be bringing my baby home and young girls were going in for their appointments, I said this is ridiculous, you know.[51] *Here they are going in no problem, getting everything handed to them, perfect babies probably. Because I had felt I had done everything by the book. You know, I don't smoke and very rarely drink, look after myself as much as I can, you know, as you do, well I always do try and eat well and whatever. I think I tried to do everything right in life, you know, not do anything wrong on anybody or you know, and was thinking this is unfair like for us, you know, we had a bad year as it was. We thought this was a turn around and a good point in time and in life. (Emma)*

Emma's diagnosis in the context of having prepared for pregnancy violated her belief that we can have some control over future outcomes, and provided evidence to support the fact that the world may not be just (Lerner 1980). Making sense of loss requires a search for meaning, and one of the first steps in this journey was for women to seek answers to the 'Why me?' question through gaining information to clarify and assess the consequences of the diagnosis for the pregnancy/baby.

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[51] Emma described how she felt these young girls were unlikely to have planned their pregnancies, unlike herself who had taken folic acid pre-conceptually and altered her lifestyle to be in good health in order to enhance the likelihood of a positive outcome.

6.1.3 Referral to the Expert

Once an opportunity to seek further clarification regarding the diagnosis was offered to women, none refused. Although some women hoped they would hear that the initial diagnosis was a mistake, none said they really believed that this would happen and they welcomed the chance to find information on the extent of the problem they were facing, as not knowing was considered to be worse. Each of the women raised the issue as to the length of time that elapsed between being referred to and meeting the fetal medicine consultant. Many of the women that received their initial diagnosis in the tertiary centre were seen by the fetal medicine specialist either the same day or within 24 hours; however, this varied depending on the individual consultant. Two of the three consultants would see women the same day or as soon as possible. The third believed that women were too shocked to take additional information on board within the first 48 hours of the initial ultrasound and deferred appointments accordingly. This was an opinion he shared openly at many meetings including during a session where I was providing feedback on the study findings to the staff.

We saw him later that afternoon, I couldn't have waited. (Doireann)

She [the midwife] couldn't answer all the questions... now I wasn't leaving there that day without seeing him [FMS]. (Erin)

J: Would you like to have seen the FMS the same day?
Yeah, if I could have got straight in to see him [FMS], definitely. The waiting was the worst [two hours]. It really wasn't nice. (Emma)

We will do a more detailed scan... initially they said [three days later] but I couldn't wait that length of time. There were two options, one much drastically worse than the other...we had a hell of a night. (Fay)

Each of the women quoted above were originally booked for care at the tertiary centre, and the feeling of uncertainty (usually no longer than 24 hours) associated with waiting

for an appointment with a fetal medicine specialist was described as agonising. However, longer delays were experienced by women referred from regional centres.

Dublin will be in touch with you in about a week. My appointment was five days later, but I would have gone up that day. (Niamh)

I'll [obstetrician] have to try and get an appointment [with FMS], you need to go and see them straight away to let them look at it

J: Why is that?
Because then he said he's [obstetrician] not 100% sure but he was 99%, but he'd have to let more professional people see it first, so. We had the whole weekend really to kind of prepare ourselves more or less for the worst, you know we kept thinking the worst but we did have a bit of hope but the waiting was, we'd waited long enough at that stage, it was a long weekend but we wanted to know one way or the other you know what it was.. I think that was the worst, but that has been the worst time actually from the Thursday to the Monday [waiting for the FMS consultation]. (Heather)

I'd kind of recommend Dublin he [obstetrician] was saying like, you know, but he said anyways the [FMS in another regional centre] is on three weeks' holidays and I said God we want it like tomorrow if we could get it like [referral to FMS]... [an appointment was made for one week later]...(Maeve)

Ironically, when questioned as to the ideal time frame from referral to appointment, women referred from regional centres suggested that access to the fetal medicine specialist within 24-48 hours would be welcomed. This difference in expectations based on place of booking may be socially constructed, influenced by the centralisation of many specialist services, where one's expectation in relation to speed of access is influenced by the care received rather than based on knowledge of services available elsewhere (Porter and Macintyre 1984, van Teijlingen et al. 2003).

All women had high expectations of the consultation in terms of certainty of diagnosis created perhaps, in part, by referring clinicians prior to the appointment. As not all

units in Ireland offer invasive testing (Lalor et al. 2006a) some women were referred specifically for access to karyotyping.

The [FMS] just said it was chromosomal and I kept pushing and pushing, I was saying well what one do you think it is like. Well he said I cannot say, but if you want we can do the amniocentesis, you know, do it today or go home and do it Friday. No, I'll have it done today...we kind of had discussed that before we went. (Maeve)

If women were likely to be offered an invasive test, preparatory information regarding this possibility and risks associated with the procedure were welcomed when provided by the referring hospital as decisions regarding consent could be made more rapidly. In general, women welcomed any avenue to access knowledge regarding the likely prognosis for the pregnancy, and almost all were prepared to accept the opinion of one 'expert' unquestioningly.

6.2 Summary

For each woman, receiving an adverse prenatal diagnosis was traumatic, irrespective of the prognostic outcome related to the specific anomaly. The belief that healthy women have healthy babies is powerful, and the assumption of the constant normalcy of fetal health contributed significantly to women's lack of preparedness for the diagnosis. Although there is a wealth of literature indicating that one of the most profound losses that an individual can experience is the death of a loved one, it is implicit from these women's accounts that the loss of the expectation that one will give birth to a healthy child is equally intense. The sub core variable of 'Shock' is derived from women's reconstructions of their experience from the moment a suspicion of fetal abnormality is raised. Transition into this phase from 'Assume Normal' is marked by receiving a non-reassuring ultrasound result, and begins the process of failure to satisfy assumptions that one will conceive and give birth to a healthy child. Just as bereavement varies from one individual to another, women's reactions to the diagnosis also differed. Progression to this second phase of the process does not always indicate that women will respond based on a high state of alarm as some will defer complete engagement with the emotional pain likely to ensue until confirmation of a diagnosis from a second party has occurred. Women recalled the context of the initial ultrasound with remarkable clarity including

their reactions to the news that all may not be well. Although initial reactions differed, their distress was apparent as many cried and actively sought further information from the sonographer regarding the baby's condition. Others used alternative strategies such as disbelieving in the credibility of the initial operator, suspending engagement with the problem until confirmed in order to avoid becoming emotionally overwhelmed.

Irrespective of the coping strategy used, women's anguish was intensified if access to sufficient information regarding the fetal condition was not forthcoming. All women welcomed the opportunity to seek a second opinion from a fetal medicine specialist, and highlighted that delayed access contributed to the distress felt, as not knowing was perceived to be relatively worse than having certainty regarding the diagnosis. However, women's early expressions of hope regarding the outcome were beginning to emerge. Expectations of the meeting with the fetal medicine specialist were high in terms of receiving certainty regarding the diagnosis. This was to create its own difficulties further on for certain women when assurances regarding the fetal prognosis could not be given. In addition to assuming that most babies are born healthy, women also felt that 'bad things happen to others'. When one holds the belief that if one is a good person certain negative events can be avoided (Lerner 1980) receiving an adverse diagnosis may leave individuals feeling that they have received an unjust punishment. This can subsequently manifest as bitterness directed towards others viewed as less likely to have prepared for the pregnancy. However, as the data presented in the following chapter will demonstrate, expressions of self reproach and guilt are more common than criticisms of others. Within the transition from 'Assume Normal' to 'Shock' a sub-process of 'Balancing Information' also emerged as women become engaged with the resultant emotional pain that accompanies a non-reassuring ultrasound result. This cyclical process relates to the dynamic relationship that exists between reconciling expectations of fetal health, the positive context in which ultrasound is offered and the circumstances that influence women's lack of preparedness for an adverse diagnosis. This cyclical process continues implicitly and explicitly as women search for meaning in this ostensibly senseless event[52].

[52] A paper describing this sub process has been published and is included in appendix 5.

7 Gaining meaning, phase three of the process of Recasting Hope

7.1 Introduction

Receiving an adverse prenatal diagnosis challenged women's view of the world, particularly because on this occasion the tragedy had struck home rather than to someone to whom they were more distantly connected. The data underpinning the stage 'Gaining Meaning' were gathered predominantly during the pre-birth interviews and represent these women's accounts of their experience of living with the knowledge of the diagnosis of a fetal anomaly. For those women who delivered prematurely or who accessed termination of pregnancy services in the UK, their experience was explored during the postnatal interview; however, chronologically relevant data are presented in this chapter. Progression from phase two 'Shock' to phase three 'Gaining Meaning' is represented temporally as being synonymous with the consultation with the fetal medicine specialist. Psychologically, however, there is no distinct marker signposting this transition for all women. This is because movement between the phases differs from one person to another with regard to both the duration and form, and is influenced by the fact that some women engaged with the event immediately whilst others did not. In addition, the time frame from referral to appointment with the fetal medicine specialist varied. For some women the transition from phase two 'Shock' to 'Gaining Meaning' appeared to be seamless, as questioning the sonographer and searching for additional sources of information regarding the fetal condition were immediate. For others the transition to this phase was more clearly delineated - particularly when confirmation of the diagnosis was delayed whereby strategies to avoid confronting the problem were initiated. Although Parkes' (1971) theoretical construct of the assumptive world has proved indispensable in my efforts to understand the psychosocial process experienced by the women in this study, I was unaware of its existence until the study had almost reached completion.[53]

However, prior to theoretical sampling of the literature, and during the earlier stages of data collection and analysis, the theoretical code that was initially applied to this third

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[53] As previously mentioned in chapter 3..

'Gaining Meaning' phase was 'Information'. This illustrated the patterns of information exchanges between the woman and the fetal medicine team, and subsequently between the woman and those others who populated her social network. The following are sample exemplars of the conceptual memos I wrote as I struggled to grasp with 'what was really going on' during this complex phase in the process and are intended to elucidate the nascent stages of analysis for the reader.

Conceptual memo (Apr 2004) (Dáire)

I'm not getting to the nub of the problem. Why does she not want to know the consequences for the pregnancy? It appears the FMS is telling her that there is a 90% chance of mortality yet she is concentrating on the possibility/hope of survival....she says she doesn't ask questions yet she is awake at night worrying about what will happen. What kind of hope is this?

(May 2004)

Unlike Dáire, Fay finds 'not knowing' torture, and wanted the diagnosis confirmed quickly. They both

Have similar anomalies, yet Fay said she 'wants the total facts, ignorance is not bliss'.

(May 2004)

Eavan says she wants to know all that can be known, yet she hasn't decided whether to have an amnio or not as the worst thing for her is a chromosomal problem, and knowing that 'could send you into

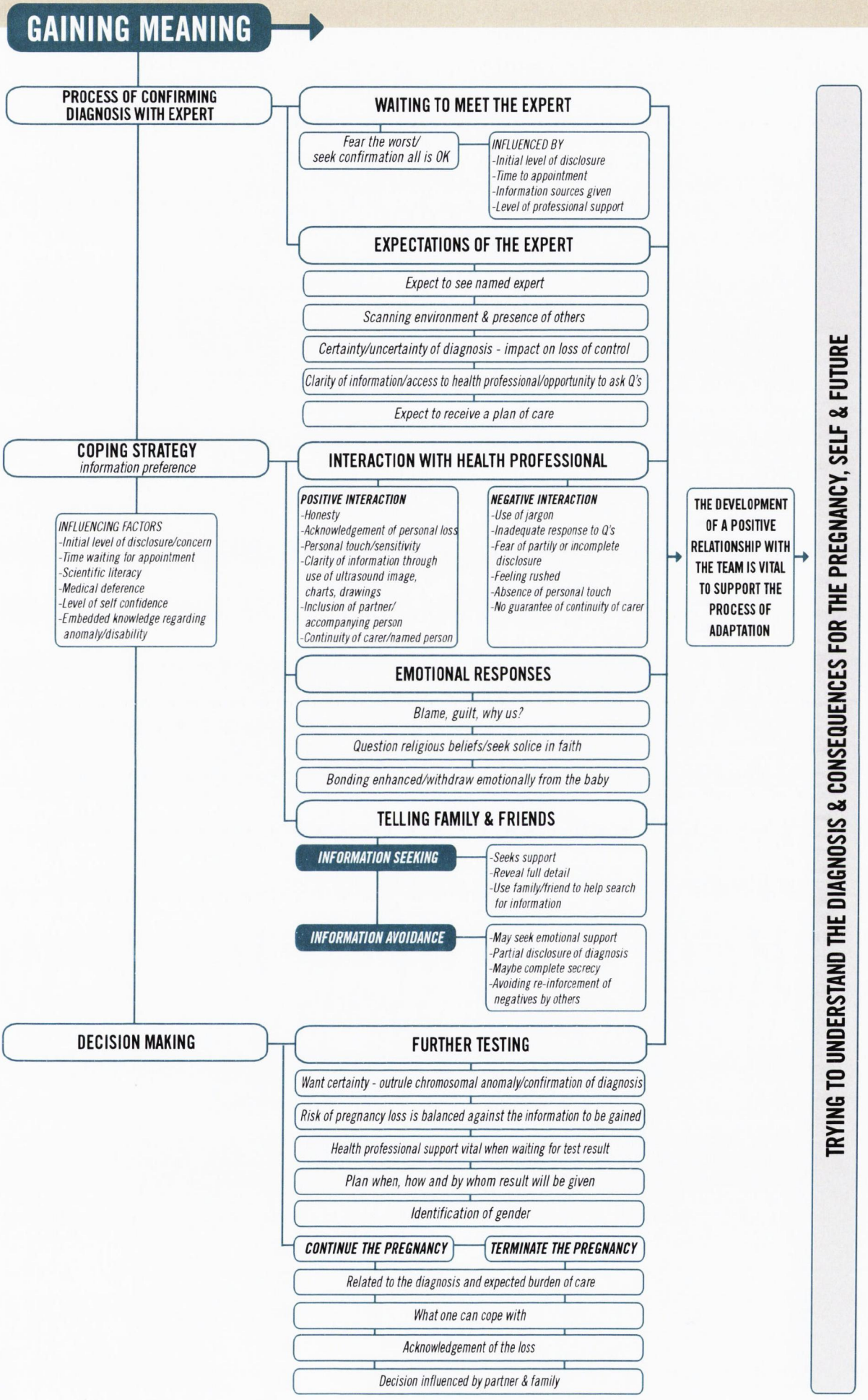
a complete depression'. Wants to know-doesn't want to know... Why?

(June 2004)

Emma says she has had many 'knocks' in her life and as a result she just faces things and doesn't try to change things that are out of her control.... What does this mean???? Why does she do this???

Why are there so many approaches to seeking or blocking information?? Is the process of information seeking, receiving, and difficulty getting accurate information, and integration of the information into what will ultimately happen. Is this about finding the meaning of the diagnosis??? This get up and get on with it mentality keeps coming through. Is it because they are all multips???

This chapter begins with the consultation with the fetal medicine specialist/team. It is characterised by women's accounts of their concerns of how they 'hope to cope' with the disruption to their lives and ultimately the outcome for the pregnancy (whether continued or terminated). It contains elements of women's individual and composite stories of how they attempted to resolve issues around this apparently meaningless event.


GAINING MEANING
PROCESS OF CONFIRMING DIAGNOSIS WITH EXPERT
WAITING TO MEET THE EXPERT
Fear the worst/ seek confirmation all is OK
INFLUENCED BY
-Initial level of disclosure
-Time to appointment
-Information sources given
-Level of professional support
EXPECTATIONS OF THE EXPERT
Expect to see named expert
Scanning environment & presence of others
Certainty/uncertainty of diagnosis - impact on loss of control
Clarity of information/access to health professional/opportunity to ask Q's
Expect to receive a plan of care
COPING STRATEGY
information preference
INFLUENCING FACTORS
-Initial level of disclosure/concern
-Time waiting for appointment
-Scientific literacy
-Medical deference
-Level of self confidence
-Embedded knowledge regarding anomaly/disability
INTERACTION WITH HEALTH PROFESSIONAL
POSITIVE INTERACTION
-Honesty
-Acknowledgement of personal loss
-Personal touch/sensitivity
-Clarity of information through use of ultrasound image, charts, drawings
-Inclusion of partner/ accompanying person
-Continuity of carer/named person
NEGATIVE INTERACTION
-Use of jargon
-Inadequate response to Q's
-Fear of partily or incomplete disclosure
-Feeling rushed
-Absence of personal touch
-No guarantee of continuity of carer
EMOTIONAL RESPONSES
Blame, guilt, why us?
Question religious beliefs/seek solice in faith
Bonding enhanced/withdraw emotionally from the baby
TELLING FAMILY & FRIENDS
INFORMATION SEEKING
-Seeks support
-Reveal full detail
-Use family/friend to help search for information
INFORMATION AVOIDANCE
-May seek emotional support
-Partial disclosure of diagnosis
-Maybe complete secrecy
-Avoiding re-inforcement of negatives by others
THE DEVELOPMENT OF A POSITIVE RELATIONSHIP WITH THE TEAM IS VITAL TO SUPPORT THE PROCESS OF ADAPTATION
DECISION MAKING
FURTHER TESTING
Want certainty - outrule chromosomal anomaly/confirmation of diagnosis
Risk of pregnancy loss is balanced against the information to be gained
Health professional support vital when waiting for test result
Plan when, how and by whom result will be given
Identification of gender
CONTINUE THE PREGNANCY
TERMINATE THE PREGNANCY
Related to the diagnosis and expected burden of care
What one can cope with
Acknowledgement of the loss
Decision influenced by partner & family
TRYING TO UNDERSTAND THE DIAGNOSIS & CONSEQUENCES FOR THE PREGNANCY, SELF & FUTURE

7.1.1 Confirming the diagnosis

Davis et al (2000) have suggested that attempts to search for meaning are frequently observed among people coping with loss. This contention certainly holds true within this study as the questions 'Why me?' or 'Why did this happen?'[54] echo in my ears having heard it voiced over and over again as women try to resolve the apparent randomness of this event.[55]

Why did this happen? ... I'm still looking for an answer so I can focus on the future as I'll have nothing at the end of this. (Heather)

Why me? I'm too young for all this to be happening to me [age 21yrs]. (Breffni)

The women in this study have demonstrated that a threat to fetal health represents a major challenge to one's assumptive world, and initially they can hardly believe what has taken place. However, the initial shock is soon replaced with a need to adapt to the news which frequently begins with finding concrete ways to determine the causal factors involved. Women consistently referred to the initial consultation with the fetal medicine specialist as the first step in finding an answer to this question, and as previously mentioned, women had pre-formed expectations of the consultation. The fetal medicine specialist was consistently referred to as the 'expert', and women expected to meet him/her rather than a substitute clinician at the consultation.[56]

Well if [named doctor] hadn't been there that day we would have been very upset. (Eavan)

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[54] In August 2004, I summarised a list of the questions Laoise asked during her first interview: What is it? How did it happen? Why me? Did I do anything to cause it? Could I have prevented it? What will happen to the baby in the womb? What will happen at the birth? Is this fixable? What is the treatment? Little did I realise at the time what those questions meant in terms of searching for meaning in order to recover from the experience.

[55] Davis et al (2000 p498) defines meaning as "an explanation for an event that renders it consistent with one's assumptions or understanding of the nature of the social world. That is, an event "makes sense" or "has meaning" when it does not contradict fundamental beliefs about justice, order, and the distribution of outcomes (see Janoff-Bulman 1992). By this definition, one may make sense of an event by interpreting the event as consistent with existing views of the self and world or by changing self- or worldviews to be consistent with the interpretation of the loss. It is this process of seeking an explanation that underpins the sub core variable 'Gaining Meaning'.

[56] There are three fetal medicine specialists in the tertiary centre (2 men and 1 woman). In order to avoid identification of any one individual, the FMS is referred to as 'FMS' or 'he'.

The need to meet the named person seemed to represent an attempt at maintaining some level of control for women in an otherwise extremely uncertain context. The anxiety associated with seeking confirmation of the diagnosis and significance of the abnormality is influenced by; initial level of disclosure/confusion regarding what was initially identified, time waiting for the consultation, access to information prior to the appointment and the level of professional support available pre-consultation from the referring clinician (midwife/obstetrician/radiographer). Women referred from regional centres each remarked that access to a named professional for advice or support while waiting for the appointment with the fetal medicine specialist was neither available nor offered. Women booked for care in the tertiary centre referred to the midwife conducting the initial examination in very positive terms if she provided her contact details and was available to answer any questions that may have arisen prior to the appointment with the specialist. However, this offer appeared to be related to individual midwives' practice rather than to unit policy.

Midwife [name] is just the kindest midwife I have ever met. She gave me her number and said don't be afraid to call me if you have any questions before you meet [FMS]. (Regan)

After that scan the midwife, the midwife I must say was very nice and she, the fact that she was caring and understanding made a hell of a difference like, she was worried about what she was telling me like, you could see that in her face like, she didn't just say that's it and away you go like, no she was very nice and she gave us her name and her number and she told us to ring her, you know after, to, ring her with any other questions. (Erin)

Expectations of the expert

Whilst many women feared the worst, some remained hopeful that the original diagnosis would either have been an error or at best the anomaly would be treatable, and could be viewed in terms of attempting to restore the assumption that fetal health is more likely than fetal ill-health.

You'd be thinking could she [radiographer] have got it wrong even though the scanner is on your tummy. (Maeve)

I was hoping, my expectation was I was hoping they would see a good picture of both of them and the [FMS] would say everything was okay

J: Right

No, I felt good, I hoped everything would be okay, you know, because I never heard of anencephaly [diagnosis made by midwife at initial scan] and I couldn't think, I knew they were identical twins as well, so I was hoping one was okay and maybe it was the position, I was battling with myself back and forth, [will they be okay or are they both affected]. (Laoise)

They [regional centre] weren't sure what it was, they were sending us to a special unit in Dublin that deals with this the whole time, it could have been just fluid on the brain he said [obstetrician] or it could be a cyst that's coming on the brain. When we were heading to Dublin all that was going through my mind was we can have an operation done that if it's fluid, release the fluid, if it's a cyst, and like you know this is how trivial I was thinking of it. Get it fixed, before the child goes to school if there's scars we'll let his hair grow long, you know what I mean, so the child won't be burdened or won't be getting slagged about it, that's all I was thinking. It was going to be bad but fixable. (Kasey)

The time period between the referral and the appointment with the fetal medicine specialist was described by women as the most distressing (Mitchell 2004); therefore receiving certainty regarding the diagnosis became increasingly urgent as time passed.

I really wanted to know exactly what it was so I did really need to know those details straight away to get it to register and not have false hopes. (Laoise)

Women also spoke of how they tried to control their emotional reaction to the loss in order to access information regarding the diagnosis.

Mm I was trying to hold them back because I wanted to get the information and I thought, you know, I was intermittently you know they were just exploding but I remember thinking don't let them start yet because you have to hold it together and find out what is happening here like. If you fall to bits people will stop talking like. And they do, they are not going to start telling you what is wrong with your baby if you are in bits. (Molly)

So it was just up to me to keep it together now, ask your questions, see what you can find out... nobody will talk to you if you're crying. (Caitlin)

Most women received diagnostic certainty; however, continuing the pregnancy when the neonatal outcome could not be predicted carried its own particular challenges. The tertiary referral centre is also a training site for registrars in fetal medicine (SPR), and consequently, a specialist registrar attends the high risk clinic with the fetal medicine specialist. It was customary at the time for the registrar to perform an initial assessment/diagnosis, which was subsequently confirmed with a follow up examination by the fetal medicine specialist. Tara describes how having waited 24 hours for her appointment, the urgency to access information regarding the fetal outcome became so acute that she couldn't cope with this process.

He [FMS] said I am going to let [SPR] have a look first, do a scan. I am going to go away and then I will come back and I will have a look and we will talk to each other and see if we see the same things because I want to be objective and that was fine, you know. We had no problem with that. I just started crying and [registrar] said what is wrong and I just said I don't know what I am going to hear today. I just, I knew things were going to be bad. I didn't know what they were going to tell me next, I really didn't. It was panic and fear I think. So actually [the midwife] went and said look we will get him back in now because I think I had waited, we had a bad night, I just couldn't wait any longer, you know. She [registrar in fetal medicine] was trying to say things mightn't be as bad, but we knew there wasn't going to be a positive outcome. Then [FMS] came in and gave it to us between the eyes...blunt, that is what you want straight talking, we were here to get the truth. (Tara)

J: How did you feel about the initially positive tone?
I think a bit resentful, yeah we are not here for that, we are here to get the truth, you know. We are here to be told exactly what you as a professional feel or think about this and not pat my hand, which is what I felt was happening. (Tara)

Nevertheless, all women acknowledged the need for training and, once the trainee was properly introduced, had no difficulty with providing them with an opportunity to learn at subsequent examinations. As with many aspects of health care the terminology used is frequently not that which is commonly used in everyday conversation, and

many women commented on the inaccessibility of the language used within the context of the consultation.[57]

10% mortality, it didn't register with me, now a 1 in 10 chance your baby could die is high ... you need to know to prepare. (Fay)

Survival in the long-term may mean something to a medical practitioner, it doesn't mean anything to me...in accounting terms it's more than five years. (Tara)

However, on occasion, women left the consultation without a clear understanding of the problem they were facing. Shannon was particularly ill-equipped to ask questions or seek clarification from her caregivers, and it would appear that any steps to ensure that she understood what had transpired were ineffective. Shannon had attended for a routine antenatal visit at a peripheral clinic and on examination the consultant could not auscultate the fetal heart and consequently arranged an appointment for an ultrasound examination.

He [consultant] said everything would be fine he just couldn't find it [fetal heart].

J: So you had to wait three days for the scan, what was that like?
Miserable. I cried a lot. I went for the scan and I could see the baby but I didn't notice anything was wrong, the black, I thought it was normal [baby had hydrops and query duodenal atresia associated with Down Syndrome]. She [midwife] just told me there was fluid and asked me to come back at 2 o'clock to see the doctor [FMS].

J: Did she tell you where the fluid was?
Yeah, in the tummy.

J: Did she tell you whether she had any idea of what it meant?

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[57] Further details regarding women's interactions with caregivers are available in data from this study in press in Birth (see appendix 11).

She had no idea. Well she asked me was I cold or was I anaemic but I was fine.[58] *I didn't know what she meant. ...[consultation with FMS]...I was upset at first because they [FMS and SPR] made it sound very serious. But he [FMS] said it would go down [the intra-abdominal fluid], that if it goes down it will be fine but if it didn't they would have to do a test [fetal blood sample] to see if it [the fetus] was anaemic. He thought it was because I had a cold the week before hand. Or that I was anaemic. So they did blood tests to see if I was anaemic.*[59] *They couldn't tell. He said that the baby, he found the baby had a blockage under its tummy going into, I can't remember what he called it, it didn't make any sense.*[60]

J: Did he draw any pictures?

After the last scan he drew me a picture. So I just thought it [the fetus] was anaemic, so I thought I had to eat red meat and drink Guinness. I gave up chocolate. I didn't have any Easter eggs. They said that if the fluid kept building it [the fetus] could give it a heart attack and it wouldn't live. But he [FMS] was hoping it wouldn't get to that. Well once he [FMS] said the fluid was going down I was feeling better. I wasn't worrying about the heart attack anymore. I did biology so I thought it was fine. I understood it. (Shannon)

As the consultations between women and the fetal medicine specialist were not observed, it is difficult to ascertain the efforts the health care team made to ensure this woman's comprehension of the situation or the extent to which Shannon may have been using denial as a defence mechanism to minimise the negative implications of the diagnosis. Fortunately, this level of cognitive avoidance or misunderstanding was isolated and women, in general, understood the range of possible outcomes for the pregnancy. Most women said that the diagnosis was explained through the use of a combination of fetal ultrasound images, centile charts and diagrams, and found that the use of visual images enhanced their understanding of what, at the time, seemed incomprehensible (Drugen et al. 1990):

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[58] Fetal hydrops has a multitude of causes; however, one of the differential diagnoses is transplacental parvo virus infection causing fetal haemolysis. One of the screening questions is to ask the mother if she has had symptoms of a cold recently.

[59] Fetal hydrops is also associated with rhesus disease, and is a sign of fetal cardiac failure secondary to haemolytic anaemia. This blood test would have been serum sampling for Rhesus factor and antibodies to ascertain if rhesus disease was a possible diagnosis, and not a test for maternal anaemia.

[60] Within this context, this blockage refers to the probable occurrence of duodenal atresia. This particular gastrointestinal anomaly has a 1:3 association with Down Syndrome.

They [fetal medicine team] showed us the back of the baby's head, the skull hadn't formed right and we could see it on the screen. (Kasey)

I had never heard of it [Triploidy]...they sat me at the computer [showed me the measurements], it made things quite clear. (Doireann)

He drew a diagram and showed me the valve, drew a diagram with a regular valve and showed me that this valve wasn't free flowing. (Orla)

....then the consultant sat the two of us down and he even drew out a little diagram of what kidneys looked like, the whole thing from beginning to end and then I knew it wasn't a big problem. (Aisling)

Given the potential to be overwhelmed by this new information, women spoke of how they welcomed the opportunity to ask questions during the consultation and sought guidance in relation to the likely plan of care for the remainder of the pregnancy.

I was given an open forum to express myself – they weren't saying here's your coat what's your hurry. (Doireann)

I asked him [FMS] what was the plan; you need something to go by. (Emma)

With the exception of Caitlin, each of the remaining twenty nine women who chose to continue the pregnancy had at least one additional antenatal visit with the fetal medicine specialist, and frequently many more. For the eight women who terminated the pregnancy all had some form of postnatal contact, either by phone or face-to-face. Early encounters with health professionals either in regional centres or within the fetal medicine team were to form the basis of the quality of the relationship that developed between the woman and her caregivers.

7.1.2 Coping strategy: information preferences

The data have shown that reactions to the initial news can and do vary, as some women confront the problem whilst others avoid engaging initially in order to protect themselves from emotional pain. However, it has emerged that irrespective of the preferred coping strategy the relationship that develops between the woman and the health care team over the course of the pregnancy is a vital link in the process of adaptation.

Interaction with health professional

Once a diagnosis of fetal anomaly was made, more often than not, ongoing antenatal care was provided predominantly by the fetal medicine team. Therefore this initial interaction was to shape the development of the relationship between the women and her caregivers for the remainder of the pregnancy and beyond. Honesty and sensitivity were key components in the development of a trusting relationship.

I wanted to know what was the bottom line, but when they [fetal medicine team] told me ...there was all kinds of pain, they were really good, good bedside manners, they had been very direct about the whole thing. (Doireann)

I was more than a bit anxious but I wasn't getting sad or upset at that point. I mean we just wanted to know, I don't know whether the scientist in me kicked in, but at that point we just wanted the facts and exactly what the problem was. He [FMS] went quite quiet and you know his hand kind of went up to his mouth while he was looking. We were very, we were anxious, nervous. I think I was being hopeful that everything was okay. We saw him focusing on the hands and feet we had read that if it's a chromosome abnormality it will affect the development of the limbs. He was saying he thought he saw a hand kind of folded up like this [make a clenched fist with her hand]. I thought the feet looked funny even though he didn't say anything. But he had got a picture of the feet and I thought why they are pointing in like that although nothing was said about it and I didn't ask. So we said what do you think it is? and he said I think it's chromosomal. At that point I got very upset and he was very kind to us. (Aoife)

I can remember it was pretty devastating. Mm I was in a room in [fetal medicine unit] and I called him [partner to give him the news] and he [FMS] had just gave me some privacy to make the call. By the time he got back the water works had started and everything, and you know he was very nice and he asked me was I okay and everything else. But mm he asked me if I was okay to go home by myself. (Orla)

Women also spoke of the need to have time to ask questions, whilst acknowledging that many of their queries often emerged once they had left the hospital. It is precisely because of this aspect of assimilating information that access to a named contact person should be available between scheduled appointments.

Look you are going to have some questions when you go home, you can ring me or the midwife tomorrow and he [FMS] circled his number and said that is no problem to contact him. (Cliona)

Come in anytime, the amount of times I was handed paper with the number on it, it was great. I've always felt the doors are wide open. (Heather)

Most women described their consultation with the fetal medicine specialist in positive terms and were particularly appreciative of any acknowledgement of the human tragedy that was involved.

I felt they cared- I was not just another interesting science experiment, they said we know this is very disappointing for us- focusing in on the emotional. (Doireann)

We were phoned at home, he [FMS] phoned me, and the midwife phoned me. That was surprisingly important to me when I look back now. (Emer)

For couples that coped as a 'unit' (Morgan et al. 2005) inclusion of the partner into the conversation was deemed to be essential.

Speaking to both of us, both of us are dealing with this... there was one midwife who didn't include him [husband] at all. (Tara)

However, some women described situations where they were dissatisfied with their consultation with the fetal medicine specialist.

[FMS] said that yeah it was a multi cystic kidney and then threw in an association with a chromosome disorder ... but he wasn't facing me. Edward's disease and it would be fatal, they could do an amniocentesis if we wanted. Now that whole conversation went very fast and he never looked at me face to face. (Erin)

Dissatisfaction was also expressed in terms of perceived insensitivity of the specialist delivering the news, and of receiving insufficient detail regarding the prognosis or treatment available as quickly as they would have wished. Women with babies with treatable anomalies also expressed acute distress and grief at this initial point of diagnosis.

Is it going to die? Is it going to have lifelong problems?... I found it difficult to get information from her [SPR] she was there to get her own information; I felt I was intruding on what she was doing. (Eavan)

He [FMS] just said to us that there was a problem, there is fluid on the brain, and we said right what does that mean? and he went on to talk about chromosomes em, it could mean putting a shunt into the baby you know, it's brain. Or the baby might not survive the pregnancy if the fluid on the baby had expanded its head and then, you know, loads of different things...He went through everything in a matter of 10 minutes... I just broke down in the middle of it and then he left the room. (Fiona)

J: Oh, ... how much of the information could you grasp?
We grasped the negative but we didn't see anything positive about it. (Fiona)

Although clinic staff are responding to time pressures, the consequences for women who feel rushed in this situation are significant.

We were booked in for 10.15 and we were told [by the secretary] we had to leave by 10.30, you need more time than that to open up. (Tara)

We were out the door before we realised, before we understood. (Hayley)

Both Fiona and Hayley were to go through the remainder of the pregnancy feeling antagonistic towards the particular fetal medicine specialist involved, placing a strain on the relationship, and limiting access to the information and support required to make sense of the situation. Negative encounters were characterised by a fear that queries would be partially resolved, therefore hindering the search for answers to the question 'why did this happen?' Within this study, some women reported feeling that they had been treated like a 'science project' when the fetal medicine specialist/registrar focused on the disease process associated with the fetal condition, rather than on the tragedy associated with the loss of a healthy baby. However, for women experiencing more positive encounters with the fetal medicine team both continuity of carer and ongoing accessibility to caregivers was seen as essential to developing a trusting relationship that formed a significant element of the support structures required to deal with the situation.

A relationship had built up, they knew where we were at, it wasn't that we had to tell our story to strangers each time. (Emer)

Being with the one person just gives you a lot of confidence in them, you feel there is more support going to one person and you know its such a big hospital and so many midwives, it has been very good that she [midwife] has been there when we come in because if we had to go to different ones it would be really hard. (Laoise)

Receiving contact from members of the fetal medicine team between clinic appointments was viewed by women as an acknowledgement of the awfulness of the news they had just been given, and this contact made women feel as though they weren't forgotten as soon as they had left the unit.[61]

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[61] There was a tendency for the same SPR to work with each of the three consultants [FMS] in their high risk clinics. A midwife was assigned to each clinic on a rotational basis; however, the midwife involved in making the initial diagnosis tended to arrange to be present for follow up visits in order to provide continuity of carer.

Although the search for meaning began either with the initial scan through seeking information from the sonographer or once the first consultation with the fetal medicine specialist had taken place, the process of confronting or restoring previously held beliefs about the world was to continue. The data showed that at varying times during the course of the pregnancy women had diverse needs with regard to the nature and amount of information they required in order to cope. Women's need for information relating to the fetal condition varied and were dependent upon the pace at which women made revisions to their assumptive world and the individual's preferred coping style. The clinical implications of recognising and meeting this need are discussed in the chapter 9.

Emotional responses

The longitudinal design employed within this study allowed for prolonged engagement with participating women and meant that changes that occurred over time in relation to women's emotional reactions to the diagnosis could be captured. As internal assumptions of fetal health were challenged, women used several coping strategies in order to encompass what was taking place. Lerner's (1980) theory of 'belief in a just world' suggests that individuals get what they deserve in life, therefore in the case of very negative events, people may often find it necessary to attribute blame rather than accept the randomness or unjustness of the experience. Similarly to Emma, Eavan was angry and resentful that this had happened to her rather than to someone else.

I feel a bit vengeful. Like one day I dropped [daughter] to school, I had my own kids but I was looking at them all healthy and I am just thinking... Why me? Feelings like that, my friend had twins, and it took her years to have them but I can't even go and see her. (Eavan)

However, other women chose to blame themselves rather than others.

I would blame a lot of it on the wine

J: Oh?

There is a difference between liking wine and loving wine, I love wine...I would drink a bottle no problem. I wouldn't have a problem with it in the world. But like you see on my first pregnancy I couldn't drink. But then when I had [second baby], I didn't drink on that

pregnancy, I drank beer or whatever but I went to wine then, you know [in this pregnancy]. But I blame it on me, and then I try to blame it on like loads of things, but mainly me. (Fiona)

I blamed myself. I was in New York with my best friend and my Mam and my aunt and I was out on the batter every night. I was getting drunk. I was a week over there and I found out I was pregnant. (Hayley)

I have not gone through the trying to blame someone because I don't see that there is anyone to blame other than myself and my husband maybe that our genes are [defective]...But we have been told most of the time it's sporadic anyway so you can't. You can't say well you know if I had a baby with someone else other than you this wouldn't have happened to me, you can't do that. So I haven't gone through the anger and I haven't gone through the 'who's fault is it?' When it comes to my baby being born yes I will probably be angry but I don't think I will have anyone to direct it at. (Caitlin)

Lerner (1980) suggests that in order to maintain an illusion of control over a random event it is tempting to attribute blame as this keeps the 'belief in a just world' intact, restoring one's sense of control. However, some women felt that their friends were attributing them with causal responsibility for the anomaly through actions that they may have taken or failed to take earlier in the pregnancy. Molly commented how several of her friends queried if she had taken folic acid on hearing the baby had a neural tube defect.

Others have often made me feel guilty, asking me if I took folic acid. I thought I was so covered I had taken it for two years. (Molly)

That was Christmas day, a friend of mine called, I mean she is genuine no more than anybody else has been about the whole thing and she was saying to me, so they just don't know why it's happening? I mean we have asked this question ourselves and they [fetal medicine specialists] just don't know why it would happen, and it's just sporadic. So I just said nothing to her, I just let it go. But she turned around and said to me I know it makes no difference but did you check if you were pregnant say when we went to [a friend's party] and you had a couple of glasses of wine and maybe you didn't know you were pregnant? I am

looking at her thinking I know it has nothing to do with that but even suggesting that there is any element of blame... we haven't spoken since. (Ava)

Lerner (1980) suggests that just as we believe in a just world so do others around us. Therefore if Ava was not to blame for the diagnosis this may have threatened her friend's security around conceiving a normal baby. Maolíosa spoke of how she went to great lengths to inform her family in particular that the occurrence of talipes was not related to maternal age (Maolíosa was 36years old at the time of diagnosis).

So the way we have found ourselves with telling people is that we move into the treatable side of it, to protect of ourselves and the baby. Some might say you are being paranoid about it but I think the thought that people have of it is, amongst my parents' generation would be that it is age related, is it something you brought upon yourself. (Maolíosa)

Some women seemed more able than others to incorporate the randomness of the event into their world; however, this was often influenced by the likelihood of a positive neonatal outcome.

There is no one to blame for this, this is happening for a reason that none of us know. (Keeley)

I never looked at myself or at [partner] because we don't smoke, I don't drink when I am pregnant, and he is a fairly light drinker. So we were never looking to each other to blame, it was just one of these things, you know. (Cliona)

However, when one had prepared meticulously for pregnancy, had taken positive action to ensure a good outcome, retaining assumptions that one has control over certain events becomes untenable.

What he [FMS] said was the baby's head hasn't formed properly. He didn't tell me until we had left the room what it was and he handed me a piece of paper and he had written anencephaly on it. He was trying to, he said to me it's to do with folic acid, and I said I had taken folic acid for 2 years and he said well then in this case it's not that. But I can't get my head around it. I had taken folic acid for at least 2 years all the time. A friend of mine, her

first pregnancy had anencephaly which I knew nothing about, at 20 weeks she went in for her 20 weeks routine scan, she has gone to London, has had a termination, has come back and was put on the higher dose of folic acid, had a perfect baby boy since. But 14 weeks ago, she became pregnant again on the higher dose of folic acid and again I think she has anencephaly. (Regan)

Rotter (1966) proposed that individuals have an internal locus of control- a belief that what happens to us is a consequence of our actions. However, when the trauma does not fit with this assumption, the individual becomes an 'innocent victim' and may become overwhelmed by the objectively uncontrollable nature of the crisis. Regan was to remain concerned regarding the likelihood of having a healthy child on a subsequent pregnancy, as her friend's experience had left her wary of the security she might feel through taking a higher dose of folic acid. When causal factors suggest that prevention of the anomaly was not within one's control, an alternative control-preserving mechanism to self-blame may be utilised. Within this study, women commonly questioned God's goodness and sense of justice.

I was real bitter at first, God I am not a bad parent... so why have you done this to me? (Dáire)

He [partner was Muslim] accepts things more easily than I would. In a way I think they [Muslims] are great because they can accept. The day mm...I got the results [amniocentesis confirmed Down Syndrome] there is this big church there beside [hospital] and I went in and I walked back out. This is not for me; I know my faith is gone now.

J: Would you have been going to church before that?
Yes, I was brought up Catholic and maybe prayed at night. I haven't been to mass for a while though. But they [Muslims] are great, they have great belief in their religion, they always think there is a reason. No such thing as I could be pregnant without a reason.

J: Did you ask why me, why us?
Yeah, Oh I was very angry, very, very angry. I mean I am sure I was saying what did I do to deserve this? I have no faith now. I had to sit in mass one day, I wanted to go for my granny's anniversary but just listening to the priest standing up there, you know the way they talk and

lecture us, and I was so angry. My baby might die and the way I am looking at it is and here is my faith coming again that if she died God is after taking her away... why take her back? (Lori)

Others used their faith as a way of coming to terms with the fact that they might never find a reason for why this has happened.

You know, I am not a religious person but I do talk to God and that...and I do say well you wouldn't want me to go through this would you? Maybe He [God] wants me to go through this. Just telling yourself, maybe this is to be, and just get on with it. (Emma)

Sian was the only woman in the study where faith was a guiding force in her life, a bedrock of support, and where God's will was never questioned.

I mean it happens to people [conceiving a baby with an abnormality], like you think it will never happen, but like I mean these things do happen and then you have to think about them. If I was to, it would seriously drag me down through the pregnancy if I was to, sort of get hung up on it like. So I thank God, I just hand it over to the Lord, like and say well, you know, God give me the grace or the strength, or please God the baby will be perfect. (Sian)

Many women spoke about how receiving a diagnosis had either a positive or negative influence on the relationship with their unborn baby, and often shaped this interaction in terms of whether they took the opportunity to look at the baby during ultrasound examinations.

I do look at the screen because they are alive; there are positive parts to the babies. (Emma)

Maybe it would be better if the baby dies, but I have already bonded you know? (Tara)

Many of the women who chose to continue the pregnancy were faced with repeated ultrasound examinations, and despite the difficulties associated with anticipating a poor outcome, most viewed the examination as an opportunity to see the baby while he/she was still alive.

I hope that he is born alive and really hope for as long as possible he will live. The longer time I can get with him the better, but I need to bond now, while he is alive, just in case [he is stillborn]. It's hard to let go. I mean just, like I really want to bond with him and have him for as long as possible. (Laoise)

However, the image obtained by two-dimensional ultrasound does not give a realistic impression of the baby's actual appearance and some women were to later fear their reaction to seeing their baby at the birth. Other women found it difficult to become attached to the baby, and not surprisingly, this was often due to fear that developing a bond would intensify the emotional pain felt if the baby subsequently died (Stainton et al. 1992).

I don't look at the scan, I can't get attached to it... I hoped it was going to die. (Fiona)

However, this response was more common in women who had chosen to terminate the pregnancy (Drugen et al. 1990).

I chose not to look, my husband looked but just at that stage [pre-termination] I couldn't look any more. (Regan)

As women's search for meaning progressed, and the presence of a fetal anomaly had been confirmed, women were now in a position whereby they could no longer confirm that the ultrasound scan had provided reassurance of fetal health. As previously discussed, there is a social aspect to ultrasound in pregnancy, whereby all women in this study had informed friends and family of the day that the examination was scheduled, some of whom were merely distant acquaintances or work colleagues.

Telling family and friends

In the space of twenty four hours most women had lost the assumption of fetal health and were still trying to come to terms with what was seen as devastating news. However, due to the positive context in which ultrasound is situated, all women had informed at least some family members or friends of the date of the ultrasound examination. Consequently, women were receiving phone calls within hours of receiving the diagnosis, and sharing the news to some extent was almost inevitable.

Oh God yeah, that was the unfortunate thing that I told a lot of people. I had a lot of people to explain it to afterwards. I regret that now. There are some obscure people that you just go God if I hadn't told them, they didn't need to know but you are just so excited you have to. (Molly)

There's only so much information you can take in. I don't even know if I slept that well that night, I can't remember if I got up the next day...I'm thinking God how am I going to deal with this...what am I going to tell people? (Doireann)

Some women felt they had no option but to inform relatives, as they were perhaps involved in taking care of their other children whilst they attended for the examination.

I had to go straight up to my mother's; [my son] was up there so I had to tell them, because they all knew that there was something happening. They knew I was going for the scan. So mm and I was supposed to be dropping [my son] back there, and then I was supposed to go back to work. (Ciara)

Some women found support in telling family and friends and, on occasion, requested that they search for information regarding the anomaly on their behalf. On the other hand, women were often mindful of how others might react to the news.

I found that a help, a great help, at least you know that you feel, not that you want to put your burden on anybody else but I find it good to talk to people anyways. I'm not one that can bottle a thing up and say nothing about it, you know, I have to talk like to people about it. And everyone was so understanding, so you know they were just saying sure it mightn't be that bad. Yeah, they were hoping like as well. (Maeve)

No, we didn't keep it to ourselves; most people knew we were going for the scan...and we are quite a sharing sort of couple, [husband's] family would be very close and very involved. I didn't say it to my close friends at the time and I didn't say it to my own parents. I didn't want my parents to be worried when I didn't know what to tell them, I didn't ring them. (Fay)

As the routine ultrasound was most frequently performed between 20-22 weeks gestation, many women acknowledged that as the risk of miscarriage receded not only did they have the confidence to tell others about the pregnancy, but often the physical signs of advancing gestation meant that they could no longer hide the fact.

I mean our families already knew at that point but I decided it was okay to tell everyone. I had also started, I mean I was changing into my maternity trousers. So I couldn't hide it any more. But once we had the amnio we had decided by that point that we probably would not want to continue with the pregnancy. It wasn't definite but at that point mm I think in many ways it brought up all the confusion and the bad feelings that we had, the sad feelings and the anxieties. In many ways it seemed to dredge it all up again. On the one hand it was good to get the confirmation but on the other hand it was just more bad news for us, loosing any hope

J: How did you find telling others?
If anything it's a desire to blurt out you know I have this terrible thing happening, you know, I look okay on the outside but there is this really, really abnormal baby growing inside me. There is this weird compulsion to tell, I have to resist doing it. I have told people at work that I can't be coming in obviously, I am going to be away for a while and I have told one of them at work what the problem is and I have told a couple of other work mates that I feel close to what the problem was. I mean it's a bit weird I leave work pregnant and I come back and I am not pregnant anymore. The last thing I wanted was people saying how the pregnancy was. So I would rather they know that I lost the baby than to think I was still pregnant. After one of the earlier scans one of the mothers [at son's crèche] had said to me oh you are so neat. I said that is because of bleeding and the baby is small, and the doctors are worried. You know, I could see that this is not what she was expecting. She was so taken aback and said oh my God I am sorry I was just trying to say you look really trim and I just thought oh God I have to be careful now...so I realised you can't just blurt it out. (Aoife)

Other women were more reluctant to inform others of the diagnosis. Alannah felt obliged to disclose the news partially, as she was asked by the clinician to try and identify if there was any history of renal disease in the family.

I was worried could the other kidney suddenly dysfunction, mm...I suppose we were probably feeling a bit taken aback at what we found on the internet as well. Like could the baby suddenly go into distress in the womb because of pressure on the other organs. I actually, I rang a couple of my family to find out because my sister had had a kidney problem mm...there was never a name for it but she had a lot of kidney infections as a kid and it was just due to I think a bad flow of urine in the kidney, and my Mum has a first cousin who had died of, she had two failed transplants. She had nephrotic syndrome. So then we obviously rang around and asked about that... and then we went back then with the information to the doctor.

J: Were the family suspicious as to why you were ringing around asking questions?
I would have told them that we just had a scan and there was a question over one of the kidneys and I just needed to know whether or not there was some hereditary problems, because I heard them growing up but I hadn't really listened, you know. Yeah. I think I just didn't want to make, to blow this up. And probably panic everyone else in the process when we really didn't know ourselves what we were dealing with. To be honest I think we wanted time ourselves to adapt to this without other people asking questions. That is even down to close family which is probably a bit unfair but you know, then you do that it starts to become a bigger thing, you are getting phone calls. We just felt it wasn't, we needed to sort ourselves out first, and we needed to find out exactly what was wrong. (Alannah)

It appeared that when the search for meaning was accompanied by a failure to restore assumptions, or when there was difficulty in answering 'why me?' there was an increased reluctance to discuss the diagnosis with others.

I don't want to talk [to people] it's actually none of their business. (Lori)

It's the worst thing about pregnancy, you can see it, I am a stranger in the street and you can see that I am pregnant, it's not a private thing, everybody knows. People are congratulating me and saying isn't it great? ... but I just don't want to tell everyone. Then people who were delighted for me they are starting to notice they haven't seen me for a few weeks.

J: How do you feel about telling people?

It's very hard. I don't want to talk about it. We asked our parents to tell them [other family members]. They are a great support, but like tomorrow when we go in to [fetal medicine unit] there will be 6 or 7 phone calls made afterwards to tell our family how it went, or they will be ringing us...a lot of repetition as well so it's difficult to get away from it. (Eavan)

Each of the women in the study commented on the fact that although family and friends were only phoning once to get updates on progress, in essence one phone call from many meant that the couple were relaying painful information over and over again. This often resulted in the couple agreeing 'a standard story' and not deviating from the script to reduce the emotional involvement associated with addressing the issue repeatedly. Many women suggested that for the future, staff should forewarn parents of this possibility and advise them to have one nominated family member who they would call, and who, in turn, would notify all relevant others. Although most women spoke of positive rather than negative experiences of telling others the news, family and friends also experienced difficulty in acknowledging that not all babies are born healthy.

Then you told people and people were saying ah sure you know so and so down the road they only have one kidney, they lost one in a bike accident and I was saying that's no good to me, don't be tell me silly stories like that, I don't need to know those stories, you know some of the stories like that were annoying. (Erin)

She [sister-in-law] still rings me and she would say mm I still have this feeling she would say that everything is going to be okay. The child is going to come out healthy, she still to this very day is saying that because it happened to a little fellow up the road from where she is living and the child was born well, he is running around the road and not a bother on him so everything is going to be okay with this child. I won't answer the phone to her now. (Niamh)

I had an older generation asking what's wrong with the baby [they keep saying] the baby is just small, they won't believe the baby is going to die. (Doireann)
My mother couldn't really understand it –a leaflet with the name and explaining it [would be helpful] you don't want people saying it's going to be ok. (Laoise)

As women began to assimilate the impact of the diagnosis, this often signalled the beginning of a process of recovery from the trauma. However, for some, reaching a final diagnosis took time and the search for meaning continued.

7.1.3 Decision making

Ultrasound is both a screening and a diagnostic tool, consequently, for some women carrying babies with structural abnormalities (e.g. anencephaly, hydrocephalus, renal defects etc) certainty regarding the diagnosis could be achieved based on ultrasound findings alone. However, there exist several other structural defects (e.g. certain cardiac and gastrointestinal anomalies) which can occur in isolation or in conjunction with a chromosomal defect. When the latter occurred, women were offered invasive testing as a means to confirm or outrule a co-existing karyotypical abnormality.

Further testing

Responses to the offer of karyotyping the fetus varied; nevertheless, there appeared to be two distinct patterns emerging in the data as to whether women opted-in or opted-out of further screening. These approaches to information gathering were categorised using two in-vivo codes 'Getting my head around it' and 'I'll cross that bridge when I come to it'.[62] The former refers to a requirement for high levels of information (information seeking), and is accompanied by strategies to access additional sources (e.g. searching the internet, seeking a second medical opinion) if the information received is insufficient to meet need. Many women spoke of accepting the test in terms of achieving certainty regarding the diagnosis, and although hope for a normal result was held by some, relief that the anomaly was fatal was experienced by others.

We cried our eyes out, you know, what can you do like, you see you're expecting so much like [prospective life with a healthy child], and we were coping you know, hoping that it won't be bad news like, and knowing deep down it will be. So I said it to [husband] should we go for it? [amniocentesis], I think we should like, you know, because, rather than not knowing...but

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[62] During the early stages of analysis I could not identify why women exhibited one preference above another, nor could I link it to the classification of the anomaly or the final decision as to whether to continue or terminate the pregnancy. Therefore my initial aim in returning to the literature was to identify if this was a manifestation of a 'coping process' .

I suppose deep down you always cling onto the little bit of hope that there might be good news. (Maeve)

Well I want it done but I just worry, I still have that hope that everything is okay, but when you know for sure [there is a chromosomal anomaly] how are you going to cope knowing? (Eavan)

[FMS] had said the amniocentesis might give us some answers, so we kind of decided in the room that day that we were going to go for it, have it done, it was just another I suppose question that might be answered. (Kasey)

[Husband] asked him straight out, you know is this going to happen again? and he said he didn't think so, it just was one of those once off situations probably happened at the moment of conception, it was that unusual ..., you know he was talking about chromosomes and of course everybody thinks when they think chromosome they think Downs Syndrome. I had the amnio to try to deal with it ... I was delighted just to get a diagnosis... there was a great sense of relief just knowing... we had been getting no information week after week, [until we got the amnio result]. (Doireann)

No, we wanted a definitive result meaning the baby would die, early, quickly. [the day of the result] I felt a mixture of nervousness and sadness and not knowing how we were going to react and not knowing exactly what we were going to say and what we were going to hear. But [FMS] was visibly upset, he didn't cry but it was clear it was extremely difficult for him to tell us this news. (Aoife)

J: Is that a good thing or a bad thing?
I am not sure, it was surprising. I know that bad outcomes don't happen all the time but clearly bad results happen fairly often and doctors have to give bad news, but I think it was nice, after all we were loosing our baby. (Aoife)

Even when a fatal chromosomal disorder was diagnosed, women often used this information in relation to planning future pregnancies.

J: Did you choose to have an amniocentesis?

Yes, I did. I suppose, well part of it was uncertainty really because we didn't know...we had no idea and I was thinking of every possible thing. I was just in floods of tears when we came home... [amniocentesis result confirmed a lethal defect]...The only way I am coping is kind of putting it in perspective by thinking that other people live with uncertainty that is never going to go away. Like we have a friend our own age that went to college with us who has MS, a guy, and he kind of has to live with uncertainty because he is fine now but he may not always be, he doesn't know if it will take a turn for the worst. I try to put mine in perspective by thinking we have uncertainty now about when this is going to end but there is going to be finality to it and you know, the baby is going to die. We have been told it is unlikely to recur, we can try again. (Tara)

For other women, information regarding the fetal karyotype was being used as the basis of the decision to continue or terminate the pregnancy.

So I don't know why I was waiting for the test to come back, I wasn't particularly expecting the test to be any different [Edwards Syndrome was suspected based on ultrasound findings], I suppose it was so we could move on and make decisions because you still couldn't make decisions without the amnio test. (Muireann)

However, some women chose not to have amniocentesis (information avoidance) on the basis that there was little value to be gained from the information the test would reveal and the risk of a procedure related loss was too high a price to pay.

I always thought there was something else underlying....I didn't believe it was as simple as a multicystic kidney, now hopefully it will have been, I do believe now it will be that simple and that's it but no on that day, I was very matter of fact that day and he said the amniocentesis and I said no, what am I going to do? I'm not going to go [to UK for TOP], so what's the point in knowing? If I lost the baby having an amniocentesis, you know and had the baby how would I cope, that would be a bigger problem than this like and that there was no point in, like they couldn't medically do anything for this baby so there was no point in having the test. (Erin)

For some women, the risk of a chromosomal abnormality was considerably higher than the procedure related loss rate. Sian had been given a 1:3 risk that her baby had Down Syndrome; however, refusing the test was seen as a way to keep the hope of a healthy baby alive, a hope she needed to keep alive in order to cope on a day to day basis until the birth.

It [amniocentesis result] could put a totally different outlook on the last few months of your pregnancy, we prefer to think that the baby will be normal. (Sian)

However, unlike other stressful medical situations, pregnancy is unique in that there are two (or three) 'patients' to consider. One woman expecting twins (one of whom was normal) was offered repeated invasive therapeutic procedures to provide predictive information regarding the affected fetus's condition, but on the balance of risk, rather than avoidance of information, refused the offer.

We didn't keep having tests done because we didn't want to miscarry both babies. (Orla)

Women also recommended four key elements (when, who, how, gender) that should be incorporated into the process of informing parents of the result: WHEN will the result be available, WHO will give it to me (named person), HOW will I be informed i.e. by phone or appointment in the unit, and staff need to be aware of whether the woman wishes to know the GENDER or not, as once it has been revealed it cannot be withdrawn.

The data have demonstrated that women's responses to the offer of invasive testing varied. In keeping with the epitome of theoretical sampling, the literature search was widened to include research from the areas of psychology and counselling. It was in this area that I discovered that Miller and Mangan (Miller 1980, Miller and Mangan 1983) have described two primary approaches undertaken by people facing stressful health-related situations. 'Monitors' are described as those that seek out information and monitor the threat, similar to the women in the first category "Getting my head around it", whilst 'blunters' avoid information that may result in increasing anxiety, as demonstrated by women in the second category "I'll cross that bridge when I come to it". Women who exhibited monitoring type behaviour needed to have control over the

situation in order to cope with what they had been told, and saw information as the key to regaining that control. This behaviour was also repeated when a new variable was introduced into the situation such as a change in the fetal condition or the discovery of an additional anomaly or variant, regardless of the impact this new variable would have on the predicted outcome. This need for control in a stressful situation has been previously described as a problem-focussed approach to coping, where the focus is to manage the problem causing the distress (Lazarus and Launier 1978). Women who adopted blunting strategies, continued to avoid taking information on board regarding the fetal condition, particularly when it was of a negative nature. This coping process has been described as emotion-focussed (Folkman and Lazarus 1980), and the authors suggest that this manifests more often in circumstances that are appraised as unchangeable. Women exhibiting this coping process required more positive information about the fetus, such as pointing out what was normal about the baby or highlighting fetal growth or movement when the fetal condition and prognosis remained grave.[63] However, although these models based on information preference confirmed that the information seeking or avoidance strategies observed had been reported in other areas of healthcare, it failed to explain how preferences for information could change over time, or indeed, how the behaviour related to making sense of the loss. Hence, theoretical sampling continued until Parkes' (1971, 1988) construct of the assumptive world, Lerner's (1980) theory of 'belief in a just world' and Janoff-Bulman's (1992) theory of 'shattered assumptions' were located in the literature on grief and traumatic loss. As previously mentioned, Janoff-Bulman's (1992) theory of 'shattered assumptions' takes account of how trauma disrupts our beliefs about the world, such as most babies are born healthy, bad things happen to bad people, we can have some control over the future (Lerner 1980). However, Landsman (2002) suggests that the process of revising our fundamental assumptions after trauma needs to be gradual. Therefore one's approach to information processing can be viewed in terms of the pace at which an individual attempts to make those adjustments, and the extent to which one tries to regain control over events. Within this study, making adjustments also involved making decisions regarding the future of the pregnancy.

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[63] Further detail regarding this information processing model are available in data in a paper peer review from this study in appendix 12.

Deciding to continue or to terminate the pregnancy

Almost all of the women in this study said the issue of termination of pregnancy emerged at some point during the process, even if only in terms of the certainty that this was not an option that would be considered. The context of the study is undoubtedly relevant, as continuing the pregnancy after diagnosis (irrespective of the outcome for the fetus) was the 'norm'. Several important differences between these women's experiences and international studies have emerged suggesting that social and cultural beliefs may be influential. Previous studies have shown that the prognosis for the fetus is a key factor in decision making (Drugen et al. 1990, Pryde et al. 1992, RCOG 1997), however, the seriousness of an anomaly was not an equally reliable predictor of whether parents choose to continue the pregnancy in this context.

The tyranny of choice

Some authors have suggested that ultrasound in pregnancy has a positive impact on improving reproductive choices; liberating women from the burden of caring for a dependent child. However, in a country where termination of pregnancy is illegal, the information gained from routine ultrasound may be more akin to a double edged sword. Women carrying babies with treatable anomalies or predicted short-term morbidity and women carrying twins, whereby one fetus was viable, seldom considered termination as a therapeutic option.

No, he [FMS] never mentioned termination and we never mentioned termination because the other baby was fine and because they were in the same placenta and he said the chances for the other baby were excellent so it hasn't entered my head about termination now. (Orla)

Whereas women carrying babies with more serious anomalies spoke in terms of basing their decision on the extent to which they could cope with caring for a child with complex needs compared to living with the decision to end the pregnancy.

At no point did I think about terminating the pregnancy, the baby was either going to make it or it wasn't. We weren't talking about dealing with a child that would be ill for the rest of our lives. (Emer)

Many women felt they couldn't terminate the pregnancy, regardless of the diagnosis, yet hoped they wouldn't have to care for a child with significant disabilities. Some women commented on how they were unaware of the gestational limits that applied to termination of pregnancy services in the UK.

I was just saying please God if it's so bad that, you know, it won't live, that's what was in me head. Oh I wouldn't terminate or do anything like that, you know. (Maeve)

I didn't think termination was an option at 18 weeks, we didn't think they allowed that and then even if they did I don't think we would do it. We did think of it in terms of do we want a baby that is dependent...it was never termination it was always if the kid dies it might be best. (Eavan)

Other women spoke of how the intensity of wanting a baby regardless of the outcome was so strong, that it seemed that coping with a neonatal death would be unimaginable. Ciara was certain that her baby had a chromosomal anomaly when she agreed to amniocentesis, yet for her the best outcome would be that the baby had a non-lethal abnormality.

It looked like the baby could have a chromosome disorder and he [FMS] said for example Down syndrome. I would like to do an amniocentesis. He said you do know there is a risk with that and I said yeah... So I said is it only going to be Downs? Do I really need to have it? You know, I was really afraid of having it. He said it is important to do because it might not be Downs, it could be Edward's syndrome and I said to him what is that? It's a fatal syndrome he said that basically the baby would either die in the womb or very soon after birth. I was hoping, praying for a good result. But I know, I know I will cope if it is Down syndrome, its not the end of the world, there is a lot more out there now but just as long as its not Edwards or Patau's. I think I will cope. Once it doesn't die. (Ciara)

The legal situation in Ireland has created the circumstance where women seeking to terminate their pregnancy have to do so abroad, uncertain of their legal position in doing so and without relevant information, financial or social support (Smyth 1992). For some women, the perceived strength of the pro-life voice instilled fear in relation to raising the subject with clinicians.

I wasn't talking about termination...society is so anti-abortion in Ireland [I thought] I can't ask this-but I didn't want to take this to full term with that outcome [lethal anomaly]. I think, I mean I feel guilty about this but I think we got what we hoped for, that sounds awful [certain in-utero demise], and I actually said this to my GP and she told me not to feel guilty about it but I was...I was hoping I suppose that it wasn't Down syndrome or something like that. That our child would have severe developmental difficulties with possibly parts of the brain missing. We have heard him say when he was doing scans ah there is a gap there [likely absent cerebellar vermis], you know, and we know there are lots and lots of things not right and I just, I just kind of felt for the child what kind of quality of life would it have. But for me it sounds selfish as well, I would probably never work again, mm you know give up my whole career, not that its that great but...it's just, it's the rest of your life, you know, and the chance maybe of this child outliving you and the worry that would be as you got older and all sorts of things. I mean, the 2nd time we went in he [FMS] gave us the 6, 8, 10 week scenario [prediction of time to fetal demise] we came out of that and I said to [husband] I feel strangely relieved. I feel am I a bad mother because you know some of these earth mothers would say I want any baby and no matter what special needs it has I will love it. I know if I did have that baby I would love it but I don't wish it for the baby or for myself or for [husband]. It's terrible but you know it's the whole society thing in Ireland as well, we felt relieved and we felt there was finality to it, probably, I don't think I would have gone to England anyway. I think, I am pretty sure I wouldn't have. Mm but I'm glad I don't have to, we stopped thinking about it pretty much because we knew its going to end naturally, and we are not going to have to lie to people and all that stuff. Now if I had been in England or America where they offered me the choice as if it was an amino or you can do this if you want I probably would have gone for it. It's also the fact that it wouldn't be socially acceptable in Ireland. (Tara)

Other women were to express surprise when clinicians raised the issue, suspecting that it was perhaps beyond their remit to do so. However, it served to highlight the seriousness of the fetal condition.

I couldn't believe a doctor in Ireland would say that we had options- but as soon as [FMS] said termination we knew, before that you wouldn't have nearly believed that it could be this bad

and as soon as [FMS] said that you knew it was...but we couldn't do that not [unless] my life was in danger. I couldn't go to a grave knowing that is what I'd done. (Kasey)

It may seem surprising to the reader outside of Ireland that religious affiliation was almost never mentioned by women considering this option, but rather that the decision needed to be compatible with the woman's future moral relationship with her fetus and the extent to which this is influenced by the social context will be explored. The RCOG (1997) report on screening for fetal abnormalities states that there is evidence to show that when a serious or lethal anomaly is detected, parents will elect to terminate the pregnancy in 80-90% of cases. However, the data referred to in this statement are derived from birth registers maintained in European countries where termination of pregnancy is legally available within the state. For women in this study, the impact of being required to leave the state can not be overstated. So difficult was the prospect of leaving that most of women carrying babies with lethal anomalies continued the pregnancy whilst hoping the fetus would soon die, therefore absolving them from making a decision to terminate the pregnancy.

I'm hoping they'll say it's fading away. My biggest fear is that the baby will survive and I'll be left with a seriously handicapped a baby. I didn't know legally what he could tell me. I would only do it [terminate the pregnancy] for my own sanity if it got to that point. (Doireann)

Many women commented that a perceived lack of support for such a decision within their family and social circle meant that continuing the pregnancy was in effect remained the only option open to them.

[the absence of a referral pathway outside of Ireland] has the same effect as saying you have this option but... there is an awful sense of abandonment...if you make that choice you are on your own. (Tara)

However, for eight women in the study, continuing the pregnancy when the outcome was so bleak was untenable.

So it was a very easy choice in that it was anencephaly and there was nothing, there wasn't... it wasn't, now of course it wasn't easy...but there was no dealing with something that had

survival. There was, he [FMS] sort of said to me the baby, I thought he said to me one to three minutes the baby would survive but that, it could be hours, the longest could be a day. (Regan)

I was totally unaware that there could be a problem; it wouldn't happen to us... it was devastating. I asked would the baby just be a little slow, and he [FMS] said it will be worse than that. I said can you not give me something to make me miscarry now, he [FMS] said there is nothing we can do. (Kerrie)

*That was it, they [fetal medicine team] said it was incompatible with life, I don't know whether I presumed that because it was the head which is so important or they did say just say that the baby won't survive. [husband] was very quiet, but he just, the minute, in fact I think even before it had sunk into me he held me, and it was when he held me that I realised oh s**t like. I think he was just petrified that I was going to break, or something. I was trying to hold back the tears because I wanted to get the information I was intermittently exploding but I remember thinking don't let them start yet because you have to hold it together and find out what is happening here like. If you fall to bits people will stop talking like. I do remember [FMS] saying that you would be expected to carry the baby full term ...I found that pretty difficult to deal with, the idea that you would have to carry it and know that it was not going to survive, I felt that's absolute torture and I thought I can't because I knew I wasn't going to get a baby. I know people choose that option and I, I don't know how they do, and they must be very strong. But for me the idea of like that decision was pretty immediate, the idea of watching yourself grow and all the other parts and mm you know one of my close friends got pregnant and she decided to get pregnant, the two of us were pregnant together. But the idea of the two of us hanging around together and you know I just think it would be very difficult for all the people in my life as well if mm they were seeing me grow and knowing that it wasn't going to survive. (Molly)*

For others, the decision to terminate the pregnancy was influenced by the perceived burden of care that would ultimately be placed on a sibling.

Yeah so you know I'm not a very patient person, I'm not the kind of person who believes that children are special, special children and all this sort of thing and all this, I think that I would find it very difficult to cope, I admire people who do but I don't think it's the right thing for

me. We had kind of discussed it and its not particularly fair if we had a child with a problem, we're reasonably elderly, so the child, well you are you know if you'd a child say that's going to live to 35, 40, we're going to be 80, [daughter] is then left with the responsibility of a sibling. I've seen friends of mine who have got Downs brothers and sisters or cerebral palsy kids or whatever and a lot of them come from families of maybe 3 or 4 kids, but we've only 1 kid, your suddenly handing that responsibility to them. (Muireann)

There were many challenges ahead for those women who chose to terminate the pregnancy, including but not exclusively the necessity to travel and having to cope with the reactions of others to their decision. For those women that continued the pregnancy, carrying a baby with a fetal abnormality up to the birth was not without its trials.

7.2 Summary

Once the diagnosis of fetal abnormality was either received or confirmed, the process of searching for meaning in this negative event was set in motion. The unexpected discovery of a fetal anomaly threatened women's belief that they could have some control over the future (Rotter 1966), as many had prepared scrupulously for pregnancy. In reacting to this crisis, women initially sought practical ways to achieve mastery over uncertainty through attempting to determine the causal factors involved. One of the preliminary steps taken to try and answer 'why me?' included seeking confirmation or refutation of the diagnosis. For most women diagnostic certainty was achieved; however, a satisfactory explanation of cause that fit with this assumption of control was seldom found. Women often proceeded to blame themselves for the development of the anomaly as an alternative strategy to restore certainty over future events, as integrating the randomness of the experience into one's worldview is not an easy task. If one can blame oneself for the crisis on the basis of an action taken or not taken, a continued search for meaning is no longer required (Landsman 2002), as preventative action can be taken in the future, restoring a sense of certainty and obviating the need to adapt one's previously held basic assumptions about the world. When the randomness of the event threatened the security of friends or family, the consequences were that causal responsibility was attributed inappropriately to the woman. The decision to inform family and friends was undoubtedly influenced by the

fact that attending for an antenatal ultrasound is seen in a positive context, fetal health is assumed, and many people were aware of when the examination had been scheduled. Some women regretted that they had informed so many people, in particular those who were not members of their close friends and family. However, the extent to which women talked openly and fully regarding the diagnosis varied, but seemed to be linked to the extent to which meaning could be found in the experience.

Although not all women required further testing to confirm the diagnosis, responses to the offer of amniocentesis were mixed. For some, certainty regarding the diagnosis as a means of regaining control was preferable to the alternative of not knowing; even when the result indicated that a lethal abnormality was present. For others, maintaining the assumption of fetal health until proven otherwise was required, as living with the alternative was too difficult to contemplate. Some women responded to a lethal diagnosis with relief, as it meant an end was in sight, which heralded the potential to move forward with their lives. For others, waiting another 20 weeks for the birth of a baby with a lethal anomaly, or caring for a baby with certain handicap was inconceivable and some regained control of the situation through deciding to terminate the pregnancy. For others, ending the pregnancy was incompatible with the moral relationship they had with their fetus, although the pro-life societal context in which this relationship exists must be acknowledged.

Information exchange proved to be a vital component in this stage of 'Gaining Meaning', as the need to match information provision with information need emerged as a clinically relevant mechanism to assist health professionals to support individual coping styles. The Miller and Mangan (Miller 1980, Miller and Mangan 1983) model of styles of information seeking has been invaluable in seeking to explain the interaction between information need and coping style. It has been established that the relationship between the woman and her caregivers forms a vital support structure in this stressful situation, as access to information is a key component in 'Gaining Meaning'. Although the model fails to explain how information seeking behaviours relate to making sense of the loss, its utility is in its clinical relevance. 'Monitor' and 'blunter' type behaviours are readily recognisable to the observer, therefore, responding appropriately to the information preference exhibited can be utilised to improve the effectiveness of the relationship between the woman and her caregivers. The following chapter presents

women's reconstructions of their experience up to the birth and beyond as the search for meaning and recovery from the trauma of diagnosis continues.

8 Rebuilding, phase four of the process of Recasting Hope

8.1 Introduction

This final stage in the process is concerned with the extent to which women make sense of their loss and resolve the inconsistency between their experience and a previously held worldview. The data supporting this stage of 'Rebuilding' were gathered pre and post birth with women who chose to continue the pregnancy and post procedure with those who opted for termination. Progression from phase three 'Gaining Meaning' to phase four 'Rebuilding' is represented temporally as being synonymous with making the decision to either continue or to terminate the pregnancy; however, an end-point in the process cannot be assigned for all women as the process of 'Rebuilding' may last for many years to come. However, a successful revision of the assumptive world seemed to be achieved by most women, and this was particularly evident in women who subsequently conceived/gave birth to a healthy baby.[64] Psychologically, however, it would appear that the emergence of a positive vision of the future (whatever that might be) is synonymous with transition into this phase, as the woman works through her experience in ways that permit her to rebuild or adapt her previously held beliefs about the world.

However, consistent with previous chapters, early phases of data collection and analysis were conducted prior to having knowledge of Parkes' (1971), Lerner's (1980) and Janoff-Bulman's (1992) theories concerning the impact that perceived injustice, uncontrollability and randomness can have on a traumatic experience. The theoretical code that was initially applied to this fourth stage of 'Rebuilding' was 'Evolution of Hope'. However, the theoretical label was revised in order to take account of the process of reconstruction which is characteristic of this phase, and is discernible through women's expressions of longing for a return to 'normality'.

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[64] The nature of the relationship that developed over the course of the study meant that many women were in contact either between and/or following their final interview. This additional contact provided valuable insights into the recovery process and the issues that emerged when a subsequent pregnancy was confirmed.

The following are sample exemplars of the conceptual memos I wrote as I struggled to make sense of 'how' women re-normalised after the loss that was common to all at diagnosis i.e. loss of a healthy baby. However, due to the nature and range of diagnoses, the pregnancies ultimately culminated in a diverse range of outcomes: termination of pregnancy, fetal death in-utero, stillbirth close to term, liveborn infant with a treatable defect, liveborn infant with a treatable defect carrying a risk of mortality, liveborn infant with a significant risk of physical +/mental disability and an early or late neonatal death.

Conceptual memo (June 2004)

Trina says when you can see them looking at the brain, you can cope with something being wrong with the foot as it is not a vital organ... best worst case scenario??? Niamh is hoping for the best of a bad world too as she can't hope for 'normal' anymore (adaptation??) definitely not acceptance as Kubler Ross suggests

(June 2004)

Emma says all planning has stopped, she has given up hoping, despair is winning out and uncertainty means a lack of quality of life. Is she hoping for it all to end when she says she just wants to deliver?? Why?

(July 2004)

Aoife wants to plan ahead for the baby and describes it as an 'Act of Defiance' but feels forced to accept her fate

(Aug 2004)

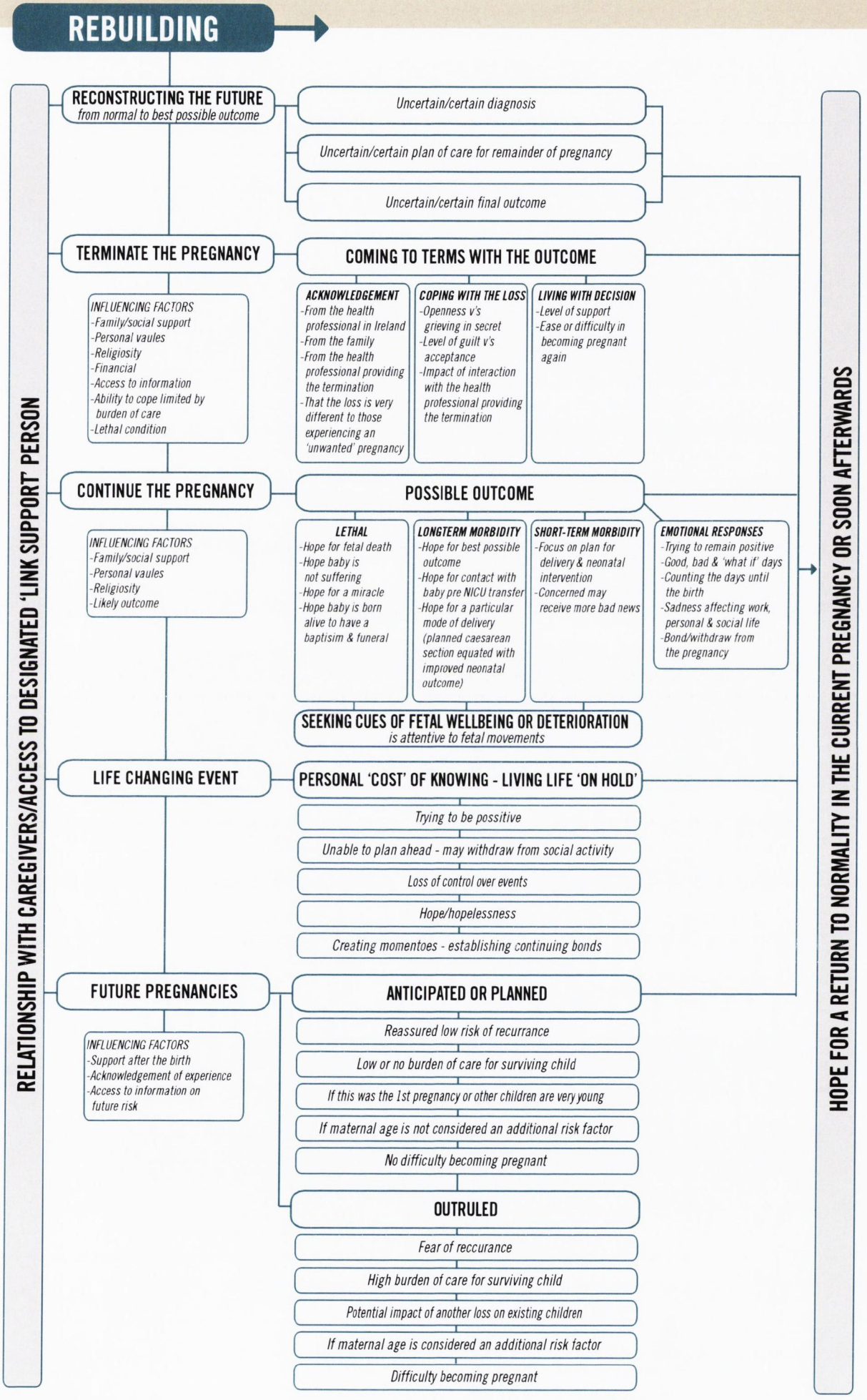
Keeley has a very poor understanding of what is going on. She is asking me so many questions re breech birth, ECV, IOL. She says they are 'words without meaning' and she doesn't know what questions to ask. Her poor understanding is interfering with rebuilding- when the experience is outside the scope of her world-coping breaks down-she plans suicide in desperation to get away from being so overwhelmed and out of control

Alannah- not crossing that bridge until you come to it keeps you 'rebuilt'. She says rebuilding is possible when things are 'normal' at home.

(Sept 2004)

Women are funnelling information. When the fetus is unstable they can return to shock and gaining meaning

This chapter begins with the experiences of women who chose to terminate the pregnancy. It is characterised by women's accounts of their experience in the UK, and the extent to which openness or secrecy impacted on their ability to grieve for their loss. For the protection of the reader, graphic accounts of certain experiences have been omitted.


REBUILDING
RELATIONSHIP WITH CAREGIVERS/ACCESS TO DESIGNATED 'LINK SUPPORT' PERSON
RECONSTRUCTING THE FUTURE
from normal to best possible outcome
Uncertain/certain diagnosis
Uncertain/certain plan of care for remainder of pregnancy
Uncertain/certain final outcome
TERMINATE THE PREGNANCY
COMING TO TERMS WITH THE OUTCOME
INFLUENCING FACTORS
-Family/social support
-Personal vaules
-Religiosity
-Financial
-Access to information
-Ability to cope limited by burden of care
-Lethal condition
ACKNOWLEDGEMENT
-From the health professional in Ireland
-From the family
-From the health professional providing the termination
-That the loss is very different to those experiencing an 'unwanted' pregnancy
COPING WITH THE LOSS
-Openness v's grieving in secret
-Level of guilt v's acceptance
-Impact of interaction with the health professional providing the termination
LIVING WITH DECISION
-Level of support
-Ease or difficulty in becoming pregnant again
CONTINUE THE PREGNANCY
POSSIBLE OUTCOME
INFLUENCING FACTORS
-Family/social support
-Personal vaules
-Religiosity
-Likely outcome
LETHAL
-Hope for fetal death
-Hope baby is not suffering
-Hope for a miracle
-Hope baby is born alive to have a baptisim & funeral
LONGTERM MORBIDITY
-Hope for best possible outcome
-Hope for contact with baby pre NICU transfer
-Hope for a particular mode of delivery (planned caesarean section equated with improved neonatal outcome)
SHORT-TERM MORBIDITY
-Focus on plan for delivery & neonatal intervention
-Concerned may receive more bad news
EMOTIONAL RESPONSES
-Trying to remain positive
-Good, bad & 'what if' days
-Counting the days until the birth
-Sadness affecting work, personal & social life
-Bond/withdraw from the pregnancy
SEEKING CUES OF FETAL WELLBEING OR DETERIORATION
is attentive to fetal movements
LIFE CHANGING EVENT
PERSONAL 'COST' OF KNOWING - LIVING LIFE 'ON HOLD'
Trying to be possitive
Unable to plan ahead - may withdraw from social activity
Loss of control over events
Hope/hopelessness
Creating momentoes - establishing continuing bonds
FUTURE PREGNANCIES
ANTICIPATED OR PLANNED
INFLUENCING FACTORS
-Support after the birth
-Acknowledgement of experience
-Access to information on future risk
Reassured low risk of recurrance
Low or no burden of care for surviving child
If this was the 1st pregnancy or other children are very young
If maternal age is not considered an additional risk factor
No difficulty becoming pregnant
OUTRULED
Fear of reccurance
High burden of care for surviving child
Potential impact of another loss on existing children
If maternal age is considered an additional risk factor
Difficulty becoming pregnant
HOPE FOR A RETURN TO NORMALITY IN THE CURRENT PREGNANCY OR SOON AFTERWARDS

8.1.1 Reconstructing the future

For some women, the search for meaning was relatively short-lived, and women's focus moved to 'maintaining control' of the situation from this point forward. Although the difficulties in making a decision to terminate the pregnancy and the potential psychological consequences of doing so have been addressed in the literature (Pryde et al. 1992, Menahem and Grimwade 2003, Statham 2003), the complexity that a national identity constructed in pro-life terms both politically and legally adds a unique dimension to these women's experiences. Although some women felt they had no choice but to opt to terminate the pregnancy, accessing services outside the state requires a certain amount of resourcefulness. The data will show that the path to exercising the right to travel could be emotionally treacherous.

8.1.2 Terminating the pregnancy

Eight women chose to terminate the pregnancy, five of whom had received a diagnosis of a lethal abnormality. The three remaining women each received confirmation of a serious abnormality which either carried a certain risk of intellectual disability or a significant risk of neonatal mortality. All of the women commented on how their decision was fundamentally based upon the extent to which they could cope with one of two options: waiting for certain death, or, the burden of care required by a child with a significant disability, the full extent of which could not be predicted accurately. Although Áine had originally travelled to the UK seeking a second opinion regarding the prognosis, she soon found herself considering termination as a therapeutic option.

We've come over here to fight for our baby and she [FMS in UK] said well its just that some people do take the route of coming here, you know for a termination because they can't get it at home, but we said no, we said we're over here to see what we can do, what's the best thing we can do for our baby. You know we were going to fight for survival as much as we could. My mother was lighting candles but my father would be very much and I think from the beginning my father thought you know I don't think if she's really fighting for this baby who is going to be so severely handicapped, God maybe she's not doing the right thing. But after a

week of fighting we were given 0% chance of survival...we had to let go now; there was no point in fighting this anymore. So we just thought we could say our goodbyes now, we could go through the heartache now rather than go through it in 18 weeks. I think I'm doing the best for everybody here, my baby, myself, my husband, my family, I think we're doing the best thing. (Áine)

Each of the remaining women spoke of the added difficulties associated with arranging treatment in the UK without professional assistance.

I had to go; you see I couldn't... go on... I was hoping against hope that she would just die on her own anyway and I wouldn't have to go to London and there were days when I couldn't feel a thing and then I would feel movement and it's terrible to feel it, it's a fright. It's not the right feeling, you know. I think that would have driven me crazy if I had of continued it was extremely sad. I wanted it to come to an end, I couldn't cope. We had to make the arrangements ourselves. I had to leave most of the internet searching to him [husband]. We had no support, and we didn't know anybody [in the UK] either. (Aoife)

I didn't do anything then that day [day of diagnosis] you know because myself and [husband] talked about it that evening I telephoned my sister, I said I am going to have to do this. I couldn't tell anyone else as they wouldn't understand so she said I will sort it out. She came up against a brick wall, and she had to ring me and say she started ringing numbers from the positive options list. It wasn't treated any differently [fetal anomaly] and she explained that you still had to do pregnancy counselling and there is a week and a half of a wait.[65] *So she rang me to tell me that and she said you have to do this counselling and you shouldn't have to do this. So in the meantime then I rang the Well Woman and was told it was 2 weeks for an appointment for pregnancy counselling. I found it very hard on the phone to say look this is because, its anencephaly and mm and she said that that doesn't make a difference. You still have to come in before we can give you any information and the next available appointment is 2 weeks. So that seemed interminable so we went onto the internet and mm got the*

[65] Many women referred to the inappropriateness of this situation when gestational limits for termination of pregnancy apply.

information on the Marie Stopes clinic. It was atrocious. From then on it just got, it just went from bad to worse

J: How did you feel about having to source information yourself?
That is understandable too because it's such a dangerous area for them [obstetricians]. I mean you know. I said to the [FMS team] I don't think I can continue with this or whatever and I said to him [FMS] mm and he was still at the scanning machine I said do I need the picture of the scan or any information if I am going to the UK and he said no. So it was like they feel they are not to be associated with this in any way and there is nothing with our name on it or whatever to be brought forward and in hindsight in the light of what happened it would have been extremely helpful if there was some kind of contact between the two [care providers]. (Bethan)

Regan understood that there were legal limitations to the assistance that medical professionals could provide; however, as she had been sharing care with her GP she chose to inform her out of courtesy of her decision to travel.

She is very good with children and mm I found her incredibly good till I told her I had a baby with anencephaly and I was planning on going to England. So I was going to go down to tell her that my test results for diabetes that it didn't matter that mm the baby had anencephaly and I just didn't like her reaction. I didn't, she wasn't very mm...You see I understand as well that they can't give any information, they can't give their opinion, they can't but... But she could be humane I sort of feel that she thought I should have gone to term... she told me how dare I say such a thing and asked me to leave. (Regan)

The structure and quality of family relationships within which women find themselves are irrefutably influential (Skjelstad et al. 1994, Tornbom et al. 1996); however, when women anticipated a perceived lack of support from family, friends or society in general, deception seemed the only alternative.

[Husband] rang a few people to say we lost the baby, but what we were saying was I had lost the baby in [named hospital], then all the questions about how it happened started. So we just

kind of passed over it, saying I had a miscarriage, I started to bleed and had a miscarriage in [named hospital], but it was awful from that point of view.

J: Did you feel you would like to have been able to say what happened?
I think it was my own reservations that were stopping me. I don't think it was anyone, because of what anyone said to us. I just don't think I was that comfortable with my decision. I just didn't think a lot of people would have been able to hear it, you know. mm...so it was easier to kind of just pretend we had a miscarriage. (Laura)

I have said nothing, I don't want to feel I have to justify my actions or feel ashamed or feel I am going to get bawled out by somebody and told I am a murderer. Beyond the physical, emotional and personal struggle that has been one of the most difficult things. (Aoife)

However, others who received support from close family and friends felt they were being warned not to expect the same from those more distantly connected.

I was hoping someone else would bring it up and give me the chance to bring it out in the open but its never going to happen here because look at us having to go to the UK it's disgraceful, and when I said it to my mother, she said oh don't tell anyone that you've gone to the UK. Just say you had a miscarriage or whatever, you know and then you think well I'm not ashamed of what I'm doing, I don't feel I'm doing something wrong, but you know, and you don't, funny a friend of mine who happened to be here when I got the call about the [amniocentesis] results, by chance, she didn't know anything and suddenly she saw my face and she said when I told her, I said we're going to have to go to the UK and she goes, well she said to me I'll say nothing to anyone, I'll just say you've lost the baby and you can tell people. You know straight away where they stand - they're marking your cards that not everybody will agree with what you are doing. (Muireann)

Women spoke of how they desperately wanted to be open about their decision and their sentiments are reflected in Laura's comment *"I wanted everyone to know something awful had happened to me- not that I did something awful"*. Some women chose to seek

support from family even though there was a risk that their decision could be subject to criticism (Mahon et al. 1998).

We were advised [by family] don't say anything to anybody because its against the law and em, tell people that you'd a miscarriage and to me it was a terrible thing but to me having not had a miscarriage you know I thought no I'm not going to, it was devastating and it was harder for me because it was an IVF pregnancy. Well the problem began with my decision to be honest. Basically what had happened was one of our family members, a sister in law, came to us and basically was practically bible bashing saying your against the law, this that and the other, 'you know you should continue, get a second opinion', so it kind of shocked us all. So our very close friends told [husband] to say it was a miscarriage in work. But if we ever had to go through it again I would put my foot down and said no I'm telling everybody, I'm telling the world because maybe somebody might do something to change this stupid law. (Kerrie)

It has been previously identified that religiosity is also significant (Statham et al. 2001). Therefore, these women were asked if their decision was influenced by a particular faith.

Surprisingly not, I thought it might, you know...but it hasn't for me. I don't feel, I don't feel I am sending the baby to hell or anything; I am not worried about that. I am more worried about it suffering, its physical suffering than its soul suffering. I am not sure if it has a soul, I really am not. I am not sure how conscious it is of what is happening to it and its hard to imagine that, and the God I believe in is not that kind of God [who would punish her for this decision], He is not so merciless I think. (Laura)

Each woman said that as long as termination of pregnancy remains unlawful in Ireland, women will be left feeling that what they are doing is inherently wrong

You think you are doing something criminal because you have to leave the country. I made the taxi to stop two roads down from the clinic. I was worried there would be protestors and my face would appear on Irish TV. (Bethan)

Coming to terms with the outcome

In Ireland, the availability of both personal and professional support was highly variable and it seemed almost inevitable that openness regarding the decision would be selective due to either a real or perceived fear of opprobrium. Once women had travelled to the UK, the need for their baby's existence and of this tragedy to be acknowledged was intense. Unfortunately, the recognition they required was not always available from staff in the centre where the procedure was performed. Many women felt that staff viewed termination of pregnancy after fetal anomaly in the same terms as termination of an unwanted pregnancy, a fact they resented deeply.

But you know it's awful what you have to go through. I think in England, you see they have no idea what I was there for or whether they thought I was this flighty young thing who had got caught when it didn't suit me and that's why they were kind of going well sod you, you know you can have the pain, look at you, you deserve it. (Kerrie)

So when I woke up [post procedure] then I was back in my chair. I heard the noises and I can't describe it, I wasn't crying but I was sobbing, but it wasn't a crying sob. It was like a panting, this kind of thing and I remember hearing one of the other girls [patient post TOP] saying – Oh my God is she alright? and the nurse said 'yes, she is fine. Some people go a bit funny after a general anaesthetic'. So I turned on my side so I was faced away from everybody and I couldn't stop doing this, you know and I kept doing it and the nurse came over and said you stop that you are upsetting all the others and twice more she came over to me and told me to stop the crying that I was upsetting everybody else in the room and I felt like saying to her but you don't understand, I wanted that baby, and you can't say it because they don't want to understand. (Bethan)

Others perceived that staff exposure to late termination of pregnancy was infrequent, perhaps due to alternative methods of prenatal screening. Six of the women gave birth to their babies in a hospital delivery suite following an induction of labour.

I was longing to be back in Ireland. She [midwife] mm...came in and I really felt the baby was about to be born and I remember calling out her name saying help, help, come quickly or something and eventually she just managed to arrive on time as he was being born and...I had to explain to her that I wanted to see the baby and hold the baby and take photographs and all that and she kept saying to me are you sure like. I think she felt I was completely barmy, everyone else wanted to get rid of their baby and not see it. So when he was born there was a paper kidney dish and he was handed to me in that. and eh....you know like an egg box and because his skin, he was only 22 weeks his skin wasn't formed properly he stuck to the dish. I couldn't even get him up properly, you know and that was just, that was horrendous. She kept saying to me are you sure you want to see him, I said yes, I really do. So he got cleaned up and I got to hold him. (Laura)

Just as Laura had experienced much of her labour alone, Aoife commented that her allocated midwife spent most of the time out of the room.

I felt I was an inconvenience-that I was subjecting her [midwife] to an unpleasant experience. I think if they could acknowledge or understand how sad we are. Or that it's a very sad thing that happened even though mm she wasn't a live baby, the people who treated us well I think they probably understood. It was just [named midwife] we felt everything we asked her was such an imposition, you know. Like she felt she had drawn like the short stick because she ended up with this stillborn birth. (Aoife)

When health professionals and significant others acknowledged the loss, women commented on how this had a positive impact on the process of grieving.

I mean [consultant's] attitude was you've been through enough and she was extraordinarily sensitive to that. The midwife came back in with a cup of tea and then they went away again and another person came in and gave me a book, this booklet, the ARC[66] book. I read it and it's not directive at all, there's no excuse for [Irish hospitals] I mean it gave us control; it answered all the questions we had. (Muireann)

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[66] http://www.arc-uk.org/

Seeing the baby after the birth was particularly important, although some women required reassurance regarding the fetal appearance.

Yeah it was internal and you see [the diaphragmatic hernia] I had asked the midwife early that day well what will he look like, he's so small and he's so and then when I did deliver I remember saying to the midwife is my baby ok? ... she said your baby looks perfect. So that's when we started opening up the blanket and saying he's perfect and that's heart breaking then because you're thinking my baby is perfect like, but you know internally he's not...and then we held him and we had him for a good while and the midwife went out and left us holding him and then she popped back in and she just happened to say would you like a priest and the 2 of us kind of said oh can we have a priest, she said well the priest will come down and do a blessing for you and I said oh yeah. Now we had the baby to ourselves all this time and my husband sat with the baby for hours. We'd had a lovely time with him and the priest and blessing him and all that, we were happy. (Áine)

We had him for a good while actually and just you know chatting about him, you know it was nice... it was quite a happy moment because you know I'll remember the experience, remember holding him, looking at him I will remember how I felt when I saw him. It makes you feel warm inside rather than all that pain. (Molly)

Although women's experiences of termination of pregnancy were traumatic, once back in Ireland, their concerns turned towards trying to live with the decision, and grieve the loss of their baby. During this stage of recovery some directed their anger towards anyone or anything they attributed with the creation of an Irish national identity based upon an anti-abortion stance (Oaks 1999).

I am sick of hearing God sent you this child...then I met a lovely priest yesterday just out of blue walking down the street, like I felt dirty and I suddenly went that is so Irish and like he doesn't know, I made myself like that, I am not even Catholic and I still feel dirty. (Regan)

Nobody knows that we do it and so the law continues and the law is an ass because we're, I mean how this cannot be construed, considered as a medical situation, to me the whole issue I find is annoying, now I'm annoyed... its all horror, shock, pain, grieving but I'm annoyed as

well because the insensitivity of us having to do this because it's not a dirty little thing that we're going there for. (Kerrie)

It was a very difficult weekend, a very traumatic weekend, I thought my God I was over here for 4 days, not to mind all the cost, all the additional things, you know it's one thing paying for things when you want them to happen but its very different if you're paying for things you don't want to happen. (Muireann)

I felt coming home on the plane that I wanted to take a case against the State for putting me into this position. For putting me into an unsafe [medically], inappropriate position and I felt you know, it just needs to be addressed. (Bethan)

Many of these women commented on how being interviewed was the first opportunity they had to tell their story, unsanitised, without fear of judgement. Each woman commented on the importance of acknowledgement for the loss in the process of rebuilding the future.

8.1.3 Continuing the pregnancy

Although most women in this study chose to continue the pregnancy, two women felt that circumstances had conspired against them, resulting in a continuation of the pregnancy by default. Fiona and Lori both wished to terminate the pregnancy but failed to gain access to services. Each of these women attributed this failure to advancing gestation, when in fact they lacked the resources required to exercise this right. However, the consequences were to have a negative impact on their ability to achieve resolution.

She [social worker] didn't judge us if we were going to have an abortion, termination, mm she said, we told her listen if we do go through with this mm you know to us it was our baby, I know a lot of people in England would go through termination quicker than we would do but to us, the whole thing was we wanted, and she said well you won't be allowed to bring it home, because it's not baggage. But it would have to be in double coffin, it would have to be cremated. She got numbers for us to ring. Like our minds wouldn't even have thought about it. Like whatever the possibilities were prior to 24 weeks, the termination option... that is not

there now. I wouldn't even let myself get up that high, thinking it might be mild. What is the point, you are just going to go back down again. I just stay low then that way you have less to fall.

J: What is the best possible outcome for you?
Apart from being normal?

J: Yeah, do you still hope the baby is normal?
No. If there is something wrong with it. That I will cope with it. We are struggling hard enough to even get a night out on our own with 2 kids without having a 3rd one with something wrong with it. I don't know how I would cope as regards that. But a handicapped child, the worst thing is that it would die but that would also be a good thing. It's a sense of relief I think. I mean it might be initially. It would be traumatic initially, but at the end of the day I think if it was brain damaged or some bad abnormality whereby life as we know it is gone. It would change their [two other children] lives dramatically as well as our own. Then you know best case would be, I think we would prefer if something did happen to it and the baby didn't survive. (Fiona)

Fiona continued to have difficulty coping with events as her baby was subsequently born alive, with a significant disability. Although I elected to discontinue Fiona's further participation in the study following this interview, we spoke once after the birth. Fiona was unable to care for her baby; refusing to hold him or nurture him. The extent of Fiona's inability to revise her assumptive world was such that she required admission to hospital for psychiatric support.

Lori also continued the pregnancy, but once again, this was not through choice. Excerpts from each interview are presented chronologically in order to illustrate the brute realities of the loss of the assumptive world, the search for meaning and the challenges to adaptation.

Interview 1
We both came up with termination. I don't agree with abortion but I think for women in my situation and other women it should be there, definitely. Medical, as I called it, medial reasons and we decided, because we had to think about long term, we had to think about

[daughter], when we die who would look after this child. It wouldn't be fair on [daughter], I phoned the Well Women clinic here but never again. People say they are great but I explained the situation on the phone and they said we can't give information like that. We both sat down and talked about it, it was a very hard decision and we both decided that this is what we are going to do and now we have to sit down and come to terms with this, it's going to be very hard. [Failed to access termination of pregnancy services, the pregnancy continues] Our life is going to change, and then we don't know is our baby going to die. Okay fair enough I will be okay with that, I don't want that to sound okay if my baby dies, but I will probably get a chance to hold the baby. We don't know how bad the heart is and like as well if there is something stopping us having this termination, there is a blockage there, everywhere we went, no, no, no, is that a sign, is that a reason like, maybe the baby is going to die, we don't know, and it will give us the chance to see our baby and hold our baby. I don't know like what way it would have affected me if I had the termination because I am against it. But like we know in the end we are still going to have to make the decision when this baby is born whether we want this child to have heart surgery, is it going to survive. These are the hard decisions we are going to have to make. I am just going to carry on with the pregnancy. Just you know, it's different than when I was pregnant before, I am afraid of what my reaction is going to be when I see this baby. I am afraid I won't have the feelings for this baby ...maybe I will have more feelings for this child because it's going to be sick, I don't know now I just wish it was over now, I just want to have the baby, I don't want to carry on. How many other women are in the same position as me now, and they probably made the choice that they wanted to have a termination, maybe they were lucky that they could get it done. It's so wrong, definitely. It should be, I mean the doctors can't even give you information, even my own doctor,...and you can tell by them that they really want to help you but they can't.

Interview 2

There's no point dwelling on it, it has to be done and that is it you know [continuing the pregnancy]. The decision was taken away from us in the first place. I don't know how I am going to feel until she is born, you know that type of way. I was doing absolutely brilliant on Wednesday, I was fine and on Thursday, I went up to the hospital and as I was getting off the train and I just completely lost it. Just out of the blue I was completely uncontrollable. Some days I talk about it and there are days I don't, but I'm glad you're here. I kind of accept it in my head that she could die but my fear was the baby would die inside me. I knew what I

wanted to do, have a termination...I'm afraid of my reaction when I see the baby. We asked about resuscitation and if we had a right to [refuse]...why put her through all that pain and suffering.

Interview 3

When she was born she looked like [daughter] and I still didn't have that outburst of love. In the neonatal unit she is always on her own but mm I started changing her nappies then and things like that. She is a little fighter. I kept saying everyday when is she coming home, when is she coming home. But she got sick and Oh my God she looked terrible, I really thought she was dying. I really thought she was dying...They [NICU staff] were all kind of standing around, I think they were waiting for us to come in...[the issue of emergency cardiac surgery was raised]...I was saying will [baby] be strong enough for it and she [neonatologist] said we have operated on day old babies. Then I wondered ... there is a chance that she could end up being very damaged; is there a chance she could die. Now I don't want to sound cruel but whatever about her dying I would hate for her to end up being brain damaged. Like I will talk to them about it up there, I am hoping that if they think she is going to be brain damaged that like if something happens maybe in the operation that they won't resuscitate her to bring her back as a brain dead baby...to be brain dead I think that is worse. Then you have that fear if something happens and she is brain damaged she is not going to be able to talk to us, and tell us what happened. Whereas please God she will be able to talk, but I suppose we don't know that yet. (Lori)

Lori's search for meaning had ended; she had come to accept that she couldn't change what had happened. Although influenced by individual particular circumstances, continued efforts to regain control such as those exhibited above were not uncommon. For women carrying babies with a treatable anomaly the pathway to rebuilding the assumptive world was more straightforward. For most, the search for meaning and a sense of control were achieved through focussing on the treatment options that lay ahead.

Again I suppose I focused my energies on what are the treatment options. There is a limit to how much you can find out about talipes or why. (Maolíosa)

For women carrying babies with an evolving prognosis, the uncertainty of the situation meant that progress was less easily achieved, as the search for meaning could be re-ignited as new information regarding the prognosis emerged as women were vulnerable to being re-traumatised by 'more bad news'.

I searched as much as I could; I was exhausted I couldn't search anymore. I don't know whether I went the full circle [from normal to death] but I mean it couldn't, it couldn't be as bad as it was at one point where we didn't know if the child was going to survive by the next week. That was pretty harsh. I suppose, it got very, very hard and then or very, very hard initially but then it got easier, it did go back up again in terms of how worried you are and it's just because of the uncertainty. God almighty you just don't know if it's permanent or correctable, we don't know anything. So why, and what can you do, there is nothing you can do, you have to just wait. So therefore I suppose while you are waiting you have to try and say well hopefully we will be at the lowest part of the spectrum or whatever. That something can be done for us. (Eavan)

Eavan's experience highlights the dynamic nature that is the epitome of the process of Recasting Hope; new negative information can have a similar impact to the original diagnosis, in particular if the fetal prognosis had been improving up to that point. This in turn may stimulate a return to asking 'why me?' as the expectation of a revised degree of fetal well-being is now threatened. As the assumption of fetal health is lost, one strategy utilised by women to reconstruct their assumptive world was to hope for the best possible outcome.

I think we would be thinking is she going to live, you know. so I think we would probably be trying to set yourselves up for best case scenario. (Alannah)

I have heard it over and over again, yes I know I shouldn't be wanting it to be over and I really do still want to think the best for the baby but dear God I am thinking how in God's name am I going to get through the next few weeks, I am hoping things wont be half as bad as what I expect. But from the day you get pregnant you hope your baby will be fine now I hope it will be the least bad problem. (Niamh)

All women expecting a baby likely to require resuscitation or immediate neonatal treatment hoped to spend some time or at least see their baby alive prior to transfer to paediatric services. Although multiparous women expressed concerns regarding the lack of mobility following a caesarean section, most women viewed this mode of delivery as an indicator of fetal outcome.

He [FMS] said one stage would be that, he started talking about caesarean section because you are only small framed, he said, and the baby's head would be quite large and to fit through your birth canal. So we would be talking about sectioning you so I was thinking and thinking. That gave us a bit of hope, they will take it out and try and drain it [hydrocephalus] and it [fetus] might be all right. (Keeley)

In each case of twin pregnancy with viable fetus, women stressed the importance of regional analgesia during caesarean section, as they wished to be awake for whatever length of time their affected baby had to live.

No, if I am having a caesarean I do not want to be put out. That is the one thing I want, you know, whatever happens I want to be as coherent as I can be...he might have only minutes. (Orla)

As mentioned in the previous chapter, women receiving a diagnosis of a lethal chromosomal anomaly hoped that their baby would soon die, as it marked an end to waiting for the inevitable. For others diagnosed with an anomaly likely to survive up to birth or soon afterwards, each hoped for a live birth.

Yeah well some quality time with the baby would be beneficial of course but that is what they say, they say that if it is born alive, it brings a lot of eh, well it would add another chapter to everything and it would be special for us as well. We have to pull through this, its going to be quite trying. To get through this as best we can, and it's going to be, its going to be a bit of a nightmare, our nightmare started 20 weeks ago so we will be in this place for a long time but we don't hate, we don't have any bad feelings towards the baby or anything, there is nothing like that, we just want a chance to say goodbye. (Ava)

Unlike Ava, Caitlin remained somewhat overwhelmed by the injustice and uncontrollability of the situation.

Yeah, well naturally, you know. But mm so we have asked for the same thing, for the cord not to be clamped and he said [consultant in regional centre] oh yeah, no problem, no problem, yeah, yeah. As soon as we go in when the baby is born no clamp, full stop, no clamp, this baby stays alive for as long as possible. (Caitlin)

Caitlin requested an induction of labour at 39 weeks to try and increase the chances of a live birth, which was refused. Her baby died in-utero five days before her due date. This, accompanied by an un-trusting relationship with her caregivers was to complicate her recovery from her loss.[67]

Clinically relevant issues

Although the theoretical constructs of Parkes (1972), Lerner (1980) and Janoff-Bulman (1992) have been crucial in developing an understanding of the relationship between women's reactions to the diagnosis and their subsequent efforts to move on with their lives, the accessibility of such theoretical frameworks to clinicians directly involved in providing care is likely to be low. Consequently, data relevant to the provision of responsive care are framed in terms of the coping styles exhibited by women, which are readily recognisable within a clinical setting. The previous chapters have highlighted that women had diverse needs with regard to the nature and amount of information they required in order to cope with the situation. Due to my interest in the caregiving relationship, and theoretical proclivities towards symbolic interactionism, interactions with caregivers for the remainder of the pregnancy and into the postnatal period became central topics of conversation. The Miller and Mangan (Miller 1980, Miller and Mangan 1983) model of information coping styles previously introduced in chapter 7 will be utilised to delineate examples of women's ongoing preferences for information as they seek to gain meaning of the experience and attempt to rebuild their lives. The relationship between women and their caregivers, which was essentially based upon the process of sharing information, became influential in women's struggle to manage their daily lives, which had fundamentally changed since the diagnosis.

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[67] See journal entry chapter 4.

8.1.4 A life changing event

Women who received a definitive diagnosis and outcome for the pregnancy searched less for meaning when compared with women propelled into a situation characterised by uncertainty over a prolonged period of time. The relative success or failure experienced in integrating the event into one's worldview was also a marker of recovery from the loss. Some women relinquished the search for meaning relatively soon following the diagnosis, and for these women, a desire to avoid repeated negative affirmations regarding the prognosis ('blunters') was exhibited as they attempted to reduce the possibility of becoming emotionally overwhelmed. However, for women who continued to search for meaning, access to information that reduced uncertainty around the diagnosis or outcome, including being able to understand how specific changes in test results affected the pregnancy outcome seemed to increase the sense of control over the situation, if only temporarily. When information to clarify the situation was not available, 'monitors' found it increasingly difficult to cope with uncertainty.

Aisling's search for meaning was limited, predominantly due to the fact that the anomaly was classified as treatable, and the likelihood of her baby having an entirely normal life was high. On that basis she chose to hope for the least negative outcome and used blunting strategies to block information that would threaten that assumption.

I wanted information but not so much that it would freak me out. It's great to be prepared but you can get information overload. (Aisling)

When women with a low preference for information received more information than they needed, the consequence was increased anxiety. Some women required frequent monitoring in the fetal medicine unit depending on the fetal condition, and found that the level of feedback at the visit regarding fetal wellbeing was crucial in supporting their coping mechanisms until the birth. Ciara and Niamh both were living with an uncertain prognosis, and although neither were still searching for an answer to 'why me?' their coping style varied.

It felt really good that they were checking everything; there was a sort of comfort in it. (Ciara)

I need those visits for the scans...you're hoping everything is stable even though [you live in fear] of getting more bad news. I can't take any more bad news. (Niamh)

Once a satisfactory level of factual knowledge relating to a definitive diagnosis was obtained, the ongoing need for information diminished. If an additional variable/problem manifested during the pregnancy the high need for information regarding the new variable returned.

Once you hear something new, you go back searching again. (Breffni)

Some women felt that even when the fetal condition could deteriorate but neonatal intervention remained a possibility, they couldn't cope with the constant demand of assimilating additional information, as the pathway to revising one's assumptive world is often gradual (Landsman 2002).

I felt I couldn't cope with anymore information, I didn't want anymore- I thought my head would explode, but my husband was full of questions. (Emer)

Emma accepted her fate soon after the diagnosis, saying how she no longer sought to change that which was outside of her control. For women who adopted blunting strategies, and where neonatal survival was predicted to be low, but mortality was not a certainty, hearing something positive at the fetal medicine visit was important.

I haven't asked anymore about the problems. I don't ask too many questions it's just my way. If they [the twins] could have a bit more weight on them they might have a chance, a bit of positivity. (Emma)

It has become custom and practice in the study site to arrange a visit to the neonatal unit for parents whose infants are likely to survive and to require neonatal support. Whilst this may have been helpful for monitors, this visit became an additional stressor for those preferring to avoid worst case scenarios.

I thought it was totally unnecessary. I didn't want to go to the unit at all, ...I went in with blinkers on and wasn't even listening to what the woman was saying ...I just couldn't face it. (Cliona)

However, providing an information booklet regarding the unit for women that exhibit information avoidance strategies may be a helpful alternative, as information could be accessed at a pace suitable to the individual.

We got a booklet about SCBU, it was helpful to kind of get your head around the amount of equipment that was going to be involved. (Emer)

Irrespective of the information preferences exhibited, there were key issues that the majority of women felt needed to be addressed by the healthcare professionals providing care. Almost all women mentioned their concern for labour or the mode of delivery. Primigravidae were concerned at never having experienced labour and delivery before, and multigravidae who had previously experienced a normal delivery were concerned regarding the need for a caesarean birth because of fetal complications.

Yeah, I suppose I have yeah, I have been hoping that it will be normal but it's the aftermath of caesarean because I mean it's a major operation and the fact then that you are not supposed to drive for so long which sort of makes it a bit awkward then if I want to be able to leave and come back [to NICU] I know obviously I will do whatever is necessary for the baby, if I don't have one it might mean there is nothing they can do so what's the point and that would be worse. (Ciara)

For women who continued to have difficulty in coming to terms with the diagnosis, most often observed in women where the extent of disability to be experienced by the infant could not be predicted, the only sense of control these women felt they had left was to decide when the baby would be born.

I said I wouldn't be able to cope with it [going to full term] I think if they said to me you have to go to 40 weeks it would kill me, literally kill me. I couldn't do it. I want an induction date at 38-39 weeks. (Niamh)

I just I feel I have been pregnant for the last 5 or 6 years. It's driving me mad...I need a date for the birth. (Keeley)

Although women were prepared for the fact that they could be separated from their babies, women also needed to know if the infant was going to be transferred to another hospital as many assumed they would have unlimited access to their baby in the neonatal unit and news of this additional separation came as a blow to some. For women anticipating a live birth, but referred from a regional centre, arranging the place of birth in advance was essential, as many women were fearful that if the place of delivery was unplanned, the requisite knowledge regarding the infant support that would be required would not be communicated effectively to the booking hospital.

When women were informed that the anomaly was lethal, one of their main concerns was when the baby was likely to die i.e. antenatally, intrapartum or postnatally, and if there were any resulting physical risks to themselves.

It's a horrible situation; we are waiting for the baby to die inside me...you need, someone to tell you what happens when the heartbeat stops.. (Tara)

I wanted to know was my life at risk? Would I miscarry? What would I feel before the miscarriage? (Kasey)

Women were also concerned about how they might react to seeing the baby, and needed reassurance that an experienced health professional would be with them to help them during that time. The information preference that was exhibited throughout the pregnancy, in general, remained consistent up to the birth. Therefore monitors preferred to have detailed information on the baby's likely appearance, as the fear of not knowing what to expect was greater than knowing, whereas blunters preferred to wait and see. All women expressed the need for specific guidance on what to bring to the hospital in preparation for the birth as this was a situation where previous experience couldn't guide them, and an opportunity to speak to the bereavement counsellor, close to the birth, to assist in the planning of a funeral was welcomed. This needed to be followed up with written information to remind women of the choices available to

them, as this facilitated women to access this information as and when they were ready. Planning the delivery can be a very positive experience for some women, as when the anomaly is lethal but has survived for many weeks after the diagnosis; their greatest hope is to have the baby born alive. Laoise was offered an elective caesarean section primarily in the interest of the healthy twin; however, she focussed on the additional benefit of both babies (one with anencephaly) being born alive.

We have them straight away, both of them... and have as much time with [baby with anencephaly] for whatever length of time he has to live. (Laoise)

All women commented on the value of continuity of care in increasing their sense of security whilst they were at their most vulnerable and the potential for a difficult relationship with caregivers if continuity was not provided.

A relationship had built up, they knew where we were at, it wasn't that we had to tell our story to strangers each time. (Emer)

I have never seen the same two people... I am very wary of going up there now. (Niamh)

Ameliorating stress for women requires healthcare professionals to observe the strategies used by women and to respond appropriately. Miller and Mangan's (Miller 1980, Miller and Mangan 1983) model of informational coping styles provides a framework for clinicians to match information need with information demand, as taking cognizance of information preferences has practical application in the provision of care for these women.

8.1.5 Future pregnancies

Planning a pregnancy in the future was a clear indicator that women were making positive progress in rebuilding their assumptive world. Their capacity to revise their beliefs about the world predicated on what the diagnosis meant for them as individuals, and as members of a family/society. For some, the desire to return to normal life manifested while they were still pregnant.

I feel what we have to focus on is getting our head around it, keep going with the ordinary every day things. We hope to cope, hope that the baby will feed and sleep....that we will become normal. (Sian)

You have to get some normality back as you have nothing to look forward to. (Kasey)

He [Dr] hasn't even checked the baby's heartbeat. All the visits I have had with him he hasn't even done that. He is not treating me like a pregnant woman anymore. (Caitlin)

Each and every woman described the experience of receiving a diagnosis of fetal anomaly as 'devastating' - 'it went right to the core of me', and for some it even threatened their very identity as a woman.

So I don't know, part of me thinks like I did everything so right and yet it went so wrong. It's weird. Maybe if ... there is something about doing everything so correct, you know, I know it would have anyway but it is a thought that goes through my mind like when you are so adamantly balancing your food and things and it still happened. The same for folic acid I am just almost, I feel so let down, you are let down by everything, you are let down by your body. (Molly)

Some women changed from being outgoing and vivacious to almost reclusive.

I stayed in and hid, I had a fear of meeting people. I didn't know if they would ignore me or want to talk about it. (Kasey)

Regan commented on how she felt her identity was threatened by the decision she made to terminate the pregnancy.

One of the big things for me was you can go into [named hospital] and the first question they ask you is have you had a termination before? I could always say, not with any glee but no I haven't and now suddenly I was going Jesus are you going to be judged? But just for a baby that was so wanted and so, I just didn't want to be on the list of sort of mm statistics. Like people saying to me, it might have been my husband or good friends, oh that is a good sign

now, things are going back to normal, and I don't want things to go back to normal, it's never going to be normal again. (Regan)

For the women whose babies didn't survive, creating memories was important, and individual. Some women had graves to visit, whilst others had photos or cards acknowledging the birth. For women who had given birth in the UK, many planted trees or referred back to their scan images in remembrance.

Now we're not sad about that or we're not upset about that because I think we're happy that the time we had with him was a bonus to us..., we do want to hold our baby... but we've got our scans. (Áine)

For others with less positive experiences, carrying the weight of secret grief was difficult to bear.

I have chosen not to tell my family that is not that saying I am never going to tell them, there might be an appropriate time afterwards, and it is unfair and I think any reasonable person would see it as unfair. But you choose to do it [termination] I think it should be made a lot easier than it is. Like we are still grieving for a child, nobody knows that, you know. Okay if you have a miscarriage people generally find out or people will find out because you are in hospital or whatever you choose to tell them quicker maybe than you would in this situation. Its not that I am looking for sympathy it's more that people would understand the situation you are in and act appropriately to it. Its just you know it's not right that, I am not looking for a public display of you know but I don't think its right that you have to be secretly grieving. I lost a baby and nobody knows. (Bethan)

However, the human spirit being what it is meant that almost all women could see a future and were willing to consider another pregnancy, however, some were adamant that they would never put themselves in this position again. This was undoubtedly influenced by the risk of recurrence, and the burden of care that was required by the surviving child. Women who had previously experienced difficulty in achieving a pregnancy were concerned that their reproductive history could inhibit their recovery.

We've never been able to get pregnant [spontaneously] so that makes it more difficult to come to terms with... if you could get pregnant you can get over it and move on.. (Muireann)

Consequently, it is vital that women receive follow up from their lead clinician in order to ensure that appropriate risk assessment for recurrence in future pregnancies is made.

Janoff-Bulman and Timko (1987 p154) have speculated that when an individual's assumptive world is altered sufficiently to accommodate the traumatic experience, survivors emerge 'sadder but wiser'.

We have been to hell and back you know. We may never get pregnant again, but if we do I know I have 16-17 weeks of hell...it takes the magic out of it... but you know they say if it doesn't kill you it makes you stronger, so it just makes us appreciate how lucky we are. (Kerrie)

This marks the successful reconstruction of the assumptive world.

8.1.6 Going full circle

As women revised their assumptions regarding the normalcy of fetal health and engaged in the future through considering or outruling future pregnancies, two questions remained to be answered. Did women (in Ireland) value having foreknowledge of the anomaly as others (Sandelowski and Corson Jones 1996a) have suggested? Did taking part in the study have an effect on the process of Recasting Hope?

Valuing foreknowledge

The overwhelming responses from women in relation to the former were that knowing in advance helped them to prepare for the outcome.

On balance I think it's better to know. I think it's... I suppose in some ways... obviously the torture is longer but at the same time we have had more time... every week that goes by you start imagining your baby more and you do probably start making plans for the future. (Tara)

It's better knowing at 14 weeks. I think it would have been much harder to find out at 20 weeks.... [I read] on the internet some (women with at risk twin pregnancies) had ordered double buggies and things so she explained how she had to ring the shop and say she had to cancel one and they said well you can't cancel them. (Laoise)

As expectations regarding fetal health increased with advancing gestation, for most women being forewarned was valorised in terms of the opportunity it provided to adjust those expectations. However, knowing was not without consequence. The tragedy of loosing one's dreams was consistently juxtaposed against the dichotomy of hoping for an ameliorating intervention versus having an opportunity to prepare for death. Although it would seem logical that foreknowledge of an anomaly is advantageous if in-utero or neonatal treatment could be instigated as a result, one could however question the value of knowing when the particular anomaly is not amenable to treatment. Previous isolated reports (Armstrong 1996, Tymstra et al. 2004) have described how women felt regret at having foreknowledge, as it placed them in a position of having to adjudicate on the value of their fetus. Regret was not a sentiment expressed by women in this study. While women described their struggle to master the uncertainty associated with living with the diagnosis, it was felt that despite the psychological burden that knowing imposed it remained preferable to discovering the problem at birth.

It's much, much better knowing, I feel really sorry for anybody who doesn't know, maybe nothing showed up on their 20 week scan and they had to go through the rest of it and then their baby born with something. (Cliona)

It has put me on alert, it's worth it in case there was anything they could do that might save the baby. No matter what, it's better than finding out at the birth. (Aisling)

We are lucky that it wasn't dropped on us at the delivery- that would be dreadful. (Sian)

The data have shown that women value knowing of the presence of a fetal anomaly antenatally, irrespective of the outcome. Consequently, issues around operationalising the emergent framework as a basis to support care will be discussed in the following chapter.

Taking part or being taken apart?

My second question relating to the possible influence of participation in the study on the process of Recasting Hope was somewhat more difficult to answer.[68] I originally introduced this issue on pages 83-84 in relation to how I had endeavoured to ensure, as much as possible, that participation in the study would not cause harm to those involved. Although particular cases in relation to withdrawal from the study have been highlighted, the process of participation for those exhibiting less overt signs of difficulty in managing this crisis requires consideration. I was also intrigued as to the reason for the high participation rate when compared with other work in similar areas of loss (Statham et al. 2001). Consequently, women completing participation in the study were asked a variant of the following questions: 'Why did you choose to take part in this study?' and 'What has it been like to take part in this study?' In response to the former, a desire to contribute to improving care for women receiving a diagnosis of fetal anomaly in the future was seen as vitally important.

No-one can help us and no-one will ever know what it's like unless we tell them. Our story might help the staff to understand. (Ava)

I thought I was the only one in the world that this had happened to. If you could just let women know they are not alone, they are not freaks- I just wanted to hear that this had happened to someone else and hear how they dealt with it. Maybe now women will know. (Ciara)

If staff could realise that we are different, if women could have the opportunity to talk to someone like you automatically- I would never have known that taking part would benefit me I just wanted to help in any way I could but now I think there should be a support person provided. (Blannad)

Although implicit in the accounts of women who continued the pregnancy, a need for others to understand the tragic nature of the experience was explicit in the accounts of women who terminated the pregnancy. As I continued to invite women to comment on

[68] I will return to this issue in Chapter 9 section 9.1.1 Re-integrating ontology: loss of the assumptive world.

their experience of taking part, it seemed that being heard within the context of the study went some way to providing acknowledgement of the experience, as recognition of this tragic loss was deeply sought after.

If staff could acknowledge the problem, a bit of care and compassion, you're a bit more vulnerable, it's nice to talk; it's been good for me-taking part. (Sian)

Although not empirically tested, it seemed that constructing the story had a role to play in the process adjustment. Women commented on how the interview provided them with an opportunity to reflect on the situation in a way they might not otherwise have done.

You just need a chance to talk. It clears things in your head. (Niamh)

I didn't need frequent scans but [you need] somebody you can ring, someone to call out... you need pregnancy information- you need support. (Erin)

It is nice to have somebody else to sound off and to ask all your questions to... somebody who does know and has the information as well is great. (Ciara)

As women spoke of the reactions of others to the diagnosis, some commented on how people who were previously friendly and approachable became embarrassed and strained in their presence, at times taking action to avoid making contact. This re-enforced the need to find a place of safety in which to discuss the situation.

You are coping as best you can with the information being given which is tough enough but yeah, well you just knew what we needed, we could talk, cry or ask questions...and it's always the bit that happens next that no one tells you about. Yeah and I think yeah someone like you where there is no feeling of awkwardness... we needed a place where there wasn't any funny silences. (Tara)

As dreams are lost, the impact that reciprocity can have in this context should not be underestimated.

There's so much pain I thought my heart would break- but the midwife calling out means you're not just a nobody -you are somebody. I am somebody because you have found it important to come and see ME. (Sian)

8.2 Summary

When the assumptive world is shattered, the loss is accompanied by grief. In this study, loss was not always death-related; nevertheless, it went to the very core of the woman's being, at times challenging her very identity as a moral person. Regaining some form of control over the situation often began with the decision to either continue or terminate the pregnancy. However, the impact of the social context on access to services, availability of support and the potential to rebuild one's life cannot be underestimated.

Satisfactory access to information in order to 'Gain meaning' is a vital component of the entire process of adaptation after fetal anomaly diagnosis. Clinical awareness of the information preference styles that women exhibit have the potential to enhance the supportive nature of the relationship, facilitating women to assimilate information at their own pace. All women suggested that a support person, such as a midwife with clinical experience in the area would be a welcome addition to the package of care provided currently, as this would provide women with an opportunity to 'open up'. Regardless of the outcome for the pregnancy, each woman described her experience as life changing. The relative success to which women rebuilt their lives was variable, and predicated on the extent to which women could adapt and develop a new worldview sufficient to permit engagement in the future. A prolonged and unsuccessful search for meaning was associated with a more complex pathway to recovery. Although a clear end-point indicating recovery was not observed for all women, planning a future pregnancy was a sign that recovery was likely. It is possible that for most forming an account of one's experience is beneficial, as talking seemed to assist in the process of making sense of the situation, facilitating the construction of pathways to negotiate the future.

9 Discussion

9.1 Introduction

Grieving for the loss of an infant is a human experience as old as humanity itself (Krueger 2006); however, our knowledge of meaning reconstruction following prenatal diagnosis is somewhat more limited. These thirty eight women's perspectives and experiences of this phenomenon have contributed to our understanding of the traumatic loss that accompanies this event. Recasting Hope is a theoretical rendering of the psychological disturbance and subsequent process of adaptation experienced by these women as they attempted to recover from this trauma. Older accounts of grief have provided frameworks for the study of bereavement (Kubler Ross 1970, Bowlby 1980), which describe discrete stages followed with the implication that following a certain period of time life reverts to how things were prior to the loss. However, the theory developed in this thesis neither sets out to disprove nor displace earlier frameworks but rather intends to expand upon previous models, whilst contributing to current theoretical debate. Recasting Hope is a conceptual framework to inform practice in the future, and as such this meets the stated purpose, aim and question guiding this research.

This concluding discussion aims to address three issues and consequently this chapter is presented in three distinct yet related parts: re-integrating women's experiences into extant theories in the field of traumatic loss, thanatology and theory development exploring the impact of the legal system and cultural norms on decision making in relation to pregnancy outcome and recovery from the loss and finally, recommendations for care are presented based on women's experiences of taking part in this study.

The following section is about staking a claim for these women's experiences within the theoretical arena of traumatic loss through theorising women's accounts (implicit) of the meaning of the loss of a healthy child.

9.1.1 Re-integrating ontology

As mentioned previously midwifery is a Magpie Discipline (Kearns and Moon 2002) and as such it gathers and utilises theory from a wide range of social science disciplines. Therefore it is not surprising that the conceptual framework that has emerged overlaps with many disciplines, not least those of psychology and sociology, as these longstanding disciplines represent a huge and disparate epistemological field that seeks to describe both individual and whole groups of human experiences. However, as previously discussed in chapters 3-4, the multiplicity of philosophical and theoretical orientations that have shaped beliefs about what constitutes knowledge have witnessed the valorisation of objectivity over subjectivity in particular within healthcare. Women's qualitative experiences of this particular aspect of childbirth have all but been forgotten about in the dominant rhetoric of scientific inquiry that pervades the practice of obstetrics and midwifery. The impetus for this section has come from my interaction with the depth of feeling portrayed in women's narratives.[69] As women spoke of their experience, their glazed eyes, gut-wrenching sobs, silences and broken voices shattered by pain epitomized the meaning of losing the dream of mothering their ideal child. Being with these women as they formed an account of a dream that was to be recast or to slip out of reach was at times a difficult place to be, as women had a tendency to understate the pain or laugh in the face of adversity in order to remain sufficiently coherent to allow their story to be told. Their eloquence has compelled me to develop an understanding of the meaning that an individual woman attributes to the loss of a healthy child at a more profound level than I might otherwise have done. As I continue to feel bound (Liaschenko 2001) by the positivist position that remains dominant in

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[69] I use the term 'interaction' to reflect the effect that reciprocity and a constructivist approach had in developing what was at times an intense (although short-lived) connection with individual women. Without this approach the data would undoubtedly have been more descriptive, more likely resembling a recall of events rather than a construction of the meaning of those events. In addition, I interacted with the 'data' both explicitly through the specific analytic procedures required by the method (CCA & TS) and implicitly as the 'memory tape' of certain words or theoretical discourses played and re-played in my mind. This brought many sub textual issues from the background to the foreground as I struggled with theorising the complexity of the experience in context -re-shaping previous assumptions about maternity care, opening my eyes as to how institutionalisation and medicalisation function as normalising practices, blinding some of us who work within them to the forces at large.

medical ideology, the emergent conceptual framework may be criticised for its objective presentation. However, the prevailing obstetric orthodoxy in Irish maternity care (Murphy Lawless 1998) will undoubtedly arbitrate upon the value of the findings, influencing the extent to which practitioners will inculcate the emergent theory into practice (Rolfe 2006). It is within this context that the generation of figures to represent the conceptual framework was seen as essential to enhance the credibility and utility of the findings in practice, although excerpts from women's accounts will frame the issues discussed in the remainder of this chapter. Part one of this discussion describes how I engaged with previous work within the wider area of thanatology and loss, searching for a satisfactory way to theorise women's experiences.

Theoretical perspectives of loss

In chapter 1, I presented the evidence currently available regarding women's experience of fetal anomaly diagnosis. Heretofore, the focus has been predominantly on descriptive reports of women's feelings and reactions to the diagnosis or attempts to measure empirically the extent of the resultant psychological trauma. The limits of an objectivist approach that pervaded the various methodologies previously chosen were apparent at the inception of this study. Confusion regarding the unpredictability of an individual woman's response to a particular adverse diagnosis remained, as published findings were limited to descriptions of a multitude of factors related to parental reactions and decision-making. The dearth of information concerning the experiences of women who continue the pregnancy is reflected in suboptimal care for women within a context of insufficient evidence to develop a scientific base to underpin practice; consequently, the development of a robust framework was required.

My ontological and epistemological perspective led to the use of a constructivist approach, as chapters 5-8 demonstrate the extent to which women's narratives are used to co-construct the framework. However, in order to shed more light on this complex phenomenon it was important to review earlier influential work in the field of grief and mourning, predominantly located within the psychology literature. Psychology and its allied professions represent an enormous and diverse theoretical field and as I searched parallel discourses I was to encounter scientific inquiry based on experimental designs

intended to develop objective measurements of the emotional and behavioral characteristics of an individual/group, to psychometric testing intended to develop disease orientated diagnostic criteria. However, many authors engaged in complex ethereal philosophical debate (at times unintelligible to a non-psychologist) regarding the connection between individual constructs such as optimism and coping whilst endeavouring to understand the relationship of life and mind to human function and behaviour, ensuring that my search for a theoretical framework to explain women's experiences was less than straightforward. During the initial stages of theoretical sampling I came to realise that psychology, not unlike midwifery, had succumbed to the uncritical acceptance of the medical model, as psychiatric hegemony pathologised a language of health and adjustment to one of disease and maladjustment (Maddux 2002). As I began to delve into literature on grief theory, questions were being raised within as to whether grief and bereavement should be considered as an illness in light of the somatic features associated with loss.[70] However the trend in earlier texts was clear, the focus was on defining abnormality and setting objective criteria for the recognition of complicated grief patterns, potentially pathologising a life event that any one of us might experience at some time or another. As the conceptual framework in this thesis began to emerge, relational theories of loss and hope were reviewed in order to ascertain if connections existed between extant frameworks or parallel discussions in other fields. Many of the issues that emerged in the initial stages of analysis were related to concepts associated with the seminal work of Bowlby, Kubler-Ross and Worden, whereby mourners experience feelings such as shock, anger, blame etc.[71] The degree to which theories of dying inform an understanding of women's experiences is discussed.

Theories of dying

At the outset of the study, my knowledge of bereavement studies was relatively superficial. Although several theoretical frameworks on death and dying have been

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[70] I had serious misgivings about pathologising these women's experiences. Although, subconsciously, I remained concerned for women's safety as I could not obliterate the real danger posed by Keeley's suicidal ideation (albeit isolated), I remained convinced that the responses I had observed (in 35/38 women) seemed essentially 'normal'.

[71] Although I remained concerned of the potential limitations of grief-related theories to explain non-death-related loss; however, I felt a starting point was required.

proposed (Glaser and Strauss 1965, Kubler Ross 1970, Pattison 1977, Corr 1992) my professional background led me to begin my search with Kubler-Ross's (1970) five-stage theory of dying as it is arguably one of the most accepted frameworks in the health care arena.[72] At the time of the theory's inception, it was both controversial and provocative as speaking about the process of dying was considered taboo, and the systematic structure put forward assisted in legitimising discussion around this human experience (Rainey 1988). The theory gained uncritical professional acceptance as it provided professionals with an orderly model to explain the process of dying, whilst filling a gap in health care theory (Kastenbaum 1974). On initial review it seemed that participating women shared some of the psychological responses such as denial and depression; however, others such as bargaining and eventual acceptance were not consistently observed. For women experiencing either a death-related or a non-death related loss, the process of adaptation following the diagnosis varied substantially depending on the circumstances involved. For example, women did not necessarily accept the justness of the diagnosis and eventual outcome as implicitly proposed by Kubler-Ross (1970), nor was an orderly progression through sequential stages observed, as additional threats to fetal well-being could result in re-traumatisation. As I continued to sample the literature criticisms of the validity of Kubler-Ross's stage theory were to emerge (Weisman 1974, Corr 1992) as the suggestion that mechanistic progress through the stages will ultimately lead to acceptance of death by the individual was questioned (Pattison 1977, Metzger 1980), confirming the limitations observed. Consequently, as a theoretical model, it was inadequately developed to take account of the multifaceted elements of loss as experienced by women in this study. More recently Buckman (1993) proposed a three-stage model of dying in an attempt to rectify some of the limitations with Kubler-Ross's model, and suggested that reactions to the threat of death are related to the way in which individual's have coped with difficulties in the past. Buckman (1993) suggested that emotional responses such as guilt, hope, despair and humour are not stages in a process of dying but are in fact indicative of an individual's make-up and provide insights into how individuals have coped with stressful situations in the past. Initially this seemed to suggest that women's disparate reactions were unrelated to the diagnosis

[72] Kubler-Ross postulated that individuals undergo five stages as they respond to their own death: denial, anger, bargaining, depression, and acceptance.

persé but rather to the woman's personality and previous life experience. Yet Buckman's (1993) model failed to explain adequately how these factors actually influenced the response observed and why women like Regan appeared actively to resist moving forward *'Like people saying to me...things are going back to normal, and I don't want things to go back to normal, it's never going to be normal again.'* Several additional frameworks such as dying trajectories (Glaser and Strauss 1965, 1970), living-dying interval phase theories (Pattison 1977) and task based models of grief work (Worden 1991, Corr 1992) were reviewed in search of a more precise understanding of women's reaction to the diagnosis, and a deeper insight into the adjustments that must be made in order to cope with the outcome. While traditional 'stage' theorists have had a major impact on our understanding of what happens during the process of grief and mourning, more recent theorists have developed representations of the grief process from sequential stages of dying to include issues regarding the environment in which one dies and the engagement in various tasks by the individual in order to cope with an incurable illness (Copp 1998). However, women were not facing their own death, nor were they confronted with the prospect of caring for an infant with a terminal illness. Although accompanied by grief, this loss was different, as the diagnosis of a fetal anomaly does not always imply fetal death as it may be the "imagined narrative of his or her life" that is altered (Green 2002 p21). Nevertheless, grief reactions were exhibited by women irrespective of the prospect of fetal death; consequently their experiences could not be satisfactorily explained within a uni-dimensional framework of dying, as death was not a common denominator. Although new approaches to re-examining the process of dying are ongoing (Bonanno and Kaltman 1999), this complex phenomenon remains partially understood to date (Krueger 2006). As these various ways of viewing the mourning trajectory remained limited in their ability to increase my comprehension of women's experience, the search for a model continued. As the transcripts were read and re-read, a common thread to the process of adaptation emerged.

With the exception of three women,[73] the majority exhibited an overwhelming desire to rebuild their lives, seeking ways to adapt and cope with the challenge they faced. There appeared to be an implicit need for hope, so frequently was the concept mentioned that it formed part of the labelling of the core category. Therefore the literature search moved from thanatology into the area of positive psychology, which is concerned with developing constructive cognitions about the future (Seligman 2002) of which hope is but one aspect.

Hoping to cope

The area of positive psychology seemed to represent a move within the field from an illness orientated ideology towards a more positive approach to understanding human behaviour, with a focus on the strengths of the human character.[74] Women's struggles and achievements were evident throughout the duration of the research and reference to their attempts to cope with this stressful event were first mentioned in chapter 7-8 as strategies to regulate the flow of information in order to maintain control of the situation were utilised. The theoretical grounding of the literature influential in the conceptualisation of the process of coping in stressful situations primarily lies in the work of Lazarus and Folkman (1984), wherein coping is defined as "constantly changing cognitive behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p141). In their framework they suggest that individuals respond to stress using two strategies: problem-focussed and emotion-focussed coping. Problem-focussed coping includes taking direct action to deal with the problem including the use of strategies such as defining the problem, generating solutions and following a plan of action. Emotion-focussed coping includes processes such as avoidance, denial, seeking emotional support and positive reappraisal in order to manage one's emotions before one literally becomes

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[73] Fiona and Keeley required psychological support to assist in coping with the overwhelming negative emotions experienced, and Regan actively resisted attempts to recover from the diagnosis and subsequent loss through termination of pregnancy.

[74] Women in general grappled with finding strategies to help them to cope with the devastation of the diagnosis. However, with the exception of a few, their journey is characterised by emotional highs and lows interlaced with varying degrees of hope. Therefore an adaptive rather than a maladaptive model seemed more fitting with that which had been observed.

overwhelmed.[75] Lazarus and Folkman (1984) observed that most people use both strategies in difficult situations, and this was certainly evident in women's accounts of how they suppressed their tears in order to seek information from the fetal medicine specialist. The authors (Lazarus and Folkman 1984) also suggested that the efficacy of the strategies proposed should be evaluated within the situational context, including taking cognisance of the extent to which the individual appraises the event as harmful or threatening. This resulted in the development of several empirically based coping instruments such as Ways of Coping Scale (WOC, (Lazarus and Folkman 1985), the COPE (Carver et al. 1989), the Coping Inventory for Stressful Situations (CISS, (Endler and Parker 1990, 1994) and the Miller Behavioral Style Scale (Miller 1980, Miller and Mangan 1983) of information seeking. However, as each group of researchers developed their instruments, the constructs included in the subscales relating to emotion-focussed coping varied widely between studies. Nevertheless, some concluded that a consistent relationship exists between emotion-focussed coping and maladjustment (Kohn 1996), whilst others have suggested that measurement of emotion-focussed coping has been contaminated by the presence of psychological distress, and therefore the association between the two may be erroneous (Stanton et al. 1994). It has also been suggested that rather than viewing a specific coping strategy as efficacious or maladaptive, that benefit may be derived from selecting a particular coping strategy to fit the individual concerned and the particular demands of the situation (Snyder and Dinoff 1999). For example, if the situation is amenable to change, the person who adopts a problem-focussed coping strategy should lessen the stress experienced. Conversely, in situations determined as not favourably disposed to change, an emotion-focussed approach is likely to lessen the likelihood of anxiety and depression. Lazarus and Folkman (1984) have postulated that emotion-focussed coping is particularly advantageous in health care settings, as it minimises the distress associated with facing setbacks. Whilst this is an analytical and not a statistical study, and preferences were not measured in a robust manner, it is of interest to note that two thirds of the women who took part displayed emotion-focused coping strategies on an ongoing basis. Locock and Alexander (2006) have suggested that men have more of a propensity to adopt problem focussed strategies

[75] Examples of each coping strategy can be found in section 7.1.2.

and women to exhibit avoidance strategies, but have suggested that further work in this area is required to confirm this. In reality, the coping strategy employed by participating women did not seem to be related to the mildness or severity of the anomaly i.e. the level of threat to fetal well-being or relative amenability of the situation to change, as both preferences were manifested throughout the entire range of diagnoses. Although Lazarus and Folkman's (1984) model provides an insight into the theoretical foundations underpinning the coping strategies employed, it fails to offer an explanation as to how an individual might select or have an innate propensity to utilise one strategy above another, therefore it seemed likely that an individual could choose or instinctively gravitate towards a strategy inappropriately matched for the situation. This could potentially result in increased negative psychological outcomes for the individual such as anxiety and depression, having the effect of minimising one's ability to cope with the event. Difficulties in coping were particularly evident in the accounts of Keeley, Lori, Fiona, Hayley, Caitlin, Bethan and Regan. Bethan and Regan both demonstrated a problem-focussed approach to coping, and although each received a diagnosis of anencephaly and chose to terminate the pregnancy (taking action to resolve the problem), neither woman associated ending the pregnancy with improved psychological well-being. In fact guilt and anger as opposed to relief or acceptance were commonly expressed as a consequence of the decision taken, as the requirement to suppress one's grief due to the social context in which the decision was made compounded the psychological burden. Caitlin also adopted a problem-focussed approach yet conversely opted to continue the pregnancy after the diagnosis of a lethal anomaly (problem could not be resolved) and her struggle to define the problem in terms of why this had happened was unrelenting. However, if one accepts that in this case the coping model selected was ineffective in the context, then one is left to seek guidance as to how to steer an individual towards selecting an alternative approach to stress management. However, an absence of practical direction on how to resolve the situation when the least effective coping strategy is chosen remains.

Keeley, Lori, Fiona and Hayley chose the alternative, an emotion-focussed approach to managing the problem. Based on Lazarus and Folkman's (1984) proposition of the suitability of avoidance strategies to a health situation characterised by setbacks, these

women should have had improved psychological well-being when compared with Caitlin, Regan and Bethan. However, this approach did not appear to minimise the risk of experiencing anxiety or depression associated with caring for a child with a disability, as two of these women required admission to hospital for psychiatric support, suggestive of the fact that the process of coping is more complex than matching the approach with the relative mutability of the problem. Nevertheless, matching information delivery to the coping strategy observed continues to have clinical relevance as it moderates further difficulties associated with accessing or blocking information for the individual concerned. Given the limitations of the model (Lazarus and Folkman 1984) to take account of the inconsistencies observed between the coping strategy selected and the level of threat and immutability of the outcome, alternative hypotheses to explain the behaviour observed were developed. It seemed that hoping for a particular outcome may be an adjunct utilised by women to moderate the stress or tolerate the grief associated with the anticipation of a negative event in the future. Yet at an individual level hope represented a myriad of beliefs and wishes for the future; therefore the possibility of an implicit relationship between sustaining hope and coping was explored. In order to pursue this hypothesised link, hope-related texts were retrieved.

The term hope has a long history, and according to the pagan Greek myth, hope was the only good force to be contained in Pandora's Box. In the past, St Paul exalted Hope as one of the most fundamental Christian virtues, whilst Dante equated the absence of hope with hell (Magaletta and Oliver 1999). In principle, hope has been referred to as a positive expectation, a wish about an issue which has a realistic prospect of coming to pass (Peterson and Seligman 2004). However a darker side to hope such as blind hope, false hope (Snyder et al. 2002a) and so on, may exist.[76] Consequently, hope has been presented in binary terms within philosophical debate as both- "a blessing and a curse" (Snyder et al. 1999 p205). As the discourse on hope developed, related constructs such as optimism and future-mindedness came to be introduced. Although differences in

[76] Although some women spoke in terms of hoping for a miracle, that the diagnosis would be erroneous or that the baby would die, none were deluded into believing that the particular outcome was possible. Rather it appeared to be a strategy to help the individual to get through the day.

operationalisation between these concepts may exist, correlates are noticeably similar,[77] as each has been consistently associated with all manner of desirable outcomes. Although many authors highlighted the role of hope in human adaptation; early scholarly work cast hope in terms of the perception that one's goals could be accomplished (Menninger 1959, Frank 1968, Melges and Bowlby 1969, Averill et al. 1990). According to Snyder (2000, 2002) goal-directed expectations are composed of two separable components -a determination that goals can be achieved, and a belief that successful plans can be generated to achieve those goals. Therefore hope has come to be defined as "a positive motivational state that is based on an interactively derived sense of successful (a) agency (goal-directed energy), and (b) pathways (planning to meet goals)" (Snyder et al. 1991 p287).[78] As the theoretical discourse developed, hope became linked to moderators of stress, and hopelessness was introduced as a significant variable in the development of depression and suicidal behaviours specifically (Beck et al. 1979, Hanna 1991). As virtually all human behaviour necessitates the identification and adoption of goals with consequent regulation of actions vis-à-vis those objectives, Carver and Scheier (1990) suggest that when impediments to goal attainment arise, optimism leads to continued efforts to achieve the goal, whereas pessimism results in the individual giving up. However, as the search for a 'fit' between women's expressions of hope and the theoretical models available continued, the elusiveness of the concept became apparent. As I moved between Snyder et al's (2002b) more recently developed theory of hope and the transcripts, I began to vacillate as to the extent to which the inherent components of agency and expectation were applicable to women within the study.

During the interviews, women frequently spoke of their hopes for the pregnancy and the future. However, hope was dynamic (Herth 1990), as it varied from woman to woman and fluctuated within the same woman over time. Women receiving a diagnosis of a treatable anomaly frequently hoped for a normal or near normal life for their child,

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[77] Hope seems more emotional and optimism more purely expectational. Future-mindedness and future orientation imply an articulate theory about what the individual needs to do to get from here to there (from the present to the desired future) (Peterson and Seligman 2004 p570).

[78] While it is not possible within of this aspect of the discussion comprehensively to review the theoretical hope-related literature, it is necessary to highlight some of the key conceptual elements of hope, as it applied to women's experience of coping after one of the most profound losses that one can experience.

whilst those facing the possibility of long-term morbidity often hoped for the best possible outcome on a continuum of mild to severe disability. For the latter, hope for a desired outcome fluctuated as the fetal condition either improved or deteriorated, suggesting that the goal was variable, dependant upon the predicted outcome. When women were facing a lethal outcome, some hoped for almost immediate fetal death as living through another twenty weeks of waiting for such a dismal outcome was too difficult to contemplate, so much so that some women chose to terminate the pregnancy. Yet a pathway to effect fetal death for women who continued the pregnancy was beyond reach. For some of these women, a live-birth seemed all that one had left to hope for, as this meant they would have memories of their baby alive, and could baptise their baby into their respective Church. However, the timing of the delivery to increase the chance of a live-birth was not necessarily within their control. Sustaining hope was seen as a necessary requisite to coping, and as such influenced women's decisions in relation to the pregnancy. For example Sian and Erin chose to refuse the offer of amniocentesis (as confirmation of a karyotypical abnormality was equated with hopelessness), as maintaining hope for a normal outcome was seen as essential to coping. On the other hand hopelessness was overwhelmingly disempowering, causing a vision of the future (illusionary or otherwise) to disappear, allowing depression and helplessness to dominate. Both Keeley and Fiona described how they felt they had nothing to hope for, so much so that Keeley planned to commit suicide in order to escape the feelings of despair as she anticipated that "the darkness of the moment will become the only reality" (Beder 2005 p263). The data have shown that women shifted their target of hope when the fetal condition proved incongruent with a particular outcome (best case scenario p178), signifying that hope is a multi-dimensional phenomenon that alters depending on the situation (Farran et al. 1990). Thus its presence or absence may be difficult to predict. Correlations and contradictions exist between Snyder's (1995, 2002b) hope theory and the study findings.[79] For example high-hope was associated with positive thinking, while low-hope was coupled with being

[79] Snyder (1995) summarises, 'the advantages of elevated hope are many. Higher as compared with lower hope people have a greater number of goals, have more difficult goals, have success at achieving their goals, perceive their goals as challenges, have greater happiness and less distress, have superior coping skills, recover better from physical injury, and report less burnout at work, to name but a few advantages' (p 357-358).

overwhelmed by negative emotions (Snyder et al. 1999). However, Snyder et al's goal-directed framework could not account for the presence of hope in circumstances where women could not act to affect the desired end. Given that hope continued to exist in situations where agency was limited (Shade 2000), it has been suggested that an analysis of hope should 'downplay the connection between hope and agency' (McGeer 2004 p103), as maintaining hope under adverse conditions may be somewhat more complex than previously thought. However, most women sustained some degree of hope within the context of agential limitations. Rather than crumbling in the face of their reality, an agential interest in the future was retained (McGeer 2004), as evidenced through hoping for the best case scenario, even if that ultimately meant fetal demise. It has been suggested that mediators of hope/optimism-outcome links have been relatively neglected by researchers, and many variables such as personality traits, modelling, gender, ethnicity, culture, sociodemographic status and religion may be influential in the range of outcomes experienced by individuals (Peterson and Seligman 2004 p578-579). Preserving a capacity to hope and keeping hope alive in adversity requires considerable inner strength and a degree of responsiveness from the world (McGeer 2004). This relationship between maintaining hope and a responsive world was evident in this study, as women repeatedly sought acknowledgement of their loss. Consequently, participation in the study may have been beneficial for women as being interviewed provided an endorsement of their struggle, while I fulfilled the role of a responsive other. If this is the case, then the role of a responsive other in fostering hope and successful coping in stressful healthcare situations has clinical relevance.[80] The multifaceted nature of hope is reflected in the variations that exist between theorists' definitions of the concept and in the individual nature of the outcomes desired by participating women. However, this conceptual ambiguity diminished the adequacy of this concept alone to account sufficiently for women's experiences.

At this point in the analysis, as the elements of grief and hope theories combined were applied to the data, a comprehensive framework to account for the multiplicity of

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[80] There is evidence to suggest that when an individual's hope begins to wane, nurses have a crucial role as an external source in promoting hope (Cutcliffe 1995, 1996, Cutcliffe and Grant 2001). I will return to this issue in part 2 of this discussion: Theory and practice.

women's reactions had yet to be found. Consequently I returned to transcripts looking for ways to use women's accounts to develop a theoretical rendering of the phenomenon.

Loss of the assumptive world

As I continued to reflect upon the impact of an adverse diagnosis on women and the relative utility of the relational theories of loss, coping and hope, I entered what I thought was to be the final stage of the research process, 'writing up' the project. As several authors have suggested previously (Wolf 1996, Pilley Edwards 2001, Charmaz 2006) the process of writing up one's findings may be viewed in terms of a continuation of the process of analysis, as the very act of forming an account necessitates further reading and thought. As I began to write, I was concerned with how I might account for the influence of emotionality in the project at an epistemological, ontological and practical level. I searched for literature regarding the impact of sensitive research on the qualitative researcher, and I came across an edited book aimed at addressing the emotional aspects of the qualitative research experience (Gilbert 2001). As contributors described their experiences of exploring areas of traumatic loss such as suicide, abuse and infant and fetal death, the proposition that traumatic events call into question our most basic assumptions about the world had resonance with participating women's experiences of an adverse diagnosis. I hypothesised that meaning reconstruction was an important element in understanding this particular phenomenon, so I searched the trauma literature for theoretical work concerned with the process of making sense of a traumatic loss. Hence, the iterative process began again, as discovery of the construct of the assumptive world influenced further analysis and the most recent rendering of the model.[81] My search was driven by the following hypothesis: gaining meaning has a role to play in the process of adaptation. The question guiding the search was: how does gaining meaning influence the process of reconstructing the future? This question had arisen as the change process I had observed was not linear, did not consistently move forward, was not always positive (hopelessness and resistance were observed) yet for the

[81] I am reluctant to use the word 'final' as further research within the substantive area is likely to result in modifications to the model.

majority was characterised by movement towards resolution, and for some seemed to confer benefit (what doesn't kill you makes you stronger).

In the literature on traumatic life events, the terms 'searching for meaning' and 'making meaning' have encompassed varied concepts such as making sense, coherence, purpose, existential confrontation and creating meaning (Landsman 1997, cited in Wheeler 2001). But why should these women search for meaning? Many authors contend that death of a child is a bereavement experience that violates previous assumptions and meanings (Miles and Crandall 1983) as it reverses the sequence of life events for parents, undermining the orderliness of the universe (Gorer 1965, Moulton Milo 1997, Morgan Strength 1999). Although not all women in this study experienced a death-related loss, each spoke of how the anticipation of the birth of a child holds multiple meanings. As women constructed their story they equated the loss of an ideal child with the loss of their hopes and dreams and of countless expectations for that child (Rando 1986). In that context they were left to face the task of making sense of what had happened in order to restore a sense that life is meaningful (O'Connor 2002). According to Parkes (1971) the assumptive world concept refers to a set of assumptions or beliefs that have been building inside ourselves from the moment of birth. We rely on this set of assumptions to maintain our orientation in the world which in turn gives a sense of reality, control, meaning and a purpose to life. Because this model is based on reality (most of the time), it becomes a valid basis for our thoughts and actions, and anything that challenges the model incapacitates us. Minor changes to the model do not threaten assumptions and are relatively easy to accommodate, extending our repertoire of coping skills. However, if the event is sufficiently momentous to challenge our deeply held beliefs, then change is difficult and likely to be resisted as the process of revising those assumptions is usually exigent. When an individual experiences a traumatic loss, disruption to the normative constancy of one's deeply held beliefs results, which is loss of the assumptive world. However, significant change also triggers the need to preserve, maintain constancy and for an assumptive world to reassert itself. Janoff-Bulman (1992) has developed the theory of the loss of the assumptive world into a compelling case for a "new psychology of trauma" (Kauffman 2002 p2), as she contends that traumatic loss

damages our beliefs of goodness, meaning and self-worth as the conservancy of the assumptive world is shattered.[82]

As women told their stories, each began in a place where fetal health was taken for granted. A knowledge that most babies are born healthy combined with maternal well-being re-enforced the assumption that the ultrasound would confirm fetal normality. An adverse result violated that assumption resulting in complex emotional reactions to the loss. In addition, when being good through preparing for pregnancy (control) in particular and in life in general (justice) did not result in the desired outcome; women were thoroughly unprepared for the diagnosis. At the risk of being overwhelmed by the event, women began to search for meaning as a way of maintaining their assumptive world. The data have shown that initial reactions to the diagnosis were expressed in different ways. The most frequently mentioned responses were shock, disbelief and fear. In the words of Maeve *"I couldn't believe she was talking to me-but there was no-one else in the room"* reflects a feeling of somehow being removed from what was happening as the shock of the diagnosis needed time to be accommodated. However, women also exhibited attempts to make sense of what had happened as questions such as *"why me?"* were re-iterated over and over again. Initial attempts to make sense of the situation often had a tone of protest as women compared their experiences with the outcomes of others i.e. *"Here they are going in no problem, getting everything handed to them, perfect babies probably"*. Emma imagined that women who had prepared less diligently for pregnancy than herself would likely give birth to a healthy baby, challenging the justness and benevolence of the world (Lerner 1980). Molly re-iterated this sense of injustice and lack of control over the future as she said *'I did everything so right and yet it went so wrong'* resulting in a sense of heightened personal vulnerability.[83] Sometimes

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[82] Janoff-Bulman (1992) proposed the following 3 basic beliefs: 'The world is benevolent' (this relates to both people and to events), 'The world is meaningful' (this implies that there is a relationship between the person and what happens to him/her, and that this relationship is based on justice, i.e. good people deserve good outcomes and we can control or influence our future- or perhaps God can), We believe in 'self-worth' (people are essentially good, decent and moral in character, as well as wise and effective in one's actions).

[83] This sense of vulnerability also extended to other members of the family, as women often spoke of how they became concerned for their husband's safety driving to work etc. When faced with potential non-existence, preciousness of life was brought to the forefront. This was also seen in data from transcribers see p70

women also placed a greater value on relationships, reflecting on what they still had- their health, other children *'we are grateful for what we have.'* However, this too was often tinged with concern for the well-being of other loved ones, fearful that lightening might strike twice and that they too could be lost (Miles and Crandall 1983, Tedeschi and Calhoun 1996). Blame and self-blame were present in women's accounts. Whilst acknowledging that blame is also a feature of death-related loss, in that context it often manifests through seeking someone to blame for the loss as when the death is personalised the bereaved may view the pain of grieving in terms of something that has been done to them- an unjust punishment so to speak (Parkes 1998). Within the theory of loss of the assumptive world, Janoff-Bulman (1992) suggests that blame is an adaptive strategy, intended to keep the assumptive world intact rather than accept the randomness of the event, and as such provides a more comprehensive explanation for this reaction within the context of this study. Many reactions in addition to blame were evident as women recalled their emotional responses to the diagnosis. In terms of the emotional pain that was felt words such as *"the pain went right to the core of me, it was devastating, it was such a blow"* were often used, at times comparing the pain of grief to actual physical pain. Many theorists have described why there is physical pain in response to a death; however, it is Bowlby's (1980) seminal work that provides an understanding of the nature of attachment and loss. Attachment theory implies that the development of affectional bonds are required if human infants are to survive. An adverse diagnosis constituted a significant threat to the pregnancy (and the attachment bond) resulting in intense emotional reactions. For those women experiencing a death-related loss, mitigation of the loss of their attachment was achieved through establishing continuing bonds (Klass et al. 1996) with the baby i.e. through visiting the grave, planting a tree, keeping photos etc.

As women assimilated this new information about the pregnancy, the process of 'gaining meaning' (although common to all) was seldom linear. It is through the process of establishing meaning that the individual can determine which assumptions are most affected. Therefore the purpose of making sense of the event in this particular context was to restore an ordered world founded upon the basic assumptions of benevolence, justice, control and self-worth (Landsman 2002 p4). In order to achieve success in this

goal, a delicate balance between confronting and avoiding negative emotions needed to be maintained if one was to manage the change required. Women varied in their search for meaning, as some had the ability to develop a relatively benign explanation for the loss (Janoff-Bulman and Frieze 1983) *'it could have been anyone-why not me?'* or perhaps *'it was God's will.'* Accepting non-randomness or assuming/conferring a degree of responsibility for the occurrence of the event on oneself or another allowed the event to re-fit into a formerly held worldview, obviating the need for significant alteration to previously held assumptions. For others, a revision of previously held beliefs was required, and to a large extent success in recovery from the trauma of diagnosis hinged on the individual's ability to rebuild a new assumptive world (Janoff-Bulman and Frantz 1997). Earlier in the analysis, aspects of coping such as the strategy employed (Lazarus and Folkman 1984) and mechanisms to moderate levels of information (Miller and Mangan 1983) were evident in women's efforts to manage this challenge to their assumptive world (Corr 2002). The concept of coping has to do with the responses an individual makes to a perceived stressor and involves all efforts to manage stressful demands associated with the crisis or in its aftermath. There are many cognitive-processing models in the literature, each concerned with understanding how individuals come to terms with a traumatic experience. However, Horowitz (1992 p92) has suggested that when one experiences a traumatic event, there is a "need to match new information with inner models based on older information and the revision of both until they agree" -at times this reconciliation can be so painful as to interrupt information processing temporarily (avoidance). Moos and Schaefer (1986) have argued that the understanding of coping provided by Lazarus and Folkman's emotion and problem-focussed approach is valuable in that it highlights the fact that skills can be developed through changing one's activities in order to cope more effectively. For example, it acknowledges the dynamic character of responses to stress, as evidenced by the fact that women used an array of strategies to respond to the problem. However, adjustments or adherence to the coping strategy chosen did not always equate with successful management of the situational challenge. If the coping strategy adopted allowed for successful management of the situation, space (cognitive) became available for women to become involved in the process of appraising the threat posed by the diagnosis. When all seems meaningless, self-worth is also threatened. When women

failed to achieve their expectations of conceiving a normal child their very identity as a woman was open to challenge. Ciara's feelings of inadequacy were expressed as follows *'We [women carrying an anomalous fetus] are not freaks- I just wanted to hear that this had happened to someone else'* reflecting the sense of failure that women felt as their bodies *'let them down'*. Therefore the transition from 'Shock' to 'Gaining Meaning' is a critical phase in the process as it is how the phenomenon is understood- it is the interpretation and meaning of the event that determines the level of challenge (Janoff-Bulman 1992). The role of coping and the emotion regulation process in this study was to allow women to try and understand what the loss meant at an individual level, as an assessment of the extent to which basic assumptions were violated could then be made. Attempts to make sense of this tragedy not only tested the woman's ability to adapt, but also her ability to rebuild an inner world that could sufficiently incorporate the traumatic experience (Janoff-Bulman 1992, 2004). In the face of an adverse diagnosis, women tried to understand why this had happened to them in particular, as their fundamental assumptions about the meaningfulness of the world were threatened. Rebuilding the assumptive world was required in order to establish a state of equilibrium. When meaningfulness was not re-established, and self-worth remained un-restored, an inability to cope and recover was evident, as anxiety, depression and a sense of helplessness dominated. According to Janoff-Bulman's (1992) model successful coping or recovery from the phenomenon does not mean returning to one's original assumptions, but rather being able to revise these basic schemas in order to engage with the future. Women now had to ask themselves *"can I conceive and give birth to a healthy child?"* as they were all too aware that misfortune and tragedy can strike anyone and that previously held assumptions may have been naïve. In the absence of a significant burden of care, it was the perceived risk of another loss that determined women's readiness to consider another pregnancy.

In the words of Ronnie Janoff-Bulman (2002) "theory building may feel like a solitary process, in the course of normal science we typically add more bricks to a structure already partially constructed by others." In my case, the work of Parkes and Janoff-Bulman has provided me with the construct of the assumptive world and an understanding as to why this world requires reconstruction in the aftermath of a

traumatic event. This theory of traumatic loss has proved crucial in my efforts to make sense of these women's reactions and has provided clues as to why women were psychologically unprepared for such an event. The constructivist approach used within this study has shown that making sense of the diagnosis is central to the process of rebuilding one's life and as such provides a new perspective of this phenomenon through re-authoring the narratives of women who have been affected. Recasting Hope represents a move away from the original return to baseline stage models of grief which have been either implicitly or explicitly shaped by a medical model (Landsman 2002, O'Connor 2002). This paradigmatic view of grief as a disease process to be 'worked through' with recovery regarded as a return to a pre-event level of negativity is limited in its inability to account for post trauma resilience and growth. According to Neimeyer newer models of mourning are characterised by; a scepticism about the universality of a predictable trajectory from disequilibrium to readjustment, paying attention to meaning reconstruction, acknowledging the implications of major loss for the individual's sense of identity and the need for possible revision (Neimeyer 1999 p66-67). Through the use of a constructivist and narrative approach Recasting Hope adds a newfound sensitivity to the pattern of adaptation that exists within the context of prenatal diagnosis, one that acknowledges the transformation of self as a new assumptive world is occasioned. Through developing an understanding of this process, we can guard against the danger of medicalising a normal life crisis and move from a pathological view of grief and trauma to a more positive view of bereavement that involves meaning reconstruction.

9.1.2 Theory and practice

One of the aims of this study was to develop a theoretical framework for practice, intended to support practitioners caring for women following the diagnosis of a fetal anomaly, consequently an exploration of the caregiving relationship was crucial. The catalyst for this section came firstly from my theoretical inclination towards symbolic interactionism and my preoccupation with women's qualitative experiences of their encounters with health professionals during this stressful time. As I listened to women I became interested in the potential impact that encounters and relationships with caregivers might have on the process of Recasting Hope. As I engaged with women

during the study I listened for implicit and explicit references to care. Hearing women's accounts of the negative impact of a failure to negotiate the hegemonic scientific model can have touched me in ways I could never have imagined. Positive encounters with caregivers were more commonly experienced by women, and although some couldn't speak highly enough of their caregivers, the negative interactions had more of a personal impact (Halldorsdottir and Karlsdottir 1996a, Halldorsdottir and Hamrin 1997). Although not explicit in women's words, hearing evidence of the agential limitations placed upon them meant that I became sensitised to the concept of patriarchy within maternity care. However the discourses that impact on women's oppression or autonomy within the maternity services are more multifaceted and wide ranging than I could expect to understand or include here; accordingly, I intend to highlight some of the encounters that women have experienced as they relate to the process of adaptation. It is hoped that in bringing some of these issues into the foreground that both the role of caregivers and the need to develop a specific midwife practitioner role to support the process of meaning reconstruction will become evident. Adaptation through making meaning following a negative life event is a concept that has been gaining interest in the psychological literature of late (O'Connor 2002). However, meaning is not seen as inherent in the situational context, or indeed in the individual affected, but rather it is constructed as "the person co-creates the personal realities to which she responds and thereby participates in reciprocity" (Mahoney 1996 p4). It has been suggested that in order to reflect women's concerns, theory and practice must remain inseparable (Stanley and Wise 2000, Pilley Edwards 2001); for that reason recommendations for practice are based on knowledge constructed from women's subjective experience of this phenomenon.[84]

The data have shown that women discover meaning in this event through constructing their story, as many felt the need to share their experience verbally (Mitchell and Glickman 1977, Rime 1995) giving some credence at least to the age old adage that 'it's

[84] By subjective experience I mean the woman's lived experience of prenatal diagnosis.

good to talk'. Consequently the role of talking as an intervention in care will be explored.[85]

The responsive other

Meaning-making has been defined as "the development of an understanding of the event and its implications" (Davis et al. 1998 p561), and is required in order to accommodate a negative event into previously held assumptions. Conversely if this cannot be achieved the creation of a new and revised assumptive world is required. However, establishing an understanding of the situation requires receiving cues from the external world, and the openness, supportiveness and potential help of the listener has been shown to be enormously valuable to those trying to adjust following a significant life event (Kelly and McKillop 1996). Cues from a responsive listener function to allow individuals to re-assess the negative experience as they attempt to restore control over future events and locate a sense that life is meaningful (O'Connor 2002). Researchers have shown that for those exposed to a major life event the need to share this with others (such as family and friends) may be quite intense (Schoenberg et al. 1975, Mitchell and Glickman 1977) perhaps even rapacious (Rime 1995). Nevertheless normal social interaction may be insufficient to process episode-related information (Rime et al. 1991, O'Connor 2002). Certainly some women in this study experienced situations where they were not given the opportunity to verbalise their feelings in depth or at length, as those in their social network also struggled to come to terms with their news. Molly and Ava felt that on occasion certain others attributed them with blame undeservedly; resulting in their recoil from openness to silence. This demonstrates that disclosure of the emotions engendered by negative life events is not tolerable in all social relationships. Aoife soon realised this fact when her compulsion to *'blurt out'* that the pregnancy was problematic to one of the women attending her son's crèche was met with alarm, confirming that discretion was required. Other women such as Caitlin and Kasey felt stigmatised by the diagnosis, as individuals that were previously quite friendly took measures to avoid socially awkward moments. Although these may be viewed as encounters with non-significant others, even within a family, certain conversations may be inhibited due to

[85] Women centred supportive interventions for hospital staff based on the process of adaptation are highlighted in figure 1.

previous life experiences or family rules about what is and what is not fitting to discuss (Nadeau 2001). This study provides evidence through high participation and low drop out rates that women did find some benefit in talking, as Niamh encapsulated beautifully when she said *'you just need a chance to talk. It clears things in your head.'* Although the role of a responsive listener has been shown to be beneficial, sufficient social support may not be available to all women, for a wide variety of reasons. However, relationships that can sustain disclosure play an essential role in the recovery process (Janoff-Bulman 1992) as those affected seek social validation of the experience (Neimeyer 1999).

The midwife as responsive other

If expression of emotion is inhibited or limited within the woman's social/family circle this can impede gaining meaning of the event, as recalling significant life events and the emotion they evoke is more therapeutic than just acting out emotionally (i.e. expressing anger, crying alone) (Greenberg and Safran 1987). One of the dissatisfactions raised in relation to social relationships and their inability to provide appropriate support hinges on the expectation that women were expected to recover from the loss after a brief period of time (Lord 1987). Although Wortman and Silver (1989) have criticised bereavement researchers for adhering to a medically orientated return-to-baseline model of grief, quite how this perspective has filtered into lay cognition I do not know. When family members suggested to women that they should be *'getting back to normal'* this was usually met with anger and frustration as individuals vary considerably in the length of time required to adapt to the loss. Although many women spoke of the benefit they received by telling their story through participating in this research, the depth of 'social' suppression of emotion was most evident in women who chose to terminate the pregnancy. Bethan spoke of the added injustice of being required to grieve secretly, and although this is offensive to hear it may also be clinically significant as perceptible social restrictions against disclosure have also been shown to predict later depression (O'Connor 2002). Thompson (1998) describes five ways open to individuals to achieve the aim of making sense of the event and these include; altering goals to that which seems more achievable, re-interpreting the event in a more positive fashion, engaging in downward comparisons, accepting some outcomes and focusing on areas

where perceived control is likely to be higher, pathways a clinically experienced midwife working in the substantive area can facilitate. Let us consider each pathway in turn as it relates to midwifery care.

Altering goals: the data have shown that women frequently altered their expectations regarding the outcome based on the fetal condition. However, stress generated within the context of the fetal medicine clinic[86] meant that women were often in a position of reviewing the information they had been given once they got home. Women frequently took the opportunity to seek clarification of the technical information they had received and reciprocity of this nature was a key component of the interview.[87] More often than not, women required information regarding future events such as labour and delivery, aspects that seldom featured during the consultation. As the information required was specific to the fetal condition and pregnancy-related issues, a clinically experienced midwife is ideally positioned to fulfil this need. Niamh's story highlights the influence that professional background and environment have on the development of a responsive relationship.

'Mm (sigh) I didn't feel at ease [consultation with social worker for counselling], maybe because I had a session with you [at home] and it was totally different. My husband even said it, like the way the table was in front of us I thought we would never get out of that room. I just felt as though I didn't relate to her. When we sat down and we were talking away about the water on the brain and everything and I said something about the hope of having a normal delivery, she kind of looked and I said why that kind of look? and she said but the size of baby's head. I said the baby's head was a normal size and she was shocked by it. Like I felt as though she was meant to be listening to us and straight away when she heard water on the brain she had this image of massive head. My husband said at least with Joan she knows exactly what you are talking about because she is a midwife, you know. Where as the social worker is just a counsellor and doesn't have all the ins and outs of it. I found it totally off-putting. I need someone that could understand a bit more about it because I found it hard ...I

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[86] Women frequently spoke of the anxiety associated with fetal monitoring, predominantly regarding the fear that was associated with potentially hearing more bad news.

[87] Information sharing between myself and the woman was a particularly important element of reciprocal relationship that developed.

actually broke down because I had to explain absolutely everything to her, rather than to have someone sit there and say I know, I have seen this before. It makes so much difference.'

Women reiterated the importance of receiving information specific to their particular situation in order to help in making sense of the event, as focussing on a cognitive understanding of the event assisted in increasing the likelihood that positive emotion could also be experienced. The strain of constantly trying to explain the consequences of fluctuations in the fetal condition to family members was very evident, therefore when women sought support from a health professional reversal of the role necessarily needed to take place. In particular information regarding recurrence risk in a future pregnancy was essential if women's belief in a more positive future was to be sustained. Most women spoke in positive terms regarding their encounters with the fetal medicine team.[88] This was particularly evident when the humanity of the situation was acknowledged. However, in order to feel confident to ask questions or to show emotion, personalised care was required, as developing a trusting relationship was crucial.[89] Women also commented on the fact they felt the support they required could not be delivered as effectively within the confines of the fetal medicine clinic, as time pressures for staff were evident. Conversely, being at home added to the woman's sense of control over the situation. A home visit was also influential in restoring a sense that there was some benevolence left in the world, as Sian so eloquently stated *'I am somebody because you have found it important to come and see ME.'* Fostering a sense of self-worth is crucial if hopelessness and despair are to be kept at bay. Whenever I reflect on women's encounters with caregivers, although I take joy from the fact that many women developed strong links with key personnel, intrusive reminders of Caitlin's story are ever present. My diary entry on p48 relates to the postnatal interview I had with Caitlin where the subject of post-mortem was raised. Although Caitlin was informed from the point of diagnosis that the fetal condition was lethal, her problem-

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[88] Specific issues in relation to delivering the news, access to a second opinion etc are addressed in data in press from this study in appendix 11.

[89] Many authors have highlighted in a wide range of childbirth experiences that personalised care from a known and supportive midwife contribute positively to women's' feelings of confidence, security and control (O'Connor 1992, Symonds and Hunt 1996, Lemay 1997, Pilley Edwards 2001).

focussed approach to coping meant her struggle with issues of meaning was inexorable. Each time Caitlin met resistance she seemed powerless to transcend the patriarchal order that dominated in the regional centre, as access to information and services was controlled by the consultant obstetrician. Caitlin coped through sustaining hope that her baby would be born alive, she requested an induction of labour at 39 weeks, which was refused, and her baby died in utero five days later. She also attempted to access information from her consultant regarding the testing required to predict the recurrence of the condition. As a result, she consented to a post-mortem examination only to discover the findings could not provide her with a future risk assessment. The consequences were catastrophic. Caitlin blamed herself for not protecting her child, even in death, the guilt became so overwhelming that she could not visit her child's grave. Caitlin was to avoid engaging in any subsequent goal-directed behaviour, and lost interest in the world around her (Archer 1999). These issues were unknown to the maternity staff in her local hospital. It was also not known to her public health nurse as many women reminded me- no baby, no postnatal care. It was when I phoned Caitlin's home to arrange her third interview that I discovered this situation. If a model of care that included planned visits from the midwife practitioner existed, issues such as these could be detected and addressed accordingly. For Caitlin, arranging an appointment with a geneticist gave her a pathway to achieve her goal. Although Caitlin's experience is an extreme example, it has been shown that a sense of hopelessness can be exacerbated through negative encounters with caregivers, in particular if the practitioner appears to be uncaring (Herth 1990, Cutcliffe 1996). It goes without saying that women did not appreciate being treated like a 'science project', and an uncaring attitude inevitably led to mistrust. Almost 1 in 5 women lost interest in their surroundings during the time proximate to the diagnosis, at times influencing their willingness to interact with their nearest and dearest. Although this was usually temporary, assisting the individual to find meaning and to become involved in goal-directed behaviour could positively influence this process.

Just as some women accommodated the diagnosis easily into their assumptive worlds,[90] some may never find meaning, but other adjustment variables such as somatic effects, negativity levels, future mindedness etc can be monitored by the midwife and appropriate referrals made if concerns develop, as complicated grief is not a self-limiting process (Zisook and DeVaul 1983). Repeat visits from the midwife would facilitate identification of the person that appears to be becoming stuck. Formal input from specialist services can be arranged (Worden 1991) as appropriate, protecting women from increased medicalisation of a normal bereavement process. However it must be emphasised that adjustment can occur while negative emotion continues (O'Connor 2002), and this was particularly evident in the accounts of women who were living with uncertainty on a daily basis.

Reinterpreting the event in a more positive fashion: A more recent finding, supported by a growing evidence base, is that complicated grief reactions go together with a sense of pervasive hopelessness (Stroebe et al. 2000). Of importance to the midwife in the role of responsive other is the relationship between hope and help. There is evidence in the literature that a person can sustain his or her own hope to a certain degree; however, this cannot continue *ad infinitum* (Cutcliffe 2004), as hope seeks for and depends upon external sources for sustenance (DuFault and Martocchio 1985). Within the area of palliative care it has been suggested that nurses have a crucial role as an external source in promoting hope in their patients (Cutcliffe 1996), as hope is seamlessly interlaced with caring (Cutcliffe 1995, 1996, Cutcliffe and Grant 2001). When any hope for neonatal survival was untenable, women shifted their goal and welcomed the opportunity to plan a funeral service, to do something practical for their child. Offering pathways to become involved in such endeavours was particularly useful, as it maintained a vision of the future, one where parents could have some influence. For other women, either post termination or facing the prospect of caring for a child with a disability, the presence of a listener who demonstrated acceptance, open-mindedness and understanding, the essential fundamentals of caring practice, may have inspired hope (Herth 1990, Cutcliffe 1995, 1996) as new identities were tested for validation

[90] Although this was more common to women with treatable anomalies, it did not occur exclusively in that group.

(Neimeyer 1999). Women carrying babies with treatable anomalies needed recognition of their trauma and fears that the baby may be less perfect than predicted. Given the potential of a dedicated midwifery role to support and monitor the process of adaptation and to inspire hope through reciprocity, it is vital that access is available to all women (irrespective of pregnancy outcome) as hopelessness and despair are a "thought process that expects nothing; and a behavioural process in which the person attempts little or takes inappropriate action" (Farran et al. 1995 p25). It is of interest to note that a positive correlation exists between the need to share and the emotional intensity experienced (Rime et al. 1991), consequently the frequency of midwifery visits would need to be based on individual need.

Engaging in downward comparisons: As previously mentioned, women often hoped for the best case scenario relative to their individual circumstances. The midwife practitioner is ideally located to talk through possible outcomes, providing information for the woman on cues to fetal health or ill-health. This facilitates the process of moving goals to match the situation. In addition, women often wished to hear of other women in similar circumstances, as the idea of attending a support group was not particularly welcomed. For women who chose to continue the pregnancy, concerns were raised that other women in worse circumstances might *'bring them down.'* For women who terminated the pregnancy, support groups were associated with families who were caring for a child with the disability and fear that they would be judged for their actions made attendance prohibitive.

Accepting some outcomes and focusing on areas where perceived control is likely to be higher: The scope for a midwife practitioner role to be influential in instilling a higher sense of control in women is boundless. In addition to fostering a sense of benevolence, meaningfulness and self-worth, reassuring women that others have experienced an increase in negative thoughts, and that these thoughts are not only realistic but are extremely common (Robinson and Fleming 1992), reduces the sense of isolation that women experience. Although some women had not developed a new cognitive schema that accommodated the event by the time their participation in the study was complete, the remainder had returned to normal levels of pre-event function i.e. diminished

somatic symptoms, returning to work etc. On hearing that other women had given birth to a normal child following affected pregnancies inspired hope and a sense of control over the future. This was particularly evident in women receiving a diagnosis of anencephaly, as a therapeutic dose of folic acid for a future pregnancy was seen as protective. Liaison with the fetal medicine team or caregivers in a regional centre regarding the woman's wishes and concerns is a strength of the role not to be underestimated. For example, when Caitlin requested a referral to a geneticist from her consultant this was met with scepticism and was seen as a challenge to his/her professional status. Her GP also refused to make the referral as he/she did not have access to the required information held in the hospital case notes, and genetic services do not accept self referral. When I brought this to the attention of the fetal medicine consultant and consultant geneticist, alternative pathways for referral were established whereby a midwife involved in the case could make a referral on the woman's behalf. However, perhaps the strength of the role in increasing women's sense of control is through accessibility- if women know they have a contact person, someone on their side so to speak, the likelihood of achieving their goals in relation to care is increased, resulting in a positive impact on the process of Recasting Hope.

A significant negative life event such as prenatal diagnosis requires cognitive and emotional re-adjustment as women's desire to contribute to the world by nurturing a capable and caring child are threatened or crushed (Archer 1999), challenging our sense of who we are (Neimeyer 1999). A sustainable responsive relationship has been shown to contribute positively to the process of adaptation, in particular for women who appear to be overwhelmed by the event, or who have been condemned to silence because of the decisions they have made. The consequences of this silence will be explored in the following section.

9.1.3 Condemned to silence - the tyranny of Irish law and cultural norms

Durkheim, in developing his philosophy of societies insisted that society was more than the sum of its parts; individuals are bound by cultural norms and values as the collective consciousness subsumes an individual consciousness, ensuring that social norms and social behaviour are well-regulated. Durkheim also made an association of the kind of solidarity in a given society and the preponderance of a legal system. He found that in societies with mechanical solidarity the law is generally repressive: the agent of a crime or deviant behaviour would suffer a punishment in order to preserve the unity of consciences, a principle that applies in Ireland in relation to the right to life of the unborn. This chapter picks up the threads from issues I addressed in chapter 2 in relation to fetal ontology and Irish law. It is about the loud cries of those women wishing to terminate the pregnancy as they struggle to access services. For those who succeed in doing so, facing a lifetime of negotiating an altered identity and the right to grieve publicly are but some of the costs associated with maintaining pervasive cultural norms. For those who fail, there is the possibility of continuing difficulty in maintaining secure attachment to their child (Hedrick 2005).

A child before birth

Although several authors have argued that technology gains currency when there is a belief in the scientific and technological developments that underpin modern medicine (Arney 1982, Oakley 1984), this belief has slipped into women's cognition of healthcare too. A pre-ultrasound era where knowledge of the fetus could only be acquired through seeking information from the mother has been consigned to history. Ultrasound in maternity care seems to have an enormous capacity for replication, as it has now successfully invaded all three trimesters of pregnancy. The race to screen for fetal anomalies is accelerating as prenatal diagnosis is being offered earlier and earlier in pregnancy and the debate surrounding the rights and wrongs of pre-implantation

genetic testing continues to rage.[91] However, the data have shown that routine antenatal ultrasound has received uncritical acceptance by women in Ireland, and even within the context of prenatal diagnosis, affected women would not discourage others from taking part in screening programmes. Is this based on heuristic reasoning of representativeness or a belief in an assumptive world characterised by benevolence, meaningfulness and self-worth? Irrespective of theoretical considerations, women are taking part in ultrasound screening programmes in order to meet their baby (Ekelin et al. 2004), often naming their child as fetal gender is revealed (Hedrick 2005). Although some have argued that this fetal person is technologically mediated (Duden 1999), the vision it creates of a future child for women is epistemologically true. The barrier of the woman's body is no longer a limitation to visualising the fetus. With the advent of 3d and 4d ultrasound, grainy, fuzzy ultrasound images are being replaced by digital technology, less in need of interpretation by the ultrasonographer. As fetal images are imbued with personality and volition, a social space for the fetal person (independent of the women) is created (Boucher 2004). Advancing fetal rights and agency are not new concepts as Casper reminds us of the extent to which William Liley advanced this view fifty years ago:

"The fetus is a young human, dynamic, plastic, resilient, in command of his own environment and destiny with a tenacious purpose...It is argued that the fetus is incapable of independent existence. However, the fetus can outlive his mother, and dead women have been delivered of live babies. Independent existence is a relative concept" (cited in Casper 1998 p61).

Ironically, in spite of Liley's argument for fetal ontology, women's expressed need for technical intervention in the fetal interest was juxtaposed against the fact that science and fetal therapy can do little for many fetuses/infants diagnosed with an

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[91] The Report of the Commission on Assisted Reproduction in Ireland (2005) have recommended that Pre-implantation genetic diagnosis (PGD) should be allowed, under regulation, to reduce the risk of serious genetic disorders. PGD should also be allowed for tissue typing only for serious diseases that cannot otherwise be treated. Each licence issued for PGD should specify the proposed procedure. The regulatory body should oversee and monitor developments in PGD. Recommendation No. 40.

anomaly (Sandelowski and Corson Jones 1996b, 1996a, Kenner and Dreyer 2000). However, developing technologies will continue to revolutionise women's experiences of pregnancy,[92] but this is not necessarily a correlate of improved fetal outcome. Yet the person we might be in a position to help most (the woman) plays a minor role. Undoubtedly, the public image of the fetus created by ultrasound creates an assumption that the fetus, if ill, can receive medical treatment. The data have shown that women had high expectations of the fetal medicine specialist, and if not expected at least *hoped something could be done.* Barbara Duden has questioned whether medical technologies, particularly prenatal diagnostic techniques, have usurped women's own bodily sensations as indicators of the baby's reality (Duden 1999), as quickening has been superseded by early ultrasound to confirm fetal viability (Ekelin et al. 2004). Yet women turned to ultrasound for reassurance. Doireann and Alannah each gave examples of attending the ultrasound department with first trimester bleeding. This paradoxical combination of ultrasound confirmation of viability and vaginal bleeding was evident to women. Doireann went on to comment on how she tried to subordinate the knowledge gleaned from physical symptoms in favour of technology, as ultrasound offered the more positive outcome at that time, although she was later to acknowledge that her body was right. Once the pregnancy was threatened, women instantly assigned the moral status of personhood and humanity to their unborn child. Many asked to be told the fetal gender in order to call the baby by name; some almost pleaded with their babies to fight for survival (Landsman 1998), whilst others were concerned that the anomaly could cause fetal suffering. Therefore, from a theoretical perspective the fetus was seen by women as a being with full moral status in keeping with the human species argument,[93] or so it would seem at the point of diagnosis. For women who chose to terminate the pregnancy, the interest view put forward by Joel Feinberg appeared to

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[92] 3d and 4d ultrasound have recently become commercially available in Ireland. The relative safety of these technologies is being debated in the media as parental desires to engage in 'boutique scanning' are cast against concerns for fetal development due to exposure to high frequency beams, and missed diagnoses.

[93] The Report of the Commission on Assisted Reproduction in Ireland (2005) has recommended that the embryo formed by IVF should not attract legal protection until placed in the human body, at which stage it should attract the same level of protection as the embryo formed in vivo. Recommendation No. 16

apply,[94] as women framed their decision in terms of what was in the fetal interest. Based on the interest view, a fetus without the prospect of extra-uterine life or a fetus likely to experience a poor quality of life (perhaps associated with suffering) is unable to take an interest in its continued existence, and therefore does not have a right to life. If only the subjective experience was as clear cut as moral argument. In fact women who continued the pregnancy, yet had considered the alternative, often spoke in terms of how the following key issues influenced their choice; fear of opprobrium, the moral relationship they had with their fetus, and the extent to which they could cope with the challenge. In many instances pervasive cultural norms influenced decision-making rather than the moral status of the fetus as Tara commented *I probably would have gone for it [termination of pregnancy]. It's the fact that it wouldn't be socially acceptable in Ireland [that influenced the decision to continue the pregnancy],* re-affirming MacKenzie's (1992) assertion that decision-making regarding pregnancy is judged within a social context. Accessibility and availability of abortion varies within the European Union, and as mentioned in chapter 2, abortion in Ireland is limited to circumstances that present a real and present danger to the woman's life, guaranteeing that abortion is practically inaccessible. Therefore within Irish law and society, it is the very personal dimension of autonomy that is at stake. Two women (Fiona and Lori) attempted to exercise their right to self-determination through accessing abortion services, and failed at every turn. For the eight women who were successful in exercising their right to choose, each woman had to leave the country unassisted and ill advised.

Deafening silences

Not surprisingly, women were accepting and excusing of practitioners' lack of assistance in arranging a referral to UK services as women acknowledged the control exerted over practitioners[95] by a pro-life national identity, shaped by cultural norms and controlled by the constitution. However, as highlighted in chapters 6-8 arranging access to abortion services in the UK was not easy. With the exception of Molly and Muireann, women were re-traumatised by their experiences of care. It was expected that as

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[94] See chapter 2.

[95] Examples of oppressive networks of power in midwifery/maternity care are available in Levy 1998, 1999, Cahill 2001 and Pilley Edwards 2001.

termination of pregnancy was legal in the UK, there would be an openness and understanding of the tragic nature of the circumstances. However, instead of receiving much needed acknowledgement of the loss from staff, women actually felt stigmatised. As Aoife recalled *I felt I was an inconvenience-that I was subjecting her [midwife] to an unpleasant experience.* Incapacitated by grief, Bethan commented on the insensitive care she received*: I felt like saying to her but you don't understand, I wanted that baby, and you can't say it because they don't want to understand.* Why is this so? Does a society that accepts a woman's right to reproductive choice simultaneously prohibit the right to grieve for having exercised that choice? Negative encounters with caregivers in the UK meant that women longed to be back in Ireland; however, this situation is liable to continue as the likelihood of access to abortion services in Ireland appears to be remote. It has been suggested that there are some members in society that seem astounded by the emotional response exhibited by couples after experiencing fetal loss (van Mourik 2003), and this may be due, in part, to the many perspectives that exist in relation to the moral status of the unborn (Dunstan 1988). Although anthropologists have long recognised that the definition of personhood can vary cross-culturally (Landsman 1998 p93-94), the profound impact that a disparity of definition could have on an individual's experience of accessing care in another jurisdiction was unanticipated. It is epistemologically true that variances exist between our two nations in relation to the recognition of the social context of pregnancy as echoed in relevant law. UK law has taken a gradualist approach to assigning legal status to the unborn, as termination of pregnancy is permitted up to 24 weeks gestation in all pregnancies, and up to term in the case of serious fetal abnormality. Philosophically, the notion of reproductive autonomy has been concerned with the woman's right to avoid the birth of another (Buchanan et al. 2000). However, this perspective has somewhat limited application to the context of prenatal screening for fetal impairment (O'Neill 2002), as selective abortion involves arbitrating on the fetal capacity to have a good or reasonable quality of life (Sheldon and Wilkinson 2001).

This raises the difficult question as to why gestational limits in the English Abortion Act do not apply to a fetus with a "substantial risk" of being born "seriously

handicapped."[96] It would appear that it is parental interests that to a large extent underlie this section of the Act. However, the difficult questions as always concern how (or if) we think reproductive autonomy might be both 'protected and limited' (Scott 2005 p66). In Irish law the fetus (without distinction) is entitled to legal protection possibly from the moment of fertilisation.[97] Unfortunately for women faced with accessing services in the UK, national differences in the moral and legal status of the fetus seem to add an additional dimension to the process that requires consideration.

The consequences for women of travelling to the UK for termination of pregnancy have been highlighted in chapters 6-8. However, several cases have reached the media in recent months in relation to this very issue. The case of *Re D* introduced in chapter 2, is a particularly poignant illustration of the difficulties inherent in the State's assertion of an interest in the right to life of the unborn.

To recapitulate: *D,* an Irish woman, took her case to the European Court of Human Rights (ECHR) in 2005, claiming that Irish law forces her to carry a baby with a lethal abnormality to term, and the requirement to travel to the UK for abortion services violates human rights. *D* did not challenge the constitutional right to life of the unborn in the Irish courts prior to lodging her claim with the ECHR on the basis that she was unlikely to succeed in achieving a hearing. However, the ECHR rejected her plea for a hearing.[98] Lawyers for the State argued that a fetus with a lethal abnormality may not be

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[96] The Abortion Act 1967 as amended by the Human Fertilisation and Embryology Act 1990 reads: "Subject to the provisions of this section, a person shall not be guilty of an offence under the law relating to abortion when a pregnancy is terminated by a registered medical practitioner if two registered medical practitioners are of the opinion, formed in good faith...(d) that there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped."

[97] The point at which life begins remains to be defined in Irish law.

[98] A challenge to the prohibition on abortion has been refused admission for hearing by the European Court of Human Rights (ECHR) on the grounds that the applicant had not exhausted domestic remedies by bringing the case to the Irish courts. The case was brought by a woman known as D, now aged 45. She claimed that the unavailability of abortion in circumstances where the foetus suffered from a life-threatening abnormality was a denial of her rights. In late 2001, D, who already had two children, became pregnant with twins. In early 2002 an amniocentesis test showed that one foetus had died in the womb and the second had a chromosomal abnormality known as Trisomy 18 or Edward's Syndrome. A second amniocentesis confirmed those findings. The woman was told that this syndrome was fatal and that the expected survival age for children

considered entitled to constitutional protection if it was established that there was no realistic prospect of being born alive, as it may not be considered "unborn" for the purposes of Article 40.3.3. The State argued successfully that *D* had not exhausted all domestic legal remedies, and that she had a reasonable prospect of success had she asked the Irish courts to intervene. Consequently, the ECHR said, following counsel's opinion on her case she should have sought an urgent High Court hearing at the time of her diagnosis, suggesting that a reasonable argument could be made to shift the balance in favour of the mother in this case. The same pragmatic approach was taken by lawyers for the State adding that the courts were unlikely to interpret this Article with "remorseless logic", particularly when the facts are exceptional. However, the question arises as to how a woman could contemplate a High Court action at such a vulnerable time. The ECHR disagreed, suggesting that the courts could hear the case urgently (taking cognition of gestational issues) and *in camera* to ensure confidentiality for all parties involved. Having engaged with these women over the course of the study, it would appear to me that the comment has been made in ignorance of the diversity of meaning that individuals attribute to the loss of a healthy child and the extent to which the loss of the assumptive world can be simultaneously paralysing, chaotic and emotionally overwhelming. The State also argued that *D's* interpretation of the Information Bill 1995 which appears to prohibit doctors from making direct referrals for abortion services was incorrect. So what does this mean for women in the future?

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with the syndrome was six days. She therefore decided that she could not carry the pregnancy to term. The abortion was performed in the United Kingdom. She was unable to remain in the UK and could not therefore take advantage of counselling on issues like the genetic implications for future pregnancies. She needed some follow-up medical treatment in Ireland but she explained to the hospital and to her own family doctor that she had had a miscarriage. She brought her complaint to the ECHR, claiming that the Regulation of Information (Services outside the State for Termination of Pregnancies). Act of 1995 limits what a doctor can tell a pregnant woman with a lethal foetal abnormality, and prohibits the doctor from making proper arrangements for a therapeutic abortion abroad. She also complained that she had been discriminated against as a pregnant woman or as a pregnant woman with a lethal foetal abnormality. She claimed her rights under the Convention on Human Rights have been infringed, including her right to protection from inhuman and degrading treatment, to respect for her family life, her right to receive information, her right to an effective remedy and her right not to be discriminated against. In rejecting her application, the court said the X case had shown that the Irish courts could develop the protection of individual rights by way of interpretation. It suggested that there was a feasible argument to be made that the constitutionally enshrined balance between the right to life of the mother and the foetus could have shifted in favour of the mother when the "unborn" suffered from an abnormality incompatible with life. Report in Irish Times: European court rejects plea to hear abortion law challenge Carol Coulter, Legal Affairs Correspondent 07.07.2006.

Legal opinion would be that the way is open for a landmark case in the Irish courts. Consequently, women attending Irish maternity hospitals who receive a diagnosis of lethal fetal anomaly should be informed that they could apply to the High Court, should they want a termination in Ireland.[99] Such a case could clarify several aspects raised in *Re D.* For example;

1. How will lethal anomalies be defined? (i.e. no prospect of extra-uterine life). If this is the case then many lethal anomalies will not fit the criteria, as many babies are born alive and die within 24 hours of birth, or soon thereafter.
2. The legality of a formal referral pathway to appropriate clinical sites in the UK could be tested.

Barbara Hewson, a lawyer for the woman said the Government's submissions to the court changes the expectations of women in this situation. However, I remain concerned that women's expectations will be dashed, as the extent to which an individual obstetric consultant - woman dyad will be strong enough to mount a legal challenge during such a stressful time is questionable.[100] In addition, if the separation of mother and fetus as occurred in *Re C* is repeated (*C* was represented by two lawyers, one for her body and one to represent her fetus), this is unlikely to result in a harmonious tone to the proceedings. Even if elements of *D's* case are tested in the court, concerns of women carrying babies with non-lethal anomalies likely to result in disability are likely to remain unaddressed. In both public and private debate, arguments presented in favour of or against abortion focus on either the moral permissibility of an induced abortion, or justification of laws permitting or restricting abortion. The *D Case* adds another dimension to an already adversarial debate- how society values and protects some of the most vulnerable members of our community, those with disabilities. Careful reflection is required regarding the enormous range of anomalies where birth is undoubtedly in the interests of the fetus (Alderson 2002, Scott 2005). It would be difficult to argue that the views of parents raising a child with a disability or

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[99] http://www.spiked-online.com/index.php?/site/printable/1286/ Barbara Hewson. After D, Antenatal diagnosis and human rights.

[100] A legal challenge would necessitate obstetric participation to confirm the diagnosis, and be assured of legal protection if termination of pregnancy services were to be offered.

that the interests of people with disabilities are not relevant to the debate, as models of disability may affect our perception of handicap and our concomitant desire to avoid it.[101] The deliberative processes of considering reproductive autonomy in terms of prenatal diagnosis and termination of affected fetuses, the value of mothering children with disabilities, the extent to which disability undervalues personhood or "equally the value of a person with that impairment" (Landsman 1998 p77), and how these values shape our socially constructed attitudes towards disability have not received public appraisal in Ireland. This is regrettable as prenatal screening will remain a central feature of antenatal care in Ireland as technology becomes a resource to 'guarantee' an ideal baby (Ginsberg and Rapp 1995) and the trauma associated with prenatal diagnosis will continue, rarely considered even as an afterthought.

Picking up the pieces

However, until Article 40.3.3 is challenged, the normalising effects of society mean that women will wait for fetal demise, choose not to travel to the UK for abortion services or hide the fact as long as termination of pregnancy remains illegal in Ireland. As women continue to grieve secretly, social restrictions against disclosure continue to militate against recovery and reconfiguration of the assumptive world (O'Connor 2002). Until the consequences of the *D Case* are challenged, more stories of inequities in social status and the impact on access to health care will emerge. While exercising the reproductive right to terminate the pregnancy requires leaving the jurisdiction, cultural diversity that result in mismatching values between service users and service providers run the risk of women being re-traumatised by negative encounters with caregivers. In cases in which abortion has been denied, it can have a negative, long-lasting outcome for both women and their families (American Psychological Association 2005). Negative liberty (making a choice a legal right) needs to be replaced by positive liberty, where the choice is supported enough for it to become a reality (Gregg 1995 p10-11). Although many women may have their expectations raised by the prospect of a legal challenge on the basis of the *D Case*, cultural norms based on a lifetime process of developing beliefs

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[101] For further discussion regarding medical and social models of disability see for example Harris, J (2000) Is there a coherent social conception of disability? *Journal of Medical Ethics*, 26, 2, 95-100 and Shakespeare, T (1998) Choices and Rights: Eugenics, genetics and disability equality. *Disability and Society* 13, 5, 665-681.

and attitudes are not easily revised. In addition, the potential willingness within maternity care providers to implement any changes that might arise as a result of a legal challenge would require exploration.

Women continue to be silenced through cultural norms and a legal framework that states 'the unborn' has an equal right to life with pregnant women. Meanwhile our airwaves and print media revealed the existence of bogus crisis pregnancy counselling agencies aimed particularly at preventing vulnerable women from seeking abortions. Although some may suggest that the "character" of Ireland is changing (Oaks 2003 p1975), our ostrich approach to issues of sexuality and reproductive health continues unabated as "changing attitudes are not yet fully reflected in law. There is huge resistance to change from the Catholic Church and other conservative forces, yet law reform on reproductive rights is vital."[102] In the meantime putting support structures in place such as the midwife practitioner role will go some way towards ensuring that women do not cease to exist on the basis of pregnancy outcome (Menahem and Grimwade 2003).

9.2 Concluding summary

The theory of loss of the assumptive world has been invaluable in providing an improved understanding of bereavement in the area of prenatal diagnosis. Routine ultrasound in pregnancy has, in general, received uncritical acceptance from women and health professionals involved in maternity care provision, yet women remain unprepared for the possibility that a fetal anomaly might be detected during the examination. As ultrasound image quality improves the concept of the fetal patient grows ever stronger, causing women to turn to technology to improve the fetal outcome. Unfortunately, although diagnostic testing is developing rapidly, few advances have been made in the area of in-utero fetal therapy. This leaves women in the unenviable position of having to consider whether to continue or to terminate the

[102] Ivana Bacik: THE final WORD: Ireland and Iran are worlds apart, but we're not so different in our treatment of women. Irish Independent 1st August 2006.

pregnancy, a decision further complicated by the requirement to leave the jurisdiction to access abortion services. Yet, in spite of this, little support is available for women experiencing the trauma of an adverse diagnosis, irrespective of the outcome for the pregnancy. Midwives and obstetricians should develop an awareness of current theoretical thinking regarding the process of meaning reconstruction following a negative event if supportive care is to be provided. The framework of Recasting Hope generated during this study is intended for use as a tool to assist health professionals through offering simple yet effective interventions based on women's experiences of the event. Consideration of the impact of a midwife practitioner role on the process of recovery is recommended to ensure that all women have continued access to support irrespective of the pregnancy outcome.

9.3 Institutional and Professional implications of this research

The data have shown that not all women who receive a diagnosis of fetal abnormality continue the pregnancy to term. Therefore, at a national level, it behoves the Government of Ireland and Department of Health and Children to establish a population based register to record and survey the occurrence of congenital anomalies, as a system based on birth registry will be inherently inaccurate. Without statutory reporting baseline epidemiological data required to evaluate the effectiveness and efficiency of health services, inform etiological and clinical research and assess the impact of environment change will remain unavailable. The current EUROCAT registry is limited in several ways:

1. Data are collated for the counties of Dublin, Wicklow and Kildare only
2. The database is limited as statutory reporting of congenital anomalies is not required
3. Data are limited as the information collated is based on births rather than pregnancies

Statutory reporting with relevant information technology systems to support accurate recording of data is urgently required if congenital anomaly surveillance is to be given the attention it requires.

This research has revealed that women receive little formal emotional support following the traumatic diagnosis of a fetal abnormality in pregnancy. Consequently, there is a need for maternity care providers, in particular tertiary referral sites, to recognise and meet women's need for formal support with meaning reconstruction. Facilitating the development and funding of the midwife practitioner role proposed in section 10.4 has the potential to impact positively on women's experience of this event and to contribute significantly to the effective co-ordination of multidisciplinary care where the woman remains the central focus.

The National Council for the Professional Development of Nursing and Midwifery have recommended clinical specialist and advanced practitioner roles as pathways for

the development of several practice areas within nursing and midwifery. Given that over 60,000 women attend for ultrasound annually in Ireland, with 600 facing the possibility of an adverse diagnosis every year, urgent consideration of site approval (in an RCOG approved fetal medicine centre) for an advanced midwife practitioner role to support women in this context is required.

9.4 Recommendations for practice

Recasting Hope is a model of adaptation based on the loss of the assumptive world and has been developed to provide a theoretical basis for care and an understanding of the multiple responses observed as women attribute meaning to the diagnosis. The model has been encapsulated diagrammatically for ease of use for clinicians, highlighting observable features and suitable interventions for each stage of the process (figures 1-5). It is recommended that;

1. Each unit should have access to the model of Recasting Hope in order that supportive interventions can be initiated once a fetal anomaly is suspected.

2. Partial disclosure of the diagnosis when first suspected was reported by women as being particularly traumatic. Policies that contribute to the perpetuation of this practice require urgent revision as this practice must be suspended.

3. Acknowledgement by health professionals of the personal loss associated with an adverse diagnosis is required, and clinicians need to be aware of the potential impact their choice of words and body language can have on affected women.

4. An initial diagnosis of a treatable anomaly can be as devastating as any other diagnosis, as women fear that additional and potentially sinister abnormalities will be discovered at future examinations.

5 A rapid referral (within 24-48 hours) from regional centres to the fetal medicine team should be arranged, as a delay in accessing a second opinion adds to women's' distress.

6. Receiving a prenatal diagnosis is traumatic, and as such, women cope differently in the aftermath. The model highlights the observable behaviours associated with specific coping strategies and relevant interventions required in order to support the individual through each phase of the process and into the postnatal period. Using diagrams and the

ultrasound image to explain the diagnosis is particularly useful in clarifying the diagnosis for women.

7. Continuity of carer is required if a trusting and responsive relationship is to be established.
8. Charts should be highlighted in some fashion[103] to indicate that this is a high risk pregnancy (in an emotional sense) to minimise the likelihood of insensitive encounters with staff unaware of the situation.

In addition to the care provided by members of the multidisciplinary team, additional supportive care was required by women, irrespective of the diagnosis. However, when concepts are ill defined (such as 'provide supportive care') researchers are held back in their endeavours as undefined concepts can hinder communication of findings (Miltner 2000, Avant 2004). Consequently, elements of the advanced midwife practitioner role (AMP) proposed as a mechanism to provide additional supportive care to women who are coping with challenges to their assumptive worlds are outlined.

[103] One woman suggested placing a sticker of a teardrop on the cover of the chart to indicate that the live birth of a healthy baby cannot be assumed.

9.5 Recommendations for an advanced midwife practitioner role

The psychological support required to assist women with meaning reconstruction following and adverse diagnosis can be provided by a skilled midwife through the establishment of a specific advanced practice role based on the following guidelines:

1. Responsiveness requires recognition of the event. This can be difficult to relay within the context of a busy fetal medicine clinic. Therefore, home visits from the midwife should provide the context whereby open appreciation the efforts women are making to cope with the loss of their assumptive world can be given.

2. Caring involves acceptance, open-mindedness and understanding. The AMP should use every opportunity to develop an understanding and respect for previously held beliefs in order to explore which assumptions have been violated by the event. Involvement of the AMP from the initial consultation stage with the fetal medicine team is advisable, as follow up can than be arranged irrespective of the pregnancy outcome.

3. Women require a safe place to talk, free from interruption, judgement and awkward silences. Home visits positively impact on the sense of benevolence, meaningfulness and self-worth, and consequently positively impact on the woman's ability to cope with the situation.

4. An understanding of the process of Recasting Hope is vital if developments in or blocks to adaptation are to be recognised, in order to ensure appropriate referral to other members of the multidisciplinary team can be arranged.

5. Reciprocity is essential to gaining meaning as women co-construct their story in order to accommodate the event or revise their assumptive world and practical information in relation to pregnancy issues will be required to foster the discovery of personal meaning and validate new identities. This also has an intensely practical

application, as mode of delivery, specific wishes regarding the birth, post-mortem or further genetic testing can be discussed and arranged in a non-emergency situation. This will also go some way to ensure that the woman has an advocate to liaise with the healthcare team at particularly stressful times i.e. pre-birth and during a planned delivery.

6. The AMP should also establish if a sustainable responsive relationship is available within the family or social circle, as silence is associated with poorer outcomes and care may need to be extended on that basis. This may be particularly relevant to women who chose to terminate the pregnancy.

7. The AMP would explore the effectiveness of the coping strategy used in relation to the potential threat, bearing in mind that the strategy may change over time but that some women will become overwhelmed by negative thoughts.

8. An exploration of issues such as hope and future-mindedness is vital. As hope is seamlessly interlaced with caring, and hopelessness and despair are risk factors for depression and suicide, the AMP must always remember to ask the woman how she feels she is coping. This would involve facilitating the process of downward comparisons through finding the best case scenario- as revising goals to that which are achievable opens the opportunity to finding the positives in the situation whilst taking cognisance of the coping strategy being used.

9. The AMP would support the woman to develop achievable goals-liaising with hospital staff may be required if practical arrangements are to be accommodated.

10. The AMP could advise supportive others to avoid speaking of future recovery/returning to normal- bearing in mind that the process of grieving is individual.

11. The AMP would remain vigilant for signs of adaptation such as reduction in somatic effects, negativity levels and development of future mindedness (often exhibited through considering another pregnancy), all the while developing strong links with the

multidisciplinary team, to ensure that referral to appropriate personnel can be made efficiently

13. The intensity of the event will guide the extent to which women need to talk so care can be planned appropriately. The AMP should be cognisant of any previous history of depression (not always revealed during the booking interview), reproductive difficulties and risk of recurrence as reconstructing the future may be intertwined with conceiving a pregnancy in the future.

Women have a great capacity to rebuild their lives in the face of this challenge; however, the presence of a responsive other (AMP) has the potential to positively impact on the process and to protect women where adjustment may become blocked or complicated.

9.6 Recommendations for midwifery education

Having knowledge of the fact that the anticipation of giving birth to a healthy baby is fundamental to understanding how women respond to fetal anomaly diagnosis is crucial for midwifery students caring for women during this time. The data have shown that self-identity is interrogated and re-formed through women's narrative construction of this life experience. The human psychological process of 'gaining meaning' entails active individual effort to think through and construct this experience through telling one's story, allowing for the interpretation of the event, of the actions of those directly (including the self) or remotely involved as well as seeking a cause for why this has happened. The findings from this study can contribute to midwifery education and preparation for practice in the following particular and general areas:

1. Methods of breaking bad news - understanding the variation in individual reactions to bad news and the relevant response required in the clinical setting

2. Through understanding the process of meaning reconstruction as a positive endeavour to recover from traumatic loss, midwifery students will be provided with an alternative perspective to the prevalent view of grief as pathology. This may in time assist in diverting the clinical focus away from the quantitative assessment of grief symptomatology (Neimeyer and Hogan 2001) towards fostering a model of narrative construction to support recovery.

3. Curriculum development should take cognisance of more recent discourse in the areas of (although not limited to) received theories of grief, loss and dying, and bonding in order to consider how individuals learn to attribute meaning to traumatic life events.

The process of meaning reconstruction is not limited to the area of prenatal diagnosis and may be applied to many aspects of the woman's birth experience in order to support midwifery students to provide responsive care in dynamic clinical settings.

9.7 Future research

This thesis has presented data on the process of adaptation following prenatal diagnosis, and has moved this experience into the area of traumatic loss and thanatology where gaining meaning is considered to be influential in the process of rebuilding the future. By implication researchers working to understand women's experiences have been challenged to reconsider this event beyond the well-intentioned but descriptive lists of emotional responses that frequently feature in literature in the substantive area. It is time for a radical shift in focus from exploring issues such as decision-making processes in relation to testing, pregnancy outcome, content-specific information to increase preparedness for an adverse outcome (which is of dubious value) in isolation from the process of making-meaning. One implication of these findings for clinicians is that women who are exhibiting intense distress and who are struggling to gain meaning shortly after the diagnosis appear to be at increased risk for a complicated process of recovery, and signs of hopelessness and despair correlate with negative psychological outcomes such as depression and suicidal ideation. Reciprocity within the context of a sustainable, responsive, supportive relationship facilitates individuals to process the meaning of the event and regain control as they organise their thoughts and feelings.

However, it is now critically important to develop and test both the framework and the strategies proposed to support the process of Recasting Hope. More specifically,

1. Intervention strategies for making meaning need to be subject to careful assessment
2. The acceptability of the midwife practitioner role warrants evaluation, as seeking help from other professionals such as the social worker or psychiatrist is seen as taboo, and reflective of an inability to cope
3. The impact of such a role on the midwife requires evaluation, and appropriate support structures should be in place from the outset
4. The appropriateness of the model to other areas of pregnancy/neonatal loss requires investigation

5. The effect of gender on the process and coping strategies used merit exploration

6. The potential to develop ongoing support for families caring for an infant with special needs within a making-meaning model should be considered

7. An exploration of the existence of a relationship between adaptation and the diagnosis, burden of care and child attachment based on a model of making-meaning is required.

9.8 Limitations

Although the project was conducted over a three-year period, this was of insufficient duration to follow-up some of the most recent participants for any meaningful length of time following the diagnosis/birth. Future research should consider increasing the length of time from the birth in order to explore the extent to which time and other life events (specifically success/failure to achieve another pregnancy and its outcome) impact on the process of Recasting Hope.

9.9 Dissemination

The process of disseminating the findings of this study to professionals working in the substantive area has begun. To date, data have been presented at four national and three international multidisciplinary conferences. Three manuscripts are in print in international peer reviewed journals, with several others in preparation for presentation or in the peer review process. In addition, three book chapters are under construction each with a particular focus and aimed at a wider audience: 1) choices for women with complex needs in Irish maternity care, 2) wellness in pregnancy complicated by fetal anomaly diagnosis and 3) the use of grounded theory methodology in sensitive research.

At a more local level, all participating women have been notified that the study is now complete and each (contactable) woman has been informed that the findings are available. Some women have requested information regarding the main findings and these have been communicated in various levels of detail based on individual requirements. The transcribers were also provided with a copy of the paper to which they contributed directly.

I continue to provide updates (and support if required) to the staff in the practice area regarding the care of women following fetal anomaly diagnosis and hope to progress a proposal to advance the development of the advanced midwife practitioner role within the integrated care pathway currently offered.

9.10 So where are they now?

Daire has moved house and has started a new job. She lives with her 4 year old son

Fay's baby has thrived post surgery, and she has returned to work

Eavan's baby has significant health care needs, she has returned to work but I don't know the extent to which she has managed to revise her assumptive world and engage meaningfully with the future

Emma's first twin died within 24 hours of birth and the second twin 16 weeks later. She has had two miscarriages since but remains positive

Maolíosa's baby is walking with little evidence of long-term problems, she has since given birth to a healthy son

Lori's baby has survived major cardiac surgery, and the guilt regarding termination of pregnancy remained

Shannon's baby was born with Down Syndrome and duodenal atresia, she died within the first week of life. She was keen to become pregnant again

Emer's baby had a complicated diaphragmatic repair, requiring revision. One year later she is trying to walk

Hayley's baby was transferred for cardiac surgery immediately after birth, she didn't survive to have the procedure

Alannah's baby was very well, a decision had not been made as to whether surgery to remove the kidney would be required when we last spoke

Trina's son had significant deformities to both feet, physiotherapy and manipulation seemed to be having little effect and repeated surgical procedures seemed likely

Cliona's daughter's lung disease seemed minimal postnatally and surgery seemed unlikely. She was discharged home with her mother

Keeley received treatment for postnatal depression without hospitalisation. Her daughter is not reaching her milestones but Keeley is coping well

Ciara's son was normally formed but weighed only 700g at birth. He grew rapidly and is at home and thriving

Aisling's son had no complications at birth. The hydronephrosis resolved spontaneously without treatment and he is thriving

Aoife recovered from her experience and has subsequently given birth to a beautiful baby daughter

Niamh's baby has had many major surgical procedures and is hospitalised three weeks out of every four. She continues to struggle with the burden of care as additional complications continue to emerge

Laoise's twins were both born alive, and her son with anencephaly lived for eight hours-she got her wish

Maeve's daughter has survived major cardiac surgery and renal failure. She is now on dialysis and awaiting a renal transplant. Maeve is coping well

Erin's baby was doing well. He required antibiotics initially and a decision regarding surgery had not been made when we last spoke

Fiona was receiving inpatient treatment for depression when we last spoke. Her baby is failing to achieve his milestones

Blannad's son was born with significant talipes. However, he subsequently had three acute life threatening events in the first six weeks of life. He is at home but is on an apnoea monitor 24hours a day. Blannad is struggling with a lack of support

Sian prayed for a miracle, and her son was born normally formed and without duodenal atresia. Her prayers were heard

Orla's twins were born alive, and she spent four hours with her son before he died

Molly has mourned her loss but continues to maintain bonds with the son she left in England. She has since given birth to a healthy baby boy

Tara has given birth to a healthy baby boy

Kerrie has given birth to another son in traumatic circumstances (she collapsed with a pulmonary embolus at 34 weeks) and is unlikely to become pregnant again

Caitlin was struggling with her grief and due to meet with the geneticist when we last spoke. I don't know if she has conceived since

Doireann is now 38 weeks pregnant, and all seems well

Muireann conceived spontaneously and has given birth to a healthy baby

Ava conceived within six months of her daughter's death. She required a lot of emotional support in the pregnancy up to 20 weeks, but has since given birth to a healthy baby boy

Breffni and I spoke two weeks after the birth. She gave birth in an ambulance on the way to the regional centre and her baby died on the way. She could not be contacted for her postnatal interview

Kasey's son died within minutes of the birth. She has a record of his movements on video which is very precious. She is now 30 weeks pregnant and all seems well

Regan has still not become pregnant and continues to struggle with the uncertainty around conceiving a normal child

Heather had a caesarean section at her own request in the tertiary centre and her daughter was born alive and baptised. She has since given birth to a healthy baby girl

Bethan does not appear to have conceived again, and I have not spoken to her since she returned from the UK

Áine is now 28 weeks pregnant and has just had a reassuring fetal anomaly scan

Laura has attended for fertility treatment and is trying actively to conceive.

JGL, February 2007.

9.11 A journey into the unknown: a narrative construction of my identity as a researcher

This section has been prompted by discussions with friends and professional colleagues in education, practice and research keen to understand the impact of the journey on me personally and the consequences it may have for other researchers. Although I am seldom stuck for words, it is somehow challenging to provide a 'narrative construction' of my experience of conducting this study in a way that may benefit others choosing to explore sensitive and complex areas of human experience. Conducting this study consumed a large part of my life over a three year period and consequently it forms part of my life story. If you believe that all knowledge is self-referential, then it follows that my direct and indirect interactions with the women and the data would have a personal impact; however, this has occurred across time and space. It seems trite to say I am not now who I was then, - but for me this is ontologically true, as the eyes I saw through at the outset are not the eyes I see through now. When I began this study, as a midwife, I was concerned primarily with the lack of acknowledgement that women receive of the personal impact of the diagnosis and consequently my aim was to develop a more responsive model of care for use in the clinical setting. As a researcher, I was laden down with the shackles of positivism and the assumptions that are advanced in relation to what constitutes evidence, proof and truth. Although this may seem to be a theoretical concern, potentially rectifiable through scholarly contemplation, I feel it is important for others to appreciate what I have learned, that is that theoretical perspective is not restricted to an ethereal world of philosophical debate for those in the higher echelons of the academy but rather has practical implications for the conduct of the study and consequently for and the wellbeing for all involved in the research process. As I seemed to be fighting a meaningless battle with philosophical writings on epistemology and ontology I wish I had known then why this struggle is worthwhile. Unpacking how we truly value the participants (and the personal cost of their contribution) in the studies we undertake is essential to understanding how as researchers we seek to construct and valorise knowledge. If I had been more comprehensively versed in epistemological discourse earlier in the process I may not have experienced some of the dilemmas I encountered in the field. I spent a lot of

time worrying about how I could protect the women during their participation and yet conduct a rigourous inquiry. I choose to place methodological concerns secondary to the wellbeing of women; however, had I chosen the alternative I may have had a negative impact on women's reconstruction of meaning. Direct, focussed, semi-structured styled interviews are unlikely to have created a space where women could create a sense of meaning out of this experience through telling their story, as the circumstances would not have existed whereby meaning could be tested, transformed and perhaps renewed. Understanding the theoretical assumptions of social constructionism and constructivism would have unburdened me of these worries and I may have been reassured earlier as to the legitimacy of my approach. Instead I received affirmation through the data obtained from the other members of the research team i.e. the transcribers and supervisor, as they described how a sense of vicarious responsibility can develop when reciprocity is absent from the relationship between the researcher and participant,- data I might not have collected had I rigidly adhered to the original research proposal. As I have stated throughout this thesis, it is this reciprocal relationship that provided women with an opportunity to 'open up'. However, this inevitably meant that I would be touched by their experiences. And if I was to protect myself from becoming overwhelmed by the 'unfairness of life' I had to develop strategies in order to continue to remain immersed in the data. I found that the time I spent driving home from interviews provided me with a space to work through my emotional responses to what I had just heard. It was a place where I could think aloud, cry aloud, and scream aloud if necessary. I could recapitulate on particular words or expressions as I tried to come to terms with the physical and socio-political betrayals and silences that these women were experiencing. I revised my own assumptions about the world and how and who I am within it. I also continued to attend weekly meetings (perinatal case conferences) in the clinical site, as these helped me to develop a sense of attachment to something other than this study and to become involved in other research projects. Being a member of a research team was necessarily diverting and consequently supportive through providing human contact with colleagues. This was particularly useful when the study was reaching completion, my relationship with the women was ending and I faced into the potentially solitary phase of writing up the thesis. It was at this point that I began to attend the research seminars for postgraduate students within the school, reminding me that as a doctoral student although we each have an individual journey to make, we are not necessarily alone on the road.

Discovery of the concept of the assumptive world has irrevocably changed my perspective on traumatic loss and the function of making meaning in recovery. It has also helped me to understand my own responses to women's stories, in particular my reaction to hearing negative encounters with caregivers. I can now utilise what I have learnt in my own life in terms of attributing value and meaning to self-experience. Although your research journey will be particular to you, I hope my experience will provoke some thought on how you may create a supportive network to carry you through as the rewards are immeasurable.

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Appendix 1: Aggregate scores for EPDS

Table 3: Aggregate Scores for EPDS.

EPDS	*N*	*Range*	*Mean*	SD
Time 1	27	1-24	12	5.6
Time 2	19	1-25	12	6.87
Time 3 (all participants)	29	1-27	9.66	5.8
Time 3 (continue only)	21	1-27	9.43	6.41
Time 3 (terminate only)	8	4-16	10.25	4

Table 4: Comparison of EPDS scores for paired samples of continuers

EPDS	*N*	*Paired t*	*df*	P value (2-tailed)
Time 1 with Time 2	15	0.379	14	0.710
Time 2 with Time 3	18	3.267	17	0.005
Time 1 with Time 3	22	2.328	21	0.030

Table 5: Comparison of EPDS scores at time 3

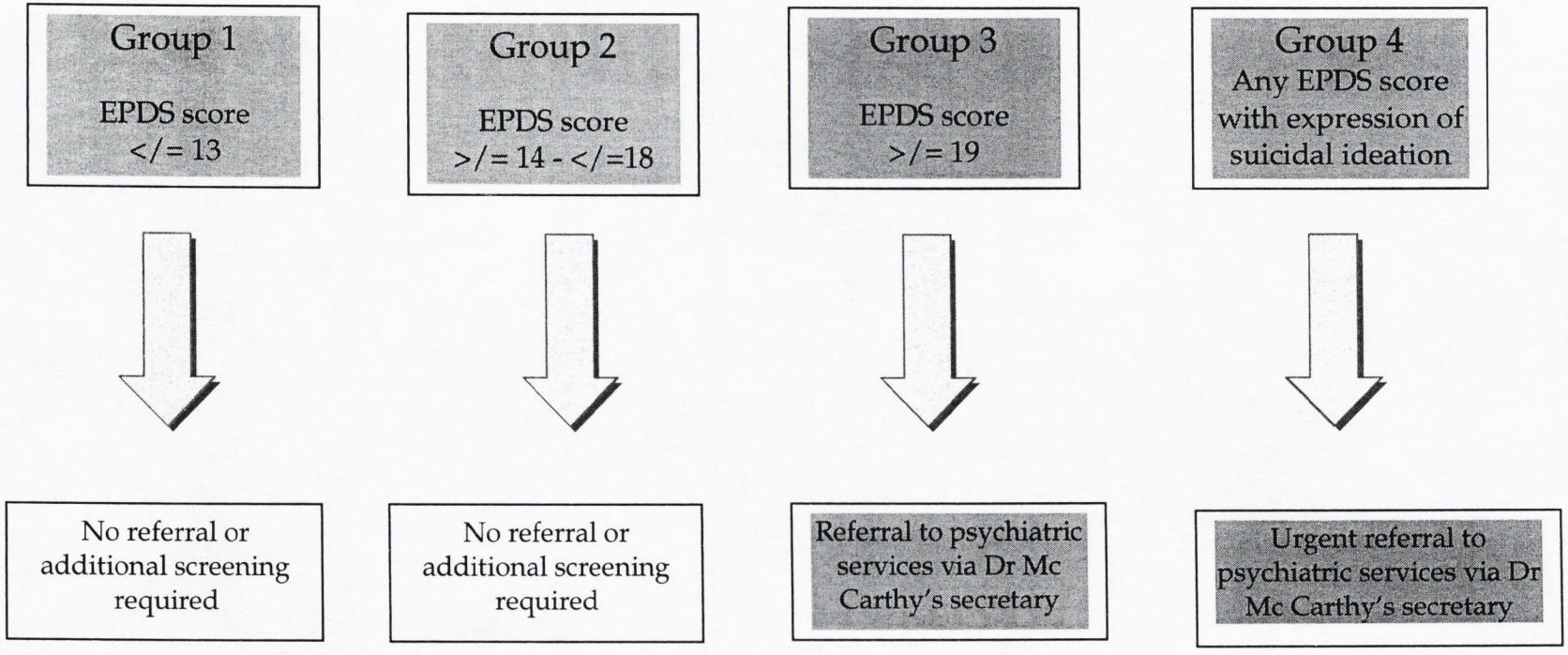
EPDS	*N*	*Mean*	*Independent Samples t*	*df*	P value (2-tailed)
Continued the pregnancy	24	9.04	0.493	30	0.625
Terminated the pregnancy	8	10.25			

Appendix 2: Integrated care pathway to psychiatry

A LONGITUDINAL STUDY OF WOMEN'S EXPERIENCES OF CARRYING A BABY WITH A FETAL ABNORMALITY UP TO AND BEYOND THE BIRTH.

INTEGRATED CARE PATHWAY FOR WOMEN TAKING PART BASED ON EDINBURGH POSTNATAL DEPRESSION SCORES.

All women are offered the opportunity to explore issues with a counsellor at the end of the interview, irrespective of EPDS Scores.



Cut off score used 12/13 based on authors recommendations (Cox, J., Holden,J. (2003) Perinatal Mental Health: A guide to the EPDS. RCOG).

Appendix 3: Exploring painful experiences

METHODOLOGICAL ISSUES IN NURSING RESEARCH

Exploring painful experiences: impact of emotional narratives on members of a qualitative research team

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Exploring painful experiences: impact of emotional narratives on members of a qualitative research team

Aim. This paper reports a study of the impact of emotional narratives on the well-being of members of a qualitative research team during the conduct of sensitive research.

Background. Qualitative data are frequently collected from participants using repeated in-depth interviews when exploring sensitive issues such as loss and grief. The research process can evoke highly emotional responses in the participant and others involved in the study. While consideration has been given to the impact of the research process on participants when a highly affective component is involved, relatively little attention has been given to research team members' experiences.

Method. Through analysis of fieldwork records from a grounded theory study of the experiences of women who were carrying a baby with a foetal abnormality, we discuss the affective issues arising in conducting sensitive research. Data sources included two reflexive journals, written comments from two transcribers and the transcript of an interview with the research supervisor.

Findings. The core category of 'Connecting with the data' emerged, to which each substantive category relates. Three substantive categories – 'bearing to watch,' 'bearing to listen' and 'bearing to support' – emerged as independent but inter-related aspects of the research process as experienced by the researcher, transcribers and supervisor. Methods of protecting the research team and the integrity of the study when the substantive issue is highly emotive are discussed.

Conclusion. The emotional impact of research on participants is normally considered prior to the conduct of any sensitive research, and efforts are made to protect them. The potential for researchers, transcribers and supervisors to be harmed should also be carefully considered when planning a project with significant affective elements.

Keywords: grief, interviews, midwifery research, nursing research, research supervision, sensitive research, transcriber

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Introduction

Nursing and midwifery research from a social perspective seeks to explore the feelings, values and reactions to life-changing events of those experiencing the phenomenon. This often involves the inclusion of vulnerable groups who are best placed to provide information on their experiences (Pinyerd 1990). Vulnerable groups include, but are not limited to, foetuses, pregnant women, children, the dying and older adults (Weaver Moore & Miller 1999, p. 1035), and consideration of their well-being during the research process has received considerable attention (Silva 1995, Kellehear 1996, Grisso & Applebaum 1998, Rowling 1999, Seymour & Ingleton 1999, Weaver Moore & Miller 1999, Rosenblatt 2001).

Shifts in the philosophy of science have seen a paradigm-move from a positivistic perception of research participants as providers of interesting data or 'subjects' to be studied to seeing them as active participants in the research process (Denzin & Lincoln 2005a). Although researchers consider a number of epistemological and methodological issues during the planning and conduct of their research, dilemmas that occur during fieldwork are often unpredictable (Wolf 1996, Rowling 1999, Seymour & Ingleton 1999), and the intensely practical matter of how researchers deal with situations in the field that arise as a result of exploring sensitive issues receives relatively little attention. Researchers are now challenged to be more explicit in writing about the effects of self in the research process (Oakley 1981, Wolf 1996, Richardson 1997, Sword 1999b, Denzin & Lincoln 2005b, Ellingson 2006, Rolfe 2006).

In order to explore the experiences of women carrying a baby with a foetal abnormality up to the birth and beyond, a study was designed using a grounded theory approach. This required that a sense of reciprocity be developed between participants and researcher, leading to a relationship between them that modified power imbalances (Mills *et al.* 2006) and led to a theory grounded in the participants' and researcher's experiences. Therefore, in preparation for fieldwork, the practicalities involved in developing a reciprocal and equitable relationship were explored in the literature. These included in-depth interview technique, developing rapport with participants, maintaining an egalitarian approach, ensuring the principles of mutual respect, non-coercion and support for participants, and safety of the interviewer. Some authors described the emotional responses they experienced in the field (Cowles 1988, Dunn 1991, Rowling 1999, Sword 1999b) as a result of the relationship developed with their participants. However, after more than a decade of postpositivistic qualitative inquiry (Denzin & Lincoln 2005a), consideration of the situatedness of the researcher in the process remains largely absent from qualitative health research reports (Ellingson 2006). This tendency to avoid any discussion of the emotional impact the research process may have on researcher(s) continues (Wolf 1996, Young & Lee 1996), despite acknowledgement that such research may cause emotional pain or trauma to those involved (Rowling 1999, Eaves 2001, Gilbert 2001, Mc Cosker *et al.* 2001, Johnson & Clarke 2003, Beale *et al.* 2004).

The blurring of boundaries between being a healthcare professional and researcher have been described (Hoddinett & Pill 1997, Rowling 1999, Sword 1999a, Johnson & Clarke 2003, Rager 2005), where tensions between remaining in a researcher role and the desire to take on a helper role are common. Other authors have identified the impact of caring and uncaring encounters across a range of care situations (Halldorsdottir & Karlsdottir 1996a,b, Halldorsdottir & Hamrin 1997, Maijala *et al.* 2003, Lalor *et al.* in press). Their findings emphasize the often devastating effects of uncaring encounters on the recipient of healthcare, and corresponding difficulties can arise for researchers (or clinicians) in deciding how to respond.

Wolf (1996) suggests that the dilemmas confronting researchers in the field – what she refers to as *secrets* – often remain hidden, as their disclosure would make us vulnerable. In the study reported here, establishing a collaborative, non-exploitative approach within a constructivist paradigm created many dilemmas for the researcher and, somewhat unexpectedly, for those members of the research team who were more distantly connected, but nonetheless involved. It is hoped that sharing the *secrets* of fieldwork associated with this project may assist others in the preparation of future studies in this area.

The study

Aim

The aim of the study was to consider the impact of emotional narratives on the well-being of members of a qualitative research team during the conduct of sensitive research in healthcare.

Methodology

Fieldwork discussed in this paper was conducted during a grounded theory study of women's experiences of carrying a baby with a foetal abnormality (Lalor & Begley 2006). The 38 women who participated in the study received an unexpected diagnosis of foetal abnormality following an

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antenatal ultrasound scan, with varying possible prognoses for their babies ranging from treatable, mental and/or physical deficit to risk of, or certain, mortality. Fieldwork consisted of repeated in-depth interviews in women's homes over 18 months (2004–2005) and the chosen constructivist approach necessitated the development of an equitable, interactive relationship with all participants (Charmaz 2000a,b, 2006).

Grounded theory is an interpretive methodology that can be used to generate research-based knowledge of behavioural patterns from any form of data (Glaser 2001). The method requires extensive memoing to compare multiple indicators or properties of concepts in order to conceptualize emergent theoretical frameworks (Glaser 2005). All interviews were transcribed by two secretaries, selected for their maturity and understanding of the need for confidentiality. The research proposal had acknowledged the possible impact of the data on the transcribers, and so regular 'check in's' between the researcher and transcribers, by phone or email, were established. It was during the process of data analysis and sorting of memos that the impact of the data and data collection on the researcher (JGL) and transcribers began to emerge. Ethical issues and decisions taken in the field were recorded in a journal and, although separate from analysis of transcripts, were important in profiling the interconnectedness that existed in the research relationship with the participant(s). Individual journal entries referred directly to issues associated with the affective component of an episode of data collection or the subsequent impact it had on the researcher. The two transcribers were contacted and asked, if they were willing, to document their views of how transcribing the interviews had affected them.

The effect that reading the transcripts and de-briefing the researcher following traumatic interviews had on the supervisor, a midwife-researcher and academic (CB), only came to light in chance conversation near the end of the study period. The supervisor had a number of years' experience of doctoral supervision, sufficient not to have qualms about the practical aspects of research supervision. However, she was, at the time of supervising this project, also involved in three other qualitative studies of sensitive issues (breaking bad news, euthanasia, and expertise in palliative care nursing), and kept a reflexive journal throughout the conduct of all studies as a means both of auditing the progress of data analysis and self de-briefing. In discussions, it was apparent that a pattern of the wider research team also being affected by the content of the transcriptions and the methodological questions that arose was emerging. A decision was taken to study the journal entries from the researcher and supervisor, and written communication from the transcribers, to ascertain if there were any common themes. In addition, the supervisor was interviewed by a researcher not involved in the present study (DD), to ascertain her views of reactions to study data that had not been recorded at the time.

Ethical considerations

Approval for the main study was obtained from the appropriate committees at the study site and university. The researcher and supervisor agreed to share their journal data and were willing to have excerpts published. The supervisor also consented to be interviewed. The two transcribers had the analysis process explained to them and both gave written consent for their contributions to be analysed and used in this paper.

Data analysis

The constant comparative method of analysis (Glaser 1978) was applied to data from the two journals, to transcribed data from the interview with the supervisor, and to the transcribers' written feedback in order to make sense of the affective component. In the following presentation of findings, brackets are used to indicate additions made to clarify meaning.

Findings

Connecting with the data

The core category of 'Connecting with the data' emerged, with three substantive categories – 'bearing to watch', 'bearing to listen' and 'bearing to support' – identified as independent but inter-related aspects of the research process experienced by members of the research team (Figure 1). The researcher's concern for balancing protection of participants with ensuring methodological rigour led to the emergence of the first substantive category: 'bearing to watch'. The effect on the transcribers of hearing the women's voices as they transcribed is represented by the category 'bearing to listen', and the impact on the supervisor of reading transcripts and the continuing dialogue with the researcher concerning these issues gave rise to the category 'bearing to support'. The overarching theory explicated through 'connecting with the data' provided a framework within which the affective responses of the whole research team are expressed.

Bearing to watch: researcher issues

The participants often displayed overwhelming emotion in telling their experiences. For the researcher this involved, on occasion, significant emotional distress revealed in crying

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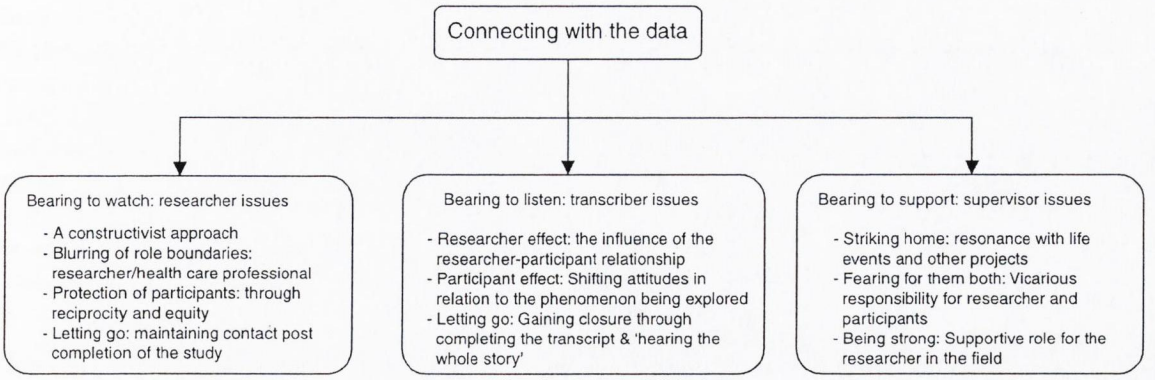

Figure 1 Connecting with the data.

after an episode of fieldwork, as emotions had been contained during the interview. This outpouring of emotion was a way of reacting to a human, humbling and heart-wrenching experience, yet containing it until one had exited from the field served to prevent it from becoming entangled in the researcher's work. Within the category 'bearing to watch', three main properties of 'role boundaries', 'protection of participants' and 'letting go' emerged.

Role boundaries

One of the first issues encountered by the researcher was in relation to difficulties associated with maintaining role boundaries, i.e. being a researcher and a healthcare professional without responsibility for providing direct care to participants:

> I'm not sure how close to get. I know my professional experience is encouraging women to talk as they don't have to explain the context. So how close do I get? How do I care for them? (Journal entry, JGL, April 2004)

Maintaining a stance of detached objectiveness during the interview was unlikely to contribute to building a rapport with the participants, facilitate the sharing of deeply personal issues or even be possible on a human level. Caring for the participants as a researcher resulted in what was first perceived as a cautious extension of the researcher's role from 'pure' research to seeking and accessing written information from the primary caregivers (e.g. prescriptions, hospital appointments, etc.) on behalf of participants. This led to uneasy tension in the role of the researcher and the effect that this role might have on the validity of the research:

> She is distraught at the uncertain prognosis and is having difficulty getting information [from clinicians]. Her questions are basic, and I can answer them, but should I? (Journal Entry, JGL, April 2004)

> Can I be human and still be a researcher? I gave so much information, could it have had an effect on the data? (Journal Entry, JGL, October 2004)

Being accepted by participants as a researcher involved developing trust, and the reciprocal nature of the relationship was fulfilled through giving information rather than sharing everyday aspects of personal life. The decision to provide information was legitimized in two ways; ethically, in order to do good, and methodologically through giving the information at the end of the interview so as not to have an impact on participants' experience of the situation whilst feeling ill-informed.

The following entry relates to a participant's difficulty negotiating access to information and test results, and is given to illustrate the ongoing ambiguity and tension that accompanies trying to maintain realistic research role boundaries:

> She has been given incorrect information and decided on a postmortem as a result. She can't visit her baby now [in the graveyard] as she feels she has let him down. Her distress is visible and palpable; her sobs came from the core of her being. Her grieving is being strangled by this block and there are times I feel my own heart is being squeezed too, in particular, in trying to determine the boundaries or remit of my role as a researcher, midwife, information source and not a member of her health care team as her destruction is like a horror movie being played in real-time before my eyes (Journal Entry, JGL, July 2005)

Protection of participants

The second problem encountered was in relation to participants expressing suicidal ideation. Due to the nature of the research, this possibility had been addressed by the research ethics committee and study design; however, the impact on the researcher was not considered meaningfully. In one interview, a woman who had been informed 10 weeks earlier

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that her baby had a serious anomaly with likely mental and physical disability was becoming increasingly concerned for her baby's wellbeing *in utero* and about how she would cope after the birth. She began to believe that the best option for her husband and children was for her to take her own life whilst pregnant so that they might, from her perspective, live their lives without hindrance by her and her unborn child. During the interview, she described how she planned to end her life, and the pre-established mechanism of referral for psychiatric care was enacted:

I know we [researcher and psychiatrist] talked this through but I can't believe its happening. What if he [husband] goes out and leaves her? Should I have taken her with me? I know he [the psychiatrist] said I did the right thing but I won't rest until I hear she made it safely to hospital for assessment. (Journal Entry, JGL, August 2004)

This encounter resulted in marked anxiety for the researcher until confirmation was received that the woman was safely treated in hospital.

Letting go

The third area of difficulty, which stemmed from the researcher becoming part of the participant's world, was in relation to '*letting go*' when a woman's participation in the study was complete. The following memo was written after a final interview with a woman whose participation had begun 9 months earlier:

I felt such anxiety leaving, tachycardia, a rash, the works. She told me she had 'celebrity' status when in hospital and now there is no attention. I felt I was abandoning her like the others, even though she described our meeting as closure. I felt she was looking for some kind of continued contact. (Journal Entry, JGL, August 2004)

This woman, and others, continue to keep in contact through phoning or texting the study phone number, providing updates on their infants' progress or requesting information and support for prenatal screening issues in a subsequent pregnancy. This continued contact has provided valuable insights into the development of a midwifery support role designed specifically to meet these women's needs.

Bearing to listen: transcriber issues

Transcription for the study was contracted out to a company experienced in transcribing sensitive health-related interview data. It had been identified at the proposal stage that the data transcribers might be affected by transcribing such heart-rending stories of distress. Therefore, regular contact between the researcher and transcribers was established, consisting of planning deadlines for transcription, forewarning of particularly distressing interviews, and ensuring that the opportunity to talk about issues that might emerge was available. Transcription was predominantly provided by one woman with another covering leave. It was not until several months into data collection that the transcribers were formally asked, as part of the process of ensuring their wellbeing, to identify the effects (if any) on them of working on the project. It was in this way that the substantive code of 'bearing to listen', with three main properties of 'researcher effect', 'participant effect' and 'letting go' emerged.

Researcher effect

Researcher effect refers directly to the transcriber's perception of the researcher's relationship with the participant during the interview and its consequent effect on the transcriber while listening to the recording:

[When the interview] is handled so well by [the interviewer] and in such a sensitive manner that also helps the person typing it up, as there is real empathy and concern. Often the interviewer [in other studies] can be cold towards the participant and just ask questions without showing any emotion or concern. That is more difficult because it leaves you then feeling sorry/worried for the person. (Transcriber 2, November 2004)

Such comments highlight that transcribers, in addition to other members of the research team, may experience feelings of vicarious responsibility for participants' well-being.

Participant effect

The principal transcriber identified several issues that had emerged for her as a result of the project, and acknowledged that she had some attitude change as a result of hearing participants' stories and gaining an insight into experiences she has never had:

Me personally, I feel it's more of a privilege to hear people's stories [than distressing] – that might sound like a strange privilege. (Transcriber 1, November 2004)

While I find the situations that people are in quite upsetting and they often would bring me to tears as I am listening, they do on the other hand give me great respect for people who have to go through these very difficult times. I have become much less judgemental of people and the decisions they make, as I now realise that you just never know what is behind those decisions. That has been quite an attitude shift...and I admire the strength of the people involved. (Transcriber 1, February 2005)

Acknowledgement of this attitude shift serves to demonstrate the extent to which the transcriber may engage with the data, and how that individual engagement may precipitate emotions or a life-changing event. Because of this, the principal

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transcriber would alter the location, use of headphones and time of day for transcription to avoid any collateral damage to others. When work was allocated to others in her office, she considered carefully not only to whom she would delegate transcription of interview data, but also their preparation:

I would be very careful and selective in choosing someone else to help me. I would only consider a more mature person and would always check before I give them any of my work, regardless of the topic, as I don't know their background and I wouldn't assume that an issue wouldn't affect them. I appreciate it when I am forewarned by the project manager that the content could be disturbing or upsetting. (Transcriber 1, January 2005)

This transcriber also described the deep emotional impact the data had on her, and how she coped with her responses by spending more time with her family and realising the 'fragility of life':

It makes me aware of how lucky I am and my family have been. It also makes me appreciate my own children and would make me take the extra time to just show them how much I appreciate them and thank God for my good fortune. (Transcriber 1, February 2005)

Letting go

'Letting go' also emerged as an issue for the transcribers, who appreciated being able to complete the task of transcribing all interviews and thus to hear 'how the story ended':

Since the interviews are held on three occasions, ending with the final outcome of the whole experience, it helps to put closure to the issue. At first the story is very harrowing and disturbing, then it can improve or not on the second interview. But no matter what the outcome is, at least you get closure on it in the final interview.

It was a very sad case and I could actually feel the woman's pain when I was doing the transcription. She had suffered terrible sadness, which was made worse by mistakes made by hospital personnel...I did not do the follow-on transcription, but would like to have known how things turned out for this woman. She seemed to be so brave, and I would like to imagine she coped quite well. (Transcriber 2, January 2005)

These data highlight the importance of the relationship between interviewer and interviewee and demonstrate that showing empathy to the participant has the secondary effect of ameliorating the experience of hearing a traumatic experience for the transcriber, allowing the latter to 'let go' of any feeling of responsibility for the participant. It is important to recognize that transcribers also need to let go, and to recognize that providing continuity of transcripts in a longitudinal study is a strategy that can support that process.

Bearing to support: supervisor issues

The affective components of this research involved significant emotional distress for the researcher. Although this was seldom displayed to the supervisor, she asked on every supervisory occasion in the early stages how the researcher was coping with the undeniably emotional experience of the participants' grief. Counselling services were in place to support the researcher if needed, and the supervisor made reference to these occasionally. While knowing that the process of interviewing would undoubtedly take its toll, the supervisor was powerless to assist, beyond putting the above supports in place, and her role consisted mainly of watching and waiting and being there for support as needed. There was thus a continued low-level anxiety once data collection commenced. The substantive code of 'bearing to support', with three main properties of 'striking home', 'fearing for them both' and 'being strong' emerged from the supervisor's data.

Striking home

Reading transcripts was in itself an emotional experience for the supervisor, although not as traumatic in this study as it had been in a previous one involving interviews with terminally ill patients (Connaire 2004). Nonetheless, some excerpts were upsetting:

Some of these stories are heart-rending. I just keep remembering my own miscarriage 21 years ago – you'd think it should have been forgotten about by now. Just shows, you never forget. (Journal Entry, CB, June 2004)

In particular, reading examples of poor care given to grief-stricken women without the opportunity for reciprocity was distressing:

JL felt that reciprocity...made it easier for her as she could give something back to the women. From the supervisor's point of view, I was reading the same transcripts and they would visibly bring to my mind what the interview was like, how the women had felt and what it had been like for them...And I didn't have the option of reciprocity...I had no way that I could do anything to help those women...or to redress the situation if I felt they hadn't received good care...and that's quite a weight on you [supervisor]...It's that helpless feeling when you want to help another human being and you can't. (Interview with CB, March 2006)

Fearing for them both

The constant background anxiety about possible suicidal ideation in participants flared up when that became a reality for one woman:

When I heard about the incident [woman expressing suicidal ideation] I was very worried about the woman, as [JL] was, but I

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was also worried for [her] because it did have an effect on her. (Interview with CB, March 2006)

Oh, it's the guilt...because you are totally responsible even though the student feels it's their study. The buck still stops with you. (Interview with CB, March 2006).

Being strong

As the study progressed, the volume of data increased and the supervisor's attention was focussed on the pressure that was building up for the researcher. The personal effects on the supervisor of reading the data and shouldering the anxiety about the safety of women in the study and the researcher's own safety had to be side-lined in order to concentrate on trying to help the researcher maintain equilibrium:

This is so hard. I'm still down after X's study [interviewing terminally ill patients] and all my own stuff [personal bereavements]. I've got to be strong to keep her strong. (Journal Entry, CB, August 2004)

You feel you can't share your feelings of the [impact of the] data with the student as you would with a research collaborator if the student is coming to you overwhelmed with the data or distressed by something that has happened...you have to be the calm, strong one. (Interview with CB, March 2006)

As the journal and interview excerpts suggest, the issues for supervisors are perhaps less obvious than to other member of the research team. Their distance from the field and sense of responsibility to care for the participants and researcher are unique to the supervisor role. This invisibility may result in supervisors finding a personal strategy to protect themselves through experiential learning, with many of these valuable lessons remaining particular to the individual involved.

Discussion

The limitations of this study include its small, local nature. It was based solely on the experiences of one research team and was designed to highlight the emotional needs of team members, identify a theory of affective responses in sensitive research and provoke wider discussion on the topic. The core category 'connecting with the data' illustrates the impact of emotional narratives on the well-being of members of the broader research team during the conduct of sensitive research. Although this process is not intended to be generalizable, it is hoped that in making the *secrets* of this project explicit we have contributed to the discourse on dilemmas that can develop during fieldwork in studies exploring sensitive issues, and outlined a theory of affective responses involved. However, the possibility that research team members have affective experiences when dealing with quantitative data also requires exploration. Although the ethical implications for the researcher and participants cannot always be foreseen (Seymour & Ingleton 1999), it remains the responsibility of researchers to ensure that their study is ethically rigorous. Therefore, consideration of the situatedness of the person/research team in the process may add further concepts for researchers to consider when embarking on future projects. Our framework may be modifiable by the experiences of other research teams, perhaps increasing its application across disciplines and to other areas of inquiry.

As a midwife in a research role, the researcher had to develop skills to monitor the possible entanglement of the women's suffering in her own life and control her own emotions during the resurgence of women's feelings while retelling their stories. It has been suggested that 'personal involvement is more than dangerous bias – it is the condition under which people come to know each other and to admit others into their lives' (Oakley 1981, p. 58) and that some participants can derive 'therapeutic benefit' (Coyle & Wright 1996, p. 434) from being interviewed.

Cook and Bosley (1995) have suggested that one mechanism for addressing the impact of the emotionality of research is to schedule time in between interviews. This was not possible in our study as data collection had to take account of the condition of the pregnancy, which could change with little warning. Instead, the researcher chose to reciprocate within the interview by responding to women's needs for additional information about the foetal condition and offering women the option of contacting her between interviews if they felt that such contact would be helpful. Building equitable relationships was key to exploring the substantive issue in this study, and ensuring ongoing participation in repeated interviews, and detachment seemed to be the antithesis of maintaining the responsibility to protect participants (Parkes 1995). The dilemma of defining role boundaries for the researcher is dominant in this study, and was similar to Rowling's (1999) account of experiencing role conflict in the field and other work on clinicians as researchers and the requirement to intervene (Hoddinett & Pill 1997). We agree with Rosenblatt (1995) that the needs of the participant supersede those of the research. Yet, in spite of the prolific discourse regarding subjectivity in qualitative inquiry, the emotional impact on the research team and practical concerns of researchers in the field (Mc Cosker *et al.* 2001) remain largely invisible in research publications (Young & Lee 1996, p. 97). It is conceivable that such invisibility may, in part, be due to the sceptical attitude of

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What is already known about this topic

- Emotional effects can occur for researchers undertaking fieldwork and other members of the research team.
- The blurring of boundaries between being a healthcare professional and researcher have been described, where the desire to take on a helper role is not uncommon.

What this paper adds

- An objectivist approach to interviewing is not appropriate when exploring issues of a sensitive nature.
- Painful narratives can cause research team members to experience emotional reactions resulting from their interaction with sensitive data.
- Researchers, transcribers and supervisors can be protected by the use of formal support structures that focus on the provision of emotional support.

some towards the qualitative paradigm (Tobin & Begley 2004).

Recommendations for the conduct of ethical research are inclined to focus on the emotional support the researcher should provide for participants (Parkes 1995). Although researcher reactions to participants and data have been acknowledged (Beale *et al.* 2004), information on the reactions of others in the research team is sparse. Gilbert (2001, 2002), in her study of couples coping with infant or foetal loss, describes her experience of including undergraduate students to type interview transcripts, and how preparation involved advising them that they might read some upsetting accounts. It was not until there appeared to be errors in transcription and difficulty in meeting deadlines that she discovered that the student research assistants had emotional responses to the data. Additional issues emerged in our study in relation to transcribers' interaction with the data. In addition to becoming upset when transcribing interviews, the transcribers described having a sense of vicarious responsibility when transcribing data from other studies through worrying about participants when the researcher adhered to the traditional/objectivist principles of interviewing, i.e. remaining detached, generating sufficient rapport to obtain data, remaining neutral (Oakley 1981). This re-enforces the appropriateness of a constructivist approach and the inappropriateness of an objectivist approach when exploring sensitive issues. Our transcribers also spoke of their own need to gain closure, and completing and sending the transcript was viewed as one potential strategy. However, when participants are being interviewed repeatedly, getting to hear the whole story, regardless of the outcome was of additional benefit in the process of 'letting go'.

As previously identified (Rowling 1999), we also encountered a number of challenges including closeness to participants, self-awareness and development of emotional connections. This raises the question of who should conduct sensitive research when the likelihood of personal connection with participants is very real. In our study, as with others (Johnson & Clarke 2003), field experience has shown that one strategy to minimize harm to the researcher is through reciprocity with participants through providing information relevant to their current clinical needs. However, this strategy is not available to other members of the research team, such as the supervisor, and perhaps more formal support structures such as supervisor 'buddies' need consideration. We support Weaver Moore and Miller's (1999) position that the inclusion of vulnerable participants in research is essential to ensure that the concerns and needs of these individuals are appropriately represented. The support needs of all involved in sensitive research necessitate deliberation and the area of protection of researchers, transcribers and supervisors and their interaction with data requires development.

Conclusion

Qualitative researchers have been criticized for presenting their findings as a 'hero's odyssey' (Thorne & Darbyshire 2005, p. 1109) and we hope that, by stripping down the affective component of the process without denying the interconnectedness that can develop between research participants and researchers, this paper will increase the belief that qualitative health research can produce credible evidence. We would argue that increased transparency within a qualitative paradigm is essential, and debate on how researchers can demonstrate integrity and creativity in exploring their research questions is required. Researchers should be aware of the emotive effects of sensitive qualitative research on all involved in the research process. Self-care strategies (Rager 2005) such as diary-keeping, liaising with transcribers through actively seeking to understand their interactions with the data, providing continuity in transcription, and asking participants to describe their experiences of taking part, may assist in protecting the emotional safety of all involved. Further research is recommended into the affective experiences of research team members when dealing with both qualitative and quantitative data. We hope that lessons can be learned from our experience to support other research teams in the future.

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Author contributions

JL was responsible for the study conception and design, data analysis and drafting of the manuscript. JL, DD and CB collected the data and made critical revisions to the manuscript. CB provided supervision.

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Appendix 4: Process of data collection and analysis

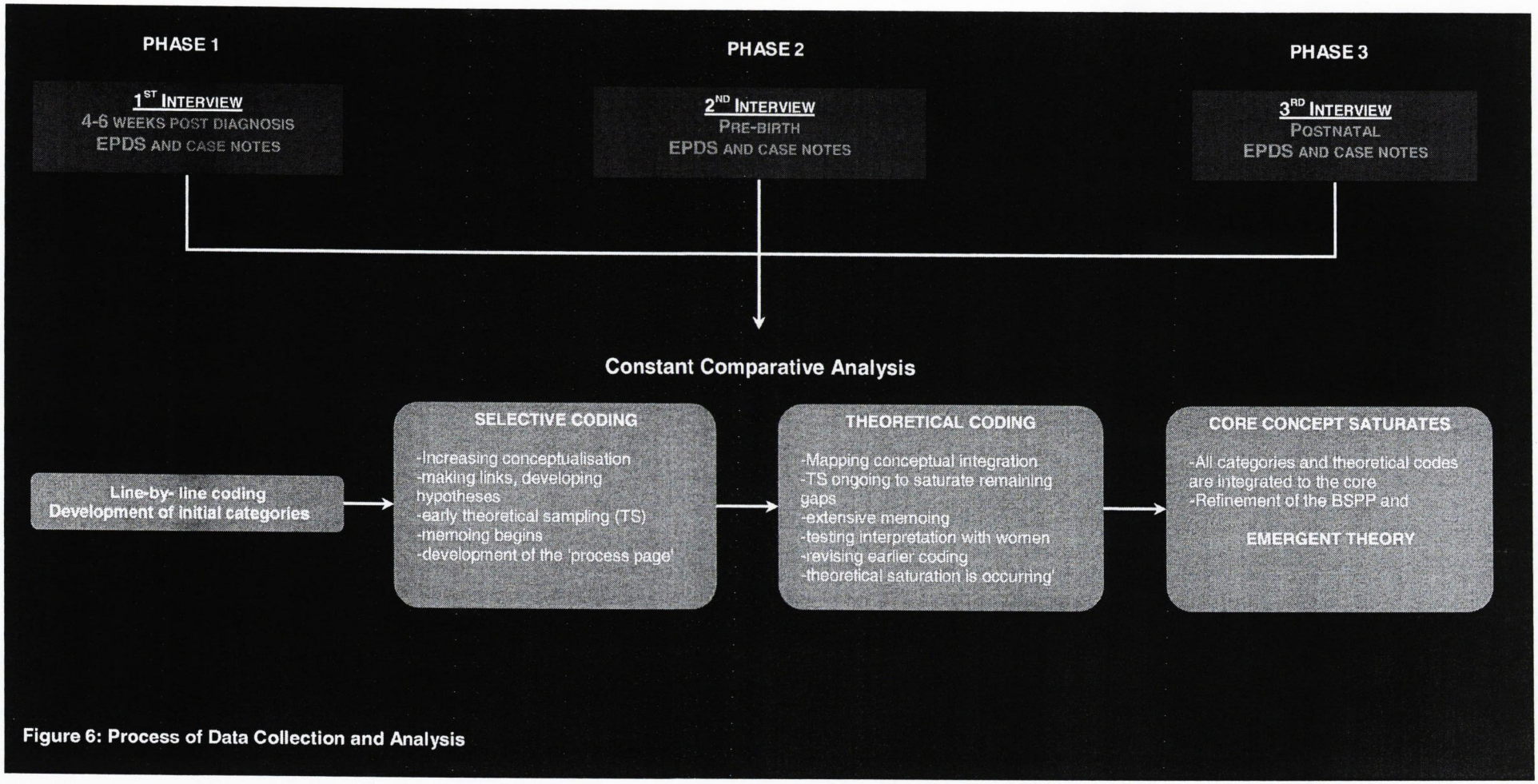

Figure 6: Process of Data Collection and Analysis

Appendix 5: Fetal anomaly screening: what do women *want* to know?

Fetal anomaly screening: what do women *want* to know?

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LALOR J. & BEGLEY C. (2006) *Journal of Advanced Nursing* 55(1), 11–19
Fetal anomaly screening: what do women *want* to know?
Aim. This paper reports a study exploring women's experiences of receiving an adverse diagnosis at a routine second trimester ultrasound examination, and the factors that influenced their preparedness for an adverse finding.
Background. Ultrasound has become a routine part of prenatal care offered to pregnant women in most developed countries and technological advances are making it increasingly possible to detect more anomalies, and at earlier gestations. When fetal anomaly detection can be an outcome of the examination, provision of effective information to ensure informed consent for screening remains a challenge.
Method. A grounded theory study ($n = 38$) was carried out in 2004 and 2005 using an in-depth interview within 4 weeks of diagnosis and constant comparative analysis.
Findings. The core category of balancing information emerged, whereby women balanced the expectation of a healthy baby and the non-threatening nature of the ultrasound examination with the shock of an adverse diagnosis. Assumed fetal health was contributed to by being in good health, experiencing normal symptoms of pregnancy and having other healthy children. The majority of women believed that provision of extensive and detailed lists regarding fetal anomaly detection would only cause unnecessary anxiety and worry, and suggested that a less detailed approach is required for a routine screening programme for low-risk pregnancy.
Conclusion. The drive to inform all women fully of ultrasound detection rates for specific anomalies may be counter-productive as it will enhance the worry pregnant women already feel in relation to the health of their unborn baby.

Keywords: empirical research report, fetal anomaly, grounded theory, information, interviews, midwifery, ultrasound

Introduction

Routine ultrasound examinations have become almost worldwide in the provision of antenatal care (Garcia *et al.* 2002) and Ireland is no exception. The Royal College of Obstetricians and Gynaecologists (RCOG) of the United Kingdom (UK) have recommended that a two-stage regimen of a booking an ultrasound scan (USS) at 12 weeks, followed by a detailed anomaly USS at 20 weeks, is most advantageous when detection of fetal anomalies in low-risk pregnancies is carried out routinely. However, they have emphasized the need for women to make informed decisions as to whether or not they wished to take part in this form of screening (RCOG 1997). National figures on ultrasound programmes offered by maternity units in the Republic of Ireland are not available, nor indeed do they appear in National Health Service statistics in the UK; however, a Royal College of Obstetricians and Gynaecologists/Royal College of

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Radiologists (RCR) survey has reported that 77% of hospitals in the UK were offering women a routine second trimester scan (RCOG/RCR 1995 unpublished).

Routine obstetric ultrasound can allow for identification of fetal anomalies and is both a diagnostic and screening tool. However, it has been suggested that women need to be clear about the purpose before they consent to examination (Seeds 1996). Targeted screening has been extended to the first trimester as the RCOG recommended a two-stage screening programme in which the anomaly scan was at 20 weeks gestation (RCOG 1997). A Scottish survey (Ritchie *et al.* 2004) has shown that units now offer fetal anomaly screening in the first trimester (between 10 and 13 weeks gestation) to improve detection, and has recommended that nuchal translucency and serum screening should be offered to all women in the first trimester.

In an Irish context, the purpose of ultrasound scanning for management of routine pregnancies warrants evaluation, as the belief that routine ultrasound can assist in reducing perinatal mortality rates and improve neonatal outcome has been challenged (Ewigman *et al.* 1993). Bricker *et al.* (2000) suggest that this can only be accomplished if detection of anomalies is fundamental to a screening programme and termination of pregnancy is widely accepted in the population being screened. In the Republic of Ireland, where termination of pregnancy is not legally available, the second assumption may not be valid.

The literature on women's views of ultrasound scanning reports an overwhelmingly positive experience (Hyde 1986, Green *et al.* 1992, Green 1994, Rapp 1999, Lalor 2000, Stephens 2000) of the examination and, on occasion, unrealistic expectations of technology (Eurenius *et al.* 1997, Lalor 2000). With a background prevalence of 2% of fetal anomalies in low-risk pregnancies, some women participating in routine screening programmes will inevitably be faced with their scan uncovering an adverse finding. Consequently, it is recommended that detailed information about ultrasound be given to women before examination (Field *et al.* 1985). To ensure that a woman is fully informed, Abramsky (2003) suggest that information should be provided on conditions being screened for, effects and prognosis of the condition, the individual woman's prior risk for the condition, whether the test is for screening or diagnostic purposes, the sensitivity and specificity of the test and possible consequences of information that may be revealed.

Most babies are born healthy and do not have abnormalities, but women's need for reassurance of this may only arise because antenatal testing has raised doubts in the first place (Katz Rothman 1988, Kolker 1989, Rapp 1999). Although few women have specific grounds to worry that something might be wrong with their baby, Statham *et al.* (1997) found this to be one of the highest scoring worries in pregnancy. This study was designed to ascertain how prepared women actually were for an adverse finding when having a routine ultrasound scan.

The study

Aim

The aim of the study was to explore women's experiences of receiving an adverse diagnosis at routine second trimester ultrasound examination, and the factors that influenced their preparedness for an adverse finding.

Design

Grounded theory, a general methodology that can be used for any data and is based on a latent structure analysis using concept indicator modelling to yield emergent theoretical frameworks (Glaser 2005), was chosen as the study design. It is an interpretative methodology used to generate research-based knowledge of behavioural patterns, or basic social processes (BSP), that shape society as people interact with their environment and those around them. It is founded on the belief that individuals within groups define circumstances with self and others, allowing common patterns of behaviour to emerge (Glaser 1978). Theory generation occurs around the development of an emergent core category, which is a dimension of the problem or main concern of the participants (Glaser 1978), and its primary function is to integrate and conceptualize the relationship between the substantive codes. Whilst a core category is always present in a grounded theory study, a BSP may not be (Glaser 1978; p. 97). Although many core categories are BSPs, grounded theory need not be restricted to the development of a BSP alone (Glaser 1978). It is a methodology used widely by social scientists (Denzin & Lincoln 1994) and its flexibility (Glaser 1992) led to its appropriateness for the study.

Participants

Participants were recruited from a tertiary referral centre in a major maternity hospital in Dublin, Ireland, which offers a routine antenatal second trimester ultrasound programme, prenatal diagnosis, invasive diagnostic testing and intrauterine therapeutic procedures.

Initial sampling was purposive, in that women with no previously known risk factors and a diagnosis of fetal

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abnormality in the current pregnancy were invited to participate in an in-depth interview within 4 weeks of receiving the diagnosis at their routine second trimester ultrasound. The clinician involved in care provision assessed eligibility, informed women of the study and answered questions. An information pack and consent form were then posted to each woman who indicated a willingness to participate by phoning or returning an 'indication of interest' form to the researcher. A follow-up reminder was posted within two weeks of the woman's receipt of the original information, and non-responders at this stage were deemed to have chosen not to participate. As women were still receiving care, they were specifically advised that they did not have to give a reason for this choice in order to ensure that they felt no obligation to take part. Women were eligible to participate if they could communicate orally in English, were Irish or had predominantly lived in Ireland, and could give informed consent. Sixty-two women were invited to take part, and 38 (61%) women with 41 fetuses (39 anomalous) agreed to participate. This response rate is acceptable as participation rates in sensitive research about diagnosis of fetal abnormality have ranged from 39·5% (29% in women who continued the pregnancy; Statham *et al.* 2001) to 44% (Paton 1999) in studies of pregnancy loss. A fetal anomaly classification system was devised in order to ensure that women carrying fetuses with all types of anomaly were theoretically sampled as the study progressed.

Characteristics of participants

The majority of women ($n = 27$, 71%) were aged between 30 and 39 years (mean: 32·89 years, SD: 5·535, range: 18–44). Ten were primigravidae, two of whom were pregnant with twins, with each woman having one fetus with a lethal or probably lethal anomaly and one apparently normal fetus. Twenty-eight women were multigravidae, of whom 20 were para 1, three were para 2, four were para 3 and one was para 10. One of the multigravid women was pregnant with twins, both with lethal or probably lethal anomalies. The frequencies of anomaly by classification were as follows: type 1 ($n = 15$), type 2a ($n = 2$), type 2b ($n = 4$), type 3 ($n = 5$), type 4a ($n = 5$), type 4b ($n = 7$), type 5 ($n = 1$; Table 1). Each category was represented, demonstrating that, in this sample, diagnosis did not appear to influence women's choice to participate. Eight women (one primigravida and seven multigravidae), each of whom was carrying a fetus with one of the following anomalies chose to terminate their pregnancy: anencephaly ($n = 3$), hydrocephalus, triploidy, trisomy 18, trisomy 21, diaphragmatic hernia.

Data collection

Data were collected from April 2004 to July 2005. Interviews took place in participants' homes and lasted 1–3 hours. Interviews were unstructured initially and, as coding proceeded and categories emerged, theoretical sampling began and interviews became more semi-structured in nature. For example, as the categories emerged it became apparent that women had received little information from healthcare professionals about the purpose of the examination. Consequently, theoretical sampling began for women's recommendations on the level of information they felt was appropriate. All data were kept strictly confidential, referral centres were not identified, pseudonyms were assigned to participants and if staff names were mentioned they were replaced by their professional status (i.e. midwife, obstetrician etc).

Ethical considerations

Ethical approval was obtained from the study site and the Faculty of Health Sciences, Trinity College, Dublin in Ireland. Women gave written consent on two occasions (i) immediately prior to interview and (ii) postinterview. Participants had up to 4 weeks from initial invitation to make their

Table 1 Classification of anomalies [$N = 38$, (41 fetuses), 39 anomalous fetuses, two normal]

Type	Description	$N = 39$
1	Lethal (e.g. anencephaly, renal agenesis, Trisomy 13 and 18)	15
2	Non-lethal with normal karyotype	
	A: likely physical handicap only (e.g. limb abnormality, skeletal deformity)	2
	B: likely physical and mental handicap(e.g. Neural tube defect, Dandy Walker malformation)	4
3	Non-lethal with abnormal karyotype (e.g. Trisomy 21, Turners Syndrome)	5
4	Structural abnormality with an option to repair	
	A: with a significant risk of mortality (e.g. diaphragmatic hernia, abdominal wall defects, cardiac)	5
	B: without significant risk of mortality (e.g. talipes, some renal anomalies)	7
5	Suspicious (e.g. multiple markers/anomalies with normal karyotype)	1

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decision to take part. The main investigator (JGL) did not have access to women's personal details until the decision to take part/consent form was received from each woman. The obligation to balance the needs of research with the emotional well-being of participants was held to be paramount. Women who chose to participate were offered the option of an exploratory session with an external counsellor in addition to the following support services that are available routinely: referral to a social worker with counselling experience in the healthcare site or referral to the psychiatric team should they feel this would be helpful in their circumstances. Pseudonyms were used to protect the identity of participants.

Data analysis

Interviews were tape-recorded and subsequently transcribed into the software package Nudist N6 Student (QSR International 2002) for data management. Data were hand-coded and initial analysis guided the direction of subsequent interviews. Constant comparative analysis was used to relate and develop codes and categories between participants, as each interview was coded prior to returning to the field. Concurrent data collection and analysis facilitated confirmation of the finding or expansion and development of the properties of the category in question, until data saturation occurred. Detailed memos profiling the development of both substantive and theoretical codes, earned relevance of categories and theory emergence were kept. The core category of 'balancing information' emerged during theoretical coding, linking two substantive codes of 'expected fetal health' and 'being prepared'. The core category integrates the relationship between how the social assumption that pregnancy results in a healthy baby (that was held prediagnosis) and the information women received before the scan influenced their preparedness for the possibility of an adverse finding. During initial coding, data were constantly compared for similarities and differences, and hypotheses were developed to test emerging patterns. Through theoretical sensitivity, these hypotheses were tested with new participants [theoretical sampling (Glaser 1978)] as women were asked if they could relate to emergent categories. Women provided corroboration of the rigour of the ongoing analysis and findings as the incidents and patterns were recognized and were confirmed as being meaningfully relevant. In addition, peer debriefing of ongoing analysis (Holloway & Wheeler 1998) was undertaken with an expert researcher (CB). [Exact quotes are given where suitable and brackets are used to indicate words added to clarify meaning. Participants' pseudonyms are included in round brackets.]

Findings

'Balancing information', the core category, relates to how women initially assume that the fetus is healthy through various feedback mechanisms or conditions (Figure 1). The expectation of fetal health and framing of information about the ultrasound examination relate in reinforcing the normality of pregnancy, and consequently intensify the unexpectedness of an adverse diagnosis. Positive indicators include the absence of warning signs, such as vaginal bleeding associated with threatened miscarriage, previous healthy pregnancies, and the existence of normal symptoms of pregnancy such as nausea or vomiting.

'Expected fetal health'

All of the women in the study anticipated that their fetus would be healthy and did not perceive themselves to be in a risk category for fetal anomaly. Multiparous women, all of whom had had an ultrasound in the previous pregnancy, spoke consistently of how this influenced their perspective this time around.

Previous healthy child

I have to say everything was brilliant (last time), which is why I suppose for number 2 all the fears were gone, I felt I have done it once so I will do it again. It was just a routine scan (in this pregnancy), there was no discussion...you don't expect anything to be wrong...I was very blasé about it...then it was like someone burst your bubble. (Fay)

I was coming from this really cocky confident place, I can make babies...there was no reason why I would have a problem. (Molly)

Women expressed how, in addition to previous healthy children, feeling well, experiencing normal symptoms of pregnancy, and an absence of fetal anomaly in their family and immediate social circle increased their confidence in fetal health.

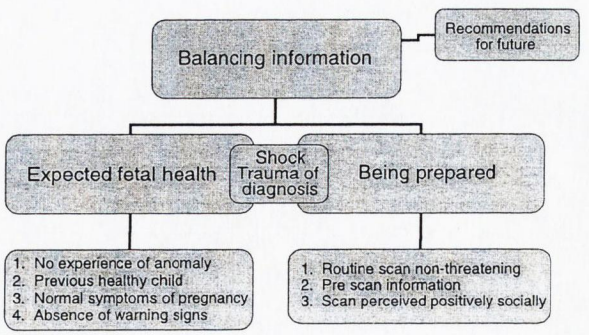

Figure 1 Balancing information after diagnosis of fetal abnormality.

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Reassuring pregnancy symptoms

I was in great health...I felt brilliant. We wouldn't be the type to think of that (fetal anomaly) (Hayley)

I was sick, I was very sick. You know everyone says if you're sick...you will have a healthy baby...so I took it for granted. We were really happy looking forward to it (USS), we were sitting there seeing other people coming out with their little photos. She (midwife) said to us it was twins...well hold on don't get too excited. (Emer, twins)

I only discovered (I was pregnant) when my husband said to me you are getting sick a lot...I mean the only thing we did think of was hopefully this is a girl, at least we will have one of each. It never crossed my mind (fetal abnormality,...everybody else had a positive experience, nothing wrong anywhere. (Alannah)

The absence of any threat to the pregnancy, such a pain or bleeding further reinforced the assumption that the pregnancy was progressing normally.:

I think once you get past the 14-week mark and your risk of miscarriage is sort of gone, I don't think women realise how much of an assumption they put themselves under that it's going to be plain sailing. It's a bit of a knock back when you are told it's not. I thought they would have just scanned and said everything is okay. (Roisín)

In addition to the health-oriented perspective held by the women, the framing of the examination as routine and non-threatening further added to the unexpectedness of the diagnosis. The substantive code of 'being prepared' emerged as women referred back to how information regarding the ultrasound was provided by their caregivers.

'Being prepared'

All women showed acceptance of the examination as part of a normal package of care, and its routine nature did not heighten their concerns regarding fetal well-being, and appeared to contribute to the women's false sense of security:

Everyone just gets a scan now don't they...so I just went in (for the USS). She (midwife) noticed this growth, to be honest it looked like another baby...so I was there totally shocked, I just expected to go in and get the picture...you don't think there is a problem, and I was thinking it had better not be twins. (Dáire)

It's routine

He said (consultant obstetrician) let's just have a look at the baby and just check...the purpose was never clearly articulated. You were going by previous knowledge and expecting things to be the same. (I thought) if it's routine (USS) I'll have it...routine is best practice. (Maolíosa)

The importance of provision of information to women before they are scanned has been debated (Eurenius *et al.* 1997) and participants in this study referred to the effect of a lack of information on their preparedness for an adverse outcome:

He (the consultant) wasn't very informative, it was actually the midwife, (who provided information) they were great. I didn't get any written stuff, I didn't even know what they were scanning for. I thought they were scanning to give you a more accurate date...I wasn't prepared really at the end of the day for what was involved. (Aisling)

They didn't say anything in the clinic as to what to expect or what the scan was about, it was just here is the number and ring up. (Emer, twins)

The routine nature of the scan, presumption of normality, non-threatening or no information on the purpose and so on, meant that women and their partners were excited and happy when coming for the scan, and were eagerly waiting to see their baby on the screen. This excitement made the breaking of bad news during the scan even more traumatic. When the assumption of normality was shattered through an adverse diagnosis, some mothers experienced a sense of incredulity when informed of their baby's anomaly, and all women described the initial reaction as one of shock and grief.

It's a shock

...a culmination of a healthy first child and being a healthy individual...you're clutching to this can't be happening to me...this is happening to me but I can't quite believe it. (Maolíosa)

I remember lying there trying not to cry. (Ciara)

We were excited (going for the scan) we'd never thought there would be anything wrong and we were excited at seeing him or her at the time and getting the picture. We were in the waiting room discussing whether we'd ask the sex of the baby...once I saw the heartbeat I thought everything is fine, then she asked me if there was a history of kidney disease...then she said there was a shadow on the kidney...I was in floods of tears. (Erin)

Data showed that women were unprepared for an adverse diagnosis, and in this context were asked how they felt about knowing of the anomaly prior to birth:

It has put me on alert, it's worth it in case there was anything they could do that might save the baby. No matter what, it's better than finding out at the birth. (Aisling)

It's better knowing at 14 weeks. I think it would have been much harder to find out at 20 weeks...(I read) on the internet some (women with at risk twin pregnancies) had ordered double buggies and things so she explained how she had to ring the shop and say she had to cancel one and they said well you can't cancel them. (Laoise)

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On balance I think it is better to know...obviously the torture is longer but at the same time we have had more time...every week that goes by you start imagining your baby more and you do probably start making plans for the future. The fact is that if medical professions can see this on the screen you wouldn't want them not to tell you. (Tara)

Women's recommendations for future provision of information

As data collection progressed, it became evident that there was an apparent lack of provision of specific information about the screening aspect of routine ultrasound. Having now experienced the negative side of screening, women were asked (using theoretical sampling) to what extent information should be provided about the ultrasound examination. A few spoke of how they should have been given information on reasons for the scan and possible outcomes:

Researcher: How would you talk to a woman about the scan?

You can't prepare everybody for problems...99% of women will not have problems. If you could explain it to them and say we are going to look for abnormalities, small ones, large, they could be anything. (Aisling)

Researcher: How much detail do you feel women should receive before the scan?

How much information is helpful to receive? Mmm, clear information on the purpose. (Maoliosa)

The majority, however, believed that it would only upset women to be told of the possibility that abnormalities that might be discovered:

Well, you hope everything is going to be alright and that's enough...you don't ever consider you'll get bad news...but if you gave me a list (incidence of detectable anomalies) I would be fretting for a week before I'd go up and who wants that? (Sian)

Mmm. I tend to think more information is better...but one of the things I really liked about pregnancy is it is not treated as a disease – it's the way it should be. Keep it normal because when there is something wrong you have plenty of time to get upset and freak out about it. I have friends who were constantly worried [pregnancies in the United States of America (USA)] for no reason, you have natural worries anyway. (Aoife)

(Finding the balance) between knowing nothing and frightening the living daylights out of people...there should be some way of maybe telling people we are going to take measurements and make sure everything is progressing normally. Most women don't want to be confronted with a big list of things that can go wrong. (Tara).

Discussion

Most women appear to want an ultrasound examination of their fetus and the offer of a routine ultrasound seems to be popular, with high uptakes in screening programmes internationally (Hyde 1986, Crang-Svalenius *et al.* 1996, Eurenius *et al.* 1997, Ritchie *et al.* 2004). Perhaps, as others have suggested (Mitchell 2004), this is because ultrasound is seen as non-invasive, leading to the examination having a predominantly social meaning where couples may even see it as an important landmark in pregnancy (Ekelin *et al.* 2004). The data from this study are consistent with others and show that participants' previous experiences of ultrasound were positive, (Eurenius *et al.* 1997, Larsen *et al.* 2000, Ritchie *et al.* 2004) and that provision of information was limited. There is an argument in the international literature that women should be informed of the diagnostic capability and limitations of prenatal tests (Green 1994, Seeds 1996, Larsen *et al.* 2000, Marteau & Dormandy 2001). Attempting to introduce evidence-based information and informed choice for women to secure their autonomy to decide whether or not to participate in screening is a worthy aim; however, recommending any specific method or guidelines for provision of information is fraught with difficulty when aimed at such a large and diverse population.

It has been shown previously that women with normal pregnancies worry about the health of their fetus (Eurenius *et al.* 1997, Lalor 2000, Homer *et al.* 2002) even when they are not at an increased risk (Statham *et al.* 1997); however, in general, they take part in ultrasound screening to seek reassurance (Eurenius *et al.* 1997, Lalor 2000). The majority of women voiced a desire to treat pregnancy as normal until proven otherwise, and raised concerns expressed by others (Oliver *et al.* 1996) that providing extensive detail about what can go wrong may create needless anxiety for the 98% of women who will not have adverse findings. Although women in this study received little pre-ultrasound information, we suggest that simply designing an information leaflet (which has been offered to women arbitrarily (Oliver *et al.* 1996)) is not an answer, and this study has raised issues about what women consider to be suitable content which does not concur with recommendations made by others (RCOG 2000).

We acknowledge the professional concern that the appeal of seeing the baby may contribute to the fact that women are unprepared for an adverse diagnosis (Garcia *et al.* 2002). Our data support the fact that balancing the expectation of fetal health and the non-threatening nature of the examination with the discovery of an abnormality leads to intensification of the shock associated with the

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What is already known about this topic

- The discovery of a fetal abnormality in pregnancy is an extremely stressful experience for parents.
- Previous experience of a normal pregnancy diminishes worry regarding fetal health in subsequent pregnancies.
- It is acknowledged that provision of information for women taking part in screening programmes is fraught with difficulty.

What this paper adds

- Initial detection of the anomaly is a shock to parents, yet all participants valued having foreknowledge of the anomaly.
- Being healthy and experiencing minor disorders of pregnancy provides reassurance about fetal health, reinforcing the expectation of normal ultrasound findings.
- Explicit information on possible anomalies to a population where the majority will not be affected may cause needless worry, and recommendations for an alternative strategy are offered.

diagnosis. However, we support Marteau and Dormandy (2001) that further research and discussion are required to evaluate different ways of presenting information and evaluating its effectiveness. In order to manage the diverse range of individual needs we would concur with others (Homer *et al.* 2002) that a strategy to overcome difficulties in providing appropriate information about routine ultrasound to all individuals is to provide sufficient time for discussion prior to the examination, and by asking women about their specific worries in order to provide information related to need (Donaldson 1991). This may avoid the concern that pregnancies can become 'tentative' (Katz Rothman 1988) until testing shows them to be otherwise, and prevent causing needless anxiety.

Our findings concur with others (Pelly 2003, Mitchell 2004) that women are unprepared for an adverse diagnosis and express disbelief when bad news is received. However, it remains to be established if providing detailed pre-ultrasound information can ever ameliorate that situation. Although as a screening test ultrasound has failed to show improvements in maternal and perinatal outcomes (Bucher & Schmidt 1993, Ewigman *et al.* 1993, Smith & Marteau 1995, Baillie *et al.* 2000, Bricker *et al.* 2000), the pleasure associated with seeing the baby means that it is undoubtedly here to stay. None of the women in this study expressed regret at having had an ultrasound scan and would continue to recommend it to other women, as the predominant feeling was that even after an adverse diagnosis it is still desirable to take part in ultrasound screening and to see one's baby on the screen. All women said that it was better to know about the fetal anomaly than not to know, irrespective of whether interventions were available to improve pregnancy or neonatal outcome. Knowing was not without consequence and, even though knowing could be described as 'torture', these women did not express concerns that their right 'not' to know (Venn-Treloar 1998) had been infringed, and none expressed negative feelings about the lack of pre-ultrasound information. This may be context-related, in that there is a cultural acceptance in the Republic of Ireland that not all babies are born perfect and children with disabilities may be more visible, and therefore more acceptable, in our society.

Our findings are also consistent with previous studies that show that women with previously successful pregnancies (Statham *et al.* 1997) are less worried about fetal health, but to our knowledge this is the first time that women have expressed the belief that having a sense of being healthy or experiencing normal symptoms of pregnancy contributes to a confident outlook for their pregnancy.

The data depict one stage on a journey, and further exploration of this experience may uncover other critical junctures likely to reveal a basic social process and substantive theory in relation to the process of coming to terms with the diagnosis. Seeking information is a common strategy for anyone facing a stressful life event, and the ongoing information needs of women in this situation require exploration. The beneficial effects of giving information to facilitate coping have been documented (Cipperley *et al.* 1995); however, others have identified the need to tailor information to the preferences of the individual (Miller & Mangan 1983, Barsevick & Johnson 1990, Egan 1999). Further research in this area could be guided by use of a conceptual model of coping to determine if information-seeking or avoidance strategies (Lazarus 1990a, 1990b) are used by women after diagnosis. Understanding preference for information will assist midwives and other healthcare professionals to provide culturally competent care and contribute to meeting the needs of the diversity of women requiring support after diagnosis.

Conclusion

The data have revealed an important finding, in that women in this context still feel pregnancy should be treated as normal and have not (as yet) moved to a position of assuming normality in retrospect. Consequently they are balancing the

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expectation and excitement of seeing their 'healthy' baby with the shock of an adverse finding. How information is presented is important in determining what captures our attention (Figueiras *et al.* 1999, Shiloh *et al.* 2001). For example, screening tests may be presented in terms of the chances of the fetus being normal or of the risk of abnormality. Shiloh *et al.* (2001) also suggest that, in addition to how information is presented, women will frame tests in terms of their personal health/illness orientations. For example, a woman who is health-oriented may have a scan to 'check if the baby is OK', and a woman who is illness-oriented may have one to 'find any abnormalities'. We recommend that midwives and other healthcare professionals giving information on prenatal screening tests should consider the value of establishing each individual's orientation to normality/abnormality in order to provide information congruent with this perspective. Data from this study show that providing negatively framed information for women with a health-oriented perspective would have increased anxiety, an unnecessary harm that could be avoided. Consequently, we urge caution in following international recommendations for information provision about prenatal screening without assessing if they are appropriate for the intended specific cultural and social context.

Acknowledgements

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Author contributions

JL and CB were responsible for the study conception and design and drafting of the manuscript. JL performed the data collection and data analysis. JL and CB obtained funding for the study. JL and CB provided statistical expertise and critical revisions to the paper. CB supervised the study.

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Appendix 6: Letter of introduction

School of Nursing and Midwifery Studies,
Tel: 087 6549012
Email: jlalor@tcd.ie

Dear

My name is Joan Lalor and I am a midwife and a fulltime student in the School of Nursing and Midwifery Studies in Trinity College Dublin. I am undertaking a research study on women's experiences of finding themselves in the situation of having a problem with the baby discovered on ultrasound.

I know that you have been told that your baby has or is suspected to have an abnormality and that this is a very difficult time for you. I also know that your doctor/ midwife will already have spoken to you about what has happened to your baby. This may not seem like the best time to think about taking part in a research study but I would like to talk to you about a study that I am conducting. I feel you may want to know about this study and have the opportunity to take part if you wish.

Enclosed please find an information booklet, which explains more about the study. I would be very grateful if you would consider being part of the study, however, participation is voluntary and you may withdraw from the study at any stage without obligation to anyone.

If having read the information sheet you would like to participate in the study please complete the attached consent form and return to me in the envelope enclosed. I will then be in contact with you to discuss the study in more detail. If you would like to discuss any aspect of the study, or would like to talk to me about the study before making up you mind please contact me at the address or phone number above.

Again, my thanks for considering taking part in this study.

Thank you.

Yours sincerely,

_____

Joan Lalor
HRB Clinical Midwifery Fellow and Doctoral Student.

Appendix 7: Letter of introduction from Fetal Medicine Specialist

Fetal Assessment Unit,
XXXXX Hospital,
XXXXX Dublin X.

Tel: XXXXXXX

Dear

We know that you have been recently told that your baby has or is suspected to have an abnormality and we are aware that this is a very distressing time for you. This may not seem like the best time to think about taking part in a research study but we would like to talk to you about a research study that a colleague is conducting. We feel you may want to know about this study and have the opportunity to take part if you wish, and our reason for writing to you is to ask if you would be willing to participate.

A colleague, Joan Lalor, is carrying out a study describing how finding out that your baby has an abnormality affects you and your family and how we as professionals can improve the care, we offer to parents in your circumstances in the future. Joan is a midwife, who has worked in this area for many years, and will appreciate how difficult this time is for you. A letter from Joan is enclosed explaining the study and what your participation would involve. She does not have access to your name and address or details, and if you do not contact her yourself, you will not receive any more correspondence about her study. Your care here at the hospital will not be affected in any way, whatever you decide; in fact we will be unaware as to whether you agreed to participate or not. You have Joan's assurance that whatever you say will be held in the strictest of confidence, and your answers will not be available to us, or any members of your family. We feel this is an important study, which may help to improve the care women in a similar situation as you receive. Therefore, we hope you will be able to help.

If you feel you would like to take part, please reply to Joan whose contact details are on the form included with this letter.

Yours sincerely,

XXXXXXXXX
Consultant in Fetal Medicine.

Appendix 8: Study information leaflet

Women's information leaflet

You are invited to be in a research study of womens' experience of the diagnosis of a fetal abnormality up to and beyond the birth of the baby.

Who is the researcher?
My name is Joan Lalor and I am a midwife. Most recently, I have been a midwifery tutor, but I have worked in a fetal assessment unit for a number of years and have been involved in performing ultrasound scans. I am currently a student in Trinity College Dublin, and I am undertaking the above study in fulfilment of a higher degree in midwifery.

Why have I been chosen to take part?
The staff in the Fetal Assessment Unit of the National Maternity Hospital have forwarded you this information leaflet on my behalf. They have not given me your name or address and I know nothing of your situation other than that you have recently had a scan where you were told that your baby has or is suspected to have an abnormality. I do understand that the last few weeks will have been very difficult for you, and I hope this invitation does not cause you any further distress.

What is the study about?
While working as a midwife in a Fetal Assessment Unit I have seen how distressing it is to receive such news about your baby, and I am writing to ask if you would be willing to take part in a study exploring the experiences of women like yourself and the care you receive during this time. I would ask you to read this document and ask any questions you may have before agreeing to be in the study. While this study will not directly benefit you, your participation will give more understanding to what this experience is actually like for you from the time of your scan until after the birth of your baby. I hope that by understanding your experience we can plan and provide the care needed in the future for women who find themselves in the same or similar situations.

What does the study involve?
If you agree to take part in the study I will need access to your maternity notes to collect information about your pregnancy, birth and postnatal period.

1. I would also like you to take part in a one-to-one interview with me on three occasions. These are:
   - within a month of receiving the news from the scan;
   - between 36 weeks and your due date; and
   - three months after your baby is born.

2. Complete a brief questionnaire on how you have been feeling in the week before each interview.

We can meet in a place and at a time of your choosing, such as your home. The purposes of the interviews are to give you an opportunity to explain what it is like to live with the knowledge of your baby's problem.

You control the length of time for each meeting. However the **total** amount of your time is likely to be three to four hours over nine months, which includes completing the short questionnaires.

My role is to listen to your story, and I will ask you some questions, which you are free to answer whatever way you choose. This is about your experience so there are no right or wrong answers. I will use a tape recorder during the interviews to help me write down the conversations on paper. While we are talking you may refuse to answer any questions you choose or ask me to erase certain sections. It is possible that you may become upset when telling me about your experience and how you are feeling. This is understandable. However, if it becomes too difficult for you, we will stop the conversation and you can decide whether you wish to resume later or stop completely. I have also made arrangements for

a counsellor to be available to talk to you at any point after the interview if you wish. I will offer you written details on how to contact the person when we meet.

Who will know if I have taken part?
If you choose to take part, the staff at the hospital or your family will not know you have agreed to take part unless you choose to tell them, which you are free to do.

Will I be paid for taking part?
No, but neither will you have to pay anything to take part, as I will meet you at a time and location of your choice.

What will happen to the information I give?
Any information you give to me will be:

- Confidential;
- accessible only by my research supervisor, the person typing the tape recording and myself; and
- used for the purposes of the study and will be destroyed at a later date.

When the study is complete, the findings may be published to help improve care. Neither your name nor any information that could identify you will appear on the tape, questionnaires or be printed in the report. You can have access to any information you give me at any stage of the study if you so wish.

If during the interview or as a result of your responses to the questionnaires I become concerned for your wellbeing, I will be obliged to pass this information on to a hospital doctor. Should this happen, I will tell you of my intention but I must point out that I do not need your consent to pass the information on. It is unlikely that this will happen but should it happen complete confidentiality with the specific issue cannot be guaranteed. This is a requirement for all registered midwives and is not specific to you taking part in this study.

Are there any consequences if I choose not to be a part of the study?
No. It's up to you whether you take part and your decision will not affect the care you receive. You can drop out from the study at any stage before, during, between or after interviews or questionnaires. If you want to do this you can contact me by phone or email. You do not have to explain your decision. Although unusual, I may need to withdraw your participation from the study if I think it would be in your best interest.

Thank you for taking the time to read this leaflet and for considering taking part in the study. If you have any questions about the study, please contact me at the number below. If you would like to take part in this study, please sign the enclosed form and post it to the address below and I will phone you to arrange to come and talk to you.

I look forward to hearing from you

With best wishes,

Joan G. Lalor
School of Nursing and Midwifery Studies,
Trinity College Dublin,
24 D'Olier Street, Dublin 2.
Ph: 087 654 9012
Email: jlalor@tcd.ie

Appendix 9: Consent forms before and after interview

CONSENT FORM

StudyTitle:

A longitudinal study of womens' experience of the diagnosis of a fetal abnormality up to and beyond the birth of the baby using a Grounded Theory approach.

Researcher:

Joan Lalor.

I, have read this consent form and the accompanying information letter and voluntarily agree to participate in this study. I have had the opportunity to ask questions prior to participation. I understand the purpose and type of information being sought and I understand this information is confidential and available to the researcher and her academic supervisor only, but that the findings will be published without identifying me on completion of the study.

As a participant I am aware of the following:

1. I am also aware that I may withdraw from this study at anytime, and this will not affect the care I receive. Neither the hospital staff nor my family will know if I have chosen to participate.
2. I can contact the researcher, Joan Lalor, at any point during the research to clarify any issues related to my participation in the study or to withdraw participation.
3. I can withhold, or amend any information I give during the course of the study.
4. I have access to any information I give during the study, and I am aware that I will receive feedback on the findings when the study concludes.

.....

Participant's Signature Date

.....

Contact details

.....

Researcher's Signature

Please keep a copy for your own records.

CONSENT FORM POST INTERVIEW.

StudyTitle:

A longitudinal study of womens' experience of the diagnosis of a fetal abnormality up to and beyond the birth of the baby: A Grounded Theory study.

Principal Researcher: Joan Lalor, Midwifery Doctoral Student

I, ..., agree to take part in the above study. I have read this consent form and the information sheet. I have had the opportunity to ask questions about the study. I am confirming that I give my consent to the researcher to use all the information I have given, **including in the preceding interview,** as part of the study. I understand that the findings may be published but my name will not appear on any part of the study, nor will any information that may identify me. The study has received ethical approval from the hospital.

As a participant I am aware of the following:

1. I may withdraw from this study at anytime, and this will not affect the care I receive. Neither the hospital staff nor my family will know if I have chosen to take part, or if I have later withdrawn.
2. I can contact the researcher, Joan Lalor, at any point during the research to clarify any issues related to my participation in the study or to withdraw.
3. I may ask the researcher to erase or not use a section of the interview.
4. I can withhold, or amend any of the information I give during the study.
5. I have access to any information I give during the study, and I will receive feedback on the findings when the study concludes.

.....

Your signature Date:

.....

Your name in block capitals

.....

Researcher's signature

Please keep a copy for your own records.

Appendix 10: Reminder letter

Re: A longitudinal study of womens' experience of the diagnosis of a fetal abnormality up to and beyond the birth of the baby: A Grounded Theory study.

Dear

Several weeks ago we sent you an information sheet about this study. We know that this is a very distressing time for you and it may not seem like a good time to talk to you about a research study, however it is an important study that aims to improve care for women who find themselves in the same situation as yourself.

As we have not heard from you, we wondered whether our first letter went astray or whether you might have mislaid the information. We are therefore enclosing another copy and hope that you will be able to spare the time to consider participating and complete consent form and return it to us in the enclosed pre-paid envelope. Your views and experiences are important to us so we very much hope you will respond.

The information you would give during the study is completely confidential and no-one will be aware that you have chosen to participate unless you choose to tell them yourself.

If you do not wish to participate and do not wish to receive any further communication regarding this study please tick the box below and return it to us in the stamped addressed envelope provided.

If your reply is already in the post, we would like to thank you for your support and will contact you shortly, and apologise for troubling you again. Thank you for taking the time to read this letter.

Kind regards,

Joan Lalor.
Clinical Midwifery Fellow and Doctoral Student.

☐ I do not wish to participate in this study or receive any further communication.

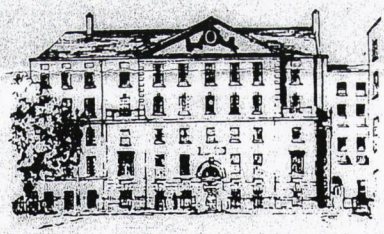
For further information, please contact:
Joan Lalor. Clinical Midwifery Fellow and Doctoral Student.
Direct Line: +353 87 6549012 Email: jlalor@tcd.ie

Appendix 11: Letters of approval from relevant research ethics committees

National Maternity Hospital

Founded in 1894

Holles Street, Dublin 2. Telephone: (01) 6373100. Fax: 6766623.



MASTER: DR. DECLAN KEANE

12th September 2003

Joan G Lalor
1 Luttrell Park Crescent,
Castleknock,
Dublin 15.

Re: **A longitudinal study of women's experience of carrying a baby with a fetal abnormality up to and beyond birth: a grounded theory approach**

Dear Joan,

Your study was considered at the last Ethics Committee meeting and I am pleased to inform you that the study was approved. There is one proviso however, and is that prior to recruitment, a delegated senior member of staff should discuss the study at length with the women and inform them that they will receive the information pack and consent form at their homes.

Kind regards.

Yours sincerely,

Peter Boylan, MAO., FRCPI., FRCOG.
Chairman,
Ethics Committee.

The University of Dublin, Trinity College
Faculty of Health Sciences
School of Nursing & Midwifery Studies
Trinity Centre for Health Sciences, St. James's Hospital, James's Street, Dublin 8.
Tel: + 353 1 6082692 Fax: + 353 1 4732984/6083001 http://www.tcd.ie/Nursing_Midwifery/

Ms. Joan Lalor
1 Luttrell Park Crescent
Castleknock
Dublin 15

11th Nov 2003

Re: Application for Research Ethics Committee Approval

Dear Joan,

Further to your recent application to the School of Nursing and Midwifery Studies Research Ethics Committee, I am writing to inform you that the committee have considered your application and granted your study *ethical approval.*

Please note ethical approval has been granted based on the information available to the Committee members at the time of their decision. If unforeseen ethical issues emerge during the course of the study, it is the applicant(s) responsibility in consultation with their supervisor to decide whether they require further approval from the ethics committee. Applicants should also advise the committee if any untoward events occur in the course of the study.

A copy of this letter has been forwarded to your supervisor.

Yours sincerely,

Dr. Michèle Glacken
Chairperson of Research Ethics Committee
School of Nursing and Midwifery Studies

THE UNIVERSITY OF DUBLIN

TRINITY COLLEGE

FACULTY OF HEALTH SCIENCES

ean: Professor Diarmuid Shanley
aculty Secretary: Ms Fedelma McNamara

Trinity College, Dublin 2, Ireland
Telephone: 353-1-608 1476
Fax: 353-1-671 3956
Email:dshanley@tcd.ie
fmcnamar@tcd.ie

2nd February 2004

Ms Joan Lalor
School of Nursing and Midwifery Studies
Trinity Center for Health Sciences
Saint James Hospital
James Street D 8

Re : A longitudinal study of womens' experience of the diagnosis of a fetal abnormality up to and beyond the birth of the baby: A Grounded Theory Study

Dear Ms Lalor

Further to a meeting of the Faculty of Health Sciences Ethics Committee on 26th January 2004, we are pleased in inform you that the above project has been approved without further audit.

Yours sincerely

pp

Professor Noel Claffey
Chairperson
Faculty of Health Sciences Ethics Committee

Unexpected Diagnosis of Fetal Abnormality: Women's Encounters with Caregivers

Joan G. Lalor, RM, RGN/RCN, RNT, MSc, Declan Devane, RM, RGN, RNT, MSc, and Cecily M. Begley, RM, MSc, PhD, FTCD

ABSTRACT: Background: *It is acknowledged that health professionals have difficulty with breaking bad news. However, relatively little research has been conducted on the experiences of women who have had a fetal anomaly detected at the routine pregnancy ultrasound examination. The study objective was to explore women's experiences of encounters with caregivers after the diagnosis of fetal anomaly at the routine second trimester ultrasound scan.* **Methods:** *The theoretical perspective of symbolic interactionism guided this study design. A purposive sample of 38 women, at low risk of fetal abnormality, who received a diagnosis of a fetal abnormality in a tertiary referral center in Ireland, were recruited to participate. An in-depth interview was conducted within 4–6 weeks of the diagnosis. Data were collected between April 2004 and August 2005 and analyzed using the constant comparative method.* **Results:** *Six categories in relation to women's encounters with caregivers emerged: information sharing, timing of referral, getting to see the expert, describing the anomaly, availability of written information, and continuity of caregiver. Once an anomaly was suspected, women wanted information quickly, including prompt referral to the fetal medicine specialist for confirmation of the diagnosis. Supplementary written information was seen as essential to enhance understanding and to assist women in informing significant others. Continuity of caregiver and empathy from staff were valued strongly.* **Conclusions:** *The way in which adverse diagnoses are communicated to parents leaves room for improvement. Health professionals should receive specific education on how to break bad news sensitively to a vulnerable population. A specialist midwifery or nursing role to provide support for parents after diagnosis is recommended. (BIRTH 34:1 March 2007)*

Key words: *prenatal ultrasound, fetal abnormality, communicating bad news, prenatal diagnosis, continuity of care*

Joan G. Lalor is a Health Research Board Clinical Midwifery Fellow and Doctoral candidate, Declan Devane is a Doctoral candidate and Midwifery Research Assistant, and Cecily M. Begley is Chair of Nursing and Midwifery and Director at the School of Nursing and Midwifery, Trinity College Dublin, Dublin, Ireland.

This study was funded by the Health Research Board, Dublin, Ireland.

Address correspondence to Joan G. Lalor, RM, RGN/RCN, RNT, MSc, School of Nursing and Midwifery, Trinity College Dublin, 24 D'Olier Street, Dublin 2, Ireland.

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Ultrasound examinations in pregnancy have become available to most women in developed countries as a routine aspect of care (1), with women in the United Kingdom (2,3) and Ireland (4) being offered at least 1 scan during their pregnancy. Currently, the debate in the literature about the risk/benefit equation of ultrasound screening is focused almost completely from the perspective of measuring clinical effect (1,5). Nevertheless, approximately 2–4 percent of pregnancies will be affected by a fetal anomaly, with a potential for detection at the routine scan. Such anomalies are responsible for approximately 30 percent of perinatal deaths in developed countries (6), and intervention to

improve perinatal outcome should be welcomed. However, controversies about the routine use of ultrasound in pregnancy remain (7), partly because of the broad range in sensitivity rates quoted and the accompanying concerns with respect to the consequent benefits in maternal and perinatal outcomes (1,8).

Although the current discourse on the complexities of prenatal screening and diagnosis continues, individual encounters are ongoing among women who have received a diagnosis of fetal abnormality and health professionals. Such encounters involve complex decisions about pregnancy outcomes. Professionals' attitudes to screening, and subsequent pregnancy management after an adverse diagnosis, are undoubtedly influential in women's experiences of this situation. Health professionals and members of the public who live outside Ireland may question the value of offering prenatal screening in a country that does not allow termination of pregnancy if an anomaly is detected. However, Farrant's (9) seminal work on the attitudes of women and health professionals toward prenatal screening and termination for fetal abnormality in 1980 identified that health professionals, in general, viewed detection of fetal anomalies as being the goal of a screening program, whereas women participated to seek reassurance of normality. This fundamental difference in the perceptions of the purpose of screening partly explains why women who would not consider abortion may still take part in screening (10). Although women may worry that something is wrong with the baby (11,12), this feeling does not necessarily imply that they prepare themselves for receiving bad news.

Although practitioners find giving bad news a difficult task (13–15) and receiving such news in relation to fetal well-being is associated with acute grief reactions for parents (16,17), little research has been conducted on communicating bad news in pregnancy (18). The psychological effects of receiving an unexpected diagnosis of fetal anomaly have been predominantly explored through qualitative analysis of women's experiences or, alternatively, through empirical measurements of level of trauma at various junctures. Frequently, comparisons are made between the psychological outcomes of women who chose to continue the pregnancy and the outcomes of women who have chosen to terminate it through the use of a multitude of standardized instruments that measure concepts such as grief, despair, coping, anxiety, and depression (19–23). This focus on loss and bereavement has created a situation whereby researchers have examined women's experience of termination after prenatal diagnosis with relatively few considering the issues pertinent to women who choose to continue the pregnancy (12,24).

When exploring the effect of the diagnosis on women, thought must be given to the likely outcome for the fetus. Most conditions are not lethal but may carry a significant risk of mental or physical handicap. Since few newborns will benefit from antenatal diagnosis and *in utero* treatment (25) or immediate specialized treatment in the neonatal period, some authors have questioned the value of antenatal identification of anomalies for parents when such a therapeutic vacuum persists (26).

Developments in prenatal diagnostic techniques over the past 20 years have led to an increase in selective termination of pregnancy (27), in particular following the diagnosis of anomalies that are lethal or associated with risk of handicap (28,29). Early studies have suggested that if an abnormality is detected, parents want to be informed, even though some have suggested that women remained "emotionally unbalanced" for the remainder of the pregnancy (30, p. 78). Assumptions that parental reactions are based on objective measures of fetal outcome, such as mortality and morbidity, and extrapolation of data from women's experience of carrying a baby with such anomalies to other women where the prognosis is uncertain rather than lethal, may result in insensitive encounters with caregivers, and may culminate in women receiving an inappropriate level of care (31).

Chitty et al's (32) analysis of the experiences of 5 couples who chose to continue the pregnancy after a diagnosis of a lethal anomaly reinforces concerns about the inappropriateness of care provided by some health professionals. Women described the unsuitability of routine antenatal clinics for ongoing care, and a lack of continuity of caregiver led to some women being treated insensitively by staff, who did not seem to be aware of the diagnosis and interacted with the woman as if a normal outcome was expected. Chitty et al (32) expressed concern over the lack of experienced staff in engaging with couples who choose to continue the pregnancy, resulting in ill-preparedness in providing appropriate care (33,34).

Several studies have identified women's dissatisfaction with the way in which the diagnosis was conveyed, supporting previous study findings that communication with caregivers is problematic (24,32,33,35–37). In jurisdictions where termination of pregnancy is available, women have expressed discontent that caregivers seemed to display little understanding of their decision to continue the pregnancy. This perception suggests that personally held views of the health professional to the effect that termination is more appropriate can have a negative effect on parents (28), and leave them feeling abandoned by the system (33,34). Some authors have suggested that the decision to continue the pregnancy is not always

clear-cut, may evolve over time, and may be followed by a process of revisiting the decision throughout the remainder of the pregnancy in order to cope (36). Irrespective of whether the decision to continue the pregnancy is passive or active, Statham et al observed that parents need support from health professionals that recognizes issues pertinent to the parents, such as difficulties traveling to antenatal visits in specialist centers, disruption to home life, and uncertainty about what to do if labor begins unexpectedly (12).

When reproductive choices are limited, presumptions are made that being forewarned of the presence of a genetic disorder provides the opportunity for emotional preparation for the birth and time to gain an understanding of the possible difficulties that lie ahead. Issues such as breaking the news have not been systematically investigated. In Ireland, termination of pregnancy is not available within the jurisdiction; continuing the pregnancy after an adverse diagnosis is the dominant course of action. This article explores the experiences of women's encounters with caregivers after the diagnosis of fetal anomaly on routine second trimester ultrasound examination.

Methods

The women in this study were part of a larger longitudinal study exploring women's experiences of carrying a baby with a fetal abnormality up to the birth and beyond. Given that the focus of this study was women's interactions with their caregivers, the theoretical perspective of symbolic interactionism (38) was used to guide this aspect of the study. This perspective is based on the premise that human behavior develops through interaction with others and the meanings that they attribute to the situation.

Data were collected between April 2004 and August 2005 through in-depth interviews conducted at individual women's homes by the principal investigator (J.G.L.). Each interview lasted between 1 and 3 hours, was recorded, transcribed verbatim, and analyzed using the constant comparative method (39). No preset interview questions were asked other than each woman being asked to describe how she felt when she discovered she was pregnant and, later, how she felt on the day she received the initial news that the ultrasound examination had revealed a cause for concern.

The study site is a tertiary referral maternity hospital in Dublin, Ireland, with 3 designated fetal medicine consultants and a specialist registrar. All women who are booked for birth in the center are offered a routine second trimester ultrasound scan. Women were purposively sampled on the basis of the fetal diagnosis to ensure experiences were not limited to women who were pregnant with fetuses with a specific type or prognostic severity of anomaly.

Ethical approval for the study was obtained from the study site and the Faculty of Health Sciences Ethics Committee, Trinity College Dublin. Women were eligible for inclusion if they had no previously known risk for congenital fetal anomaly, a diagnosis of fetal abnormality in the current pregnancy, could communicate in English, and were Irish or had lived predominantly in Ireland if born elsewhere. Women booked for birth at the tertiary center received the initial diagnosis from either a midwife or a radiographer in the routine ultrasound clinic, and those booked for birth elsewhere and referred for specialist opinion received the initial information from midwives, radiographers, or obstetricians.

The fetal medicine specialist(s) involved in the diagnosis assessed women for eligibility, provided information, and answered all questions related to the study. In addition, an information pack inviting participation and detailing the purpose of the study and all tenets of informed consent was mailed to the women's homes by the fetal medicine staff. All women who were invited to participate were unknown to the researchers until consent to take part was received, and data were only collected about those giving consent. Women who chose not to participate were not required to provide a reason for so choosing. Women had up to 4 weeks from the initial invitation to consider participating to ensure adequate time to make their decision and to allow for further testing as appropriate. One follow-up reminder was sent 2 weeks after the initial invitation, and nonresponders to the reminder were deemed to have chosen not to participate. Postal recruitment was chosen to ensure women would not feel that their decision to participate, or not, could have any influence on their care because clinicians were unaware of the woman's decision.

Those choosing to participate returned a written consent form or contacted the principal investigator by telephone. They gave their written consent before and after the interview. Interviews were conducted within 4–6 weeks of the diagnosis. All participants were offered access to an external counselor in addition to support services routinely available within the study site. Pseudonyms are used to protect participants' identities.

Data Analysis

Data collection and analysis were performed in parallel. Data were analyzed using the constant comparative method (39), with ongoing analysis used to facilitate the development of emergent categories from interviews with subsequent women.

The constant comparative method is a systematic approach to data analysis. To minimize the risk of searching for incidents to confirm or deny theoretical ideas or phenomena that may exist in the literature, researchers are challenged to set aside previous knowledge and speculation as much as possible. This process necessarily involves deferral of a comprehensive literature search until completion of the analysis to ensure that emerging categories are closely related to the population being explored (40–42). Data are collected and analyzed into initial categories. These categories are developed and refined as repeated visits to the field are made to collect additional data, and hypotheses specific to the emergent categories rather than the literature are tested (e.g., greater depth of detail given at the initial disclosure is associated with higher perceived satisfaction with care).

This systematic method of analysis involves identifying a specific phenomenon and exploring the context and intervening conditions that affect a participant's experience of the phenomenon. Women's responses to receiving the diagnosis were analyzed based on whether the initial diagnosis was given in a regional center (requiring referral for confirmation) or in a routine ultrasound clinic in the tertiary center, and were grouped initially on the basis of encounters with caregivers that women found helpful or unhelpful. Since these women were participating in a larger study involving repeated in-depth interviews, the rigor of analysis was verified with each participant at subsequent interviews (43), with an expert researcher (C.M.B.), and on completion of data collection with 9 randomly selected participants. Finally, our findings were compared with studies in the literature in the substantive area.

Results

Between April 2004 and August 2005, 62 women with a range of fetal anomalies were invited to participate, of whom 38 (61%) women with 41 fetuses (39 anomalous) agreed to take part. Ten women were primigravidas, 2 of whom were pregnant with twins with each having 1 fetus with a lethal or likely lethal anomaly, and 1 apparently normal fetus. One multigravida was pregnant with twins, both with lethal or likely lethal anomalies. Eight women (1 primigravida and 7 multigravidas) chose to terminate their pregnancy outside the jurisdiction. Each of these women was carrying a fetus with one of the following anomalies: anencephaly (n = 3), hydrocephalus, triploidy, trisomy 18, trisomy 21, and diaphragmatic hernia. These women's experiences of their care in Ireland before traveling to the United Kingdom for termination are included in the data presented. Classification of fetal anomalies and maternal sociodemographic characteristics are presented in Tables 1 and 2.

The 6 main categories in relation to women's encounters with caregivers that emerged from the data comprised information sharing, timing of referral, getting to see the expert, describing the anomaly to parents, availability of written information, and continuity of caregiver.

Information Sharing

Initial Diagnosis

The data demonstrated that women positively anticipated the ultrasound examination and were looking forward to "seeing" their baby. Since the scan was offered routinely, women viewed it as non-threatening in nature. Because the women were not selected for screening based on the presence of fetal anomaly risk criteria, all described being shocked to discover that everything was not normal. Women who received clear information from caregivers at this initial point in the diagnostic process were more satisfied with their interaction with the caregiver than those who had inadequate responses to their questions.

> I said (looking at the screen) that doesn't look right ... she [midwife] didn't fudge around ... it looks like some of the

Table 1. Classification of Anomalies (41 Fetuses, 39 with Anomalies)*

Type	*Description*
1.	Lethal, normal karyotype (e.g., anencephaly, Potter's syndrome)
2.	Significant mental/physical disability, with normal karyotype (e.g., neural tube defect, limb abnormalities, Dandy-Walker malformation)
3.	Significant structural abnormality with an option to repair carrying a risk of mortality, with normal karyotype (e.g., diaphragmatic hernia, abdominal wall defects)
4.	Significant structural abnormality with an option to repair (a) with a significant risk of mortality (e.g., diaphragmatic hernia, abdominal wall defects) (b) without a significant risk of mortality (e.g., talipes, some renal anomalies)
5.	Abnormal karyotype ± structural abnormality (e.g., trisomy 13, 18, 21; triploidy, Turner's syndrome)
6.	Suspicious (structural or placental anomalous findings with normal karyotype)

**Based on the classification of Statham et al (24).*

> bowel has come out ... but it's operable ... at least we knew. (Fay, Type 4a)

> We didn't have any reason to think there would be a problem, but the [midwife] picked it up straight away ... she gave us quite a bit of information and then said, look, you know you'll have to come back and talk to an obstetrician (for confirmation). (Muireann, Type 1)

Women described a need for prompt information about their baby's anomaly, and their perceived difficulty in accessing information as quickly as they would have liked added to their distress.

> I was trying to find out what about the other organs, was there something else (affected), where was this coming from, where was it originating from, but she [the midwife] couldn't answer all the questions ... (referred to consultant). Now I wasn't leaving there that day without seeing [the consultant]. (Erin, Type 4b)

All women who had their routine scan in regional centers, where the procedure was to have the examination performed by a radiographer and subsequently receive results from an obstetrician, were unhappy with this process. During the examination, they felt frustrated and distraught when the suspicion of an anomaly was raised, and they thought that the radiographer/radiologist was insensitive to their questions or need for information.

> So then she scanned me, and then a doctor [radiologist] came in and he just basically pointed out the problem to her and then he walked back out again, there was no talking. I said, is there something wrong? She said, I can't read it. (Kasey, Type 1)

Many women thought that they did not receive enough information at the initial scan and accessed additional information resources. This response was influenced by access to the Internet and information-seeking preferences; that is, some women expressed a high need for information, whereas others commented on needing time to process what information they had already been given. It was not unusual for women to search the Internet with an uncertain diagnosis while awaiting an appointment for the fetal medicine specialist. However, information sources that were not subjected to critical appraisal by health professionals were not without consequence:

> If I had been told even in passing don't be alarmed by what you read on it. I have seen some horrific stuff on the Internet. I actually feel now that the information should be available quicker. The Internet is a very dangerous tool. (Blannad, Type 4b)

Table 2. Maternal Sociodemographic Characteristics (n = 38)

Description	*Data*	
Age at diagnosis (range 18–44 yr)	Mean (yr) 33	SD ± 5.53
Booking site	Tertiary center (n = 29)	Regional center (n = 9)
Education level	University (n = 14)	High school (n = 24)
Parity (range 1–10)	Primigravida (n = 10)	Multigravida (n = 28)
Socioeconomic status	Class 1–3 (n = 26)	Class 4–5 (n = 12)

Timing of Referral

All women said rapid access to the fetal medicine specialist, preferably within 24 hours of the initial ultrasound scan, was desirable. Women experienced most distress when waiting longer than this period and especially if the wait spanned a weekend, when they believed access to information was hindered.

> If I could have seen [fetal medicine specialist] straight away I would definitely take it. The waiting was the worst. It really wasn't nice. (Emma, twins, Type 1)

Getting To See the Expert

Women had high expectations of the visit with the fetal medicine specialist and described it in terms of finally getting the facts from the "expert." At this point, all women had described the destructiveness and stress of "not knowing" the diagnosis and were eagerly anticipating receiving a definitive result irrespective of how poor the outcome might be. Most women were positive about their encounter with the fetal medicine specialist; however, some women described situations where they were dissatisfied with this encounter:

> [The consultant] said that, yeah, it was a multicystic kidney and then threw in an association with a chromosome disorder ... but he wasn't facing me. Edward's disease and it would be fatal, they could do an amniocentesis if we wanted. Now that whole conversation went very fast and the consultant never looked at me face to face. (Erin, Type 4b)

Dissatisfaction was also expressed in terms of perceived insensitivity of the specialist delivering the news, and of women not receiving sufficient detail about the prognosis or treatment available as quickly as they would have wished. Women whose babies had treatable anomalies also expressed acute distress and grief at this initial point of diagnosis:

> As soon as you get into the realm of possibility, you need to be much more supportive, and take more time to explain issues. (Maoliosa, Type 4b)

> It's not just the condition ... it's is there anything else or is it worse than they think it is? (Trina, Type 4b)

Most women mentioned the effect of the presence of others at the examination in the fetal medicine unit. Since the urgency to receive a diagnosis was paramount, women thought that their distress was compounded by being first scanned by a trainee in fetal medicine:

> [The consultant said] 'I'm going to let the registrar look first, then I will come back and have a look.' But when she [specialist registrar] started looking, I just started crying, panic and fear I think. I needed him back in. We had a bad night. I just couldn't wait any longer. (Tara, Type 1)

Nevertheless, all of the women acknowledged the need for training and, once the trainee was properly introduced, had no difficulty with their presence. Although most women were satisfied with their first encounter at the fetal medicine unit, they described practices they found particularly supportive and unsupportive when receiving the diagnosis.

Describing the Anomaly to Parents

Women consistently raised the issue of health care professionals' use of unsuitable language, including the inappropriate use of medical terminology:

> "10 percent mortality," it didn't register with me. Now a 1-in-10 chance your baby could die is high ... you need to know to prepare. (Fay, Type 4a)

> Survival in the long-term may mean something to a medical practitioner; it doesn't mean anything to me ... in accounting terms it's more than 5 years. (Tara, Type 1)

Most women said that the diagnosis was explained through the use of a combination of fetal ultrasound images, percentile charts, and diagrams. They all commented that the use of visual images enhanced their understanding of what, at the time, seemed incomprehensible:

> I had never heard of it ... they sat me at the computer, it made things quite clear. (Doireann, Type 1)

> Then the consultant sat the two of us down and he even drew out a little diagram of what kidneys looked like, the whole thing from beginning to end, and then I knew it wasn't a big problem. (Aisling, Type 4b)

Availability of Written Information

All women described the need for supplementary written information either after the initial scan or after the appointment with the fetal medicine specialist. They described the usefulness of such information in several ways, from protecting parents through referral to appropriate Internet sites, enhancing recall and understanding, to assisting in explaining the problem to significant others:

> It would sort out things, rather than have us looking at American sites, here we are in (the hospital) and we can't get (written) information ... just to be able to take it away. (Fay, Type 4a)

> Well, it was really hard to convince our parents ... miracles can happen (they'd say). You don't really want people saying it's going to be okay. So for them, yeah, it would be easier to see it written in black and white. (Laoise, twins one Type 1)

Continuity of Caregiver

All women who continued the pregnancy valued the continuity of seeing the same clinician(s) on repeated visits and described the importance of developing a trusting relationship. On some occasions, women were offered shared care with the referral site to minimize traveling to appointments or were discharged back to the referral site to facilitate birth within their own community when the outcome was incompatible with life. Women in these situations reported a lack of continuity of care in the regional unit, which led to fear and frustration:

> I have never seen the same two people ... I am very wary of going up there now. (Niamh, Type 2b)

All women appreciated an opportunity to contact the relevant health professionals with queries that may have arisen between one appointment and the next, and were particularly receptive to gestures indicating a caring and sensitive approach to their particular needs:

> You are going to have some questions when you go home, so you can ring me [consultant] or the midwife tomorrow and he circled the number and said that is no problem. (Kerrie, Type 2b)

> I felt they cared—I was not just another interesting science experiment. They said we know this is very disappointing for us—focusing in on the emotional. (Doireann, Type 1)

Circumstances deemed as insensitive by women included excluding the partner from the discussion and the consultant appearing to be rushed and leaving before it was established if the parents understood the diagnosis. All women identified a need to receive ongoing and individualized support from the health care team, irrespective of the significance of the anomaly:

> I didn't need frequent scans, but [you need] somebody you can ring ... you need pregnancy information as well as support. (Erin, Type 4b)

Women identified this support as most desirable if it came from a midwife with expertise in the area,

particularly if it could be provided in their home environment and away from the tension and busyness associated with the fetal medicine clinic:

> ... you need someone to tread lightly with you, if they have midwifery experience you can ask pregnancy questions. I'd be afraid of a psychiatrist, they could mess with your head and you'd end up worse. (Heather, Type 1)

> You are less inclined to bother them [clinical staff], you know how busy they are ... someone coming out to me at home is better. (Ciara, Type 5)

Additional reasons cited by the women for choosing a midwife to provide this support included having a skilled person to ask questions on an ongoing basis about the specific anomaly, and pregnancy, delivery, and postnatal issues. Receiving support from the departments of social work or psychiatry was associated with social stigma by women and was seen to reflect an inability to cope:

> You need someone like a midwife who has the [clinical] background as he/she will fully understand what we are going through. (Aoife, Type 1)

> No one would think there is anything is wrong if you say the midwife is calling to see me because there are problems, but the social worker—I think there is a stigma attached to that. (Maeve, type 1)

Discussion

Receiving an adverse diagnosis was traumatic for all participants irrespective of the severity of the anomaly, as previously reported in other studies (16,24,44). Seeking information is a common coping strategy for anyone facing a stressful event (45), and women in this study, in common with others (6), consistently described the need to receive as much information as possible at the point of diagnosis, to enable them to come to terms with the news, irrespective of the nature of the outcome. Dissatisfaction with the level of information received was particularly evident when the suspicion of anomaly was raised in a regional unit, which is consistent with the experiences of women elsewhere who continued the pregnancy after receiving an adverse diagnosis (24). This finding may be due to operator uncertainty about the diagnosis when compared with clinicians in specialist centers. The authors acknowledge that the presence of a fetal medicine specialist in all maternity units is neither feasible nor desirable; however, full disclosure about what *is* seen by the operator before referral to a tertiary unit is necessary.

Women were particularly distressed when the operator performing the initial scan did not respond to questioning. If limitations are imposed on operators at a local level as to how much he or she is permitted to discuss, immediate access to an appropriately trained (16) professional should be available to explain the findings to the woman. In addition, referral to a fetal medicine specialist, preferably within 24 hours, was seen to limit the distress associated with an uncertain diagnosis.

Positive aspects of care included staff providing guidance to appropriate Internet sites, communicating clearly without the use of jargon, and enhancing understanding through the use of diagrams and other visual aids such as the ultrasound screen and percentile charts. As in other studies (18,33,44,46), women valued the continuity of seeing the same health care professional(s) on repeat visits. When continuity of care was not available, it led to a degree of frustration and fear. The decreasing amount of time available to spend with individual clients and families has been identified previously as a barrier to effective communication (46). Women were particularly receptive to gestures they perceived as indicating a considerate and sensitive approach to care, such as being telephoned at home and receiving acknowledgment of the magnitude of their loss.

This study highlights that all women, including those whose babies were diagnosed with treatable anomalies, require acknowledgment of their concerns, which related to the possibility of additional abnormalities being discovered. Women were sensitive to the pressures that clinic staff were under and indicated that their need for skilled support could be met outside the clinic environment. Because the ongoing need to access information about the pregnancy and birth was seen as fundamental to coping with the situation, women suggested the most appropriate person to provide this aspect of care would be a midwife with expertise in the area. It is possible that this recommendation may have been influenced by participants knowing that the principal researcher was a midwife. Nevertheless, it does not detract from participants' perception that a midwife was the most appropriate person to provide the skilled support they needed outside the clinic environment. Provision of supplementary written leaflets was identified as useful in enhancing women's recall, assisting them in informing significant others, and helping them to understand the diagnosis (47).

The context of the study is undoubtedly relevant since continuing the pregnancy after diagnosis (irrespective of the outcome for the fetus) was the "norm" in this study setting. Several important differences between our findings and international experiences have emerged, suggesting that social and cultural beliefs may influence professional attitudes to pregnancy management after an adverse diagnosis.

Internationally, evidence suggests that the care received by women who choose to continue their pregnancy is compromised in settings where health professionals view termination as a more appropriate decision (30,32,33,48,49). This factor did not emerge in our study.

Unlike other studies in this area, the seriousness of an anomaly was not an equally reliable predictor of whether or not parents chose to continue the pregnancy (50–52). The data suggest that professional attitudes to screening and pregnancy management are influential in interactions with women and support Maijala et al's (16) suggestion that parents' experiences of care can be either enhanced or weakened by caregivers' actions. Although the study findings are influenced by the context, the prospective design, inclusion of a wide range of anomalies, and relatively high participation rate in this study enhance the potential for these findings to contribute to the knowledge base of health professionals involved in caring for women who choose to continue their pregnancy after the diagnosis of a fetal anomaly.

Implications for Care

Communication issues are a central component to care provision in this area, and although women, in general, expressed satisfaction with their encounters with the fetal medicine team, this study suggests a need for improvement in how an adverse diagnosis is communicated to parents when first suspected. It would seem sensible and entirely reasonable that those performing the initial scan respond to parents' questions honestly with whatever information is available at that time. Professional boundaries that prevent this response, real or otherwise, mitigate against providing women with the sensitive care they need and deserve. Subsequent prompt referral to fetal medicine specialists when uncertainty exists is essential, followed by the provision of written information resources and support outside the clinic, preferably from a specialist midwife or nurse. Health professionals in the area of prenatal diagnosis should have access to education on how to break bad news sensitively to a vulnerable population since negative consequences are significant for all when unsupportive encounters occur.

Conclusions

This study highlights the influence that personally held attitudes toward pregnancy management after an adverse diagnosis can have on women's care. To avoid unsupportive encounters between caregivers and women, any education in this area should endeavor to assist health professionals to identify their personal beliefs and consider the possible influence they may have on women's experiences when caregivers' and women's choices diverge. Acknowledging and managing personal views in the clinical setting have the potential to improve care irrespective of national boundaries. Continuity of caregiver was highly valued by these women, and we suggest establishing a specialist midwifery role to provide ongoing support for parents to meet this need.

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Continuing a pregnancy after fetal anomaly diagnosis: how much information is enough?

Information preference and coping strategy

ABSTRACT:

Aim The aim of this paper is to explore if informational coping styles in women who continue the pregnancy after diagnosis of a fetal anomaly have implications for providing supportive healthcare interventions.

Background The identification of a fetal abnormality on ultrasound in pregnancy is both shocking and distressing for women, and seeking information in this stressful situation is a common response. Individuals differ in the amount of information they require to assist them with the coping process.

Method A longitudinal study involving 38 women was conducted using a grounded theory approach. Data were collected in 2004-2005 through in-depth interviews at three time intervals: within 4-6 weeks of diagnosis, 4-6 weeks before the birth and 6 to 12 weeks postnatally. Data from the second time period are presented here. Ethical approval was obtained and women gave written consent to participate. Qualitative analysis using the constant comparative method was performed.

Findings Women described their main concern from the point of diagnosis until the time to give birth in terms of "Maintaining control". Two main categories emerged in relation to preferences for seeking information: "Getting my head around it" and "I'll cross that bridge when I come to it" These main categories describe two differing preferences for seeking information.

Conclusions Matching of information preferences with coping styles may reduce anxiety. Women with high information needs respond well to detail. However, women with information avoidance behaviours should be facilitated to 'opt-in' to information when they are ready, to reduce the stress caused by perceived information overload.

Keywords. Antenatal ultrasound, fetal anomaly, midwifery, information preferences, grounded theory

What is already known about this topic

- Provision of information for women taking part in screening programmes is fraught with difficulty
- Providing explicit information on possible anomalies to a population where the majority will not be affected may cause needless worry
- Providing information in stressful events can assist individuals to cope

What this paper adds

- The level of information needed regarding the anomaly varies between women, but all women welcome information to prepare for labour and birth

- The majority of women wish to avoid receiving too much information but a sizeable minority have high information needs that are not always met
- Clinicians should take account of information seeking and avoidance strategies in order to provide appropriate information to meet individual demand, while providing supportive care for women

INTRODUCTION

Second trimester ultrasound examinations have become an almost universal aspect of antenatal care packages (Garcia *et al.* 2002) offered to low risk women in pregnancy. Previous studies have demonstrated that when ultrasound examinations (USS) reveal normal findings, women's views of screening are extremely positive (Hyde 1986, Green 1994, Rapp 1999, Stephens 2000, Lalor and Devane 2006). A national survey of antenatal ultrasound services in Ireland (Lalor and Devane In Peer Review) has shown that 95% (n=21) of units offer a second trimester ultrasound scan (USS) to some or all women, with wide variations in the management of pregnancy after an anomaly or variant are diagnosed. With such widespread availability of ultrasound in pregnancy it is unavoidable that some women taking part in screening programmes will be faced with the USS uncovering a fetal anomaly. Consequently, it is recommended that detailed information be given to women before the examination (Field *et al.* 1985, Abramski and Chapple 2003), to ensure that they are aware of the capacity for diagnosis and limits of the scan (Green 1994, Seeds 1996, Larsen *et al.* 2000, Lalor and Begley 2006).

The psychological distress exhibited by parents in response to a diagnosis of fetal abnormality has been described as comparable to an acute grief reaction (Statham *et al.* 2000, Lalor and Begley 2006). Lazarus and Folkman (1984) view stress/distress as an interaction between an individual and their environment, stating that psychological stress occurs when there is an imbalance between the strength of the demand and the individual's perceived options/resources to deal with that demand. Individuals often respond by seeking information (Garvin and Kim 2000) and the positive effects of providing information in order to assist individuals to cope have been recognized (Cipperley *et al.* 1995). However, it has been acknowledged also that there is a need to adapt information according to the individual wishes and reactions of each person (Krantz *et al.* 1980, Miller and Mangan 1983, Barsevick and Johnson 1990, Garvin and Kim 2000). Personal attributes are thought to influence how one responds to stress (Folkman and Lazarus 1980) and it has been suggested that other influencing factors include the availability of options and resources to deal with the issue. Although much has been written of the technical aspects of fetal anomaly diagnosis, there is relatively little known about how women cope with the demands of continuing a pregnancy after such diagnosis. In particular, due to the accessibility of termination of pregnancy in other countries, many health professionals may lack the knowledge and skills to care properly for women who choose to continue their pregnancy (Chitty *et al.* 1996). Research in this area is therefore crucial.

THE STUDY

Aim

The aim of this paper is to explore if informational coping styles in women who continue the pregnancy after diagnosis of a fetal anomaly have implications for providing supportive healthcare interventions.

Design

A longitudinal grounded theory study of women's experiences of receiving a suspected or confirmed diagnosis of fetal abnormality on routine second trimester ultrasound up to the birth was undertaken. Grounded theory is an interpretative method used to construct behavioural patterns from data that are rigourously collected and analysed (Glaser 2001). It is based on the principle that all shared patterns of behaviour emerge from groups, developed from group members' definition of the circumstances affecting them (Glaser 1978). Theories are generated around the emerging of a core category, which is the main problem of interest to the participants (Glaser 1978), and develops from the integration and conceptualisation of the relationship between identified substantive codes. In order to conceptualise the theoretical framework as it evolves, extensive memoing is required to compare the properties of the ideas and perceptions as they emerge (Glaser 2005). For further detail please refer to Lalor and Begley (2006) (in press).

Participants

The work was based at a tertiary referral maternity hospital in Dublin, Ireland. Data were collected from April 2004 to August 2005 (18 months) from women booked at the main centre, and women referred from a number of regional centres for tertiary care. Women were purposively sampled initially on the basis of a diagnosis of a fetal anomaly in the current pregnancy, without previously established risk factors, and were subsequently theoretically sampled on the basis of the type of anomaly/likely pregnancy outcome.

Characteristics of the participants

Thirty women from the full sample of 38, three of whom were expecting twins, chose to continue their pregnancy. Nine were primigravidae and 21 were multigravidae. Of the 30 women that continued the pregnancy, 22 women were interviewed pre-birth. Seven of the women (23%, n=30) who had taken part in the initial interviews delivered unexpectedly shortly after the diagnosis, and consequently were not interviewed again until 6-12 weeks after the birth. One woman developed a depressive illness and was receiving care from the psychiatric team. In order to ensure that this woman did not become increasingly vulnerable through taking part in the second interview, she was excluded from the study. There were no particular differences between women who delivered prematurely and those whose pregnancies continued to term in relation to the type of abnormality (Table1). Of the seven women that delivered prematurely, 5 were primigravidae and 2 were multigravidae, 3 babies died in utero and 2 in the immediate neonatal period, compared to one death in utero and 6 neonatal deaths in the pregnancies that continued to term.

Data Collection

Over the duration of the study, data were collected at three time intervals: within 4-6 weeks of diagnosis, again 4-6 weeks from the likely timing of the birth and 6 to 12 weeks postnatally, and were conducted in the woman's home at a time convenient to

her. Conceptual analysis of the data from phase 1 (4 weeks after diagnosis) resulted in the generation of the process 'balancing information', whereby women described their experience of this traumatic event in terms of weighing up their expectations of a healthy baby and the positive anticipation they felt towards the ultrasound examination against their lack of preparation for an abnormal ultrasound finding, leading to an exacerbation of the shock experienced at diagnosis (Lalor and Begley 2006).

In phase 2, the results of which are reported here, data were collected within 4-6 weeks of the anticipated delivery using digitally-recorded in-depth interviews lasting 1-2 hours. They usually began by asking the woman how she had been since we last met, which was sufficient to generate dialogue without further questioning. However, theoretical sampling to clarify both interpretation of the data from phase 1 and to request more detail or explanation to obtain accurate information regarding the current situation meant that each successive interview became more focussed. However, this does not mean that the woman's conversational prerogative was limited, as the interview remained sufficiently open to facilitate her to tell what she wanted to tell and how she wanted to tell it.

Ethical considerations

Ethical approval was obtained from the study site and the Faculty of Health Sciences, Trinity College Dublin. Women gave written consent before and after each interview. Clarification was also sought on completion of the interview as to whether the participant wished to withhold, or amend any of the information given at this time. The data presented in this paper are from phase 2, consequently, participants had agreed to being contacted for this phase at their initial interview at least 6 weeks previously. As protection of the emotional well-being of participants was held to be paramount all participants were offered the option of an exploratory counselling session with a counselling psychologist external to the study site. Access to the routine hospital based support services such as: consultation with a social worker with counselling experience or referral to the psychiatric team could be arranged if a participant felt that this would be helpful. All data were kept strictly confidential, referral centres were not identified, pseudonyms were assigned to participants and if staff names were mentioned they were replaced by their professional status (i.e. midwife, obstetrician etc).

Data Analysis

Data were analysed by the principal researcher (JGL), concurrently with data collection, using the constant comparative method (Glaser 1978). Fieldnotes were recorded after each interview in a diary where the iterative process of developing codes into categories was recorded, which was subsequently mapped on an A1 sheet. The diary entries were made for two reasons; firstly, to record thoughts or links to data collected or analysis already performed that came to mind as a result of something that was said in the interview that had just transpired. Secondly, entries were made as the transcripts were being hand-coded and links between codes and categories became

apparent. These links were tested for accuracy in future interviews. Use of the constant comparative method (Glaser 1978) allowed comparison of data between: phase 1 and phase 2, between emerging categories within phase 2, and facilitated the development of relations between concepts and categories as data saturation occurred. The researcher's interpretation of events was clarified with the women to ensure the truthfulness of the ongoing analysis and findings. The rigour of iterative process was verified by peer debriefing (Holloway and Wheeler 1998) with an expert researcher (CB). Finally we compared our findings to literature in the substantive area.

FINDINGS

Insert table 1

Maintaining Control

The data showed that, at varying times during the course of the pregnancy, women had diverse needs with regard to the nature and amount of information they required in order to cope with the situation. Although women's need for information at such a stressful time will undoubtedly vary between individuals, the goal of the analysis was to move beyond description toward the development of an explanatory model, sufficiently flexible to identify the main concern whilst acknowledging the individuality of multiple participants' experiences. Ongoing antenatal visits and interactions with caregivers regarding the pregnancy were central topics of conversation in phase 2. The relationship between women and their caregivers, which was essentially based upon the process of sharing information, became influential in women's struggle to manage their daily lives, which had fundamentally changed since the diagnosis. "Maintaining control" emerged as the core category, and relates to the strategies that women used to control their access to the amount and type of information they needed from health professionals over the course of the pregnancy in order to cope with both the current situation and with that which lay ahead. Two distinct coping strategies in relation to whether women sought or avoided information emerged, and are categorised using two *in vivo* codes of "Getting my head around it" and "I'll cross that bridge when I come to it". Each describes two distinctly different relationships between participant's need for and responses to information regarding the pregnancy, the former reflecting a high preference and the latter a low preference for information. The data are presented chronologically; and delineated by preference from diagnosis to birth.

1. Post diagnosis

Getting my head around it

After the initial shock, for some women the diagnosis was confirmed based on ultrasound findings alone, and additional invasive testing was not required. Even when a certain diagnosis was given, all possible outcomes relating to the remainder of the pregnancy could not be given at this initial consultation. However, some women described their need for this information in order to cope between that point and their

next scheduled visit at the fetal medicine centre. When this was the case it was very common to find women accessed sources such as the internet, whilst some sought a second medical opinion.

I went home to do my research, the internet cleared up a lot of things for us, it helped us ask the right questions when we went back (Cliona)

Access to information seemed to reduce the uncertainty around the diagnosis or outcome, and being able to understand how specific changes in test results affected the pregnancy outcome seemed to increase the sense of control over the situation. For other women the diagnosis was less clear-cut and the outcome was not definitive. In this case information to clarify the situation was not available, and women with a high preference for information found it difficult to cope with uncertainty.

"I searched everywhere, but I had to put up barriers, there are so many unknowns. I was so down today, it's so unclear, you don't know what to hope for" (Eavan)

I'll cross that bridge when I come to it
Although the case for giving whatever information is available to parents is compelling, some women felt they were receiving information at a level that exceeded their needs. This behaviour to avoid information was categorised with the in-vivo code of "I'll cross that bridge when I come to it".

I wanted information but not so much that it would freak me out. It's great to be prepared but you can get information overload (Aisling)

When women with a low preference for information received more information that they needed, the consequence was increased anxiety.

2. Decision making regarding invasive testing

Getting my head around it
For some women, their need for additional information regarding the diagnosis influenced their decision as to whether to opt to have amniocentesis or not:

I had the amnio to try to deal with it ... I was delighted just to get a diagnosis... there was a great sense of relief just knowing... we had been getting no information week after week, [until we got the amnio result]
(Doireann)

When the amniocentesis confirmed that the fetus had a lethal anomaly, this information was often used as a basis to inform the planning of future pregnancies.

The more information we could find out the better, in terms of whether to try [and get pregnant] again (Tara)

I'll cross that bridge when I come to it
Other women preferred not to have a certain result and to hope for a positive outcome. Refusing the test was seen as a way to keep the hope of a healthy baby alive, a hope they needed in order to cope on a day to day basis until the birth. Sian had been given a 1:3 risk that her baby had Down Syndrome:

It [amniocentesis result] could put a totally different outlook on the last few months of your pregnancy, we prefer to think that the baby will be normal (Sian)
However, unlike other stressful medical situations, pregnancy is unique in that there are two (or three) patients to consider. One woman expecting twins (one of whom was normal) was offered repeated invasive therapeutic procedures to provide predictive information regarding the affected fetus's condition, but on the balance of risk, rather than avoidance of information, refused the offer.

We didn't keep having tests done because we didn't want to miscarry both babies (Orla, Twins, one lethal)

3. Ongoing monitoring at the fetal medicine centre

Getting my head around it
Some women required frequent monitoring in the fetal medicine unit depending on the fetal condition, and found the feedback at the visit regarding fetal wellbeing crucial to how well they managed to keep going until the birth.

It felt really good that they were checking everything, there was a sort of comfort in it (Ciara)

I need those visits for the scans...you're hoping everything is stable even though [you live in fear] of getting more bad news (Niamh)

Once a satisfactory level of factual knowledge relating to a definitive diagnosis was obtained, the ongoing need for information diminished. If an additional variable/problem manifested during the pregnancy the high need for information regarding the new variable returned.

Once you hear something new, you go back searching again. I focussed my energies on treatment options (Maolíosa)

I'll cross that bridge when I come to it

Some women felt even when fetal wellbeing could deteriorate but neonatal intervention was possible they couldn't cope with the constant demand of assimilating additional information.

I felt I couldn't cope with anymore information, I didn't want anymore- I thought my head would explode, but my husband was full of questions (Emer)

For some women where neonatal survival was predicted to be low, but when mortality was not a certainty, hearing something positive at the fetal medicine visit was important.

I haven't asked anymore about the problems. I don't ask too many questions it's just my way. If they [the twins] could have a bit more weight on them they might have a chance, a bit of positivity (Emma, Twins)

4. When specialist neonatal intervention is anticipated

It has become custom and practice in the study site to arrange a visit to the neonatal unit for parents whose infants are likely to survive and to require neonatal support. Whilst this may have been helpful for some, for women with low preferences for information this visit became an additional stressor.

I thought it was totally unnecessary. I didn't want to go to the unit at all, ...I went in with blinkers on and wasn't even listening to what the woman was saying ...I just couldn't face it (Cliona)

However, providing an information booklet regarding the unit for women that exhibit information avoidance strategies may be a helpful alternative.

We got a booklet about SCBU, it was helpful to kind of get your head around the amount of equipment that was going to be involved (Emer)

Irrespective of the information preferences exhibited, there were key issues that the majority of women felt needed to be addressed by the healthcare professionals providing care.

Type of labour and birth

Almost all women mentioned their concern for labour or the mode of delivery. Primigravidae were concerned at never having experienced labour and delivery before, and multigravidae who had previously experienced a normal delivery were concerned regarding the need for a caesarean birth because of fetal complications.

I'm hoping it will be a normal delivery, a caesarean is a major operation and I want to be able to leave the hospital [to visit the baby in the paediatric unit] (Ciara)

Some women frequently expressed their difficulty with coming to terms with the diagnosis, and this was most often observed in women where the extent of disability to be experienced by the infant could not be predicted. The only sense of control these women felt they had left was to decide when the baby would be born.

I said I wouldn't be able to cope with it [going to full term] I think if they said to me you have to go to 40 weeks it would kill me, literally kill me. I couldn't do it. I want an induction date at 38-39 weeks (Niamh)

I just I feel I have been pregnant for the last 5 or 6 years. Its driving me mad...I need a date for the birth (Keeley)

Although women were prepared for the fact that they would be separated from their babies, women also needed to know if the infant was going to be transferred to another hospital as many assumed they would have unlimited access to their baby in the neonatal unit and news of this additional separation came as a blow to some. For women anticipating a live birth, but referred from a regional centre, arranging the place of birth in advance was essential, as many women were fearful that if the place of delivery was unplanned, the requisite knowledge regarding the infant support that would be required would not be communicated effectively to the booking hospital.

If the anomaly is lethal

When women were informed that the anomaly was lethal, one of their main concerns was when the baby was likely to die i.e. antenatally, intrapartum or postnatally, and if there were any resulting physical risks to themselves.

It's a horrible situation; we are waiting for the baby to die inside me... I think at the very outside it will go to term and die at birth... you need, someone to tell you what happens when the heartbeat stops (Tara)

I wanted to know was my life at risk? Would I miscarry? What would I feel before the miscarriage (Kasey)

Women were concerned about how they might react to seeing the baby, and needed reassurance that an experienced health professional would be with them to help them during that time. The information preference that was exhibited throughout the pregnancy, in general, remained consistent up to the birth as some women required detailed information on the baby's likely appearance, as the fear of not knowing what to expect was greater than knowing, whereas others preferred to wait and see. All women expressed the need for specific guidance on what to bring to the hospital in preparation for the birth as this was a situation where previous experience couldn't

guide them, and an opportunity to speak to the bereavement counsellor, close to the birth, to assist in the planning of a funeral was welcomed. This needed to be followed up with written information to remind women of the choices available to them, as this facilitated women to access this information as and when they were ready.

Planning the delivery can a very positive experience for some women, as when the anomaly is lethal their greatest hope is to have the baby born alive. Laoise was offered an elective caesarean section primarily in the interest of the healthy twin; however, she focussed on the additional benefit of both babies (one with anencephaly) being born alive.

We have them straight away, both of them... and have as much time with (baby with anencephaly) for whatever length of time he has to live (Laoise, Twins)

DISCUSSION

This paper begins to address the issue of providing information to meet the needs of women who continue the pregnancy after the diagnosis of fetal abnormality. The data presented depict the second stage in the journey, whereby women are "maintaining control" from the point of diagnosis up to the birth and trying to manage the stress of the situation on a day-to-day basis. Two distinct preferences emerged: information seeking or information avoidance. The first category of "Getting my head around it" represents the requirement for high levels of information, accompanied by strategies to source additional information if the amount of information received from the health professional did not sufficiently meet their needs. The second category "I'll cross that bridge when I come to it" describes how women preferred to hear positive, or less threatening information about their baby's condition, and tried to block additional information to avoid becoming stressed. After these two distinct preferences emerged, we returned to the literature to compare our findings to the substantive research in the area. Our search revealed few published data on women's experiences of continuing a pregnancy after prenatal diagnosis. Perhaps this is due to the availability of termination of pregnancy in other jurisdictions, and there is evidence to suggest that prenatal diagnostic techniques have led to a increase in selective terminations (Peller et al. 2004), in particular if the diagnosis is lethal or carries a significant risk of handicap (Mansfield et al. 1999, Tymstra et al. 2004). Although there are some accounts in the scientific literature of parents' experiences of continuing the pregnancy after an adverse diagnosis, they are limited on the basis of the severity of the anomaly.

The literature search was widened to include research from the areas of psychology and counselling. It was in this area that we discovered that Miller and Mangan (Miller 1980, Miller and Mangan 1983) have described two primary approaches undertaken by people facing stressful health-related situations. 'Monitors' are described as those that seek out information and monitor the threat, similar to the women in our first category "getting my head around it", whilst 'blunters' avoid information that may result in increasing anxiety, as demonstrated by women in our second category "I'll cross that bridge when I come to it". Women that exhibited

monitoring type behaviour needed to have control over the situation in order to cope with what they had been told, and saw information as the key to regaining that control. This behaviour was also repeated when a new variable was introduced into the situation such as a change in the fetal condition or the discovery of an additional anomaly or variant, regardless of the impact this new variable would have on the predicted outcome. This need for control in a stressful situation has been previously described as a problem-focussed approach to coping, where the focus is to manage the problem causing the distress (Lazarus and Launier 1978). The authors have, however, suggested that this approach is more common when the situation is perceived as changeable. Whereas in our study, women who responded initially with a high need for information focussed on the difficulty of coping with an uncertain diagnosis/outcome, and at times adopted avoidance strategies to protect themselves. However the desire to regain control of an unchangeable situation did not disappear, and re-emerged in relation to controlling the timing of the birth. Women who adopted blunting strategies, continued to avoid taking information on board regarding the fetal condition, particularly when it was of a negative nature. This coping process has been described as emotion-focussed (Folkman and Lazarus 1980), and the authors suggest that this manifests more often in circumstances that are appraised as unchangeable. Women exhibiting this coping process required more positive information about the fetus, such as pointing out what was normal about the baby or highlighting fetal growth or movement when the fetal condition and prognosis remained grave.

In this study, monitors needed to have whatever information was available, irrespective of the result, whereas blunters preferred to hold on to the possibility that the result would be normal; this was evidenced in the differences in uptake when invasive testing was offered to confirm a diagnosis. Some women did comment on a discrepancy in information seeking preferences between themselves and their husband, which on occasion caused tension between them. Locock and Alexander (2006) have suggested that men have more of a propensity to adopt monitoring strategies and women to exhibit blunting strategies, but have suggested that further work in this area is required to confirm this. Whilst this is an analytical and not a statistical study, and preferences were not measured in a robust manner, it is of interest that two thirds of the women who took part used 'blunting' strategies on an ongoing basis. The information level required did not seem to be related to the mildness or severity of the abnormality, as both preferences were manifested throughout the range of diagnoses.

Whilst women want to be informed about the fetal condition it seems apparent that the desired level of information varies. Monitors require ease of access to information, whilst blunters need to be allowed the freedom to 'opt-in' to detail as and when they wish. Women that exhibited monitoring strategies became increasingly distressed when sufficient access to information was not available to meet their need, whilst women using blunting strategies became increasingly distressed with information overload. Ameliorating stress for women requires healthcare professionals to observe the strategies used by their patients and to respond appropriately. Perhaps it is timely for health professionals to reflect on the appropriateness of 'one size fits all' policies that have been introduced with the intention of supporting women, such as

arranging a visit to the neonatal intensive care unit for all, when in fact it may be an additional stressor for many. However, the data show that specific aspects regarding preparation for labour and the birth should be raised by health professionals irrespective of the coping strategy manifested, as they are welcomed by all.

This complexity of responses to traumatic situations has been highlighted in other areas of healthcare (Steptoe and O'Sullivan 1986, vanZuuren and Wolfs 1991, Alderson *et al.* 2006, Locock and Alexander 2006). Similar problems regarding the disparity between the recommendations given in professional standards to inform parents regarding their child's wellbeing and parents' preferences for information have been recognized in other areas (Alderson et al. 2006) of healthcare. We have previously urged caution regarding the presentation of information about prenatal screening tests to large numbers of women without assessing its suitability for use in the intended context (Lalor and Begley 2006). Some authors have expressed concern that staff experience of couples continuing the pregnancy is limited and they seemed ill prepared to provide appropriate care (Chitty et al. 1996, Edwins 2000). It is hoped that this study will help to some extent in rectifying that situation.

CONCLUSION

Data from phase 2 of this study have highlighted another dimension to providing appropriate information, demonstrating that information preferences vary between individuals and may vary in the same individual depending on the situation. For health professionals to respond effectively, continuity of carer to develop a supportive relationship is essential. As fetal screening programmes become ever more routine and screening is moving to the first trimester, a mechanism to ensure that women are informed appropriately is required. We would suggest that development of our model 'balancing information' (Lalor and Begley 2006) to include taking cognizance of information preferences, provides a framework for clinicians both to match information need with information demand and to guide further research in this area. Such emphasis on planning information-giving depending on one's observation of women's coping strategies and resultant information needs will result in realising our shared goal of more woman-centred care.

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