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Women's experiences of communication with medical staff during complicated pregnancy

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Acknowledgements

To

Jamie for the patient love

Abstract

This study explored the ways in which women experienced non-facilitative communication with medical staff during a complicated pregnancy. Complicated pregnancy has been associated with a higher risk of mental health difficulties. The research was carried out in Ireland and focused on women's relationships with medical hospital staff during this time as they are ideally placed to offer relational support, and potentially prevent longer term problems.

In-depth interviews were conducted with six women. The qualitative methodology of interpretive phenomenological analysis was used to understand their experiences. Four superordinate themes emerged. These were 'Information difficulties' 'Disempowerment', 'Empathic failure' and 'Relational impacts'. Crucial information was withheld, private details were discussed in public spaces and key aspects of women's experiences were omitted from their hospital notes. Participants spoke of feeling disempowered and manipulated by staff. All participants referred repeatedly to feeling that the majority of staff failed to demonstrate empathy. Women felt isolated and unseen, with staff focused on tasks rather than holistic treatment and their infant's needs but not those of the women. Finally, women described how their relationships with themselves, partners, and crucially, their infants had been impacted.

Participants' accounts may represent a gap in the care of women who experience the trauma of serious pregnancy complications. Findings suggest a role for counselling psychologists in providing training and consultation for medical staff in order that they might develop the capacity to offer improved support to women and infants during this time when they are more susceptible to mental health difficulties.

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Chapter 1: Introduction

1.1 Introduction

Penticuff (1982) has defined a high risk pregnancy as one with increased risk for maternal or foetal mortality, foetal anomaly or which compromises maternal and/ or foetal health. There are many factors which can contribute to a pregnancy being considered 'high risk'. These may include the age or weight of a woman, problems in a previous pregnancy or pregnancy complications. Pregnancy complications are problems that only occur during pregnancy. Some examples of complications are placental abruption where the placenta separates prematurely and hyperemesis gravidarum where vomiting leads to severe dehydration. The World Health Organisation (1996) have estimated that at least 15% of all pregnant women suffer from complications which require skilled and rapid obstetric intervention, without which they are likely to experience serious and long term illness.

While considerable research has been carried out with pregnant women, little is known about those with complications as they are often excluded from research samples (Brandon et al, 2008).Research which has been conducted in this area has shown that complications are associated with higher risk of psychological distress. Many of these studies have utilised a quantitative approach, or they have been carried out in the field of nursing and obstetrics. As a result women have been written about in a way which does not always reflect the co-created field or capture the depth of their experiences. Subsequently, psychological understanding of this area remains limited.

The domination in the research by nursing and obstetrics is not surprising and reflects the clinical environment, in which women with complications are cared for physically by medically trained staff. Research participants are therefore often a convenience sample of hospitalised women. As most maternity hospitals do not employ staff with training and

expertise in the psychological therapies, nurses and doctors are therefore likely to play an important role in the mental health of women with complications by default.

Within the Irish context, professional psychological support is limited to a psychiatric service for severe problems and a small number of part-time nurse led 'support and education' services. Counsellors, psychotherapists and psychologists are not employed at any maternity hospital. The research gap therefore appears to be rooted in a clinical gap:

an absence of psychological clinicians in this area. However this absence of psychological expertise is puzzling given the fact that women with complications have been shown to be a vulnerable population (Berg Lundgren & Lindmark, 2003) at high risk of developing mental health difficulties (Burger et al, 1993). One possible explanation for this anomaly is that it reflects the value system of these medical institutions in relation to both women's mental health and psychological expertise.

A pilot interview at a maternity hospital in an Irish city offered some insight into how women may be impacted by this arrangement. During this interview the support midwife at this hospital explained that in fact women with complications rarely present for support and that on the occasions they do, they are not encouraged to 'delve' into their situation. Should they however request it, the support midwife offers a level of 'support and education' aimed at helping them to *cope.*

One way of understanding this process is that conscious and nonconscious communications from staff *may* subtly serve to isolate women within their distress. This perspective places the issue very clearly within the co-created space and suggests that staff communications may act to discourage women from openly exploring their anxieties at this time.

This process is reminiscent of Glaser and Strauss's (1965) work on awareness contexts. In their seminal study on dying in hospitals they showed how staff interactions with patients could lead to isolation. While no studies documenting this experience for women with complications were identified, it is possible that they too are enmeshed within similar power-based relationships and processes which may lead to collusion and alienation.

Finally, and in stark contrast with the related area of death and dying: following the birth, the tumultuous task of child rearing begins. However, as a result of the trauma of complications, these women may not possess sufficient psychological reserves to face the challenges of caring for themselves and their new child.

Overall then, there are several indications that suggest that the communications of medical staff might play an important role in the experiences of women with complications and that this area warrants exploration :the significant numbers of women who experience pregnancy related complications, that complications are associated with higher levels of psychological difficulties, that in addition to the trauma, women face the exhaustive challenge of childcare following birth, that psychological therapists have no presence in the area, that medical staff and medical training dominate in the psychological care of women with complications and that the procedures for mental health support may serve to further isolate women.

1.3 **Relationship to the research topic**

In the spirit of transparency I believe it is important to acknowledge that this study emerged from personal experiences of pregnancy complications. This is with a view to increasing the rigour of my study by exploring how my experience might affect the research and how I will address this.

In my first pregnancy in 2005 I was diagnosed with grade 4 placenta previa and hospitalised . While this is a life-threatening complication the implications were never discussed, support was never apparent nor offered, and I was therefore left quite isolated during this time. As far as I am aware this was also the case for the other women I was hospitalised with at the time.

During my second pregnancy I was told that one of my twins had died during a routine scan. This was communicated without any apparent empathy and no support of any form was offered. When I commented on this some weeks later in my pregnancy to the senior consultant, I was told I should have been offered counselling. Nonetheless the consultant did not offer counselling during *this* exchange (and unfortunately I felt unable to ask) leading me to reflect on her understanding of complications as a traumatic experience.

My experiences therefore in (three) maternity hospitals in Ireland (together with a subsequent exploration of the literature), led me to reflect on how other women had been impacted and if staff could improve the way in which they communicate in order to support women with complications. I wondered if this might help during the trauma and afterwards, potentially helping women to avoid more complex and/or longer term psychological difficulties in the future.

I am aware that my own experience will impact what I take from and write about, participants. I may focus on connections and commonalities with my own story and while my method acknowledges the researcher's interpretive lens I understand that I will need to attend carefully to the process to ensure the study concerns the participant's experiences. Some of the ways I will manage this will include the use of supervision and writing a reflexive diary which will feed into the interpretation and be woven into the research project.

1.3 Research aims

This study initially aimed to highlight the aspects of staff communication that are both facilitative and non-facilitative to the mental health of women with complications.

However, once data gathering began, the enormous significance of *non*-facilitative communication to the women became clear. In response to this, the research aim was re-focused upon this aspect of experience. However this is not to suggest that participants were not asked about facilitative experiences. Each woman was asked several questions specifically designed to encourage descriptions of experiences of facilitative communication. When pressed, three of the women (Abbey, Donna and Maeve) identified a positive communication experience and these are detailed in the findings in chapter four.

Understanding the value and impact of the more difficult interactions the women experienced could be useful in guiding and supporting healthcare staff in their relationships with individuals in the future thus facilitating healthier functioning for women, infants and other's within the family system.

With regard to staffing and funding, this could mean beginning to delineate potential roles for counselling psychologists either directly with women or through provision of training for medical staff and support in policy development.

Philosophically, an important aim of the work relates to the drawing of attention to particular power processes. Specifically, this concerns the voicelessness of women (during a critical life transition) when they may be particularly vulnerable. This is set within the more general powerlessness of women in the bio-medical context and the dominant patriarchal 'ethic of justice' as discussed by Carol Gilligan (1982, 2011).

Gilligan's concepts are particularly appropriate to this study as they address the challenges and multi-layered communicative processes that women may become a

part of within the patriarchal and medical environment of a hospital. Her articulation of these subtle complexities highlights the complex and rich nature of communication. Her work will be utilised here as a framework to illuminate and explore the central question of the research; How did the participants experience communication within the co-created relationship with staff?

The research question gives rise to the issue of how we define communication. In this study, the term encompasses implicit non-verbal as well as verbal communication. Nonverbal communication may be defined as communication that is exchanged through nonverbal cues which are not purely linguistic (Hall & Knapp, 2013). Some examples include eye contact, posture, facial expression and gestures (Finsett & Del Piccolo, 2011). This inclusion is important as non-verbals incorporate implicit, subtle, involuntary and often rapid processes, which are likely to contain rich information pertaining to affective states (Schore, 2003). In fact the Boston Change Process Study Group (2008) have emphasized that both the implicit and reflective-verbal domains are *central* in all of our interactions with others. Therefore understanding implicit non-verbals as an integral part of communication directly leads to its inclusion in any psychological research which aims to capture and understand participants' worlds.

Another vital aspect of communication in this project, and which is at the heart of relational psychotherapy, is that communication, like the self, is experienced in relationship. For example, intersubjectivity theory describes how two people relate 'in a continual flow of reciprocal mutual influence' (Stolorow and Atwood, 1992). This is somewhat in contrast to the individualistic reductionism which is common in our western culture and which often separates out the person from their relationships and historical, political and cultural contexts. The relational approach views

meanings as mutually constructed. Such meanings will to a large extent hinge on reflective function as discussed by Fonagy et al (2004) which, importantly for this research, can be impacted by a range of factors including trauma.

Therefore, communication in this study refers to a rich, relational and integrative concept which places ideas from relational psychology in a central position, in order to produce an analysis which understands (in as far as this is possible) participant experience.

Chapter 2: Literature Review

The following review explores the literature in relation to women's experiences of communication with medical staff during pregnancy complications.

I begin the review by exploring the voicelessness of women in pregnancy as demonstrated by the predominance of quantitative and obstetric research in the field. Following this I outline the powerlessness of pregnant women within the Irish context. Next I look at the research focus on vulnerable women whose infants do *not* survive in pregnancy, and contrast this with the paucity of studies of women whose infants survive.

I then move to the mental health research which demonstrates the relevance of women's mental health both for the women themselves and also for their infants. Finally, I conclude by highlighting the possible importance of staff communication as a relational opportunity to impact on mental health and increase women's power and voices. I connect this into my theoretical framework; Carol Gilligan's seminal ideas of how women's voices have historically been silenced because they are different and potentially a threat to the dominant patriarchal order.

2.1 Psychological contributions to understanding the challenges of pregnancy

Psychological research has contributed to a substantial interdisciplinary research base in the area of pregnancy and health. Through this work, researchers have illuminated links between pregnancy anxiety and preterm birth and stress and depression and low birth weight (Dunkel-Schetter, 2010).

Other important psychological areas have included pregnancy and eating disorders (Turton, Hughes, Bolton & Sedgwick,1999), the impact of earlier sexual abuse

(Leeners, Richter-Appelt, Imthurn & Rath, 2006), anxiety and depression (Heron et al, 2004, Ross & McLean, 2005), adolescent pregnancy (Mollborn & Morningstar, 2009), substance mis-use (Sherman, Sanders & Trinh, 1998), abortion (Major et al, 2009) miscarriage (Lee & Slade, 1995), stillbirth (Turton et al, 2006) post-traumatic stress disorder (Seng et al, 2010; Callahan & Borja, 2008,) antenatal (Ross & Grigoriadis, 2007)and post natal depression (Dennis, 2005).

While some have criticised this research for approaching pregnancy from the position of dysfunction, the work has done much to demonstrate that pregnancy is a challenging transition which can trigger a considerable degree of distress and difficulty for some women. In this it questions the romantic, unproblematic concepts of pregnancy which pervade society and which are often based on stereotypical married, middle-class affluent women carrying healthy and planned babies. Perhaps partly in recognition of these needs and the corresponding limited psychological services available to support pregnant women, a unique specialist service 'Facing Parenthood' was developed in the UK recently. This private sector organisation is run by psychologists and psychotherapists and aims to complement the existing ante-natal services 'that focus on the *physical* preparation for birth'. As yet no such service exists in Ireland.

Further acknowledgement of pregnancy as a psychological challenge can be seen in the NICE guidelines on prenatal and postnatal mental health (2007). This document recommends a lower threshold for access to psychological therapies in the pre and post-natal period. Additionally it recognises the role of mental health in pregnancy by suggesting that psychological therapies should be offered as part of a preventative approach to maintain functioning.

Overall then, psychological research has explored a number of important issues in the area of women and pregnancy, and clinically, services and national guidelines are beginning to identify this as an important area for psychological intervention. However in reviewing the literature a clear bias became evident: quantitative studies dominate the field of pregnancy complications. While clearly it is vital to be able to draw upon statistical data, it has led to a silencing of those principally concerned: the women. Furthermore the area of communication may be more amenable to qualitative study.

2.2 A Predominantly quantitative research base on pregnancy complications which maintains women's voicelessness

While understanding women's experiences of communication with staff remains a challenge, there are a range of mostly quantitative studies, which demonstrate with clarity that women who experience complications are certainly likely to face significant distress.

Correia and Linhares' (2007) review of nineteen studies on maternal anxiety in the pre and post-natal period reflected this correlation, finding that high maternal anxiety in the prenatal period was related in part to obstetric problems. Similarly, Brandon et al (2009) found a higher rate of major depressive disorder in women with severe obstetric risk when compared with low risk samples.

Other research also supports these findings: for example Berg, Lundgren and Lindmark (2003) found women at high risk are a particularly vulnerable population, and experience more anxiety and ambivalence regarding their pregnancies (Gupton, Heaman & Cheung, 2001; Hatmaker & Kemp, 1998; Stainton, Lohan & Woodhart, 2005). They also appear to have lower self-esteem (Gray, 2001; Stainton, McNeil &

Harvey, 1992) as well as higher levels of hostility (Langer, & Langer, 1998). Research on women on bed rest due to complications (Maloni, Kane, Suen & Wang, 2002) also showed that dysphoria scores were higher for those with the highest obstetric risk. Similarly, Burger et al (1993) concluded that pregnancy complications may increase women's risk of post natal depression.

2.2.1 Exploration of the usefulness of diagnostic categories for distress in complicated pregnancy

With an increased understanding that aspects of complicated pregnancy can be experienced as distressing, some researchers have explored the usefulness of Post -traumatic stress disorder (PTSD) as a diagnosis. The Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; American Psychiatric Association, 2013) specifies that an individual must have experienced an incident in which they had felt their own or someone else's live was at risk: and that the person responded to the event with helplessness, horror or intense fear. The distress should manifest in three ways: re-experiencing of the event, avoidance and heightened arousal. Symptoms need to be present for over one month and significantly impact the person's quality of life.

Several studies and reviews have demonstrated a link with PTSD. A review by Olde, van der Hart, Kleber and van Son (2006) confirmed that childbirth may lead to post traumatic stress symptoms and indeed a full PTSD diagnosis. In a study exploring women with pre-eclampsia, Engelhard et al (2002) found an association between the illness and PTSD symptoms.

One more recent systematic review of the relationship between severe maternal morbidity and post-traumatic stress disorder (Furuta, Sandall & Bick, 2012) found

inconsistent evidence to support the association. However, it was suggested that this was in part due to issues with study design.

More generally in uncomplicated pregnancy, research *has* indicated a relationship with approximately 2 % per cent of women going on to develop PTSD post-natally (Ayers, Joseph, McKenzie, McHarg, Slade & Wijma, 2008). While this is important, the figures pale in comparison to those for *depression* which appears to affect 10 to 15 % of women (O'Hara & Swain, 1996).

The usage of the diagnosis of post-natal depression (PND) has been criticised however. Some have argued that it is overly utilised in order to avoid the stigma of other labels which are viewed as more shameful by society (Brockington, 2004).However, Austin and Priest, (2005) while agreeing with the issue of over-diagnosis, have suggested that this is actually a reflection of the power of the medical model within pregnancy and early motherhood, which ignores women's psycho-social contexts when attempting to understand women's experiences. Importantly, both the DSM 5 and the ICD 10 no longer recognise PND as a separate diagnosis, suggesting that its usefulness might be viewed as limited.

Similarly, PTSD may not be helpful in building up a picture of women's difficulties. Wenzle, Haughan, Jackson & Brendle (2005) found that when PTSD was studied together with other anxiety-related problems such as phobias and panic, 16 % of women were shown to suffer with anxiety-related symptoms. When we take into account the fact that anxiety is often co-morbid with depression the picture becomes still more complex and elusive.

While PTSD may (or may not) represent a helpful concept for women with complications, we know that as a diagnostic criteria, it is not without problems. Judith

Hermann (1992) has written extensively on the history of PTSD as a diagnostic category. She has argued cogently that PTSD is not a useful framework in understanding the experiences of particular groups of people in society. As a concept which was developed to understand and help men traumatised by war, it may not be appropriate. Instead Hermann's 'Complex-PTSD' may be a more useful concept to understand the complex experiences of women suffering through complicated pregnancy followed by birth.

The research on pathology and women with complications has an important additional problem: it focuses almost exclusively on childbirth. Indeed a majority of research on obstetric risk and complications utilises childbirth and/or labour to delineate study boundaries. While this is clearly an important aspect of experience, it is only *one* short part of an almost year long journey. This avoidance by most researchers of the months prior to labour could in part be due to the need for clarity to support research design. Labour and birth can offer the researcher a relatively short intense experience with clear and convenient timelines.

Overall then, while the literature presents some difficulties, it seems clear that mental health problems *are* associated with complications and this suggests that these women would require particularly sensitive care.

2.2.2 Qualitative studies on complicated pregnancy

While little research has been done to understand how women with complications experience communication with staff, a small number of qualitative nursing studies indicate that this population *would* benefit from relational support with them.

Maloni and Kutil (2000) found that women preferred to communicate their distress in a group rather than remain silent, and that their relationships with staff were of importance. Interestingly, they generated research themes through confidential and non-directive group work. This containing and open environment reflects the quality of psychotherapy and indicates that psychological therapies may have a useful role to play in the lives of these women.

In another small scale nursing study, Katz (2001) hints at the enduring trauma of women with Placenta Previa who are at risk of losing their lives and that of their infant through sudden and massive haemorrhaging. Women reported experiencing significant stressors during this time together with loss of control and feelings of isolation. Interestingly these feelings are reflective of Glaser and Strauss's (1965) work on death and dying.

Only one article (Murira, Lutzen, Lindmark & Christensson, 2003) was found which specifically sought to understand communication between women with pregnancy complications and medical staff. While the findings were interesting and relevant, the study had sample and cultural limitations: the ten 'women' were mostly adolescents with ages ranging between fourteen to twenty years of age and the research was carried out at a clinic in Zimbabwe. Furthermore the researchers were all medical doctors or nurses. However, the study identified several relational components that were considered by the women to have been significant obstacles to good quality care.

Specifically women highlighted communication which was impersonal and authoritative. Women also related experiences of feeling shamed by staff as well as not being informed, or being given information which was inaccessible. For example

midwives and doctors often used medical terminology which was difficult for the women to understand.

These findings are clearly limited, but taken together they indicate that sensitive communication with staff is a key factor for some women with complications. The importance of communication skills in maternity care is not a new concept. For example a review of communication in maternity services by Rowe et al (2002) explored the impact of changing methods of communication on health outcomes for women. However the 11 trials concerned the impacts of antenatal screening information, women-held records and computer versus manual history taking. The identification of these as appropriate areas for a review of communication highlights how narrowly the term is sometimes defined.

The Healthcare Commission (2007) identified communication in a far wider sense as a key component in *safe* maternity services, highlighting the role of communication within a system where both physical and emotional outcomes are impacted. Further evidence for the foundational role of communication in normal pregnancy is detailed below. This data begs the questions: if women are reporting that communication is integral to their experiences is this reflected in practice? If so how have findings been adopted and if not, why not?

2.2.3 Are medical staff meeting the communication needs of women?

While midwives continue to provide care for women with complications, obstetricians *lead* care for high risk cases to optimise safety (NICE 2010). It is possible therefore that this is part of the reason for the relative silence of women in the literature. The

nine indicators of quality prenatal care utilised by obstetricians and gynaecologists (Vause & Maresh, 1999) are predominantly biological with virtually no acknowledgement of the value of the communication or of the woman as an active agent with needs outside of the biological sphere.

However the ability to communicate has been identified as a *core* requirement for health workers (World Health Organisation 1991). It has also been identified in several reviews as vital by pregnant women who indicate that good and sufficient information is crucial to them (Young, 1998). Hodnett's (2002) systematic review of 137 studies, while focused on birth, was unequivocal. It found that two out of the four priorities for women were of a relational nature: the quality of the staff-woman relationship and the amount of support from staff.

A review of perceptions of risk of women with high risk pregnancies (Lee, Ayers & Holden, 2012) adds further depth to the importance of communication in this environment. Differences were found between perceptions of risk of medical staff and women. While the authors underline the paucity of research available, communication was highlighted as a central factor needed to improve perceptions of risk and ultimately, care and outcomes. The review underscores the contribution of communication in complicated pregnancy to good care, the maintenance of health and avoidance of mortality.

Importantly though, there is evidence to suggest that some medical staff may not actually have the capacity to listen to and communicate with women in a way that meets their needs (Smith, Slack, Shaw & Marteau,1994; van Nuland, Hannes, Aertgeerts, & Goedhuys,2005; McCourt, 2006). Therefore, if obstetricians are leading care of women with complications, and their guidelines on good quality care

do not include any relational component, and further they are not skilled in or do not value the area of communication, one might begin to wonder whether communication *is* prioritised or valued in spite of women's documented need for it.

2.3 Irish context of shame, risk and powerlessness for pregnant women

Improving understanding of women's experiences of communication is relevant in Ireland which ranks 21st amongst industrialised nations in infant mortality (Oestergaard et al, 2011).Perhaps more disturbingly, World Health Organisation data (2014) on maternal mortality rates in Ireland shows a decrease in deaths until 2005 (two maternal deaths per 100,000 live births), with a sharp rise to nine maternal deaths (per 100,000 live births) in 2013. This is an increase of 33%.

One maternal death which was highly publicised was that of a young Indian woman named Savita Halappanavar in October 2012. Savita was seventeen weeks pregnant when she was forced to suffer a long drawn out miscarriage in Galway University hospital. She died one week later as a result of septicaemia. Irish laws did not allow terminations on any grounds. This tragic occurrence polarised Irish society and politics, finally resulting in new legislation being passed: The Protection of Life in Pregnancy Act 2013. While this law brings in limited change in extreme circumstances, it will not affect most women. It only allows for termination when the woman's life is at risk. The UK Department of Health annual abortion statistics show that 3,982 women who had abortions in the UK in 2012 gave Irish addresses. It is unlikely therefore that this will change with the new Act.

Both the inquest and the Health Service Executive (equivalent body to NHS) reports clearly describe a litany of errors in Savita's case. These errors principally concerned communication problems and incompetence. The Irish Times headline following the

release of the report read: 'Tragic. Inadequate Assessment. Treatment Delays. Devastating.'

So it seems that in this case both incompetence and legislation came together to result in a death. Importantly the legislation was grounded deeply in religion and the Catholic Church which holds a strictly anti-abortion stance. Indeed with the Catholic Church owning the land that many maternity hospitals are built on, having representatives on hospital boards of directors, and with some hospitals actually being *Catholic hospitals* there is an undeniable and direct relationship between maternity care and the Catholic Church in Ireland.

The Catholic Church has had an uneasy relationship with women and children historically in this country. In June 2014, the minister of state at the Department of Education, Ciaran Cannon, called for an urgent enquiry when, what appeared to be a mass grave was discovered on the old site of a mother and baby home in Co. Galway. It appears that up to 796 infants may have died on the site during the years the Sisters of Bon Secours ran the home between 1925 and 1961.

Unfortunately extraordinary high death rates were not uncommon in these homes across the country, together with forced adoption and forced labour. However this is not the first time that enquiries on the matter have been called for, with the Adoption Rights Alliance having requested investigations from the former Minister for Children, Frances Fitzgerald, in 2011. The tragedy of so many women and children was clearly in the public forum also, with films such as 'The Magdalene Laundries' and more recently 'Philomena' starring Judi Dench.

Therefore vulnerable pregnant women (particularly those out of 'wedlock') and their children have been forced into an extremely disempowering position in this country

historically. Shame and a dark perspective of religiosity were at the core of their often abusive treatment.

2.4 Particularly vulnerable women: a research focus on women her child dies

Another particularly vulnerable group in the area of pregnancy complications is women whose infants do not survive. These experiences of miscarriage, stillbirths and abortion *have* been widely explored (Major et al, 2009; Turton et al, 2006; Lee & Slade, 1995). However complications which result in *live* births have not.

This gap with regard to women and complications was referred to by NICE in June 2012, in its plans for guidelines on early complications. They call for specialist services including psychological support for women experiencing complications in early pregnancy and *communication* training for medical professionals. Professor Mark Baker of NICE noted that pain or bleeding in early pregnancy can be a 'very frightening time' which requires sensitive care and support. As Ireland's maternity services utilise NICE guidelines as their gold standard, this announcement also has potential implications for women in Ireland.

However, while these guidelines do highlight the distress caused by complications, once again they emphasise support for those women who *lose* their babies through miscarriage or ectopic pregnancy and highlight sensitivity with regard to communication and the subject of 'breaking bad news.

2.5 Acknowledgement of the relevance of women's mental health on infants

Sensitive care and communication is particularly important in working with women with complications. This is in part because as previously indicated they have been shown to be at increased risk for psychological problems.

In fact high rates of psychological difficulties due to the experience of complications as a traumatic event mean that women may demonstrate avoidance as is characteristic in the manifestation of post-traumatic stress disorder and depression (DSM 5). This means that staff capacity to communicate and respond sensitively to women becomes of even greater importance. Furthermore, while physical complications may impact psychological well-being, conversely mental ill-health has been shown to effect the biology of the foetus (Altshuler, Hendrick & Cohen, 1998) making for a dynamic and complex dilemma.

Unfortunately, this added complexity highlights an equally valid additional rationale for exploring the potentially invaluable relational support of staff: that maternal mental health has also been implicated as a factor in the health of the *infant*.

2.5.1 The impact of pregnancy complications on the child

Fonagy and colleagues (2002) have shown how a mother's capacity for reflective functioning is more predictive of their infant's security than adult attachment style. However this capacity may be compromised by the trauma of pregnancy complications. It has also been argued that overwhelming experiences may lead to splitting in consciousness (van der Kolk, McFarlane & Weisaeth, 1999). In such circumstances it is therefore possible that reflective functioning could be compromised by complications and their psychological sequelae. It is also indicative of a possible link between complications and a *child's* lifelong capacity for affect regulation and reflective capacity.

Similarly in a meta-analysis (Atkinson et al, 2000) which explored attachment classifications and maternal mental health, both depression (15 studies, 19 samples and 953 dyads) and stress (13 studies, 14 samples and 768 dyads) were significantly related to attachment security.

This area has become of interest to medical researchers also and resulted in a growing field. The work is helping us in understanding the impacts of maternal trauma on both the child's body and mind. Disturbingly, findings demonstrate that infants may be significantly impacted. Initially this field utilised solely animal studies, extrapolating findings to human populations. This is no longer the case however and recent years have seen a burgeoning evidence base grounded in human studies.

One review (Beydoun and Saftlas, 2008) examined 103 human (60) and animal studies (43) in order to establish a parallel between these two sets of findings. They found evidence showing the independent effects of *prenatal* maternal stress (PNMS) on infants both during pre and post-natal periods. PNMS has more generally been linked with a variety of health difficulties in both animal and human babies.

One other review (Talge, Neal and Glover, 2007) looking at only human studies underlined the complexity of the area. The authors noted the need for caution in separating out causal and correlational factors from each other. However they also showed that *pre*natal maternal stress and anxiety is a significant factor in exposing the child to increased risk of neurodevelopmental problems. These findings are independent of *post*-natal difficulties such as Post-natal depression. Potential problems for the child included anxiety, language and attentional deficit/hyperactivity. One of the mechanisms by which foetal changes may occur is through the mother's hormonal profile which can be altered by anxiety.

However the work in this area is complex and while it seems clear that the woman-infant system can be negatively impacted by distress in utero, the narrowness in the research does not often attend to the importance of psycho-social factors.

For example, one study (Brand, Engel, Canfield and Yehuda, 2006) looked at the interactions of salivary cortisol levels and infant distress in pregnant women who had developed PTSD in response to the terrorist attacks of 9/11. The study showed that maternal cortisol levels were inversely related to how they rated their infant's distress levels. They also rated their infant's distress levels as higher than mothers who did not have PTSD. The authors note that results might reflect genetic and/or epigenetic shifts with the potential for maternal distress to impact inter-generationally.

While these conclusions may be important routes for exploration, they do not take into account the wider context. Most obviously, that the psychological aspects of PTSD are likely to impact the person's *perception* of their child's distress. In other words, that this is a psychological and social process also, and not simply a biological one which can be solely based on salivary cortisol samples.

Clearly however, biological models have been very useful. They indicate possible pathways to understanding the dynamic interplay within the mother-foetal relationship and the effects of anxiety in particular on neurodevelopment. It might be still more useful however, for psychological and biological researchers to communicate more with each other in order to create richer and more multi-dimensional findings.

As anxiety in complicated pregnancy is common (Ross & McLean, 2006), these findings are particularly relevant. The evidence for the existence of anxiety *during* pregnancy and the potential detrimental effects of this, challenge the monopolisation

in the literature on labour and birth. All of the studies above explored the effects of distress in the *pre*-natal period. Results from these and the overwhelming evidence discussed earlier regarding anxiety and complications suggest that pregnancy too requires psychological attention and intervention.

2.6 Limitations of existing research and a relational opportunity for staff to empower women

While the research outlined thus far is important in highlighting the psychological experience of aspects of obstetric complications and is indicative of the need for sensitive support, it is also problematic in several ways: there are few studies which seek to understand women's needs; they are generally embedded in the field of nursing and obstetrics; they are based for the most part on non-Irish populations; and they focus primarily on experiences of birth and labour and they use what might be the problematic concepts of PTSD and PND to understand women's distress. Finally women have been studied in isolation without relational and other contexts.

The implications therefore are that the data is limited, culturally bound and lacking in psychological depth. This has resulted in women represented as disconnected from their contexts, particularly from the medical staff carrying out the research and other nurses and doctors.

This avoidance of both women's voices and their relational contexts is reminiscent of Gilligan's work that this study draws on as a theoretical framework. While not separating out human traits into male and female, she spoke of differences in women's and men's 'qualities'. Within a patriarchal society, this had led to men's qualities and values being viewed as the gold standard while women's qualities which were more relational, were viewed as deficient and ignored.

While criticisms of Gilligan's research in this area led to her academic reputation being negatively affected, the impact of her work has been important in drawing attention to valuing a diversity of voices. In particular she highlighted the voices of girls and women who had traditionally been ignored in psychology. Her text 'In a Different Voice' (1982) was grounded in studies of women and girls carried out by Gilligan and her colleagues and sold 700,000 copies.

The patriarchal society she described was a Cartesian one which split reason from emotion, body from mind and the self from relationships. Women with complications are cared for within this same model: a medical model grounded in Cartesian divides. If however women's power and voice is grounded in the relational as Gilligan suggests, communication with medical staff may represent an important relational opportunity to support women's power, voices and mental health. Following the findings and analysis in chapter four, Gilligan's concepts will be used in chapter five to contextualise the findings and explore potential implications and obstacles to change.

Chapter 3. Methodology and Procedures

3.1 Methodology

3.1.1. Rationale for a qualitative approach

With little known in the area of the study I felt that it was important to utilise a method that had the capacity to be exploratory, open and sensitive to the unexpected (Dahlberg, Drew, Nystrom, 2001) so as to capture as much meaning as possible.

The existing data reflects a Cartesian/medical epistemological position often using a quantitative approach and/or separating subject from object. With a focus where women's bodies, felt experience and relationships were absolutely central, it was necessary to utilise a qualitative approach in this study, which would have the capacity to capture these aspects of experience.

3.1.2 Epistemology and phenomenology

From an epistemological position, I am keen to understand (in so far as this is possible) the constructed, phenomenological and subjective nature of participant's experiences. A relevant context is that of women's bodies.

The particular experience of pregnancy complications connects with Merleau-Ponty's (Bazzano, 2014) emphasis on embodiment. He challenged Cartesian dualism for splitting the physiological from the mental, and empiricism for attempting to reduce the perceiving subject and ignore connectedness. He also highlights and critiques Descartes' and Kant's view that thought is privileged over experience. I find Merleau-Ponty's ideas on phenomenology brave. He is able to acknowledge our limitations and shows us the potential joy to be found in the wonder of not-knowing, once we

can disengage from our need to know. Merleau-Ponty's view on the function of phenomenology is to understand our experience in the context of the social, historical and of course the physical.

Pregnant women in Ireland have certainly been impacted by their social and historical contexts as indicated in the literature review. More obviously they are bound by their bodies, unable to escape and therefore may experience an embodied powerlessness. As Merleau-Ponty recognizes we are a 'body-mind' and deeply connected into the world. In this study, an important part of women's worlds is that of the powerful 'expert' or 'professional' hospital staff.

The issue of power is also an integral aspect of this study and indeed of counselling psychology (BPS, 2011: Woolfe et al: 2003). The work aims to give a voice to women who may have experienced embodied and relational powerlessness. Where in previous research in complications, women have at times been observed as subjects in isolation under the researcher's microscope, this study aspires to offer them a more honest space to contribute their subjective relational experience.

However, this space does not pretend to provide an impossibly power-free opportunity for these women. After all, as the researcher I ultimately had power over which questions are asked and which data is retained. Others including my supervisor and individuals from my institute also contributed to this process. Therefore exactly which or whose reality is created and also how this reality is perceived, is clearly not wholly within participant's control. In this report, and in recognition of my part in this process I will use 'I' when referring to myself (the

researcher), as opposed to the more traditional style which utilises the third person.

3.1.3 Rationale for Interpretive Phenomenological Analysis

Given the central epistemological concepts of the research as outlined above, I chose Interpretive Phenomenological Analysis (IPA) as the best fit. IPA has the capacity to fulfil the central phenomenological aim of the study: that of describing and understanding the women's felt experience. Furthermore, the double hermeneutic of IPA acknowledges the interpretive role of the researcher in the research: that the researcher is attempting to understand how the participants are making sense of their world (Smith and Osborn, 2003). This honesty in clearly stating that there is no 'pure' knowledge that can be in some way 'uncovered' is very important to me. While it also presents challenges, it feels like a more mature and fluid approach that does not promise absolutes but rather invites us to struggle with the messy possibilities of our worlds. It also offers hope to the vulnerable and oppressed because it may lead to fixed narratives being questioned and therefore open possibilities of change.

Of course as the researcher this provides challenges as I am required to understand and question my own biases and values. Given my personal experience of pregnancy complications this is a difficult task, but one for which tools were available including a reflexive diary and supervision. This and other measures utilised to support reflexivity are detailed later in this chapter.

There are of course many methods of qualitative enquiry (Miles and Huberman, 1999) and while IPA was eventually chosen, I considered other methods.

Grounded theory could have been utilised but it became quickly apparent that as the prime aim was to give a voice to women, and not develop inductive theory and hypotheses, it would not provide a good fit.

A form of discourse analysis was also a possible method. As the research focuses in on a relationship, language could be seen to be of primary importance. Furthermore the political aspect of some approaches, such as Foucauldian discourse analysis (Arribas-Ayllon and Walkerdine, 2008), was particularly appealing and offered an excellent framework for the Power-ful relational context at the core of the study. However, while language is indeed important in the study, it falls into a secondary position behind the personal meaning-making and embodied experience of the participants. Therefore, given the objective of understanding women's felt experience, I considered IPA to be an excellent fit.

3.1.4 Research design

This study used a qualitative approach. I used purposive sampling to select as homogeneous group as possible as suggested by Smith, Flowers and Larkin (2009).I conducted in-depth semi-structured interviews with six women. These were digitally recorded and transcribed verbatim. Interviews were analysed using IPA Procedures.

3.2 Procedures

3.2.1 Sampling

I recruited six participants through advertising (see Appendix 1) in Public Health Nurse Clinics, Parent and Toddler groups and internet forums. Six were chosen as an appropriate number following the recommendations of Smith et al. (2009) who

suggest between four and ten participants. The emphasis here is on the quality rather than quantity of data though clearly it is vital also to ensure interviews are also of sufficient duration to support the acquisition of sufficiently rich data. I found the issue of quantity and quality usefully addressed by Harre (1979) who explores the balancing of loss of richness and depth that is likely to occur with larger samples versus the capacity to generalize with thinner data. IPA does not aim to produce generalisations to the greater population or make claims outside the group studied. However I do feel that like Smith (2004) and Harre (1979), experiences found through the research *may* possibly resonate or be shared with other women elsewhere.

Inclusion and exclusion criteria for participants were:

- Pregnancy complications which had been experienced between six months to two years prior to interview.

- Participants had experienced complications which were a threat to their own life or that of their child for duration of more than one week.

- Participants had been aware that they were experiencing complications

- Complications had affected the pregnancy/period prior to birth rather than exclusively impacting the birth.

- Both mother and child had survived the complications.

Participants were chosen by self-selection. Thirty women responded to advertisements by telephone and/or email. Seven met the sampling criteria and one of these subsequently dropped out due to family commitments. While there are clear differences between the participants, the aim in line with IPA, was for the women to be as similar as possible. This was not in order to make wider claims but rather to

support the depth and intensity of the study of the phenomenon within the small group.

I carried out several telephone conversations with the six women to confirm that they were willing and had the capacity to commit to the process and subsequently to arrange meetings to conduct interviews. Each participant was emailed a research consent form together with detailed information on the study to ensure that consent would be as informed as possible. Of the six participants, three were first time parents while the remaining three had pre-existing children. Four were employed while two had left external employment to work at home and care for their children full-time. They ranged in age from thirty -four to thirty- nine years of age. Each lived with her partner/husband. The women were all white and Irish. Two lived in Dublin, one in County Galway, and three were based in County Cork. The women's complications were identified as: intrauterine growth restriction (IUGR, two women), anti-partum haemorrhage, premature rupture of membranes, brain –related abnormalities (child), obstetric cholestasis and hip displacement.

3.2.2 Data collection

I conducted face to face Individual semi-structured interviews with each of the women. A flexible interview schedule (see Appendix 3) was utilised and comprised of broad open questions with a range of prompts to encourage depth. I began the interviews with a very broad opening question to allow the women to essentially tell *their* story (rather than that which they might feel I wanted to hear). This is in line with Smith's (Smith and Osbourne, 2003) analogy of a funnel. This begins broadly to later narrow down to the finer minutiae of the experience.

The first interview informed subsequent interviews. For example following the first interview I withdrew one question which I felt could have been interpreted as blaming (Question 9. What do you think stopped you from saying or doing these things at the time?). I also added a question which I felt would allow women to elaborate on the impact of their experience on them at the current time (What are you left with now?).

Additionally, this first interview highlighted some strong themes (isolation within the self, disconnection from staff, the impact of lack of information and the use of the internet in supplementing the information gap and powerlessness) and I kept these in mind during subsequent interviews.

The mean duration of interviews was eighty- three minutes. I digitally recorded and transcribed the interviews verbatim. In order to protect participant's identities, I used numbers and pseudonyms as participant identifiers. The locations of interviews were: participant's home (two), researcher's office (one), hotel meeting room (three). At times this meant that I was required to engage in a significant amount of travel in order to conduct interviews in locations that were as convenient and comfortable as possible for participants.

3.2.3 Analysis

I followed the key stages of Smith et al's (2009) procedure for IPA analysis as outlined below.

Immersion in data

Interviews were listened to post interview, transcribed, and then read and reread. I experienced this as an exciting and fertile period and my reflective diary was well

utilised at this stage to record initial impressions, ideas and experience. On reading the hard copies of the interviews I made tentative descriptive notes in the margins. In fact the entire analysis was carried out with pen and paper. This was a personal preference and led to a more free-flowing and creative process. This also follows Smith et al's (2009) guidance which suggests initial concepts may be better supported to emerge in this way. However, having done this for the entire analysis meant a good deal of additional work was required in typing up the data.

On completion of initial notes of the first interview I moved to the right margin I had created on the hardcopy. Here I added more in depth comments line by line. Crucially these included reflexive comments. Within the analysis, this tracking of my responses was significantly helpful in understanding and making transparent my part in the research and the ways in which I had been more or less present in the process. In looking back over the analysed interview I was also able to clearly identify how and where I had felt impacted (or not) by the story.

I then wrote up a table of this participant's emergent themes on a large sheet of paper (1 metre x 1 metre), together with the key quotes which I felt best captured the themes.

I repeated this process after each interview, with each one supporting and feeding into the next, while simultaneously attempting to remain open to the emergence of new themes and hear each woman in her own right throughout subsequent interviews. I found this balance difficult. When I found an 'interesting' theme I would notice that I became excited and would wait to see if it might reoccur in subsequent interviews. I wonder at the degree to which this impacted the participant and the story they narrated. In my examination of this issue within the transcripts, while I did

not find evidence showing that I had led the women, I did note that at times my excitement was evident in my tone, and no doubt this is likely to have encouraged participants to be encouraged to elaborate possibly in ways they might not have otherwise done.

Upon completion of all of the interviews together with this analytic process I set to work with the six large sheets of paper I had created (see Appendices 8-13). Many days were spent moving between sheets attempting to understand the commonalities and differences between the women's experiences. It is important to note that while it might appear from the above to have been a methodical and intellectual process this was far from the case. It was in fact an exciting, frustrating and overall highly emotional and exhausting experience, or adventure. This provided an additional difficulty however. My growing commitment to the women meant that at times, while I was aware of helpful guidelines to support this task, I became paralysed with indecision at which themes should be reworked into the superordinate themes and which should be discarded. In this way I experienced a felt sense of how I myself had become woven into the work and the stories.

At the end, I felt that the four superordinate themes arrived at (see Appendices 4-7) were as close a reflection as possible of their experiences together with my interpretations.

3.2.4 Trustworthiness

Increasing interest in qualitative research methods has led to a plethora of validity related terms and strategies in the last 30 years. Morse et al (2002) have argued that

not only is this confusing but also that too many of these approaches are external to the researcher and are only implemented once a study has been completed. This reliance on external reviewers at the end of the process is problematic as by this stage it is too late to make corrections. In order to address these difficulties I adopted the following verification strategies during the process:

Peer checking

Two colleagues with experience in qualitative research reviewed my coding to confirm and disconfirm themes. This was an excellent experience leading to a high level of matching themes in both cases. On both accounts my colleagues outlined an additional theme each, both of which were interesting and added depth to the work. These were ideas (1) concerning the women's strength which was highlighted in an excerpt where I had not noted this theme and (2) the specificity and difference of Irish culture. This process was therefore useful not only in reviewing my existing themes but also in yielding additional ones which supported further reflection.

Peer review

I participated in two conferences on completion of analysis in June and July 2014. The first was a poster presentation for the Global Congress of the World Association for Infant Mental Health in Edinburgh and the second was a paper presentation at the BPS Counselling Psychology annual conference in London. In preparing for these events I sought support from two psychologists at my workplace to explore my research and the evidence for my interpretations. This was an interesting experience leading to my questioning of some aspects of my work. As these psychologists were

not counselling psychologists it also highlighted how my research may be received by non-counselling psychologists and which aspects might be scrutinized. Furthermore the particular focus of counselling psychology on issues of power and subjectivity became increasingly clearer to me.

Negative case sampling

Miles and Huberman (1994) suggest that seeking evidence which disconfirms preliminary themes may support the credibility of an account because it reflects the multiplicity of the world. This was an interesting process as I noticed in myself a search for patterns across participants. Therefore a particular effort was required at times to remain alert to difference. This was also due to a narcissistic search for my findings to demonstrate significance of some kind. Underlying this was an anxiety that my findings would not be useful to women if I did not find some coherent results.

I was able to shift this position in myself by reminding myself of the importance of noticing and indeed valuing difference. My supervisor was extremely helpful in this regard and highlighted that in noting the differences in women's experiences I would actually be helping to show how complex women's needs were and subsequently how these complex and subtle needs would need to be identified and supported by adequately equipped staff. This 'developmental' process really supported me in loosening the defensiveness that had been present and allowed me to respond in a more flexible and critically reflexive manner to the findings. My process connects in ways to Levinas' (1989) encountering of otherness. He shows how it is impossible to truly know the other. The ultimate 'other' is found in people and in my case I can see how my assumption that I had understood the women, in fact was detrimental to both

them and myself. It was only when I was able to create some space to see that I in fact had/could not see the other in their totality, that was I able to learn.

While I think the above strategies were useful I also think that they focused in the main, on the solidness of my *findings*. While this is clearly important I decided that in order to support the process I would require additional guidelines upon which to gauge the validity of the work.

With this aim I found Yardley's guidelines for trustworthiness (Yardley, 2000) helpful. These consist.

Yardley's Criteria

Yardley's criteria consists largely of four principles which are intended to flexibly support the achievement of quality. These are; sensitivity to context, commitment and rigour, transparency and coherence, impact and importance**.**

The term context is used to include a range of environments that the researcher needs to understand and take into account including: the research method and its philosophical foundations, the socio-cultural context and of course the relationship between participants and researcher. I feel that I grappled with each of these aspects. I was very much aware of Ireland as a geographical context and the uncomfortable history some pregnant women had experienced here in a variety of environments. I was also highly aware of my own experience: of not being taken seriously or being cared for sufficiently in two pregnancies. I was also keenly aware of the deterioration in healthcare service due to the catastrophic collapse of the economy in recent years and the implications for resource limitations on an already stretched healthcare system.

In particular I worked hard with the relationship with the women. Partly due to my work as a psychotherapist, I found it natural to prioritise the participants and the relationship in the process. Additionally as I was working with women who had not been seen, heard and had in fact felt generally disrespected, it was paramount to me that I did not repeat this experience. In fact I found this naturally guided the entire project and supported me in remaining committed to what has been a long process.

Commitment, together with rigour is Yardley's second principle. I think that I have been rigorous throughout the process: in applying the methods, in conducting thorough interviews and struggling to ensure that each theme is as honest and close to the experiences as possible. Also relevant here was the support and counselling hand-out I furnished each woman with, to support her in accessing counselling services. Here I researched reputable and low cost services in each of the localities the women resided in.

The third principle is transparency and coherence. Transparency is evident in my efforts to fully inform participants of what they would be involving themselves in (in as far as this is possible). My process has also been made transparent through my detailed description of the research experience and in the provision of an audit trail providing illustrative quotes for each master and superordinate theme (see Appendices 8-13).

I am also aiming to make transparent what was my 'three dimensional' experience through the weaving in of my own part and process in the work (in addition to a reflexivity section). Through this transparency I hope that the coherence is apparent to readers, including those parts where I have found the complexity of contradiction.

One area in which I decided not to be transparent however was in revealing my own experiences to participants. This was a difficult decision to make and was based on the idea that discussing my own story could possibly lead to the prioritising of me rather than the women within the interviews. I looked at this decision in a similar way as the choices I make as a psychotherapist when deciding whether or not to share my own experience. While this was different, I felt that not telling the women would be of greater benefit to them in the telling of their story. I am aware that this has a paternalistic aspect and I continue to struggle with what was a difficult decision.

Finally there is the impact and importance of the research. I feel that this is a most important principle for while I do understand the value of knowledge for knowledge sake, this is not what I seek to do. My approach is pragmatic and I find far more worth in highlighting issues in order to contribute to change. I hope that this research will in some way achieve this and that in some small way women and their families might feel a tiny ripple which will positively impact their experience. I have already begun to work on this through presenting the research. Importantly I have assured the participants that they will be the first to read the research on completion. I hope that this might be helpful in supporting them to create their narrative but also in holding tangible evidence that they had been heard.

3.2.5 Ethics

Ethical approval for this study was granted by the Metanoia Ethical Committee (see Appendix 2). Ethical issues including confidentiality and informed consent as laid out by the British Psychological Society (BPS, 2011) and Metanoia Institute were carefully attended to. However, I do feel that it is important to note that while these

were of course important, they might not take account of the many subtle ways in which a researcher might quietly adopt a coercive approach through the relationship with participants. Therefore while I detail the more explicit ethical issues below I would like to clarify that I aspired to an ethical 'process' (Parnis, 2005). The reflexive space which was integral to the research generally, was also foundational here as it allowed me to ponder my less palatable thoughts and feelings, thus leaving them more open to be resolved with integrity.

Informed consent

I understand that in line with my philosophical position, there is no such thing as truly informed consent. However I made efforts to effect as informed a consent as possible through telephone conversations prior to interviews, as well as through the participant information sheet .Before and after interviews I reiterated the rights of the participant in withdrawing at any time. It was however most important for me *during* difficult and emotional parts of the interviews that I clarified to the women that recording could be stopped immediately. I noticed however a determination from participants on these occasions, to continue. The process seemed very important to them.

Potential to do harm

I was aware prior to interviewing of the potential for distress due to the sensitivity of the subject matter. I was therefore prepared to 'put the brakes on' (Rothschild, 2000). It was important also, given the difficult relational experiences that women had endured, that the process was a sensitive one. However, while I worked hard to maintain a safe environment for the women, I cannot actually say that participating in the research harmed or indeed helped any of them. While I explained that I was

contactable throughout and indeed after the process, and I provided relevant contact details for support services, this does not necessarily imply that no harm was done. In this I wonder and struggle somewhat, with what was gained or lost by the women upon whom the research is based.

Confidentiality

Participants were fully informed of confidentiality and its limitations. For example while transcripts were kept securely in a filing cabinet, they were made aware that my supervisor and peers would read anonymized transcripts. They were also informed that they would be quoted in the thesis and any papers or articles which arose from this, but that all identifying information would be removed. Furthermore some participants requested that certain details be omitted from the study due to the potential for them to be recognized. This was complied with. Therefore while their material would be anonymized it would be likely that they would recognize themselves in the work.

3.3. Reflexivity

While I have aimed to reflect my reflexive process throughout my research and write-up, I am also dedicating a specific section to this area. Here I aim to more explicitly disclose some of my personal experience, assumptions and prejudices and detail how these impacted up*on* and were *by* impacted the work.

Part of my story

Nine years ago I gave birth to a beautiful boy. However, it had not been an uneventful pregnancy.

At week thirty-two an abnormality was found by a radiographer during an ultrasound scan. The scan was carried out as part of a study I was participating in at a hospital in Belfast. The radiographer explained that on my return to my home in Dublin I should contact my hospital there to attend for an immediate appointment as I might require hospitalisation. She suggested that I appeared to have a condition called Placenta Previa. I returned to Dublin and was seen the following day.

Following several scans by senior radiographers I was discharged. They were clear that the scan had shown no indications of a problem. I was advised to continue living normally as this was a healthy pregnancy. Had I not consulted with my friend who was a nurse I would have followed this advice. However my friend encouraged me to return to the Belfast hospital for a second opinion as the condition could be life-threatening and required careful monitoring. The next day my husband and I drove to Belfast. I was seen and swiftly scanned, and told within one minute that I did indeed have Placenta Previa. It was at the most severe level, grade four, and that as a result they could not allow me to leave. I was hospitalized and remained in Belfast until one week after the safe birth of my boy.

Whilst I was distressed and in shock I was unaware of the degree of seriousness of my condition. I was placed in a ward full of women with various pregnancy complications. I noticed an acceptance of their realities together with a dark humour and disconnectedness between women but also between women and staff. This environment brought home to me the institutional flavour of my new and unexpected home. The wider political context was also very present to me and I was keenly aware of my English/Southern Irish accent in this environment. Unusually for me, I kept quiet in my corner.

While the staff were never cruel and were generally friendly, no one spoke with me at any time outside of the medical tasks they were required to complete. A junior doctor inserted a line into my hand. Apparently I might haemorrhage at any time and so I required a line for my entire stay. He informed me also that my blood was on standby in the event I should require it.

One day, when I was feeling particularly trapped, my husband visited. I suggested we walk around the hospital grounds. Twenty minutes later upon my return the usually pleasant staff sister cornered me. She was angry. Clearly frustrated, she asked me what I had been thinking in wandering outside of the ward as no one would have known where I was had I experienced a haemorrhage. I felt confused, and wondered was she overreacting or was my condition in fact more fragile than I had imagined.

I had requested a letter from the registrar, as my employer was seeking documentation for my absence. I remember her handing it to me. Upon reading it I began to realise the seriousness of the problem. The letter stated that further haemorrhages (I had experienced one already) could kill both me and my child. I laughed and expressed my gratitude for the dramatization of the situation which I believed she had written to ensure my employer would not question my leave. She assured me however that there was no magnification of the truth, and the letter reflected the reality. My condition meant that severe and extensive haemorrhaging could occur at any time and lead to maternal and infant death. The conversation ended and no further communication occurred on the subject at any time with anyone.

One evening a short time later, I remember lying in bed and the panic that gripped me as I realised I was haemorrhaging. I managed to stand and when I looked down at the gushing blood I froze. Focusing sufficiently to walk to the nurse's station took a great deal of effort. When I got there initially I was unable to speak. I remembering at some point explaining robotically: 'I've had a bleed…I can't lose this baby…I don't think I can have another child'. I was then sent back to assess how much blood I had lost and if it had stopped. I was confused at how to assess quantities, but attempted to do as I had been asked. I did not question this process. I was in shock.

Looking back on this now, with my beautiful strong nine year old child, with his shock of red curls, I realise how incredibly lucky I am. I also however understand that I was deeply impacted by this experience. In fact, I have an embodied sense that I will always carry this with me.

The experience of communication and lack of it, during this time affected me. I had a clear sense that what had occurred in the pregnancy was unspeakable and I experienced a lonely unspoken terror regarding this. This isolation in turn led to further anxieties as I agonised over how my embodied fear might have impacted my child.

 I felt an intense need to protect my child post birth and this of course manifested within the attachment. I felt distressed and anxious. I found myself avoiding contact with others and had difficulty leaving him even for a few minutes while he slept, in order to take a shower. Unfortunately I had no insight into my experience and how the pregnancy difficulties had affected me. Therefore I did not seek support.

The process of co-creation

I have reflected at length for over almost two years upon my own process and how this intertwines with the world of my participants. The process has been so dynamic and filled with interactions. What was previously *my* story has become something very different and more unwieldy. With the telling of six stories, my experience has been wakened thoroughly: more so than it had previously had an opportunity to. With the listening, reading, remembering and analysing of the women's stories, at various times, what I thought were dead remnants of my own account, have leapt up apparently full of life to commune with the women's sadness, hope or anger.

The intensity of the material and the level of intensity in my immersion in the data have led to a variety of outcomes. Being given such a privileged insight into the women's worlds has been a gift. It has facilitated a shift in my felt sense that my own experience was unspeakable. Also my experience of isolation has been replaced with a sense of belonging. I know now that I am not alone in my experience and this has led to a letting go of self-blame. However this has all come at a cost. While I was pulled and drawn into the data, this immersion was difficult. I experienced the emergence of very powerful emotions, from which I could not easily separate myself. Conversely, the sense of collaboration with participants through the material was helpful both in processing my own latent experience and in feeding my motivation through the project.

Awareness in co-creation

Finlay's (2009) ideas on a collaborative approach to phenomenological work appeal to me. In fact in the IPA literature, it is acknowledged that the product of the interview and indeed the entire study is co-created. This occurs through the 'double-

hermeneutic' where there are two intertwined circles of meaning-making: the researcher is making meaning of the participant's meaning-making (Smith and Osbourne, 2003).

In this study I feel that the data very clearly emerged from the co-created space between the participants and me. However my challenge was in maintaining some boundary in this in order to retain clarity and validity. My supervisor was pivotal in this process.

She helped me to identify and understand the importance of my personal responses to the participant's accounts. In focusing in on this and using my reflexive diary, I was able to then create a clearer understanding of my biases and assumptions. I noticed where and why I focused more on certain aspects of the women's experience than others. This helped me to create a clearer understanding of the system that mine and the women's worlds have become.

My supervisor also drew my attention to a potentially damaging bias. I was ignoring the participant's role in their experience of being isolated and unsupported. We were able to unravel that behind my avoidance in naming a participant's role in the co-creation , was a fear that women would be blamed for not accessing support, indeed that I would be supporting the idea that the lack of support that women experienced was their own fault. In my own story, of course I saw this as blaming myself for not seeking support.

In exploring my bias within what felt like a very safe space I was able to understand the implications of what had been a non-conscious process. This helped me to understand the level to which I was polarising women and staff and led to improved awareness and analysis. Furthermore, it led to a personal shift where I was able to

refrain from locating the shadow in the staff and begin to view both my own

experience and the women's in a more mature and less split off manner. In this way

the research has led to healthy changes in my own narrative.

Chapter 4: Analysis and Findings

Interpretive Phenomenological analysis of the 6 semi-structured interviews led to the development of four superordinate themes and subthemes. This chapter explores each of these themes using verbatim extracts together with the researcher's detailed analytic interpretation of the text. The information is summarized in a table below.

Superordinate theme	Theme
1.Information difficulties	1.Women's unmet need for information 2.Ethical information issues 3. Fear and distrust
2. Disempowerment	1.Institutionalisation 2.Control 3.Dignity and shame
3. Empathic failure	1.Invisible women 2.Isolation and abandonment 3.Mind body split –Emotional support
4.Relational impacts	1.Relationship with self 2.Relationship with baby 3.Relationship with partner

Table 1: Master table of themes for group

The themes were chosen due to their relevance to the research question and were common to all six participants. The extracts below represent the themes which developed through the research process and include those instances that

demonstrate contradictory (to the majority) experiences. A case by theme approach has been adopted (Smith et al: 2009) which sets out the data thematically.

The use of the notation (…) indicates where text has been omitted due to lack of relevance.

4.1 Superordinate Theme One: 'Information difficulties' (Appendix 4)

This theme demonstrates the foundational role of information for women experiencing pregnancy complications. There was a clear information gap that led to a lack of containment and increased anxiety. This omission subsequently impacted their capacity to cope with the tension of the unknown, not only for they themselves but additionally for their child, partner and any other siblings and wider family members.

At times this lack of information appears to be unintentional. However, there are also clear instances where information is actively withheld, or used and misused in questionable ways.

Additionally, when information *was* provided, other problems became evident. Women were confused by inconsistent information, distressed by the delivery of information in an insensitive manner and distrustful of their carers and the system due to staff errors and issues of competence. The first of three subthemes presented below concerns a deep unmet need to access information.

4.1.1 Sub-theme one: 'Women's unmet need for information'

Being informed was seen as a basic need by all of the women. They provided clear accounts of the function of this need being grounded in being prepared for possible negative outcomes and in maintaining an internal locus of control.

Aoife described the intensity of this need for information. She was told to attend hospital for fortnightly ultrasound scans during her pregnancy but not informed clearly as to why this was. As a result she sought information elsewhere with the clear goal of somehow preparing for whatever difficulties lay ahead. This led to Aoife identifying the nature of her complication online.

'I needed to be prepared (…) I couldn't stop myself (googling) because I was thinking: "I need to be prepared for this." (Aoife)

Similarly Abbey found herself relying heavily on the internet when she was told during a routine scan that her baby had signs of brain damage:

'I just needed to be prepared (…) I just needed to know (…)I needed to know what we were facing and what I could do for her (…) if anything. All I wanted was to be told was what was wrong. Do you know what I mean? Like in a sense, even if the worst was wrong, I needed to know what it was…in my mind I was thinking: "I have to prepare, I've got to talk to these people. I've got to look up grants for a wheelchair." (Abbey)

This need to prepare implicitly highlights the role of control in pregnancy and pregnancy complications and this link is made explicit by Annie who suffered with a rare pregnancy complication called obstetric cholestasis.

> *'It (information) made me feel in control, 'cos we're not in control when we're pregnant (…) I like to understand (in context of preventing loss).' (Annie)*

So here the need for information is connected explicitly to its role in extending control and lowering anxiety. This makes sense particularly with serious complications where the lives of the woman and her baby are at high risk for an extended period of time.

However with some exceptions, there was an overwhelming sense that this need was not met.

> *'More information really (if I could change something) that's a significant thing. There wasn't even a leaflet stand.' (Aoife)*

> *'…they told me nothing.' (Annie)*

> *'Somebody to just hand out a list (…) somewhere you could go and ask a question (…) there was nothing, no little pack.' (Amy)*

In reflection on my own experience, I realised that as I had been hospital-based like Maeve, I had had less access to external information. This meant that I had relied solely on staff and visitors for information (and indeed everything else). As a result I wondered about the implications for staff in differentiating between informing hospital-based and non-hospital based women.

A further aspect of the omission for women was that staff did not appear to *understand* the centrality of information for women. Abbey's question to the interviewer above: *'Do you know what I mean?'* may be reflecting the experience of not having this need truly understood or 'got'. She went on to elaborate on the experience of not being understood later:

> *'…they were jollying me along (…) I don't think they got my need to know the facts (…)I used to get(partner) to ask the questions 'cos me lying on the bed with my jeans down was getting less attention than him in a suit.' (Abbey)*

Maeve picks up on the sense of feeling somehow patronised and generally not having the need for information taken seriously:

> '*You might feel like a complete idiot with some of the questions you want to ask…you'd feel like the doctors (…) high and mighty.' (Maeve)*

In response to being asked about facilitative experiences, Maeve was able to identify the staff sister's behaviour. She explained that the staff sister had the capacity to act as patient advocate going to bat for women and filling in information gaps at times:

> *'…the midwives were very good … you would be able to find out information and ask them questions(…)the doctor wouldn't be allowed to skim over it because she would repeat the question.' (Maeve)*

Exploration of Maeve's relationship with the midwifery staff showed that while this support was important for Maeve, it was limited to facilitating information. She clarifies this with;

> '*There's no…overly kind of friendly engaging with patients there at all'.* (Maeve)

The lack of understanding regarding the need for information was regularly experienced following long journeys to the hospital, upon which women would wait for hours for their 'appointment' only to have their questions ignored and be despatched after a few minutes:

> *'…he was like: 'Oh it's fine', so when you did get your opportunity to say it to a consultant you just got: 'its fine' (…) they want to rush you out the door (…) you'd be waiting hours.' (Aoife)*

The women's experiences of being rushed in and out of appointments with questions remaining unanswered was familiar to me. In my experience of one hospital in particular I remember the apologetic, rushed manner in which I couched my questions. I was highly aware of feeling childlike, that I was just one more pregnant woman and my requests for information were somewhat superfluous to requirements.

While participants sometimes referred to this rushed conveyer belt treatment in the context of the harsh economic climate and subsequent resource limitations and cut-backs, it seemed clear to the women that this need for sufficient and appropriate information was neither met nor understood by staff.

4.1.2. Sub-theme 2: Ethical information issues

This dearth of information can be viewed in a passive sense, however there was also consistent evidence, as hinted at in Maeve's experience above of a more *active* lack, or a *withholding* of information. Women also described breaches of confidentiality and the privileging of staff precepts over women's experience in hospital notes.

Often this was felt in women's unanswered questions, as in Abbey's case below.

'(Information) helps, we can deal with things better, we don't like to be fobbed off, and proper, because I mean, somebody would answer my questions very medically so I didn't know what he meant.' (Abbey)

In Abbey's story the issue of active withholding of information was an explicit aspect of her experience. She was informed of the range of possible outcomes in relation to the brain abnormalities staff had discovered during a routine ultrasound of her baby in utero. .

'He said: 'In your case, we had to get you back, so we had to tell you (about the pregnancy complications), we couldn't have not.' (Abbey)

The doctor is explaining that they were forced to be open with Abbey because she was required to return for additional scans. This suggests that women might only be informed of complications when it is absolutely necessary. Indeed the doctor went on to explain to Abbey that within the hospital this debate was very current with difficult questions being asked such as:

'Do we need to tell the patient everything on the scan?' (Abbey)

The transparency that Abbey experienced sat well with her as, as indicated above, she 'needed to know'. However this issue was and continues to be a source of contention in her household with her husband feeling strongly that informing parents to this degree was irresponsible and unnecessarily distressing. As Abbey explains:

'…it's a big debate in our house.' (Abbey)

I had previously felt quite indignant on the issue of staff making what felt to me like patriarchal decisions about what women should know about their bodies/conditions. I myself had put myself at risk as a result of not being given sufficient information

regarding my risk. However, on understanding the different experiences of Abbey and her husband I was able to reflect more on the complexities of this issue. This allowed me to see the co-created piece between some staff and individuals, who might choose to let medical staff take more responsibility in the process.

This open discussion surrounding the debate of what the 'patient' is told is unique in this research. In other parts of Abbey's experience and in the stories of the other women there are many examples where they are required to somehow ascertain information indirectly.

This issue was a core theme in Aoife's distress throughout her pregnancy where she was suddenly told to attend hospital for additional scans but given little additional explanation for this change:

> '…the numerous scans went on…"your baby is measuring small" but nothing else.' (Aoife)

With staff unwilling to discuss the issue further Aoife was forced to rely on outside sources of information such as an antenatal group and the internet. In interactions with the radiographer she also found herself to be hyper vigilant, attempting to ascertain information indirectly through the radiographer's tone of voice and facial expressions:

> 'You could just tell by the tone of voice.' (Aoife)

For Amy who also experienced intrauterine growth restriction (I.U.G.R.) there is a similar experience but as this was her second pregnancy with complications she is familiar with the staff modus operandi and indeed appears quite accepting of it:

> 'When they started to monitor me more carefully, I knew.' (Amy)

Later she gives an indication of the horrible thoughts and fears that were fed by the lack of information:

'Cos I didn't know, like do all these babies die?' (Amy)

The theme of withholding information is continued with Donna who was shocked to discover on reading her notes that staff had unbeknownst to her been testing her for cancer:

'…like they were looking for cancers, tumours and they didn't say it.' (Donna)

Donna was considerably impacted by this experience, and explained in the interview how she remains anxious and unable to bring herself to read about an additional complication which was only named for her by the staff near to the time she was discharged.

Confidentiality

Participants' descriptions of confidentiality problems suggested a lack of adherence to any coherent guideline or policy, and at times an ingrained systemic contravention of patient rights.

Annie gives an insight into what appears to be a commonplace breaching of confidentiality when she explains how she discovered staff were about to admit her to hospital:

'…you can hear the (staff) talk about everyone, they were going to admit me…I find out 'cos I over hear it. They do have a glass partition…just don't use it.' (Annie)

Donna describes how a midwife repeatedly attempted to convince her to seek surgery against the express advice of the surgical team caring for her. In one attempt to persuade her, the midwife tells Donna a gruesome story of a woman whose wound had opened at her son's christening together with identifying information of the woman concerned:

'…she told me the area the lady was from and everything.' (Donna)

It is reasonable to imagine that given this breach, Donna might assume that her own story and identifying information might be used as a tool with other women in the future. These and other instances can be seen as contributing to the breaking of women's trust. Together with their existing distress then, women must also contend with these breaches by those very individuals who are charged with their care. Importantly these breaches often occur at a time when the women are too vulnerable to mount a challenge.

Privileging of truth and reality

When women returned home and were able to access their hospital notes they sometimes became aware of what might be described as omissions in information. Key information had not been recorded, or had been altered giving a representation that did not match the experiences of the women. For example, Annie was angry to find that a midwife had recorded her questioning of admission as a refusal to be admitted to hospital:

'…she'd written (in notes) that I'd refused admission!' (Annie)

This caused her anxiety, and there was clear frustration in her voice as she related during the interview that she did not wish to be represented as not caring about the

health of her child. She had simply questioned the rationale for being admitted. Indeed, her questioning had been borne out at a later point when her consultant agreed with her suggestion that admission would not have been helpful at that point in time.

Similarly, Donna had experienced a high level of insensitivity and carelessness during an internal examination. The nurse recorded in her notes that:

> *'Donna was upset by exam.' (Donna)*

However this line gave no indication of the shame and humiliation that Donna experienced during an extremely intrusive internal examination carried out by a male doctor. In fact she had been left feeling angry and humiliated as she was left with the doctor with a metal speculum inserted into her vagina (swiftly following heavy haemorrhaging and emergency admittance to hospital) while the midwife was sent off to find swabs which the doctor had not been prepared with.

Thus this apparently innocent line gives no indication either of Donna's reality or of the wider relational context and the co-created aspect of her distress.

4.1.3 Sub-theme three: Fear and distrust

For all of the women, fear and distrust developed early in their relationships with staff and this was partly due to insensitivity in the delivery of information, inconsistent and therefore unreliable information and the witnessing of incompetence and errors.

Errors and competency

Maeve noted a sequence of errors, some of which had the potential for fatal consequences. Firstly she refers to a laboured process of diagnosis and says:

> 'It took four of them to actually discover …it took from Wednesday to Saturday to find that out.' (Maeve)

And in more detail she reveals what may have been an embodied knowledge and her subsequent shock that the doctor was mistaken:

> 'What was so shocking was…it was a registrar…she said "it's definitely not premature rupture of membranes" and I knew at that stage that it probably was. I just knew.' (Maeve)

Maeve goes on later to speak about a doctor attempting to take bloods from her when in fact he was in the wrong room. An additional error with the potential to be lethal was only avoided through, her flat refusal to comply with staff. This occurred when a doctor who was seeking to do a speculum examination was sent packing. As Maeve explained, she was aware that this was in error as the exam could have brought her into labour.

The litany of errors led directly to a breakdown in trust for Maeve and she began to question the capacity of the staff to provide safe care:

> '…what's wrong here? Can I……I actually sort of felt: "Can I trust them…….to get it right?" (Maeve)

And:

'…there were lots of things that just kept sort of adding up and just leading me to, you know, just be very sort of…mistrusting of…what was going on.' (Maeve)

This aspect of Maeve's process for me was reminiscent of my own misdiagnosis. It helped me to understand the cold terror that might have been experienced by a seemingly calm Maeve in interview. I remember the moment I realised that those charged with my care were not equal to the task. Maeve's story revived those old feelings of disbelief and betrayal for me.

Distrust, disbelief and fear is highlighted too by Annie when she is faced with the unexpected situation where staff lacked sufficient knowledge of her condition. She describes her shock when she first realizes that she is not in competent hands:

'…so they didn't actually know what to do…I was shocked' (Annie)

If she was in any doubt of the limitations of staff understanding, this is clarified once again when a hospital doctor asks her:

'What do you think we should do now?'(Annie)

She explained with exasperation in interview:

'I knew more than the staff!' (Annie)

The theme of staff competence and women's' diminishing trust is interconnected with the confusion participants experienced due to inconsistent information from staff.

Inconsistent information

Inconsistent information was a strong theme which once again led to fear and distrust and lack of containment. When faced with opposing information from staff within the same hospital Annie asks:

'…who's wrong?'(Annie)

And later:

'Look, which is it?' (Annie)

In my own story, being faced with two hospitals offering opposing information, I became aware of how lucky I had been in being able to seek a second opinion which I felt able to rely on. In Annie's story this safe space had not been found and I felt deeply for her.

Similarly inconsistency results in additional distress for Donna when different staff offered opposing solutions for her difficulties:

'…one person would say: 'Fast' the next would tell me to eat!'(Donna)

This had been distressing for Donna leaving her emotionally isolated and physically weak and in pain. However a subsequent experience which Donna recalled brings this issue to a more disturbing level. She described her fear and dread of a midwife who consistently and aggressively attempted to persuade her to demand surgery in direct opposition to the advice of the surgical team. This led to a great deal of distress. In her efforts to maintain her equilibrium, Donna followed her husband's advice to face the wall and pretend she was asleep to avoid the distress of further contact with this individual.

> *'God knows what she's gonna say…I know she's gonna try and convince me and I'm afraid….. "Pretend you're asleep." (Donna)*

So in addition to the confusion of diverse medical advice, some participants were also faced with a highly insensitive manner, leading to them feeling attacked and vulnerable while in an unfamiliar environment and without their normal supports.

This piece fed into my polarized view of the power dynamic. I felt a great deal of rage towards this midwife , however I did reflect over time on the idea that it is likely that while her behaviour was clearly misdirected and seriously damaging, her motivation was not 'bad'. In acknowledging this, I felt forced to 'give up' the inflexible and very comfortable polarities which I had thus far held so separately.

Insensitive delivery of information

This insensitive delivery of information was an experience shared by all participants.

For example, Annie was met with panicked junior doctors who talked of:

> *'Intrauterine death' and 'maternal death.' (Annie)*

In response to this she explains:

> *'I felt terrified.' (Annie)*

While in this case pertaining to Annie the insensitivity can be seen to be due to the junior staff's lack of experience and subsequent anxiety with this particular condition, this was not always the case. One case in point concerned Abbey who was attending for a follow up scan in the weeks following the diagnosis of her baby's brain damage.

Abbey was confronted with a consultant who spoke into her Dictaphone during the scan, rather than to her, regarding bad news of her unborn child's health:

> *'…speaking into her Dictaphone: 'suspected P.H.A.C.E.' I went home and googled it: it was horrific!'(Abbey)*

It was in this way that Abbey discovered the possible extent of her child's difficulties. This meant that she was left to deal with the associated emotional impact at home, alone in front of her computer screen.

These experiences and the way in which participants describe their responses to them, highlight the fear and lack of containment that result. Rather than containing and regulating women who are in already challenging circumstances, these communications (or at times lack of them) function to escalate their anxiety. For all the women this was difficult, however for those who were confined for any period to hospital, competence issues and insensitive delivery of information were quite overwhelming because they were unable to escape and were therefore quite powerless.

4.2 Superordinate theme two: 'Disempowerment'
(Appendix 5)

Power was at the heart of each participant's story. It was evident that they felt disempowered in many realms of life and in part this was due to the need to prioritise the seemingly fragile life that they were nurturing within their bodies. Experiences of harshness and being treated as a number rather than a person emerged repeatedly from the stories. Women's relationships with staff were particularly susceptible to the power differential due to the fact that women were so heavily reliant on staff for the survival of themselves and their babies. It was at times noted by some (Amy) that

they were aware of a need to be cautious with staff with regard to getting their needs met. They were also aware of the intra-staff hierarchy and their accompanying power relationships.

The three sub-themes below concern the women's experiences of institutionalisation, their lack of control within the relationships, and the impact upon their dignity on the occasions when respect was not accorded to them.

4.2.1. Institutionalisation

There was evidence of institutionalisation in women's experiences of harshness, manipulation and force. Some staff members were regarded with fear and the environment was at times likened to a prison with women speaking of being treated as a number and not a person.

Aoife was clear in her description of the process she experienced from the very first visit:

> *'You're given a number, you go and get your urine sample.' (Aoife)*

This was the beginning of Aoife's loss of herself, and the sense of having to become a faceless number is echoed within the narratives of other participants. For example Amy recalls her sense that

> *'…you're a number.' (Amy)*

This early experience of the disintegration of individuality turns out to be only the beginning for Aoife. By the time she needed to return to hospital for her post-natal check-up her terror is palpable:

'Yes I was afraid to go back there (hospital) and my heart started getting palpitations. I thought I was going to have a panic attack. I was so afraid I didn't want to go back. Still to this day I can't go near the building…My mum had to nearly drag me back it's like a prison…no warmth….I thought I was in a prison, you're stripped down…draconian.' (Aoife)

Clearly, Aoife was experiencing intense horror and dread at the prospect of returning to the hospital environment. Her use of language provides powerful imagery and conjures up a picture of a harsh, cold and punishing prison where her sense of self was stripped away. There is a clear sense of the power differential too. Aoife seems to feel powerless and infantilized. In fact Aoife comments at one point:

'I was treated worse than a child.' (Aoife)

Interestingly this powerlessness is not representative of Aoife within her other contexts. Indeed this is true of all the women who were articulate and bright and had enjoyed successful careers. However their experiences appeared to render these stronger parts of themselves inactive leaving them unable to draw upon their usual resources. This power differential together with the sense of being psychologically deconstructed or ground down is also apparent here in Donna's account of her distress toward the end of her hospitalisation:

'I think it was psychologically I needed to get out of there…"If I eat they'll let me go…if I don't go home I'll end up in a psychiatric ward"…'cos they put me into isolation…wasn't allowed to leave the room…room was tiny…like a prison cell.'(Donna)

From this we see that Donna understood that her mental health was deteriorating rapidly and that this was connected to her environment. Though eating and drinking caused her agonizing pain her thought pattern reveals that this was preferable to remaining in hospital in what both she and Aoife refer to as 'a prison cell'.

Implicit in all of these accounts, and a central reason for distress was the loss of control that the women experienced through their relationships with staff.

4.2.2. Loss of Control

Several women commented on the fact that pregnancy in and of itself limited ones sense of control, however instead of supporting women in this difficulty, it appeared that often staff contributed to cement this loss further. In one instance Aoife explained how the consultant had told her that her new born baby, who was underweight and in special care, would require a particular type of formula. However the nurses withheld this food insisting that she breastfeed exclusively. This left Aoife in great distress. One nurse had taken pity on her and 'smuggled' the infant formula into her room.

> *'They have it (infant formula) but they wouldn't give it to me…I was hiding them (formula) under my pillow…the pressure was horrific and she was premature. This was awful. This was one of the most traumatic parts, really bad. I remember just balling my eyes out saying: "I need to give her the Nutri-Prem, she needs to grow"' (Aoife)*

Understandably Aoife's narrative was scattered with rage. This was particularly so in recalling this experience. The only time she swears it is with regard to this withholding and her subsequent inability to help her child:

'My partner…He couldn't-excuse me- fucking find the Nutri-Prem. He was trying to find it here, there and everywhere.' (Aoife).

While I was genuinely shocked when Aoife described this, I remembered that I had experienced similar interactions with staff with my second child who had become ill soon after birth. Her story alerted me to the horrible realization that my relational process had not been an isolated case. I also began to understand that I had been viewing that disempowering experience as due for the most part, to my own distress, anxiety and exhaustion. That is I had been locating the problem within myself rather than the co-created relational process. This was a most freeing process.

In a similar vein Aoife comments on how the hospital rules meant that only her partner was permitted to visit her. In fact she felt a strong need to have contact with her mother. She described the impact of this separation:

'My mother couldn't come and see me, that was just hospital rules…I needed to see my mum and I was really really sad…I was lying there…I thought I was in a prison and no one could come and see me, , my mum couldn't come and see me.' (Aoife)

While there were no doubt rational reasons for this rule, the impact of being separated from such a key support at such a challenging time, was deep and unacknowledged.

This theme of separation is carried through with other women in their experiences of being separated from their new-born infants. Disturbingly, the taking or separating of babies and women appears to be commonplace practice. While this is often clearly necessary for the wellbeing of the child, the importance of contact and the intense

distress caused by the separation often went unacknowledged. In fact, new-born-mother contact was often not prioritised at all and women who attempted to accompany their infants for tests or visit them at the NICU were often not only *not* supported to do this but actively discouraged or indeed refused.

In particular, Amy speaks at length and throughout the interview of this experience, the deep impact on her, and the manner in which staff appeared to understand the separation. Amy had been raised on a dairy farm. Initially she explained that the terrible pain of being separated from her child reminded her of this past.

> *'I feel like a cow in the field…'cos the farmer will take the calves away from a cow and put them into different sheds to wean them off the milk…and you'll hear the cow in the yard pining for the calf…yeah. And you'll hear the calf pining for his mother.' (Amy)*

In this terribly moving narrative, Amy identifies with the powerless protesting animals. The usefulness of the metaphor is extended to the staff, who like the farmer, removed Amy's child, seemingly without insight into her distressed state of mind:

> *'Like there's nothing more unnatural than to deliver this baby and the next thing they're matter-of-factly taking the baby off you and expecting you to be fine about it because you can't be fine about it…you can't….because you spend like 8 months waiting and anticipating…Lucy came with me for a bit and then was taken…but…"Taken" is very strong then but…yeh, it's taken….but um but it's an awful, awful thing and I don't think the staff give the person in the bed enough credit for it….. "Yeah, she's in the best place. She's grand where she is" but they could have been a little bit more….My baby was*

taken: nothing will set you up more for a fall than to have your baby taken away.' (Amy)

Amy was clear about her use of the word 'taken'. There was a deeply felt sense of this, and 'the fall' that this withdrawal had affected within her.

Perhaps more disturbing however was an apparent 'throwaway' line which gives us a chilling insight into the staff's limited understanding of infant parent separation:

'… the nurses would say I recover very well when my babies are gone.' (Amy)

The staff were referring to the fact that when Amy had her child taken away she was then motivated to make contact with the child at any cost. This led to her pushing herself to get out of bed very quickly following the birth. However in the time before she was able to leave the bed to visit her baby, Amy described her 'hysteria' as a result of staff not bringing her to the NEO unit to see her child:

'and the first day, it went…I'm jumping all over the place now but they told me when I had (baby) that they'd take me down about two in the morning to see her and they didn't. And they kept kind of pushing me off. They were busy I'd say, more than anything else…So dinner came on the Saturday…half 12, and I couldn't eat. I was in hysterics. And they're like "What is wrong with you?" I said "You told me all night you'd take me down to see her" I said "You haven't taken me down yet" I said, "All I want to do is see her, you know. That is all I want to do"…and I met this old biddy of a nurse and um, "Actually she's fine, she's below". I said "Yeah, but I want to see her!" I said: "I have", I said "You've promised me and so I stayed awake to try and get down to see her", I said, "You won't take me down" I said, "All I want" I said, "That woman next

door has her baby. You know I'm hearing her baby" I said "it's unnatural".
(Amy)

The 'going all over the place' and general disjointed nature of this material may be indicative of the high level of distress Amy experienced. However it is also suggestive of lack of processing and integration.

My own response to this aspect of Amy's story was a dramatic one. I was unable to speak and felt both nausea and physical numbness at the time. While I had not been separated from my children in this manner, it had become a fear due to the threatened loss or separation through death due to the complications. It was this which had fed the separation anxiety which followed the birth of both my children.

The next morning, disturbed that as human beings we can separate our own and other species so coolly in this manner, I changed my diet from vegetarian to vegan and pressed on with the research, with my motivation to continue the research renewed.

Abbey picks up on the same theme of having her baby taken and the loss of control that accompanied the experience:

"No, you're not allowed to go with her"…I wasn't even allowed…it's insane…I
had her and they took her off me so I couldn't follow her.' (Abbey)

With the words 'I had her and they took her off me' Abbey highlights the particular cruelty of the separation following the months of waiting to hold her child and keep her safe. That she is 'not allowed' to follow her underlines the patriarchal quality of the relationship where the woman is infantilized and powerless in what might be considered the ultimate separation: that of mother and child.

Abbey was keen to breastfeed. With this in mind she insisted on having contact with her child. However it appeared to Abbey that this was an inconvenience for staff that had tests and tasks to carry out with the child. She later discovered that had she not insisted, her child would have received formula from a midwife, as this was standard procedure:

> *'Begrudgingly gave her to me. They got annoyed with me wanting to feed her myself. It was a whole issue that happened a number of times.' (Abbey)*

In this instance Abbey had the capacity to assert herself. However this raises the question of what the outcome might be when women do not have this capacity.

4.2.3. 'Dignity and shame

All six women reported relational experiences of shame and embarrassment where their dignity was not respected. Often these sharply felt occasions seemed to be due to a lack of sensitivity by the staff. There was a sense from women that they may have had difficulty responding appropriately to each new individual's experiences due to the fact that they witness so many women enduring difficult pregnancy related situations. As a result they appeared at times unable to connect into women's intense experiences or shame.

For Donna this was a painful reality on several occasions. In the beginning of her account she describes how she presented to the hospital with haemorrhaging. When the bleeding stopped staff proceeded with an internal speculum examination. Donna was understandably anxious and the lack of dignity of the situation is clearly evident as she begins to weep for the second time in interview. She goes on to explain how she felt as a result of the way in which the exam was carried out:

'…like he was nice at the start but like after that I really felt like this piece of meat.' (Donna)

Shortly after this experience, staff decided to break Donna's waters. As a result of one of her complications (polyhydramnios: excess amniotic fluid) she became drenched in amniotic fluid. This experience was humiliating for Donna:

'I was lying at the bed and it's just like it was just gushing and gushing and you're literally lying in the bed sopping…Sopping with fluid. Um and I was told to lie there until or for a while until it kind of eased then coz there was no point… No point. And I can kind of understand that probably until it stops but I just felt uh as I said I felt like a cow. Do you know what I mean? Lying in like… soaked. And so then they came and they said, "Oh, get up and walk around." So they didn't offer me to go for a shower.' (Donna)

Donna's sense of powerlessness within this shameful situation is evident through her language but also through the frustration and anger of the tone she used here. For example she was 'told' to lie there and again when she is told to: 'get up and walk around' she follows this instruction silently in spite of wanting to wash. Finally, the utilisation of the animal analogy 'a cow' gives us a sense of both the level of powerlessness and shame experienced.

In following the staff instructions of walking around the experience is repeated and Donna is once again drenched in fluid. However this time the humiliation feels still more intense because she is in a public space:

'…but it was just so humil-- I said "I don't believe how just can they get worse like, you know. Like he said (husband), coz he said to me, "Just stay there. I'll go get somebody like," and um I call, "Come back come back", "You're grand. You're grand"… So I'm crying… Yeah. It was like I was mortified. Like people passing, you know.'(Donna)

What appears to make this worse is the staff response of: "You're grand, you're grand". Not only does this not acknowledge the mortification and public exposure felt by Donna, but furthermore it might be seen as patronising. Donna goes on to explain this lack of understanding in more detail:

'Making light of it is what happens and you know, it's kind of like 'Sure we see this every day' And it's like 'You might see it but it's not what I would like happen to me', do you know ?.'(Donna)

Here Donna confirms here experience of not having this excruciatingly shameful experience acknowledged by staff. Donna's account of her experience is important for an additional reason: it reminds us of how the messiness of our bodies is normally a private affair. In this case, there is a clear breaching of these boundaries, during a period of extreme vulnerability, not only in relation to staff but even with the public.

What Donna goes on to describe as an 'audience of strangers' to her shame, is also a theme which is very present in Maeve's story. Maeve was on bed-rest at a teaching hospital for ten weeks. While she had allowed students to be present on

several occasions during her treatment, she recalls a distinct breaching of boundaries during her labour:

> *'I thought it just became intrusive. Right up to the point where on the day I was being induced and they were actually inserting the gel, and there were students in the room and there was a midwife there and I was kind of going: "well, the students are not staying, you know, to watch this…this really is too much." And one of the midwives who was there, she said "You can all leave"…and there was another student who um he asked to watch the labour and I just refused. I had had enough at that point…there should be, you know, limits and you know boundaries need to be set' (Maeve)*

This account highlights the vulnerability and lack of control of women within staff – patient relationships. It is also a reminder of the fundamental importance of explicit boundaries that mark out women's rights. Had Maeve not been able to vocalize her need for staff to leave, it seems likely that she would have been watched going through the stages of labour. The behaviour of the student in particular, indicates a disturbing voyeuristic curiosity that lacks the humanity the situation and post clearly requires.

At times women were able to find humour within the challenges to their dignity as in the case of Abbey:

> *'Lying on the bed with my jeans down to my knees was getting less attention than him (husband) standing there in a suit… we used to laugh saying they were like estate agents when we were buying our house. I would make all the appointments and I would turn up to meet these agents and they would talk to my husband' (Abbey)*

4.3. Superordinate theme three: 'Empathic failure'
(Appendix 6)

While each woman was able to recall a staff member who had demonstrated kindness, there was overwhelming evidence of empathic failure. Regularly women described feeling voiceless and invisible. At times women described staff that were 'nice' but who did not demonstrate accurate empathy leaving women feeling isolated. This isolation was sometimes due to staff directly avoiding or even abandoning them in spite of distress and requests for help. Finally the women identified with clarity the stark separation between the treatment by staff of the body and emotions.

Importantly, there was a co-created nature to this difficulty, in that often, women seemed unable to express their feelings or needs or certainly to ask for their non-physical needs to be met. There seemed to be many reasons for this and these are elaborated in the first sub-theme.

4.3.1 Invisible woman

Each woman spoke of the experience of being unseen and unheard. This meant that not only were their needs not met but also, that they went unacknowledged. There was a consensus too of the sense that all attention was on the infants leaving women alone. At times it was clear that while they too needed to be kept in mind, the women themselves wrestled with the idea, because actively seeking help might be seen by others (and even themselves) as detracting attention from their child. This dynamic of needing to be focused on but having difficulty in articulating this is demonstrated by Amy who remarks at one point:

> *'You can't ask somebody all the time to be nice to you.' (Amy)*

This indicates an unfulfilled need for social/emotional care and attention. It also gives us an insight into Amy's lack of trust that staff will 'be nice' to her if she did find the courage to voice her need. This unhopeful view of support seeking at the hospital is extended when she says:

'I wouldn't burden staff unless I needed.' (Amy)

So it might appear that Amy views her non-physical unseen needs as a 'burden' on staff and therefore not a priority. There seems to be an element of shame with the word 'burden' suggesting that the staff would not welcome her emotional needs. Several times during the interview Amy tells us why this is:

'I don't think they understand.' (Amy)

And

'It's a pity they don't recognise it….there was days you'd be above and…you'd be teary out…do they get immune to it?'(Amy)

Here Amy is attempting to understand why no one saw her distress and wonders whether staff become immune to women's experience as they treat so many or perhaps she wonders, they simply do not understand. Whatever the reason might be, she offers clarity concerning how she felt:

'I feel I was forgotten…you're just…you're there, you're just not on their list.'

(Amy)

Similarly Annie's experience shows how a woman's invisibility can be connected into the baby they are carrying:

'…there was concern to the baby like I didn't exist…at one point I had to say: "Will you please listen to me" and she was: "Won't you be much better off in the hospital?"' and I say "No! You're not listening. I won't be better off sitting here for three days worried out of my mind…and my boys are all at home and I'm worried about them and nothing's ready" and you know the basket wasn't out of the attic, and, you know, 'cos I still have another two weeks to work at that stage' (Annie)

At the beginning of this quote we become immediately aware of Annie's frustration at being ignored but also of her strength and capacity to fight. In spite of having expressed her needs she remains unheard and is required to assert herself once again. This links, and lends credence to Amy's sense (above) that had she articulated her needs, she would not have been heard.

However Annie's narrative is also useful in indicating an additional issue: the way in which women's additional responsibilities and contexts seem also to be invisible to staff. Naturally Annie must take into consideration her other children ('my boys') at home as well as her work responsibilities. Annie has built up a career for herself and

this cannot be ignored. Furthermore, when she remarks that the (Moses) basket is still in the attic she signals that she is unprepared for the child she is carrying. She is clearly a woman with multiple responsibilities that require her attention, and this is not taken into account, at least openly, by staff. While Annie fought being admitted, for Amy it was very different. She talked at length of a terrible responsibility for her unborn baby and how she often wished to be admitted for a rest from this weight.

> *'And then you kind of get to the stage where you're kind of thinking "What if I tell them, you know, that I had a bleed? They might keep me in". (Amy)*

The very different responses of Annie and Amy are important in that they highlight the complexity of women's experiences. This complexity means that staff require the skills to understand and respond to this diversity and the fact that as Donna comments:

> *'One size does not fit all.' (Donna)*

The additional hospital appointments that women were required to attend when not admitted proved for many to be exhausting. This was partly because they impinged on an already intense world of work and relationships. In addition, they were contending with the fatigue and distress of a complicated pregnancy. No allowances were made for women with these relentless regimes who would often drive miles back and forth to appointments several times each week. Financially too, this resulted in substantial additional expenditure to cover childcare, petrol and the hospital car park.

The strain of this process and the person of the woman in general, were not recognised however and this appeared an important omission. In a similar vein to Amy, Abbey explains:

'I just felt very stressed and forgotten about.' (Abbey)

Being admitted did not seem to change this experience of being unseen and forgotten. For Donna who was hospitalised, not being seen was a consistent thread throughout her account. One instance she recalled evoked particular frustration. As Donna was unable to eat or drink for an extended period due to intense pain she consumed nothing from her hospital food trays:

'…they didn't care, trays of food coming in, coming out, coming in, coming out. "What would you like for your tea?" and you're like "Hello?" It's going in it's going out untouched.' (Donna)

There was a horrible sense here of Donna's invisibility. At a later point a midwife did take time to notice and help Donna, and interestingly Donna was finally able to begin to feed herself again:

'So I tried it and it was fine…but she was nice and she came in...I was like "I don't know what this is" and she goes "Look it could just be a bit of gastritis…don't be worried about it and you'll get to the end of it." (Donna)

Finally a member of staff saw and connected with Donna, and she began to improve. This is clearly an example of a facilitative experience of communication which had a significant positive impact on Donna both physically and emotionally.

4.3.2. Isolation and abandonment: avoidant and unavailable staff

The second (of three) facilitative experiences with staff was reported by Abbey. During a particularly isolating night in the hospital, alone and feeling overwhelmed,

she sat on her bed and began to sob. A nurse on night duty heard her, sat down on the bed with her and was moved to tears by Abbey's distress;

> 'I just felt very lonely…I was crying and she (empathic nurse) was crying. I
> think that's a problem with every maternity hospital (loneliness and isolation).
> (Abbey)

However this connection with staff is rare in the women's accounts. Overall there is overwhelming evidence of disconnection and even marked harshness at times with women being abandoned at key moments of need. A striking example of such abandonment occurred to Abbey and her husband in the early stages of her pregnancy. They were told that their routine scan had revealed evidence of brain damage in their child. Following this they were told to leave the hospital and return in two hours to speak with a consultant.

> *'…so they told us we just had to leave…that was the biggest problem I*
> *had with it: we just wandered around (location) for 2 hours in shock*
> *crying' (Abbey)*

In this way and at a crucial moment, Abbey and her husband were left alone in deep distress. While it is clear that the staff's intention was not to harm, the context within which the omission occurred, resulted in Abbey and her husband being deeply impacted.

Donna too, experienced painful abandonment when she was at her lowest ebb. She endured days of relentless agony which left her unable to care for her new-born child. When two doctors arrived at her bedside to discuss medication she pleaded for their help in alleviating the pain.

> *'I was just so desperate. I was in so much pain and I said "Please, can you*
>
> *not just do something for me?"…and I started to cry and she (doctor) looked*
>
> *at the man (male doctor) and she goes "Let's get out of here!"(Donna)*

This blatant abandonment of Donna when she is so vulnerable is most disturbing due to the apparent absence of empathy. Understandably, following this failed attempt to garner help, Donna reported further emotional deterioration and says:

> *'I just really felt awful after that…it was kind of like it had been an*
>
> *inconvenience for them.' (Donna)*

This statement smacks of shame and indicates that the interaction was experienced as a rejection. So both Donna and Abbey were abandoned and isolated when they clearly required connection. Furthermore, in Donna's case, we see that when connection with staff is explicitly sought but not forthcoming, the capacity to maintain hopeful and reach out to others can be damaged.

While these are both individual experiences, all of the women described isolation and staff avoidance as an integral part of the hospital system. This was particularly the case with doctors. Maeve was confined to hospital for ten weeks. She was very clearly able to identify one doctor's avoidance as his coping mechanism which allowed him to remain disconnected from women.

> *'He'd come in, he'd run out, because that's I suppose how he managed*
>
> *his…patients…that's how he knew that people would never get to talk to*
>
> *him.'(Maeve)*

Interestingly, this comment suggests that fear may have been an underlying motivation in the consultant's avoidant process. This intelligent interpretation from

Maeve positively impacted both my capacity for empathy and my process of sometimes dehumanizing medical staff. I experienced a new sense of sadness for the staff whose rigid and avoidant process was threatened constantly by the demands of women's emotions.

Maeve's account is scattered with examples of this avoidant approach. In fact one example which inspired particular rage was that the consultant assigned to Maeve was actually on leave. This meant that Maeve had absolutely no contact with her during her entire hospitalisation.

> *'I'd probably like to have a conversation with the consultant…just to let her*
> *know of my disgust…clearly taking on patients when in fact she was going to*
> *be on leave, and how, how could a team be left basically to their own*
> *devices.'*
> *(Maeve)*

While Maeve describes her disgust in her account, it was her anxiety which was the prevalent emotion during her hospital stay. Her fear was apparent throughout the story and this was often connected to the absence of a consultant:

> *'She (registrar) was in this new hospital making all these decisions because*
> *the consultant wasn't there… That was a major issue for me, that I wasn't*
> *seeing you know, anyone…they were supposed to be having meetings…how*
> *can you have meetings with somebody (consultant) who isn't even there?*
> *(Maeve)*

Later on Maeve returns to this issue saying:

'I had picked out who are the good consultants and who are the rubbish ones…and yeah it is 'rubbish' because they don't do anything…team are left to their own devices…she (registrar) wasn't up to par, not by any stretch of the imagination.' (Maeve)

Maeve's anxiety and anger that she was under the care of a leaderless team is both clear and understandable. Maeve struggles to comprehend the mind of a practitioner who has essentially, completely avoided her duty of care. As a result the team and Maeve are left unsafe and isolated.

When she is attended to her interactions with staff are short and functional, lacking in any connection.

'… they just talk and leave…there was no engaging in conversation.' (Maeve)

Interestingly Maeve spoke positively of communication with the midwifery staff and highlighted the strong leadership as the reason for this. However on further exploration it was clear that once again that while this was helpful it was also limited to a functional level.

'There's no…overly kind of friendly engaging with patients there at all.'

(Maeve)

Aoife recalled virtually identical interactions with staff. She described her experience as being overwhelmingly characterised by isolation as a direct result of staff communication. For some reason unbeknownst to Aoife, she was never given a midwifery appointment. As in the cases of other women, she would wait hours for her 'appointment' with a consultant only for her questions to be avoided as she was rushed out of the door'

'…he was like "Oh its fine" so when you did get your opportunity to say it to a

consultant you just got "its fine"…they want to rush you out the door…you'd

be waiting hours.' (Aoife)

Aoife, recounts how eventually toward the end of her experience, in an effort to

protect herself from staff, she retreated into herself in the ultimate form of isolation:

'I withdrew…because I thought they were all the Devil, I just felt they were all

against me.' (Aoife)

Sadly, the absence of connection and empathy from staff led to Aoife responding in

kind, and she disconnected to avoid further pain. Maeve describes a similar

disconnection or possibly dissociation as a coping strategy:

'When I was in there I suppose I became resigned to you know, well things

were kind of out of my hands here…the overriding thing was that I wouldn't go

into labour too early…not to get too upset or annoyed…really not go against

my own body.' (Maeve)

Here is a stark reminder of what exactly is hanging in the balance: Maeve is aware of

the potential impact of her relationship with staff on her own life and that of her child.

In this way we can understand that while the women did need empathic connection

with staff, it was not safe at the time to explicitly articulate rage or frustration when

they experienced abandonment and isolation. Suppression of affect and self-

imposed isolation became the least dangerous option.

This was useful at a practical level, where caution may have been needed to not

antagonize those who were charged with their care. It was also useful in terms of

women's emotional and physiological responses, as repercussions of any

confrontations were likely to affect outcome for mothers and their babies.

Clearly then, the lack of emotional support was felt keenly by the women. In fact women often described how care was focused exclusively on their bodies while the person was missed. In this way women described being experienced as a number by staff, and care as task-focused.

4.3.3. 'Mind body split: an emotional support gap'

Aoife spoke angrily of the absence of support:

> '…the non-support! Non -existent support!' (Aoife)

She recalled how she had resorted to seeking support in areas that were unlikely to lead to help. This had led to experiences of shame and embarrassment. In describing her experience, she began to understand her process with greater clarity:

> 'I was in a way going "Someone! Please, help me!" I went away feeling
> embarrassed, Oh God! I just wanted the ground to swallow me up!'(Aoife)

She is clear that formal support would have been helpful:

> 'Someone to talk to (would have helped) some sort of counselling.' (Aoife)

Similarly, Abbey wishes the experience had been different:

> 'I was never offered support…even if they'd brought us in once a week.'
> (Abbey)

And again later she returns to the subject:

> 'If there'd been something: a person, a room…' (Abbey)

It seems that both Aoife and Abbey feel that emotional support would have led to a different outcome. While Aoife had experienced particular harshness from some staff, Abbey's account reminds us that we do not have to experience cruelty to require support. Abbey recalls how staff were:

'…business-like, not talking to me.' (Abbey)

And

'The consultants were very nice…they just didn't see beyond the scan'
(Abbey)

Again we are reminded of the range of experiences and varying needs of individuals and the matching level of communication skills that are required to respond to the person as an individual.

Amy speaks movingly throughout her account of how she understood the emotional support gap and how she wished it had been:

'If (baby) had died there'd be counselling staff…but there's nothing for the poor woman sitting…crying for her (taken) baby…they don't have time for the person…you're a number so they miss out on the "How are you?", "Let's ask Mammy how she is…how's everything at home?". They'd be aware of, "she's not right today; she's only fighting back the tears."(Amy))

If my leg had fallen off, "checked blood pressure, fine"…but no one said: "Are you alright?" 'Nothing from the neck up' (Amy)

Within these lines Amy highlights a number of pertinent issues. Initially she brings our attention to how women and babies who survive pregnancy trauma are not

flagged for support. This differs to women who experience loss. Amy was able to find support through an online forum for mothers. She found this invaluable. Next Amy explains how she was not seen as in individual and so as a result no one noticed when she was not herself as they did not know Amy 'the person'. Finally Amy compares the support void she experienced to the support she would have received had her injury been physical thus highlighting the privileging of the physical health over mental health. She goes on to underline the body-mind split succinctly with the comment: 'nothing from the neck-up'.

In this way we have the sense of emotional life essentially being cut-off and non-existent. We might wonder what happens to the powerful unacknowledged emotional experience of these women in this environment.

Donna reiterates these themes and the omissions within her experience of hospitalisation. She tells us:

> '*I didn't get it (support) at any stage…I feel they don't address women holistically…they're so job-focused, task-orientated…not person-centred.' (Donna)*

Here again there is a strong sense of both the lack of emotional support and of being missed as an individual person. Donna goes on to sum up very simply how she could have been supported:

> '*Its basic things: a little bit of humanity, understanding, compassion.' (Donna)*

Finally Maeve relates how, of the many problems she experienced with staff, she is left in no doubt as to the priorities staff need to address:

'Of all the major things I would change…medical care: it's not just care of the body...it's emotional care as well…going home…new baby…you may not be physically or emotionally well yourself .'(Maeve)

Maeve's clarity concerning the need to incorporate emotional care indicates that she was impacted by this issue, though she does not explicitly outline this. Below however she becomes quite animated regarding this void:

'I'm telling you nothing (no support) there was nothing. Like I really…I went through my notes and there was absolutely nothing apart from medical care. Like really and truly there was nothing! … After some sort of traumatic event…to just be in there and have no support offered and not even any details of any.' (Maeve)

Maeve is justifiably angry at this system which clearly failed her. She is expressing disbelief at such an obvious gap and with the strength of her anger there is a sense that she is reflecting perhaps for the first time on the impact of her experience.

The women's experiences lead us to wonder about the implications of the lack of support. While this void itself is clearly an important one, what is also clear is the fact that women were not *offered* or *given* support. Whilst more subtle, it would seem that being offered is in itself an acknowledgement that a trauma has occurred.

As highlighted at the beginning of this superordinate theme there was a co-created aspect to this issue. Therefore not only were women regularly abandoned and avoided emotionally, but it was sometimes the case that they did not directly voice their emotional requirements to staff. While this is of course understandable, given the power dynamic, the bio-medical environment and the complications, it is

nonetheless important. However, I had difficulty myself acknowledging this factor. I felt the need to hold to the inflexible position that locating any difficulty within the women was akin to blaming them for challenging relational circumstances within which they found themselves. I was angry with how my own difficulties had been managed by staff and the healthcare system and I was not about to let them locate those problems in me and the other women.

It was only through a process of communicating with my supervisor that I was able to see very clearly how stuck and potentially damaging this polarity had been for both me and everybody else. Firstly this was not a healthy and authentic position for me to hold. Secondly presenting as true findings as possible with all the co-created complexities meant highlighting the need for staff expertise which would have the capacity to understand and work with these subtle processes.

In fact the relational reciprocity between staff and women, women and staff, while important, is just one of several dynamic relationships impacting on women. As we shall see in the next and final superordinate theme other relationships were also present and impacted on and by the experiences. The next section focuses on three of these: the women's relationship with themselves, with their new born children and with their partners.

4.4 Superordinate theme four: 'Relational impacts' (Appendix 7)

The fourth and final theme refers to the relational impacts outside that with staff. The focus therefore here concerns the woman's relationship with herself, with her partner and with her new born child.

4.4.1. Relationship with self

Throughout all six accounts it was clear that women's sense of self had been and remained impacted. Some blamed themselves for continuing to be impacted, feeling stupid and weak and often this was linked to the lack of emotional connection and support from staff. The impact was also born out in the process with a range of indicators which suggested that the experiences had not been processed and integrated.

Almost immediately from the beginning of the interview Donna became overwhelmed by emotion and began to weep. At times during particularly difficult reflections her pace would race or slow down dramatically and her body would become noticeably rigid. She demonstrated a great deal of self-blame and harshness toward herself. In particular she seemed to be angry with herself for having been unable to act more assertively with staff:

> *'I'm disappointed in myself, I knew the questions to ask…I should have known better to ask. Even retrospectively I say "Why didn't I?" or "why wasn't I more assertive or stand up for myself?" (Donna)*

Clearly Donna's sense of self remained impacted. She uses powerful parental language such as 'should'. These judgements do not take the various contexts and factors into account. For example these comments do not take into account her vulnerable state due to the physical and emotional implications of the complications. While she was able to recover over time, she did not have the resources she would normally have had available to her. This very partial interpretation could indicate that Donna had not yet processed and integrated her experience.

Self-blame was also evident for Aoife with language strongly indicative of this same process:

> *"I should have been proactive, why did I go public?" So I was blaming myself'*
> *(Aoife)*

While Aoife has created a degree of space to reflect and understand that she had been blaming herself, it is clear from the use of 'should' used earlier in her narrative that confusion and self-blame remained.

Abbey too demonstrates a lack of compassion toward herself in relation to how she coped with the experience two years on:

> *'It went from this huge issue to "You're grand…you're nothing."*
> *'embarrassment…I felt stupid…making a fuss. I feel silly that I'm still upset about it…I should just get over it…no, it isn't gone 'cos I didn't deal with it…I got through it in the first year and it's hitting me now, it's all coming out'*
> *(Abbey)*
> And
> *"Maybe it wasn't that serious: if there was some really wrong it wouldn't have been like that." (Abbey)*

Here we see Abbey struggling to make sense of not being supported through such a difficult experience. In this moment she begins to doubt the degree of risk and her own internal experience. Importantly, Abbey has clarity concerning her recovery. She understands that as a result of not processing the experience, it remained unintegrated, and she can no longer contain it now, two years later. A reflection of

this within the process was the exhaustion that Abbey commented at the end of the interview:

> *'I'm exhausted, it (unprocessed distress) was still there' (Abbey).*

Abbey's conclusion that the lack of emotional support from staff reflected that she was overreacting was also felt by Amy:

> *"Maybe I'm overreacting…it seemed so matter of fact to them, Maybe it's me overthinking, maybe it's not that high risk", oh it's completely psychotic thinking, it's just all over the place.' (Amy)*

Here once again we hear the confusion due to the dissonance between staff behaviour and the woman's experience. Like Abbey, Amy wonders if she should disregard her own experience. It would seem therefore that for both Abbey and Amy the dissonance between ones experience and the external response one receives has led to a shift in their experience of themselves. Amy goes on to explain that while her mood had now improved: she would not have made contact to participate in the research previously:

> *'if you spoke to me last year…I wouldn't speak to you…I've had time(…)I'm better now but I'd cry and cry 'cos they got their babies you know?'*
> *(Amy)*

In this piece, Amy clearly indicates that the way in which she had been separated from her child had directly impacted her mood. Her comment that she would not have spoken with me last year provides us with an understanding that this was a significant impact and that this partly manifested in social silence and withdrawal and

mourning. Finally she informs us that the passing of time has helped her to come to terms with the loss.

Annie explains that she remains impacted by her experience. This highlights what may be the central role of time for some women.

> *''I'm not 100%...Look what happened and I'm supposed to be back to*
> *normal…it's taken a lot out of me and no one realises.'*
> *(Annie)*

There is a sense of anger and energy in Annie's narrative. Rather than locating blame internally, Annie identifies the mismatch as belonging outside of her. She understands that she is justifiably impacted, but others do not. This means that she is left alone and isolated within her distress.

Annie's energy is present throughout her account and particularly so when she tells us of her 'fight' against the distress:

> *'I try to fight past it…I don't know how to…as much as I can I limit it…I don't*
> *want to give in.' (Annie)*

Annie provides an insight into both her strength and vulnerability here. We get a clear sense that she goes to battle each day in spite of not being sure how to fight this. What makes this story particularly moving is that we know that she is in this fight alone.

The isolation which comes after the storm of medical intervention was a familiar and difficult experience articulated by other women. For example, Abbey described how at the end of her hospital experience she felt abandoned and confused:

> *"There's your baby…good luck…off you go" You go "What!" Now I didn't know*
>
> *if I could stop worrying, I didn't know how to feel.' (Abbey)*

Abbey gives us the sense here that though the danger was over for the staff, Abbey could not suddenly feel 'ok'. The 'off you go' refers to her experience of being figuratively ushered out the hospital door by staff with her infant as if the previous months had simply not occurred. She has not had any space to 'catch up' with or even address her experience.

Maeve articulates a remarkably similar experience upon leaving hospital care after ten weeks. She reports a clear sense within the non-verbal communication of the trauma being minimized or ignored:

> *'It's you know "Oh yeah you've had a baby. So what? Get on with it…oh*
>
> *women do this all the time…people do this all the time…it's no big deal."*
>
> *(Maeve)*

Here Maeve offers us a powerful sense of a deeper, implicit staff communication that appears to have been experienced by all of the women. It is an alarmingly clear message to remain silent, and that they are not entitled to articulate or even feel their distress. With all six women having been significantly impacted by their relationships with staff, we now move on to participants relationships with their babies.

4.4.2. Relationship with baby

Perhaps most disturbingly, five out of the six participants, described themselves as highly overprotective while the sixth explained that she now over-estimated her

child's strength. Unlike other participants, Maeve's experience appears to have led to viewing her child as extremely strong:

> *'I think it might have affected us the other way. We reckon, "Oh she's just really strong." (Maeve)*

Maeve's sense was that as her child had survived the trauma of complications she must be robust. In supporting this statement Maeve goes on to explain how she took her new born into the city just days after they returned home from the hospital.

Interestingly, Maeve did however describe an ongoing relief that her child had indeed survived, and conveyed a sense that she could still not quite believe that she and her child had survived the experience:

> *'We look at her now and then and go: "Oh my god, I'm just so relieved, It was really funny…but then we know that everything worked out fine with her…yeah.' (Maeve)*

This comment together with the process indicators (pauses) gives a sense that Maeve is in fact not sure that everything worked out fine. Furthermore, while several women commented on the exhaustion they felt at the end of the interview process, Maeve did not. Instead I, the researcher/interviewer commented on my own exhaustion.

All of the remaining participants demonstrated the opposite pattern with women feeling anxiety regarding the *fragility* of their child. Abbey spoke about the role of breastfeeding and the difficulty she has separating from her child two years on:

> '*She was breastfed to fourteen months, overfed: it was the one thing I could do for her… I find it hard to let go of her…I find it very hard…I've never been away from her.'(Abbey)*

Within the context of the confrontations abbey endured with staff regarding wanting to breastfeed her child, it appears that breast/feeding may have become linked to her loss of control. Similarly, Abbey continues to experience separation difficulties into the present. She identified an intense bond with her daughter which began on the day she learned that her daughter might experience serious difficulties:

> '*It sounds silly but I bonded with her that day.' (Abbey)*

This might indicate a direct link for Abbey, between the trauma and the type of relationship that developed.

Annie too identified a tremendously strong bond with her daughter, to the degree that it caused her to feel guilt:

> '*I feel guilty…I probably enjoy her more…I could look at her all day. Is it because I didn't know if we'd have her at the end of the pregnancy?' (Annie)*

Again here is a question around the possibility that the intensity of the bond might be directly connected to the threatened loss of the child. Annie's need for connection to her child also manifests within her marriage:

> '*I don't like it when he's feeding her…I want to do it.' (Annie)*

And again later:

> '*I'm hoping he'll say he's too busy to feed her.' (Annie)*

While Annie goes on to explain her awareness of this pattern, it remains clear that she was describing a need for her child that she understood as having a different quality from that with her previous children, possibly born from the trauma.

Donna reiterates both this process and an awareness of it:

> *'Oh yeah (with emotional tone) I would be very over protective, very, might keep people from holding him… I didn't want people to hold him, even my mum…it was all me…I was very clingy to the point where I couldn't rest…'til they'd give him back...I didn't like people even calling in, "He's asleep, don't pick him up"…I suppose if anything, I'd be guilty of loving him too much.'(Donna)*

The use of language in Donna's account powerfully highlights her eagerness to protect her child. It is as if Donna is still required to protect him from danger. Aoife too was aware of the intensity of the relationship particularly as her protectiveness was pointed out by her mother and sister.

Common to the accounts of Donna, Annie Aoife and Abbey, is this sense of continuing danger which is reflected within their intense relationships with their children. There is what feels like a frenzied hunger for the child and a need to have exclusive contact with them.

4.4.3. Relationship with partner

Finally in looking at women's relationships it became clear that their partners were in need of attention and support, in their relationships with themselves, the women and their babies.

Abbey and her husband highlighted the relevance of different coping mechanisms in their experience. While for Abbey it was vital to be informed, her husband found this extremely distressing. Abbey focused 'externally' on her child while her husband's focus was more internal. Their differing approaches appeared to place an additional strain upon each of them and their relationship. Abbey's husband had attended counselling in order to address this:

> *'We're not quite there yet…it hadn't occurred to him how I felt: that hurt more than anything else…he came home (from counselling) and said, "Was I there at all?"…Whatever scant consideration was given to me, none was given to (husband's name). We've never been out together since she was born (2 years ago)' (Abbey)*

Abbey's husband had been terribly affected by the experience, leaving him inadequately equipped to support his wife. While Abbey felt this keenly, she is also able to understand that he did not receive the support or 'consideration he so clearly required. They are left impacted, both as individuals and as a couple.

Abbey also noticed how his relationship with their daughter was affected:

> *'He was upset at how angry he was, he was afraid of her, he was afraid he was going to break her…I would try and give her to him, and he would sort of rock her like he was physically moving away from her. He held her and played with her, but, it just wasn't…' (Abbey)*

Clearly then, each relationship within this triad had been deeply affected. There is distance between Abbey and her husband and her husband and their child, while Abbey herself holds on to her child tightly.

Annie demonstrates similarities in her pattern with her partner. She feels angry with him for expecting her to be '100%'. The following is an excerpt from Annie's interview.

> *Annie: I said (to husband) 'Look at all the things that happened in six months' and I'm supposed to be back to normal…which I am 90% but I'm not 100'*
>
> *Interviewer: Are you pissed off with him?*
>
> *Annie: 'Um, it sounds like I am, doesn't it.*
>
> *(Annie)*

Annie is angry it seems because her husband, like the staff, has not acknowledged the experience and the impact of this upon her. She feels he is behaving as if this had been a normal pregnancy, when it clearly had not. In fact when Annie describes how he interacts with his new daughter, we become keenly aware that he *does* understand.

> *'I would notice that with all of them, that he bonded way more…so I was trying to make sure that he <u>had</u> to hold her in a way you know…like he didn't change her nappy 'til she's about three weeks, and that, that was I fell asleep on the couch. When I woke up, he was changing her but I think if I had been awake, he wouldn't have' (Annie)*

While Annie was aware of her own need to 'monopolize' her child, she pushed herself to avoid this to ensure that her husband and daughter's fragile relationship would have the opportunity to grow, which it happily did.

Donna too highlighted her husband's difficulties though, though anxiety rather than anger was the predominant emotion:

> *'I didn't tell him too much 'cos I didn't want to freak him out…he was so stressed…husbands get forgotten about…it affected him…he was trying to be strong for me…he was worried about me and worried about the baby.' (Donna)*

Donna paints a picture of a vulnerable couple desperately attempting to support and protect each other and their child from the trauma. She echoes Abbey when she tells us that 'husbands get forgotten about'. Later she recounts how the experience has left him:

> *'He was a rock…he's cross…exhausted from the process and frustrated, really frustrated.' (Donna)*

She tells us that his strength has been sapped from him, and he remains angry and frustrated.

It is evident and understandable that partners were impacted by these experiences. Furthermore, some men had not recovered from this impact many months and sometimes years following the events. In terms of the woman, man and child as a triadic system it is also apparent that this placed an additional strain on all three relationships at an extremely sensitive stage in these families' lives.

Chapter 5 Discussion

5.1 Overview

The purpose of the study was to understand women's non-facilitative experiences of communication with medical staff during complicated pregnancy. As women with complications are at higher risk for psychological distress it was thought that staff were in a useful position to identify and support them thus potentially avoid more significant distress. Six women who had experienced complicated pregnancies within the last two years participated in semi-structured interviews and Interpretative Phenomenological Analysis was used to analyse data.

Overall the research found however that communication with staff acted to intensify the women's distress rather than ameliorate it. The women in the current study described with great clarity and depth surprisingly harsh relational experiences.

Information difficulties where the most basic information was not offered or indeed, was withheld was a common experience and one which led to a sense of lack of control for women. Confidentiality was broken and data manipulated. Generally women did not challenge these breaches of trust, which, given their vulnerability and the environment is not surprising. Women also became afraid when they noticed errors that staff made or a lack of basic information with one woman (Maeve) actively needing to refuse treatment which she knew was intended for another patient.

Women found the medical environment a disempowering one where they felt infantilized at times. They described being treated like a number with some speaking of being 'stripped down' and imprisoned. The lack of warmth from staff together with

separation of women from their babies or mother made for a particularly disempowering combination that left women and their babies significantly impacted.

The lack of empathy left women feeling isolated and abandoned. This omission was a key factor in women's confusion regarding the seriousness of their situation. They demonstrated doubt in themselves and described how this had affected how they viewed themselves. As a result of the empathic failure and lack of support they were unsure how to feel. Implicit staff communications to 'get on with it' meant they had not processed their difficult experiences and remained distressed at the time of interview. They spoke emphatically and with emotion of the need for staff to see the whole person, for holistic care and for support.

In listening to the impact of all of this on their relationships with themselves and others I was deeply saddened. All remained impacted and for some their sense of who they were remained damaged. Of course the damage had seeped through their systems with one partner being fearful of having additional children and another attending counselling. Divergent coping strategies meant that some partners were unavailable to support the women thus resulting in additional isolation and distress.

Sadly five of the six women described themselves as over-protective and fearful of separation while the sixth appeared to over-estimate her child's strength and resilience. This could indicate that the children's attachments were adversely affected by the experiences.

Therefore while many women in Ireland have no doubt experienced positive communication with staff during complications, these women described an overwhelmingly dark and damaging relational picture

The women's experiences of communication reflect aspects of reviews of (non-complicated) maternity care as cited in the literature review. For example the findings are consistent with Hodnett's (2002) key review of women's experiences of (non-complicated) *birth.* In Hodnett's research two of the four principle factors which women prioritised, directly concerned staff-woman communication. The emphasis on interpersonal skills also fits with other reports such as Lewis's 2007 review of maternal deaths and safety in maternity services in the UK. This report identified poor interpersonal skills, information processes and team work as contributing to maternal mortalities in the UK.

The types of communication problems identified by the women in this study were also an extremely close match to the only other study found which explored communication in the context of complicated pregnancy.

Zimbabwean research carried out by Murira, Lutzen, Lindmark and Christensson (2003) reflects the current study in explicitly addressing the issue of communication during complications. Both groups of participants identified significant problems related to lack of privacy and dignity, a task-focused relational approach which did not take the individual into account, lack of information and an authoritarian or patriarchal communication style.

Overall, Carol Gilligan's work (2011) on women's voices as referred to in the literature review provides a good fit for what the women in this study appear to be communicating: that they had a deep need for good quality caring relationships, but that they did not receive this in part due to the patriarchal, Cartesian environment which split mind from body, reason from emotion and self from relationships.

Generally research has not directly addressed complications in a non-medical and more relational context. Studies have tended to ask questions which are located in an individualistic framework. This locates issues within the individual, in this case the woman. However findings of the current and other studies show how women are responding to both general and more specific research questions very clearly and telling us that communication matters in maternity care. An important question therefore is why are the voices of women not being heard?

This chapter will explore the findings in the context of the existing literature and research. Additional research, not discussed within the literature review will also be used to understand some of the more unanticipated results. This is consistent with IPA where 'the interview and analysis will have taken you into new and unanticipated territory' (Smith, Flowers, Larkin, 2009, p.113).As discussed in chapters one and two, Gilligan's work on women's voices will be used a theoretical framework to understand the women's experiences personally and politically. The framework will also be utilised to predict possible obstacles to change in the future.I will also discuss women's needs for communication and relationship through the lens of attachment theory. Within attachment some fundamental conceptual ideas concern containment and regulation which the following discussion will address within the context of the findings.

The discussion will explore the central research question in relation to superordinate theme one (information difficulties) first and then address the remaining three themes as a whole.

Following this, study limitations and ideas for future research directions will be discussed. Finally I will summarize the conclusions before exploring the potential contribution and applications of the work.

5.2 Theme 1: Information difficulties

Information difficulties were identified by all women as a fundamental problem. At the most basic level there was a gap in the provision of information. In an already terrifying situation, this omission functioned to intensify the tension and anxiety of the unknown and the lack of control which appeared to be an integral part of complicated pregnancy. Women described a deep unfulfilled need for information which left them feeling uncontained, unprepared and misunderstood. The Department of Health's position (UK) (2007) reflects the importance that the women placed on information by emphasising the key role of information in decision-making for pregnant women.

This centrality of provision of information was also found by Creasy (1997) in a study of pregnant women who were required to transfer to an alternative maternity service (transfer of care). Creasy found that being given sufficient information led to the women feeling more in control. Other studies have shown the links between adequate information and making informed choices. For example the work of Green and Baston (2003) and Walker, Hall and Thomas (1995) have shown how in labour, women's sense of control is connected to having enough information so that they are in a position to make informed choices.

Generally in the current study, unlike the majority of the research which focuses on pregnancy screening tests, labour and birth, the choices that women could make

were few. They were often required to be quite passive recipients of care. However they were nonetheless keen to be equipped with as much reliable information as possible. This need was often spoken of in relation to being prepared. For example both Aoife and Abbey were passionate on this point. It was vitally important both emotionally and practically. As they were unable to access information through staff they sought it online and from books.

5.2.1 The relationship between staff and alternative information sources

The wider research which explores uncomplicated pregnancy and information suggests that the internet is a source of information for a substantial proportion of women. For example Lagan, Sinclair and Kernohan (2006) conducted a structured review to understand the use of the internet in pregnancy. They found a total of 18 papers from Canada and the U.S, the U.K, Australia and Finland. The research indicated that for approximately one quarter of women, the internet was their *first* choice for accessing information.

However, this is not the case in Australia where in a study on prenatal screening information, Jacques Halliday and Bell (2004) found that only between seven and nine percent of women depended on the internet. Interestingly, in Australia women access individual 'counselling' with a health advisor. This would seem to indicate that if women are given the opportunity to access information through medical staff, they might have less need to seek information through the internet.

While this could be important for all pregnant women, it is certainly crucial for those with complications. This was made particularly evident through Abbey's story, where a doctor described her daughter's condition into her Dictaphone rather than to

Abbey, leaving Abbey to discover the horrifying implications of the condition online, when she was alone at home.

Amy highlighted an unexpected and related benefit of being motivated to seek information online due to the lack of information from staff: she developed very meaningful and supportive connections with other women with complications. Lagan et al (2006) identified this aspect for women also. Interestingly, Irving Yalom (2008) has suggested that any individual who is experiencing a life-threatening condition might benefit from on-line support groups.

A Swedish study by Larsson, (2009) which used questionnaires to understand 182 pregnant women's internet usage, found that all women (84%) who had a home computer sought pregnancy related information this way. Interestingly although they often used it to access information following communication with a midwife they did not mention any information they had found at subsequent appointments. In the light of the findings from the current study, this may be related to the lack of time available to speak with medical staff. Alternatively as in Aoife's case, they may have been aware that seeking information online was actively discouraged. This discouragement, while not addressing the problem of the lack of information for women may be due to issues of trustworthiness of online data.

Naturally, questions have been raised concerning the reliability of information gained through the internet (Weiss and Moore, 2003). However this makes it still *more* important for women to be able to access reliable and appropriate information through medical staff in a safe and containing environment.

Realistically however, even if changes were implemented leading to improved information flow from staff to women, it is unlikely that resources would allow for

women to be able to always access staff when required. For this reason the internet is likely to continue to play a vital role in providing information to women with complications. With this in mind some researchers have suggested that there is a place for midwives to pass on reliable internet sites to women (Weiss and Moore, 2003).

Similarly information leaflets may be a useful source of data for women. Aoife specifically spoke of the information void and noted that there were not even relevant leaflets available. She explained as other women in the study did, that she liked to read information and understand. There was a clear sense that information offered women some control in an environment in which they often felt powerless. Annie articulated this explicitly when she associated information with control in pregnancy.

O'Cathain et al's (2002) trial of information leaflets speaks to this issue. The study was an RCT carried out in thirteen maternity units in Wales. The researchers found that the leaflets which were created with the aim at helping women understand and make informed choices, did not in fact have a significant impact on them.

This same trial was explored by Stapleton, Kirkham and Thomas (2002). They aimed to understand the role of the staff in using the tool to support women in being informed and making informed choices. Staff had been asked to discuss the leaflet information with women to promote its usefulness.

 The researchers found that in fact staff had *not* discussed the leaflet information with women. While midwives indicated that this was due to time constraints, the researchers actually cited lack of staff commitment and were critical of the doctors and midwives practices. They also suggested that staff were unwilling to change the very traditional approaches they used. In fact, rather than supporting women to make

informed choices, staff attempted to persuade women to follow their own traditional preferences by describing frightening stories and withholding more balanced information.

5.2.2 Ethical issues in communicating information

Stapleton's study (2002) reflects Donna's experience with one midwife who insisted on relating a gruesome story of a traumatised woman in order to persuade Donna to follow her surgical advice which was in direct contrast to that of the surgical team. This coercion of Donna, who was in an extremely vulnerable position at the time, highlights a more active and unethical information problem. Donna was already coping with several complications. These impacted her own health and wellbeing significantly as well as her capacity to care for her infant. As a result she was under tremendous strain. The communications with this midwife only functioned to increase her levels of anxiety. Other women's information related experiences represent additional ethical dilemmas. For example, where Abbey was at times given significant and disturbing information regarding possible outcomes of her daughters health. While Abbey felt that this information was important for her, her husband was angry at the distress it triggered. He felt strongly that they should not have been given the information as it led to them worrying about difficulties which did not in fact develop. This difference in preference for information and the resulting debates acted as an additional stressor on their relationship. Similarly when information was withheld from Aoife, she was unable to find comfort in her partner as he, like Abbey's husband, was satisfied with less information.

This issue of what and how information is given to women is not a new concept. MacKenzie Bryers and van Teijlingen (2010) have suggested that the manner in

which some doctors give information is designed to control women and the choices they make. Similarly other researchers have shown how some staff will deliver information so as to result in 'informed compliance' (Jordan and Murphy, 2009) as opposed to informed consent.

O'Cathain et al's study described above (2002) was included in Rowe et al's (2002) review of maternity care. The review also looked at five trials on antenatal screening information and also found links between information and anxiety (Graham et al, 2000; Simpson et al, 1998; Michie, Smith and Marteau, 1999; Smith, Shaw, Slack & Marteau 1995; Thornton, Hewison, Lilford and Vail, 1995). It was shown that when additional information was provided, women reported higher levels of satisfaction and lower levels of anxiety. Anxiety has been identified as a significant factor in complicated pregnancy as highlighted in the literature review.

5.2.3 Information and neuro-developmental implications for the child

With research showing that pre-natal anxiety impacts infants' neuro-development (Talge, Neal and Glover 2007), there is an additional reason to pay more serious attention to women's anxiety. Similarly to Abbey's experience of being given information regarding the potential difficulties her child might have, there is now the question of whether and how women should be informed of the potential impact of PNA on their child. There is also the added complexity that simply informing women of this potential is likely to increase (or indeed decrease) distress. Importantly, as we saw from Annie's experience, there is also the question of whether staff are even aware of these study findings or have the capacity to reflect on the ethical dilemmas involved.

Clearly this is difficult information to offer to women, but who should decide whether they should have it? Furthermore do medical staff have the skills to make these decisions or deliver such sensitive information?

5.2.4 Staff expertise in delivery of sensitive information

Whether medical staff have these skills is questionable in the light of Annie's experiences. She was terrified on several occasions by doctors who delivered information to her without any attempts at containing her. Indeed it was clear to Annie that the staff themselves were panicking and unable to contain themselves leaving Annie feeling unsafe and frightened.

This tallies with research cited earlier in the literature review which indicates that medical staff are not necessarily skilled communicators (van Nuland, Hannes, Aertgeerts and Goedhuys, 2005; McCourt, 2006). It is also in line with the absence of communication as a feature in obstetrician's nine indicators of quality prenatal care (Vause and Maresh, 1999) and the poor information/communication experiences of the women in the current study.

A medical study (Sheppard, Zambrana and O'Malley, 2004) which looked specifically at trust between health workers and pre and postnatal women also reflected some of these difficulties. While the research focused on the experiences of American women on low-incomes or from minority groups in normal pregnancies, nonetheless women described significant difficulties concerning information. In particular they identified having a sense that information was being withheld.

Sword et als (2012) recent Canadian research on women and medical staff perspectives of prenatal care also supports the crucial role of information for women.

Women in that study were unambiguous in describing the importance of staff informing them of all information even when it is of a distressing nature. One woman explained:

> *'they also have a way of breaking it (information) down so that it makes sense to people who don't have medical degrees and help you to understand the ramifications….and he didn't beat around the bush. He just told me outright what they were…that was kind of nice as well…because then we know what we're dealing with…and because then we're more prepared'.*

(Sword et al, 2012, W04-04))

This statement reflects the sentiment of all of the women and in particular is strikingly similar to Abbey's reflections on one of her more positive experiences with a consultant. It is clear from both the women in the current study as well as those in Sword et al's research that being fully informed in a clear manner is vital. Women in both studies also cite the role of the information in facilitating a sense of all important preparedness. This same need was found in earlier research through Young's review (1998) and other studies (Larsson, 2007 ; Lagan et al, 2006; Rowe et al,2002; O'Cathain et al, 2001) discussed above in this chapter.

What the current study would appear to add to the existing research is a perspective from women with complications within a more in-depth and psychological context. Essentially I think the current study has helped to facilitate the voicing of women's deeply felt emotional experiences. In this way it differs significantly from the narrower

more medical evidence base. While the extant research discussed above pertains to non-complicated pregnancy, it does reflect the current study findings in relation to women's deep need for and difficulty in accessing full and reliable information which is delivered in a containing and sensitive manner . While some studies and surveys show a majority of pregnant women are satisfied with their experiences of information, other studies have shown an unwillingness on the part of staff to provide unbiased information (Stapleton et al, 2002), with matching unwillingness by women to discuss the information they access from alternative sources (Larsson, 2009).

Finally the Australian model showed that where women have one to one 'counselling' they access internet information far less: seven to nine percent as opposed to about twenty-five percent. While only a correlation, this information might suggest that staff need to be less biased and more open in providing information. Also they need to be working to understand whether women are satisfied with the information they are given as it would seem that currently, women are unwilling to speak openly of their information needs. This is understandable given the inherent power dynamic and the somewhat closed systems which some providers may be offering.

The Australian research highlights the potential value of one to one sessions which may result in women feeling less need to utilise alternative sources. For women with complications this is important, as they would be likely to be accessing potentially distressing information on their own, which could lead to additional anxiety.

Prenatal anxiety is a common feature of complications and additionally is linked to neurodevelopmental foetal difficulties (Talge et al, 2007). This adds another layer to the debate on what information women should be given and how this could best be

delivered. This is particularly as this study together with others has shown that medical staff may not be skilled communicators. The complexity and seriousness of the implications of complications might therefore point to a need for additional communication skills training for medical staff, in particular, obstetricians who lead the care.

However it would seem that alternative sources of information are important to women. For example Amy found internet forums invaluable in connecting with other women experiencing complications. Here was an environment in which she felt heard and understood. Furthermore most of the women cited time constraints as a difficulty due to the regime of hospital appointments together with their existing schedules. The internet allowed them to connect in with others and find answers to questions at their convenience thereby offering them the needs-based service they could not receive in hospitals. This would suggest that the internet offers an invaluable service to women with complications. Weiss and Moore's (2003) suggestion that midwives inform women of reliable and helpful sites would therefore make sense in this context. Against arguments of time and funding constraints this small change might cautiously offer the beginnings of a more needs-based approach.

5.3 Themes 2, 3 and 4: Disempowerment, Empathic failure and Relational Impacts

While approaches such as the internet-based one discussed above may be of value, women are telling us that they do need to be part of a more *relational* approach. If we listen to women's experiences, needs and ideas we hear that the core need for information is clearly set within this holistic framework. They articulated that the

information needed to be delivered in timely, respectful and sensitive ways which took into account the person's individual circumstances and needs.

It is important to highlight then that this did *not* occur for these women, indicating that many staff could or would not communicate in a way that met the needs of this highly vulnerable group. It is therefore not surprising that women have described their experiences with staff as disempowering and unempathic.

Not only did problems with some of the most obvious and basic needs not attract attention (such as Donna's feeding needs for example), but in addition central relational requirements often went unacknowledged and unmet, resulting in experiences of abandonment, isolation and distress.

Similar experiences are to be found in the research of the Association for Improvements in Maternity Services Ireland. AIMS Ireland is a consumer led organisation which was set up in 2007 with the help of AIMS UK. The group's research generally concerns experiences of women with non-complicated pregnancy. While this clearly places limitations on any comparisons, it also highlights the issue of paucity of research in this area in Ireland and indeed internationally, with Muirira et al's (2003) Zimbabwean work being the only study found in the area of pregnancy complications and staff communication.

 AIMS Ireland's most recent survey of women's experiences (2010) found that while many women reported positive experiences, others had been deeply affected by problematic care. For example the avoidance described so succinctly by Maeve was also apparent to women in the Aims study. As one woman explained:

> *'I only saw the consultant once, came in and said: 'we will give her another hour and then it's a C-section' and walked out. He did not even speak to me'.*
>
> *(AIMS Ireland 2010, P.95)*

Donna, Amy, Annie, Abbey and Aoife also spoke of this sense of being ignored or invisible. The similarities are not restricted to this difficulty however. For example, the AIMS comments also included not being believed (when in pain), a lack of choice, explanation and informed consent regarding procedures, and general experiences of being bullied or treated rudely.

Some of the women in the AIMS survey also described lack of empathy and callousness on the part of staff. Below is an excerpt from one woman which gives us an insight into the impact on the individual who experiences a lack of empathy and a resulting powerlessness:

> *'Felt that the midwife could not care less about the pain I was in and I felt completely powerless. It was all hospital policy and I had absolutely no rights'*
>
> *(AIMS Ireland 2010, P.63)*

This comment helps us in understanding how empathy and power difficulties can be inextricably linked. It would seem that when we try to understand the experience of others, this communicates an important message which acts as a buffer against the pain of powerlessness and the accompanying isolation. This is reminiscent of Yalom's ideas on our interconnectedness (2008) and the comfort we might take from this during times of distress. There was little sense of this interconnectedness for the

women from some staff both in the current study but also for some women without complications in the wider population in the AIMS study.

As discussed in the literature review women with complicated pregnancy are a population more likely to suffer with emotional difficulties (even without the disruption of bonds). While the AIMS research was not based on complicated pregnancy, it did highlight the fact that emotional health was not discussed at times with high risk women. For example, one woman with a history of Post-natal depression spoke of how she was surprised that mental health was not raised at any stage of the process (P.135).

Similarly, mental health was not discussed at any point with participants in the current study. Importantly though, *every* woman commented individually on unmet needs for emotional support, empathy, and person-centred care. While three of the women (Donna, Abbey and Maeve) noted an individual staff member who had shown some kindness or helped them in some manner, this was not a hospital-wide experience and importantly, mental health or emotional support was *never* directly addressed or offered.

Additionally, the women all pointed to the mind body split, wherein physical needs were viewed as worthy of attention while the rest of the experience was not. As Amy commented that if her leg had fallen off she would have received attention, despite her obviously difficult circumstances however no attention was forthcoming.

Maeve, Donna, Aoife and Annie reiterate this omission together with sharp assessment of the issue when they describe how staff approached them as a task to be completed thus leading to the missing of the individual person. For most of the women this issue was the central one.

The fact that we know that these women were at higher risk for distress and indeed *were* deeply impacted by their experiences raises some important questions. Most obviously: why was mental health and support not discussed? While this question could require its own study we do know that medical staff are not trained as psychotherapists or psychologists. Quite simply then, it makes sense that they do not attempt to address mental health nor offer emotional support when they are not equipped with the necessary skills. While resources pose serious problems to women in the care of maternity services at the current time, the AIMS research and indeed the current study, involve experiences prior to the economic collapse in Ireland or at least prior to the current more severe staffing cutbacks. Indeed my own experience of misdiagnosis occurred in the midst of the 'Celtic tiger'. Therefore we are left to conclude that the omissions experienced by women are likely deeply ingrained in the dominant medical world and wider culture of Ireland.

In exploring the extremely limited research base of relationships and pregnancy complications, we can see from the Zimbabwean medical study cited earlier in the discussion (Murira et al, 2003) that Ireland is not unique in its adherence to the medical model in pregnancy.

In fact Murira et al's study reflects very similar findings for the mostly adolescent participants. The interactions between medical staff and women in the Zimbabwean study were found by both the young women and researchers to be impersonal, rigid and authoritative. They were also seen to be carried out without regard for the women's privacy and dignity leading to, for example women being subjected to intrusive physical examinations without explanation. This reflects the current Irish study where women spoke of being shamed together with a lack of dignity and not being seen as an individual person. Again this was also identified by the

Zimbabwean women who were referred to not by name but by characteristics or the clothes they wore.

While the Zimbabwean women were keen to ask questions of the staff this was not permitted, as the next woman would be called once the midwives had completed a checklist. This led to women remaining isolated in their difficulties, some of which were very serious and likely to impact the health of both the woman and her child. Midwives spoke with each other but only interacted with the women to give task-based instructions. Similarly doctors did not speak with women and both midwives and doctors would walk past women as if they were invisible.

These experiences of shame, powerlessness and Invisibility bear a remarkable similarity to the current study. As described earlier the women were often treated in a perfunctory manner, with questions unanswered and dignity and other basic needs ignored. For example it took days for a staff member to comment on Donna's untouched trays of food. For Donna understandably this translated into a sense that the staff did not care. Abbey and Amy also commented sadly and with clarity that their distress was compounded by being forgotten about.

This was in direct contrast to the babies the women carried. A clear message from the women was that the baby was prioritised, leaving the women feeling insignificant and more akin to a functional vessel. Annie remarked on this invisibility in relation to the baby, and while she finds the capacity to assert herself with staff, the message is unchanged: the women feel marginalized and important only in so far as their role as a mother. This invisibility led to unseen needs going both unacknowledged and unmet and culminated in an overwhelming sense of isolation for the women. They were most definitely alone with their distress as the Zimbabwean women had been.

Within this power infused system, where women were unseen and relatively powerless, it was evident at times that they were attempting to understand and make meaning from their experiences.

5.3.1 Women's meaning-making in a disempowering and unempathic environment

The Irish women were frustrated and angry at times in relation to their experiences of poor communication, but I was often surprised at how reasonable they were. Regularly they would highlight the part of resource limitations and challenging working conditions in difficult staff behaviour. This was also the case for the Zimbabwean women who cited time pressures on staff as central in the problem. I wondered were the women attempting to make meaning from their experiences in the safest possible way. No doubt external factors such as resource limitations play a role in some of these behaviours as mentioned above, but it certainly cannot not explain 'away' the difficulties. Interestingly a small qualitative Irish study (Larkin, Begley & Devane, 2012) on non-complicated childbirth experiences also noted this same unwillingness to assign blame to staff following difficult interactions. While participants expressed strong emotions regarding their treatment, this was held alongside an acceptance of what had been done to them.

It is possible that this approach maintains a degree of trust and belief in both the self and the medical staff and system: that by attributing blame to factors external to the self and the staff, both structures remain relatively trustworthy and intact. The alternative is to question staff motivation and/or the self in being sufficiently worthy of their help. *Both* approaches are evident in this study. That is, there were competing

narratives which at times blamed resource limitations and staff workload, individual staff, and there were also times when women questioned themselves and whether the lack of empathy and support was due to their own lack of need. In this the impact of the experience on women's sense of self became apparent.

5.3.2 Impact on woman's relationship with self

The women described the impact of their relational experiences with staff on their sense of self with clarity. Principally, they spoke of their resulting guilt and shame, confusion, stupidity and self-doubt. For some of the women like Amy there was an actual questioning of her reality and the conclusion that her distress was an overreaction. This thought process was directly linked to the lack of empathy and response from staff in general. Abbey reiterated the same sentiment.

It was clear to me that it was vital to respond to the women with great care so as not to re-traumatise. Not only had they not been heard or seen, their experiences had gone unacknowledged and unvalidated and this had led to confusion and self-doubt. I saw the interview process and the wider research process as an opportunity to acknowledge the women's stories.

The development of self-doubt and confusion is important as it can lead to a delay in the processing of distress. In effect the response or lack of it added an additional layer for these women to contend with. The acknowledgement of trauma by others is a familiar concept in psychological therapy. While a therapist who acknowledges a client's trauma is not 'curing' a client, the validation that this might bring is potentially powerful. This process is reminiscent of Herman's research (2005) and the sense of dishonour and shame that trauma victims speak of. Hermann outlined how victims are concerned with the need for acknowledgement by their communities for what has

occurred and that this is an integral part of the process of lessening their sense of shame and dishonour.

Similarly the women would likely have benefitted from an acknowledgment that their circumstances were not 'matter of fact'. This may have given them permission to begin to feel the emotions associated with the trauma. Instead they were conflicted regarding their distress, and left to question their emotional and behavioural responses leading to the deterioration of their relationship with self.

While pregnancy complications are clearly very different to the sexual assault which Herman was studying, the women nonetheless described how their recovery was substantially hampered by the lack of acknowledgment and validation. In fact not only was the experience of trauma not acknowledged, women reported feeling that staff were communicating that they *should not* be distressed. This was described in terms of implicit staff communications indicating how the women 'should' get on with 'it' and just be 'ok'. Relatedly women spoke of their sense of inadequacy for not being so.

While Maeve and Annie's comments regarding this process are often infused with a healthy anger and realisation that this was wrong, Abbey's contains more confusion and self-blame which indicates that she may have integrated the staff's implicit communication. She has internalised the distress rather than externalising it and giving it back to staff. This process was not unique to Abbey. Donna and Aoife also attacked herself for not challenging the more distressing relational experiences with staff. At one point in the interview Donna wept as she revealed the degree to which her sense of self had been damaged and apparently irrevocably altered. Similarly, through Abbey we are given a disturbing insight into the enduring impact of the

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experience. She explained that the conflict (of not having her distress acknowledged or allowed) had led to the trauma being suppressed and the emergence of the distress two years later. In this she felt stupid, weak, inadequate and changed.

These examples of harshness toward the self, highlight that a shift has occurred in identity. Herman (1992) has described the effect of chronic trauma as leading to this change in the person. She spoke of a 'debased self-image' (p.94) and the unexpressed rage and hatred the person feels towards those who were indifferent to her distress. Importantly this rage may lead her to withdraw and therefore isolate her further, and it may then be directed inwards leading to depression and ultimately suicidality. Ultimately then, these unsupported experiences may have led to a dark shift in how the women related to themselves and others. With staff communicating at several levels that they were not available to support women and that in fact women should not require support, an important question is: how did the women cope?

5.3.3 Avoidance and dissociation as coping mechanisms

The message to women from staff that they should not need support was likely to send with it a message to suppress any distress (as they should not have any). Indeed Abbey alerts us to the shame that she is left with for having experienced distress or as she puts it: 'made a big fuss' for no apparent reason. The women did attempt to comply with staff. Indeed as there was no support this may have seemed to have been the best available option. Naturally however their compliance could only ever be time-limited. As Abbey explained, it (the distress) could no longer be avoided in the second year and it began to emerge leaving her feeling overwhelmed.

An equally avoidant but more dissociative process is evident for Maeve when she describes a sense of strangeness on her return home after 10 weeks in hospital. In Maeve's description of her experience I remember feeling a distinct oddness and dissonance. In trauma terms there was a sense of depersonalization or derealisation and dissociation. That is, she seemed to be expressing confusion as to the reality of the situation and as to whether everything had in fact worked out fine .This lack of congruence can be seen to be reflected in the brokenness of the statement, and indeed the oddness that Maeve herself refers to explicitly with the word 'funny'. Furthermore Maeve showed no evidence of fatigue following our interview, whereas I felt and indeed remarked in the (final page) interview on the exhaustion which I felt in relation to the distress she had 'experienced'. This had not occurred in any previous interview and led me to wonder whether I was feeling Maeve's dissociated distress.

While the women were all at different stages of processing they each utilised a degree of avoidance and suppression. Annie spoke of 'limiting' her distress in order to not 'give in', Aoife and Donna avoided contact with nursing staff and the hospital that they associated with distress, while Amy described avoidance of social situations.

Numbing and dissociation has been the subject of a great deal of discussion in the psychological therapies. Kardiner (1941) like Janet before him (van der Hart, Brown & van der Kolk, 1989) described how constriction served to separate traumatic experience from awareness. This can be seen in Maeve's efforts to preserve herself and her child by attempting to dissociate or separate herself from the emotional impact of the powerlessness and the relational environment:

While this strategy of course makes rational sense, research has definitively indicated that it brings with it severe disadvantages (van der Kolk, 2014; Herman, 1992). Essentially, while the experience may remain partially or indeed completely out of conscious awareness, it is likely to continue to impact the person. Furthermore, because of the fact that traumatic memories are held in the brain (and body) in a different way, they cannot in fact be accessed easily and therefore integrated (van der Kolk, 2014). As a result, a considerable research base has shown that dissociated trauma will remain with the person far longer. For example research on rape survivors (Nadelson, Notman, Jackson & Gornick, 1982) war veterans (Van Dyke, Zilberg & McKinnon, 1985) and those taken hostage (van der Ploerd & Kleijin, 1989) has shown that significant numbers continued to experience intrusive and constrictive symptoms many years after the event with one second world war veteran re-experiencing symptoms following a thirty year period of being asymptomatic.

Sadly as we have seen, there is clear evidence too of the continuance of trauma for Maeve, and also Abbey, Annie, Donna, Aoife and Amy.

In the light of our current understanding of the long term implications of constriction and dissociation then, supporting staff to, as a minimum, *not* communicate to women that they should *not* be distressed could be crucial for women's long term health. Of course these consequences are not limited to the health of the women. As seen both in the literature review and the findings, difficulties do not impact women in an isolated fashion. Their relationships with others are also affected. Perhaps none more so than that with their babies.

Women and babies

Five of the six women experienced separation difficulties and over-protectiveness with their children while the sixth (Maeve) appeared to over-estimate her child's strength. Somehow though for Maeve, this did not seem to be a coherent sentiment with Maeve expressing ongoing relief at her child's survival as well as presenting with a process which could be considered consistent with having utilised dissociation. Specifically that the impact of her dissociating from fear had led to her continuing not to feel this and therefore overestimate the strength of the child in order not to experience more fear.

These difficulties are not surprising given the experiences the women endured. Indeed they reflect our current understandings of the impact of stress on the attachment relationship. For example the National Institute of Health and Clinical Excellence, (NICE, 2010) has identified maternal stress and a reduced capacity for developing a healthy attachment relationship as two out of the three risk factors to unborn babies, the third being social inequality. It has also been shown that maternal distress is likely to itself contribute to a reduced capacity to form a healthy relationship (Schechter & Willheim, 2009) making for a complex dynamic. In this study maternal stress was certainly present as a result of the complications, and it is reasonable to suggest that the psychological implications of the complications may impact on the women's capacity to form healthy attachment relationships.

In addition to the complications themselves, some of the most stressful experiences which the women described were directly related to staff communication and the infant-parent relationship. For example, the separations from their children for Abbey

and Amy or the instances when they were not supported to meet their children's feeding needs as in the cases of Aoife and Abbey.

The women in the AIMS study (2010) also referred to the issue of separation, and as in the current study there appears to be a lack of understanding of the importance of infant-parent contact from the staff:

> *'My baby was taken from me unnecessarily (to have the stiches done)'*
>
> *(AIMS survey 2010)*

The word *'taken'* was also used most notably by Amy. She used the term to describe the powerlessness and pain of having her child removed from her in hospital. As in the current study, the women in the AIMS survey alluded to an apparent lack of importance placed on separation by staff. It appeared that there was no effort exerted to maintain mother-child contact. This might seem to be counter-intuitive behaviour for staff who possess a good working knowledge of the impact of contact and loss of contact at this critical time. Women however had a clear felt sense of this. One woman articulated it in the AIMS survey when she described how the bonding between her and her child was 'hampered by early separation' (p.124).

Importantly the AIMS survey highlights the foundational role which policy may play in some hospitals in Ireland in maintaining a laissez faire attitude toward the breaking of contact. For example in describing her separation from her child, one woman informs us that it is actually hospital policy to separate new born infants from mothers immediately after birth in the recovery room so as not to disturb other women (p129). While it was not possible to confirm that this was indeed a written policy, the experience reflects that of the current study. Both Abbey and Amy

described this experience. Amy explained that the manner in which she had been separated from her child had led to her remaining deeply impacted and isolating herself for some time following the event. Importantly this highlights that the emotional consequences and their relational implications can endure for a considerable length of time.

Abbey described how the staff's practice was to remove babies for testing and also for *staff* to bottle-feed the first feed without consulting the woman or father. It was only the fact that Abbey had challenged the staff on this that she had been able to feed her child herself. The strength which Abbey was required to demonstrate to fulfil such a basic right could be seen as an indication of the potency of the staff power. Fighting this ordinarily would have been difficult, with the additional context of the complications, this task is likely to have involved a great deal of additional stress.

While maternal stress has been identified as a factor in attachment security, attachment security has been shown to be a powerful predictor of social, emotional and cognitive development (Kochanska, 2001) and appears to act as a relational template for the future (Brandon, Pitts, Denton, Stringer and Evans, 2009).

The links between maternal stress and complications as well as attachment and social, emotional and cognitive difficulties in the infant were highlighted within the literature review. Importantly however the research discussed did not attempt to place these constructs within a relational frame. In this study however women described their stress and to a degree their attachment relationships as partially and *directly* linked to staff communication and controlling practices. The fact that this appears to be an important factor is generally avoided by the mostly medical researchers in the field. It is both 'messy' and outside the expertise of medicine.

Furthermore it is important to remember that women in this study and elsewhere (Larkin, Begley & Devane, 2012; Muirira et al, 2003) have shown avoidance in attributing blame to staff. In this too therefore there has been co-creation.

Therefore, when we take the attachment relationship into account, we can see that the impact of the women's experiences with complications needs to be viewed relationally and through an intergenerational lens if we are to understand the power of staff communication more fully. This means that the implications of these women's experiences with staff (and not just the actual complications themselves) could be contributing to very serious ripples in the lives of infants.

5.3.5 Women and partners

While it is of course vital to take into account the impact of the women and children in this research , the third point on the relational triangle can be one which is often unseen in pregnancy research (Locock & Alexander,2006; Jessop & Fox, 2011); the relationship with the partner. However this gap does not reflect the importance of the partner in the process, in particular during complications when they may be required to provide even greater support. Hinton, Locock and Knight (2014) identified this gap in their recent research on partner experiences of serious birth trauma or 'near miss' events. 'Near miss' research in pregnancy is generally limited to birth experiences but could be useful in understanding longer term complications such as those in the current study. For example the researchers found that while partners too can be deeply impacted psychologically, their distress went unacknowledged and unsupported.

This finding reflects that of the current study. For example both Abbey and Donna described with sadness how their partners were alone in the experience.They

explained how both their partners had been impacted with Donna's husband afraid to have another child in case he lost her, and Abbey's husband having spent time in counselling to process the experience. However perhaps the most poignant descriptions of the impact on partners were those regarding their relationships with their babies, in particular that of Abbey and Annie's husbands. Here the women described the men's avoidance and apparent fear of their infants, due to the sense that they might hurt or 'break' their children.

Donna at one point described her husband as her 'rock' while other women spoke of conflicts which had emerged sometimes as a result of differing coping strategies. For example both Aoife and Abbey outlined how they clashed with their partners on the issue of information and that this had led to both feeling additionally isolated. Amy and Annie also described difficulties in relation to partners whom they felt did not appear to have the capacity to appreciate their experience and the longer term impact of it on them. For example Amy spoke of her husband not really understanding the depth of her distress because he was a man and therefore could never really understand. Annie felt angry with her husband for expecting her to be '100 %' after the experience thus reflecting the implicit staff communications. If the distress of partners was acknowledged however it is not difficult to understand the potential for this to positively ripple out both within their relationships with themselves, with the women and with their babies.

So the role of the partner in complicated pregnancy can be viewed as a crucial one (Erlandsson & Lindgren, 2011) upon which a great deal is weighted. It is also clear and understandable that they too like the women can be deeply impacted by this type of trauma. This reflects the rather more limited partner research in non-complicated pregnancy which has shown that men's mental health can be

significantly impacted resulting in paternal depression (Ramchandani, Stein & Evans, 2005) and PTSD (White, 2007).Furthermore it appears that this distress (like that of the women) goes unseen and unsupported by staff.

While this and other research previously referred to, has underlined the value women place on staff communication it might be considered strange that hospitals appear not to be responding. Many research findings are often incorporated into staff and hospital systems so why not this one?

 Hodnett's key review (2002) for example found that two of the four key factors for women in giving birth concerned the quality of the relationship with staff and the support received from them.

Similarly in Sword et al's study of women and care providers perspectives of quality ante-natal care (2012) the need for a caring relationship was a key finding. They concluded that it is crucial for maternity care to encompass more than just biomedical care. They point to the need to focus on the development of supportive *relationships.* While they acknowledge the difficulties that this requires, it is nonetheless what women are clearly articulating both in the current study and elsewhere.

The researchers in the near miss study (Hinton et al, 2014) suggest that partner distress is ignored because medical staff view a 'near miss' as a success. If this is the case it would in part explain the lack of empathy and support for women also. This explanation would fit within the medical framework where the emphasis is on physical survival and health of the body in isolation.

5.4 A new integrative framework to facilitate acknowledgement of the power of staff communication

As discussed in chapter one and two, Carol Gilligan's work (1982, 2011) provides a useful theoretical framework for understanding the power processes at the heart of the women's experiences in this study. Her writings have intelligently uncovered the underlying patriarchal systems such as those within medicine and psychology which can lead to the voicelessness of women and girls. Gilligan speaks directly to multi-layered issues within this research. She describes an enduring battle with regard to the ethic of care. The fact that care is an embattled ethic she says is due to the underlying patriarchal foundations which promoted care as feminine. She uses the Obama and Hilary Clinton presidential campaign to suggest that while racism is not tolerated; gender-based prejudice remains acceptable.

Unfortunately she points to the collusion of women in maintaining this system by excusing gender-based prejudice. This is reminiscent of some pregnancy research (Larkin et al, 2012) and at times the conflictual narratives of some of the women in this study where there was an occasional reticence to speak out and blame staff for difficult relational experiences.

This reflects Gilligan's work (1980) with adolescent girls which showed that they felt they needed to choose between having a voice or having relationships and that in order to have relationships they would be required to be silent. The women's conflictual narratives might also reflect what Gilligan describes as the 'power of the

opposition between selfishness and selflessness' (2011). In listening to women in her research in the 1970's Gilligan found that women appeared to feel that meeting one's own needs was selfish or bad while responding to others needs was selfless which equated with 'good'. So women had internalised the dominant patriarchal model. Both of these ideas could make sense in this study within the context of women having to prioritise their babies above all, and thinking about their own needs rather than being a 'good' mother could be considered selfish. This is the ultimate situation for fulfilling women's expectations of being a 'good' woman.

In looking back at her seminal 1980's text 'In a different Voice', Gilligan shows us the frightening implications for our culture which continues to view and internalize care and other qualities as either feminine or masculine. In splitting the body from mind, emotion and rationality and the individual from their relationships we are encouraging our boys and girls to split off parts of themselves or face shame and/or exclusion.

In this way Gilligan's work provides us with a beautifully insightful framework into the deep roots of our culture and for the purpose of this study, its possible role in maintaining the voicelessness of women with complications. In shining a light on the splitting of parts of ourselves: emotion from logic and body from mind, it lends the study a clear framework to understand and perhaps bring about change. It shows us that attempts to discuss integrated care as reflected in this study's findings will most likely be met with resistance by hospitals. It would also suggest that women themselves who work as staff may collude in this resistance by not valuing relationship, emotion and mind and possibly justifying this by attempting to polarise body, rationality and the individual and the mind, emotion and relationships, and 'logically' prioritise the former. Indeed the dominant voice is very powerful and was

possibly at work in Gilligan's own work being criticised in the 1980s subsequent to its publication.

Clearly then the way forward will continue to be a slow one with women and men needing to be open to consciously noticing underlying processes in order to begin to be in a position to challenge them. This is a significant challenge as these structures and biases are often embedded so deeply as to seem invisible.

In the medical world the most obvious ally for women with complications are midwives. Midwifery purports to provide the very type of integrated care that the women wished for and most often did not receive. While as noted in the literature review, obstetricians lead the care in complicated pregnancy, midwives continue to play a role. That their training and ethos is a less traditionally medicalised can be seen in some of their research. For example the 'ethic of care' described by Gilligan would appear to be an excellent fit for nursing ethics.

One midwifery researcher who stands out in promoting the importance of relationship and emotions in caring for pregnant women is Billie Hunter. Hunter and her colleagues (2008) have written of relationships as being the hidden threads in the tapestry of maternity care. They note together with others (Berg & Lundgren, 2004; Waldenstrom, 2007) that while research evidence clearly indicates the importance of relationships, on the ground this has not impacted on women's care.

Gillian Proctor (2014) has written about these debates in healthcare and the underlying power processes which help us understand these barriers to women's' voices. She identifies movements by Beauchamp and Childress (2001) to shift ethics in healthcare from the traditional and powerful biomedical role which was grounded in paternalism, to focus more on an ethic of autonomy. However this remained very

different to Gilligan's more relational 'ethic of care'. The biomedical model and that of Beauchamp and Childress are both grounded in an ethic of justice and this it has been argued, does not take account of people as social and relational. An ethic of justice therefore behaves as if decisions based on logic do not affect relationships and emotions. Gilligan however does not suggest replacing an ethic of justice with one of care. She speaks of adding to it, so as to reflect the complexity of people in the world.

As suggested earlier however, it is important to also acknowledge that Investing in an ethic of care and relationships is different from and more complex than other types of change. Importantly, it takes considerably more time than more concrete or practical interventions. This reminds us of a significant block in bringing communication and relationship to the fore in caring for women with complications: it is very different to the work of the medical world and it is therefore unlikely that medically trained staff have the capacity to provide the complete range of care that women require.

Therefore in relation to Gilligan's point that the dominant bio- medical model of ethics may feel threatened by emotion and relationships, an additional reason for this may be that staff are simply not equipped to deal with this aspect of care. Maeve in particular managed to capture this when she spoke of the doctor's use of avoidance as a coping mechanism. While medical training now involves communication skills, trainees are not assessed for their capacity to reflect, develop rapport or contain the distress of their patients. They bring an equally valuable but different skillset. This may be partly why the women hear a 'don't talk about it/complain' message from the staff. This reflects the experiences of dying patients in the Glaser and Strauss (1965) research referred to in the introduction of this study. The researchers identified a

communication difficulty with staff lacking the capacity to meet the needs of the individuals who were dying in hospital. Ultimately this led to the individuals feeling that they could not speak of their death.

Yalom (2008) too has highlighted how the emotional evasion from others (with a life threatening condition) due to their own fears, are likely to leave the individual alone with their distress. He describes how in being open to hearing the distress of the other we are making an important sacrifice. This is because to be 'with' the other we must also face our own existential fears.

I was very much aware of this process at a wider cultural level during the research process. Keen to reflect on the research and receive feedback, I mentioned the work in passing in a variety of environments. The *only* occasion it was received with interest was with peers from my training. Without exception other responses were muted or indeed openly angry. I learned (again!) that I should not be 'complaining' about staff who care for the nation under exceedingly difficult circumstances. I found not being heard repeatedly, a difficult experience until I noticed the pattern and layers of resistance.

It is also important to remember that in the hospital environment, the reflexive practice which is clearly required to perceive these patterns and allow women's voices to be heard is not valued in the bio-medical model. Therefore not only is this type of open containing communication less likely to occur, but furthermore, without it, staff are likely to be at higher risk of low morale and indeed burn out. With the additional strains of funding cuts in the public sector and longer hours we can understand how these factors interact together to present a real threat to staff and therefore women's psychological health.

Low morale, burn out, inadequate reflexive capacity and indeed a dominant medical culture that ignores rather than values the wider contexts of communication and relationship may also lead to the pathologising of women. Indeed this is reflected in much of the medical based-research referred to in the literature review which showed the relationship between complications and women's psychological difficulties. These studies generally ignored relational contexts and the co-created nature of these difficulties.

While diagnosing women can be helpful particularly in treatment direction, it is also problematic. Like any diagnosis, it locates the problem in the individual without taking psycho-social contexts into account. In the case of women in pregnancy the WHO (2010) and others (Austin and Priest, 2005) have indicated that some women have been unnecessarily pathologised due to the power of the medical model in this life-stage transition.

So while describing women's experience in terms of dysfunction and diagnostic criteria alone may afford a less messy route for clinicians and researchers, it also lets others off the hook. In addition, it means that treatment will be insufficient as it will not acknowledge and address the entire picture. So a view which takes into account wider relational and emotional contexts such as staff may be seen to be more complex or messy but it is also crucial in being more realistic, functional and just.

In terms of the research, PTSD symptomology could have been matched to most of the women in the study. However there would have been no space in this for their difficult relational experiences with staff and the subsequent impacts on themselves and their loved ones. Thus diagnostics utilised in isolation can be seen as a powerful

tool in maintaining the status quo, preventing change and in this case, maintaining the voicelessness of women with complications.

5.5 Limitations of the study and future research directions

As a qualitative study which aimed to understand six women's experiences in depth the results cannot be generalized to the wider population. As there was no quantitative aspect it is not possible to understand numerically the contributions of the various variables involved. Nor has the research generated a theory. However as stated, this was not the aim. On the contrary, it was viewed as paramount in this study to afford the women an opportunity to voice their experience within the context of their relationship with staff and to attempt to understand this. This was important as previous research had been quantitative, grounded in medicine and culturally bound.

In terms of heterogeneity, the women were of different ages but perhaps more importantly some of them had experienced previous births (three) and others had not (three). This factor meant that those who had pre-existing children had had experiences with staff which impacted upon how they behaved and sometimes felt in the most recent pregnancy. A further study could work with participants who had children previously or were either first time mothers.

A further difference was that the complications were diverse. Two of the women had I.U.G.R while the remaining four had other difficulties. Much of the extant research focuses on women with gestational diabetes to support uniformity and while finding participants with a single complication which is not diabetes is likely to be challenging it could contribute to heterogeneity. Simply working with women with the same complication however does not in itself provide the solution as within each

complication there can be different grades of severity making heterogeneity a complex problem.

As women volunteered there may have been a self-selection bias. For example women who had no access to the internet (to view the research advertisement), had a positive experience of communication with staff, or who remained significantly impacted by the experience would have been less likely to have participated in the study. This latter point is borne out by several of the women including Annie and Amy who avoided social contact during and after the pregnancy. In fact Amy specifically stated in interview that she would not have spoken to me a year previously.

We know that we can never truly access participants' worlds exactly as they are. In this the research is limited. I have only been able to articulate a proportion of what I understood. While new forms of research may open up additional opportunities to communicate more of the essence of the participant, they will still not have the capacity to reflect the whole experience. As much as I want to I cannot communicate the depth of pain I felt and saw when Donna's voice began to race, and the tears flowed from her eyes. In this research remains somewhat two dimensional.

Relatedly, the cultural issues concerning power that Gilligan reminds us of, while less obvious, are also a limitation. What Gilligan adds is the additional layer; that participants too (and each of us) will not be able to articulate all of the near invisible cultural layers which nonetheless heavily influence experiences.

Van Teijlingen, Hundley, Rennie, Graham and Fitzmaurice (2003) make a similar point in their critique of survey research in which they explain how inadequate maternity care experiences cannot be captured through surveys. Women do not tend

to criticise their experiences because they know nothing else other than their experience. These methodological and philosophical difficulties are a healthy reminder of the limited nature of this and all research.

Women were interviewed up to two years after the birth of their child. Several women who made contact to participate had given birth prior to this. My own experience had remained somewhat unintegrated for almost nine years and therefore I think it would be important to either re-interview the women in the current study at some point in the future and/or interview additional women who had experienced complications more than two years previously. As the work of Kardiner (1941) has shown, trauma may remain frozen in time for decades. Additionally, as a result of the way in which trauma can be experienced, memories may not be accessible and available for processing. This can lead to long term retention of the experience which is not updated (van der Kolk, 2014) and retains the sense that the person is re-experiencing the trauma in the present. It might also be fruitful to re-interview the six women to understand whether their relationships with themselves continued to be impacted.

A longitudinal study which could follow women from after the birth might be useful. This could focus on understanding women's various relationships over time (between women and babies, partners and babies and the couple relationships).

Finally as this study concerned the relationship between the women and staff it would be interesting to repeat the study with another sample and also interview staff, so as to hear both sides of the relationship. This might give important insights and reasons behind the types of problematic communication the women experienced and it would also give staff an opportunity to voice their experience.

5.6 Conclusions

This research found that the six women interviewed were deeply impacted not only by complications but also through their relationships with medical staff. They experienced these relationships for the most part as disempowering and unempathic, with competency and information problems leading to further deterioration of their capacity to trust and feel safe. This resulted in women feeling isolated and invisible and significantly affected their relationships with themselves, their partners and their children.

5.7 Clinical applications

This research has essentially concerned the role of the relationship during trauma and this is set within a power infused environment. Considering these issues I suggest that Counselling Psychologists would be ideally placed to take a lead role in promoting change in relation to the issues raised by the women in this study.

As discussed in section 5.4, the women are seeking deep systemic change which calls for integration of an ethic of care. While women have voiced this need in previous research (Berg & Lundgren, 2004; Waldenstrom, 2007) the required change has not occurred. One reason for this is due to the fact that those leading the care in maternity hospitals do not have the (significant) skills to bring about such complex relational change. They have other (significant) skills. However, counselling psychology specifically trains individuals both personally and professionally to doctoral level in the precise areas of need which the women have described. They have a deep understanding of power dynamics and relationships in general, trauma, isolation and empathy, burn-out and reflexivity. Counselling psychologists understand and combine the centrality of relationship together with the rigour of

research based practice and therefore are in a strong position to offer a bridge from the medical world to the more integrated care that women and their families are seeking.

With substantial numbers of women and their families being affected by complications, it is likely that counselling psychologists will have contact with this client group. As evidenced through the findings of this study, this could be through individual or couple therapy or infant-parent or family work. It would therefore be important for counselling psychologists to understand how these clients may have been impacted by their experiences both during assessment and in-session work.

For example, the therapist would need to be sensitive to the power dynamic, and indeed have the capacity to work through power issues which emerge in the here and now relationship, in a sensitive manner which affords the client the opportunity to process any previous power-based conflicts and co-create an alternative experience. The therapist might find it helpful to understand the particular relationship between the parents and the child. It could be invaluable perhaps to support a parent to reflect on this if it is troubling for them and possibly refer on to a therapist with infant-parent expertise if appropriate.

In couples or indeed individual work it would be important for the therapist to address the fears and frustrations the couple may continue to carry for each other. The research has shown that resentments and trust issues may remain within the couple relationship years after the birth. Both these conflicts between the couple but also the actual complication trauma could also affect the sexual relationship of the couple. With this trauma being very much an embodied one, both may feel anxiety around

sexual intercourse. This would require the therapist to work through the feelings from the past or refer the client/s on to a therapist with sufficient expertise in the area.

With women or couples with a subsequent pregnancy, the therapist would also need to be alert to the re-emergence of the trauma again, even if the current pregnancy was not complicated. It might be helpful for example, for the therapist to support the couple through this pregnancy and thereby offer an alternative experience.

All of the women noted the absence of support or even enquiries into their mental well-being. It was absolutely clear that they considered this omission to be highly problematic. While formal supports need to be available, some of the women in the study suggested that with their existing work and childcare responsibilities as well as the intense regime of hospital appointments and travel they were not sure additional appointments for support would be helpful. In fact they felt that this might act as an additional strain on their already exhaustive timetables. Should women choose not to participate in more formal supports then, for this or any other reason while in contact with the hospital staff it would be vital (with permission) to flag women with complications for possible future support should they so choose. An information and referral pathway would need to be designed to ensure follow up. This could involve links with women's GPs and or Public Health Nurses as women will utilise these services for themselves and their children into the future.

For those women who choose to engage with formal support during pregnancy, hospitals could offer a range of supports including group and individual sessions. Certainly the limited research that has been carried out has indicated that women with complications can benefit from connecting in with each other in groups (Maloni et al, 2000). The value of connecting with others with complications was also

highlighted by both Maeve and Amy. Groups could be facilitated by a nurse or doctor together with a counselling psychologist. In this way staff could learn experientially and potentially, with additional training provided, to take on the roles of lead facilitators.

Enquiring into the maternal state of mind of women with complications by counselling psychologists might also act as an intervention for women with complications. Maternal state of mind has been shown to be a good predictor (75%) of attachment at one year (Fonagy, Steele & Steele, 1991). The concept of prenatal attachment (Cranley, 1981; Muller, 1992; Condon & Corkindale, 1997) could also be a useful construct to hold in mind for interventions but it remains a problematic one (Brandon et al, 2009).

Such an intervention might serve two purposes: identifying women who would like to engage with supports during pregnancy and also flagging those who may be likely to experience attachment difficulties and distress later on. With attachment and developmental theory being a core aspect of some counselling psychology trainings, this area would be one that many counselling psychologists would be equipped and competent to work in. In fact this developmental knowledge, which has come so far over recent decades, would be pivotal in supporting women's relationships with themselves and their children. Understanding neurobiological development and affect regulation together with attachment and epigenetic processes underlying the transmission of intergenerational trauma could be important for women and families over the longer term.

However I believe that this knowledge base and skill set could have a still more useful application. If we listen to what women have described as the crucial missing

piece of their experience it is not actually formal support. While access to counselling on site, in women's communities or even in their homes may be extremely helpful for some women, this is not actually what they appear to have prioritised. Counselling interventions would not have stopped the manipulation and loss of dignity experienced. Nor would it have meant improved communication of basic and crucial information which was missing. It would not have helped when women were separated from their babies or left alone to cope with the news that their lives and/or that of their child was hanging in the balance. When Maeve was left alone in the darkness each night, or when Donna was writhing in pain with no-one to believe her what was actually required was an integrated culture of care.

Had this been in place with appropriately trained staff leading it from the top down someone would have noticed and responded to Amy who felt she was going to fall apart. Abbey and her husband would not have been told to leave the hospital having just been given the news that their child was likely to suffer with potentially severe brain damage, and Aoife would not have had to hide infant formula under her pillow to feed her underweight child.

I think that the reflective capacity, research training and humanistic underpinning of counselling psychology could be precisely what is required to redress the oppressive experiences of these women. However given Gilligan's (2011) and others insights into the issues at play we can see that any shifts would be both slow and difficult. The initial hurdle may be the most challenging: that of power. That is, negotiating territory with patriarchal medicine.

I see one possible entry point and path to passing the gatekeeper as through those women and families themselves who have found a voice by forming charitable

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organisations. AIMS Ireland is one such organisation. Through producing research, offering women a platform and lobbying for change they and others like them are causing ripples.

I intend to also contribute to such ripples by linking in with women through these organisations initially through articles based on this research. As a relational psychotherapist I believe that connection with others is the route to change both at a micro and macro level.

In time when Counselling psychology *is* in a position to utilise its skills in this area, I think that a principal role could be a training and consultative one. While counselling psychologists would also be usefully employed in direct work with women and families, this study strongly suggests that whole staff and organisational change should be the primary aim. This will not occur if counselling psychologists, with their skillset which maps on so ideally to these gaps, do not work to support staff and systems to make this shift.

This is likely to be a somewhat more organic process with midwifery staff whose ethos centres on woman-centred care (WCC). The core aspects of WCC concern respect, safety, holism and partnership in being <u>*with*</u> (woman) rather than doing *to* (woman) which can lead to empowerment (Lida, Horuichi & Porter, 2012). These reflect both what women missed and what counselling psychologists aspire to. Hunter et al (2008) suggest that supporting the development of 'communication skills and emotion management skills' of midwives and obstetricians is the first step.

Other researchers such as Rowe et al (2002) have made similar comments as discussed earlier in the literature review and discussion. Hunter et al (2008) note both the lack of attention to this in midwifery and obstetric training as opposed to

other medical trainings. While they suggest that possible routes for supporting staff with emotion and communication could include peer support and clinical supervision, they also highlight the paucity of research on which to base such supports. Further research in this area would therefore appear to be a way forward and some areas have been discussed in section 5.5.

I would suggest that this research would need to prioritise women's voices and as such, survey research as previously discussed (van Teijingen et al, 2003) might not be very useful. While quantitative studies can of course provide invaluable data, what is missing here is the relational piece. To understand this omission and learn how to meet it, I believe that staff need to hear the richness of women's stories and to feel how they have been impacted by them and the systems within which they work. This could trigger the reflection that is required for change.

Finally then the future for women with complications and their families is likely to involve resistance. However Gilligan holds the hope by highlighting our reflexive capacity as humans when she declares:

'If along the path we lose our way, we can remind ourselves to listen for voice, to pay attention to how things are gendered, and to remember that within ourselves we have the ability to spot a false story'

(Gilligan, 2011)

5.5 Final reflections

Almost two years ago when I sought approval for this study I had no sense of the journey I was entering into. I did not understand the degree to which I would be moved by the stories of Aoife, Abbey, Annie, Amy, Donna and Maeve.

The meetings with these women provided me with a vitality which has fed my motivation over this period. Fortunately for me their courage and strength and the trust they gave encouraged me to work harder to look at my own experience and the rage which remained. This together with an insightful and supportive supervisor afforded an opportunity to acknowledge my own experience alongside that of the women's, while understanding that that their stories are not mine. Paradoxically, this has afforded me a welcome sense of belonging. For this I am grateful.

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7. Appendices

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Appendix 1: Research advertisement

I am carrying out a study into women's experiences of communication with hospital staff during a complicated pregnancy. This research will focus on women's relationships with medical staff during this difficult time. In particular I would like to understand what aspects of these relationships were helpful and unhelpful in order to highlight where improvements might be needed.

If you experienced serious pregnancy complications and gave birth to a healthy child within the last two years, and are interested in taking part in this study please contact me on the number or email below. If you agree to take part you will be interviewed on your experiences for between 60 to 90 minutes. Information gathered from the interview will be securely stored and participants will remain anonymous throughout the process. Participants will also be given the opportunity to withdraw from the study.

If you would like to take part or have any questions on the study please contact me on (researcher's telephone number) or at (researcher's email address). If you would like to contact my research supervisor she can be reached at (supervisor's email address).

I am a qualified psychotherapist accredited with the United Kingdom council of Psychotherapy and the European Association of Psychotherapy. This research is part of a doctoral training and will lead to the award of Doctorate in Counselling Psychology and Psychotherapy by Professional Studies. This study has received ethical approval from the Metanoia Research Ethics Committee. Many thanks in advance for any help you can offer.   Zuleika Daly

Appendix 2: Ethics approval letter

METANOIA INSTITUTE

13 North Common Road
Ealing, London W5 2QB
Telephone: 020 8579 2505
Facsimile: 020 8832 3070
www.metanoia.ac.uk

Friday, 1st February 2013

Dear Zuleika,

RE: **Women's experiences of communication with medical staff during complicated pregnancy.**

I am pleased to let you know that the above project has been granted ethical approval by Metanoia Research Ethics Committee. If in the course of carrying out the project there are any new developments that may have ethical implications, please discuss these with your research supervisor in the first instance, and inform me as Chair of the Research Ethics Committee.

Yours sincerely,

Dr Patricia Moran
Research Co-ordinator
Chair of Metanoia Research Ethics Committee

Registered in England at the
above address No. 2918520

Registered Charity No. 1050175

Appendix 3: Semi-Structured Interview Schedule

Interview schedule

1. How would you tell the story of your experience with staff?

2. How did/do you think of/feel about the relationships between you and the various staff members you were in contact with during this time? Since? Possible prompts: Were these relationships important to you? How were they important? Why do you feel they were not important?

3. How do you think the various staff members felt about their relationships with you? Possible prompts: Was there anything in particular that gave you that sense?

4. Can you tell me something of your experience with staff that you found helpful/unhelpful?

5. Can you tell me of any experiences with staff which impacted you deeply in a positive/negative way? Possible prompt: How did this impact on you? For how long did this impact you?

6. Would you change any part of the system if you could? Possible prompt: Why would this be important to you to change? How would your experience have been different had this been in place for you?

7. Is there anything you would like to say to the staff if you had the opportunity?

8. What are you left with now?

Appendix 4

Women's experience of communication with medical staff during complicated pregnancy

Table of master themes: superordinate theme 1 Information difficulties

Theme 1 (passive)Women's unmet need for information	Pages/s	Key words
Aoife	2,3,	P2-I couldn't stop myself (accessing info online) because I was thinking: 'I need to be prepared for this. I need to be prepared' P3-More information really (if I could change something) that's a significant thing. There wasn't even a leaflet stand.
Abbey	3,11 12,43,51,54	P3-I remember googling Dr…..(following being told to leave hospital post bad news)/P11-I just needed to be prepared…I just needed to know/P12-I needed to know what we were facing and what I could do for her/P43-went home and googled it :it was horrific/P51-They were jollying me along, I don't think they understood how much I needed to know the facts/P54-(information)helps, we can deal with things better, we don't like to be fobbed off….and proper, because I mean, somebody would answer my questions very medically so I didn't know what he meant.
Annie	30,7	P30-It (info) made me feel in control, :cos we're not in

		control when we're pregnant/p7-I'd read it in Dr.Google
Amy	57	If there was somewhere where you could go and ask a question: there was nothing
Donna		(conflictual case ?) to this day I actually still don't read about it
Maeve	62	You might feel like a complete idiot with some of the questions you want to ask…you'd feel like the doctors…high and mighty
Theme 2 Ethical info issues: (active)Withholding information from woman, blurred information boundaries & the privileging of staff truth over women's through written information(hospital notes)		
Aoife	1,3,4	P1-the numerous scans went on….your baby is measuring small but nothing else/P3&4-You could just tell by the tone of voice(attempting to ascertain info indirectly)
Abbey	7,26,51	p7-'they should have just said nothing'(husband) it's a big debate in our house and has been since:(how they handled it(in terms of telling/not telling)/P26 He said, 'In

		your case, we had to get you back, so we had to tell you, we couldn't have not.' Because there's only one scan when you're public, you see. So, it would have been very unusual for me to come back for a scan./ P51-they were telling you everything and nothing so you were left with doctor Google
Annie	2,10,21,27,	P2-she'd written (in notes) that I'd refused admission!/P10They told me nothing/P21-you can hear them (staff) talk about everyone, they were going to admit me…I find out 'cos I overhear it. They do have a glass partition…just don't use it/P27-no one's told me she was small: everyone's saying she's average!
Amy	12,106	P12-When they started to monitor me more carefully, I knew (no direct info)/P106-because I didn't know like: do all these babies die?
Donna	12,38,51,56,	P12- notes: ' Donna was upset by exam'/P38-I was looking at my notes and there's very little reference to it, nothing about the pain/P51-she told me the area the lady was from and everything/P56-like they were looking for cancers tumours and they didn't say it./pancreatitis…I didn't know what it was…when I came out of hospital…looked it up(online)… to this day I still don't read about it
Maeve	56	P56-they kind of minimized information even about it
Theme 3-fear and		

distrust through Inconsistent info, insensitive delivery of info, errors & incompetency		
Aoife	12,13	P12-I was saying (to midwives) : 'The doctors have told me I need this!'/P13-the aftercare was terrible
Abbey	43	P43-speaking into her Dictaphone: 'Suspected P.H.A.C.E.' I went home and googled it: it was horrific!
Annie	1,2,10 64,68,74, 82	P1- 'intrauterine death and maternal death'…it frightens the life out of me/P2-'who's wrong?'/P10-midwife…'We'll just do the bloods again…doctor: :…gonna admit you for obs'/P64-'Look, which is it?/P68-'we have no choice but to give them formula…'/P74-they're not really having a clue and trying to cover themselves P82-I think the word 'Death'
Amy	13	P13-They'd say: 'the baby hasn't moved….Down syndrome!'
Donna	42,47,49	P42-one person would say :'fast' the next would tell me to eat!/P47-take out my staples…girl totally distracted…wound opened/ P49-'I don't like the colour of him' …just out of the blue!...it was nothing…alarmist./P49-midwives and surgeons/
Maeve	1& 2,5,7,9,	P1&2-it took 4 of them to actually discover/P5-trust/P7-

	8,13,18,19 20.21,23,24	'we're probably gonna send you home' and I said: 'the midwife says there's no way…faith/P8 mistrusting/P9-hit & miss(care)P13-'You won't be going anywhere'…shocking!/P18-the story was changing/p19-wrong room(bloods)/P20-bloods/P21-dramatic errors/P23-rubbish consultants/P24-wasn't up to par

Appendix 5

Women's experiences of communication with medical staff during complicated pregnancy

Table of master themes: Superordinate theme 2: Disempowerment

Theme 1: Intimidation in a cold institution	Page/s	Keywords
Participant		
Aoife	9,15,21 &22	P9-You're given a number , you go and get your urine sample/p15-My mum had to nearly drag me back(to hospital) it's like a prison….no warmth/-P22-I thought I was in a prison You're stripped down…draconian
Abbey	21	21-Pushy about it…I felt really pushed by her
Annie	63, 72, 79	P63-Regret not challenging the aggression/p72-I'm made to feel like I'm being demanding! /p79-it was appalling.
Amy		
Donna	28,50,51,60,62	P50&51-She'd go: 'I'll tell you now, there was this woman…2

		they were her words Friday night/p60-It was just like a prison cell
Maeve	12,13	P13-He was so completely rude… this man has a reputation for that P12-That midwife is not afraid to face the consultants because some medical staff are
Theme 2: Control		
participant	**pages**	**Key words**
Aoife	12,13,15,17,22	P-12-They have it(formula) but they wouldn't give it to me/p13-I was hiding them (formula) under my pillow/P17&22- my mum couldn't come and see me, that was just hospital rules. I needed to see my mum and I was really sad.
Abbey	36,37	p36-'No you're not allowed to go with her…I had her & they took her off me…& I couldn't

		follow her/p37-begrudgingly gave her to me. They got annoyed with me wanting to feed her myself. It was a whole issue
Annie	60 (add all the waiting stuff)	They'd taken my baby!
Amy	17,18,19,20,21,23,24,67,68	My baby was taken: nothing will set you up more to have a fall than to have your baby taken away/ the nurses would say I recover very well when my babies are gone
Donna	17,28,62	P17-I was told to lie there…I felt like a cow P28-You're disempowered in a situation like that P62-I'm afraid she'll want to speak with me..' pretend you're asleep'
Maeve	13,16,49	p13 'You won't be going anywhere…' shocking./p16-I had no choice/p49-I became resigned….really not to go against my body

Theme 3: dignity & shame		
participant	page	keywords
Aoife	12	I was treated worse than a child
Abbey	51,52/36	I didn't feel I could ask questions lying down….belly up/p.36-we had no choice but to leave…we used to laugh…estate agents
Annie	21	P21-You can hear them talk about everybody. I find out…admitted cos I overhear it…glass partition
Amy	73,74	73'We'll check the bag' in front of (husband & kids)/p74-I was like a pig: so cross…like my kids were there! I couldn't take it in.
Donna	7,12,14,17	p7-ward with just a curtain so you could see everything/p12-I'm there for all the world to see…metal speculum inserted/P14-felt like a piece of meat/ / p18-annoyed, soaking…so

		humiliating….mortified/p19-audience of strangers/p51-She told me the area this lady was from and everything/ p64-'she's very emotional, very hormonal'
Maeve	71,72,77	Just to be lying there pregnant….at that stage of the game it was not what I needed/72-actually inserting gel and there were students in the room.

Appendix 6

Women's experience of communication with medical staff during complicated pregnancy

Table of master themes: Superordinate theme 3: Empathic failure

Theme 1 Unseen woman-disconnection	Pages/s	Key words
Aoife	12,13	P12-13-They told me it was a breastfeeding hospital: I was balling my eyes out, just balling my eyes out saying: 'I need to give her Nutriprem, she needs to grow…' this was one of the most traumatic parts.
Abbey	29,35,39 ,43	P29-I just felt very stressed and forgotten about. /P35-So nobody in my life said: 'How are *you* feeling?'/P39-'There's your baby…good luck…off you go' you go: 'What?!'/P43-Talking into her Dictaphone: 'PHACE'/
Annie	19,43,47 ,63	P19-At one point I had to say: 'will you please listen to me: you're not listening to me!' /P63-She'd written (nurse) that I'd refused admission!
Amy	22-25,37,62 ,78	P-22-25-I don't think they understand/p37-It's a pity they don't recognise it (my unseen /unspoken need)…they get immune to it./P62-you can't ask someone all the time to be nice to you./p78-I feel I was forgotten…you're just…you're there, you're just not on their list
Donna	12,	P12&38-notes written-my notes…very little reference

	38,47,57	to it/P47-It really felt like they weren't listening or there was nothing being done./P57-trays of food coming in….out…in …out like: 'Helloooo?'/p67-I wasn't making it up! I wasn't lying! (Donna struggling with why I wasn't being listened to)
Maeve	56,58	P56-It's you know: 'Oh yeah you've had a baby, so what? Get on with it….women do this all the time'/P58-'People do this all the time: it's no big deal!'
Theme 2 (n.b.-Hermann p.81) Isolation and abandonment: avoidant & unavailable staff	Page/s	Key words
Aoife	6,7 (& 14),10,18	P6-I was very isolated./P7 that may have been my fault, I don't know why I never met a midwife./P10-so when you did get your opportunity to say it to a consultant you just got: ' It's fine'….they (staff) didn't want to be there/-P18-I was on my own the whole time(through the birth)
Abbey	3,8,27, 29,38,39	P3 -they just said: 'Go away and come back at 2pm'/P8-so they told us we just had to leave…that was the biggest problem I had with it: we just wandered around (location) for 2 hours in shock, crying./P27-that was it! That was the goodbye from him!/P29-I was dropped(by staff & service)/P38-39:I just felt very

		lonely…I was crying and she (empathic nurse) was crying . I think that's a problem with every maternity hospital (loneliness & isolation)
Annie	12	P12-so I was there (waiting in A&E), 7 hours and nothing's happening!
Amy	52,77,81	P52-I'm the only one… solely responsible/P77-I needed company/P81-you're very alone even though you're talking to people
Donna	43,53,60	P43-They put me into isolation: I was isolated in a room not the size of that alcove (pointing): and I was on my own for a really long time/P53-'Im in so much pain….' And I started to cry and she looks at the man and she goes: 'Let's get outa here' and she just walked away!...crying…desperate…felt awful after that…an inconvenience (my distress) P60- '…if I don't go home I'll end up in a psychiatric ward…cos they put me into isolation
Maeve	6,10,14, 21,49, 59,64	P6-'We're gonna keep you here for another night ', that was it, and left!/P10-three weeks before I saw a consultant (during hospitalisation)/P14-they just talk and leave: there's no engaging in conversation./P21-He(consultant) just left./P49-She (baby) wasn't checked by a paediatrician…I couldn't believe any of it/P59-He'd (consultant)come in, he'd run out, because that's how I suppose he managed…his

		patients./P64-They're either rushed or they're not coming to see you.
Theme 3 DE Cartesian mind body split: emotional support gap		
Aoife	3,5,17	Someone to talk to (would have helped) some sort of counselling/P5-I was in a way going: 'Someone! Please, help me!'I went away feeling embarrassed, Oh God! I just wanted the ground to swallow me up!/p17-the *non*-support! Non-existent support!
Abbey	16, 19,24,48	P 16-I was never offered support….even if they'd brought us in once a week/P19-business-like, not talking to *me*./P24 -The consultants were very nice…they just didn't see beyond the scan /P48-If they'd been *something* : a person, a room…
Annie	19,43, 47,74	P19-they were more worried in terms of covering themselves…like I didn't exist/P43-It was always': 'How's the itching? How's the movement?'/P47-It would have been nice if someone had asked how you were and given you the option (counselling)…like then you'd know it was there. /P74-It's not really 'caring' for you and your baby. It's not the kind of care you would want.
Amy	25,31,	P25-if (baby) had died there'd be counselling staff…

	32,40, 48,49, 57,63, 80,100, 103,104	but there's nothing for the poor woman sitting….crying for her baby/P31-If my leg had fallen off…/P32-just to be able to talk and say 'that's normal'/P40-they don't have time for the person…you're a number so they miss out on the 'how are you?'/P48-they're seeing so many…if my chart was stickered…they'd say: 'Oh, this is a special case/ P49-'Let's ask Mammy how she is….how's everything at home? They'd be aware of: 'she's not right today, She's only fighting back the tears/ P57checked blood pressure 'fine' …but no-one said: 'Are you alright?'/P58-be lovely just to be 'cuddled' a small bit. /P63-nothing from the neck up. (plus lots more)
Donna	26,27,48 , 65,69,	P26-I didn't get it (support) at *any* stage/P27-there's not that warm fuzzy feeling the images portray…I didn't get that. I think they're just really busy…there was a lack of support/P48-I feel they don't address women holistically/P65-It's basic things, a little bit of humanity, understanding, compassion/P69-They're so job-focused, task-orientated…not person-centred, one size does not fit all!
Maeve	5,35,37, 39,55,58 ,60,78,	P5-Of all the major things I would change….medical care: it's not just care of the body…it's emotional care as well…going home…new baby….you may not be….physically or emotionally well yourself./P35-there

		was *nothing* offered…*never once*…very poor…not *any* counselling./P37-She said: 'Well, there's Mass'…like this is sick!/P39-I'm telling you: <u>*nothing,*</u> there was <u>*nothing*</u>. Like I really…I went through my (hospital) notes and there was *absolutely nothing* apart from medical care. Like really and truly there was *nothing*!/P55-after some sort of traumatic event…to just be in there and have no support offered and not even any details of any./P58-more patient-friendly…more approachable/P60-It certainly would have been easier…even if they would have say external people come in(for counselling)/P78-there's no thought for you know: 'who's the individual in this bed here?' you know?

Appendix 7

Women's experience of communication with medical staff during complicated pregnancy

Table of master themes: Superordinate theme 4: Relational impacts

Theme 1 Relationship with self: guilt shame, fear, self-doubt & confusion & coping	Pages/s	Key words
Aoife	5,7,22	P5-I went away feeling embarrassed, Oh God I wanted the ground to swallow me up/P7- I *should* have been proactive /P22-Why did I go public? So I was blaming myself
Abbey	17,27,28, 33,39,49	P17-Maybe it wasn't that serious: if there was something really wrong it wouldn't have been like that./P27&28-it went from this huge issue to: 'You're grand…you're nothing'…embarrassment…I felt stupid…making a fuss/P33-I feel silly that I'm still upset about it…I *should* just get over it(projections?)…no it isn't gone 'cos I didn't deal with it/P39-'Off you go' 'what?': Now I didn't know if I could stop worrying, I didn't know how to feel./P49-I got through it in the first year and it's hitting me now, it's all coming out.
Annie	50,52,53	P50-I'm not 100%...look what happened & I'm supposed to be back to normal…it's taken a lot out of me & nobody realizes/P52-I try to fight past it…I don't know how to…as much as I can I limit it/P53-I don't want to give in
Amy	35,41,42,	P35-I'm better now but I'd cry & cry 'cos they got their babies

	70,95	you know?/P41&42-Maybe I'm overreacting…it seemed so matter of fact to them/P70-If you spoke to me last year…I wouldn't speak to you…(I wonder how many other women won't speak about it?)I've had time/P95-'Maybe it's me overthinking, maybe it's not that high risk', Oh it's completely psychotic thinking, it's just you're all over the place.
Donna	35,36	P35-I'm disappointed in myself, I knew the questions to ask…I should have known better to ask/P36-even retrospectively I say: 'Why didn't I?' or 'Why wasn't I more assertive or stand up for myself
Maeve		
Theme 2 Attachment relationship with baby		
Aoife		My sister and my mother would say I was very over-protective, very.
Abbey	11,46,48, 49	P11-It sounds silly but I bonded with her that(traumatic) day very strongly/P46-I find it hard to let go of her/P48-she was mine and I looked after her and he(partner) didn't and I'm the best and she was mine./P49-I've never been away from her
Annie	54,56,59	P54-I feel guilty…I probably enjoy her more…I could look at her all day: Is it because I didn't know if we'd have her at the

		end of the pregnancy?/P56-I don't like when he's feeding her…I want to do it/P59-I'm hoping he'll say he's too busy to feed her
Amy	30,65,68	P30-I'd sit with her (sleep on sofa) for the first 3 months because I never noticed (that she had stopped breathing)/P65-I didn't want anyone to come down because we were only allowed to have her when we could visit her so I wanted no one else to come near her /P68-there's a bridge in the hospital when you get to carry your baby home: that's like me having my baby… I kind of gave birth to her when I got to take her home (delayed psychological birth?)
Donna	74,77	P74-Oh Yeah(emotional tone) I would be very overprotective, very alright…keep people from holding him/P77-I didn't want people to hold him even my mum…I didn't like people even calling in: 'He's asleep, don't pick him up'
Maeve	45,68,71	P45-We look at her now & again & go: 'Oh my god, I'm just so relieved!'/P68-I think it might have affected us the other way (overestimating baby's strength). We reckon: 'Oh she's just really strong'/P71-It was really funny …but then we know that everything worked out fine with her…yeah.
Theme 3 **Relationship with** **partner**		
Aoife	2,3	P2-…. (Partner name) was saying: 'she's a small baby…so

		what?'/P3-His way of dealing with things is: 'Would you ever stop worrying?'
Abbey	12,40,41,47	P12-He just wasn't as supportive as he could have been/P.40-We're not quite there yet…he (went to counselling) was upset at how angry he was, he was afraid of her, he was afraid he was going to break her…he still has that anger/P41-It hadn't occurred to him how I felt….that hurt more than anything else./P47-whatever scant consideration was given to me none was given to (partner's name)…he came home and said: 'Was I there at all?'…we've never been out together since she was born(2 years)
Annie	51,60	P51-I think he expects too much of me: look at all the things that happened…/P60-He didn't change her nappy til she was 3 weeks…he was nervous of her
Amy	80	P80-(partner's name) has never had a baby so he doesn't fully understand.
Donna	28	Husbands get forgotten about…it affected him, he was trying to be strong for me…I didn't tell him too much 'cos I didn't want to freak him out
Maeve		
Aoife	12,16,18	P12-(anger around withholding of baby food)'fucking find the Nutriprem' continued anger into the present indicated by unusual use of swearing together with tone./P16-the use of present tense around distressing feeding experiences & nurses./P18-I feel like calling her (frightening senior midwife)

		every name under the sun.
Abbey	6,40	P6-I'm sorry I've probably gone all over the place (during particularly traumatic/emotive piece/P40-I'm exhausted, it was still there(unresolved trauma processing during interview)
Annie	15,43,53	P15-(use of present tense)You start to panic if she wasn't moving/P43&53-It'ss only now you're saying it that I'm realising it(reflecting in the moment of continued impact on her)
Amy	17,31,53	P17-I'm jumping all over the place now(lack of integration on particularly traumatic piece of separation from baby)/P31-Hearing it now I'm saying: 'Yeah…Jeez…really…no when you're saying it to me(realisation in the moment of support gap)/P53-no one thought about…(difficulty articulating 'me' for unmet needs alternatively uses 'you')
Donna	1,2,3,15, 29	P1-Quick & irregular pacing at start & sense of panic with breathing: sense that she was back there(PTS related symptoms)/P2-(voice breaking & sense she would be disbelieved by interviewer) like I was actually bleeding through pads, my clothes/P3-I've never cried like this/P15-becomes visibly distressed again/P29-& this has just come into my head now(reflecting/processing experience in the moment)
Maeve	4,70,71	P4-(multiple pausing indicating unprocessed/unformulated experience)I was obviously upset….I wasn't sure….if I was

		going into labour…that day/….a few days?...a week?.../P70-(strange dissociated sense here/sense of continued confusion and unintegrated material which links into M's coping strategy-imp to discuss the impact of the women's dissociation & other strategies))very strange to have left here…it was 10 weeks later…I arrived back with the baby…it was a really strange feeling/P71-(same sense here)It was really funny…but then we know that everything worked out fine with her….yeah. (seems as if part of her hasn't understood that this is the case.

Appendix 8

Table of superordinate themes and themes from 'Aoife' interview 1		
Women's experiences of communication with medical staff during complicated pregnancy		
Themes	**Page/s**	**Key words**
<u>**Information difficulties**</u> Incongruence, withholding of information and closed communication style of staff (and partner) concerning baby's health leads to heightened anxiety & distrust	1,3,4,7,8	P.1-we were to go for a scan nearly every two weeks… So as these scans and the numerous scans went on, obviously this was causing a lot more anxiety ….. but because I was part of this: 'let's measure your baby every two weeks' that was really scaring me./P3 & 4-You could just tell by the tone of voice(attempting to ascertain information indirectly)/P3-I suppose more information really(if I could change something)…I suppose that's a significant thing, there wasn't even a leaflet stand /P7-he was like : 'Oh it's fine' so when you did get your opportunity to say it to a consultant you just got: 'it's fine' / P8-they want to rush you out the door…you'd be waiting hours
Centrality of access to information in preparing woman to care for child leads to the seeking of	2,3,4,5.	P2-I needed to be prepared/P2&3-I couldn't stop myself (googling) because I was thinking I need to be prepared for this./ P2-Google is the worst thing especially when you're pregnant./P2- And she said,

information in alternative places and subsequent disapproval for information seeking and repetition of shameful failed support seeking experience		'look, stop looking up things(online), don't be worrying yourself'/ p4-I just blurted it out…(P5)-It was in a way…going 'someone please help me' and the whole place went quiet…I went away feeling embarrassed, Oh God I just wanted the ground to swallow me up then/ P5-'Don't be worrying, don't be looking at the computer'.
Isolation and support difficulties	3,6,16,17	
Absence of emotional support (identified as representing missed opportunities that could have made a positive difference)	6,17,18,21,22	P3-some sort of counselling around it or someone to talk to would have helped./P6-I didn't have a support network at all/ /P.16-(group/individual therapy) I mean I enjoy that type of thing or even one on one. I certainly don't think that was the case/ P17-The non-support, non-existent support (in hospital)/ P17- the most logical question: 'Is there anyone I could talk to about how I'm feeling?' Maybe there was.
Isolation and Separation in hospital leads to distress and withdrawal and silencing of woman (breakdown of woman's trust &support seeking		P.6-I was very isolated/)/P17-My mother couldn't come and see me, that was just hospital rules/p17-I needed to see my mum and I was really really sad./ P18-I was on my own the whole time (through the

capacity)		birth/ /P21-I withdrew…because I thought they were all the Devil, I just felt they were all against me./ P.22-I was lying there…I thought I was in a prison and no one could come and see me, my mum couldn't come and see me
Experience of being a burden on staff	8,10	P.8- I also felt like they didn't want to be there so there was a big element of the doctors thought, 'Geez, I'm in public today and I've got this many patients to see, this is a nightmare'./ P10-they didn't want to be there
Regime of hospital appointments leads to emotional and physical exhaustion.		I was doing all those scans I was thinking this is enough, this is just draining me.
Disempowerment and fear Experience of hospital as	9,10,11,12, 16,22	P9-You're given a number, you go and get your urine sample/P9-you're not allowed to bring children in./ /

impersonal, harsh & frightening Institution steeped in a power differential that leads to emotional deterioration of woman.	10,12,13	p.10-horrific/P.11-The place is horrible/It's like a prison…no warmth/ p12-I was treated worse than a child./16-it's a disaster….a lot of them are stuck in the dark ages…the culture. /P22-you're stripped down…draconian.
Withholding of food from needy child due to staff insistence on breastfeeding leads to high levels of disempowerment & distress.	9,15,17,23	P10-The pressure was horrific…this was one of the most traumatic parts./P10-I was hiding them(formula)under my pillow.P12-they told me it was a breastfeeding hospital, I was balling my p.12-they have it but they wouldn't give it to me…I was saying: 'the doctors have told me I need this!'/P13-…it was really horrific, the feeding aspect…Just balling my eyes out saying: 'I need to give her Nutri-prem, she needs to grow.
Terror and anxiety	7,9,14,22	P.9-People with drug issues, heroin addicts, all walks of life…you can feel the anxiety in the(waiting) room /P15-My mum nearly had to drag me…because I was so afraid to go back(hospital)/P.17-Oh God, Oh Jesus, it was terrible(palpable fear)/P23-she was really scary(staff sister).
Retrospective thoughts & feelings		P7-I hadn't a clue what I was letting myself in for./P7-I should have been proactive in some way. /P9-In hindsight if there was anything I'd do

Hindsight & Self-blame	12,13,17,18,	differently…mount Carmel(private)…don't care how much it costs/P14-That may have been my fault, I never knew why I never met a midwife/ P22-'Why did I go public?' so I was blaming myself.
Previously unspoken anger	16,21,23,	P12-'Fucking find the Nutri-prem…'/P.13-the aftercare was terrible…really angry about that, generally/ P.17-I also would probably want to use strong language, rage with a few of them… I would have liked to say, 'Why the hell isn't anyone coming to check on me?' and screaming from the rooftops./ P18-I feel like calling her (senior midwife) every name under the sun
Process issues Becoming lost in affect/re-experiencing of trauma- PTSD related Exhaustion of processing/narrating story		P16-use of present tense discussing feeding. P21-I was really annoyed with that: can you ask me that question again P23-I…feel a little bit exhausted, but it's good to get it all out, you know.
Relational Different coping styles of woman and partner impacts how they deal with the trauma.		And (partner) always said to me, 'Don't worry, everything is going to be fine, the baby is measuring small. We have a small baby.' He would even say, 'We are going to have a beautiful wee tiny baby. Stop Googling things!'

Appendix 9

<table>
<tr><td colspan="3">Table of superordinate themes and themes from 'Abbey' interview 2

Women's experiences of communication with medical staff during complicated pregnancy

</td></tr>
<tr><td>Themes

</td><td>Page/s

</td><td>Key words

</td></tr>
<tr><td>**Information issues**

'Getting' my need to

know</td><td>12,25,51,54</td><td>P12-I needed to know what we were facing and what I could for her/P25-Do we need to tell the patient everything on the scan (current ethical dilemma)/P51-they were jollying me along… I don't think they got my need to know the facts/P51-I used to get …..(partner) to ask the questions 'cos me lying on the bed with jeans down was getting less attention than him in a suit./P54- (Information)helps, we can deal with things better, we don't like to be fobbed off.</td></tr>
<tr><td>Meeting the

information shortfall

from hospital through

Dr.Google and

bookshops</td><td>3,43,51,52</td><td>P3-I remember googling Dr……(following being told to leave hospital post bad news)/P43-went home and googled it :it was horrific/P51-they were telling you everything and nothing, so we were left with Dr.Google./P52-turning to Dr.Google/</td></tr>
<tr><td>Information as vital

component in feeling in

control and

preparedness to meet</td><td>11 &12</td><td>P11&12-I just needed to be prepared/ I just needed to know. I needed to know what we were facing and what I could do for her…. if anything all I wanted to be told was what was wrong. Do you know what I mean? Like in a sense, even if the worst</td></tr>
</table>

child's needs		was wrong, I needed to know what it was… In my mind I was thinking, I have to prepare, I've got to talk to these people. I've got to look up grants for a wheelchair.
Staff ignoring woman and/or using unclear medical terminology in discussions of bad news	43,54	P43-Talking into her Dictaphone 'suspected P.H.A.C.E. in child'/ P54- and proper. Because I mean, somebody would answer my questions very medically so I didn't know what he meant
Support and empathy Abandonment & shock	P3&8,27,29	P3-so they told us we just had to leave…that was the biggest problem I had with it, they just said go away and come back at 2 pm…we just wandered around Merrion Square for 2 hours in shock, crying…I couldn't think straight/p27-that was it: that was the goodbye from him/p29-I was dropped
Conflict of wanting special support but not being able to ask for this need to be met Feeling forgotten about/not held in mind	12,16,22,26, 29,35,38,48,49	P12-I've pushed people away/P16-I was never offered support….even if they had brought us in once a weekP22-it was all about him for a few minutes, 'Hello?, Ehem?'/p22-None of the consultants ever asked how I was feeling...how I was/p26-the only time it came back to me…/ P29-I felt very stressed and forgotten about/P35-So nobody in my life said: 'how are you feeling?'/P38-I felt very lonely, I was crying, she was crying/P48-If there'd been something…a room , a person…/P49-it's all about the child.

and isolated		P6-(during traumatic piece in interview) I'm sorry, I've probably gone all over the place./ P19-I think I just zoned out/P9-I had to just be 'mum' for him (older son)….it didn't occur to me at the time/P35-I couldn't afford to breakdown (children)/
(relatedly)Needing to remain strong to meet (additional) responsibilities (leads to no space for woman's needs to be met(& implications for how services can offer support)	6,9,19,35	
The positive aspect of dealing with responsibility of other child		Spending time with him on days out/Hot chocolate and the fair/giving him the information & not keeping him in the dark
Feeling 'silly', confused and not entitled to distress of unresolved trauma due to lack of empathy and positive outcome	17,28 &29,33,40	P17-Maybe it wasn't that serious…if there was something really wrong…it wouldn't have been like that/p28&29-went from huge issue to 'you're grand…you're nothing, embarrassment …I felt stupid….making a fuss./ P33-I feel silly that I'm still upset about it…..I should just get over it….no , it isn't gone 'cos I didn't deal with it/p39- 'There's your baby…good luck…off you go' you go 'what?!' everything had been so focused on…. Now I didn't know if I could stop worrying, I didn't know how to feel at that stage./P40-I'm exhausted, it(distress during interview) was still there/p49-if she had been sicker (I wouldn't feel silly for still

		being distressed)/p49-I got through it in the first year and it's hitting me now, it's all coming out
Conflict of 'nice' but insensitive staff (lack of accurate empathy)	4,19,20, 21,23,24	P4- and into the room with everybody else who was….it felt wrong/ P4-'well it could be any number of syndromes' saw me bursting into tears /P19-business-like…not talking to me./P20-I was like 'Great way to burst my bubble'/p21-pushy about it, I felt really pushed by her/p23-He was lovely…but still never asked me abouP24-the consultants…very nice…just didn't see beyond the scan.
Power and choice Staff taking away control by taking baby and woman attempting to compensate for loss of control through breastfeeding	36,37,44,48	P36-'no you're not allowed to go with her (new born)' I wasn't even allowed…it's insane… I had her and they took her off me so I couldn't follow her/p37-begrudgingly…gave her to me…they got annoyed with me wanting to feed her myself. It was another whole issue that happened a number of times/p44-breastfeeding was great/p48-she was breastfed to 14 months, overfed: it was the one thing I could do for her.
Vulnerability and loss of dignity	42,51&52,	P42-Feeling like someone punched me in the side of the face when I wasn't looking/p51&52-didn't feel I could ask (questions)lying down belly up…look at screen not me(staff)my belly up and jelly all over it…lying on the bed with jeans down/they were like estate agents….I would make all the appointments…turn up… and they would talk to my

		husband…man to man
Lack of choice	3,7,49,11&12	P3-We had no choice but to leave (hospital)/p7-so just try to get through the next 3 weeks basically. So that's all I could do/p11&12-It was out of my hands but I could prepare for her/.p49-I had no choice(getting on with it)/
Other relationships		
Partner and impact of different coping mechanisms and their relationship on how they dealt with the trauma	6,7,12,40 ,41,47	P6-I said (to partner)'this is not happening to you, it's happening to her/p7-it's a big debate in our house/P12-He just wasn't as supportive as he could have been/P40-(partner counselling)He was upset at how angry he was, he was afraid of her, he was afraid he was going to break her /48-I would try to give her to him, and he would sort of rock it like he was physically moving away from her. He held her and played with her, but, it just wasn't… /P40-he still has that anger, I felt I was doing this on my own again….we're(relationship) not quite there yet/P41-hadn't occurred to him how I felt-that hurt more than anything else./P47-he came home and said 'was I there at all?'/P47-We've never been out together since she was born(2 years)
		P11-It sounds silly but I bonded with her that day (traumatic), very strongly/P46-I find it hard to let go of her…. I find it very hard to... / P48- she was mine and I looked after her and he didn't and I'm the best and she was mine./P49-I've never been

Attachment relationship	11,46,48,49	away from her/

Appendix 10

Table of super-ordinate themes and themes from participant 'Annie' interview 3		
Women's experiences of communication with medical staff during complicated pregnancy		
Themes	Page/s	Key words
Information problems inconsistent information and processes and development of distrust	1,2,10,11,27,64,75	P1-I just wanna talk to a consultant/p.2-Who's wrong ?/p10-midwife-'we'll just do the bloods again-doctor-'we're gonna admit you for obs./p27-No one's told me she's small, everyone's been saying average/p.64-Look, which is it?/p75-Well you rang me with them last week!.
Confidentiality breaches	21	P21-You can hear them (staff) talk about everyone, they were going to admit me….I find out cos I overhear it. They do have a glass partition…just don't use it.
Information and control	2,7,10,30	P2- she'd written that I'd refused admission!(in notes)p.7-I'd read it in …Dr.Google /p10-they told me nothing/p.30-It made me (information)feel in control cos we're not in control when we're pregnant…I like to understand(in context of preventing loss)

Power & choice	1,9,12,14,19,38,	
Coping with the Impact of multiple hospital appointments within woman's wider contexts and responsibilities(children, work etc)	39,47,73,61,62	p.1-Sitting there at 3am for 5 hours/p.9-get to hospital in a panic…don't see anyone (for 4hours)/p.12-so I was there 7 hours and nothing's happening/p14-The next day I was crosser…I was cross, I was exhausted, been to work, been up at 6.30 with the boys, bed at 2:30/p.19-No one can make a decision & I have to just sit here/ p.39-they bring you in…before 8..there's no beds…didn't bring me down til 12/p38-I had to get the whole house organised in my head/p39-I had to give them their time/p.47- I just didn't have the time(for counselling)…if they had built it into appointments I might have(laughs)/p73-by 5:30 I'd seen nobody / p.61&62-It's ridiculous, I'm just sitting here and I don't know what's happening/p61-You can't go home 'til….
Conflict of remaining silent or challenging authority(Annie the fighter)

(nb: Milgram, white coat effect etc… highlights huge potential for both positive and negative impact on woman) | 2,10,12,29,63,72,77 | p.2- Well can't I come in for a trace every day?/p.10-What are you admitting me for?/p.10-is this safe?/p.12-you shouldn't have let me go!/ p.29-I'm happy to take medical advice but I'm not under instruction, I'm an educated adult. It's my baby and I get to decide/p.63-I get to thinking saying nothing-getting through/it's annoying especially as I'm made to feel like I'm being demanding/ p.72-regret not |

		challenging aggression/p77-I don't feel I was bossy, I kept on bugging them
<u>Obstacles in supporting emotional versus bodily needs</u> Unable to seek support with the emotional impact and resentment for support need not being acknowledged	43,47,52	p.43-How's the itch? Nobody ever asked how I felt. / p.47-It would have been nice if someone had asked how you were and giving you the option….would've been more comfortable with some counselling….because it's kind of in a box/ 52-It has taken a lot out of me and nobody realises it /p.52-I'm not 100%/p52-Look what happened and I'm supposed to be back to normal…/
Becoming aware of the emotional impact in the wake of using avoidance and 'fighting' as coping strategy.	43,44,52,53,54	p.43-It's only now when you're saying it now that I'm realizing it coz you don't have time to think about itp.44-I avoided people…I didn't want to talk….because it made it more real….coz it was just frightening/I try to fight past it….I don't know how to…..as much as I can I limit it/ p53-I don't think about it and when you're talking to me, It's making me….I think realize,.. it more./p53-I don't want to give in/p54-I don't have time to think out things I probably should
Roles of risk management, job security and resource limitations in feeling ignored	19,43,52,65,74	P.19- 'they were worried…covering themselves….like I didn't exist….at one point I had to say 'will you please listen to me….you're not listening to me' / /p.65-She

Containment versus the fear and distrust	,.	said some people are minding their jobs/p.74- trying to cover themselves…not the kind of care you'd want/p74-I didn't feel any of the others were(listening)really./p74-you'd see different midwives all the time
	1,2,5,12,13,14,17,23, 24,40,70,74, 75,79,80,82	P.1-'intrauterine maternal death' in that language. It frightens the life out of me/ p.1-The junior doctors were in a complete panic/ I felt terrified/ p.4-they could induce me before that(37 weeks) which was frightening/P.12- Doctor: 'I don't know, never seen this before'/ p.13 -So they didn't actually know what to do…I was so shocked./P14-this started to frighten me/ p.33- seemed to be examining me constantly and just hurting me/p17-they were going to monitor it so we were very happy/p23-Fantastic, agreed I didn't need to be admitted…'don't worry, I think you're right'/p24- the 3 of them were very calm(consultants)/ p40-'Oh they won't be sending you home anyway'/p40-and I was: 'don't listen to them…' /p.70-They'd taken my baby…why they had to frighten the life out of me I'd no idea. P.74-not really having a clue…/ p.75- 'what do you think we should do now?'/p.79-I knew more than the staff/p.80-we don't know what's going on./ p.82-I think the word 'death'
Process related (generally concerning		

possible lack of processing)		
Use of present tense & 2nd person for 'I'		
Sense of elongation of time	15	p.15-you start to panic if she wasn't moving
Temporal jumps	15	p.15-feels like ages ago
Other relational	21	p21-sorry…been convoluted jumping back and forth
Attachment relationship		
	54,56,59	p54-I feel guilty…I probably enjoy her more…I could sit looking at her all day...Is it because I didn't know if we'd have her at the end of the pregnancy?/p56-I don't like when he's feeding her…I want to do it/p.59-I'm hoping he'll say he's too busy to feed her.
partner		
	51,60	p51-I think he expects too much of me look at all the things that happened and I'm supposed to be back to normal/p60-he didn't change her nappy til she was 3 weeks…he was nervous of her

Appendix 11

Table of super-ordinate themes and themes for participant 'Amy' Interview 4		
Women's experiences of communication with medical staff during complicated pregnancy		
Themes	page/s	Key words
<u>Conflict of needing support</u> <u>& difficulty asking for need</u> <u>to be met</u> Maintaining isolation for fear of being a burden	47,48,51,53,61,62,78, 77,81,92,101, ,103	P61-I wouldn't burden staff unless I needed/p62-you can't ask somebody all the time to be nice to you.p47-even staff don't know me enough…cos they have so many/p48-they're seeing so many/ …/p53-noone thought about…./p.78-I feel I was forgotten…you're just…you're there, you're not on their list/ p77-I needed company…someone to say 'oh how are you?'/p81-you're very alone even though you're talking to people/ p 103-there should be a system whereby they know the more needy patients. p92-what if I tell them I had a bleed they might keep me in…just a rest…be lovely to be kept in
Feeling alone with burden of responsibility for baby's survival	33,36,52,80, 81,	p33-It's an awful burden because I'm the only one,/p36-It's almost surrogate/p.52-I'm the only one…you feel totally responsible…solely responsible/p80-I don't want sole

		responsibility any more…very cold thing to say/p81-torture/
Resentment at staff for lack of holistic care	25,76,31,37,40,50,57,63,	p.25-If (baby) had died there'd be counselling staff…but there's nothing for the poor woman sitting…crying for her baby./ p76-they'd have been in …checking(no staff attention without baby)P31-If my leg had fallen off there'd be something(support)/ p37-it's a pity they don't recognise it…they just get immune to it(emotional pain)/ p40-they don't have time for the person…you're a number so they miss out on the 'how are you?'can't give you the time/ p.44-I'd be breaking my neck…didn't matter…they didn't call you by time …by number p.50- they p57-checked blood pressure…fine…but no one said 'Are you alright?'/p63-nothing from the neck up/.
Conflict of needing to be seen as a 'special case' & resentment at non-complicated pregnancies	48,49,58,101,102,	P48-They're seeing so many…if my chart was stickered…they'd say: 'Oh this is a special case'/P49-'Let's ask Mammy how she is…how's everything at home?' or have a specific midwife…they'd be aware of : 'she's

		not right today, she's only fighting back the tears'/ p58-be lovely just to be 'cuddled' a small bit, just someone to say:' aren't you fantastic'/ / p101-she came along in the journey whereas other midwives they wouldn't even notice/ p102-I want a small bit of recognition/ I didn't stand out…if I was having triplets/ p108-you don't wanna be sitting there with…4th baby…have it at home and eat the placenta
Meeting support needs by accessing online and group support	31,32,97,98, 105,107,108	P31-that's where I depended on 'Magicmum'/p32-Just to be able to talk and say 'that's normal'./p.97-so we could sit and say: 'Oh you're IUGR? Yeah I'm IUGR…/p98-it was our little group/p105-you can see people who've only just been told…it was nice to say 'I'm nearly at the end'/p106-'Cos I didn't know, like do all these babies die or do they have…?/ p107-It's like a cancer support group for me/

Blasé staff response creating confusion	34,38,41,95	P34-it's only a short one….not a huge length of time/p38-would tell them I'm kind of getting tired of this (minimizing distress/internalising projections?)P41-maybe I'm over-reacting…it seemed so matter of fact to them (staff)./p95-maybe it's me over-thinking…maybe it's not that high risk, oh it's completely psychotic thinking…it's just you're all over the place
Separation 'the Taken'	21,22,24,67,68	P21/farmer takes the calves from the cow and you'll hear the cow pining for the calf and the calf pining for the cow/p.22-(baby) was taken…a very strong word, yeah it's taken, oh yeah it's an awful, awful thing/p24-nothing will set you up more than to have a big fall than your baby to be taken away. Like it's afterwards…when you come home…and suddenly….they did nothing to prepare you for going home without/p67-mine were taken off me…if I hadn't had that extra yearning p68-I kind of gave birth to her when I got to take her home/p68-There's a bridge in the

		(hospital) when you get to carry baby home: like that's me having my baby…all that loveliness.
Staff lack of prioritizing/understanding of child-mother separation	17,18,19,20,21 22,23,24,25, 75,86	P17-They told me they'd take me down…to see her…and they didn't, and they kept on kind of pushing me off/p.18-I said 'you've promised me and I've stayed awake to try and get down to see her…you won't take me down…the woman next door has her baby…I'm hearing her baby…It's unnatural/p18-'she's fine' Yeah but I want to see her!/p19-the nurses would have said I recover very well when my babies are gone/p20-Staff think baby's in NEO and they're looking after it, but it's totally unnatural!/p21- They're matter of factly taking baby off you and expecting you to be fine…you can't./p22-I don't think staff give the person in bed enough credit for it./p23-'she's in the best place, she's grand where she is'/p.24-'baby's in NEO, ….so sure you won't miss it…enjoy the rest'-how can I rest?!...I'd rather her be at home crying the whole night! / p25-I don't think they understand.p75-they

		expect you to rest but you can't cos you're in such a mixed up place….I'm sitting there waiting for a porter with the wheelchair…no sign…I want to go now!/'you'll wish you had this time back'(without baby).
Bodily recovery driven by desperation for contact/woman's strength	19,	P19-so if I want to get there…it's unnatural. I said 'I'm going to walk'…I was on the go because I had to…it was mind over matter…could have been waiting for hours
Separation experience contrast with media portrayal	35	p.35-massive(impact of separation) because it's what you expect: t.v., magazines, baby books, you kind of hope and imagine…you do dream of it
Power & control Dignity	72,73,74	pp72-73- Kieran's dad came up…they came in 'we'll check the bag' and in front like!. It was horrible…the kids were like: 'what was that bag?' That now stands out. / p74-I was like a pig! So cross, remember bawling ….like my kids were there! I couldn't take it in!

Lack of information	3,12,57	P3-Uh oh this baby isn't growing to plan: so I knew where I was going /p12-when they started to monitor me more carefully I knew/p57-somebody just hand out a list…somewhere you could go and ask a question…there was nothing, no little pack.
Lack of control	7,32,33,65	P7-you feel as if the baby is not yours…told to bring your bags with you every time cos you might have to stay/p32-so much intervention…I had no control. I couldn't plan the week. /p65-I had no choice…we were only allowed…
Managing staff safely & passively	60,61,62	P60-if I didn't like the nurse I'd ring back again/p.61&38-I know you're busy but…/p62-I did learn that if you're nice when you say it your needs can be met
Other relationships(not with medical staff)		
Woman & self	35,70	p35-I'm better now but I'd cry and cry 'coz they got their babies you know?/P70-If you'd spoke to me last year…I wouldn't speak to you…I've had time to…

Woman & infant	30,65	p.30-I'd never noticed and I was her mother/p65-so I wanted no one else to come near her/Didn't want anyone else to hold her
Woman & partner	80	p80-husband has never had a baby so doesn't fully understand....Magic mum(online forum) they understand
Process related		
Temporal jumps	17,36,	p17-I'm jumping all over the place now(around separation)/p36-I'm going from pregnancy to birth
Reflection in the moment	31	P31- Hearing it now, I'm saying 'Jeez... Really... no when you're saying it to me
Sense of elongation of time	34	p34-I look back now
Conflicting narratives	48,49,50	It's the system, it's not them, it's turnover. No one thought about....
Use of 'You' for 'me'(possible difficulty articulating my needs	P53 etc...	

Appendix 12

Table of superordinate themes and themes from 'Donna' interview 5		
Women's experiences of communication with medical staff during complicated pregnancy		
Themes	Pages	Key words
<u>Mind and body as a</u> <u>dynamic system</u> Needing compassionate care	20,21,26,27,33, 53,65	P20-Everything seems to be rushed, the body obviously wasn't ready/p.21-It's kind of 'get them on, get them fast'/ /p26-I didn't get it (support) at any stage. /p27-there's not this warm fuzzy feeling that the images portray…I didn't get that./p33-I got the feeling it was coming up to off time /p53- she just walked away trying to get out of there. I was left, crying. I was just so desperate: 'Please can you not do something?' I started to cry and …she goes: 'let's get outa here!'…. I just really felt awful after that. It was like it had been an inconvenience for them to come./p65-It's basic things, a little bit of humanity…understanding compassion/
The bodily experiences of pregnancy and birth	1,2,3,8,11,16 ,17,18,29,30,31, 41,42,54,55	P1-I dispensed a kind of fluid…very frank blood/p1-I was after soaking through pads and everything there was that amount of blood/p2-like I was actually bleeding onto the seat/p3-speculum in to examine and it was then just I felt

		a whoosh of like blood/p8-really bad heartburn and I spotted like all through /p11-he was standing next to the bed with a speculum in me waiting for the midwife/p16-I couldn't eat…nauseous…heartburn still bad/p17-worst thing ever….gushing and gushing and …told to lie there…felt like a cow/p18-soaking through everything and down my legs, all over the floor fluid./p29-anaesthetist…'can you feel that?'…If I tell her I can't feel it and she cuts me…/p30-I was going to vomit in the middle of it/p31-and they were like 'We need to cut her' and she was like:'No'./p41-the whole wound is undermined which basically means it's open…potentially gonna burst any moment/p42-I took a sip and I thought I was gonna pass out (with pain)/p54-I think the stretcher was soaking….I could smell it…sometimes it's weird actually. Something will trigger it and I can smell it.(trauma /PTSD indicator?)p55-it was weeping (wound)you see and it was oozing
Connection between body and emotions	5,46,47,48,55,69,	~ P5-I was nervous about the bleeding/p5-I know complications…lack of oxygen…nervous about all

		that/P46-when he (baby) used to cry I used to get diarrhoea/p47-If I couldn't settle him my body would react/p48-they were addressing the section but not the other one (other problem)…because I feel that they don't address women holistically/p55-this wound, big wound. it was like depressing me/p69-person-centred:one size does not fit all!/ p69-they're so job-focused, task orientated…other than that there was very little contact
Feeling dismissed & unheard and the angry at subsequent failures in care	1,2,18,33,34,36,37 39,47,57, 65,35,36	P1-I was always reporting it (pain) and they kept putting it off/ p2-I felt she thought I was being alarmist./ p3-I knew by their faces…they were starting to panic/ P18-'You're grand, you're grand' making light of it……'sure we see this every day'/ P22-staff were slow…I could have been brought down with more time/P23-didn't necessarily have to be this emergency/p34-They should have done it early, there'd have been no emergency P33-Dissmissive (all staff)/p34-they should have done it early, there'd have been no emergency ./p36-We made a choice to go public…they'd listen to you if you were private/p37-constant pain…on & on and they

		weren't listening to me about it./p39-I couldn't eat…couldn't drink…the pain was phenomenal…severe. I kept reporting it, reporting it and everyone was kinda 'Oh you know it's fine, it's nothing' You know it was kind of dismissing it again./p47-the pain was the worst thing ever and it really felt they weren't listening or there was nothing being done./p57-trays of food coming in…out….in….out…like 'Hello!?'/p65-I wasn't making it up, I wasn't lying./
Feeling trapped in isolating & distressing environments	7,43,59,60	P7-couldn't understand why they were putting me into the induction ward…hearing all the pain, moaning and screaming/p43-They put me into isolation….isolated in a room not the size of that alcove…& I was on my own for a really long time./p59-I think it was psychologically I needed to get out of there…if I eat they'll let me go/p60-if I don't go home I'll end up in a psychiatric ward….cos they put me into isolation…wasn't allowed to leave the room…room was tiny…like a prison cell…just needed to get out of there.

Powerlessness	2,7,11,12,14,17,18,19,	P2-It was kind of like 'pull your pants down and let me see'/p7-ward with just a curtain so you could hear everything/p11& 12-It was really hurting(speculum)…waiting for midwife to come back with the swab….(p12)I'm there for all the world to see…uncomfortable….and you have a metal speculum like inserted/p.14-I really felt like a piece of meat/p17-I was told to like there…I felt like a cow/p18-I was annoyed…soaking…it was just so humiliating…so I'm crying…I was mortified, like people passing you know, How embarrassing is this?/p19-Audience of strangers
Breach of the body's boundaries, exposed, humiliated and ignored		
Intimidating & inappropriate communication and regret & internalisation of blame for not having asserted self	15,28,50,51,54, 62,63,64,68	p.15-(powerless language) So that's what I was told…then…they decided that they were going to induce me…then I was told I will be going down…induced/p.28-You're disempowered in a situation like that/p50-then she'd come back & she'd say….'you have to…you just have to. Just go down & do it….She'd go 'I'll tell you …. & bang her guts came open…If you want to be the yummy mummy with the weeping wound, you go home!' Those were her words Friday night./p62-God knows what she's gonna say…I know she's gonna try & convince me & I'm afraid …'pretend
Powerlessness		

		you're asleep'./p63-d'you know what frustrates me?/P64-It was the only way I could feel I could stop them./p64-& she goes like 'very emotional, very hormonal'/p68-The woman who was killed was pregnant…this fellow jumped into a car to commit suicide and drove into their car/p35-I'm disappointed in myself, I knew the questions to ask…I should have known better to ask myself… looking back I say 'why wasn't I more assertive or stand up for myself? '/p36-even retrospectively I say 'why didn't I or why wasn't I more assertive or stand up for myself?'
<u>Information problems</u> Manipulation of notes data by staff Information boundaries	 12,38 51,59,66	p-12-notes'Donna' was upset by exam'/38-I was looking at my notes and there's very little reference to it, nothing about the pain P51-She told me the area the lady was from and everything like/P59-pancreatitis…I didn't know what it was…when I came out of the hospital…looked it up (online)…to this day I still don't read about it.P66-Like they were looking for cancer tumours (in notes) and they didn't say it.

Conflicting information	42,49,50,54	P42-One person would say fast, the next would tell me to eat, it was getting conflicting/p49-Arguing in what should happen to me…stay or go/p50-we were confused /p54-I was like: 'they told me…'
Other relationships Attachment	76,77,78	p76-I would be very overprotective. Very. might keep people from holding him/p77-didn't want them to hold him, even my mum…it was all me…I was very clingy to point where I couldn't rest…til they'd give him back…I didn't like people even calling…if they'd call 'he's asleep, don't pick him up'/P78-I suppose if anything, I'd be guilty of loving him too much.
With partner-trying to protect each other	28,29,72	p28-I didn't tell him too much 'cos I didn't want to freak him out/p28-he was so stressed…husbands get forgotten about…it affected him…he was trying to be strong for me/p29-worried about me and worried about the baby/p72-He was a rock…he's cross…exhausted from the process and frustrated, really frustrated.
Process related	1,2,11,3,15,29,59	P1-Pacing at start of interview fast, sense of uncontained panic, rapid breathing, sense that Donna was not present but back in time/p2& 11-

		voice breaking with emotion/ p3-begininning to weep 'I've never cried like this'/ p15-Donna begins to weep again/p29-and this has just come into my head now/p59-to this day I still don't read about it

Appendix 13

Table of superordinate themes and themes from 'Maeve' interview 6
Women's experiences of communication with medical staff during complicated pregnancy
<u>Positive experience of communication</u>:
Midwife picks up pieces of' hit n run'
p.4-…later on 'I'm really sorry…'went into more explanation.
Midwife fills in info gaps& bridge trust
p.9-midwives very good…u would be able to find out info& ask them questions …& what the midwives would tell you would in fact be the case
Staff sister as advocate
p.12-'This is a disgrace: you need to come & see her'
p.32 &33-doc wouldn't be allowed to skim over it because she would repeat the question.
Containing, caring staff Sister-
p.28 It was really down to…there was a ward sister….she was really into patient care.
p29 It was patients first & that was it. She really looked after women, your well-being, she spoke to everyone….very approachable.
p30 ' I'm going to move you to a single room you're getting no peace at all'
p30-I Don't think you could complain about the midwives…and I think that it was really down to her.
Nb:Links to importance of therapeutic relationship in the first moments of therapy in terms of building trust and success of outcome:
<u>Development of distrust through inconsistencies, errors and omissions</u>

Experiences of inconsistency and incompetence
p.1&2: it took four of them to actually discover….It took from Wednesday to Saturday to find that out.
P7-'We're probably gonna send you home'…and I said 'the midwife says there's no way I'm going home'.
p.2 what was so shocking was…it was a registrar…she said 'it's *definitely not* premature rupture of membranes'…. and I knew at that stage that it probably was. I just knew.
p5-what's wrong here? Can I…I actually sort of felt: 'Can I trust them….to get it right?'
p.7-I had no faith in the registrar.
p.8-there was lots of things that just kept sort of adding up & just leading me to, you know, just be very sort of, u know, mistrusting of…what was going on …
p.9-The care of the team…was hit and miss really.
p17- it was impossible to talk to somebody …I could have some trust in or some faith…that there would have been a proper plan….day to day…'oh let's see what happens'…definite plan.
P 18- You know the story was changing…I'd been told 37 weeks,…and I started to get, you know, really mad about it…oh I was really angry
p23-I had picked out who are the good consultants & who r the rubbish ones…& really yeah it is rubbish   because they don't do anything…team are left to their own devices.
p24 -she wasn't up to par at all really, not by any stretch of the imagination
Errors

p-19- there were just inconsistencies along the way…just in general care: a doctor came in to take blood & I questioned him…He was in the wrong room!
p.20--another day, another doctor…arrives in 'I need to do a speculum' and I said 'no you don't cos if you do that you could bring me into labour' & this was a qualified doctor.
p21- So many things must happen on a day to day basis because people don't speak up….they're not even slight errors…very dramatic errors really
Unavailable staff
p46-We were told you'll have an I.V, and maybe a paediatric team when she's born, there was nobody there when she was born….further to that, I wasn't examined by a doctor at all before I left the hospital.
p49- She wasn't checked by a paediatrician….I couldn't believe any of it
P10- 3 weeks before I saw a consultant.
p.15-That was a major issue for me, that I wasn't seeing you know, anyone…they were supposed to be having meetings…how can you have   meetings with somebody (consultant) who isn't even there?
P.15- She (registrar) was in this new hospital making all these decisions because the consultant wasn't there
P.24- & I was worried about the level of care…because who was making the decisions?
p.64-I'd probably like to have a conversation with the consultant….just to let her know of my disgust…clearly taking on patients when in fact she was going to be on leave, & how, how could a team be left basically to their own devices…..
Isolation and escalation of distress through disconnection and empathic void

Insensitive and unempathic (verbal and non-verbal) communication
p.13- He was so completely rude…this man has a reputation for that….and he just looked at some books I had on the bedside table… 'I'm glad you're interested in that because you'll have lots of time to read them. You won't be going anywhere'. I don't know if I have a word to describe it because it was just kind of shocking.
p56- It's you know ' oh yeah you've had a baby. So what?. Get on with it…..oh women do this all the time'.
p.58-'People do this all the time...it's no big deal'
p37-she came up to talk about the prenatal classes..& um I didn't really feel like going….because they …were aimed at people who were having full-term babies & she started saying…what do u do…with ur day?…what do u recommend? She said 'well, there's mass'. That was a serious comment, & I'm an atheist…..It's actually such a backward comment…like this is sick !
Withholding and avoidant communication
p.14-they just talk n leave….there was no engaging in conversation
p.3-She said it at the bedside and left
p.4-I was obviously upset….i wasn't sure …if I was going to go into labour….that day---a few days….a week….this wasn't communicated to me.
p.6-'I'm Dr….We're gonna keep you here for another night ' and that was it & left.
p.18-She said 'I can't believe that consultant didn't even come down to deliver that news to you'
p.21-He just left
p34-they would rush into your room ….and rush back out….two minutes & gone

56-they kind of minimized information even about it…
p.57-we did realize the seriousness of it but we didn't really kind of <u>wallow (possible projection?)</u> in it too much
p.57- We didn't really get to talk about it….we weren't offered any opportunity to…
p.59-He'd come in, he'd run out, because that's I suppose how he managed his…patients…that's how he knew that people would never get to talk to him
p.64-they're either rushed or they're not coming to see you.
Mind body separation and the support void
p35- There was nothing offered….I've thought about this you know since I contacted you about your research….nothing
p.36-There's no …overly kind of friendly engaging with patients there at all
p37-not in that sort of level…never once…I wouldn't have thought anything about it but now when I look back over it….it's very poor…not any counselling offered…just even some sort of slight thing
p.39-I'm telling u nothing: there was nothing, Like I really….i went thru my notes and there was absolutely nothing apart from medical care. Like really & truly there was nothing.
p.54-one of the major things I would change….medical care it's not just care of the body… it's emotional care as well…..going home….new baby…you may not be….physically or emotionally well yourself….p.55-after some sort of traumatic event....to just be in there & just have no support offered & not even details of any
p.58-more…patient-friendly…more approachable
p.60-it certainly would have been easier…even if they would have say external people come in
p.78-there's no thought for you know 'who's the individual in this bed here', you

know
Suppression of affect, resignation to disempowerment for survival
Impact on mother & baby safety of power dynamics amongst staff
p.2- she (midwife)wasn't allowed to say that…it had to be a doctor who would confirm it
p.12-that midwife is just not afraid to face the consultants because some medical staff are
Resigning self to powerlessness to prioritise baby's survival (connection to dissociation)
p.16- it shouldn't have been the case but it…I had no choice, I asked…could I change to another consultant & there was no chance of doing that
p49-when I was in there I suppose I became resigned to, you know. Well things were kind of out of my hands here….the overriding thing was all I wanted was that I wouldn't go into labour too early….not to get too upset or annoyed…really not go against my own body
p.5o – I resigned myself….get the best possible care but …not getting…too annoyed…and I suppose it worked.
p.62-I didn't know what was happening….to me exactly…….you might even feel like a complete idiot with some of the questions you want to ask….you'd feel like the doctors are kind of…they're kind of high and mighty maybe
p.20-I told him not to do it. I refused to let him do it (negative case example due to protecting child safety)
Redressing the power imbalance post healthy birth

p.51 -I think it (anger) turned into relief when she was born. We came home the day after she was born & I just felt like I just had to get up & get out
p.51- I left the hospital after a kind of argument really because it took them so long to come & look at her
p.52- 'You weren't interested enough to look at my child after she was born…there was nobody present at her birth and quite frankly I don't trust your care any longer'
p.47-I kept saying 'Am I going to complain?'…I just thought, 'No I've had enough…..and if I have another child (which we do now) we're going private'.
Intrusiveness
p.71/72- the impact of um Galway hospital is a teaching hospital & the impact of having so many students, it had a kind of negative impact
p.72- It just really became…intrusive….right to the point on the day I was being induced & they were actually inserting the gel & there were students in the room
p.73- and I was kind of there going 'well the students are not staying, you know , to watch this'…I know it's medical but, you know…I just *thought*….(notice she did not speak) 'This really is too much'….
p74- It was very intrusive….way too much
p.75- There should be limits…boundaries need to be set
p76- everyday they would be in….It's a very vulnerable position ….to be in…
p.77- just to be lying there pregnant…..at that stage of the game it really was not what I needed
Public -Private
p.12-Dr……. I was just told kind of bluntly enough that he doesn't see public patients.

p21-22-We actually paid for private care on our…second baby. We wouldn't go public again. We want to know exactly who is going to be looking after us.
p.22- It just put us in a better position to demand things…public…you've no choice…afraid I would get stuck with the same 'non-consultant' as we started to refer to her as…it's kind of a lottery
p23-If u can afford it in any way go private,
p27-It's amazing, money talks
p.65-I'm really disgusted ….I'm sure she was probably able to see private patients
Other relationships
Peer support
p41-We just had so much in common…we had a pretty good time…when….we were forgetting about the seriousness of   everything.
p43-When you meet somebody in a certain situation you can develop a very strong friendship. We're still friends
p43-We kind of ignored it (trauma)
Attachment relationship-
p45-We look at her now & again & go 'Oh my God. I'm just so relieved. I think it was relief.
p.66-we were just so delighted she was ok
p67- just like 'is she alright'….'is she alright ?'….we didn't expect her….we didn't expect her not to be in special care….we didn't expect her….just to be so well....

p.68-against all the odds she was so strong…a normal pregnancy we might have been more, more protective….i think it might have affected us the other way….we just reckon oh, she's just really strong.
p.70-very strange to have left here….it was ten weeks later, I arrived back with the baby…it was really strange feeling…
p.71-It was really funny….but then we know that everything worked out fine with her. Yeah