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Experiences of couples in pregnancy after stillbirth:

an interpretative phenomenological analysis.

Thesis presented by

Margaret M. Murphy,

MSc, BSc, RM, RGN

https://orcid.org/0000-0001-9979-9462

For the degree of

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School of Nursing and Midwifery

Head of School: Professor Eileen Savage

Supervisors: Dr Patricia Leahy-Warren, Professor Eileen Savage

Table of Contents

Declaration

Catherine McAuley
School of Nursing and Midwifery
Brookfield Health Sciences Complex
University College Cork

Thesis Title: Experiences of couples in pregnancy after stillbirth: an interpretative phenomenological analysis

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Abstract

Background: Despite advances in maternity care, 2.6 million babies die at or before their birth each year across the globe. The majority of couples will proceed to a pregnancy after loss, often within a very short timeframe of their index loss. However, little is known about how couples, as a unit, negotiate the experience of pregnancy after loss.

Aim: To understand how couples, as a dyad, make sense of a pregnancy after stillbirth.

Method: The experiences of eight heterosexual couples, who were pregnant again in the immediate pregnancy after stillbirth, was explored using Interpretive Phenomenological Analysis (IPA). Data were collected by joint, semi-structured, face-to-face interviews with a convenience sample. Interviews were audiotaped, transcribed verbatim and analysed using IPA principles. To ensure both the individual and dyadic experiences were explored an additional layer of data analysis was performed.

Findings: Two superordinate themes emerged from the data '*Hoping for a born alive baby'* and '*Journey of Loss*. The first theme, '*Hoping for a born alive baby'* was the aim of all of the couples in a pregnancy after stillbirth. The processes of negotiated decision-making and lived experience of a subsequent pregnancy were explored. Couples made sense of their experiences of pregnancy after loss via the lens of the death of their babies. In the second theme, '*Journey of Loss'*, couples spoke about the unexpected death of their babies, their experiences at the time of loss and in its aftermath, and the impact that these events had on them as a couple.

Conclusion and Implications: Perinatal loss and pregnancy after loss are common occurrences in maternity services. The original findings of this study adds to the understanding of pregnancy after loss, from a couples' perspective and will assist in the provision of appropriate support services for couples both at the time of loss and in the pregnancy that follows. How couples negotiate the experiences of loss and subsequent pregnancy will help to inform policy and improve services for future couples pregnant after stillbirth.

Dedication

This thesis is dedicated to

my husband Tony

and

my children

Luke, Lily and Izzy

who have taught me so much about love, joy,

and happiness.

And to all of the children whose stories

are shared here in these pages.

Acknowledgements

Just as it takes a village to raise a child, no doctoral degree can be completed without the effort, patience and support of many individuals. I would like to take the opportunity to publically acknowledge and thank them here.

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Immense words of thanks must go to my family for all the turmoil you have endured over the past six years.

To my darling children Luke, Lily and Izzy, thank you for all your patience and understanding while I travelled this path, I love you all to infinity and beyond. I just hope that my efforts will not deter you from academia but will encourage you also to reach for your dreams, whatever they may be.

To my parents Mary and Tadhg, thank you for your unquestioning love and support. I am who I am because of you and I love you both. To my brother John, who with every passing year continues to amaze and impress me, you may be my small brother but you are my big hero, I love you. To my late Uncle John, whose illness and death accompanied me in the final years of my degree today is all the more poignant because you are not here to share it with me. To Uncle Jerry who was always my supporter

To Joan and the late Tom, my in-laws Brian, Frances, Colin, Helen, Aidan, Kay, Finbar, Stephen, and Maggie thank you all for your love and support and for not asking, "Are you not finished that thing yet?" To Treasa, Peter, Siobhan, Tracie, Ivan, Sinead, John, Alana, Daniel, and all the Murphys and Nolans thank you for all your love, support and encouragement. To Micéal, my everlasting gratitude. Grief endures but so too does love.

To my husband, and my best friend, Tony. Your enduring faith, love, and belief in me and in my ability to do the best for our family are why I am finally typing these words. You are the most remarkable father, husband and friend that anyone could ever hope for and I love you and am honoured to be loved by you in return.

Finally, to the women and men who agreed to share their experiences of loss, love, and joy with me selflessly. Thank you for trusting me with the stories of your daughters and sons, I hope that I have honoured their memories and accurately reflected your experiences herein.

"While we try to teach our children all about life,

Our children teach us what life is all about"

Angela Schwindt

Introduction

The death of a child is an unimaginable loss for any couple. For loss to occur around the time of birth is contrary to the most fundamental law of nature. There is an expectation that there will be a lifetime that separates the two events of birth and death (Jones 2001). The loss of stillbirth is unique and compounded by the fact that the baby has never lived outside of its mother's body. More than 2.6 million babies are stillborn every year, globally and the impact of these babies losses on their parents, families and wider society is vastly unacknowledged and underappreciated (Burden et al. 2016, Gravensteen et al. 2012, Heazell et al. 2016).

Studies show that women and men experience the emotions of loss, sorrow, and grief. The expressions of these emotions may have gender specific manifestations (Avelin et al. 2013, Cacciatore et al. 2008a). In some couples the apparent emotional dissonance and the expression of grief in the wake of stillbirth has been reported to cause relationship disharmony (Avelin et al. 2013, Gold et al. 2010b, O'Leary 2004). It has been suggested that couples experience disenfranchised grief if their loss is not openly acknowledged resulting in enduring trauma, distress and negative psychological legacy (Armstrong 2007, Armstrong et al. 2009, Hughes et al. 2006, Lamb 2002, Reed 2011, Turton et al. 2009a, Warland et al. 2011b, Warland et al. 2011a). However, other couples will negotiate this loss, grieve and emerge stronger and more cohesive because of their traumatic experiences (O'Leary and Warland 2012).

Many couples proceed to a subsequent pregnancy or pregnancy after loss (PAL) within a short time frame of their baby's death (Hughes et al. 1999b, Lee et al. 2013, Saflund et al. 2002). There is lack of consensus about the optimal timing of a subsequent pregnancy (Gold et al. 2010a). Pregnancies after loss are at increased risk of complications such as recurrent losses, and adverse maternal and perinatal outcomes, including preeclampsia, operative birth, preterm birth (Bhattacharya et al. 2010, Black et al. 2008). Previous studies have shown that pregnancy after loss poses the potential for psychological harm to mothers, partners and the subsequent children born after perinatal loss. These include increased rates of anxiety, depression and disorganised attachment to babies conceived after loss (Armstrong 2007, Armstrong et al. 2009, Hughes et al. 2006, Lamb 2002, Reed 2011, Turton et al. 2009a, Warland et al. 2011a, Warland et al. 2011b).

Couples are adjusting to a new pregnancy and attempting to bond with a new baby while still actively grieving the loss of their previous baby (O'Leary 2004). Couples have reported difficulties in attaching to their new baby as a protective means of coping, not wanting to bond to the new baby in case it too should die (Côté-Arsenault and Donato 2011). Yet another study suggested that some parents would actively engage with their new pregnancy seeing it in a new light and an opportunity to bond antenatally (O'Leary and Warland 2012). Women require additional supportive measures and attend maternity services more in pregnancies after loss (Hutti et al. 2011, Gold 2012, Mistry et al. 2013).

Nonetheless, couples do negotiate the challenges that confront them in a pregnancy after stillbirth. However, little is known about how a couple reaches the decision to attempt another pregnancy after loss. What has been reported is the overwhelming desire for some women to want to achieve another pregnancy and may have led to the description of a replacement child for the baby that has died, though recent research has refuted this idea (Reid 2007). Even less is known about fathers' views. The majority of women do progress to a pregnancy after loss within a relationship. This study aimed to explore how couples', as a unit, make sense of pregnancy following previous experience of stillbirth.

Chapter one provides an introduction and background to stillbirth including the debate on stillbirth definition; an introduction to global stillbirth rates; and causes of stillbirth. The importance and impact of stillbirth within the human context will be examined.

Chapter two examines the theoretical, conceptual, and empirical literature on the experiences of couples in pregnancy after stillbirth. Several theoretical concepts, which informed thinking during this thesis, will also be discussed.

In Chapter three, the methodological approach adopted for this study will be presented and discussed within the context of Interpretive Phenomenological Analysis.

Chapter four presents the findings of this study around the two superordinate themes that emerged '*Hoping for a born alive baby'* and '*Journey of loss'*.

Chapter five presents the discussion section including conclusion of the thesis and recommendations for further research, implications for clinical practice and policy development.

Chapter 1: Background

Definition of stillbirth

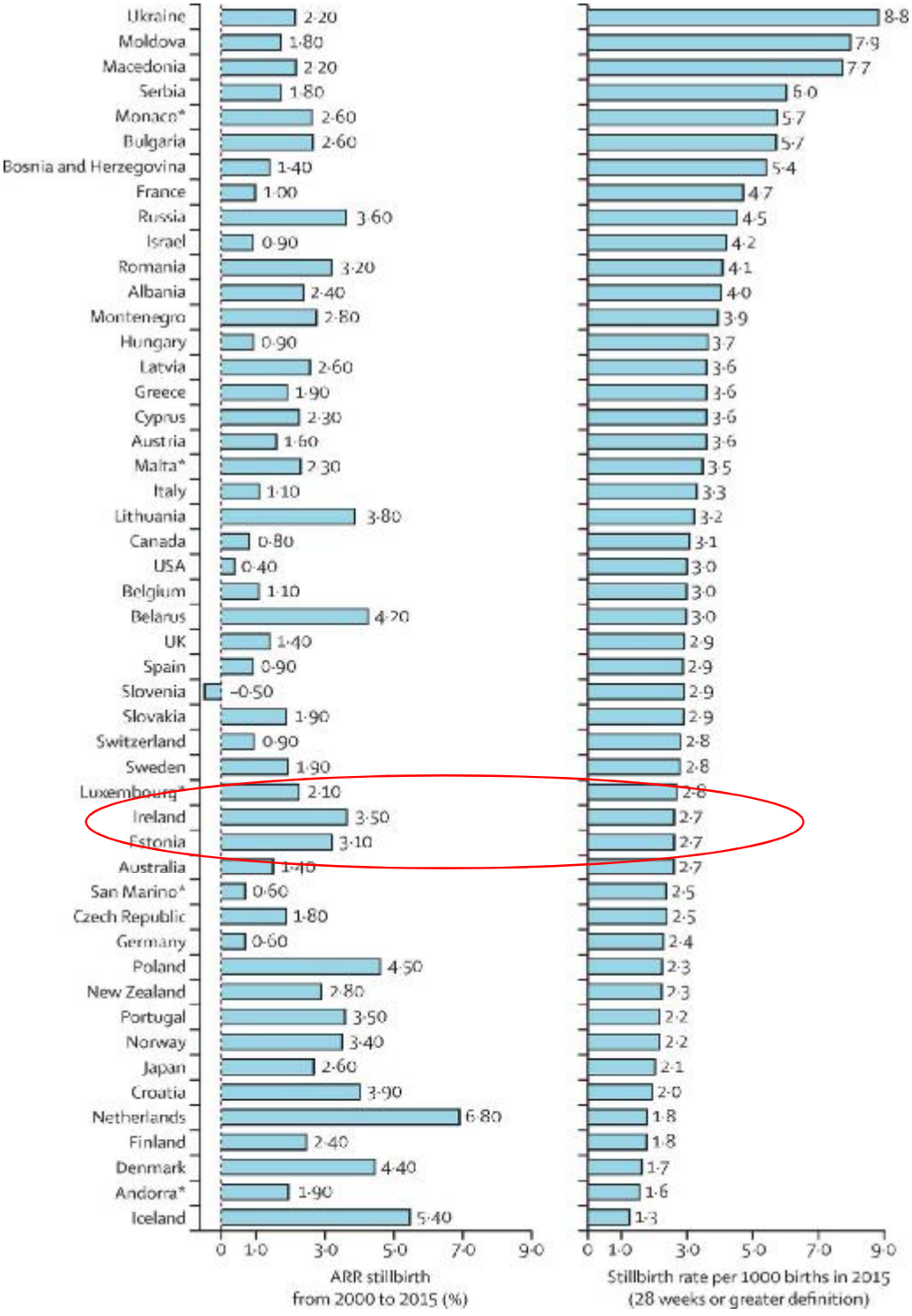
Stillbirth is defined as the death of a baby in utero born without ever showing signs of life (Government of Ireland 1995). There is no international agreed consensus on a definition for stillbirth gestation and limits range from 20 weeks in the USA to 28 weeks by the World Health Organisation (WHO). This lack of global agreement on the definition of stillbirth gestation remains challenging and international comparison rates tend to be problematic. However, many researchers use the WHO definition of an infant born without showing signs of life, greater than or equal to 1,000 grams or 28 completed weeks of gestation to facilitate comparisons (Blencowe et al. 2016, Cousens et al. 2011). In Ireland the definition of a stillbirth differs from that used by the WHO, in that infants born at 24 weeks of gestation or weighing greater than 500 grams are recognised as a stillbirth and can be registered as such (Government of Ireland 1995). For the purposes of this study, the Irish definition of stillbirth is used.

Rates of stillbirth

Notwithstanding advances in maternity care, babies still die before or at the time of their birth and the reasons can be varied and complex (Frøen et al. 2011). Global stillbirth rates vary widely, from more than 40 per 1,000 births in low-income countries such as Nigeria and Pakistan to 2 per 1,000 births in high-income countries such as Finland (Lawn et al. 2011). It is estimated that 98% of the 2.6 million annual global stillbirths occur in low resource countries (Frøen et al. 2011, Mullan and Horton 2011). It is further estimated that two thirds of stillbirths are clustered in

sub-Saharan Africa or South Asia (Cousens et al. 2011). Although the rates of stillbirth are dramatically lower in high resource countries, they remain an issue and stillbirth is of concern to parents, practitioners and policy makers alike (Frøen et al. 2011, Mullan and Horton 2011). The WHO, *Every Newborn: an action plan to end preventable deaths*, aims to end preventable stillbirth by 2030 (World Health Organization 2014). Internationally, Ireland's stillbirth rate (see Figure 1.1) compares favourably when forty eight countries were examined in a recent Lancet Series paper investigating stillbirth in high income countries (Flenady et al. 2016). It is noteworthy that this study used the WHO stillbirth definition of twenty-eight-weeks' gestation as its working definition for cross-country comparison purposes.

Figure 1.1 International Comparison of the rate of stillbirth (Flenday et al. 2016)



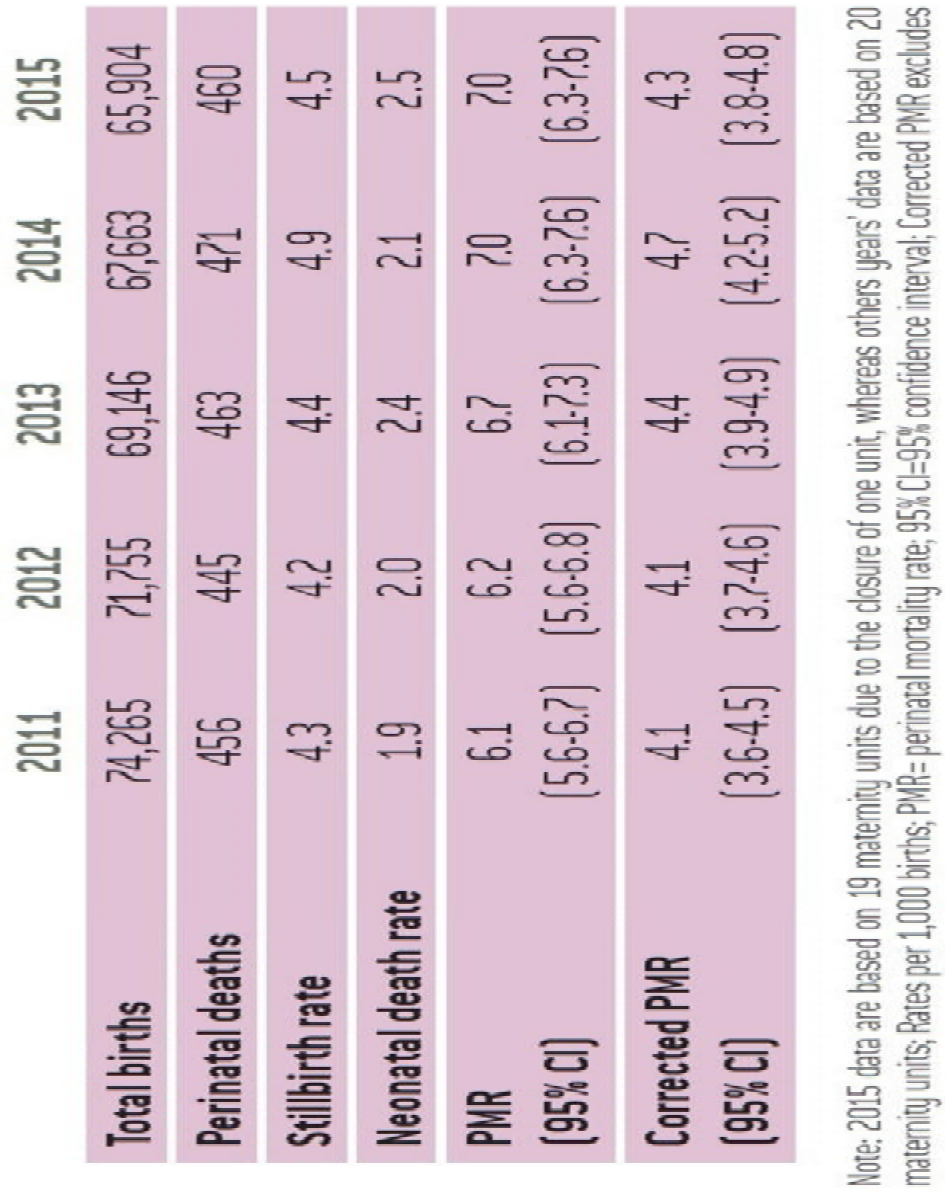
Source: Flenady et al (2016) *Stillbirths: recall to action in high-income countries* The Lancet Ending Preventable Stillbirth Series Volume 387, No. 10019, p691–702, 13 February 2016
Appendix I: Permission to Reprint: Granted 4th July 2017

Ireland has the second highest total fertility rate among the European Union 27 member states at 1.92 children per woman. The birth rate in Ireland plateaued and has even dropped marginally from its peak of 76,021 births in 2009 (Economic and Social Research Institute 2011). The most recent published statistics show that in 2015, there were 65,905 births in Ireland and there were 294 stillbirths registered during that year (a stillbirth rate of 4.5 per 1,000). That equates to an Irish Perinatal Mortality Rate of 7.0 per 1,000 births and when corrected for the exclusion of congenital malformations, of 4.3 per 1,000 births (O'Farrell et al. 2017).

Ireland reports a higher than the European Union average rate of infants born with congenital malformations because certain antenatal screening programmes and termination of pregnancy for fetal anomalies are not available within the State. Once the data are corrected for congenital malformations, Irish perinatal mortality rates are comparable to the European Union average, where Ireland ranked 8th out of 17 EU Countries (EuroPeristat 2013).

The rates of stillbirth in Ireland have remained fairly constant over the past five years (see Figure 1.2) and this may be reflective of greater understanding of the causes of stillbirth, improved antenatal surveillance of small for gestational age infants and an increase in uptake of perinatal post mortems at the time of loss (Manning 2013).

Figure 1.2 Comparisons of perinatal statistics, 2011-2015 (NPEC 2017)



	2011	2012	2013	2014	2015
Total births	74,265	71,755	69,146	67,663	65,904
Perinatal deaths	456	445	463	471	460
Stillbirth rate	4.3	4.2	4.4	4.9	4.5
Neonatal death rate	1.9	2.0	2.4	2.1	2.5
PMR	6.1	6.2	6.7	7.0	7.0
(95% CI)	(5.6-6.7)	(5.6-6.8)	(6.1-7.3)	(6.3-7.6)	(6.3-7.6)
Corrected PMR	4.1	4.1	4.4	4.7	4.3
(95% CI)	(3.6-4.5)	(3.7-4.6)	(3.9-4.9)	(4.2-5.2)	(3.8-4.8)

Note: 2015 data are based on 19 maternity units due to the closure of one unit, whereas others years' data are based on 20 maternity units; Rates per 1,000 births; PMR= perinatal mortality rate; 95% CI=95% confidence interval; Corrected PMR excludes deaths due to a congenital anomaly.

Source: O'Farrell IB, Manning E, Corcoran P, McKernan J, Meaney S, Drummond L, de Foubert P, Greene RA, on behalf of on behalf of the Perinatal Mortality Group. Perinatal Mortality in Ireland Annual Report 2015. Cork: National Perinatal Epidemiology Centre, 2017. Appendix I: Permission to Reprint: Granted 5th July 2017

Causes of stillbirth

Classification of the causes of stillbirth is contentious and there is little consensus or agreement in the use of one classification system over another (Flenady et al. 2009). In their review of perinatal classification systems, Flenady et al. (2009) described 33 separate classification systems, with an additional 12 variations of these systems. In perinatal statistics reports, as many as one quarter to one-half of stillbirths are classified as unexplained (Economic and Social Research Institute 2013, Lawn et al. 2011). This may have implications for pregnancy after loss.

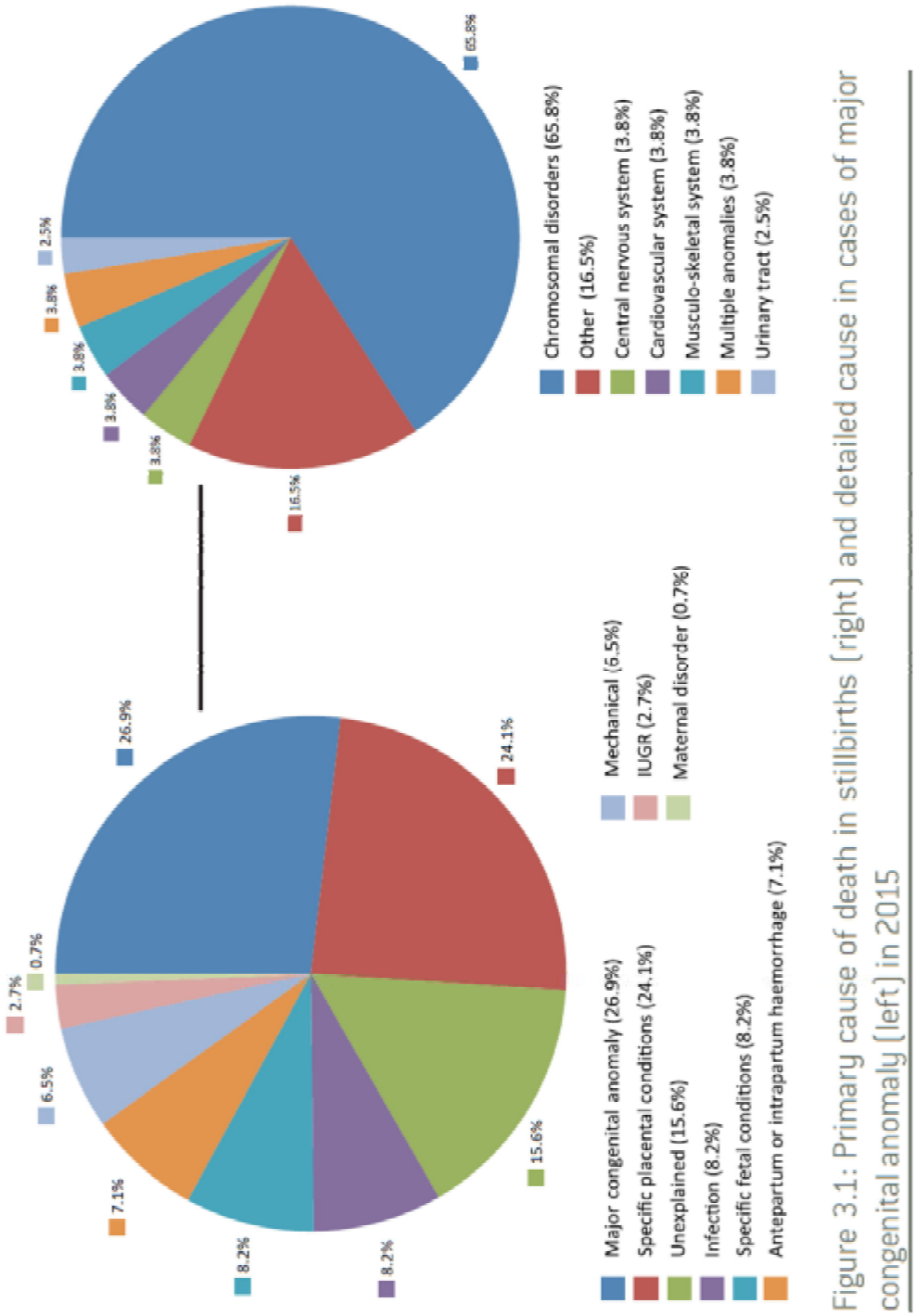
It is acknowledged that the majority of stillbirths globally occur in low and middle-income countries and are multifactoral in origin. These include lack of access to trained birth attendants, absent antenatal care, poor sanitary and housing conditions, and lack of availability of safe contraception (Lawn et al. 2009). In high-income countries, due to the variety of classification systems employed, the causes of stillbirth are challenging to compare across regions. However, causes can be broadly categorised as due to placental pathologies; congenital anomalies; infection and preterm birth (Flenady et al. 2016).

The causes of stillbirths in Ireland have remained constant over the past decade. Major congenital anomaly and placental insufficiencies account for approximately 25% of stillbirths each (see Figure 1.3). The remaining 50% of stillbirths are attributed to causes such as infection (8.2%), specific fetal conditions (8.2%), antepartum or intrapartum haemorrhage (7.1%), mechanical (6.5%), Intrauterine Growth Restriction (2.7%) and Maternal Disorders (0.7%). Over the past ten years, there has been improved availability and access to specialist in fetal medicine, perinatal

pathologists and an increased uptake of perinatal post-mortem (Breeze et al. 2011, Meaney et al. 2015). Therefore, as a result, the rate of unexplained stillbirths in Ireland is comparatively low at 15.6%.

In the latest 2015 Irish Perinatal Statistics Report, 270 women experienced antepartum stillbirths, which is the death of a baby before labour begins. The rate of intrapartum stillbirth, defined as a non-anomalous baby who enters labour alive but dies before birth, is low in Ireland. There were only eighteen intrapartum stillbirths recorded in the last perinatal report (O'Farrell et al. 2017). Of those eighteen babies, eight had life limiting anomalies and infection accounted for a further five of these deaths. It is suggested that the rate of intrapartum stillbirth is indicative of quality maternity care (Darmstadt et al. 2009, Flenady et al. 2016, Lawn et al. 2011).

Figure 1.3 Primary Cause of Death in Stillbirths in Ireland 2015 (NPEC 2017)



Source: O'Farrell IB, Manning E, Corcoran P, McKernan J, Meaney S, Drummond L, de Foubert P, Greene RA, on behalf of on behalf of the Perinatal Mortality Group. Perinatal Mortality in Ireland Annual Report 2015. Cork: National Perinatal Epidemiology Centre, 2017.
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Although the death of a baby may be expected, for example, due to a diagnosed fatal fetal anomaly or unexpected, as may be the case with infection or certain placental pathologies, the death of any baby whether before or during birth is a tragedy for its family.

With advances in diagnostics and fetal medicine, couples are discovering at early time points in pregnancy that their baby may have a fetal anomaly that is life limiting. This discovery may result in couples deciding to continue the pregnancy, although the expected outcome may be poor. Antenatal diagnosis can allow couples the opportunity to begin to prepare for the forthcoming death and the grieving process (Côté-Arsenault and Denney-Koelsch 2011, Côté-Arsenault and Denney-Koelsch 2016, Denney-Koelsch et al. 2015, Lalor et al. 2009, O'Connell et al. 2014). There are also instances where stillbirth is entirely unexpected, for example, couples may present to the maternity services with decreased fetal movements or may experience an intrapartum stillbirth. Unlike instances where fetal anomaly has been diagnosed and couples have time for preparation for their baby's death, couples who experience an unexpected stillbirth have little time between discovery of their baby's death and the birth of their baby (Erlandsson et al. 2011a, Hunt et al. 2009, Malm et al. 2011).

Importance of stillbirth

Despite advances in maternal and child health, stillbirth remains a worldwide public health challenge. Low stillbirth rates are indicative of quality maternal and perinatal maternity services (Flenady et al. 2011, Partnership for Maternal and Newborn Child

Health 2011, Goldenberg et al. 2011). However, stillbirth has failed to achieve the global health agenda status that for instance, neonatal and child health has, despite its common occurrence and rates commensurate with infant mortality in many countries (Cousens et al. 2011, Frøen et al. 2011, Goldenberg et al. 2011). Disappointingly, stillbirth was not explicitly highlighted in the WHO Millennium Development Goals (Frøen et al. 2011, Partnership for Maternal and Newborn Child Health 2011, Requejo et al. 2015). However, the WHO has somewhat addressed this oversight in its 2014 document *Every Newborn: An action plan to end preventable deaths,* which has included stillbirth reduction as a global target (World Health Organization 2014). Goal Two of this document hopes "by 2035, all countries will reach the target of 10 or less stillbirths per 1 000 total births and continue to close equity gaps" (World Health Organisation 2014 p.7). High-income countries have been charged with the eradication of all preventable stillbirths, which may be challenging to achieve given the paltry sums available to public health services to do so (Lawn et al. 2014). It is recognised that the loss and impact of stillbirth has been under appreciated and under financed for far too long (Blencowe et al. 2016, Cousens et al. 2011, Frøen et al. 2011, Frøen et al. 2009, Goldenberg et al. 2011). Indeed, it is only in recent years, that stillbirth has been the subject of increasing attention (Qureshi et al. 2015).

Stillbirth has been described as an invisible death, as it often goes unrecognised and its impact under appreciated by wider society (Cacciatore 2009, Cacciatore 2013). Cacciatore and Bushfield (2008) have suggested that this is because of the socio-cultural association between stillbirth and therapeutic termination of pregnancy. The

death of an infant has greater societal recognition as the child has lived outside its mother's body (Cacciatore 2013).

Stillbirth can call into question a woman's moral identity as a mother. For instance in Murphy's (2012) qualitative study, women disclosed feeling that their baby's death had damaged society's view of them as good mothers. This was especially evident in women whose baby died unexpectedly and without reason. Stillbirth can subject women to social stigma. Men too have reported feelings of lack of identity. In McCreight's (2004) study, men highlighted a sense of discord in their perceptions of self-identity following stillbirth. Participants reported feelings of dissonance and were unsure of their paternal role without the presence of a living child to parent. In spite of this, they still referred to themselves as fathers even in the absence of a living child. This was also true when the men were discussing the issue of how many children they had. However, there was an unwillingness of family and friends to talk about the deceased baby (McCreight 2004). Weaver-Hightower (2012 p.473), in an auto-ethnographic study of becoming a father to a stillborn child, also discussed the stigma of stillbirth. He suggests parents become the living embodiment of what society fears, "the living representation of the worst case scenario". These responses may reflect a wider societal lack of recognition and social identity of paternity for parents of deceased babies (Murphy and Thomas 2013).

What can help couples in making sense of the death of their baby is the importance of social ritual, including stillbirth recognition. In Ireland this situation has improved somewhat. Since 1995, there is State recognition of stillborn babies through the Stillbirth Registration Act (Government of Ireland 1995). Parents of deceased babies

are eligible to receive a certificate of stillbirth registration if their baby is born greater than 24 weeks' gestation or weighing more than 500 grams. The certificate of stillbirth provides couples with official recognition of their baby and allows for access to State entitlements such as maternity leave. Funeral rituals are another major form of social ritual for death.

Despite increasing global secularisation, the 2016 Census reports that Ireland remains predominantly a Roman Catholic country (Government of Ireland 2017). Therefore, the teachings of the Roman Catholic Church dictate the majority of funeral rites. According to these beliefs as stillborn babies are not born alive, they cannot be baptised and without baptism cannot obtain eternal life. Historically, the teachings of the Roman Catholic Church were that stillborn babies instead reside in limbo. It was not until 2007 that the Roman Catholic Church addressed the issue of eternal salvation for stillborn infants. Although the idea of stillborn babies residing in limbo has not entirely been discounted, the Vatican has relaxed its view on the subject and suggest that eternal salvation may be possible for these infants (International Theological Commission 2007). In Ireland, stillborn babies can be buried in consecrated Christian graveyards. That was not always the case, and religious teaching influenced historical care practices for bereaved parents. Although most hospital chaplains will offer parents a naming ceremony and prayer services, should they wish, and many Roman Catholic priests will officiate at such services (Nuzum et al. 2016).

Ireland, as a society, is not unique in facing challenges with funeral ritual practices. Stillborn babies often cannot officially be in receipt of full funeral service rites. Many

of the world's major religions Hinduism, Judaism, Buddhism, Christianity and Islam have very specific teachings on death before life and these can influence care practices afforded to couples (Schott and Henley 1996).

Historically, the impact of babies' deaths was not fully understood. Women were not encouraged to see or hold their babies. Indeed, it was not until Bourne and Lewis (1984) discussed the importance of caring for couples at the time of loss that the concept of compassionate care at the time of stillbirth began to be addressed. It was believed that the birth of a subsequent baby would ameliorate the loss and grief women felt (Reid 2007). The development of bereavement care guidelines have been introduced across various countries and influenced care practices (Schott et al. 2007, Hunter et al. 2016). However, there remain instances of poor care practices for women and their families at the time of pregnancy loss and Ireland is no exception in this regard (Health Service Executive 2011, Health Information and Quality Authority 2015).

The maternity services in Ireland have in recent years, faced ever-increasing public scrutiny. The Health Information and Quality Authority (HIQA), an independent authority charged with ensuring the delivery of high quality and safe care was established in 2007. The Authority's establishment came about as a recommendation from The Lourdes Hospital Inquiry, a public inquiry into peripartum hysterectomy practices at Our Lady of Lourdes Hospital, Drogheda, Co. Louth (Government of Ireland 2006).

Since its inception, HIQA has produced various reports into care practices within the Irish maternity services. The most recent occurred following a 2014 investigative

television programme concerning the deaths of several babies around the time of their births at the Midland Regional Hospital, Portlaoise, Co. Laois. HIQA conducted an independent review of the safety, quality and standards of services provided by the Health Service Executive (Health Information and Quality Authority 2015). As a result of the findings of this review, the Department of Health and the Health Service Executive commissioned and launched National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death in 2016 (Health Service Executive 2016). These guidelines were developed by a multidisciplinary group and are currently undergoing national implementation. The standards focus specifically on bereavement care, the hospital environment, the baby and parents, and the staff health and wellbeing.

Coinciding with the Health Information and Quality Authority (HIQA) review into practices at the Midland Regional Hospital, Portlaoise (Health Information and Quality Authority 2015) was the development and launch of the first ever, National Maternity Strategy for the Irish Health Services (Department of Health 2016). This National Maternity Strategy has been adopted as government policy, forms the blueprint for the future development of the Irish maternity services. Implementation of the National Bereavement Standards is a key recommendation of the National Maternity Strategy. The publication of an Irish National Maternity Strategy and bereavement standards are timely. A global multi-language research study that I was invited to co-author discovered that care practices worldwide, following perinatal loss still remain sub-optimal (Wojcieszek et al. 2016). Although Ireland fared well in this web survey of 2,716 parents, from forty high and middle-income countries,

several key areas require improvement. There also exists a policy gap, as pregnancy after loss is not specifically addressed in either of the Irish documents thus far.

Human context of stillbirth

How couples are cared for at the time of their loss can have a profound and lasting impact. The shock on hearing the news of their baby's death; having to proceed with the birth process; the fear and excitement at meeting the deceased baby; the silence of birth; and the care practices of staff, all leave lasting impressions on couples (Campbell-Jackson et al. 2014).

Knowing that their baby is already deceased or may have a life limiting condition and likely to die in labour or soon after birth, labour and birth have been reported to be physically and emotionally very difficult for women and men (Radestad et al. 1998, Erlandsson et al. 2011a). Despite receiving analgesia, women reported labour in cases of stillbirth to be more physically and unbearably difficult than women with live births (Radestad et al. 1998, Erlandsson et al. 2011a). Trulsson and Radestad (2004) found that health professionals might also induce unnecessary psychological trauma or weaken a woman's ability to cope with perinatal death by insensitive care practices and lack of respect. Redshaw et al. (2014), in their UK survey of 473 women who had experienced a stillbirth, found that overall, women were positive about the care they received during pregnancy, birth and the postnatal period. Two-thirds (63%) of women reported that they were satisfied or very satisfied with the care they received. However, that means that a third of women were less satisfied with the care they received.

Downe et al. (2013) carried out a UK-based, interpretative phenomenological analysis study of 25 parents: 19 mothers and 6 fathers. The study sought to explore how couples were cared for at the time of their baby's stillbirth. The researchers found that healthcare professionals had a profound impact upon couples' experiences by the provision, or not, of empathic care during this time. Participants stressed the importance of respectful bereavement care, as a one-time-only opportunity for health care professionals have to get this care right.

Death is an unexpected, unnatural event for couples, even if their baby was diagnosed with a life-limiting anomaly. Some studies suggest instances where couples suspected that something was amiss with their baby. In an international internet survey of the experiences of 1,714 mothers with a late stillbirth, Warland et al. (2015) found that a majority of respondents (63%) reported perception of changes in fetal movements or described a "gut instinct" that something was amiss with their pregnancy. However, not every maternal perception of fetal movement changes are similar. In this study, in the days before their babies' deaths, 30.5% of women reported significantly less fetal movement and 8.5% of women reported significantly more movement. The women who commented on an increase in fetal movements did not perceive this as alarming, nor did they seek professional help. These women also reported experiences of decreased fetal movements. This may signify that the change in the fetal movement pattern is important, whether there is an increase or decrease.

Similarly, in the study by Redshaw et al. (2014) about two thirds of women also reported feeling that something was wrong before their baby died and 56 % of

women felt that their baby died during the night. In both surveys, women struggled to have their concerns heard and acknowledged, by healthcare professionals. These findings are concerning given that provision of good quality, empathic care at the time of stillbirth and after loss have been shown to help parents cope and ameliorate the potential for negative outcomes for couples (Downe et al. 2013). Facilitation of the grief process by providing empathic care may empower mothers (Lundqvist et al. 2002). Some mothers have reported that meeting, seeing, and holding their dead baby is important to them (Radestad et al. 1998, Cacciatore et al. 2008b, Saflund et al. 2004). Good quality photographs of the dead baby are very important to couples grief processes (Radestad et al. 1998, Alexander 2001). Principles of good practice include family centred care; dignity and respect; honest and open communication; trained, educated and empathic staff; individualised care to facilitate informed choice; continuity of care; and the importance of creating memories (Schott and Henley 2009, Health Service Executive 2016, Hunter et al. 2016).

In the aftermath of stillbirth, couples begin to search for reasons why their baby died. While there have been advances and improvements in rates of perinatal pathology and parental consent for such procedures, in many cases causes for a baby's death remain undetermined (Horey et al. 2014, Manning 2014, Meaney et al. 2015). Regardless of the cause of the stillbirth, women can have feelings of guilt and self-blame for the demise of their baby (Barr 2004, Cacciatore 2013). These feelings can have a profound impact upon relationships and can be associated with greater negative mental health outcomes (Barr 2004, Cacciatore 2013). Men too have reported feelings of guilt and self-blame. In McCreight's (2004) study, men recounted feelings of guilt at not listening to their partners concerns about premonitions or

unease when they believed something was amiss. Another theme was guilt at not doing more to ensure their partners concerns were heard and understood by healthcare professionals.

Stillbirth places an immense burden upon couples, their families and indeed wider society. It is a well-recognised as a risk factor for psycho-social trauma, complicated bereavement, and disenfranchised grief (Badenhorst and Hughes 2007, Burden et al. 2016, Cacciatore 2010, Campbell-Jackson and Horsch 2014, Erlandsson et al. 2011b, Gold et al. 2010b, Halland et al. 2016, Harper et al. 2011, Leon 1990, Leoni et al. 1998, Nordlund 2012, Radestad et al. 1996, Schaap et al. 1997, Surkan et al. 2008, Turton et al. 2006). Men may experience sorrow, which may go unrecognised as society is more attuned to female grieving styles (McCreight 2004).

The impact of stillbirth on couples includes reports of increased marital disharmony and breakdown (Gold et al. 2010b). Even increased parental mortality has been reported in the aftermath of stillbirth. A UK study of more than 3,000 bereaved parents, found that individuals who have experienced stillbirth are at two to four times greater risk of mortality in the years following their child's death than those of non-bereaved parents (Harper et al. 2011).

Couple's faith in the normality of pregnancy is effected because the unthinkable has already happened and their baby has died. Weaver-Hightower (2012) refers to this as the rupture and seam nature of death. Death ruptures one's life, but it is sutured together by the mundanities of life. However, things never return to 'normal' as the grief and trauma of their baby's death are enduring and last a lifetime. Parents can never simply get over the death of their child. The experience changes them at a

fundamental level and every aspect of existence is forever altered (Rubin 1993). Eighty-seven participants in an ethnographic study of an online perinatal bereavement support group articulate the concept thus, 'the death of a child is a life changing experience' (Capitulo 2004 p.307). Yet despite this loss, many couples do embark upon a subsequent pregnancy after loss.

It is these couples and their experiences that are the focus of this study. The research exploring couples' experiences of stillbirth and their experiences of pregnancy after loss will be critically discussed.

Chapter 2: Literature Review

Introduction

This chapter presents the literature reviewed on pregnancy after stillbirth. The empirical literature of pregnancy after loss (PAL) will be presented first followed by an exploration of the theoretical literature and conceptual perspectives pertaining to pregnancy after stillbirth. These concepts were identified during the planning, data collection and analysis of this thesis and may be useful in providing a perspective through which to examine the phenomenon. While theory may not frame a qualitative study as it does in positivist approaches, it is useful to sensitising the researcher to the data under analysis (Wu and Volker 2009, Kelly 2010). The theoretical literature was read to sensitise me to the issues of concern for couples experiencing pregnancy after loss.

Empirical Literature

Aim

The aim of the literature review was to examine the experiences of couples undertaking a pregnancy after stillbirth.

Search Strategy

Prior to ethical submission and data collection, a comprehensive search of the literature was conducted in February 2015. This search was re-run during October 2017 to update the literature review and identify any pertinent studies published in the intervening time. Six electronic databases were searched to elicit available

published research on pregnancy after loss: Academic Search Complete; CINAHL with Full Text; MEDLINE; Psych Info; PubMed; and Soc INDEX. Search terms included couple*OR parent* OR wom*n OR mother* OR female OR m*n OR father*OR male AND stillbirth OR still birth OR pregnancy loss OR perinatal loss OR intrauterine death OR intrapartum death OR f*tal death OR miscarriage AND subsequent pregnancy OR next pregnancy OR pregnancy after loss. Inclusion criteria were that the focus of the paper was pregnancy after stillbirth, which included studies where the initial loss was greater than twenty weeks' gestation. Studies were excluded if the focus was solely on early pregnancy loss.

Limits were applied to elicit citations that were peer reviewed; written in English; and original research, theses and systematic reviews (including meta-analysis; metasynthesis and integrative reviews) were included. This search resulted in 1,671 citations from 1951 to 2017. These citations and abstracts were reviewed for relevance to the aim of the study. As a result, 1,423 citations did not meet the specific aim of the study and were discarded. In depth reading of the remaining 248 abstracts took place. Searches were carried out on the reference lists of these citations which yielded a further 20 papers. All search outputs were once again read in-depth, for relevance to the aim of the study. This resulted in 117 studies that met the inclusion criteria and were incorporated in this review. Studies on the experiences of women, men and couples were included.

Pregnancy after loss

Studies estimate that 50-80% of couples will proceed to pregnancy after loss and many couples proceed to a subsequent pregnancy within a short timeframe of their index loss, often within 12 months (Cordle and Prettyman 1994, Cuisinier et al. 1996, Hughes et al. 1999b, Hughes et al. 1999a, Robertson and Kavanaugh 1998, Wojcieszek et al. 2016). Couples have reported a strong desire to get pregnant again after stillbirth (Cordle and Prettyman 1994, Cuisinier et al. 1996, Swanson 1999). In the review of the literature on pregnancy after loss, the majority of studies were quantitative examinations of mental health or psychological sequelae in pregnancy after loss including anxiety, depression, grief, couples' relationship or attachment issues to the baby born after loss. The literature pertaining to pregnancy after loss (PAL) has been reviewed and will now be presented under the following themes: deciding to try again, parenting both babies during PAL, competing emotions in PAL, coping with PAL and couples' relationship in PAL. Finally, a summary of the literature review will make the case for the current study.

Deciding to try again

There is little agreed professional consensus on the ideal inter-pregnancy interval (IPI) to achieve optimal pregnancy outcomes. There is lack of agreement on the ideal IPI after stillbirth to optimise outcomes for couples (Bigelow and Bryant 2015, Davis et al. 1989, Gold et al. 2010b, Moore et al. 2011, Saflund et al. 2002, Wallerstedt et al. 2003, Wong et al. 2015). Findings on the impact of short or long IPI on couples, is uncertain. In their meta-analysis of 67 cohort, cross-sectional, and case-control

studies, Conde-Agudelo et al. (2006) reported that a short IPI (less than 18 months) or a long IPI (greater than 59 months) resulted in increased adverse perinatal outcomes (low birth weight, small for gestational age and perinatal death). They recommend spacing pregnancies appropriately to achieve optimal perinatal outcomes. However, this review was limited to fetal outcomes and parental outcomes were not considered.

Studies have examined the negative psychological impact of IPI on couples, including depression, Post Traumatic Stress Disorder (PTSD) and anxiety. Hughes et al. (1999a) in their longitudinal, cohort study of 60 bereaved and 60 control women found that there were increased levels of negative psychological sequelae (depression and anxiety) in women with a short IPI of less than one year. Rates of depression and anxiety were commensurate with the control group in women with an IPI of greater than one year. Within the study, 52% of women had conceived within 12 months of their index loss. However, the same research team acknowledge, in a follow up study with 103 of the women, that the pregnancy loss group were more socially disadvantaged than the control group. These factors may have contributed to the findings of negative sequelae in the original research study by Hughes et al. (1999a).

Armstrong et al. (2009) in their quantitative, cohort study of 36 couples found that negative psychological sequelae were lessened after the birth of a live baby. Couples were surveyed individually at three time points: T1 in the third trimester of the PAL; T2 at three months postpartum; and T3 at six months postpartum. Outcome measures included posttraumatic stress (The Impact of Event Scale), depressive symptoms (Center for Epidemiologic Studies-Depression Scale), anxiety (Spielberger

State-Trait Anxiety Inventory), and parental concerns and attitudes (Maternal/Paternal Attitudes Questionnaire). Women's levels of depression and anxiety were found to be higher at each time point although they decreased somewhat after the live birth of the subsequent baby. Levels of PTSD remained equal and constant for all participants. Other studies too have suggested that a live baby can assist with healing from grief and be therapeutic (Cuisinier et al. 1996, Wallerstedt et al. 2003).

Davis (1986) devised and delivered a Perinatal Loss Interview (PLI) to 24 women with a history of stillbirth who achieved a subsequent pregnancy and were parenting a subsequent baby. The PLI was a self-report, open-ended interview that explored the effect of perinatal loss by examining women's experiences of loss, of grief, and of subsequent pregnancy and parenting. The length of time from the index loss to the interview ranged from one to ten years. Among the 24 women, 14 were advised to wait longer than six months before attempting another pregnancy. Of the remaining ten, five were advised to achieve a pregnancy immediately and a further five were given no specific advice at all. In this cohort, 17 of the 24 women waited less than six months before attempting to get pregnant. Women, who were advised to wait, reported dissatisfaction with this advice believing it to be a woman's personal decision (Davis et al. 1989). Although the sample size in Davis's (1989) study was small, it provides valuable insight into women's' thinking about the timing of subsequent pregnancy. The study did not examine the role that the women's partners had in their decision-making processes.

In 1997, Saflund et al. (2002) conducted a postal survey of 594 Swedish obstetricians. An open-end question about what advice they would give to women about pregnancy after loss was included in their 48-item questionnaire. The response rate for this question was 93% (n=522). Data were analysed using content analysis of the 802 individual responses provided. Researchers discovered the majority of respondents were mindful of the additional supportive needs in a pregnancy after loss. However, among this cohort, only a minority (21%) of doctors gave specific time advice about the next pregnancy. They were not explicit about what evidence informed this advice. There were gender differences noted in this study. Female doctors were more likely than their male counterparts to suggest that women recover emotionally, before attempting a subsequent pregnancy. However, the researchers acknowledge that this response may have been influenced by the cohort's gender composition, years of practice and experience in caring for women with perinatal loss. Similar to the women in Davis et al.'s (1989) study, doctors in this study believed the timing of pregnancy after loss should be individualised and a woman's personal choice and not dictated by healthcare professionals.

Gold et al. (2010b) conducted a postal survey of 804 US obstetricians' attitudes on IPI. A random sample of 1,500 US obstetricians were mailed the 51-item questionnaire. Of this, 804 returned the questionnaire giving a 54% response rate. The researchers found the majority of doctors (37%) would advise couples to achieve another pregnancy when they felt emotionally ready to do so or as soon as one normal post-loss menses had occurred. Unlike Saflund et al. (2002), there were no gender differences apparent in the responses.

Short IPI has been associated with obstetric, fetal, and maternal morbidity (Black et al. 2008, Bhattacharya et al. 2010). In a literature review, Bigelow and Bryant (2015) analysed the available evidence on IPI following a variety of pregnancy losses. Based upon the limited studies included in this review, the researchers suggested that IPI following stillbirth should be 15 to 24 months. However, this recommendation is based on a limited review of three papers reporting on only two study cohorts, one in the US and one in Bangladesh. It was unclear from the paper how the review was conducted and the inclusion and exclusion criteria applied to them.

On the other hand, a comprehensive systematic review and meta-analysis by Kangatharan et al. (2017) which examined 16 studies, including more than one million women, would suggest that rates of adverse outcomes are not increased for women who have an IPI of less than six months following a previous miscarriage. This review looked only at outcomes following miscarriage, which it defined as a loss less than 20 weeks gestation, and gives clarity to this cohort of women and their partners. It does not make specific recommendations regarding advice to women following later pregnancy losses. Therefore, disagreement on the recommendations for IPI following stillbirth remains.

The lack of consensus on advice for couples may emanate, in part, from previous studies that suggested short IPI increased the risks of recurrent loss, as well as other maternal and fetal complications (Hughes et al. 1999b, Black et al. 2008, Bhattacharya et al. 2010). Very little work to date has explored how couples actually reach a decision to get pregnant after stillbirth. In a modified grounded theoretical study of 11 recently perinatally bereaved women, Lee et al. (2013) suggest that

women's desire to mother, to honour their deceased baby and their ability to cope with the chance of another pregnancy loss, all contribute to their decision to have another pregnancy. In this sample, eight of the eleven women in the sample were pregnant again at the time of interviews. The women in Lee et al. (2013) study fell into three distinct categories. Firstly, women who chose to try very quickly to achieve another pregnancy after their loss; secondly, women who opted to wait for another pregnancy until they felt ready and able to proceed, and finally women who made a definite decision to not try again to become pregnant. What is not clear from this small sample is how the women reached these decisions or what involvement their partners had in their choices as the men's views are only reflected through the prism of their partner's narratives. Men's views were not specifically sought for this study. It is unclear if men in this study wanted another baby or if men were engaged in the decision.

Campbell-Jackson et al. (2014) did elicit the experiences of fathers, when they used an IPA approach to interview seven women and their partners, about pregnancy and having a child, after stillbirth. Participants were interviewed separately to unearth their experiences. While their experiences of pregnancy and parenting are reported, there are no insights into decision making for the subsequent pregnancy. All of the mothers were recruited from a sample of women involved in a previous study on mental health concerns in women after stillbirth. The fact that the participants were recruited from a sample of women who had previously been involved in research into mental health issues may have biased the results. If these women had reported mental health challenges after their stillbirth, this may have influenced their decision-making about a subsequent pregnancy.

As part of a larger study into the causes and consequences of pregnancy loss and perinatal death, Meaney (2016), used an interpretative phenomenological analysis approach to explore women and men's experiences. Ten women and five men who had experienced a stillbirth, four to sixteen months previously, agreed to take part. Ten men had initially been invited to participate along with their partners; five declined to do so. Two different researchers, one female and one male interviewed participants separately. Meaney (2016) reported that women and men had differing views on a decision to have a subsequent pregnancy, as well as reporting interpersonal communication difficulties in their relationships. However, several issues remained unclear from the reporting of the study, whether any of the participants were pregnant again at the time of interview or if they had had live children since their loss, and if they had achieved a pregnancy, how exactly the participants reached an agreement on a subsequent pregnancy (Meaney 2016, Meaney et al. 2016).

Parenting both babies during pregnancy after loss

Historically, conceiving soon after loss was negatively perceived and several case studies suggest that the children born subsequent to loss were a replacement child for the deceased baby, often with negative sequelae for that child (Cain and Cain 1964, Olmsted and Poznanski 1972, Legg and Sherick 1976, Sabbadini 1988). It has been suggested that instances of disorganised attachment in the children born after perinatal loss may be due to unresolved parental grief (Zeanah 1989, Hughes et al. 2001, Hughes et al. 2002). However, other studies would offer an alternative

explanation. In a qualitative, psychoanalytical study of three women's experiences of parenting after loss, Reid (2007) suggests that subsequent pregnancy after stillbirth may not be an attempt to provide a replacement child for the one that has died, but rather a women's effort to repair her own maternal identity. Reid (2007) further suggests that women are attempting to mother both the deceased baby and the live baby born after loss and in so doing repair their sense of maternal identity after loss. However, Reid's (2007) work needs to be viewed in the context of her profession as a child and perinatal psychotherapist as the experience of treating children with disorganised attachment may have informed Reid's thinking. The study also is reflective of the experiences of a small number of participants included in her study.

The findings of Grout and Romanoff's (2000) grounded theory study of ten parents from seven families concur with those of Reid (2007). Individual interviews were conducted with six women and four men. All participants had children aged three to five years of age who were born subsequent to stillbirth, late miscarriage or neonatal death in the United States. They found that couples co-created three distinct family representations following loss. Firstly, couples maintained a connection to the deceased baby by preserving that child's missing space in the family unit. Alternatively, couples sought to identify a definite space for that child within their family unit. Finally, that couples may cope by replacing the loss, with a subsequent pregnancy. Although participants clarified that subsequent pregnancy was to replace the loss, not the child that had died. Three of the four fathers in this study were identified as displaying this third pattern of behaviour and described a reported detachment from the babies who died. Others have suggested that the birth of

subsequent infants may help with couples grieving processes (Dyregrov and Matthiesen 1987, Theut et al. 1989).

Ünstündag-Budak (2015) conducted a systematic review of the literature on replacement child syndrome. Cain and Cain (1964) first mentioned the term in the 1960s. Ünstündag-Budak (2015) suggests there is a need for everyone to reconsider the way in which women and men experience their relationships with babies born after loss. There is a need to be mindful for couples' desire to maintain continuing relationships with the deceased baby even after the birth of subsequent children.

The need for parents to maintain continuing bonds and to assimilate their deceased baby into their families has also been reported. O'Leary and Warland (2012) conducted a meta-synthesis of two previously completed studies and explored experiences of pregnancy or parenting children after pregnancy loss. Two studies, involving 46 mothers and 27 fathers' experiences were included. Parents reported wishing to assign a separate, distinct identity to their subsequent baby to both acknowledge them as unique from their deceased baby and to be able to welcome them into their family, even during pregnancy. The parents in this meta-synthesis were very clear about the need to create a new identity for their new child as a means of honouring both of their children. This draws attention to the concept of intentionality of parenting as a means of coping during PAL and seeks to refute the belief that couples are seeking in some way to create a replacement child. However, the limitations of this meta-synthesis including lack of systematic approach and quality review, are acknowledged and the authors did not utilise an accepted protocol for such a review.

Competing emotions in pregnancy after loss

Once a pregnancy has been achieved, couples begin a challenging process that may result in the emergence of competing negative and positive emotions, which persist throughout the pregnancy and into the postnatal period. These have included grief, anxiety, depression, stress as well as couples' efforts to nurture positive emotions such as optimism and hope.

Grief has been defined as the emotional response to loss (Badenhorst and Hughes 2007, Thompson 2012). The grief following a death of a stillborn infant is unique because the death is often not societally recognised and its impact is underestimated (O'Leary 2004). Similarly, the persistence of grief throughout pregnancy after loss is often under-appreciated and under-acknowledged by the couple's wider societal group (Badenhorst and Hughes 2007, Cacciatore et al. 2008a, O'Leary 2004).

There has been a wealth of theoretical and empirical literature written on grief within the general population, grief after perinatal loss and some studies exploring the concept in pregnancy after loss. It is evident from the specific literature on pregnancy after loss that there is a continuation of grief throughout the subsequent pregnancy (Barr 2006, Franche and Bulow 1999, Franche 2001, Gaudet 2010, Hutti et al. 1998, Hutti et al. 2013, Hutti et al. 2015, O'Leary 2004). This is not surprising given the fact that inter-pregnancy interval to the next pregnancy is very short for most couples and parents need to continue to parent their deceased baby. The experience of grief after loss has been examined qualitatively and quantitatively. Two instruments predominate in the quantitative literature on grief in pregnancy after loss, they are the Perinatal Grief Scale (Toedter et al. 1988) and the newer Perinatal Grief Intensity Scale (PGS) (Hutti et al. 1998), specifically developed to measure this concept among

the pregnancy after loss population. Both consist of self-reported questionnaires, which have been empirically tested and validated.

There is often a reactivation of acute grief responses during a subsequent pregnancy and this can be very upsetting and traumatic for couples if they are unprepared (Cavanaugh 2001, Franche and Bulow 1999, O'Leary et al. 1998, O'Leary 2004). Several studies have equally reported that grief may be reduced in subsequent pregnancy (Lin and Lasker 1996, Cuisinier et al. 1996, Theut et al. 1990). Lin and Lasker (1996) conducted a longitudinal study of grief in 93 women and 29 bereaved men. Data were collected using the Toedter et al.'s (1988) Perinatal Grief Scale at two months, one year, and two years after pregnancy losses of variable gestations. Less than half the sample displayed what the researchers termed 'normal grief' scores. The remaining results varied while some participants who showed evidence of chronic grief at the one-year mark recovered quite well during the subsequent year. However, for 16 other participants', their grief symptoms intensified in severity over time.

Likewise, Cuisinier et al. (1996) found that pregnancy and subsequent birth lessened grief in the women in their study. They carried out a prospective, quantitative survey of 227 women pregnant after loss. At four time points since their loss, women were asked to complete the Perinatal Grief Scale (Toedter et al. 1988). Women were also asked if they had conceived since their loss and any feelings they may have had about this subsequent pregnancy. Only 15% of the women in this sample had a stillbirth as their index loss.

Franche and Bulow (1999) postulated that the subsequent pregnancy might promote psychological healing from grief by restoring a woman's concept of self that had been

fractured because of pregnancy loss. Franche and Bulow (1999) reported that although the levels of grief remained high in both women and men in their cross sectional, quantitative study of twenty-five couples pregnant after loss, the women who were pregnant again reported less despair and difficulty coping than the women who had a loss but who were not pregnant. Conversely, pregnancy made no difference to fathers reported levels of grief, anxiety or depression between the groups pregnant or not after loss. This may be because while a woman may find healing through the symbiotic relationship between the fetus and her maternal body, the same cannot be said for a man. A critique of the scales used to measure grief is that they are too specifically focused on feminine models of grief expression and may not fully encapsulate the male experience of grief, in particular within the pregnancy after loss population (Nelson et al. 2017).

Reports of contrasting grieving styles have also been reported in the literature (Barr 2006, Franche 2001, Wallerstedt and Higgins 1996). It has been suggested that women and men have different grieving styles: a female grieving style is said to be emotional while a male to be more stoic and protective. There are scant studies that only explore men's experiences of pregnancy after loss that address the issue of men's grief (Armstrong 2001b, O'Leary and Thorwick 2006, Ricklesford et al. 2014). As with much of the research in this area, men's voices are underrepresented. However, this may be to do with the fact that traditional supports available to parents are tailored specifically toward the feminine understanding of grief and support and may not fully meet the needs of men (McCreight 2004, Weaver-Hightower 2012).

O'Leary (2004) conducted a literature review of grief and its impact upon prenatal attachment in the subsequent pregnancy. She suggests that couples experience a new dimension to their grieving in a pregnancy after loss, which may not be recognised and could potentially lead to emotional complications. She observed through years of clinical practice that grief intensity was not dependent upon time since bereavement nor gestation at the time of loss.

Mills et al. (2014) found that couples are often isolated from the support structures because of the misassumptions that a new pregnancy will remedy the grief that they are feeling when in fact the opposite may be the case. The authors conducted a systematic review and metasynthesis of qualitative studies into parents' experiences and expectations of care in pregnancy after loss. Fourteen studies published from 1996 to 2011 were included in the review. All included studies were quality appraised using a tool developed by Walsh and Downe (2006). The metasynthesis was conducted using the stages described by Noblit and Hare (1988). Mills et al. (2014) suggest that there is a co-existence of various emotions in pregnancy after loss. Although, the study was titled 'parents' experiences', the majority of the studies included represented the experiences of women. Only four of the included studies represented men's views.

Couples have reported unpreparedness for the intensity of grief after stillbirth. In Caelli et al. (2002) phenomenological study of eight women and five men participants reported feeling unprepared, because members of their support structures had forgotten about their loss and expected them to get on with the pregnancy after loss. In Caelli et al. (2002) study, of the thirteen participants included, six were interviewed together and the remaining seven were interviewed separately. Although the

authors reported that only one man in these joint interviews contributed in any meaningful way to the dialogue. This may reflect the common misconceptions among wider society which imagines that grief is something that someone 'gets over' and that life returns to normal, when for the bereaved there is only the new normal of life after death (Mills et al. 2014).

It is accepted that grief may never fully abate after pregnancy loss, rather grief persists and changes and will continue throughout the pregnancy that follows (O'Leary 2004). Cacciatore (2014) discussed this issue of continuing grief called remourning, when writing about the twentieth anniversary of her daughter's death. Described as when the bereaved are confronted anew with the raw, visceral emotional grief that first visited them in the early days, weeks and months of their grief.

One area extensively researched in the literature is that of anxiety, stress and mental health for both women and to a lesser extent for men in the pregnancy subsequent to the loss. The largest body of work to date has focused on the concepts of anxiety, stress, and depression as the issues of concern for subsequent pregnancies after loss (Hutti et al. 1998, Theut et al. 1988, Armstrong and Hutti 1998, Côte-Arsenault 2003, Couto et al. 2009, Fertl et al. 2009, Hunfeld et al. 1996, Hunfeld et al. 1997a, Hunfeld et al. 1997b, Hughes et al. 1999b, Hughes and Riches 2003, Hughes and Cockburn 2007, Gong et al. 2013, Turton et al. 2001, Turton et al. 2009b).

Studies have reported that women in PAL groups have higher levels of both generalised and pregnancy specific anxiety when compared to first time mothers and second time mothers without a history of perinatal loss (Hutti et al. 1998, Theut et

al. 1988, Armstrong and Hutti 1998, Côte-Arsenault 2003, Couto et al. 2009, Fertl et al. 2009, Hunfeld et al. 1996, Hunfeld et al. 1997a, Hunfeld et al. 1997b, Hughes et al. 1999b, Hughes and Riches 2003, Hughes and Cockburn 2007, Gong et al. 2013, Turton et al. 2001, Turton et al. 2009b). Anxiety levels were also reported as higher in women than men, in studies when both partners were compared (Theut et al. 1988, Franche and Mikail 1999, Robertson and Kavanaugh 1998, Franche 2001). Pregnancy specific anxiety has been reported as varying over the course of the pregnancy and has been reported to peak at certain time points, such as clinic appointments or anniversaries of loss and as the end of pregnancy approaches. While some studies reported improved anxiety levels, the nearer to term and live birth, other studies showed a reported increase in anxiety levels as birth was imminent.

A great fear for couples is that this baby too will die, as their trust in the normality of pregnancy has been shattered (O'Leary 2004). For the majority of women and men, fear and anxiety are a component of pregnancy after loss. Some women believe that once the baby is near to term it needs to be born just in case it dies unnecessarily (Côté-Arsenault and Donato 2007, Côté-Arsenault and Morrison Beedy 2001, Keith 2005, Morton 1997, O'Leary 2002, Sun et al. 2011, Thebert-Wright 2003).

How women view their loss, if they perceive that loss as a baby or assigns fetal personhood have been suggested to influence maternal anxiety. Côté-Arsenault and Dombeck (2001) in their quantitative descriptive study of 72 multigravid women with a history of one or more perinatal losses found that the more a woman assigned personhood to the deceased baby, the higher her rate of anxiety in a subsequent

pregnancy after loss. The authors developed a tool for measuring the women's attribution of personhood to their pregnancy loss.

Personhood was conceptualised simply by asking the women to answer if they felt they had lost a pregnancy; a baby; a baby with a name; or a child who would now be a certain age. The answers provided indicated increasing degrees on assignment of personhood to the fetus. Among women who reported having only one loss, a quarter of the women disclosed the feeling they had lost a pregnancy, with 50% feeling they had lost a baby. In the remaining women, 11% felt they had lost a baby with a name and 14% felt they had lost a child who would be a certain age now. A quarter of the sample (26%) had two losses. Among the women who had only one loss, there was a positive and significant correlation with pregnancy anxiety. There was no relationship found with women who had more than one loss.

Gestational age was positively related to the degree of fetal personhood the women assigned, despite the fact that the mean gestational age of the index loss in the sample was only ten weeks. However, the authors caution in assuming that gestational age is a predictor of assignment of fetal personhood. Fetal personhood is often controversial as there is no universal agreement on the issue and there are conflicting discourses such as the medical, religious and feminist, which often do not help women in seeking clarity (Layne 1997, Layne 2006, Morgan 1989, Simmons 1989)

Milestones are an important component of any pregnancy. They can include confirmation of the pregnancy at 4-6 weeks, the arrival of pregnancy symptoms at 6 weeks, first ultrasound scan at 10 weeks, placental implantation at 12 weeks, public

announcement of pregnancy 12 to 14 week, first fetal movements felt 16 to 20 weeks, fetal anomaly scanning at 20 weeks, fetal viability at 24 weeks, preparation for baby's arrival, among others. In PAL, milestones take on a new meaning. They are at once a reminder of what has past and a hope for what is yet to be. The importance of reaching milestones, in particularly reaching the time at which their previous baby died, is a theme that emerges in the literature particularly related to fear and anxiety (Armstrong 2001b, Caelli et al. 2002, Côté-Arsenault and Marshall 2000, Côté-Arsenault 2007, Côté-Arsenault and Donato 2007, Morton 1997, Sun et al. 2011, Thebert-Wright 2003).

In a quantitative correlation study of 82 women exploring threat appraisal, coping and anxiety in PAL, Côté-Arsenault (2007) found that the threat appraisal remained for the duration of pregnancy. However, the author found that pregnancy anxiety decreased over the duration of the pregnancy as certain milestones were achieved. Likewise in a qualitative, descriptive study of 69 women in PAL, Côté-Arsenault and Donato (2007) noted that as pregnancy progressed beyond certain milestones, such as fetal movements or ultrasound scans, that the women in this study felt more able to anticipate a positive birth outcome.

Fathers too have discussed the milestones in PAL and how it affects their level of concern for their partner and baby. In the phenomenological study of four men Armstrong (2001b) discovered the more milestones the pregnancy achieved, the more reassured the men in this study became and the more hopeful they became of a positive outcome. Although the numbers in this study are very small, they do elicit the seldom-heard men's viewpoint.

Interactions with healthcare professionals also proved to be especially stressful for women including antenatal appointments and ultrasound scans (Côté-Arsenault and Marshall 2000, O'Leary 2002, O'Leary 2005, Sun et al. 2011). Although couples welcome the opportunity to see their baby, they often report feeling unprepared and taken off guard, by the intensity of feelings that ultrasound scans evoke. In a phenomenological study of 12 women and 9 men, O'Leary (2005) reported the experiences of antenatal ultrasound were viewed as a source of intense stress for participants. In this study, couples were interviewed separately, between 22 and 34 weeks' gestation, in a subsequent pregnancy after loss. This was despite the fact that ultrasound scans are often greatly anticipated events and parents look to them to provide reassurance. Couples reported that they were unprepared for the overwhelming, intense feelings of reactivated grief that the scans evoked. They also said that these feelings made it difficult for them to remain present in, and focused on, the current pregnancy. The couples had resultant feelings of conflict, which was very distressing for them. These findings should not be unexpected as for many couples the last time that they would have been in that position may have been when receiving the distressing news of their baby's demise in their previous pregnancy. Indeed, ultrasound scans in PAL provoked the same responses in participants in several studies (Côte-Arsenault and Freije 2004, Keith 2005, Mills et al. 2014, Morton 1997).

There is a reported underlying fear for women of a repeated negative outcome, that their bodies will somehow 'fail' them again. This uncertainty may be because the experience of loss, has affected their belief in the bodies' innate ability to grow, nurture and birth new life. These were the findings of Côté-Arsenault et al. reporting

on two studies, with 135 women (Côté-Arsenault and Dombeck 2001, Côté-Arsenault and Morrison Beedy 2001, Côté-Arsenault and Donato 2011) and Lee et al. (2013) in their study of 11 women.

Coping with pregnancy after loss

Women and men engage in similar activities to cope with their fears and anxieties in PAL, these include an emotional distancing from the pregnancy or a reluctance to form bonds with the growing baby. These activities are engaged in to minimise the fear of getting hurt again, should this pregnancy too end in a death. Couples also try to engage in controlling coping strategies such as observing pregnancy symptoms or not engaging in any strenuous activity or achievement of personal milestones (Ockhuijsen et al. 2014).

Women have described utilising many emotional-survival tactics to deal with their uncertainty, fear and anxiety. One such strategy is emotionally distancing themselves from their baby in subsequent pregnancies following stillbirth (Côté-Arsenault and Donato 2011). In this study, the term emotional cushioning emanated from the findings to describe the defence mechanism employed by sixty-three women in this mixed methods study of pregnancy after loss (Côté-Arsenault and Donato 2011). Emotional cushioning is described as a unique, specific set of mechanisms designed to preserve a woman from getting hurt from recurrent loss in PAL. It involves limiting attachment to the developing baby and using this strategy in attempting to strike a balance between anxiety and hope. As women are unsure of a favourable outcome, they may be unwilling to commit themselves emotionally to motherhood until they have tangible evidence of a successful outcome that is, a living child (Campbell-

Jackson et al. 2014, Côté-Arsenault and Donato 2011, Lee et al. 2013, Morton 1997, O'Leary 2002). This strategy was recognised in earlier research studies (Cŏté-Arsenault 1999, Côté-Arsenault and Morrison Beedy 2001, Côté-Arsenault and Donato 2007, O'Leary 2002).

Men too have reported engaging in emotional distancing activities in PAL. Campbell-Jackson et al. (2014) conducted an IPA study with seven women and seven men who were interviewed separately on becoming a parent to a child born after loss. In this study, men reported delaying their bonding during pregnancy with the baby born after loss as a protective measure against recurrent loss. The researchers reported that if the participants did engage in bonding behaviours it was in "preparation for loss rather than life" although the study did not offer any substantive supporting quotes for this claim (Campbell-Jackson and Horsch 2014 p.6). In this study women and men reported similar accounts of becoming parents after loss including limiting attachment and having conflicting emotions about attaching to the unborn baby.

It has been reported that women and men engage in various other behaviours to try to cope with their worries and anxieties in PAL, such as seeking to exert control over the pregnancy by increasing interactions with healthcare providers. This may include attending high-risk clinics, specialist obstetricians and submitting to a pro-forma of diagnostic tests and interventions that accompany a PAL. Women also consider giving birth early to avoid a reoccurrence of loss (Kint 2015, Mills et al. 2014, Meredith et al. 2017).

In an IPA study of 19 women in PAL, Kint (2015) found that the women resorted to these controlling behaviours to maximise their baby's chances of a successful outcome. To these women, the label of a high-risk pregnancy was viewed positively,

as it was a gateway to improved access to services and healthcare professionals. These findings are similar to Simmons and Goldberg (2011) who, in their phenomenological study of eight women in PAL, explored the concept of high-risk among this population. While other pregnant women may view the classification of high risk to be a troubling label, to women in the PAL group, that label was not viewed negatively. Women in this study welcomed the additional hospital visits, screening tests and surveillance that the high-risk label implied and perceived the label to afford protection for themselves and their babies. However, in both studies participants' wondered if they had been receipt of this additional surveillance in their index pregnancy, would it have prevented the loss in the first instance and in some participants' this realisation elicited an anger response. This may speak to the issue of maternal blame and guilt for the baby's death as well as the need to elicit a cause for the stillbirth.

Women also exert control over pregnancy after loss by becoming more aware of fetal movements, by being aware of their baby's behaviour in PAL, and by being constantly attentive to them. Women view fetal behaviour as a reassurance of wellbeing and so are constantly attentive to it (Armstrong 2001b, Caelli et al. 2002, Côté-Arsenault and Marshall 2000, Côté-Arsenault 2007, Mills et al. 2014, Côté-Arsenault and Donato 2007, Morton 1997, Sun et al. 2011, Thebert-Wright 2003). Often women engage in excessive activities such as drinking cold liquids or excessive night-time waking to prompt fetal movements that might reassure them of fetal wellness. Women in Campbell-Jackson et al.'s (2014) study talked about the practical strategies they employed such as eating ice pops in the middle of the night to elicit fetal movements. Yet in many cases the reassurances achieved by women from these strategies was

short lived (Armstrong 2001b, Côté-Arsenault and Marshall 2000, Caelli et al. 2002, Côté-Arsenault 2007, Côté-Arsenault and Donato 2007, Mills et al. 2014, Morton 1997, Sun et al. 2011, Thebert-Wright 2003, Campbell-Jackson et al. 2014). Quantitative studies also found empirical evidence of women seeking increased engagement with hospitals and healthcare professionals on pregnancy after loss (Gravensteen et al. 2018, Hutti et al. 2011, Mistry et al. 2013).

Men too have been reported as engaging in coping strategies in pregnancy after loss often attempting to exert control by maintaining a hyper-vigilant stance on the health and wellbeing of the mother and unborn baby (Armstrong 2001b, Campbell-Jackson et al. 2014, O'Leary 2002, O'Leary and Thorwick 2006, Ricklesford et al. 2014).

Couples have also reported engaging in intentional parenting strategies to ensure that they make the most of the time that they have with the new baby, mindful that they may not have done so with the baby that had died. So while many couples are employing avoidance or coping strategies to deal with their anxiety in PAL others would attest that parents in their studies reported bonding with their unborn infants and engaged in deliberately preparing for their role as parents during pregnancy (Campbell-Jackson et al. 2014, O'Leary and Warland 2012). In the meta-synthesis of parent's experiences of pregnancy and parenting after loss, O'Leary and Warland (2012) found that parents were both cognitively and emotionally preparing for parenthood. Participants actively chose not to adopt emotional avoidance strategies to deal with their anxiety but rather became acutely aware of their developing baby. Murphy (2012), in her grounded theory study, interviewed 10 couples and 12 mothers in the aftermath of stillbirth. The majority of participants were interviewed

individually although five of the couples were interviewed jointly. As a desire to reclaim control, participants spoke of becoming empowered because of their loss. They often challenged healthcare services to ensure they receive improved care in PAL and to protect others from poor outcomes. Couples viewed this empowerment as a positive outcome from their experiences of loss.

It has been reported that a lack of understanding or appreciation of the reality for couples in PAL from family, society and healthcare professionals can lead to a sense of social isolation for couples. In their US ethnographic study of two established support groups for parents pregnant after perinatal loss, Côte-Arsenault and Freije (2004) found study participants reported a paradox of being present in the PAL groups separate from the general society. They described the sense of isolation experienced by couples, due to lack of understanding by the dominant culture. For PAL couples, the regular rules of pregnancy do not apply. In their experience, pregnancy does not guarantee a live baby. Couples may also feel isolated from each other as they try to negotiate their individual grief in PAL, sometimes unable to take on one another's pain. In their grief and their efforts at creating new normality, participants acknowledged that good quality care at the time of loss and afterward can help parents through their journey.

These were similar to findings from Meredith et al.'s (2017) qualitative, descriptive study of ten women pregnant after perinatal loss. In this Australian study, five of the women had previous babies who were stillborn and five were premature neonatal deaths. One woman in this study articulated the views of many women by saying in PAL "you weren't a normal mum anymore" (Meredith et al 2017 p.5).

Maintaining hope has been suggested as a necessary component of coping with pregnancy after loss, to allow couples to prepare mentally for the birth of their new baby (Côté-Arsenault and Marshall 2000, Côté-Arsenault and Donato 2007, Côte-Arsenault and Freije 2004, Lee et al. 2013, Mills et al. 2014, O'Leary 2002).

Parents in O'Leary and Warland's (2012) study discussed restrained hope in the sub theme '*treasuring the time with the baby'* when describing intentionally parenting their baby in pregnancy in PAL. Mothers also allude to hope in a second sub theme '*new awareness of fetal movements*' as signs of life, though conversely fathers describe this vigilance as a coping strategy. The subordinate theme of '*staying strong'* in Campbell-Jackson et al. (2014) study speaks to the need for couples to remain hopeful and positive in the PAL as a conscious strategy to engage with their subsequent baby. Similarly, Meredith et al.'s (2017) participants' spoke about allowing hope to develop in PAL. Maintaining hope as a coping strategy was a major theme in Lee et al. (2013) study of eleven women in PAL. Maintaining hope of a live baby, may have mediated women's coping responses in PAL including a fatalistic approach to the pregnancy outcome, living in the moment, avoiding the pregnancy, or by emotionally shielding themselves from attachment to the developing babies. The women in this study were mindful of maintaining a future orientation and the positive impact that PAL could have, although acknowledging the additional supports needed.

Hope however, can be a nebulous concept in PAL. Hope is part of the human condition and a factor in couples' experiences though often on an ever-changing continuum from hope to little hope. In their grounded theory study Rillstone and

Hutchinson (2001) interviewed thirteen women and nine men in pregnancy following termination of pregnancy for fetal anomaly. They found that participants had a fear of hope and were afraid to allow themselves the luxury of hoping in case it may negatively influence the pregnancy.

Couples relationship in pregnancy after loss

The loss of a baby can adversely affect a couple's relationship. Gold et al. (2010b) surveyed marriage and cohabitation outcomes from almost eight thousand relationships. Data were extracted from Cycle 6 of the US National Survey of Family Growth. The NSFG is a nationally representative of women 15-44 years of age in the civilian, non-institutionalized population of the United States. The survey, conducted every four years, collates information on family life, marriage and divorce, pregnancy, infertility, contraception use, and women and men's health. For Cycle 6, data were collected from 7,643 women who discussed 13,593 pregnancies, by postal questionnaire and telephone interview, between March 2002 and March 2003. Researchers found higher rates of martial breakdown and disharmony among couples who experienced perinatal loss. These couples were 40% more likely to experience relationship breakdown in the first three years after loss, though the risk continued up to ten years. The risk was higher for couples who experienced a stillbirth than other types of loss.

Similarly Shreffler et al. (2012) in a US study of 3,461 women who were ever pregnant and married, found a higher rate of divorce among women with a history of pregnancy loss compared to those who had no such history (32-43% in PAL and 27%

in non-PAL group). Data from the National Survey of Fertility Barriers (NSFB) were analysed. The NSFB is a nationally representative telephone survey of women age 25-45. There was also a higher incidence of marital dissolution in the later perinatal loss group (43%) compared to the early loss group (32%). There remains a high rate of relationship breakup reported, similar to Gold et al. (2010b). Both of these studies were conducted from large data surveys in the US. The US reports a crude divorce rate 27% (Centres for Disease Control and Prevention 2015) and only 57% of all first marriages and 31% of all first cohabitations survive 15 years (Bramlett and Mosher 2002).

Conversely Cacciatore et al. (2008a) reported that very few (<10%), of the seventy-four participants in their study considered divorce in the aftermath of their stillbirth. The participants stated, that although the loss was challenging to deal with it had brought them closer together in their relationship. This is a much smaller sample of bereaved parents accessed through two Internet-based parental support organisations and at a parental grief conference. It could be argued that by attending these services, these couples were committed to their ongoing relationship in the aftermath of their loss.

For couples facing the prospect of deciding to have another baby and their experiences of sexuality after the loss of a baby are not very well researched. Two studies were identified that examined couples' views about their intimate relationships in the aftermath of loss (Hagemeister and Rosenblatt 1997, Dyregrov and Gjestad 2011).

In both of these studies, couples were interviewed together about their intimate relationship following the death of a child. Not all of the deaths were because of stillbirth, but couples who had experienced that loss were represented. Hagemeister and Rosenblatt (1997) conducted a qualitative, interpretive study of 24 couples' experiences. Couples usually reported a decline in their intimate sexual relationship in the immediate aftermath of loss. That decline persisted for some time in sixteen out of the 24 couples interviewed. The decline was attributed to a variety of factors including fatigue, depression, grief and a psychological discomfort with intimacy.

Communication difficulties between the couples added to the challenges. The meaning of intimacy was seen as important to couples and their responses under this theme varied. Some couples equated sexuality to the act of procreation that begat the deceased child. For some participants, sexuality equated to pleasure, which was incongruous to their grieving persona at that time. There were examples where couples were fearful that sexual intimacy would lead to another child and they were not ready to conceive. Likewise, others were aware that sexual intimacy was necessary in order to procreate and that was viewed as a positive healing from death. There was also a life-affirming meaning in sexual intimacy following death, which too was viewed as healing.

For men in the study, sexual intimacy was also viewed as comforting and for both women and men even if they did not resume sexual intercourse immediately, the sexual intimacy of touch was seen as very important to them. This was a qualitative study, conducted over 20 years ago in the US and the sample was homogenous white, middle class, married couples.

Dyregrov and Gjestad (2011) conducted a mixed methods study in Norway exploring sexuality following the death of a child. They analysed the results of questionnaires (n=285) from women (n=169) and men (n=116) recruited from two major bereavement organisations as well as conducting in-depth interviews with ten couples. They found that the majority of respondents (75%) had resumed sexual activity by three months and up to half (50%) had begun sooner than that, in the first month following the loss. It must be noted that the authors did not provide the breakdown of cause of index death although they did note that couples who had a stillbirth took longer to resume sexual activity than parents whose children died through SIDS or by accidental means.

When asked if their loss had an impact upon their sexual life three quarters of parents (75%) reported that it was negatively affected. Women, more than men, were affected in this sample. It was reported there was good within-couple agreement though greater between-couple variance was noted. Similar to Hagemeister and Rosenblatt's (1997) study there was an increase in sexual activity when couples decided they wanted to have another child though for many this lead to conflicted emotions and powerful negative associations for both women and men who were interviewed for the study. It was not until a decade into this century that second study was carried out to explore this issue. Sexual intimacy for couples in the aftermath of loss remains a hidden and taboo subject. Indeed, only 11% of respondents in Dyregrov and Gjestad (2011) noted having discussed the issue with any healthcare professional.

Sexual intimacy is an integral part of achieving a pregnancy after loss. Couples do decide to continue or resume sexual intercourse to achieve a pregnancy. However, little is known about how this is achieved. Only one identified study explored decision making in a PAL. Lee et al. (2013) in their modified grounded theory study with 11 women developed a model of women's decision-making processes. The researchers identified three factors that women identified as contributing to their decision. These included their desire to become a mother, memorialising their deceased baby, and judging their own ability to cope with a PAL and the potential of another loss. Women in this study based their decision on personal reasons rather than being mindful of the views of healthcare professionals or others. This is similar to findings of Davis et al. (1989) study. Women spoke of their partner's involvement in PAL decision-making but as men's views were not sought, it was women's interpretation of their partners views that were reported. Having made the decision to get pregnant again, some women reported disappointment when their attempts to achieve pregnancies 'failed' despite their enthusiasm (Lee et al. 2013). This study was the first time that decision-making was explored within this population. However, women do not make reproductive decision in a void and the views of men were absent from the findings.

Summary

Pregnancy loss remains the most common complication of pregnancy and the numbers of couples experiencing a stillbirth remain unacceptably high. The majority of couples will go on to have another pregnancy after loss.

Many of the studies identified in the literature review exploring PAL used a quantitative approach to examine the phenomenon. There were several studies that examined pathological sequelae in pregnancy after stillbirth including depression (Hamama et al. 2010, Hughes et al. 1999b, Theut et al. 1988, Turton et al. 2006, Turton et al. 2009b); post-traumatic stress disorder (Turton et al. 2001); anxiety (Hunfeld et al. 1996, Hunfeld et al. 1997a, Blackmore et al. 2011, Shapiro et al. 2017); and grief (Barr 2006, Franche and Mikail 1999, Franche 2001, Gaudet 2010, Hutti et al. 2013, Hutti et al. 2015, Hutti et al. 2017). Attachment, parenting after loss and vulnerability of the subsequent child has also been explored quantitatively (Heller and Zeanah 1999, Hughes et al. 2001, Mehran et al. 2013, Theut et al. 1992, Turton et al. 2009a, Wilson et al. 1988, Yilmaz and Beji 2013). Quantitative studies have focused upon instrument design or on measuring combinations of these negative emotions in pregnancy after stillbirth among woman and to a lesser extent, men. Quantitative approaches have also been used to examine women's wishes for care in pregnancy after loss (Robson et al. 2010, Robson et al. 2009) and also experiences of services available to women in PAL (Mills et al. 2016, Wojcieszek et al. 2016). The experiences of women, men and couples have also been explored qualitatively. Many studies have used a qualitative descriptive design (Côté-Arsenault 2003, Côté-Arsenault 2006, Côté-Arsenault and Donato 2007, Côté-Arsenault and Marshall 2000, Meredith et al. 2017, Robertson and Kavanaugh 1998, St. John et al. 2006, Van et al. 2004). There have been several studies that employed a grounded theory approach (Lee et al. 2013, Rillstone and Hutchinson 2001, Van 2012) and a couple that have utilised a feminist methodology (Simmons and Goldberg 2011, Thebert-Wright 2003) and three that used a mixed methods approach (Cavanaugh 2001, Côté-Arsenault

and Donato 2011, Côté-Arsenault et al. 2014). One study used an ethnographic methodology (Côte-Arsenault and Freije 2004). Several studies used a phenomenological approach to experiences of pregnancy after stillbirth including the three studies that have explored fathers' experiences solely (Armstrong 2001b, Caelli et al. 2002, Côté-Arsenault and Morrison Beedy 2001, O'Leary and Thorwick 2006, Ricklesford et al. 2014). Several studies have employed an Interpretive Phenomenological Analysis approach to women's experiences (Keith 2005, Kint 2015, Sun et al. 2011, Ünstündağ – Budak et al. 2015).

Although some studies have used IPA to explore the experiences of couples (Campbell-Jackson et al. 2014, Meaney et al. 2016, O'Leary 2002, O'Leary 2005) none have specifically focused on their experiences as part of a couple nor interviewed couples together as a dyad.

Theoretical Literature

Aside from the utility of theory to qualitative research methodologies, disagreement still exists as to the broader role of theory in qualitative research and this has not been well defined (Anfara and Mertz 2014). Although theories are not utilised in qualitative research to frame a study or empirically test statements about a phenomenon, theoretical literature is useful to sensitise the researcher to concepts that may influence the experiences of the participants (Wu and Volker 2009). To sensitise me to the issues of concern for couples experiencing pregnancy after stillbirth the theoretical literature was read.

In spite of the traumatic loss of a baby before birth, the research suggests that many couples do decide to embark upon a pregnancy after loss. The very act of embarking upon this venture could be described as future orientated. Couples remain hopeful of a positive outcome, which is a live baby. The concept of hope in pregnancy after loss was suggested by participants in several studies (Côté-Arsenault and Morrison Beedy 2001, Côté-Arsenault and Donato 2011, Lee 2011, Lee et al. 2013). Likewise, many studies suggest that in order to remain future orientated couples seek to make meaning of their baby's death (Cacciatore et al. 2008a, Callister 2006, Forhan 2010, Hsu et al. 2002, McCreight 2008, Nuzum et al. 2017, O'Leary 2004, Sturrock and Louw 2013, Sun et al. 2014, Ünstündağ – Budak et al. 2015). Therefore, in spite of a traumatic experience, such as stillbirth, couples do remain hopeful and seek to create meaning. The reasons why they adopt this positive approach in the face of adversity may be explained under the umbrella concept of salutogenesis. To further explore these issues the available literature on hope, meaning, and salutogenesis within the context of pregnancy after loss was read.

Search Strategy

To explore these concepts from a broad perspective, a scoping search of the Academic Search Complete database was conducted in February 2015. This search was re-run during October 2017 to update the literature review and identify any pertinent studies published in the intervening time. To provide a wide overview of the concepts under consideration from a multidisciplinary perspective Academic Search Complete database was considered appropriate. The terms *pregnancy after loss*, and the conceptual terms under reflection for this study *hope, meaning*, and *salutogenesis*.

Hope

Hope is a trait shared by all humans but is unique to each individual's experience. It has many aspects and is context dependent. Hope has been defined by theologians, philosophers, psychologists, and psychiatrists and has increasingly been explored in the healthcare literature (Schrank et al. 2011a). Hope has been defined as *a process of anticipation that involves the interaction of thinking, acting, feeling, relating and is directed towards a future fulfilment that is personally meaningful* (Stephenson 1991 p1459). Researchers have described hope as an essential attribute to mental health and wellbeing (Schrank et al. 2011a). Indeed an absence of hope or hopelessness has been known to have detrimental effects on an individual's health and wellbeing resulting in despair, depression and even suicidal ideation (Cutcliffe and Herth 2002).

Promoting and sustaining hope has been demonstrated as an important role for healthcare providers in other aspects of healthcare, for example patients with terminal illness or mental health issues (Clayton et al. 2008, Schrank et al. 2011a). Several researchers have proposed theories of hope including researchers such as Stotland and Snyder. Stotland's Model of Hope described hope as a desire for future goal attainment (Stotland 1969). Although Stotland's work was not operationalised or tested, his work laid the foundations for those who came after. One of the most prolific and well known theories of hope was proposed by Snyder who stated that 'hope is defined as the process of thinking about one's goals, along with the motivation to move toward (agency) and the ways to achieve (pathways) those goals' (Snyder 1995). Snyder et al. (1991 p. 287) define hope as 'a positive motivational

state that is based on an inter- actively derived sense of successful: (a) agency (goal-directed energy), and (b) pathways (planning to meet goals). Snyder's theory has its origins in cognitive/behavioural psychology and describes the three components of goal-related thinking which he describes as the 'goals', 'pathways' and 'agency' to achieve a hoped for aim (Snyder 2000 p. 9). Snyder attested that the hoped for goal must have resonance for the individual and it must be seen to be attainable, although a degree of uncertainty about goal attainment is to be expected (Snyder 2000). Although the fundamental principle is similar to Stotland's proposition, it introduces the possibility of uncertainty to the idea of goal attainment. This may apply more to the pregnancy after loss population because the hoped for pregnancy and positive birth outcome is not guaranteed as the couple are aware. Snyder and colleagues later added the third strand of 'goals' to define 'cognitive component anchoring hope and providing the target of mental action' (Schrank et al. 2011a p.229). Snyder operationalised his theory beginning with the development of the Trait Hope Scale (THS) by using the scale with healthy adults and then with adults with psychiatric illnesses. Subsequently Snyder and his team developed State Hope Scale (SHS). Snyder's theory assumes that in hoping, an individual can clearly define their goals, have the wherewithal to reach them and are inspired to do so (Lopez et al. 2004). A critique of both Stotland and Snyder's work is the emphasis on the cognitive and goal focused traits as well as absence of the '*other*' or relational aspects of hope, as well as the absence of a spiritual dimension (Schrank et al. 2011a, Schrank et al. 2011b).

Healthcare researchers have examined the concept of hope with patients who have terminal illness; chronic illness; spinal injury; mental health issues and for their

families and carers. Hope has been found to be a positive attribute, something aspirational and meaningful with positive and useful results. Hope, when discussed in the literature is also discussed with reference to hopelessness and despair. They are considered on a hope-hopeless continuum and often one cannot be considered without the other. Hope has been shown to be beneficial during times of illness, crisis and grief (Hendricks-Ferguson 1997, Nekolaichuk 1999, O'Connor 1996, Tracy et al. 1999, Fitzgerald Miller 2007, McClement 2008, Tutton et al. 2009).

In a concept analysis, Amendolia (2010) examined the concept of hope pertaining to a neonatal population. She postulated that hope is very much present for parents of critically ill infant within the neonatal setting. She found that hope was present even in end of life care. She acknowledged that hope has been under researched within maternity populations and recommended further investigation of the phenomena (Amendolia 2010).

In an Irish study, Lalor et al. (2009) investigated women's experiences of pregnancy outcomes following antenatal diagnosis of fetal anomalies using grounded theory methodology. Recasting Hope was the theory developed, whereby women reconstructed a new normality following the diagnosis of fetal anomaly in pregnancy. Similar to Amendoila (2010), hope is referred to as 'hope for an early (fetal) demise, hope (fetus) born alive and hope to cope with the loss' (Lalor et al. 2009 p.466). Indeed, Lalor et al. (2009) recommend the need for further research into future pregnancies for women and the effects that their experiences may have on pregnancy after loss.

Hope requires exploration in pregnancy following stillbirth as recommended in previous studies (Amendoila 2010; Lalor 2009). Hope is a nebulous concept in PAL. It exists in the margins, in the penumbra of loss. Hope although a part of the human condition and a factor in couples' experiences is not often openly acknowledged. Hope exists in a hope-restrained/hope continuum in the literature. The thirteen women and nine men in Rillstone and Hutchinson's (2001) exploratory study on their experiences of pregnancy after loss discussed their fear of hope following termination of pregnancy for fetal anomalies. Parents in O'Leary and Warland's (2012) study too highlighted the concept of restrained hope. In the sub-theme 'treasuring the time with the baby', parents spoke about intentionally parenting their baby in pregnancy in PAL as a means of connecting with their unborn baby. Mothers also allude to hope in a second sub theme 'new awareness of fetal movements' as signs of life. Although fathers describe this as vigilance, a coping strategy discussed previously. In Campbell-Jackson et al.'s (2014) IPA study of seven couples exploring pregnancy and parenting in PAL participants spoke of 'staying strong'. Reflected in this theme was couples' need to remain hopeful and positive in the PAL as a conscious strategy to engage with their subsequent baby. Parents also talked about parenting the children born after loss and the theme of 'changed view of self as a parent', which could be seen as a positive transformative statement. This transformative aspect of PAL was mentioned in Wilson et al.'s (1988) quantitative comparative study of eight couples with and without pregnancy loss. In that study the birth of the baby after the loss made the revisiting of the stillbirth experience easier for parents. In spite of previous poor outcomes, many women have reported that they were simultaneously expecting the worst and hoping for the best in

pregnancies after loss (Côté-Arsenault and Morrison Beedy 2001, Côté-Arsenault and Donato 2011, Lee 2011, Lee et al. 2013). This suggests that sustaining the hope of a good outcome made pregnancy tolerable. Research has also discussed the need for women to maintain unspoken hope in PAL (Lee 2011, Lee et al. 2013).

Meaning

There are various theoretical perspectives that help explain the concept of meaning (Park 2010). These perspectives can draw attention to the possible meanings that couples may seek to make about the death of their baby and helped sensitise me to their experiences. One definition for meaning in life is "a subjective experience that provides a sense of coherence and is achieved through creative values, experiential values and attitudinal values" (Weathers 2016 p.59). In their concept analysis of the quest for meaning following adverse events, Skaggs and Barron (2006) meaning was said to be defined under two overarching themes. Firstly, global meaning, where an individual is cognisant of their place within a greater, universal world-view and secondly situational meaning, that is the meaning an individual ascribes to a particular situation (Skaggs and Barron 2006). The researchers suggest that if there is incongruence between the meaning an individual may attach to an event and global meaning then resolution is hindered and a search for meaning continues. In this search, individuals may attempt to alter the meaning ascribed or the global meaning attributed to this event. Park's (2010) integrative review suggested that meaning could be considered either as global or situational. She addresses the complexity of agreement on a model of meaning making. Although not specific to

the pregnancy loss or perinatal bereavement population, the findings of these papers may be applicable to this population. For example, where the death of a baby is not societally recognised then global meaning may not be ascribed to such an event. However, the event has significant situational meaning for that parent.

While there have been several theoretical perspectives on meaning, two of the most pertinent to this study, Frankl's theory of Will to Meaning developed as a consequence of his incarceration in a concentration camp during the Holocaust (Frankl 1984, Frankl 1969) and Neimeyer's model of meaning reconstruction (Gillies and Neimeyer 2006, Neimeyer 2000, Neimeyer et al. 2006, Neimeyer et al. 2010) will be considered.

Frankl suggested that man had vast potential for hope despite seemingly harsh conditions and once he had free will, was able to choose his responses even when faced with hardship. It was the meaning that man ascribed to his life and situation that influenced the outcomes (Weathers and Murphy 2014). The definition of meaning is a good fit for the salutogenic framework proposed by Erikson (2014). Frankl contended that we all are driven by a "will to meaning," to find meaning and significance in our lives, and that if we do not, psychological distress may result (Steger et al. 2006). Frankl's theory is based on three concepts. Firstly, the search for meaning in life is man's primary raison d'être and that to each individual's meaning is unique to them (Life Purpose).

Secondly, that individuals have a freedom to be responsible for the realisation of the meaning of their life that is, to choose how to be in their lives (Freedom to Choose).

Finally, that human suffering is common to all man and that suffering is the meaning that individuals attributed to their own travails (Human Suffering) (Starck 2008). 'Life Purpose' proposed as key to the theory. Making positive and lasting contributions to the world are identified as central to this concept. For couples, their contribution to the world may be the birth of children. Stillbirth and pregnancy loss may disrupt this contribution and in turn interfere with this achievement of meaning. The second way that an individual can find meaning and achieve Life Purpose is in their loving emotional encounters with others. There is said to be no deeper love than that between a parent and child. The search for that love may drive couples towards achieving a "successful" pregnancy outcome that is a living baby. The third way of finding meaning is utilising hope as a means of finding meaning along the path of life's purpose. An illustrative way of finding meaning may be choosing to remain positive, brave or optimistic in the face of difficult circumstances (Starck 2008). Couples who remain hopeful of a positive outcome to a pregnancy, despite their experience of pregnancy loss, for example, or just the very act of becoming pregnant after loss could be viewed as a hopeful act in itself. It could be suggested that without hope couples might never even consider the possibility of a subsequent pregnancy, given the trauma of the stillbirth and the possibility that such a loss may happen again.

The second concept of the theory 'Freedom to Choose' discussed the individual's right to choose how to 'be' in the world or what attitude to adopt (Starck 2008). For couples, choosing to remain hopeful in the face of uncertainty, fear or anxiety of pregnancy after stillbirth could be an example of this construct. The final concept in

the theory is 'Human Suffering', which Frankl asserts is a component of human existence. For example, the couple may attain meaning from their experiences of human suffering of the stillbirth and yet may struggle with it in the uncertainty, fear and anxiety in subsequent pregnancy. This may manifest itself in the couple thinking why me, why my baby? Several instruments including the Crumbaugh and Maholick (1964) Purpose in Life (PIL) test and the Steger et al. (2006) Meaning in Life Questionnaire (MLQ) have been developed to measure and empirically test the constructs (Weathers 2016). No studies were discovered using these measurements between the pregnancy loss and pregnancy after loss populations.

Neimeyer (2011) suggests that as humans we are continually making sense of our world by the creation of meaning. However, when an event such as the death of a loved one occurs, particularly if that death is sudden and unexpected, we seek to reconstruct meanings around that event in order to make sense of it. He suggests that in the aftermath of loss, individuals try to search for meaning in these events through practical (why did my baby die?); relational (am I still a parent if my baby is dead?); and the spiritual (why us? why my baby?). Neimeyer (2011) suggests that we create a reconstructed narrative in this search for meaning. This search is a two-phase process of sense making and benefit finding. This necessitates that the bereaved attempt to find new meaning in their life or the life of their deceased loved one; integrate that meaning into their lives; construct meaning as personal and interpersonal processes; provide a cultural context for their meaning; and concentrate on the process of meaning-making not just the outcome (Neimeyer 2000). Neimeyer's work has been used with perinatally bereaved individuals

(Hagemeister and Rosenblatt 1997, Klass 1999). The search for meaning is a concept that appears in many explorations of perinatal grief, bereavement and pregnancy after loss. The death of a child is catastrophic for couples and can result in a crisis of meaning (Wheeler 2001). The loss of that child will forever be significant and irreplaceable and the search for meaning is very important to those whose babies have died (Wheeler 2001). Researchers have suggested that unsuccessful efforts by couples to find meaning may result in lingering grief, leading to mental health issues such as depression (Neimeyer et al. 2006).

Within the pregnancy loss literature, the theories of meaning have not been well operationalised or quantitatively tested to ascertain an individual's levels of meaning making. However, there are very many qualitative studies exploring women and men's experiences of meaning making. The meaning of perinatal loss has been highlighted by participants in several qualitative studies exploring women and men's experiences of stillbirth (Cacciatore et al. 2008a, Callister 2006, Forhan 2010, Hsu et al. 2002, McCreight 2008, Nuzum et al. 2017, O'Leary 2004, Sturrock and Louw 2013, Sun et al. 2014, Ünstündağ – Budak et al. 2015). The use of rituals, memory making, and integrating the deceased baby into the family have all been associated with meaning making in the aftermath of perinatal loss (Blood and Cacciatore 2014, Castle and Phillips 2003, Côté-Arsenault 2003). Several qualitative studies have also reported the meaning of loss among women and men, within the context of pregnancy after loss (PAL) (Armstrong 2001b, Côté-Arsenault et al. 2014, Côté-Arsenault and Dombeck 2001, O'Leary 2004, Ünstündağ – Budak et al. 2015).

Salutogenesis

The term salutogenesis comes from the Latin for health (salus) and origin (genesis). It is a theory first described by the medical sociologist Aaron Antonovsky in the late 1970's (Antonovsky 1979). Antonovsky described the concept of health as being on a continuum from wellbeing to illness. Based on his work with Israeli holocaust survivors, Antonovsky's theory attempts to explicate how individuals maintain a positive outlook when they have experienced exceptional hardship. Antonovsky described Generalised Resistance Forces (GRF), which are individualised and help people to cope with hardship. These GRFs can be internal, such as an individual's attitudes and beliefs or external, such as social support. The central construct underpinning the theory is that individuals possess a Sense of Coherence (SOC), defined as their ability to utilise their GRFs and is composed of three sub-constructs. They are, the sense that individuals can make of their experiences (comprehensibility); the capacity an individual has to cope with experienced stressors (manageability); and the sense of personal meaning the individual can ascribe to an experience (meaningfulness) (Antonovsky 1979). Antonovsky's theory explains what maintains individual wellbeing instead of focusing on what makes individuals ill. Sense of Coherence scales have been developed and tested to operationalise the theory and been used in many aspects of healthcare. Since the untimely death of Dr Antonovsky in 1994, several researchers have developed his work and expanded the umbrella term of salutogenesis to include concepts as well as Sense of Coherence (Figure 2.1) (Erikson 2014).

Salutogenesis theory sensitised me to the worldview that, despite the death of their baby, couples who embark upon a pregnancy after loss may be adopting a hopeful approach and seeking to make meaning from their experiences of death and loss.

Among maternity populations, salutogenesis is of increasing interest (Engelhard et al. 2003, Hillowe-Donahue 2006, Rennie 2016, Sturrock and Louw 2013, Uren and Wastell 2002). The health focused, rather than a pathological focused approach is appealing. A social model of pregnancy and childbirth philosophically underpins midwifery, and that view is sympathetic to a salutogenic paradigm. Maternity outcomes have traditionally focused on pathological measurements such as mortality and morbidity (Perez-Botella et al. 2015). A salutogenic focus has underpinned research on pregnancy loss or some studies have utilised Sense of Coherence measurements (Engelhard et al. 2003, Hillowe-Donahue 2006, Rennie 2016, Sturrock and Louw 2013, Uren and Wastell 2002).

Figure 2.1 Salutogenesis Umbrella. Eriksson and Mittelmark, 2016

Source: Eriksson and Mittelmark, 2016. Reproduced with kind permission of the author.
Appendix I: Permission to Reprint: Granted 4th July 2017

In a prospective, quantitative study, Engelhard et al. (2003) sought to elicit the pregnancy experiences of 1,372 Dutch women. In particular, they were interested in whether there was a relationship between sense of coherence and adverse psychological outcomes following pregnancy loss. They utilised Antonovsky's SOC scale with the Beck Depression Inventory, the PTSD Symptom Scale (PSS-SR), and the Crisis Support Scale (CSS). Of the one hundred and twenty-six women who experienced a pregnancy loss, one hundred and eighteen agreed to participate one month after their loss. The majority of women experienced first or second trimester losses and mean gestational age at the time of loss was twelve weeks. The researchers discovered that a stronger sense of coherence was protective of women developing PTSD and depressive symptoms at one month. However, the PTSD association was weaker than in other studies. The study design and the relatively short interval between the pregnancy loss and the postpartum time point may help to explain this finding. It was unclear from the study how the data were collected, whether by the individual or the researcher or whether face to face or by postal response. Hillowe-Donahue (2006) used Antonovsky's SOC scale and found that lower SOC scores were associated with greater grief distress among the 110 women who took part in the study. These findings are in keeping with those of Uren and Wastell (2002) who found that SOC was a strong predictor of level of grief experienced by women following stillbirth among the 109 women who had experienced a stillbirth or neonatal death. These findings were supported by those of Rennie (2016) who found that high levels of SOC were protective for anxiety and depression among the sixty-six women who took part in the longitudinal, mixed methods study.

Summary

In summary, the search for meaning is an important component of grieving the loss of a baby. Yet despite these unexpected events, couples remain hopefully by embarking upon a pregnancy after loss. This could this be suggestive of a salutogenic stance. What has not been explored is the significance of the combination of hope, meaning, and salutogenesis for couples who are pregnant after a stillbirth. The current study attempts to address this gap in the literature by exploring the following question: what sense do couples, as a unit, make of their experiences of pregnancy after stillbirth.

Chapter 3: Methodology and Methods

Introduction

This chapter will present the methodology applicable to this study and attention will be given to the ontology and epistemology underpinning the study including the appropriateness of Interpretive Phenomenological Analysis (IPA). The principles of IPA as espoused by Smith et al. (2009) informed all stages of the study and are embedded throughout. The methods by which the study was conducted and presented in this chapter include research design; sample access and recruitment; data collection and analysis; ethical considerations; and ensuring methodological quality.

Aim

The aim of the study was to understand how couples, as a dyad, make sense of a pregnancy after stillbirth.

Research design

As mentioned in Chapter 2 several studies have employed an Interpretive Phenomenological Analysis approach to explore women's experiences of PAL (Keith 2005, Kint 2015, Sun et al. 2011, Ünstündağ – Budak et al. 2015). Although some studies have used IPA to explore the experiences of couples (Campbell-Jackson et al. 2014, Meaney et al. 2016, O'Leary 2002, O'Leary 2005) none have specifically focused on their experiences as part of a couple nor interviewed couples together as a dyad.

Therefore, a qualitative approach and more specifically, an Interpretive Phenomenological Analysis (IPA) methodology was deemed the most appropriate to explore the research question under consideration.

Interpretive Phenomenological Analysis

Interpretive Phenomenological Analysis (IPA) is an approach to qualitative inquiry that has its origins in phenomenology and hermeneutics. It is concerned with the particular, individual experiences of a phenomenon (Smith et al. 2009). It has been specifically suggested that IPA is especially useful when exploring phenomena that are challenging and poignant such as how couples, make sense of their experiences of pregnancy after stillbirth (Smith and Osborn 2015).

Phenomenology, by its "use of thick description and close analysis of lived experience (*helps us*) to understand how meaning is created through embodied perception"(Starks and Trinidad 2007 p.1373). Phenomenology is the exploration of human experiences and how meaning is attributed to these human experiences. It has its origins in philosophy and the work of Edmund Husserl (1859-1938) (Langdridge 2007, Sawicki 2017). The central pillars of Husserl's philosophy are description and phenomenological reduction, and by so doing unearthing the 'essence' of an experience. In order to do this, Husserl attests the researcher must 'bracket' their understandings or pre-conceptions (Behnke 2017, Langdridge 2007, Spear 2017). Husserl's work greatly influenced his student Martin Heidegger (1889-1976) who posited that all experiences are grounded in the experience of 'being in the world'. Therefore, researchers could not 'bracket' themselves, rather they

needed to explicitly 'out' themselves by means of reflexivity. This concept of self-awareness by the researcher is a key component of IPA. The researcher can influence every stage of research process and this influence must be explicitly outed and acknowledged.

Heidegger's philosophy was to delve deeper than mere description and develop a hermeneutic approach to experiences to try to understand them fully. He suggested that experiences are context dependent and need to be interpreted rather than just described (Korab-Karpowicz 2017, Langdridge 2007). The hermeneutic cycle is the continuous development of the individual making sense of their experiences. Within IPA, there is a double hermeneutic cycle at work whereby the researcher is constantly trying to make sense of the participant's making sense of their experiences (Smith et al. 2009). Thereby in IPA the researcher is attempting to enter the participants' life world to explore, in as far as is possible, these experiences. The participant is the expert in his or her own experiences and the researcher is attempting to be an empathetic conduit for these experiences.

Other 20th century philosophers have built upon these seminal works including Merleau-Ponty (1908-1961). Merleau-Ponty supported Husserl's belief in the need for bracketing. He emphasised the embodied nature of experience that influenced our understandings of the world (Langdridge 2007, Reynolds 2017). He believed that our lived experiences could not be separated from our embodied experience of the life world.

The use of dyadic interviews in IPA research requires consideration. Polak and Green (2016) cite the fact that the terms 'joint', 'couple' and 'dyadic' are often used

interchangeably in the research, so there can be confusion and lack of methodological agreement. As this study was concerned with, understanding how couples, as a unit; make sense of PAL it was necessary that both partners in the couple should be able to contribute to the research. The experiences of both women and men are unique and valuable. Men are not only a support to the women in PAL but have personal experiences in their own rights. Men's experiences are under-represented in the research and their needs are often unmet with the maternity services. In PAL research, men's experiences are underexplored and the researcher was mindful of the challenges that dyadic interviews could have in permitting the male voice to be heard (Seale et al. 2008). By agreeing to participate in joint interviews, the researcher was mindful that some men might be participating to please their partners. However afterward each interview all men expressed gratitude at having the opportunity to discuss their concerns (Braybrook et al. 2017, Mellor et al. 2013).

Within IPA, the researcher is not looking for agreement on experiences per say, rather wishing to explore the couple dynamics (Braybrook et al. 2017, Taylor and de Vocht 2011). Joint interviews can contribute to the helical or spiral nature of hermeneutic interpretation because of the presence of both members of the couple (Conroy 2003). Researchers have previously used joint interviewing techniques to elicit couples' responses on sensitive issues relating to perinatal loss. Both Hagemeister and Rosenblatt (1997) and Dyregrov and Gjestad (2011) interviewed couples together about their experiences of sexuality and intimacy in the aftermath of child bereavement. They also interviewed several of their participants individually to ascertain if any information that was withheld in the dyadic interviews. They found

no difference in information disclosed. IPA was therefore identified as the most useful method of qualitative enquiry in which to explore couples' multiple realities (Smith et al. 2009).

Study Sample

In keeping with the principles of IPA it was planned that a small, homogenous sample be recruited to the study (Smith et al. 2009). Over the course of a six-month period from March to August 2015, a convenience sample of eight women and their partners, who were pregnant again following a stillbirth in their previous pregnancy, agreed to take part in the study.

Inclusion criteria were women and their partners who had experienced a stillbirth, due to any cause, in the immediately, preceding pregnancy; participants who spoke fluent English; and who were aged 18 years or over at the time of recruitment. These criteria were to obtain fully informed consent and to facilitate in depth discussion of the issues of concern to the couple. Exclusion criteria were women and their partners who had a live birth since their index loss; who did not speak English fluently; and who were less than 18 years at the time of recruitment.

Access and recruitment of participants

In 2015, of the 65,869 births that occurred in Ireland, 52.4% were born in hospitals having more than 8,000 births per annum. This study took place in one of these large hospitals, with approximately 8,000 births per annum. On average, 45 couples annually experience stillbirth within the maternity services where the study took

place (O'Farrell et al. 2017). Perinatal Statistics Report for 2015 estimate there are 9.5 women per 1,000 maternities, pregnant with a history of previous stillbirth (Healthcare Pricing Office 2017). This translates to an estimated 76 women annually, pregnant following stillbirth, in this service. Given the small numbers involved and the issues of confidentiality, it is not possible to subdivide these statistics into those women who are pregnant in the immediate pregnancy after stillbirth or women who have a history of stillbirth in any of their pregnancies.

This hospital has a well-developed pregnancy loss service with two obstetricians specialising in the area of pregnancy loss, two bereavement midwives, a dedicated pregnancy loss unit and a chaplain who support couples at the time of a pregnancy loss. All staff provides follow up support services for couples and are available for support during the next pregnancy after stillbirth.

The obstetrician and clinical team lead was consulted on the feasibility and design of the study at the outset. Full support was given, as it contributed to the research aims of the pregnancy loss research group (Appendix 6). Access to the study sample was through the clinicians (doctors and midwives) involved in the maternity service provision. The researcher did not have direct access to the population and was dependent upon the clinicians to provide information leaflets and information on the study, to couples who met the inclusion criteria (Appendix 7). To assist with recruitment, information sessions on the study were provided to the relevant

gatekeepers (doctors and midwives) by means of a Grand Rounds[1] presentation and by providing one to one information in the antenatal clinic.

It is unknown if women acted as gatekeepers for this study recruitment. The researcher did not have direct access to the couples and so was not aware of how many couples in total were informed about the study nor how the clinicians informed them. Information about the study and a letter of invitation to participate in the study was given to couples who met the inclusion criteria by the antenatal clinic staff (Appendix 7). Couples who expressed an interest in taking part in the study were invited to make telephone contact. At the initial telephone contact, the aims of the study as outlined in the letter of invitation was expanded upon and questions answered. Couples who were interested in participating further met with the researcher at a location and time of their choosing. Voluntary, written, informed consent was obtained from both study participants (Appendix 8). Couples were advised they could withdraw from study at any stage. Confidentiality and data security were guaranteed, pseudonyms were ascribed and participants were assured that their data would not be shared with the clinical sites.

Data collection procedures

Face to face interviews were conducted with eight couples. Five couples chose to be interviewed in their homes, usually late in the evening when they could sit together after smaller children were put to bed. Two couples wished to be interviewed in a

[1] Grand rounds is a weekly, multidisciplinary meeting of clinical and academic staff working in the maternity hospital.

small private meeting room in the maternity hospital following one of their antenatal appointments. The final couple asked to meet at an outdoor coffee shop near to their obstetrician's office. Interviews were carried out when women were greater than 20 weeks' gestation in a PAL. At this point in pregnancy, women are considered beyond the risk of miscarriage, have confirmed an ongoing pregnancy, and have had an anomaly scan to ensure the wellbeing of their baby. The couples were interviewed together in the late second or third trimester of the immediate pregnancy following a stillbirth. The interviews varied in length from 72 to 134 minutes. With permission, the interviews were audio recorded with an Olympus digital voice recorder (Model WS811). This provided high quality, audio recordings.

A brief, semi-structured interview guide was used to provide structure to the interview (Appendix 9). Biggerstaff and Thompson (2008) suggest that an interview guide is not prescriptive, per say, but rather used to frame the interview process. Since the experiences of couples was the focus, the researcher aimed to ensure that their agenda did not unduly influence the interview schedule. During the interviews, and in keeping with the recommendations of Smith et al. (2009), I endeavoured to remain neutral, allowing the participants stories to emerge. Open questions were used, for example, *'can you tell me how this pregnancy has been for you as a couple?'* If necessary, clarification by using reflection or paraphrasing was sought. Only when particular information was needed were closed questions used, for example *'did your family meet the baby?'*

Field notes (Appendix 10) were made immediately before and after each interview as is in keeping with IPA principles (Smith et al. 2009). As suggested by Biggerstaff

and Thompson (2008) these notes included thoughts, impressions, observations and reflections of each interview. For example, in my meeting with Jill and David I noted that their house was filled with photographs of Jill before their daughter's death. These photographs showed Jill as a vivacious, colourful woman. Yet the woman I interviewed appeared the opposite of the woman in the photographs. Jill dressed entirely in black with her hair scraped into a ponytail and without any makeup. Jill attributed her dour attire as an outward manifestation as to how she was '*changed by loss'*. This observation added to the richness of the data this couple shared and assisted in the data analysis of the issues of concern for this couple.

Data analysis

The processes of collecting and analysing data were done concurrently. The interviews were audiotaped and transcribed verbatim. As a professional data transcription service was used, data protection measures were secured (Appendix 11). The data were transcribed and formatted using accepted data analysis annotations (Appendix 12). Once the data transcripts were received, the raw data were checked. This involved listening to the interviews for accuracy and correcting any errors or omissions by the data transcription company. The data were anonymised and all participants ascribed pseudonyms prior to further analysis.

When wishing to explore how couples experience a phenomenon, Polak and Green (2016) suggest that joint or dyadic interviews are a strong data collection tool because it facilitates the discovery of the shared nature of experiences (Morris 2001, Radcliffe et al. 2013). The aim of this study was to understand experiences of couples

in pregnancy after stillbirth. For the purposes of this study, dyadic interviews were used. Couples who had a pre-existing relationship were interviewed together and their data were analysed together. Joint interviews are particularly beneficial when conducting relationship-based interviews as they allow for the interactions between participants to inform the data (Morgan et al. 2013, Morgan 2016). Shared understandings may be more apparent in joint interviews because couples can co-construct narratives (Taylor and de Vocht 2011). For example, this co-construction was evident in Iona and Evan's exploration of their attendance at couples' therapy sessions. The presence of one another can stimulate couples' discussion and memories can be shared (Valentine 1999). Joint interviews may enlighten participants to issues where they may not have been previously fully aware (Taylor and de Vocht 2011). In the interview with Grace and Adam, Grace revealed she '*didn't want to turn into one of those psychos'* in their efforts to achieve a pregnancy. Adam's response was '*but you did'*. Grace then acknowledged '*I suppose I did'.* Adam's presence and responses allowed Grace to make sense of her behaviour.

Conversely, the presence of the other couple member may affect the individuals' disclosure of their personal truth. For example, it has been suggested that men may not fully share their own experiences in the presence of their partners (Seale et al. 2008). For examples, in this study men believed *'my job was to protect her'.* However, "The shared identity of a couple can become authentic as long as partners are freely 'choosing to choose' to adopt this identity" (Taylor and de Vocht 2011 p.1581). While what couples reveal sheds light on their lifeworld, what they conceal may also shed light on their lifeworld. Obvious expression of feelings may not always be present so the researcher has to be aware of non-verbal cues that may indicate agreement or

disagreement among couples (Braybrook et al. 2017). Certain topics may create tension between couples for example, Jill and David's discussion of cutting down a recently planted tree (Braybrook et al. 2017). However, joint interviews are usually seen as safe spaces where issues can be openly discussed. It is unlikely that couples will raise issues that have not previously been discussed by themselves (Braybrook et al. 2017).

The study had to take cognisance of the additional layer of dyadic interpretation required. Dyadic analysis is useful when exploring the individual's experiences and the relationship between them (Palmer et al. 2010). Data were coded and analysed confidentially using IPA principles (Smith et al. 2009) and in addition, the works of Palmer et al. (2010), Tomkins, and Eatough (2010) informed the stages of data analysis to ensure the individual as well as the couple voices were heard. The following processes were completed with supporting exemplars:

1. Familiarity with the data. Reading and re-reading, noting strong recollections.
2. Initial noting- free textual analysis, close to the original data and noting the objects of concern. Noting descriptive, linguistic and conceptual comments of individual participants (Appendix 13).
3. Repeat step 2 for couples; noting the differences and similarities and acknowledging the interplay between the two (Appendix 14).
4. Developing emerging themes (Appendix 15).
5. Searching for connections across emerging themes (Appendix 16).
6. Moving to the next case (repeating steps 1-5)
7. Looking for patterns across cases.

(Palmer et al. 2010, Smith et al. 2009, Tomkins and Eatough 2010)

There were several drafts of the findings before the full themes were agreed. Each stage of the process was reviewed and discussed with supervisors experienced in qualitative methods. Tables outlining the themes as they relate to the participants' voices are included (Appendix 17 and 18).

Methodological rigour

It is incumbent upon all researchers to ensure the trustworthiness and accuracy of the research process. Methodological rigour is vital in advancing the science of qualitative research (Finlay 2009, Smith et al. 2009). The ontological and epistemological stance will inform the methods by which this can be achieved, as there cannot be a blanket approach (Guba and Lincoln 1994). IPA is considered a trustworthy and rigorous method because of its attention to the particular lived experience of the individual. However, the application of quantitative measures of quality such as validity and reliability to qualitative research has proved to be problematic (Smith et al. 2009, Langdridge 2007). To demonstrate trustworthiness in an IPA study, Smith et al. (2009) suggest the framework proposed by Yardley (2000). The following Figure 3.1 demonstrates how this was achieved in this study.

Yardley (2000) Principles of Quality	IPA Smith et. al (2009)	Strategies employed
Sensitivity to context	Context and sensitivity of study. Rapport with key gatekeepers. Verbatim extracts	Did ground work and consulted with key stakeholders. Built on existing relationships with clinical staff. Large number of verbatim extracts to demonstrate findings.
Commitment and rigour	Degree of attentiveness in data collection. Care with data analysis. Thoroughness of the study.	Focused on individuals within the couple as well as the couple dyad. Each case analysed extensively as per IPA principles. Attention to description and interpretation. Worked closely with experienced supervisors.
Transparency and coherence	Clarity at all stages of the research process. Coherence with underlying theoretical assumptions.	Clear, extensive write up with use of tables, images and raw data transcripts. Thesis reports lived experiences and interpretation.
Impact and importance	Interesting, important or useful.	Address gap in literature. Will inform policy, education and research.

Figure 3.1 Methodological Rigour

Ethical considerations

Prior to conducting the study full ethical approval was obtained from the Research Ethics Committee of the Local Teaching Hospitals (Appendix 2). Permission to conduct the research and to access participants was obtained from the Director of Midwifery (Appendix 3) before data collection began.

Pregnant women are often classified as a vulnerable population within research ethics, although there is a growing body of literature supporting the necessity for their inclusion as research subjects (American College of Obstetricians and Gynecologists 2007). It is important to explore the experiences of this cohort of women and their partners because they are the experiential experts and have a unique perspective on stillbirth and of subsequent pregnancy after loss. Adherence to stringent criteria to protect a vulnerable population group is recommended (Liamputtong 2007). It has been suggested that gatekeepers can be over-zealous in their duty of care to vulnerable populations, often to the point of denying them a voice (Bond Sutton et al. 2003). Recent studies have shown that bereaved couples wish to participate in research and to have their stories heard, to improve clinical care (Breeze et al. 2011, Siassakos et al. 2015). Regulations on conducting research set down by the Code of Professional Conduct and the Ethical Conduct in Research: Professional guidance were strictly adhered to (Nursing and Midwifery Board of Ireland 2007, Nursing and Midwifery Board of Ireland 2014).

In consideration of the ethical principle of non-maleficence, the issue of minimising potential risk to study participants was addressed at every stage of the research process. Women who are pregnant following stillbirth and their partners are at

increased risk from reactivated grief responses during their subsequent pregnancies. Therefore, it was imperative that measures were implemented to ensure the emotional safety of this particular group of research participants. It was endeavoured that no harm would come to either the women or men participating in this research. I was aware that the participants may become upset when talking about their experiences and when that arose, I dealt with these issues sensitively. For example, when women did become tearful during the course of the interviews, they were offered comfort measures and offers to suspend the interviews were made. None of the participants wished to stop the interviews, they expressly wanted to continue with the process. All of the study participants were offered the support of the Hospital Chaplain (Appendix 4) and the Clinical Midwife Specialist in Bereavement (Appendix 5), whose services were secured in advance to support this study. These experienced staff were available to provide counselling and support services to any woman or man participating in the study should they wished to avail of it. These staff were familiar to the women and their partners as they form part of the Pregnancy Loss and High Risk Pregnancy team within the maternity services. None of the study participants availed of this additional support. I also brought my clinical and academic experience to bear in conducting these interviews and supporting these couples when these issues arose. I was observant of participants' verbal and non-verbal cues, was vigilant for indicators of distress or upset concerning their experiences.

Although it is acknowledged that they are not without the potential for causing harm, joint interviews allow for a glimpse into the couples co-created lifeworld and their shared meaning making. Respect for couples was protected in this study, as it was up to each person how much they did or did not wish to share. There could have been

the potential for harm when disagreement was noted among the couples' narratives. The researcher was sensitive to the subtle non-verbal cues and did not draw attention to them in case doing so may potentiate harm, even if not doing so may have resulted in less data. The researcher instead asked if the other partner wished to add anything and did not probe further if they demurred. When occasion arose during an interview where there was obvious discomfort with one participant in the couple, the researcher interpreted and paraphrased their understanding (Taylor and de Vocht 2011). Bjørnholt and Farstad (2014) argue in favour of dyadic interviews on ethical grounds, because the couple has joint control over what is and is not disclosed.

To ensure the ethical principle of autonomy full disclosure of the aims and objectives of the study were furnished to every prospective participant. As previously mentioned, it has been suggested that women can act as gatekeepers for their partners in joint interviews (Mellor et al. 2013). It was not possible to ascertain if this was the case in this study, among women who were informed about the study. There may have been women who decided that their partners would not be interested in taking part and so did not even tell them about the study.

Likewise, Mellor et al. (2013) suggest that some men may feel pressurised by their partners in taking part by persuasion or as a means of placating the women. This was a challenge for this study as its focus, was the experiences of couples. To address this, the researcher spoke with men as well as women by phone when they contacted me to answer any questions they may have about the study and when we met face-to

face by ensuring that written, informed consent was obtained from both members of the couple.

Bjørnholt and Farstad (2014) suggest that interviewing couples together is preferable to individual interviews in that it assists with participants' sense of consent, anonymity and control especially when the area of research interest is the couple as a dyad, as in this study. Several studies have suggested that maintaining confidentiality and anonymity is very challenging when individual interviews with couples are carried out (Eisikovits and Koren 2010, Forbat and Henderson 2003, Hertz 1995). Mellor et al. (2013) discovered that men were able to maintain autonomy in joint interviews by regulating the data they were willing to disclose.

Reflexivity

Reflexivity is another strategy that contributes to trustworthiness of the study (Finlay and Gough 2003). Reflexivity is defined, as the influence of the researcher on all stages of the research process (Langdridge 2007). Therefore, cognisance was taken of the impact that I as a midwife, bereaved person, and female could have on all stages of the study (Hertz 1995). This requires a degree of self-disclosure on the part of the researcher (Hertz 1995, Johnston et al. 2017). Acknowledgement of my own lifeworld view as a midwife requires consideration, as it influenced every stage of the research process. I espouse the social model of birth and believe in the primacy of women and men as experiential experts. Therefore, only by exploring the lived experiences of couples can we explore the concept of pregnancy after loss for them. These beliefs steered the original research question and similarly, informed the

literature searching, data collection and analysis. However, I was cognisant of my own position and sought to 'out' my lifeworld view at every stage of the process. Reflection is a key component of the IPA process so a reflective diary was maintained throughout (Smith et al. 2009). This included critical analysis of thoughts and experiences throughout the study design, data collection, data analysis and thesis write up. Field notes were completed before and after each interview (appendix 10). Reflective diaries were also used during the data transcription and data analysis stage to inform the analysis and as an aid memoire (Finlay and Gough 2003, Smith et al. 2009). However, I was conscious that the act of reflection did not become an exercise in self-absorption in itself (Finlay 2009). Rather, attempts were made at every stage to remain close to the participants' words to inform understandings of their lifeworld (Rubin and Rubin 2005).

Summary

This chapter has outlined the development of the research question and study aim. The rationale for the research design was presented including the ontological, epistemological and methodological approach taken. The methods for the study completion were presented, including the sample, access, recruitment, and ethical issues. As espoused by Smith et al. (2009) and in keeping with IPA principles, a sample of eight couples, pregnant again after stillbirth were interviewed to elicit their experiences. Transparent accounts of the data analysis process and adherence to methodological rigour were discussed. The findings of this process will now be presented in the next chapter.

Chapter 4: Findings

Introduction

This chapter presents the study findings relating to eight couples in the immediate pregnancy following stillbirth or late miscarriage. Based on the principles of IPA, two superordinate themes emerged '*Hoping for a Born Alive Baby'* and *'Journey of Loss'*. To provide context and background the characteristics of the couples and their families are first presented then the two superordinate themes scaffolded by their subordinate themes are presented.

Characteristics of the sample

Eight heterosexual couples agreed to be interviewed for this study. Couples were in the immediate pregnancy after their loss and were in the late second or third trimester of this subsequent pregnancy. Seven couples were of Irish nationality and one couple was of British nationality, living in Ireland. All of the couples were married and/or cohabiting at the time of the subsequent pregnancy and interview. All but one couple (Valerie and Tim) were living together at the time of their index stillbirth or miscarriage. The couples were aged 30-40 years and all were parents prior to loss except Valerie and Tim who were both younger (25-29 years) and had no living child prior to their index loss. All members of the couples were in employment outside the home.

Biographical and relevant study sample information

In keeping with the idiographic principle of IPA, a brief synopsis of each individual couple's circumstance is presented (Figure 4.1). This provides particular background information and adds specific detail to their experiences, which adds context to the findings.

Figure 4.1 Biographical and relevant study sample information

Number Participant Pseudonyms	Parental Age (years)	Country of Origin	Marital Status	Mother's Occupation	Father's Occupation	Pseudonym of Stillborn Infant(s)	Gestation/ date of loss	Diagnosis	Pseudonym/ Ages (years) of Siblings	Time from loss (months) to PAL	PAL Gestation (weeks) at interview	Time loss (months)
1. Anna & Mark	35-40	Ireland	Married	Sales Admin	IT Advisor	Julia	32+4/40 IUD/IOL (Jan 2013)	Triploidy/Dx AN @24/40	Sarah (3.5)	9	32/40	16
2. Jill & David	35-40	Ireland	Married	Post-primary Teacher	Hotel Porter	Zoe	32/40 IUD/IOL (June 2013)	Cardiac Anomaly/ Edward's Syndrome/ Dx AN @24/40	Molly (12)	15 (had a miscarriage at 6 weeks, 9 months after SB)	27/40	22
3. Valerie & Tim	25-29	Ireland	Single/Cohabiting	Midwife	Self Employed	Rachel	25/40 SOL/IUD (Aug 2012)	PPROM/Dx AN @ 17/40	None	24	35/40	33
4. Kim & Simon	35-40	England	Married	Property Developer	Property developer	Ruby	22/40 IUD LUCS@38/40 (Oct 2013)	IUD Twin/Dx AN @22/40 Unknown cause	Harry (5) Euan (4) Louis (15 months)	14	38/40	20
5. Nadine & Jonah	30-34	Ireland	Single/ Cohabiting	Sales Assistant	Unknown	Imogen	39/40 IUD/IOL (Sept 2014)	Group B Strep/ Unexpected IUD	Liam (10)	3	34/40	11
6. Naomi & Doug	35-40	Ireland	Married	Primary Teacher	IT Consultant	Dylan	19/40 IUD/IOL (April 2013)	Hypercoag/ Unexpected IUD	Jamie (5) Suri (3.5)	7	26/40	13
						Oliver	19/40 IUD/IOL (July 2014)	Hypercoag/ Unexpected IUD				
7. Iona & Evan	35-40	Ireland	Married	Sales Admin	Unknown	Kristine	32/40 IUD/IOL (Jan 2013)	Major Cardiac Anomaly/Dx AN @14/40	Cait (6) Eva(4)	23	36/40	31
8. Amy & Brian	35-40	Ireland	Married	Office Admin	Farmer	Conor	22+6/40 SOL/IUD (Nov 2014)	Preterm ROM @22/40	Bill (3) John (2)	3	38/40	11

Dx AN = Diagnosed Antenatally PPROM = Premature Prolonged Rupture of Membranes Hypercoag/ Unexpected IUD = Hypercoagulability/Unexpected Intrauterine Death

IUD/IOL= Intrauterine Death/Induction of Labour SOL/IUD=Spontaneous Onset of Labour/Intrauterine Death IUD/LUCS=Intrauterine Death/Lower Uterine Caesarean Section

Grace and Adam

Grace and Adam are parents to Sarah who was aged 2 years in 2014 when their second child Julia, was stillborn at 32^{+4} weeks. Julia was diagnosed with a major cardiac anomaly at 24 weeks' gestation. Grace's hope always was for more children and she became pregnant again 9 months after Julia's death. They decided to try for another baby once they had the results of the post-mortem and they had honoured the timescale of Julia's events. It was very important to Adam to respect the time of Julia's pregnancy, birth and death as 'her time' before they decided on another pregnancy. In the pregnancy after loss, Grace was conflicted and struggled with attachment to their new baby. Grace wanted to look forward to meeting her new baby but was afraid of trusting in the reality of a live baby. Adam encouraged Grace to remain focused on a positive outcome. He saw his role being to 'look after Grace' by 'man-ing up', keeping things to himself, and letting her 'talk things out'. He admitted to being fearful of another loss, doubting his ability to cope. Adam believed that the loss of Julia was far greater for Grace than him because of Grace's physical connection to Julia. Grace acknowledged she was well supported in her grief by her family and female co-workers. Adam's co-workers rarely acknowledged his loss saying 'men don't really talk about these things'. He relied upon Grace for his emotional support.

Jill and David

Jill and David are parents to Molly and Zoe. Molly was aged 10 years when their second child Zoe was diagnosed at 24 weeks with a major cardiac anomaly in 2013. Jill did not want to acknowledge the implications of this diagnosis, opting to defer confirmatory diagnostic procedures until the risk of a pregnancy loss had passed.

However, Zoe was stillborn at 32 weeks before that procedure could take place. Jill and David reported a lack of family support and appreciation of their loss, which proved hugely problematic for them both, Jill in particular. This resulted in Jill isolating herself from family, friends and the wider community. Jill felt this lack of recognition meant she had to constantly defend and stand up for Zoe. Jill acknowledged that her erratic behaviour may appear ridiculous but believes the veiling of her current pregnancy is due to a loyalty to Zoe. She equated it as having two faces, a private and a public one. Jill allows the public mask to slip with her daughter Molly when they plot the new baby's growth and look forward to the birth of the new baby. Jill and David struggled with their differing approaches to grief and were anxious to learn how other couples in the study have fared.

Valerie and Tim

Valerie and Tim live together in a town over 100 miles from the maternity unit where Valerie booked in for her maternity care. Two and a half years prior to their interview Valerie and Tim's first child, Rachel was stillborn in 2012. Rachel was born at 25 weeks following a Premature Prolonged Rupture of Membranes (PPROM) at 17 weeks. Rachel's loss was exceptionally challenging for Valerie and Tim's relationship. They had not been a couple very long when the unplanned pregnancy with Rachel was confirmed. Valerie and Tim did not live together, or geographically close, at the time of the loss. They also did not live together after the loss of their daughter. Valerie found the experience of being a mother without a living child and not having her maternal status publically recognised very difficult. She welcomed any opportunity to discuss her experiences of Rachel. Tim coped with his loss and grief by immersing himself in work. There was a time when their relationship appeared in difficulty. Over

time, the couple worked through their individual grief and despite these hurdles, their relationship endured. They began planning a future together and bought a new apartment in Tim's hometown two years after Rachel's death. Valerie became pregnant within two months after they began living together in December 2014. Although not unexpected, this pregnancy was also unplanned. Valerie expressed worry at the prospect of facing labour again as Rachel died during labour. They both were looking forward to bringing the new baby back home where they could 'find their own way' and parent together.

Kim and Simon

Kim and Simon are parents to Harry (5 years) and Evan (4 years) and Louis (15 months). Harry was 3 years and Evan was 2 years when Ruby their daughter was an Intrauterine Death at 22 weeks gestation. Ruby was a half twin to Louis and remained in utero with him to full term. Ruby became a fetus papyraceous. This is a very rare complication of multiple pregnancies where one fetus dies, becomes mummified and remains in the womb alongside its surviving half twin. Louis and Ruby were both born at 38 weeks' gestation by caesarean section. Harry was 3.5 years and Evan was 2.5 years when their siblings were born. This very unusual circumstance created enormous conflict for Kim as she suppressed her grief for Ruby to continue her pregnancy with Louis. The couple's ability to cope with Ruby's loss was greatly compromised by a perceived lack of care they received at the maternity unit they were attending at the time. It was not until both babies were born at 38 weeks that Kim allowed herself permission to grieve the loss of her daughter. She describes funnelling her love for both infants into the surviving infant, Louis. Kim always wanted to have four children, as she herself was an only child. She waited for Simon

to agree to another pregnancy; although initially reluctant for another pregnancy, he maintained that the ultimate decision always rested with her.

Nadine and Jonah

Nadine and Jonah are parents to Liam and Imogen. Liam was 9 years old when Imogen was unexpectedly stillborn at 39 weeks' gestation in September 2014. Nadine presented with decreased fetal movements and was unexpectedly informed that her baby had died in utero. On post-mortem, Imogen was diagnosed with Group B Streptococcus (GBS), a common vaginal commensal, that in very rare cases causes unexplained intrauterine death. Nadine and Jonah wished to get pregnant immediately and did so within 4 months of their daughter's death. Jonah believed that although the pregnancy was an anxious time for them both, being pregnant helped Nadine's grief for Imogen. Nadine said she wants to give the love she had for Imogen to this new baby. The very recent death of their otherwise healthy term baby has been challenging for Nadine and Jonah to make sense. The anniversary of Imogen's birth had not yet occurred at the time of interview. Due to the presence of GBS Nadine believes that her body is not a safe place for her babies to be and wants her new baby born soon.

Naomi and Doug

Naomi and Doug are parents to Liam, Suri, Dylan and Oliver. Liam was 3 years and Suri 2 years when their son Dylan was an intrauterine death at 19 weeks in April 2013. Liam was 4 years and Suri 3 when their son Oliver was also an intrauterine death at 19 weeks in July 2014. Losing two babies in rapid succession was very challenging for Naomi and Doug, particularly when it was discovered that it was the same medical complication that caused both deaths. The couple were accepting of Dylan's death

but were devastated by Oliver's subsequent death. Naomi felt Oliver's death might have been prevented if more thorough investigations had been carried out after Dylan's death. The couple only felt able to plan for another pregnancy once more thorough investigations were done, a definite cause had been identified and treatment recommended for a subsequent pregnancy. However, the pregnancy for them remains fraught with anxiety and worry.

Iona and Evan

Iona and Evan are parents to Eva, Cait and Kristine. Eva was 3.5 years and Eva was 1.5 years when Kristine was stillborn at 32 weeks in January 2013. Kristine was diagnosed with a major cardiac anomaly, incompatible with life at 14 weeks' gestation. The couple had their care transferred from a smaller maternity unit to a larger tertiary maternity unit for review by a Paediatric Cardiology specialist in Dublin. Iona and Evan did not share news of Kristine's death with their children as they felt they were too young to understand and did not wish to burden them with that information at this time. They took some time (2 years) before embarking upon another pregnancy. Evan was mindful of not wishing to replace Kristine with a new baby.

Amy and Brian

Amy and Brian are parents to Larry, John and Conor. Larry was 2 years old and John was 1-year-old when their third son Conor was stillborn at 22 weeks and six days in November 2014. Amy wanted to be pregnant again for Conor's due date, which they achieved. The anniversary of Conor's birth had not occurred at the time of interview. Amy and Brian's first son Larry was born 11 weeks prematurely and he spent 10 weeks in a neonatal unit. John, their second son was a term pregnancy. In her third

pregnancy, Amy experienced a premature prolonged rupture of membranes at 22 weeks. The couple were optimistic about Conor's survival prospects during pregnancy. They believed that if he reached a viable gestation, he stood a good chance of surviving. Their prior experience of having a preterm baby and their knowledge of other parents whose infants survived at the margins of viability gave them hope of a positive outcome.

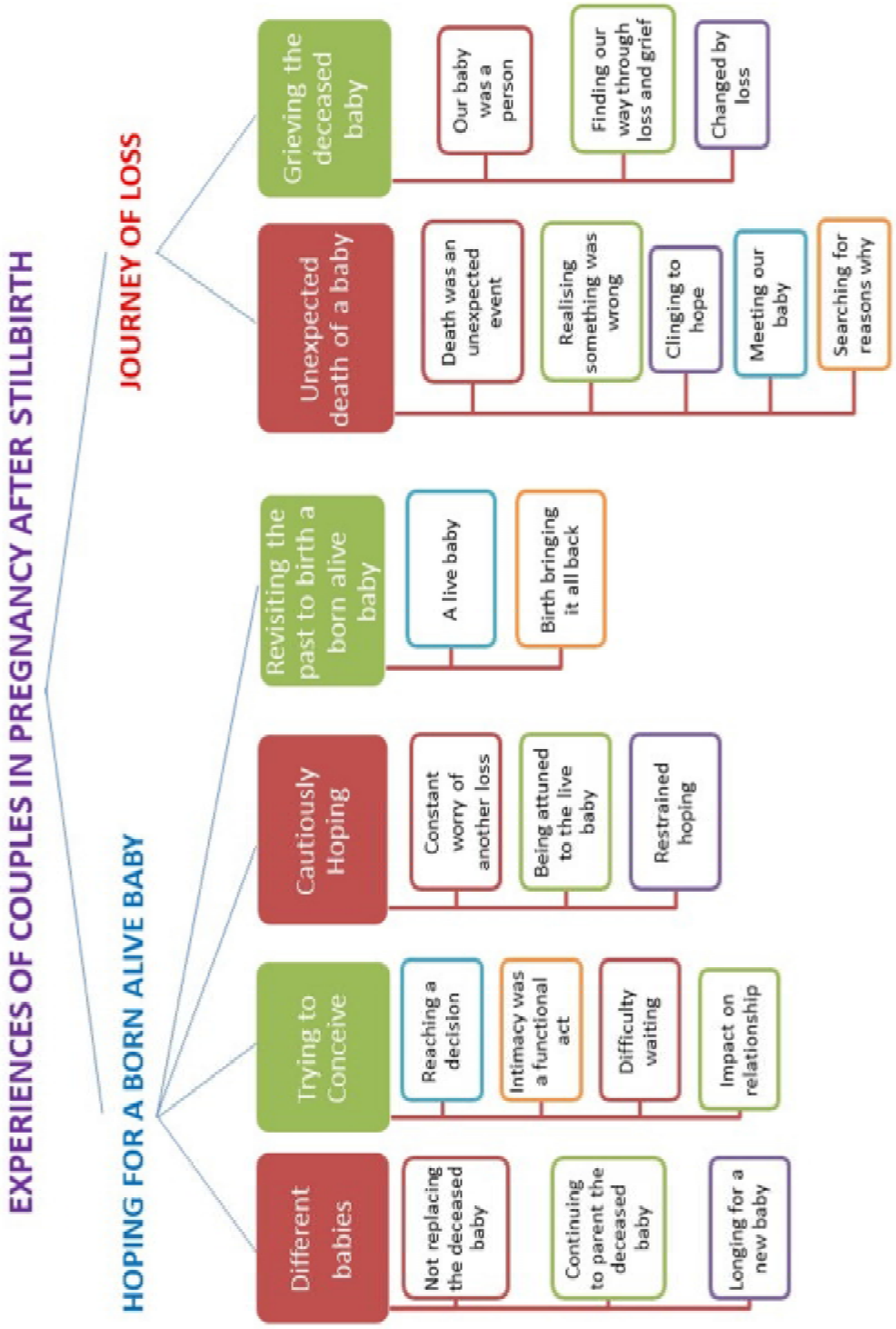
Superordinate themes

Using the systematic method of IPA outlined by Smith et al. (2009), core data analysis identified two superordinate themes *Hoping for a Born Alive Baby* and *Journey of Loss.* These superordinate themes were developed from subordinate themes and informed by emergent themes directly from the participant voices and were the product of the iterative processes of IPA. Figure 4.2 outlines the superordinate, subordinate, and emergent themes in grid format as represented across the eight couples in study and Figure 4.3 demonstrates these themes in graph format.

Figure 4.2 Superordinate, Subordinate and Emergent Themes Grid

Superordinate Themes	Grace/Adam	Jill/David	Valerie/Tim	Kim/Simon	Nadine/Jonah	Naomi/Doug	Iona/Evan	Amy/Brian
HOPING FOR A BORN ALIVE BABY								
Different babies								
Not replacing the deceased baby	X	X	X	X	X		X	X
Continue to parent the deceased baby	X	X	X	X	X		X	X
Longing for a new baby	X	X	X	X	X			X
Trying to conceive								
Reaching a decision	X	X	X	X	X	X	X	X
Intimacy was a functional act	X	X	X	X			X	
Difficulty waiting	X	X	X		X	X		X
Impact on relationship	X	X	X	X	X	X	X	X
Cautiously hoping								
Constant worry of another loss	X	X	X	X	X	X	X	X
Being attuned to the live baby	X			X	X	X	X	X
Restrained hoping	X		X		X	X		X
Revisiting the past to birth a born alive baby								
A live baby	X	X			X	X	X	X
Birth bringing it all back	X	X	X	X	X	X		X
JOURNEY OF LOSS								
Unexpected death of a baby								
Death was an unexpected event	X		X	X	X	X	X	X
Realising something was wrong		X	X	X	X	X	X	X
Clinging to hope		X	X		X		X	X
Meeting our baby	X	X		X	X	X	X	X
Searching for reasons why	X	X		X	X	X	X	X
Grieving the deceased baby								
Our baby was a person	X	X	X	X	X	X	X	X
Finding our way through loss and grief	X	X	X	X	X	X	X	X
Changed by loss	X	X	X	X	X	X	X	X

Figure 2.3 Superordinate, Subordinate and Emergent Themes Graph



Hoping for a born alive baby

How couples made sense of pregnancy after loss is presented in the first superordinate theme '*Hoping for a born alive baby'*. To move forward and contemplate a subsequent pregnancy couples first acknowledged that they were parents to '*different babies'* before they began '*trying to conceive'*. Throughout the subsequent pregnancy they were '*cautiously hoping'* for a live baby all the while knowing that they had to '*revisiting the past to give birth to a born alive baby'*.

Different babies

It was important for couples that they could separate out the identity of their babies, that is, the deceased baby and the new baby conceived following pregnancy loss. Couples were adamant that the subsequent baby was *'not replacing the deceased baby'*. Rather a new pregnancy was to get back to where they should have been in terms of parenting. They were '*continuing to parent the deceased baby'* and although their experiences brought conflicting, grief and happiness, couples were '*longing for a new baby'*.

Not replacing the deceased baby

Subsequent pregnancy was often described as fulfilling a desire to complete a picture of pre-conceived family life as illustrated by Valerie:

> *"Well I was always like really motherly like I always said I wanted twenty kids like I have always been like that, but I suppose it wasn't to replace her, definitely. It was to get back to where it was meant to be, do you know what I mean? I was a mother but wasn't" [Valerie 219-222]*

Valerie and her partner Tim were not parents to living child (ren) prior to their loss. Her comment on 'getting back to where I was meant to be' might seem akin to a

statement on wanting to be in her previous state of pregnancy progressing towards the birth of the baby she carried then. This was not what she meant. She made sense of her current pregnancy in terms of her maternal status such that she wished to mother again. The idea of getting back to where they were meant to be offered the opportunity for a new beginning as in 'turning the page' referred to below by Adam:

> *"But we will also be very happy, I know we were very sad with Julia but we will be very happy. Not our chapter but kind of turning the page and what happened with Julia we will always remember but I am due something new now you know maybe like yeah we can forget about 2014 as if it didn't happen. Well not that it didn't happen but you know as if were at a stage where we should have been with Julia you know getting exciting I can't wait." [Adam 1197-1202]*

Turning the page however towards a new pregnancy and baby involved mixed emotions of both sadness and happiness. Similar to a changing story line in a book, happiness was experienced in the new page turned, moving on from the previous page about sadness. Evan spoke of being mindful of the need to respect the individuality of each of their children:

> *"I had a big issue with replacing her (Kristine) at the start, didn't I? I was afraid that we would be replacing her, you know. But, I don't think, as we get into it that we are. This baby stands alone as well. It's not a replacement; it's just another one of our children. Kristine is one; this baby is one as well, please God." [Evan 410-414]*

As illustrated by Evan, initial fears and concerns about replacing the deceased baby can be overcome by couples, although this takes time. Seeing the baby from the previous pregnancy as one of their children in its own right, helped a couple's sense of loss.

Continuing to parent the deceased baby

There were tensions between being happy because of the new pregnancy and being sad because of their previous loss. Couples spoke about remaining cognisant of their ongoing bond and relationship with their deceased baby and of remaining loyal to

and honouring the memory of that baby. Some couples spoke of feeling guilty about being happy again with the new pregnancy as if this in some way was negating the love they felt for their deceased baby. As Nadine said:

> *"Yeah you feel like you've abandoned her (Imogen). I'm not grieving right. And then this little one now is in here (pregnancy after loss) and it's another girl and I kind of want them both. And it not that I want, I don't want her to be Imogen at all, because she's not Imogen, she's not a replacement for her. It's just, it's just very sad. It's the saddest thing that ever happened in my life." [Nadine 727-731]*

Nadine's feelings of 'not grieving right' implies that there should be one correct way to deal with the death of a baby and how one moves on to a subsequent pregnancy. Yet Nadine was clear that she wanted both her children, Imogen and this new baby.

Couples had mixed feelings about the sex of the new baby. They wondered whether that would affect their relationships with the deceased baby and the new baby. Some wished for a baby of the same sex again, while others wished for a baby of a different sex admitting that it would feel like less of a betrayal of the deceased baby. This quotation from Amy described this conflict:

> *"People ask me all the time, 'Oh would you like it to be a girl' and I'm like in some ways I would like it to be a girl, I feel like if I have a boy that somehow he'd would feel as a replacement. Conor is not to be replaced, like he's not for replacement. If I have a boy will I be more sad? Because I'll be looking at him going 'Conor would have been one of four boys now'." [Amy 875-884]*

Longing for a new baby

'Longing for a new baby' was a sentiment expressed by women in particular. There was a sense of longing for a baby they did not have. Although women were quite adamant, it was not to replace the baby that had died:

> *"It's not that we wanted to replace her and have another baby but I just want my baby so much I'm longing for my baby, which you are, you are longing for this baby that you don't have." [Nadine 1488-1490]*

The longed-for baby engendered a nurturing experience in women and was strongly articulate in particular, by the two women whose babies died very suddenly (Amy and Nadine). They expressed a desire to be pregnant again for the anniversary of their baby's birth/death. Amy spoke of her experience as being in a 'nurture mode' with Conor, before he died:

> *"Even though I was only 22 weeks. But from about week 17/18 I had actually gone into the nurture mode. So I had a baby but I didn't have a baby and I was in nurture mode." [Amy 72-81]*

The 'nurture mode' draws to mind a caring and protective state that women enter when they are anticipating the birth of their babies. Amy recalled that state of being, and how only a living baby would meet this need.

Trying to conceive

Couples spoke of the challenges they experienced '*trying to conceive'* the pregnancy after loss. For couples, the first stage on this journey was '*reaching a decision'* to try for another pregnancy. For couples, '*intimacy was a functional act',* they struggled with the *'difficulty waiting'* to get pregnant, and that the process had an *'impact' on (their) relationship*.

Reaching a decision

Reaching the decision to get pregnant was not undertaken lightly or without thought by the couples. How they negotiated the decision to get pregnant again, varied upon their individual circumstances. Several participants admitted to having an idea of their family make up ever before they were pregnant. Some women even aspired to

a set number of children with several women wanting '*big families'* from the outset of their relationships. Grace's quotation is such an example:

> *"I come from a big family you know so I'd love loads of kids if I could. So the decision I suppose was always there and I knew that Adam was on board, he loves kids and he wanted kids as well." [Grace 241-243]*

These parenting aspirations were often deeply embedded in their own family traditions. Men too talked about wanting a pre-conceived family group; however, men were aware that the ultimate decision rested with the women, as Brian said:

> *"I've always wanted lots of kids, so it really was a question for Amy." [Brian 679]*

Couples spoke about how it was important for them to agree on the decision for a pregnancy after loss. They were conscious that disagreement could have negative repercussions later in their relationship:

> *"And it probably would have ended up with us having more arguments in ten years' time if we didn't try it again so. It's just, I think like, we'd made our decision no matter what way we were going. [Doug 1305-1309]*

For some, the decision to try again appeared almost a fait au complit and they were adamant from the outset to have another pregnancy after loss. Valerie spoke of wanting to get pregnant immediately:

> *"It was definitely the first thing I wanted was and I even said it in hospital like, it was definitely the first thing I wanted but not for Tim, because Rachael was definitely unplanned" [Valerie 312-313]*

However, others spoke about being more cautious, insistent that the decision could only be taken once they had received the full information from test results, when they discovered a cause for their baby's death and when they were given reassurances that the likelihood for recurrence was slim:

> *"I suppose coming back to the decision thing, before we ever got the results we had agreed on it really, if there was no answer to what happened we weren't going to try again, if we got an answer we would try again" [Doug 979-983]*

Getting the results of post mortem investigations was of paramount importance for couples whose babies had a genetic or congenital anomaly:

> *"…having a reason of course is huge." [Evan 565] "It was a 4% chance of it happening again" [Iona 559]*

Couples whose babies had no obvious congenital or chromosomal anomalies expressed the desire of wanting to get pregnant immediately and had the shortest inter-pregnancy intervals of approximately 3 months:

> *"So I think because I was so desperately excited about having him, then when he was stillborn I thought I'm not going to get through the due date time. I would like to be pregnant, so I just felt I wanted another baby, we wanted another baby especially me" [Amy 26-29]*

Some men viewed a subsequent pregnancy as a means by which their partner's grief could be ameliorated. Jonah shared his experience:

> *"I was kind of thinking in my own head that it would take your mind off it, not that was the only fact that we got pregnant but I do think it did, the fact that you did get pregnant when you did, it did help with the grieving process" [Jonah 1732-1734; 1739]*

Women were aware that the decision to achieve a pregnancy after loss was facilitated by men to make them happy:

> *"I suppose I felt Brian supported me in that when we decided to have another child, Brian said whatever makes you happy." [Amy 759-760]*

Amy was cognisant that Brian was doing 'whatever' to make her 'happy' in planning a pregnancy after loss. However, as Tim's quotation demonstrates not every man interviewed was willing or able to agree to a hasty pregnancy after loss:

> *"It wasn't really a decision …It wasn't planned but it wasn't unexpected" [Tim 203; 205]*

Couples spoke about the fear and readiness for a subsequent pregnancy after loss and the challenges that making the final decision brings. They agreed that there was no 'right' time for them to try to get pregnant:

> *"Yeah, but then we were really weren't sure if we'd carry on and then we said yeah sure go on so sure. I was always afraid so you know it happened straight away then. And we were delighted and the girls were delighted." [Iona 401-408]*

For many couples, a crux came when there appeared to be no point delaying the process of trying to conceive any further. Jill's quotation exemplifies this challenge:

> *"We thought look 'Are we going to be like this forever?' We probably will be. So is trying now or in two years or should we have tried way back, straight away? Would it have made any difference or would it ever be any different?" [Jill 906-914]*

For Jill, there was a realisation that she could be 'like this forever' in her grief and there did not appear to be any point in postponing the decision any further. However, the decision was approached with caution and could only be considered when both parties were willing to engage in the discussion and agree with their decision. For some couples that decision was reached very soon after the death of their baby, while others chose to wait for test results and other couples had to wait until they reached a point at which that decision became a now or never situation.

Intimacy was a functional act

Once the decision was made to have another baby, couples began the process of trying to conceive. For several couples' sexual intercourse became less about emotional connection and more about a means to achieve a pregnancy as illustrated by Jill's quotation:

> *"It (getting pregnant) was kind of just a functional thing. Like, because, I don't know about other couples but relationships and all that was the furthest thing from my head totally and utterly. It wouldn't have crossed my mind at all" [Jill 912-914]*

For most couples, actively trying to conceive a pregnancy was unchartered territory, as they had never planned a pregnancy before. None of the couples disclosed requiring assistance with reproduction. Previously they engaged in sexual intercourse and fell pregnant without much planning. Grace articulated the

experiences of many when she alluded to the uncertainty in describing her reproductive history to that point:

> *"I just didn't know when it was going to happen or how easy it was going to happen. Like Sarah and Julia weren't exactly planned as in, we just let it happen, and it just happened. I never knew about my body like how, you know how fast it would happen for us, or anything like. That was all new to us; I had to look at my cycle. This was all new to me. I never had done any of that on both pregnancies before, we were lucky." [Grace 258-265]*

Indeed, Grace acknowledged that they were 'lucky' in their previous reproductive efforts because they got pregnant quickly.

In their efforts to achieve a pregnancy some couples admitted that sexual intercourse often took on an automatic role, lacking in intimacy and emotion:

> *"'Why are you kissing me?' (laughs) sorry" [Adam 393]*

Adam's quotation alludes to a perfunctory role whereby activities such as the intimate act of kissing were superfluous to requirements. Couples also spoke about how functional and regimented sex became as they focused on achieving a pregnancy. Adam described his and Grace's efforts to get pregnant thus:

> *"She had an alarm on her phone that would be like 'beep, beep' and like 'right' (indicates to go upstairs)" [Adam 395]*

Adam's quotation illustrates the routine nature of sexual intercourse and some couples became exasperated with the process of achieving a conception as illustrated by Adam's quotation:

> *"She gave out to me one time. 'What's wrong with you, what's wrong with you?' … It was like, seriously, it was like homework." [Adam 438-443]*

Adam's use of the word 'homework' in this quotation is interesting as it alludes to sexual intimacy as routine and chore-like. Yet other couples did not experience such pressure to conceive, as Simon alluded:

"I don't think there was a decision to be had. (Laughs) I think hormones kicked in, amorous feelings were had; the deed was done." [Simon 988-989]

Likewise, for Iona and Evan pregnancy was achieved relatively quickly:

"Yeah, but then we were 'Will we, won't we?' and then we said 'Yeah, sure, go on, so we'd try'. And then I always get pregnant straight away; so it happened straight away" [Iona 313-315]

The desire for parenthood often drove couples on to attempt another pregnancy.

Difficulty waiting

In couples' experiences of waiting to achieve a pregnancy after loss, the arrival of monthly menstrual period was particularly stressful for women and some, like Amy, likened it to losing a baby again:

"That is a stressful time because when you are trying to get pregnant you have your period and you're like, for the first, for one, I think for one of them time I felt like I had lost Conor all over again because I was like what if I don't get pregnant again?" [Amy 692-695]

Amy spoke for many women who voiced the fears that a successful pregnancy may not be possible because:

"*What if I couldn't conceive and I didn't want my last experience to be: / I found the labour horrific with Conor". [Amy 72-81]*

Therefore, for women every month they were not successful in achieving a pregnancy proved a very stressful time. As Jill's quotation illustrates:

"Every time I got my period it was like; oh I was a mad woman." [Jill 1230]

Jill's use of the word 'mad' in this context is similar to Grace's use of the word 'psycho' where women were conscious that their actions even to themselves did not appear to be the most rational while waiting to achieve a pregnancy. The men too commented upon the stressful effects of waiting to conceive:

"And every time it didn't happen it was really stressful then" [Doug 44]

Two couples (Jill and David and Naomi and Doug) experienced early miscarriages after the loss of their stillborn babies. Jill, like Amy, also described feeling that a successful pregnancy might never happen:

> *"And then Easter (miscarriage) was only shortly after that. I was thinking then there is something wrong with me now, it's (pregnancy) never going to happen. I was thinking there must be something wrong with me, that no baby will ever be <u>normal</u>" [Jill 921-923; 927-928]*

Jill's stressed use of the word 'normal' to describe a baby is insightful as her daughter died from a congenital anomaly and her experience of a subsequent early miscarriage alluded to her perception that there was 'something wrong' physically with her and it cast doubt on her body's capability of sustaining a pregnancy.

Impact on (their) relationship

Couples spoke honestly about wanting a baby, the tension between wanting to achieve a subsequent pregnancy and the difficulty in achieving intimacy to do so and the *'impact on (their) relationship'.* Some coupes were able to use humour to dissipate the stress as the interaction alluded to previously between Grace and Adam shows:

> *"…It was funny because, we had said like from the start, when we first started trying, "I don't want to turn into one of these psychos" "but you did (laughs)" [Adam 387] "but I did, but in a funny way, it didn't tear us apart but it was getting, but I was getting kind of impatient yeah because I didn't know how long I it would take me to get pregnant, I didn't know if I was going to be able, I didn't know" [Grace 385-390; 397]*

Adam confronted Grace with the reality that she had become what she had feared. However, she was at pains to point out that she was 'impatient' to get pregnant and this impatience was driving her actions. Her desperation to be understood was obvious in the pleading nature of her vocal tones at this point in the interview.

Although Adam was using humour to be understood, Grace's tone was much more serious and plaintive.

Couples spoke too about the repeated attempts to achieve a pregnancy and how much stress they could sustain as a couple:

> *"We had to decide how much more we could put up with it, you know" [Naomi 73]*
> *"Yeah endure it, mentally and physically" [Doug 77]*

Doug's description of how much they could 'endure' in their efforts were tempered with their repeated experiences of loss. They had two sons who died Dylan and Oliver, and a subsequent early miscarriage prior to achieving this pregnancy. Their absolute desire for parenthood drove them on to attempt another pregnancy. These stresses of trying to get pregnant, particularly if a pregnancy was not easily achieved, had repercussions on couple's relationships. David said:

> *"The grieving was definitely affecting you big time at the time" [David 915]*

Even though pregnancy was what couples wanted, finding out they were indeed pregnant was a poignant occasion, as Grace said:

> *"We did with the pregnancy test I was just so happy; do you remember? I just wasn't going to tell anyone to remember there was just happiness in the house that day there just was there was just so much joy the house that day" [Grace 235-241]*

Trying to conceive a baby after perinatal loss was a stressful time for many couples. Once the decision was made, achieving conception took on a paramount role and affected couple's relationship.

Cautiously hoping

Once they achieved a subsequent pregnancy couples were '*cautiously hoping'* for the outcome of '*a born alive baby'.* Although the '*constant worry of another loss*' was an

omnipresent force couples engaged in '*being attuned to the live baby'.* The outcome of this attunement couples described as *'restrained hoping'* for a live baby.

Constant worry of another loss

The '*constant worry of another loss'* was expressed by both women and men. As Jonah said: *"What is the worst fear with a child?" [Jonah 550].* The ultimate fear for any parent, the death of their child, had already befallen these couples. Therefore, couples' paramount worry was of this baby dying too and some openly articulated this fear:

> *"It's just the worry of the whole thing… It's just the worry of something going wrong, you know. And being told again, but, I know you could be told at any stage. That's it; it's just the worry of everything like you know." [Iona 44; 47-49]*

Iona's comment that it is 'the worry of everything' is a telling statement. Couples spoke about having a myriad of worries in pregnancy after loss; blame for the death of their baby; betraying the deceased baby; the recurrence of pregnancy loss; fetal wellbeing; for the men, their partner dying; preparing to meet the new baby and guilt at being happy again.

Couples' worries did not dissipate over time or as their pregnancy progressed. Regardless of when their baby died, their worries persisted throughout the next pregnancy. Even Kim, who was interviewed six days prior to giving birth, said:

> *"There is still a part me like, there is still six days to go, like anything could happen… find my anxiety about it is the most when I have to come and see (doctor)" [Kim 1430-1431]*

There were times that were more stressful than others were. Anniversaries of their babies' births, when couples had received bad news, before and after clinic appointments, and as birth was imminent were especially stressful occasions. Regardless of the waxing and waning in their worry levels, there was no time at which

the couples reported they were anxiety-free. While women openly articulated their concern of a recurrence of baby loss, men articulated a concern of not being able go through '*this'* again:

> *"Grace was spotting one day I remember walking into the hospital I remember crossing the road from the shopping centre thinking God I can't go through this again now you know (be) cause I couldn't now you know. Because that was the first time we visited you know it was hard on our way over there thinking we could, could be back doing this now again you know" [Adam 31-35]*

The 'this' Adam appeared to be referring to was the entire loss and grief process associated with the death of their stillborn child.

How couples coped with their worry and stress throughout the pregnancy after loss varied. It was stressful for some couples to return to the same healthcare institution, visit the same clinic rooms and meet the same staff where their baby had died:

> *"Everywhere we go reminders of her. Up here (in hospital) you come in and you see the odd doctor you remember and you go (sic: say) 'Ah! I know her, I remember her over there' or we go downstairs and 'Do you remember I was in that room?' all these things are coming back to us. It's weird." [Nadine 81-84]*

If couples had bad memories of the last time they attended the maternity hospital, this was especially pointed:

> *"Even the room that we just came out of, that was where it was confirmed that her heartbeat was gone. And although your heart would be beating today, you still know there's news. I have nothing but bad news up here. Every time I walk through the front door the minute I hear them heart machines like. My own heart it just flutters." [Jonah 85-89]*

Concurrently, many couples spoke of the importance in having continuity of carer and increased access to healthcare professionals at antenatal clinics. As Nadine said: *"I need my Mondays, every week now." [Nadine 72]*. Nadine's reference to 'Mondays' is the day of the week when she visited the high risk clinic at the local maternity hospital. Although for some women, attending antenatal clinics themselves were the source of considerable stress. As Kim said: *"I find my anxiety about it is the most when I*

have to come and see (obstetrician)" [Kim 1165-1166]. It was as if antenatal clinic visits brought the reality of the current situation to the fore in a very tangible way. Some women spoke about antenatal visits as obstacles to overcome. As this quotation from Jill illustrates:

> *"I suppose after each appointment when you are reassured that things are going ok like we would have a chat that evening then and say at least now that is another hurdle, we kind of call them hurdles don't we?" [Jill 1219-1221]*

Jill's use of the word 'hurdle' is interesting; it was as if pregnancy after loss is an obstacle course to be endured and conquered, and a live baby was the prize at the end of it. It is almost as if, pregnancy after loss was the ultimate survival of the fittest.

When not face to face with the antenatal clinics some men felt they could cope by placing their worries to the back of the mind. As Evan said:

> *"And they gave breaks for about 4 or 5 weeks and eventually we'd have to worry and not travel up and all that kind of stuff. So that was great but towards the end its, they're closer together and the pressure builds a bit again and it is then a bit more anxious and anxious. Scans only bring it to the forefront like, you know what I mean" [Evan 32-34; 47-50]*

Women could not put worries to the back of their minds because they were constantly aware of the baby they were carrying and conscious of the baby's movements. As Nadine said:

> *"I'm just constantly aware of being pregnant, that's what it is. For me it won't go until the baby comes out." [Nadine 853-854]*

Worry and anxiety were overwhelming emotions experienced by couples throughout their pregnancy after loss. Worry helped couples made sense of their current pregnancy in coming to terms with their loss.

Being attuned to the live baby

How couples looked for reassuring signs of fetal wellbeing throughout pregnancy after loss was '*being attuned to the live baby'*. Fetal movements were seen as a

source of reassurance that babies were healthy and well. Fetal movements were an area of intense focus of reassurance for couples that their baby was surviving. Fetal movements are an embodied experience of pregnancy, particularly in early pregnancy and experienced vicariously by men. Even women, like Valerie, who normally would describe themselves as non-worriers found the issue of fetal movements to be an especially worrying topic:

> *"I am actually like very relaxed and chilled but definitely this time I am a bit more, do you know, like even if he has not moved a bit I am a kind of panicky like" [Valerie 48-50]*

There were differences for the woman carrying the baby and feeling the baby moving (or not) and the man who may be oblivious to the movements or lack thereof. Women often delayed in reporting their concerns around fetal movements, to their partner, for a variety of reasons. They did not wish to worry their partners; they believed intrinsically that the baby was ok, or felt that their expectations of a constantly moving baby were unrealistic. The following exchange between Nadine and Jonah is an example. Jonah's quotation describes the mental exhaustion that he imagined Nadine to be experiencing when she withholds her worries about the baby's movements from him:

> *"I think definitely (it) takes more mentally out of you because you've the baby inside you and she might not tell me for an hour and a half that 'I haven't had any movement'. So for that hour and a half she's down in the sitting room on her own worried about: /" [Jonah 944-946]*

Yet when probed, Nadine felt if she reported her concerns, she was having unrealistic expectations for the baby as she disclosed wanting the reassurance of a constantly '*awake*' baby:

> *"Because I know, maybe something in my head that it's all okay. I remember one day he said 'When did you get movement?' and I said 'About 5 minutes ago' and he said, 'Jesus like, what do you want her (baby) to do? She has to sleep as well' and I said 'I*

know. I just want her awake'. I nearly want her to stick her hand out of my belly and let me know that she is fine" [Nadine 827-840]

Nadine equated fetal movement to signs that all is well with the baby and seeks this reassurance constantly. Other couples too spoke about the excessive efforts women went through to obtain fetal movements, to reassure themselves that their baby was still alive. Doug recalled Naomi's efforts:

"But you bought things like cold drinks to try and get movement, you've had sugary sweets not knowing, maybe after having a movement in the morning, that evening you would get sugary sweets to see could you get movement that night. But still it's still there Naomi; you still do worry about it like." [Doug 169-172]

Couples reported a need to maintain a state of vigilance throughout the pregnancy. Grace said:

"I never let the guard down, I still haven't, although I know this baby is fine and I can feel this baby is <u>way</u> more lively than Sarah or Julia and I know Julia was so small she wasn't really a mover but this pregnancy is <u>completely different</u>, completely different physical, like there is just <u>constant movement</u> so I don't worry that way but I don't know I never let the guard down." [Grace 1116-1118]

Grace's description of 'never let the guard down' provides insight into how couples felt the need to remain alert even in the presence of reassuring fetal movements as even with this new baby Grace had 'constant movement' it still was not enough reassurance.

Women also spoke about the tension between trusting their judgement as a mother to be able to recognise if her child was in trouble and trusting again the very body that had failed in the past to keep their baby safe and alive. Amy's quotation illustrates this point:

"What has been hard in this pregnancy, especially in the last few weeks is trusting your judgement, so, now like we'll say if the baby doesn't move for a few hours my thought is 'Oh my god is the baby dead'. That shouldn't be, but I mightn't tell him for hours because I don't want to make him afraid. Now there is a lot more tension than there actually is, but before if you got a pain you'd be like I'm going to sit this pain out, now you go to sit this pain out and you're going but what if that, what if I sit it

out too long, so that can be difficult. It just trusting your judgement really" [Amy 466-474]

Amy's struggle to 'trust your judgement' in pregnancy after loss with regard to fetal movements is very difficult. The majority of women reported an enormous struggle in trusting their judgement and often resorted to multiple visits for external validation with numerous healthcare providers at all hours of the day and night to calm their fears. When women did vocalise their concerns men were supportive. Often it was to the point of the men rushing the women to the maternity unit for assessment. Jonah's quotation is an exemplar:

"But even last week when you said to me, 'I feel kind of wet down there'. There wasn't even a question, get into the car and go. We weren't even going to ring just go." [Jonah 879]

Women valued the support provided by their partners, especially when women themselves questioned their actions as Naomi did here:

"I must say he's very patient obviously and very understanding. Like any other fella might tell me to calm down or forget about it. But anytime I had any doubt, he supports me all the way and takes me to the hospital and drops everything. Like, I'm not a hypochondriac in general and I do try to put any doubts out of my mind, but until I can't contain it any longer and then if I say it to him, he's very understanding, because he knows what happened like because it was the exact same for him." [Naomi 245-249]

As pregnancy progressed, some women relied again more on their own judgement and instincts. They were less likely to rush immediately to the hospital for reassurance:

"(Laughing) I'm like 'No, let me see how I get on for the next hour' so I think in the last week or two I've calmed down a lot about it where Brian is like 'We just need to go to the hospital' and I'm 'Let's just wait a few minutes'." [Amy 564-566]

Men felt reassured too by the external validation of baby's wellbeing particularly by access to hospital-based ultrasonography. As David said:

"They (GPs) can't tell you what the doctors can see on the scan. It's just reassuring the doctors words and the scans." [David 574; 1225]

However, the 'enjoyment' of the ultrasound experience and in visualising the baby that may have existed in pregnancies before loss was no longer present for couples. As Kim said:

> *"I am sort of a bag of nerves. I am never going to enjoy a scan ever again… the most stressful days for me were the scan days. Like I check in with myself like regularly, I will lie down to check the baby is moving and stuff like that, but I don't find days when I come to see X(obstetrician) particularly you know pleasant or nice. You know it's chalk and cheese the whole experience" [Kim 1140-1144; 1144-1149]*

For some women, no matter how many ultrasound scans or how much reassurance they received, they could never assuage their fears and anxiety:

> *"Yes stressful I suppose because no matter, no matter how many scans you have you're always afraid in case something might go wrong. I'd be worrying whether I'd have the scan or not. And I suppose then you feel <u>then</u> that you are having a baby and you can be more. I suppose it's just a worrying time, <u>all over</u>. It's just a worrying time from start to finish; it's just worrying you know?" [Iona 18-19; 65-68]*

Men also saw it as their role to monitor their partners' antenatal appointments, particularly if they were absent when the bad news was broken in the previous pregnancy:

> *"I didn't even go to the scan for Dylan because it was just another scan. It was just a straightforward thing. I haven't missed one since I can tell you. There's been a lot of them. But we just thought it to be so straight forward and we were just a case of you turn up and come home with your baby like." [Doug 1198-1201]*

Couples were constantly aware of the worry and anxiety in pregnancy after loss and they coped by '*being attuned to the live baby'*.

Restrained hoping

While being mindful of their worries, couples articulated a desire to maintain an optimistic and hopeful outlook as they anticipated the birth of their new baby. They verbalised the positive feelings:

> *"I'm quite positive, thinking about (new baby) and planning" [Naomi 233-237]*
>
> *"It (new pregnancy) is brilliant because to be honest with you it has definitely lightened our spirits it has there is no two ways about that" [Jill 612]*

They were conscious about being fair to the new baby who was joining their family and this drove their hopes of a positive outcome. As Amy explained:

> *"But my big thing is, that I don't want our new baby to come into the world, feeling; being delivered through anxiety, I don't want that. I want them to have their glory. It's important that they have their glory and I'm so worried about them having their glory that I'm making myself more anxious whereas if I just stopped worrying about it I'd be fine." [Amy 727-732]*

This quotation from Amy exemplifies the struggle couples had of balancing their worries with staying optimistic for this new baby. However, optimism and positive orientation was always with a caveat and couched in restraint. The undercurrent of these couples' experiences was that nothing could be guaranteed until they were holding the live baby. As Doug said, they were: *"Cautiously excited now: / [Doug 1356].* Couples existed in a state of '*cautiously hoping'*, just in case their hopes were once again destroyed. As Doug's partner, Naomi said:

> *"We are very excited and obviously nervous, like we don't want to build our hopes up too much either: /" [Naomi 1353]*

Couples were very conscious that even though they were becoming more confident as their pregnancy was progressing, they would remain cautious until they had a live baby in their arms. *"You're never sure until your baby is in front of you" [Iona 20]*. History had taught them that events can change suddenly and they were cautious of truly believing in a positive outcome until it actually occurred as this quotation by Jonah illustrates:

> *"I think we're almost afraid of imagining that we're going to have the baby, in case anything happens. You're afraid of building it up and, of having it all taken away again" [Jonah 924-925]*

Couples were cautious too about their other children bonding with the new baby: *"You are a little bit cautious; you don't want them (siblings) to bond too much" [Naomi 1028]*. Some couples kept the news of the impending new baby from their siblings for as

long as possible. They did these actions as a way to protect their children from further hurt should this current baby also die. As Naomi said:

> *"And like we're trying to keep it from the children for as long as possible but because I've got so big. Because we don't want to hurt them either because they knew what happened the last two times" [Naomi 368; 375]*

Other couples with older children actively encouraged their children's engagement with their new sibling. This may have been easier to facilitate because Molly, aged 10 years, was much older than many of the other siblings:

> *"When I am with her on my own all the stuff about hiding (her pregnancy) is out the window. When we are on our own I would be encouraging her to feel the baby kicking and she looks up the You Tube videos every week. This stage and the next stage and the next stage and all that. I really encourage it around her" [Jill 1262-1269]*

For Jill, this engagement with Molly and the new baby helped her to make sense of her loss and grief.

To foster their hopes, couples engaged in deliberate activities designed to bolster their confidence and optimism, such as beginning nesting activities and start small purchases for the new baby:

> *"We have started talking a little bit now and we have started to buy a few things" [Grace 1216]*
>
> *"but for this pregnancy we are after picking up a few things…Maybe we are trying to say to ourselves, <u>yes</u> you will need this stuff or what I don't know what it is." [Jill 1233-1242]*

Women spoke more about proactively preparing for the baby's arrival. Men remained far more circumspect and often restrained women's attempts at nesting too early providing rational arguments to the women as to why it would be preferable to wait. Valerie and Tim spoke about how Valerie was not permitted buy any clothes for the new baby until after 6 months gestation. This was in contrast to their behaviour in their previous pregnancy:

> *"Yeah but like I didn't want to buy anything. Waiting a while to see, using the excuse to see what he was, to find out" [Tim 971; 976]*

> *"Yeah I suppose every week end (in the previous pregnancy) we were out looking around to see what we wanted for the baby, this time it was just after six months like" [Valerie 973-974]*

Likewise, Naomi and Doug spoke about how Naomi was not permitted to buy anything new or get her bag ready for the hospital before the mutually agreed 30-week gestation:

> *"We've agreed at week 30 we'll pack the bag" [Doug 1362] "We'll get ready and stuff like that. (I) wouldn't be allowed buy anything before that" [Naomi 1364]*

When an individual, within the couple, needed help in sustaining their hope, they often looked to their partner to sustain that hope for them and indeed the partner often saw that as their role. As this quotation from Adam illustrates:

> *"…just trying to encourage Grace. But just like I'd always say to her just try to think positive all the time about things" [Adam 215-217]*

When the couple were wavering in sustaining their hope as a unit, they often looked externally to trusted healthcare professionals to help nurture and maintain their hopes:

> *"Because the consultant is talking about delivery now, and that's fantastic to be talking about induction and delivery. And we're delighted that they feel we can talk about it that makes us way more positive" [Naomi 338-339]*

Couples were aware that pregnancy after loss was a very worrying time for them both and they tried to sustain hope for their baby and for one another. At times, they were able to foster this hope internally; they relied upon one another to help sustain hope. They often looked to trusted healthcare professionals to bolster their hopes while waiting for the birth of their baby.

Revisiting the past to birth a born alive baby

Couples spoke about '*revisiting the past to birth a born alive baby*' as the final stage in their journey of pregnancy after loss. The arrival of '*a live baby'* was the ultimate

goal for all couples. To achieve this goal couples needed to revisit labour and birth but they were aware that '*birth brings it all back'* to them.

A live baby

The birth of '*a live baby'* encompassed the couples' ultimate pregnancy aim. Several coupes were aware that birth was imminent and were cautiously anticipating the event. The stage in the pregnancy at which they were interviewed, may have influenced their thinking. Couples who were at an earlier gestation in their pregnancies were less likely to have thought about the immediacy of birth. Jill and Grace articulate this area of concern:

> *"And a live baby is my thing… Live we will cope with anything else once the baby is alive" [Jill 530; 532] "That's all I want, is it to be born alive" [Grace 1436]*

Couples said that they would be so grateful to have a newborn live baby that they do not really mind what baby they receive. As Evan said:

> *"No, don't care, just that they're healthy and they live a long happy healthy life that's all I care about. We will take what we are given" [Evan 495-496]*

As Evan stated once the baby was 'healthy' too. In fact, after everything that they have been through, couples were even relishing the prospect of a screaming baby; wanting a working, kicking, and live baby, as Nadine said:

> *"What was nice too is that we will never complain if a child screams all night… But I don't care, I actually don't because we want our baby now to be screaming and kicking and doing what they want." [Nadine 364-367]*

Achieving *'a live baby'* required a journey for the couple as Doug described:

> *"We're on the home straight. We both kind of feel like we are on the home straight, but it's a long home straight you know." [Doug 267-268]*

Doug was aware that, in their third trimester, they were on '*the long home straight'* but that *'a live baby'* was going to take time. Several couples spoke that the

experience would not be over until the birth of the baby was completed and the baby was born safely, alive and well:

> *"Definitely, not until the baby is <u>out</u> five minutes…Yeah then I can, I suppose breathe a sigh of relief and then actually enjoy it, you know. We haven't really enjoyed this pregnancy. This pregnancy is all about getting to the finish line, getting to that 5 minutes after the baby is born I suppose hoping, and I suppose this is the same with all parents, all hope that it has ten fingers, ten toes, two ears. You know." [Brian 459-465]*

Although the end was in sight for Brian, like many, he was mindful that *'getting to the finish line'* was the ultimate goal. Many couples did not wish to tempt fate by prolonging pregnancy any longer than was necessary:

> *"The last two weeks the baby is fully cooked so let's make sure that nothing goes wrong like let's get this baby out." [Amy 445-447]*

Amy's description of her baby now being 'fully cooked' implies a time that is just right for her baby to be born. Any longer and there is a risk that something could 'go (es) wrong'. The aim of a pregnancy after loss was a live baby and even though couples were cognisant that pregnancies were ending, until birth was over, they were very mindful that a live baby could not be guaranteed.

Birth brings it all back

The prospect of facing into labour and birth again was seen as very challenging for couples. To achieve the goal of a live baby couples were going to have to revisit their past births, all the while mindful that '*birth bringing it all back'*. Women spoke about the need to find coping strategies to come to terms with their fears. They were preparing psychologically for labour and birth, knowing that they would have to enter the birthing space and re-connect with their new babies as well as their deceased babies. Amy's quotation describes the experiences of many:

> *"I'm either going to have come to peace with it or be really anxious, what I don't want to happen is that I get all tense and nervous because I would like to enjoy it, it will be painful but it's a joyful time, and I don't want to be anxious." [Amy 714-719]*

Women spoke of the need to separate the two birth experiences from one another. As Kim and Valarie said:

> *"I have to really try to look at this as a totally different and positive experience. I can see that it might bring back…but it is not, it's going to be very different" [Kim 1414-1417]*
>
> *"(I have to) find a way to and to get Rachael's delivery out of my head do you know what I mean it's a new experience" [Valerie 1563-1564]*

Women were fearful that experience of stillbirth would negatively influence their experiences of and decisions around their forthcoming birth, as Amy's quotation shows:

> *"My fear is with this labour (is) if somebody says to me you know, 'Oh we're just having trouble finding a heartbeat' I'm going to be; I don't want to go into panic mode, I don't want to say just 'Can you please do a section and get the baby out' because I really don't want to have a section" [Amy 835-836]*

Amy was conscious of not going into 'panic mode' during labour because of the repercussions that may have on her birth choices. Women were also fearful of re-entering the birthing environment because for some, their babies were alive entering labour and died during birth. As Valerie said:

> *"I suppose I just have a little bit of a worry of when I do go into labour that because she possibly died in labour…actually I probably can still see the room…" [Valerie 1488-1491]*

Although challenging at the time, women also spoke of the benefits gained from giving birth to their deceased babies. As Nadine said:

> *"I'd do it again and I would do it again purely for the reason I did feel like I had a baby…But looking back on it I think, you know your body has a baby inside you and you need to give birth… So I wouldn't change it at all she deserves the same respect as a baby that is breathing like" [Nadine 383-397]*

Nadine, like other women viewed birth as a way of paying homage to their baby and mothering them, as if they were alive.

Men spoke somewhat differently about birth. They viewed it as a process that had to be endured, to reach the ultimate goal of a live baby. They were very aware that things could still go wrong and were focused less on labour and more of the desired outcome of a live baby. As Brian and David said:

> *"Yeah, we know there are so many things that could go wrong. We're not at the finish line. We're not, there is so much more to go" [Brian 502-503]*
>
> *"We're just hoping, come on let's get the birth through and finished with it and then we'll start. Just getting the birth out of the way" [David 668; 674]*

David's comment of 'then we'll start' is telling because, for him only when the baby is born could life begin anew.

Several couples spoke about the nature of pregnancy, labour and birth with a sense of déjà vu and thinking about birth brought those emotions and feelings back to the fore for them. Returning to the maternity hospital in this pregnancy can cause old feelings to flare up again:

> *"There were one or two times … it brought back a lot of déjà vu because with Julia we were going every two weeks." [Adam 854-856]*
>
> *"It's like deja vu kind of, it's very, very similar because I wasn't sick and I had no problems. Whereas this time I am aware of what happened" [Nadine 817-818]*

Couples were very aware that the day of the birth and meeting their new baby would be challenging for them, as it would be a mixture of joy and sadness, as they will be faced with remembering the baby that had died too. Adam's quotation illustrates:

> *"I would say it will be very emotional, I would think there will be a fair few tears shed by everyone because we it will always make you think about Julia and things. But we will also be very happy" [Adam 1469-1442]*

Adam highlighted the fact that birth would '*always make you think about Julia*'. Couples believed they would be faced with the reality of what they should have had with the baby that was stillborn and they now would have with this new baby. Jonah spoke for some who were not looking forward to that prospect:

> *"I think that's going to be the hardest thing when this baby is born… I think the day when she's born it's going to be probably the toughest challenge yet because it's going to be bittersweet…we're going to be so happy and so sad at the same time… I'm kind of dreading it to be honest…I think our toughest challenge is yet to come" [Jonah 436-439; 733-734]*

Couples were very aware that they faced an enormous challenge of revisiting the past to give birth their new live baby. A live baby was the ultimate aim of the pregnancy after loss. For women achieving a live baby would necessitate revisiting birth in a physical, psychological and emotional sense. For men too it meant confronting the loss of their deceased baby in a very real way.

Journey of Loss

In making sense of their experiences of pregnancy after stillbirth all couples began their stories with death of their previous baby. This superordinate theme *Journey of Loss* comprised two subordinate themes *unexpected death of a baby* and *grieving the deceased baby.* When describing their experiences couples spoke of *death being an unexpected event.* Although an unexpected event, for some couples, there was a *realising something was wrong* with the baby. Even when they received bad news, couples described *clinging to hope* that their baby would be born alive. They discussed *meeting our baby* and couples found themselves *searching for reasons why* their baby had died. On this journey of loss, couples spoke about *grieving the deceased baby*. Acknowledging that *our baby was a person,* by *finding our way through loss and grief* assisted their grieving. Afterwards they described being *changed by loss.*

Unexpected Death of a Baby

Death was an unexpected event

As couples reflected on the loss of their baby, it was clear that this was an unexpected event: *"You don't expect it to happen to you" [Iona 111].* Iona's baby died when she was 32 weeks pregnant. Iona and her partner Evan were aware that she would lose their baby from the time of 14 weeks' gestation. From that time, it was known that the baby had a fatal fetal abnormality with no chance of survival.

While Iona's comment above implies that a death of a baby during pregnancy was an event she had not expected to happen to her, the death of a baby was also seen as going against nature. Couples spoke about pregnancy as a natural life event with the expectation of a live baby. Nadine commented that:

> *"It's against nature for your baby to die. Your baby's not supposed to die "[Nadine 124].*

Similar to Iona, Nadine was in her third trimester of pregnancy. While being in the third trimester might seem as if couples had a greater sense of security about reaching full term with a live baby as a natural process, loss of a baby in earlier gestation was also seen an unnatural. One couple, Naomi and Doug, spoke of losing their baby at the 19th week of gestation due to *"a blood clotting disorder".* The undertaker reinforced their sense of this event being unnatural as they prepared to bury their baby:

> *"I asked the undertaker 'What happens in these situations?' and he said 'Nothing is normal when there is a baby involved'...Yeah it is a very strange experience. [Naomi 1099-1102]*

The 'very strange' experience referred to by Naomi indicates the unnaturalness of a pregnancy not reaching full term and having to bury a baby. Some couples spoke of

expectations of reaching a safe point in pregnancy meaning they were past a point of danger:

> *"I (had) literally just gone 'collective sigh of relief' everything looked fine at that scan. It has gone past the point; we are nearly at 24 weeks when they can be delivered anyway and all this stuff." [Kim 1488-1490]*

For Kim and her partner Simon, who were having twins, they became aware of the death of one twin at 24 weeks while the second was alive. Both were born at the 38th week of gestation. This was Kim's fourth pregnancy and her second experience of loss. Prior to this, Kim had experienced a miscarriage in the first trimester of a previous pregnancy. Kim's experience of loss at 24 weeks or earlier as well as continuing pregnancies to full term seemed to be the basis for her sense of safety in pregnancy time points. Nadine also articulated the expectation and sense of safety that a pregnancy into full term is well beyond a danger point of losing the baby:

> *"Especially at the end… They're so big now, they're so full that there's nothing that can really kind of damage them" [Nadine 44-50]*

Nadine's reference to 'they're so big now' is a telling statement of expectations around pregnancy such that a thriving 'big' baby is a guarantee of a live birth 'at the end', that is, full term. The suddenness of losing a baby at term changed these expectations:

> *"In the blink of an eye it just changed like. Just like that, in the blink of an eye…And then everything just went wrong." [Nadine 10-12]*

This 'blink of an eye' draws to mind an image of an involuntary movement over which there is no control. Other couples shared this suddenness of losing a baby and seeming loss of control:

> *"…suddenly it stops. It's not lovely. Everything is gone bad" [Adam 1352]*
> *"The last time everything was grand until it wasn't." [Tim 22]*

Realising something was wrong

Although sudden and unexpected, it was apparent that for some couples, they experienced a growing 'realisation that something was wrong' with their baby. Nadine and Jonah, spoke of how this realisation kept them awake at night when they had a '*feeling*' that something was '*wrong*' with their baby when they were 39 weeks pregnant:

> *"We were awake all night" [Nadine 464] "Yeah it was this feeling in the pit of our stomachs we were just lying in bed and we knew there was something wrong" [Jonah 466-467]*

Jonah's description of how they felt with reference to 'pit of our stomachs' illustrates the fear and nervousness as they tried to make sense of what was happening at this late stage in pregnancy:

> *"Even going up to the hospital and we knew there was something wrong but we still didn't think it was going to be what happened" [Jonah 54-57]*

From Jonah's comment, even though they were aware that something was wrong, there was no realisation that death would be the outcome.

The realisation for some couples that something was wrong with their baby came about as the woman experienced physical changes in her body. For example, Iona [115] spoke of when she '*just felt a change*' in her pregnancy at 32 weeks. The physical changes experienced by women indicating that something was wrong related to their baby's movement in the womb. Jill spoke of her experience when 32 weeks pregnant:

> *"I thought 'God, it's very quiet' and the movements are very sluggish." [Jill 94]*

Jill and her partner David were informed at 22 weeks that their baby had a fatal fetal anomaly. Although they were regularly attending the GP and maternity services for

pregnancy care, which included monitoring the baby's heartbeat, they checked the baby's heartbeat themselves at home:

> *"I had a heart monitor all the time. Since hearing about the heart I used to check it myself once a week" [Jill 93-95]*

Jill described her experience of not '*feeling much movement*' one Sunday night, and saying to her partner:

> *"I said to David 'I think I will do the heartbeat there now' even though the doctor only did it the day before and I think I will do it because I'm not feeling much movement or whatever. So whenever we were doing it, I couldn't get it" [Jill 99-101]*

The measurement of a heartbeat with a monitor indicates Jill's need for an objective sign that her baby was still alive in her womb. This illustrates that when something is wrong there is a need for external objective validation of life rather than relying on bodily changes experienced internally. For other couples the realisation that something was wrong was based on external objective evidence such as ultrasound scan. They experienced no physical changes of concern regarding a risk to their baby's life in the womb.

Most couples saw the ultrasound scan as routine part of pregnancy care, with the expectation of seeing a live, growing baby. There was little consideration given to the fact that something may be wrong. For example, Doug explained why he did not typically go with Naomi for her ultrasound scans:

> *"I didn't even go to the scan for Dylan because it was just another scan. It was just a straightforward thing…But we just thought it'd be so straight forward and we were just a case of you turn up and come home with your baby" [Doug 1640-1643]*

However, when a routine scan revealed that the baby had died since the previous scan this was wholly unexpected and a shocking experience as described by his partner Naomi:

> *"This (confirmation) was done on a routine scan …I never in my wildest dreams thought that there would be no heartbeat. So I was in an awful shock. I couldn't even dial Doug's number." [Naomi 1004-1014]*

What was particularly shocking for Naomi was that for both pregnancy losses she had no warning that her babies might die. She believed she should have experienced some sign or signals to alert her that something was wrong:

> *"I never had any sign …I just went up (to the maternity hospital) and found out by scan... It's a fact that we didn't get any signals if something was wrong. If you were there waiting for a bleed, it would have been easier or a pain or something. But the fact that we never knew about it happening made it worse." [Naomi 17-18; 138-140]*

Naomi's reference to the situation 'made (it) worse' by never realising that her baby was in difficulty, not just in one pregnancy but also in a second pregnancy, suggests that if she had been aware she might have been better prepared for the situation.

Clinging to hope

On the realisation that their baby was not going to live, it was apparent that couples found themselves *clinging to hope*. Almost, where there is life, there is hope:

> *"Originally we thought a few operations might fix the problem you know" [David 60]*
> *"So we just asked what can be done, is there an operation? And he said no, he said basically that you're keeping the baby alive he said that it's not compatible with life." [Iona 89-91]*

Likewise, Jill spoke of her experience of clinging to hope even though she was aware that her child had a 'heart problem', which she knew was serious:

> *"I thought 'Oh sugar what will I do?' So then I thought 'Will I go to the hospital?' 'What will I do?' So I said look, I will wait until the morning and see...I still had that small bit of hope. When you are going up there thinking, 'No it will be grand when you get there'." [Jill 105-109]*

One woman described clinging to hope as a natural instinct as a mother, even though she was aware that her baby was dead:

> *"And you know you're not being rational; you know it's not logical. But it's just; it's your instinct as a mother. Because I suppose you still hope. Well I didn't, I knew he was dead, but yeah, you still, I suppose. [Amy 112-113]*

Her partner, Brian referred to hoping that the baby would be born alive because professionals had not told him that the baby was 'definitely dead':

> *"I suppose I still had hope. I still had hope that the baby would be born alive, because they didn't say he was definitely dead. There was still hope, so you still had hope. And even though he wasn't at the twenty-four weeks, there was hope that he be big enough that he might make the weight even though you know" [Brian 145-148]*

Brian's description of hoping seems tainted with a belief that if a baby is 'big enough' in terms of weight, it was unlikely they would reach a situation where he would be 'definitely dead'. It was difficult for Brian to make sense of the situation that their baby had died before birth, which in this case was at 24 weeks of pregnancy. Likewise making sense of birth before death was difficult for other couples.

Meeting our baby

Couples spoke about their experiences of 'meeting our baby' at birth. Although there was the desire to meet their new baby, they knew that the meeting would be short lived. Iona described this desire, even to the point of asking for induction of labour so that they could meet their baby while she was still alive:

> *"I did ask alright, could they bring her on, you know so we could we have her around for a bit." [Iona 113]*

Preparing to meet their baby was laden with inherent tensions where the beginning of labour signalled the end of life. Amy and Valarie, whose babies were alive at the outset of labour, spoke particularly about these tensions. Amy described the conflict of wishing to simultaneously remain and not remain in the birthing moment as illustrated in the following quotation:

> *"I suppose knowing what the outcome was. I knew what the outcome was going to be, not wanting the labour, you want labour to stop, because you're in pain, but you don't want to stop because it's really over then you know; which in hindsight it isn't … but at the time you think 'Oh once the labours over that's our baby gone'. But it's not, but at the time that's what I thought." [Amy 68-74]*

Amy went on to describe her experience of dealing with two tensions during labour. Even though she was aware that her baby was already dead, she was concerned about her baby being hurt while giving birth.

Part of this tension was concerned with postponing the reality of meeting the baby, knowing that it was dead and thereby the realisation of having to let the baby go and at the same time being concerned about protecting the baby. This dual position presented a challenge for women as Amy described:

> *"Yeah like I really struggled with that … because you want it (labour) to go on forever but if you think about 'My baby is dead inside me'… I knew he was dead at that stage but I was so worried that he was uncomfortable because he was half inside the birth canal, I was like 'It must be really uncomfortable for him in there'; but I knew he was dead" [Amy 77-87]*

In Valarie's case, although informed that her baby may die during preterm labour, Valarie did not appear to be able to process that information fully:

> *"We were told she was gone before she came out because they knew by the cord or whatever because she was breach like we were told. It wasn't, it wasn't a shock, we did have time to: / She must have been, because they did check a heartbeat at 10 or 11 and it was still as strong as it had always been so it must have been the labour that: / And I was moody that day and I presumed it was the steroids you know, I was very agitated like and tired and pain in the head and just never thought that it might have been time to go you know" [Valerie 222-231]*

Valerie's quotation illustrates that couples can struggle to make sense of the fact that a baby could die in labour before birth, even if that death was expected.

Couples spoke about their expectations for signs of life on meeting the baby such that their baby would breathe or cry when they were born, even though they knew the baby was dead:

> *"We were nearly expecting her cry when she came out… We thought she was going to cry: /" [Nadine 390; 394]*

Some couples spoke of the perception of movement in the baby following birth:

> *"So then, when she came out, they put her straight into my arms, and I actually, for a moment thought I felt her moving but I suppose it was just reflexes like." [Jonah 396-397]*

For some individuals from the couples interviewed, it was apparent that they were not readily able to take in the fact that they were meeting their baby dead rather than alive. Doug explained that:

> *"Jees, it took me the bones of the first day to look at Dylan. Oliver it was a bit easier I suppose. I didn't look into the coffin the first day I don't think" [Doug 429-434]*

Doug's comment seems somewhat hesitant with reference to 'I don't think' implying that he may have actually looked at Oliver, his first baby, on that first day. However, looking at his baby may not necessarily equate with actually seeing and internalizing that his baby as dead. David commented, "*Looking at a dead baby is a hard thing to do" [933].* His sense of emptiness and loss was apparent:

> *"Going through the whole birth and to see nothing at the end of it was terrible" [918].*

Couples spoke about wishing they were better prepared by healthcare staff prior to birth for meeting their baby. In particular, about what to expect about their baby's physical condition at birth. Jill spoke of her experience:

> *"They (healthcare staff) don't want to scare you either. I don't know but I would have liked to have known that (physical deterioration) before it happened…and her head got really soft, squidgy" [Jill 842-843; 847]*

Couples referred to others in their lives needing strength to face this challenge and to meet the deceased baby, as was illustrated in the following quotation from Naomi:

> *"I don't think my parents were even able to meet them, it was just ourselves… I don't think anyone is strong enough, bar ourselves." [Naomi 423; 427]*

Naomi's reference to 'strong enough' implies that meeting their deceased baby was too onerous an experience for anyone but the couple themselves. Naomi's comment above suggests that despite the difficulties and emotional experiences for couples in

seeing their baby dead rather than alive, they have a strength that helps them though this situation. This strength seemed to help them make sense of their experiences. Couples spoke of the surreal experience of meeting their dead baby: *"It seemed so surreal like you are looking in on somebody else" [Jill 1078]*. Even the logistics and ergonomics of the cramped birth environment seemed jarring for some. Simon particularly spoke of the juxtaposition of his two children, Louis who was born alive and Ruby who was stillborn occupying the same small space:

> *"Like we had a mosses basket with our live baby and then we had a mosses basket with a cooler thing underneath for our dead baby in the box and it was kind of like, Kim's in the middle and left and right and I was kind of like 'Wow!' that is such a lot: / And yellow room. A kind of like weird, hellish, purgatory kind of a scene and then people coming in" [Simon 584-590]*

Couples also spoke about the difficulties of being confronted with the happiness of live births around them in the maternity unit. With reference to going to the hospital café, Jonah commented that: *"To be so happy and to be so sad in the same room, it's a strange feeling." [Jonah 282]*. It was a 'strange feeling' to Jonah, that happiness and sadness; birth and death could co-exist in the same space.

Time since the loss of their baby was an issue that couples also struggled to make sense of during the interviews. Couples spoke as if death has always been a feature in their lives and they could not remember a time in their lives before loss as illustrated by Nadine's quotation: *"It feels like it always happened, it's always been in our lives" [Nadine 1679]*. Time was a concept discussed by all couples. Both those who knew in advance about their baby's death and those who received the news unexpectedly. Some couples spoke about time when discussing the death itself while others when discussing their own or others reactions to the events. Couples

struggled, in particular, to make sense of how life and the world around them continued after their baby's death. As Nadine said:

> *"You really do expect the worse like, you think the whole place is going to shut down around you but it just doesn't like, but like, life goes on, that's the way it is" [Nadine 1922-1923]*

Searching for reasons why

In trying to make sense of the death of their baby couples spoke of *searching for reasons why* their baby died. Women looked firstly to themselves often citing an exhaustive list of possible causes for their baby's death as illustrated by Naomi's quotation:

> *"Was it something we ate or something we did? What was it? Because you're totally paranoid because you blame yourself first. The clutch went in the car… Then you think about everything that's happened in the past few weeks and you're blaming yourself. Was it the cats out of the farm? I don't really go near the cats but I'm afraid of my life I got toxoplasmosis or something. Listeria, all these things going through my head. I went through every meal I had." [Naomi 919-921; 925-927; 930-932; 1229]*

Naomi, like many women, spoke of 'blaming' herself for her babies' deaths. Women viewed sustaining life as a maternal responsibility and if that went wrong, despite their best efforts, they blamed themselves:

> *"I don't know being just the woman … I follow the letter, everything you shouldn't eat, you know, all of it, you know and if something goes wrong, because I remember when I was speaking to Simon on the phone like saying you know apologising to him what had happened and I don't think- it was just one of those things but you do have, the responsibility physically, it literally lies with you know" [Kim 157-162]*

Women inevitably questioned their bodies in terms of capacity to keep a baby safe:

> *"I don't feel my body is safe for her…I just don't feel my body at that point was safe for Imogen." [Nadine 134]*
> *"I always felt in my head that maybe I just my body couldn't cope with having a twin pregnancy" [Kim 12-13]*

Women doubted their reproductive ability and indeed believed that their bodies were not 'safe' places for their babies to be. The experience of having other children

was a reassurance to couples with children that they were reproductive successes. Adam's quotation highlights the experiences of these couples:

> *"because it didn't happen on our first child… we had one healthy child…If it so happened whereby it was your first child that passed away and you didn't have any other healthy child you'd always be nearly second guessing saying like well, 'It might happen again' like because we already have Sarah were kind of, I suppose, confident" [Adam 127-132]*

Couples sought to make sense of the death of their babies by trying to rationalise the universal nature of life's challenges. Doug and Naomi spoke of trying to make sense of the loss of their first son in a reasoned way:

> *"The first one (loss), I suppose we kind of accepted as…it was a cross to bear" [Doug 54; 56] "(as) Bad luck, no one goes through life without a problem" [Naomi 55]*

The use of the phrase 'bad luck' by Naomi implies that this baby's death was a chance occurrence over which there was no control. Brian too reasoned that their son's death was a chance occurrence and that there was nothing that they 'could have done' to prevent it:

> *"I was dead sure, if you asked me I would have said 99.9 per cent that there was something wrong with Conor…that's what I kept saying to Amy, 'This is why it happened, and there's nothing we could have done'…that there was something wrong like, that it just wasn't meant to be" [Brian 356-359;369-372]*

Brian too tried to rationalise his son's death, convincing himself that there had to be 'something wrong' with the baby.

For some couples, their baby's death involved a questioning of faith in a higher power. Some found comfort in that faith such as Evan:

> *"Maybe there's a reason for everything, you know. Maybe something to do with this baby, maybe something will happen to me years down the line or maybe it will be one of us getting cancer. I don't know, won't have all the answers. I've strong faith and I believe in God. You've got to accept it, it's not easy, but you've got to accept it. [Evan 581-589]*

For others faith proved to be little consolation and was a source of anger and frustration. As David said:

"You know at times I'd be swearing at him up there. Why me? Why us?" [David 1467]

Nadine's quotation below highlights the struggle of many as she came to terms with the belief that life is 'not fair' as other babies live while her baby died:

> *"You think of life and how precious it is, and then babies being born in war zones and babies being born during earthquakes ...it's not fair… There's babies being born to heroin addicts and god love them, they are very sick but they're alive." [Nadine 19-20; 29; 560-561]*

Finding a cause for their baby's loss was a welcome relief when a diagnosis finally came. It provided couples the opportunity to meet with healthcare staff and to have: *"all my questions answered." [Amy 442]* For some couples, definite answers not available which was both stressful and worrying for them. For example, there were no investigations or analysis that could be offered at the time of Ruby's death or on her remains and this left Kim and Simon with no reason or explanation for her death:

> *"There was no explanation was offered to us as what might have been behind losing the baby at 22 weeks, obviously continuing on in that pregnancy was incredibly stressful and worrying and you know you felt something was going to wrong every time" [Kim 15-17]*

For other couples, the lack of a diagnostic explanation for their baby's death seemed less of an issue:

> *"It (Julia's death) was just a fluke, so it was just a few a complete fluke. There was no problem as having more kids, in that suppose, that kind gives you more confidence. It (was) more relief when you hear things like that that it was just a freak, flukey thing." [Adam 107-113]*

The belief that Julia's death was a 'freak, flukey thing' was helpful to Adam and his partner in helping them experience the death of their baby as a very unusual and unexpected event and improbable occurrence, unlikely to occur again. Hence, there was 'no problem with having more kids' leaving them with a sense of 'confidence' to consider trying for another pregnancy.

Grieving the Deceased Baby

Our baby was a person

One way that helped couples make sense of their experiences of loss was acknowledging their baby was a person. As Jonah said of his baby who was stillborn at 39 weeks:

> *"But with Imogen we physically held her and had our baby in our arms, we lost a baby." [Jonah 1430]*

For example, Simon was convinced of his daughter's existence because he had seen her on a detailed ultrasound scan of the twins and they had named the babies following the scan:

> *"I knew there was going to be something because she (Ruby) was so real. We had a scan in London and it was very detailed one. You know the images and it was all really graphic. So from that, to saying there was nothing, that is just physically, impossible, just physically impossible for someone to just disappear" [Simon 425-427; 431-433]*

For Simon, the babies' personhoods were real. The graphic images from ultrasound testify to his need to acknowledge his baby as a person. Here there was a person named Ruby. This contrast with the notion that there 'was nothing' and his baby, albeit dead, could 'just disappear' as if she never existed was a 'physically impossible' concept for Simon to consider. Their doctor's suggestion caused considerable distress to the couple.

There were differences between women and the men in their accounts of acknowledging their deceased baby based on their sense of knowing that baby. These differences were often a source of tension within the couple. Women were better able to articulate their sense of knowing the baby that had died and counting them among their children: *"Yeah, I <u>have</u> three children" [Amy 645]* Amy was emphatic in acknowledging of her children living and deceased.

Knowing their deceased baby was, for some men, a more complex issue and they struggled in identifying with the deceased baby as a person. They spoke about women knowing the child more because of their physical relationship with the baby. Adam, whose baby Julia was stillborn at 32 weeks following a diagnosis of a life-limiting anomaly at 24 weeks' pregnancy, said because his partner Grace "*felt the child moving and she kinda knew her a bit more than me." [Adam 180].*

Brian too, commented that his sense of knowing his son began only when he was born until the baby was buried and that this was short lived. The physical relationship with a child during pregnancy may explain differences between a woman and a man in getting to know a baby as a person during pregnancy:

> *"Like it is very, very sad, but it's not, it's different to me losing Larry or John (older sons) to Conor. I knew Conor for 4 or 5 days, Amy knew him for 22 weeks, she knew the person. I didn't know the person, so." [Brian 220-222]*

Later in the interview, Brian went on to describe his difficulty in making sense of acknowledging his deceased baby when he is asked how many children he has:

> *"I still struggle with saying 'How many children have you, three or two?' I don't automatically say three and every time someone asks me, subconsciously it goes through my head, 'Two or three, two or three?' do you know." [Brian 640-643]*

While Brian found it challenging to include his deceased baby in number of children he has to others, it seems that subconsciously he is acknowledging this baby.

Although men described difficulties with getting to know their deceased baby as a person, this did not mean that they did not want to have this baby acknowledged, either subconsciously as in Brian's comment above, or more consciously. For example, David said:

> *"Yeah it doesn't matter; you're still going to be missing one. That is the hardest thing like. I know if people acknowledge it, she is still going to be missing. But it just makes that bit: / well we know where we stand…not one person hasn't mentioned Zoe here, are they thinking about her at all?" [David 551; 557-558; 574]*

His partner Jill explained that:

"you are always trying to defend her or stand up for her" [Jill 572].

As suggested in David's comment, having the deceased baby acknowledged by others was important to couples although not always experienced.

Some couples expressed the belief that others such as family members or work colleagues had difficulty communicating with them about their deceased baby. As Valerie said:

> *"So the girls in the Nursing Home they were very good (at letting her talk) but then other people would not talk about it, even if I said it, they were like, the look they'd give me was… I went through it and it is a part of my life forever you know. It's definitely taboo. People do not want to discuss it or talk about it whereas I actually quite enjoyed it, you know" [Valerie 354-356; 365]*

Valerie and Tim did not have other living children at the time so for Valerie talking about her baby was a pleasant thing to do because it acknowledged her as a mother. In contrast to the notion that others may forget about their deceased baby over time, couples did not forget. While they recognised the need to deal with the loss and move on, this did not equate with forgetting their baby.

All of the couples continued their relationships with their deceased baby and were always cognisant of the ongoing bond and relationship to them. They were especially conscious of remaining loyal and honouring the baby's memory. Iona's quotation highlights couples' experiences of not wanting to forget their deceased baby:

> *"You just have to find some, a good place in your mind and just handle it. I don't mean park it, like I said before. See if you can move yourself on from it you know and that can make things good for yourself…We weren't forgetting about her" [Iona 606-608]*

Couples were also mindful about being happy again and of having feelings of guilt, as if this happiness in some way was negating the love they felt for their deceased baby and allowing themselves to feel joy was lessening the grief the felt. As Nadine said:

> *"And this feeling, of being happy with this baby and the love you wanted to give to Imogen and she didn't get from us and she does have it from us but not physically. It's guilt as well isn't it?" [Nadine 908-909]*

However, for other couples, over time the memory of their baby became a more pleasant experience, with less intense with grief:

> *"No not sad I mean just like thinking, thinking back do you know, it should be an unpleasant experience for us but it's not really any more… which (would) be unusual for people "[Valerie 1133-1134]*

Some couples continued relationships with their baby encompassed thinking of their baby developing along a chronological timeframe. Thinking not only of the deceased baby but that child as they would be now: *"She'd be a great age now" [Iona 442-443].* Couples continued their relationship with the deceased child, mourning the baby and as Adam said: *(honouring) her memory and who she would have been [Adam 338].* They described their need to continue loving their deceased baby at an emotional level:

> *"And this feeling, of being happy with this baby and the love you wanted to give to Imogen and she didn't get from us and she does have it from us but not physically. It's guilt as well isn't it?" [Nadine 908-909]*

Their need to remember the deceased baby and avoid the risk of forgetting him or her as a person was articulated by couples and for some this influenced their decisions when to consider a new pregnancy in their lives:

> *"I don't think we wanted to start (trying to conceive) obviously straightaway just because, you nearly want to remember Julia you don't want to like, the moment she is being buried and things like 'Okay let's have a baby as fast as possible, let's forget about this' because you don't want to forget about this." [Adam 245-249]*

Finding our way through loss and grief

Acknowledging the deceased baby as a person, as presented above, illustrates one approach that helped couples come to terms with their loss. Grieving was a process however and it was apparent that couples used various strategies to help them through. As such, they had to find their way through their loss and grief to learn what

worked best for them. This differed across couples and within couples with reference to talking about loss, being present with one another, keeping occupied, and support through counselling, family members, or other healthcare professionals.

Some women spoke of how they wanted to talk about their loss, which they found helpful:

> *"…anything that was in my mind I just come straight out with it" [Grace 201]*
> *"But (partner) is the only person that I really want to (talk to)" [Kim 1379]*

The use of the first person pronoun 'I' in the above quotations clearly indicates that both Grace and Kim were referring to themselves wanting to talk, and there is no specific reference here to their partners. Naomi does use the plural first person, saying: *"We can talk about it" [Naomi 779]*. Her reference to 'we' was about couples being able to talk about loss. In other instances, women described their desire to talk about their loss spoke of being very open about this to their partners:

> *"I will never shy away from saying anything to Adam like, he will talk and talk and talk back and you know, we talk things out…I say, anything that was in my mind I just come straight out with it" [Grace 196;201]*

Although Grace's comment indicates that Adam talked to her in return, Grace's use of 'we talk things out' was not borne out in reality. It was often difficult for men to discuss openly their thoughts and feelings even with their partners. Men spoke of the differences between the genders in this regard. As described by Adam: *"it's different with guys (as opposed) to girls; we don't really talk" [Adam 421].* That being said, Adam spoke about his partner Grace, as his main source of support:

> *"Yeah (she) would be (main support) …it's mainly just Grace" [Adam 451-252]*

Men spoke of their supporting role in helping their partners through the loss of the baby, for example: "*I tried to kind of help Valerie [Tim 459]*

> *"It was my job to look after Grace a lot of the time. Grace was in bits and bits a lot of it, so I just nearly had to man up and just, that was my job I had to look after Grace and make sure she kind of got through it" [Adam 225-234]*

However, it was apparent that men too were experiencing loss and had to find ways of dealing with this:

> *"I had no real choice but to keep busy (work), kept my mind occupied" [Tim 459]*

Likewise, Adam said:

> *"I suppose keeping busy and stuff, for me was what I did" [Adam 266]*

Talking about their baby's death and how they were feeling at an emotional level, seemed a challenge for men based on beliefs that men need to be strong for their partners:

> *"But as a man, I suppose I would see for that period our job was to mind (care for) Amy" [Brian 232-233]*

Brian's comment with reference to what was required of him as 'a man' in terms of minding his partner suggests that he made sense of his role in terms of societal expectations of men as the stronger sex in the face of perinatal loss. Jonah's comment too was very poignant and revealing in this regard:

> *"I don't think men get (the same support) … they're almost expected to suck it up and take it on the chin for the kids and the woman." [Jonah 1239]*

For some men however, the supportive role they desired for their partners was difficult, especially bearing witness to their partner's grief when very emotional. This was very difficult, for men because of not knowing what to say leaving them with a sense of feeling 'useless':

> *"Grace would be crying all the time and I just felt so useless because I didn't know what to say, there was nothing I could say and when she would be crying on my shoulder and you couldn't say anything and I felt so useless because there is nothing I could have said and I felt like I should say something and try to make it better." [Adam 1069-1073]*

On hearing Adam say this, Grace reassured him that his presence alone was all that she needed: *"But you didn't have to. You were far from useless…even just sitting there." [Grace 1074; 1076]*

Although women liked to talk through their feelings, sometimes couples just needed the physical presence of their partner. Words were not necessary, 'even just sitting there' in each other's company was all that was required:

> *"Even not talking to each other, to be with each other" [Iona 210]*
> *"Some days just say I don't want to talk to you, but I'm okay" [Naomi 1651]*

Other couples spoke of the need for mutual support in dealing with their loss. A couple's ability to make sense of loss could be dependent upon their ability to share the loss together. Many couples spoke about how their experiences had strengthened them. Iona's quote demonstrates this:

> *"I think as a couple it made us stronger… Maybe it brought us closer together, it definitely did. But I know I wouldn't have done it without Evan only for his support" [Iona 446-449]*

Therefore, couples relied greatly upon one another; drew strength from each other and their pre-existing relationship. However, there were strains that loss and grief placed upon relationships as evidenced from Valerie's quote:

> *"I nearly felt like we were going our separate ways or and then we were too afraid to talk about it do you know. We did not know how to deal with each other as well do you know" [Valerie 486-487]*

Couples were aware that they were 'too afraid to talk about' their loss even within the confines of their relationships. Some couples spoke of needing to process their grief individually before they could talk things out together:

> *"We did not talk about it for a while, do you know, it was kind of, he didn't want to upset me. I did not know how he was feeling … I suppose after we grieved in our own way and it was just kind of, became ok to talk about it then between the two of us" [Valerie 248-255]*

Valerie's comment of having 'grieved in our own way' and then moving 'to talk about it, between the two of us' illustrates the complex nature of grieving for couples such that working through grief together may not always be feasible from the outset. Processing grief at an individual level may be required in the first and earlier instance. One explanation for this may relate to differences between men and women in finding ways to deal with their loss and grief:

> *"No two people are the same men and women's brains are wired differently you are not going to be on the same trajectory. You know you have to say there are seven steps to grieving one of them might be up to three one of you might be up to five you know that could be and I suppose that is weirdly I know that seems like kind of competitive edge" [Kim 1241-1245]*

Kim made sense of the experience of grieving as a trajectory, that is, a journey over time that needs to be processed taking one-step at a time. Her reference to the 'competitive edge' implies one individual in a couple being better than the other in terms moving along these steps as they process their loss and grief.

Through this process, there can be conflict within the relationship characterised by misunderstandings. Jill and David shared a story of such challenges. The couple spoke of Jill cutting down a tree in the garden that David had planted to remember their baby, Zoe. The couple had previously agreed that everything in their house was to remain unchanged until after Zoe's first anniversary. Jill viewed David's tree planting as an act of defiance, which led to conflict within their relationship. This story was reflective too of their contrasting grieving styles:

> *"There was a conflict there. I know it is only a small thing now because I mean we had plenty of more stupid arguments where I said he wasn't honouring Zoe enough or he would say I was going overboard" [Jill 1269; 1406-1408]*

Jill went on to suggest that there was a need for counselling to support couples through their grief:

> *"Well I do think that if there was a couples counselling, I do think that a couples counselling session, I do think that would help." [Jill 1050-1051]*

Her explanation for the benefits of counselling as a couple was that this would help couples see and understand each other's differing perspectives:

> *"I do think a counselling thing to show well people that's your opinion and this is yours and it is ok to have the two [Jill 1269; 1406-1408]*

In their efforts to process their experiences of loss, couples began to engage in talking with third parties outside the relationship. Five of the eight couples had attended counselling sessions. However, joint couples counselling was not common, as all but one of the five couples had attended individual counselling sessions. Evan and Iona were the only couple in the sample who attended couples counselling. Evan's initial intention was to go with Iona to support her, rather than gaining benefit from it himself:

> *"The counsellor was, for me, she was a big plus. I'm kind of private but I didn't want to let her (Iona) go on her own. So eventually we decided the best thing was to go. Even though I wasn't looking forward to it" [Evan 362; 366-369]*

In contrast, David saw no benefits to attending counselling because this would not bring his deceased baby back:

> *"At the same time what can they do for me? She is gone, what can you do for me? You are not going to bring her back to me." [David 1092; 1094]*

Other couples spoke about peer-to-peer support groups where they could meet other bereaved couples. Although women and not men mostly attended these sessions:

> *"Yeah around that time we went to a support group meeting together and then it wasn't for Adam so I used to go on my own" [Grace 596-597]*

Women who attended these groups found them to be beneficial by helping them identify with others with similar experiences and thereby feel 'normal':

> *"But I did find them really helpful at the start because it was the only place that I felt normal" [Jill 1158-1164]*

However, these support groups were beneficial only in the early stages of their journey of loss. As couples began to consider a subsequent pregnancy and as soon as this was achieved, they stopped attending these support groups:

> *"…the more I went the more stories I heard, the more I heard and then when I did get pregnant, that's when I stopped going" [Grace 464-470]*

It appeared that continually hearing stories of other people's experiences of loss diminished the benefits of peer support, which also contributed to their decision to stop attending:

> *"It was just more and more sad stories coming all the time and none of them did me any good." [Naomi 539]*

This was particularly when they began to continually hear new stories of baby loss at each subsequent meeting.

Apart from supporting couples to process their grief either individually or together, it is possible that counselling may also have a role in helping them talk about loss of the baby to others, especially siblings of the deceased baby, and their own parents. Couples were conscious of the ripple effect the loss of their baby and their grief had on their family:

> *"You don't realise how much it impacts your whole extended family and yourself until it comes to your door. Like you hear of it happening to other people but you don't realise the devastation it causes to a whole family network like. … but it's just the way it affects people" [Jonah 1257-1261; 1264]*

Seven of the eight couples were already parents to living children prior to their experiences of loss. Their children were a source of comfort to them and helped them with their loss, as Doug said: *"if we didn't have them we would be totally lost" [Doug 1690].* Having other children also gave the couples physical comfort and a source of

distraction from their loss. Iona spoke of how her children helped physically comfort her:

> *"I had an awful longing to hold her (Kristine), I was lucky because I had the two girls and I could give them a hug" [Iona 681-683]*

However, the issue of how loss affected their children was to the fore for couples. Some couples spoke of openly talking to their children about their baby's death, meeting the baby, and involving them in creating memories. Jill spoke of her older daughter walking the baby around introducing Zoe to her home:

> *"So then Molly was bringing her around the house showing her 'This is my room' 'This is you, would have been in here in your basket'" [Jill 972-973]*

Other couples strove to protect their children from loss. Some couples with very small children did not tell them about their sibling's death nor have them meet with their deceased sister or brother. They made this decision with the best intentions for their family, though it was a difficult choice:

> *"The hardest thing for us was I suppose we didn't even tell the girls" [Iona 115-117]*

Couples also spoke about their relationships with their immediate families, especially their parents, acknowledging that they also experience loss. Grace's quote exemplifies the empathy that most couples shared in describing their parents' experiences of loss:

> *"…for a (grand) parent to see an adult child going through that like you know it is hard for them" [Grace 1313]*

Couples also described numerous examples of when they felt cared for and supported by their social network. Often their family or closest friends provided this support, as Jonah said:

> *"I think the fact that our families do support us a lot and that fact that our friends really support us a lot" [Jonah 592]*

However, for other couples, families were sources of stress rather than helping them in dealing with their loss, which was challenging as Simon's quote demonstrates:

> *"I got to the point when my mum; like having a conversation with her, but she is getting upset…because of it, doesn't allow you space to cry or to feel upset" [Simon 642; 647]*

As shown in Simon's quotation, attempts to have a conversation with his mother resulted in her getting upset, which in turn was inhibitive in terms of allowing him share, his grief. This implies that some couples or individuals have difficulty openly expressing their grief in the presence of family members who become upset about the loss of their baby. This reinforces the earlier suggestion that counselling may benefit couples in communicating about their loss to others beyond themselves, that is, family members.

Changed by loss

All but one of the couples began their stories by talking about their lives and pregnancies before loss with reference to how unencumbered their lives had been. However, the death of their baby had tainted their feelings about pregnancy:

> *"Yeah, yeah I feel like before we were so laid back [Grace 57]*
> *"…my first two pregnancies I hadn't a care in the world …" [Naomi 1603-1604]*

There is a wistful quality to the descriptions, of a 'laid back' and carefree life without a care in the world, untainted by the experiences of loss. Pregnancy, like life, is no longer simple or uncomplicated. Couples say they were changed by the experience of loss. Even couples' views on newborn babies were affected by their experiences of loss. Nadine described her awe when she sees a living baby born to others:

> *"Because I don't look at babies the same any more… It's weird. I don't look at babies as healthy things anymore. I am in awe that they had a baby and the baby is alive [Nadine 46-52; 657]*

Nadine use of the word 'weird' hints to her struggle to make sense of her experience of Imogen's death. Couples spoke about how their experiences of loss changed them, their outlook on life and altered their view of pregnancy:

> *"But when this (loss) has happened to you, your whole life actually has changed. You do feel different; you don't feel the same. I definitely don't feel like the same person as I was twelve months ago" [Jonah 721]*

Couples spoke about the loss of their baby resulting in a reassessment and reordering of life's priorities. People and things that seemed important before loss were subsequently viewed as less important:

> *"I think I have changed, I have changed and I have toughened up I don't really care about certain things or you know.... trying to please people..." [Grace 1126-1132]*

For Grace the loss of her baby resulted in a prioritising of her own needs. For one woman, the change was not just internal but also external; Jill described the physical change in her appearance as an outward manifestation to others of her loss. She changed her appearance from bright and colourful to black clothes as a way of demonstrating her grief to her unsupportive family and friends. She even changed from wearing make-up to wearing none. She acknowledged the change in herself and struggled to make sense of her actions:

> *"I am a totally different person, totally different person I don't think I could ever have seen more different to people than the way I was before and the way I am now, it's mad isn't it?" [Jill 278-280]*

Jill's use of the word 'mad' is telling. Here she uses the word in its crazy or insane derivation and it illustrates that she struggles to make sense of the dramatic alteration in her outward appearance. She goes on to say that she uses her drab outward appearance as a public display of her enduring her loss especially to those close to her who refused to acknowledge it, in the first instance: *"And now the worse people see me the better (laughs) 'Oh God'" [Jill 1799]*

Couples also spoke about their internal conflict between sadness and happiness in everyday life and the guilt they feel when experiencing happiness after loss:

> *"There's this sadness that you always have with you but then there's times if you're happy for a prolonged period you actually feel guilty for being happy" [Jonah 622-627]*

Couples' experiences of loss and grief changed their lives and their perceptions of pregnancy. Yet despite these experiences, the couples chose to decide upon a subsequent pregnancy.

Summary

These findings represent the experiences of couples in the immediate pregnancy after perinatal loss. All couples began their stories with the babies they knew best, the babies that had died. It was clear that their experience of loss had a profound and lasting impact upon their lives and was the lens through which they viewed all of their experiences, particularly their subsequent pregnancies. The death of their baby, even if that baby was diagnosed with a life-limiting anomaly, was an unexpected event, with which they struggled to make sense. Their baby's death and its aftermath affected how they made sense of their experiences. They drew comfort from their empathic relationships but acknowledged that they were forever changed by their loss.

The desire to parent again was very strong and couples were definitive in their need to assign identities to the babies who had died before they could contemplate another pregnancy. Women appeared able to do this more quickly than men. Both were adamant that the new baby was never to replace their dead baby, as that child

was unique and irreplaceable. Couples believed their children had a unique family position. In the pregnancy subsequent to loss, it was challenging couples, to maintain an ongoing loyalty to their deceased babies and attach to their new babies. Couples efforts to achieve a new pregnancy required negotiated decision making that was different for each dyad. Both parties needed to be in agreement and ready to embark upon the journey of a subsequent pregnancy before that decision could be achieved. Conception was fraught with anxiety and stress for some couples. Sexual intercourse lost its intimacy and became more functional and goal oriented. Waiting to get pregnant was often very stressful as women questioned their reproductive abilities. These anxieties affected couples' relationships. Once pregnancies were achieved, couples began a finely tuned balancing act of worry and hope. Couples tuned into signs of life in their baby for constant reassurance. However, they attempted to keep their hope restrained to avoid further hurt, should this baby die too. Nonetheless, all couples were hopeful of a live baby. All couples were interviewed in the second half of their subsequent pregnancy and were mindful they would have to revisit their experiences of stillbirth in a visceral way, in birth to meet their new live baby. This process would bring them face to face with birth and death once more.

Chapter 5: Discussion

Introduction

In keeping with the principles of IPA as espoused by Smith et al. (2009). This chapter will discussed the study's findings, strengths and limitations, and recommendations for practice, research, education and policy. The two superordinate themes that emerged from the data were '*Hoping for a Born Alive Baby'* and '*Journey of Loss'.* The superordinate theme '*Hoping for a Born Alive Baby'* emanated from the subordinate themes: '*different babies'; 'trying to conceive'; 'cautiously hoping', and 'revisiting the past to give birth to a born alive baby'.* The superordinate theme '*Journey of Loss'* emanated from the subordinate themes: *'unexpected death of a baby'* and *'grieving the deceased baby'*.

The experiences of eight heterosexual couples in the immediate pregnancy after stillbirth contributed to the data. Couples were interviewed together to explore their experiences of PAL. All of the couples were either married or co-habiting at the time of the interview and had been in a relationship for a minimum of six years. All but one couple were in their thirties and had other children prior to their loss. The remaining couple were in their late twenties and experienced a stillbirth in their first pregnancy.

This study makes an important contribution as it extends our knowledge and understanding of the experiences of couples in pregnancy after loss. In the current study couples were interviewed together, to garner greater in depth understanding of how they as a dyad, made sense of pregnancy after loss. The experiences of individuals, rather than the couple have been the focus of previous research. Past

research has predominantly focused on women's experiences with occasional studies exploring men's experiences. This study adds to our understanding of PAL as it was informed by a salutogenic perspective and to date, a predominantly pathogenic focus has underpinned research. There has been an omission in exploring the health-focused substructures that assist couples in achieving and surviving pregnancy after loss. Identifying what helps couples during a pregnancy after loss can assist with ensuring that the experience is less stressful.

Hoping for a born alive baby

The act of getting pregnant again following a stillbirth could be viewed as a hopeful one. From the outset, couples spoke of their hope for a born alive baby and remained focused on that outcome. Couples were aware, from their experiences, that pregnancy does not guarantee a live baby and their hopes were tempered by that knowledge. They were engaged in balancing hope and fear throughout the pregnancy. These findings suggest that hope, as a concept defined by Snyder et al. (1991) is present for couples in pregnancy after loss.

Couples in the current study were very definite of the individual personhood of the baby that had died and the subsequent baby they were expecting. They spoke with conviction that each baby was an individual in their own right and occupied a unique place in their family unit. Similar concerns were highlighted in other studies (Grout and Romanoff 2000, Campbell-Jackson et al. 2014). Uniquely, in this current study, participants were interviewed together. They were a homogenous sample as all had experienced a stillbirth as their index loss. Couples were adamant that their new baby

was not a replacement for their deceased baby, as that baby was irreplaceable. This acknowledges the findings of previous research (O'Leary and Warland 2012, Reid 2007). The men in this study were in agreement with this point, similar to participants in Armstrong's (2001b) male only study.

Earlier research cited brief inter-pregnancy interval as predisposing children born after loss to negative psychological sequelae (Cain and Cain 1964, Grout and Romanoff 2000, Olmsted and Poznanski 1972). However, more recent research has drawn different conclusions and this may be because of a greater understanding of the issues involved (O'Leary and Gaziano 2011, O'Leary et al. 2011, Ünstündag-Budak 2015, Warland et al. 2011b). The participants in this study too suggest that parents are very much aware of the differences between their individual babies. Couples in this study were very definite about the personhood of each of their babies therefore; it is unlikely that these babies born subsequent to loss would be a risk of replacement child syndrome as discussed in the literature (Cain and Cain 1964, Grout and Romanoff 2000, Olmsted and Poznanski 1972, Ünstündag-Budak 2015). The findings from this study are contributing to knowledge on this issue, as unlike previous studies, they are reflective of both members of the couple dyad.

Just as couples were definite about their deceased baby's place within their nuclear family, couples in this study were engaged in securing and protecting their deceased baby's place within their wider family units. In acknowledging or not the deceased baby's rightful familial place, the behaviour of the couples' support networks, helped or hindered the experiences of couples. Support networks either acknowledged the deceased baby as a member or not. Couples whose networks were supportive spoke

of how helpful this recognition of their baby and their loss was to their grieving. Similarly, couples who were not well supported also spoke at length of the impact this lack of familial recognition of their baby had on their grief and their ongoing relationships with their families. Several couples experienced fractures of key relationships with family members in the aftermath of stillbirth. The finding of this study supports the need for acknowledgement of deceased babies and of women and men's parentage of these babies. Couples' need for acknowledgement of their deceased baby supports the findings of other studies (Côté-Arsenault and Denney-Koelsch 2011, O'Leary and Thorwick 2006, Rajan and Oakley 1993).

Couples were mindful of their conflicting emotions throughout, trying to bond with their new baby and remaining loyal to the baby that had died. Many reported feelings of guilt and a wish to remain loyal to the deceased baby that interfered with their enjoyment, pleasure and joy at their new pregnancy. It appeared, for some couples, that bonding to the new baby equated to a disloyalty to the baby who had died. This finding is supportive of parental desire for ongoing relationships with their deceased babies. It could be suggested that this struggle was a process of meaning-making for the couples as they negotiated the experiences of parenting both babies, in the aftermath of loss.

This is the first study that explored the nuances of planning and deciding on pregnancy after loss from a couples' perspective. In this study, couples jointly made the decision to have another baby after loss. However, there were gender differences noted among the couple-pairs. Couples spoke of the need for each partner to be in agreement with this decision for a pregnancy to occur.

Most women in this study were resolute in their wish to have another baby very soon after loss. For some women this was to fulfil a nurturing desire, while for others it was to reaffirm their reproductive success. Women's longing for a new baby and wanting to mother a baby was described by Reid (2007) and other studies have reported this as a natural instinct to be pregnant again (Keith 2005, Lee et al. 2013, Meaney et al. 2016). For the women in this study, the meaning of mothering appeared to be very important. They spoke of the need to mother all of their babies as well as having their motherhood of their deceased baby acknowledged.

These findings provide new insights into couples' and especially, men's thinking about the decision to get pregnant after stillbirth. These gender differences may be explained by the need for men to parent fully the baby who has died, as stated earlier. Men admitted needing more time to reach a decision about a subsequent pregnancy. Some men expressed a belief that their partners knew the deceased baby more than they did and they needed more time to get to know their baby after birth. Several men spoke that the immediate time after loss, was their only time to get to know their baby. They wished to protect the time they saw as belonging to the deceased baby before contemplating another pregnancy. This may be reflective of the gender differences inherent in transition to parenthood, whereby men's transition may not be fully realised until the birth of the baby (Draper 2003). There are very few studies exploring this issue and none specifically exploring couples' experiences in depth. This is an important finding for clinicians and couples alike in the provision of sensitive, respectful care. Lack of awareness of these gender differences may result in distress and trauma for couples. These findings support previous research and provide new insights into how men make meaning of

fatherhood in the face of pregnancy loss. It was apparent that some men in this study struggled, at times, to make meaning of their paternal role to a deceased baby, as it was at odds to their paternal experiences with previously live born children.

Meaney's (2016) study also alluded to a gender disparity in terms of the timing of PAL. In it, the women interviewed discussed the desire for a subsequent pregnancy in the immediate aftermath of loss. However, unlike this current study, women and men in Meaney et al. (2016) study were not interviewed together nor considered as part of a couple. The current study sought to explore couples' experiences as a dyad. While other studies have reported men's views, through the prism of their partners' experiences (Lee et al. 2013, Keith 2005, Kint 2015) no studies have explicitly explored the views of couples as a unit before now.

Interestingly, although all participants in this study expressed a desire for another pregnancy, men often acted as gatekeepers to a subsequent pregnancy. Although women spoke about wanting a subsequent pregnancy soon after loss, they could not achieve this alone. Among the couples, pregnancy did not happen unless the men too were willing to commit to such an eventuality. This was at odds with the fact that men said the final decision to have another pregnancy lay with their partners.

In this study, the timing of PAL varied with couples' experiences of loss. Couples whose babies died because of a congenital anomaly wanted to wait to receive post mortem and laboratory test results before contemplating a subsequent pregnancy. This issue was particularly important to men who expressed a desire to have concrete explanations for loss and risk ratios of a likely recurrence. Women were more likely to want to achieve a pregnancy based upon their own desires rather than waiting for

professional advice to do so, similar to the women in Davis et al. (1989) study. Conversely, men preferred to wait for doctors' permission before contemplating a pregnancy.

Couples, whose baby died unexpectedly and without an anomaly, were more anxious to achieve a pregnancy immediately. In these instances, women expressed an almost raw desire to be pregnant again and some men felt that being pregnant again was beneficial to their partners' grief trajectory. It could be that for both individuals in a couple, a sudden, unexpected death may be more challenging. Men, in these instances, may submit to agreeing to fast conception as a mean of lessening their partners' grief, about which they can do little to solve, and as a means of caring for them. The two couples in this study to whom this situation pertained, had the shortest inter-pregnancy interval.

This study contributes to our understanding of how couples negotiate their different concerns when planning for a pregnancy after loss. It suggests that women and men are both concerned with differencing aspects of their gender role performance pertaining to conception. Once they had made a decision for a subsequent pregnancy, couples began the process of trying to conceive. They spoke about this as a very challenging process. For several couples this was their first time actively planning a pregnancy and they were uncertain even of the process. Wanting to get pregnant, resulted in perfunctory sexual intimacy for some couples. Men commented upon the lack of intimacy that became the hallmark of their lovemaking during this time. Women experienced different issues. They spoke of the challenges of waiting to achieve a pregnancy and the difficulty they had with the arrival of each

menstrual period. There was an ongoing fear among women that their bodies may be faulty and that a subsequent pregnancy may never be possible. These findings are similar to those of other studies that have explored sexual intimacy after loss (Hagemeister and Rosenblatt 1997, Dyregrov and Gjestad 2011, Dyregrov and Dyregrov 2015).

The experiences of trying to conceive after loss had an impact on the couples' relationships. This study contributes knowledge that couples, who were able to discuss their feelings with one another, even if there was disagreement, appeared to fare better than those who struggled to communicate in the aftermath of loss. It may even be that couples; hearing one another's stories during this interview process contributed to them making sense of their experiences.

Couples spoke of the importance of recognising the impact trying for a baby was having on them and their relationships. They balanced their desire for a baby with how much of this pressure they, as a couple, could sustain. Most couples acknowledged the benefit of the strength of their pre-existing couple relationship. Two couples openly acknowledged communication difficulties, in the aftermath of loss. They spoke of how their relationship was challenged by the difficulty they had in communicating with one another after the loss of their baby. Communications difficulties in the aftermath of loss have been shown to affect couples intimate relationships (Hagemeister and Rosenblatt 1997, Dyregrov and Gjestad 2011, Dyregrov and Dyregrov 2015).

Similar to other studies the presence of worry and anxiety in pregnancy after loss was a feature for couples in this study too (Abbaspoor et al. 2016, Agterberg et al.

1997, Armstrong and Hutti 1998, Chojenta et al. 2014, Couto et al. 2009, Fertl et al. 2009, Gaudet 2010, Giannandrea et al. 2013, Gong et al. 2013, Hughes et al. 1999b, Hunfeld et al. 1996, Hunfeld et al. 1997a, Robertson Blackmore et al. 2011, Shapiro et al. 2017, Theut et al. 1988, Turton et al. 2001, Turton et al. 2006, Yilmaz and Beji 2013).

For couples in this study, there was no time through the pregnancy journey when these negative feelings dissipated, or no time point beyond which the couples felt able to relax about the outcome (Côté-Arsenault and Dombeck 2001, Gaudet 2010). Couples admitted that certain time points, like anniversaries and clinic appointments, were more challenging supporting the findings of other research (Armstrong 2001a, Côté-Arsenault and Marshall 2000, Cŏté-Arsenault 1999, Phipps 1985, Robertson and Kavanaugh 1998).

Once couples achieved a pregnancy, they embarked upon a challenging journey and they admitted to feeling constantly worried about the possibility of another loss. In this study, it was as if couples achieve a perverse satisfaction from their worry. It was almost as if worry gave them an anchor in their PAL journey and indeed, they were often concerned if they were not engaged in worrying. This is an important finding to be considered in supporting couples in PAL. Indeed, worry and anxiety reported here and in other studies, may be an integral component of the experience of PAL. Therefore trying to achieve a state whereby couples are not worried or anxious may be impractical. Rather, adopting a salutogenic approach focusing on the supports and resources that assist couples in negotiating this process may be beneficial.

All couples in this study spoke of adopting a state of constant vigilance about the wellbeing of the baby. Couples coped by paying attention to their live baby as a source of reassurance. Within the couples, there were gender differences experienced. This is an important finding to those supporting couples in PAL. Women spoke of being continually cognisant of their pregnant state and how exhausting that constant awareness was for them. It appeared as if the very thing women craved, fetal movements and reassurance of their baby's wellbeing, was often the source of their greatest distress. This uneasy relationship with fetal movements supports similar findings of Mills et al.'s (2014) metasynthesis, although the studies in this review did not explore couples experiences but concentrated on women's experiences. Women have an embodied experience of pregnancy that their partners cannot share exactly. Men therefore are reliant upon women's proxy accounts of fetal wellbeing. Men related to their baby's wellbeing through their partner's embodied experiences of fetal movements and through external confirmation of fetal wellbeing, such as ultrasound scans and fetal heart monitoring. Women often did not immediately share their concerns about the baby's fetal movements with their partners immediately. These new findings need to be considered by all caring for couples in PAL.

Couples went through various processes of trying to cope and re-exerting control over their worries. When women had concerns about fetal movements, they did not always immediately disclose these concerns to their partners. They tried to exert control over the situation by containing and not vocalising their worries. It may be that women hoped to re-establish trust in their own judgement, at recognising that all was well with their baby. Only when women were not reassured or if the worry

became too great for them to bear, would they disclose their concerns to their partners. Partners sought to reassure women that the baby was well and helped them create realistic expectations of fetal movements. However, men too were often very worried but were reluctant to share their concerns preferring instead to remain silent. Only when the couple could no longer contain their fears, did they resort to external validation of fetal wellbeing by visiting healthcare professionals and seeking external proof of life. This proof was usually via sonicaid, cardiotocograph or ultrasound. The use of interactions as described between couples supports +

A new insight of this study is that men favoured the use of ultrasonography over sonicaid or CTG. This may be because ultrasonography gave them visual proof of life. This may be because men, similar to men in Armstrong's (2001b) study, reported a greater sense of attachment to their unborn baby through their experiences of ultrasonography. This may explain why this type of fetal wellbeing validation is preferred. However, this finding needs to be balanced with the awareness that ultrasound scans themselves can be a source of stress in PAL. Confirmation of their baby's death in the previous pregnancy was usually done by scan (Mills et al. 2014, O'Leary 2005).

Couples in this study were conscious about their worries for PAL interfering with their pregnancy experiences and all expressed desires to be fair and treat the new baby similarly to the deceased baby. Couples experienced feelings of guilt as they admitted the death of their previous baby influenced their interaction with this new baby. Other studies too have reported that couples withhold attachment to the subsequent baby due to fear of another death and worry for health of the baby, as

well as for emotional self-preservation (Côté-Arsenault and Donato 2011, Côte-Arsenault and Freije 2004, O'Leary and Thorwick 2008).

If no reason for the index pregnancy loss is found, it has been reported that detachment can be more common (DeBackere et al. 2008). By trying not to think too much about the new baby until it was born, the couples in this study were engaged in emotionally protecting themselves. However, they acknowledged that they were conscious that this is what they were doing but felt they could not help themselves.

In spite of these feelings of worry, couples in this study admitted to being cautiously hopeful of a live baby and discussed preparing for the new baby's arrival. Importantly, couples spoke of holding and sustaining hope for one another throughout their PAL journey. They constantly sought to reassure one another. Men in particular engaged in this activity to provide support for their partners. Likewise, couples also looked externally, to trusted healthcare professionals, to sustain their hopes and were reassured when professionals were hopeful. Similar to other studies, couples here found supportive care by healthcare professionals to be beneficial (Meredith et al. 2017, Mills et al. 2014).

Hope, as a future orientated act was present in the findings from this study, although it was couched in restraint. Snyder et al.'s (1991) theory of hope attests that the hoped for outcome must be wanted and achievable by the individual and similar to the participants in this study, that a degree of uncertainty around the goal attainment can be expected.

Couples spoke about the ultimate aim of their pregnancy, giving birth to a live baby after loss. In this pregnancy, they had revised their birth expectations, acknowledging

that a live baby was all they wanted now. They admitted they would be willing to accept a less than idealised baby (such as a fussy baby) if it meant that the baby was born alive. They felt that their journey was incomplete until their baby was born alive. To reach that goal, couples were conscious that they still had hurdles to overcome. Couples spoke about the challenges facing birth again would bring. They envisaged that birth would bring back emotions about the birth of their deceased baby.

There were gender differences apparent among couples. To achieve the aim of giving birth to a live baby, women were mindful that they had to revisit the birth space to labour and give birth. The idea of revisiting the birth space was challenging for women as their last experience was of giving birth to death. Amy's story was especially poignant in this regard when she spoke about remembering her previous birth. She shared the experience of her body not wanting to let go of her deceased baby. This story alludes to the fact that women remain protective of their babies, even when they know they are deceased and this can affect their birth experience. Women spoke of the need to be able to separate their two birth experiences so that could contemplate birth again. Valerie's story was an exemplar of this where she knew that her baby had died during labour and she associated the death with continuous fetal monitoring. She was already planning strategies to help her deal with CTG monitoring in her upcoming labour. These findings support those of Keith (2005) and Meredith et al. (2017) where women found returning to the birthing environment very challenging. However, in both those studies women's views only were articulated. The benefit of this study is that it also obtained men's experiences and they too spoke of the challenges of the impending birth. Men tended to think about the outcome rather than the process of labour and birth. They were more

goal-focused and spoke of birth as something to get over, to get to the other side, and a live baby. This may be because, for men, there is an absence of physical connection to the birth process. However, men too acknowledged that birth would be emotional and the hardest experience they had yet faced. It would mean revisiting their baby's death and reactive feelings they had when that child was born. For men, the prospect of meeting their new baby was challenging to contemplate. Similar to Sun et al.'s (2011) study couples were aware that birth might not bring closure to grief. This study expands our knowledge because it shares the male experience of revisiting birth while Sun et al.'s (2011) study only explored women's experiences.

It was apparent that couples were seeking to create meaning of their birth experiences by both revisiting their prior births and contemplating their future ones. They attempt to create a different, perhaps new meaning of birth so that they could revisit that sacred space again, to birth this new baby. Similar to Frankl's (1984) theory of meaning, couples negotiated exceptional hardship yet strove to create resonance in their new experiences of pregnancy after stillbirth.

In summary, couples were very mindful that their previous experiences of loss tempered their experiences of their current pregnancy. Their efforts to get pregnant were challenging and they were fearful of another loss. They engaged in coping activities to manage these worries. In spite of their worries, they remained hopeful of a live baby and worked together to support one another and to negotiate the journey of pregnancy after loss.

Journey of Loss

Couples in this study all began their stories with the baby they felt they knew best, the baby that had died. Pregnancy loss was such a catastrophic, life-changing event that it changed their worldview, their perception of pregnancy, of parenthood and of themselves. Couples experiences in this study support the findings of studies and reviews that have explored perinatal loss (Burden et al. 2016, Campbell-Jackson and Horsch 2014, Heazell et al. 2016). What this study contributes is the voice of participants as a couple, who shared this seminal event.

Couples in this study spoke of death as an unexpected event and were struck by the abruptness and unanticipated nature of this occurrence. What is striking is that all couples spoke of this experience of regardless of the cause of their baby's death. The unexpected way in which death occurred caught couples off guard, even when couples had been informed of their baby's death or likely death in advance of birth. This is an important finding for clinicians to consider when caring for couples antenatally, in the case of diagnosis of fatal fetal anomaly, and with unexpected stillbirth. Couples may need additional supportive measures to coping with the hopeful expectation that their baby may survive. This finding contributes to our understanding from previous research on couples' experiences of perinatal loss but is strengthened in this study by the inclusion of both members of the couple dyad (Burden et al. 2016, Campbell-Jackson and Horsch 2014, Heazell et al. 2016).

One explanation for these experiences is that couples' viewed the death of their baby as an unnatural event. While couples admitted they were aware of the risks of earlier pregnancy loss, they believed that there was a critical point, beyond which babies

were safe from danger. Likewise, while some couples were aware of the possibility of pregnancy loss, there was an assumption that this was not something that could happen to them. Again, this reiterates the belief that the death of a baby before birth is an unnatural event, which couples struggle to make meaning of as it conflicts with the natural order of the world. It may also help to contribute to our understanding of how society tries to make meaning around perinatal death. This is very important finding about the understanding of pregnancy loss, especially stillbirth, in light of Nuzum et al.'s (2018) recent survey, which highlighted a lack of public knowledge about stillbirth.

Perinatal loss shatters an individual's self-perception. It may be because in our children we see our self-reflection and contribution to the world (Leon 1990). Keith (2005) also refers to the fact that couples have no frame of reference when a baby dies and that a veil of secrecy exists around stillbirth. The couples in this study, similar to the women in Keith's (2005) study spoke of now belonging to a secret club, which no one wants to be a member. This secrecy envelops couples as they struggled to acknowledge '*how many children have you?*' Couples may even regulate the spread of this secret knowledge when discussing whether to speak to others about their deceased baby, gauging as Brian said: '*how much can this person take?*' Keith (2005) claims that healthcare professionals too, are guilty of perpetuating this culture of non-disclosure. The findings of this study support the need for open discourse about the babies who have died with couples and among wider society. The contribution of this study was the inclusion of the male voice in the findings.

Some couples spoke of a feeling that something was not quite right with their baby prior to receiving any bad news. These concerns were mostly vocalised by women and referred to their perceptions of the baby's movement or behaviour. However, in this study, for the first time men also articulated this concern. This finding strengthens the need for empowering women with knowledge about when to voice concerns about their baby's movements. When speaking about these feelings, couples in this study disclosed delaying help seeking behaviour and instead tried to rationalise their 'gut' feelings. This may have been a coping or avoidance mechanism. It may well be that couples were fearful of bad news and by delaying attendance at the maternity unit they were delaying external confirmation. All couples struggled to make sense of their baby's diagnosis or death. Even when couples did seek healthcare assistance, they were unprepared for hearing that their baby had died. Once the news of their baby's anomaly or death had been broken, couples spoke of retaining hope that something could be done to help their baby. In cases of a diagnosis of severe fetal anomaly, couples remained hopeful that operations or procedures could be performed to save the baby's life. Even when couples knew that their babies would not be born alive, they retained hope that the doctors were wrong.

Conversely, couples who did not have any feelings of foreboding, admitted to upset at not realising that something was amiss with their baby. This finding was especially articulated by women who believed that, as a mother, they should have recognised that something was wrong with their baby. These concerns may reflect couples' views of their parental protection role. They may be reflective of feelings of self-blame and that in not recognising this issue; they somehow failed in their parental

protection role. These findings are similar to those reported by Warland et al. (2015) where women reported a '*gut feeling'* that something was amiss. Women often try to rationalise this feeling or seek help and women have found it difficult to articulate their fears or have their fears taken seriously by healthcare professionals (Warland et al. 2015).

All couples vividly remembered hearing the news of their baby's death or anomaly diagnosis. Women were often unaccompanied when hearing the news and several were given the additional responsibility of imparting the news of their baby's anomaly to their partners. This finding is worrying as would be contrary to accepted, best practice (Pullen et al. 2012, Hunter et al. 2016, Health Service Executive 2016).

Men spoke of their upset that they were not present to hear the news of their baby's diagnosis. This finding may be a reflection of the routine nature of ultrasound scanning in high-income maternity care. The impact of ultrasonography is an important finding, given the National Maternity Strategy for Ireland (Department of Health 2016) recommends that all pregnant women have access to a routine, mid-trimester, anomaly ultrasound scan. When this programme is enacted, men should be encouraged to accompany their partners for this ultrasound. Ultrasound scanning has become an integral part of maternity care in Ireland. It would usual for women to have three or four ultrasound scans during a normal risk pregnancy. Women view ultrasound scans in pregnancy reassuringly, Lalor and Begley (2006) suggest that women routinely submit to ultrasound scans without comprehending the implications of the results.

Women, in particular, spoke of the challenges of having to give birth to their babies, knowing that they were already dead or unlikely to survive outside the womb. Even though, they acknowledged the importance in so doing. They felt that giving birth vaginally honoured their baby and afforded the baby the care it would deserve, if it were alive. This finding has important implications for clinicians caring for couples at the time of stillbirth. While the baby remained inside them, the women in this study believed they were still able to perform that maternal protective role. It is interesting to note the conflict between the pain and the challenges of labour, and the need to relinquish the baby physically in order to give birth. This struggle may co-exist with the maternal desire to protect her unborn baby from harm when there is nothing more harmful than death. This may also mirror the mother's conflict and struggle to let go of the imagined live baby and confront the reality of death. This finding mirrors that of women in Erlandsson et al. (2011a) study who valued the act of birthing their babies. Among the women in this study birth, was described as difficult and some women spoke of struggling to relinquish the baby from their bodies, to allow their babies to be born. It was as if in so doing they would finally be confronted with the reality of their baby's death. These findings add to the existing knowledge about women's experiences of labour during stillbirth (Trulsson and Radestad 2004). When their baby was born, couples spoke of an expectation that the baby might move or breathe. This finding adds to our understanding of this phenomenon described also in other studies (Lalor et al. 2009, Nuzum et al. 2017, O'Connell et al. 2016). Couples remained hopeful of a live baby and struggled to make sense of their baby's death even when faced with the physical reality. The couples' stories here support that

concept that even in the face of enormous odds, hope remains. Perhaps suggesting that hope is a necessary component of pregnancy loss as well as pregnancy after loss.

Both women and men in this study articulated the co-existence of death and birth as a surreal experience. There was an expectation from couples in this study, that because the world as they knew it had ended, time should also stand still for everyone else. Couples found it distressing when confronted with the reality that this was not the case. Men, spoke of being confronted with the reality of their baby's death within the confines of maternity units, seen as places of live births. These findings are important for all maternity services, as pregnancy loss is such a common occurrence. Women in Ryninks et al.'s (2014) study also discussed similar findings. These issues reflect wider existential struggles, temporality and difficulty in making sense of death before birth and adds to the work of Ünstündağ – Budak et al. (2015) who reported these issues when interviewing only women. The contribution of this study is in identifying that this is also a concern for men whose babies are stillborn.

Couples acknowledged that meeting their dead baby was very challenging and required an inner strength on their part. Given the recent debate around this issue, this is an interesting finding of this study and has implications for policy development and service delivery. The findings from this study confirm that meeting their deceased baby may not be an easy task for every parent to do. Sensitive discussion and support should be provided to couples prior to the birth of their baby. Care should be taken when presenting babies to meet their parents. How healthcare professionals interact with couples and how deceased babies are presented to their parents have shown to improve the experiences of couples (Downe et al. 2013,

Erlandsson et al. 2013, Kingdon et al. 2015b, Wilson et al. 2015). Facilitating couples meeting their babies as soon as feasible after birth, form the cornerstone of current guidelines (Health Service Executive 2016, Hunter et al. 2016).

There were gender differences noticeable in this current study. Men in particular, said that even looking at their dead baby was a hard thing to do. This reluctance in meeting their baby appeared to be associated with the gestation and condition of the baby at birth. It was more apparent in parents whose babies were of younger gestation or babies who had been dead for some time prior to birth. This difficulty in meeting the deceased baby was often a source of conflict between the couples. Men in the study by Samuelsson et al. (2001) also reported a difficulty in coming face to face with their deceased babies and highlights an ongoing concern for everyone caring for bereaved parents. The issue of whether parents should be routinely encouraged to meet their baby has been raised in the recent literature for discussion. Some authors have suggested that meeting the deceased baby could be a source of parental distress. Studies have questioned couples' routine meeting their babies and the risk for negative psychological sequelae (National Institute for Health and Clinical Excellence 2007, Hennegan et al. 2015, Redshaw et al. 2016). Some studies have reported higher levels of grief in parents who have seen and held their babies (Hughes et al. 2002, Turton et al. 2009b, Wilson et al. 2015). However, it is recognised that the gestation of the baby may influence these findings. Others studies and reviews suggest that although the experience of meeting their baby is distressing, parents seldom regret meeting their deceased baby and that their fears can be ameliorated by sensitive and empathic care (Downe et al. 2013, Kingdon et al. 2015a, Kingdon et al. 2015b, Radestad and Christoffersen 2008, Ryninks et al. 2014). Similar

to the couples in this study, women in Ünstündağ – Budak et al. (2015) qualitative study felt that meeting their baby was profoundly beneficial in coming to terms with their baby's death. Researchers have acknowledged that with small sample sizes in perinatal loss, it remains challenging to support practices with higher order empirical evidence (Alderdice 2017, Crispus Jones et al. 2015, Koopmans et al. 2013).

Whether the baby's death was expected or unexpected, all couples in this study needed to discover a reason why this happened. In the first instance, women looked to themselves as a source of blame for their baby's death. Women viewed their body as an unsafe place for a baby to inhabit. The very thing that a mother is supposed to be able to do, keep her child safe, they felt they were unable to achieve. This is similar to other studies who explored the effect negative that stillbirth has upon a women's sense of identity as a mother (Murphy 2012, Murphy and Thomas 2013). When couples in this study were provided with a reason for the baby's loss it allowed women an opportunity to externalise the blame they felt. This was particularly noted if the reason for the stillbirth was due to a chromosomal or genetic anomaly. Self-blame as a grief response to perinatal loss has been reported regardless of the cause of the baby's death among women and men (Barr 2004, Barr 2012). Self-blame is an important issue for practitioners to consider when caring for couples.

The need for couples to establish a cause for their baby's death appeared to be an important component in their efforts to make meaning of their baby's death and to contemplate a future orientation.

A benefit of the joint, couple interviews in this study was in allowing both members to hear the experiences of their partners within a safe environment. Key to the

underpinnings of IPA this helped participants to continue to make sense of their experiences of their baby's death. It reinforces the need to explain to couples that gender differences in grieving are to be expected after perinatal loss and of the necessity in providing bespoke supports that acknowledge these differences.

Research has explored gender differences and contrasting grieving styles in the aftermath of pregnancy loss which states that feminine and masculine styles of grieving can be a source of conflict and misunderstanding between couples (Barr 2006, Barr 2012, Bergstraesser et al. 2015, Cacciatore et al. 2008a, Lichtenthal 2013). Couples in this study similarly, reported noticeable gender differences in the aftermath of their baby's death. Women often coped by wanting to talk about their experiences. Men, found talking challenging and coped by attempting to keeping busy and often avoiding the issue of their personal grief. These different grieving styles were often a source of conflict for couples. The findings support the acknowledged discrepancy in female and male grieving styles and reinforces the fact that male responses to grief are less acknowledged (Barr 2006, Barr 2012, Bergstraesser et al. 2015, Büchi et al. 2009, Cacciatore et al. 2008a, Lichtenthal 2013, Vance et al. 2002).

The findings of this study also support the conclusion that discordant grief is a specific feature of couples' responses to perinatal death (Büchi et al. 2009, Bergstraesser et al. 2015, Vance et al. 2002). In fact, Bergstraesser et al. (2015) study reported that dyadic coping with loss can often be a reflection on each individual couple's ability to cope with stressful events and is dependent upon the strength of their initial relationship. This was supported in this study whereby there were varying

experiences of coping with loss, which couples' acknowledged was reflective of their pre-existing relationship. The participants in this study spoke about the challenges and difficulties they experienced as a couple in the aftermath of loss.

The realisation that they often had different grieving styles was a key moment in making meaning of grief as a couple for participants in this study.

All couples acknowledged a changed view of the world and of pregnancy in the aftermath of loss. They admitted an altered perception of themselves too because of their loss. There were positive and negative changes disclosed. From a positive perspective, nearly all couples acknowledged reinforcement and strengthening of their couple relationship through their experiences of loss. Each partner acknowledged the role the other had played in helping them navigate the experience. Couples' reports of being changed by their experiences of loss, supports the findings of other studies where women (Côté-Arsenault and Marshall 2000, Keith 2005, St. John et al. 2006) and men (Armstrong 2001b, Campbell-Jackson et al. 2014, O'Leary and Thorwick 2006) disclosed how much they changed because of loss. For some participants in this study, they attempted to find a deeper meaning for their child's death that was congruent with their personal, philosophical world-view (Cacciatore and Bushfield 2007, St. John et al. 2006).

This is reflective of both Frankl (1984) theory and Neimeyer's (2011) work on meaning making. Whereby human's strive to make meaning from what is often a meaningless event. It was evident that all couples in this study wished to create meaning from their babies deaths so that they could face the future with hope.

It was clear the death of their baby was an unexpected life event, which forever changed couples. It affected their worldview and their view of pregnancy. They struggled to make sense of the death of their baby, so close to birth. Couples continue to struggle to make sense and gender differences in coping with their loss was apparent. A strong, pre-existing relationship and an ability to communicate helped couples to navigate this journey. The findings disclosed by interviewing couples together as a dyad have implications for policy, practice, education and further research.

Strengths and Limitations

As with any research, this study had strengths and limitations. A major strength of this study is that it focused on the experiences of couples as a dyad. Interviewing the couples together allowed detailed exploration of these experiences for them as a dyad. It is the first study to explore PAL with couples as a unit. The study helps in our understanding of the joint decision-making process that couples use when contemplating a PAL. In keeping with the principles of IPA, the data collection method may have helped women and men in making sense of their experiences by allowing them to hear one another's experiences of loss.

The use of IPA necessitated face-to-face interviews, which allowed participants to explore fully their experiences. This methodology unearthed a wealth of deep narratives on what is a very sensitive topic area. IPA allowed for an in-depth interpretation of how couples make sense of pregnancy after loss.

IPA necessitated the use of a homogenous sample and all couples were pregnant again at the time of their interview. This is the first study that explored couples' experiences while they were currently pregnant, in the immediate pregnancy after loss. The narratives are influenced by their experiences at this time.

This study also had some limitations. The sample was recruited from a single maternity service. This service has a well-developed pregnancy loss service. The experiences of these couples may not be reflective of those of a wider population, who did not have access to such a service.

All of the couples in this study were aware going into labour in their previous pregnancy that their baby was either deceased or unlikely to survive outside the

womb. None of the couples in the study experienced an unexpected, intrapartum stillbirth. It may be that couples who encounter this additional trauma may have different experiences.

Women with co-morbidities that would place them at risk for stillbirth and who are over-represented in the perinatal loss statistics did not volunteer for this study. It may be that these additional risk factors may influence a couple's experiences.

Summary

Couples experiences of the stillbirth of their babies profoundly and perpetually altered their lives. The pregnancy after loss was viewed through the lens of stillbirth and could never be contemplated or considered without reference to the couple's experiences of loss and grief. Nonetheless, couples remained hopeful and embarked upon a subsequent pregnancy. Although anxiety and worry were the hallmark of these pregnancies, couples hope for a positive outcome endured.

The two superordinate themes '*Hoping for a born alive baby'* and '*Journey of loss'* emerged from interpretive analysis of the in depth interviews with couples, in the immediate pregnancy subsequent to their loss and seeks to explicate how they made sense of their experiences. The first theme, *'Hoping for a born alive baby'* captured how the hope of a live baby was experienced and how the couples made sense of deciding to get pregnant after loss; their experiences of trying to get pregnant and their experiences of pregnancy after loss. The second theme, '*Journey of loss'* articulated couples' experiences in making sense of the death of their baby and how they coped, with their grief, in the aftermath of loss. These findings add to the understanding of men's distinct experiences of stillbirth and loss.

The death of their baby was an unexpected life event, which forever changed couples. It affected their worldview and their view of pregnancy. They struggled to make sense of the death of their baby, so close to birth. Couples continue to struggle to make sense and gender differences in coping with their loss was apparent. A strong, pre-existing relationship and an ability to communicate helped couples to navigate this journey.

Couples were very mindful that their previous experiences of loss tempered their experiences of their current pregnancy. Their efforts to get pregnant were challenging and they were fearful of another loss. They engaged in coping activities to manage these worries. In spite of their worries, they remained hopeful of a live baby and worked together to support one another and to negotiate the journey of pregnancy after loss. Indeed, it was evident that couples in this study, despite their previous experiences of death, were displaying concepts of salutogenesis. That is they were striving to make meaning of their experiences and they strove to adopt a hopeful orientation. Interviewing couples together, elicited nuanced descriptions of their shared experiences that may not have been apparent if they were interviewed separately.

The findings disclosed by interviewing couples together as a dyad have implications for policy, practice, education and further research. The following recommendations are suggested from the findings of this study.

Recommendations

The loss of a baby is a profoundly life-changing event in the lives of any couples. The impact of this event and the effect it has on their lives remains poorly understood by those closest to the couple, by wider society and sometimes by the healthcare professionals caring for couples. The following recommendations are suggested from the findings.

Recommendations for clinical practice

It is recommended that:

- Each couples journey of loss is unique and requires individualised care pertinent to that couple's needs. Therefore, beginning at the time of their loss, a personalised programme of support should be planned for each couple. This should include either individual or joint counselling bereavement by an appropriately trained person and delivered at a time-frame suitable to each couple.
- Couples planned and decided on a pregnancy after loss in consultation and agreement with one another. Therefore, the individualised programme of support needs to be cognisance of this fact by offering information and advice to couples after loss.
- Gender differences within couples require specific and individual support and care. Maternity services should introduce supports that are couple-focused and specific to pregnancy after loss. Consideration should be given to providing gender-specific care.

Recommendations for research

In relation to research, the recommendations are:

- Worry and anxiety are inherent components of pregnancy after loss for couples. Consideration should be given to the development of a supportive intervention that is mindful of these issues and that are tailored to suit each couple's individual needs. This intervention could be tested using a randomised, cross over trial.
- Further research is needed to explore fully men's specific experiences pregnancy loss and the pregnancy that follows. Including the identification of gender-specific, appropriate supports.
- Sense of Coherence measurement, using appropriate scales should be measured amongst the pregnancy loss population to ascertain couples' levels of hope and meaning. To identify if there are differences between couples who choose to embark upon a pregnancy after loss and those who do not.
- Consideration should be given to a longitudinal, in-depth study exploring couples' journey of pregnancy loss, pregnancy after loss and parenting after loss among couples whose demographics are over-represented in the perinatal loss statistics.

Recommendations for policy

In relation to health policy, it is recommended that the findings from this study be used to inform the development and implement national guidelines on maternity care:

- National maternity policies acknowledge the significance of pregnancy loss. However, greater consideration needs to be given to the impact that pregnancy loss has on couples at the time of their loss and in the pregnancy that follows. The results from this study could be used to inform a policy on pregnancy after loss.
- Maternity services need to give consideration to the provision of specific pregnancy after loss services that encompass the unique needs of couples. Appropriately funded support services and resources should be put in place.
- Funded support for couples should be provided after loss and throughout the pregnancy that follows.

Recommendations for education

The findings from this study should be used:

- To inform the development of a perinatal loss education programme for all healthcare staff who care for pregnant women and their partners. This programme should be tailored to the specific needs of couples, not just solely women, who experience pregnancy loss and for the pregnancy that follows.

- To develop couple-focused, educational support material. Providing information on the experiences of others who have experienced pregnancy after loss.
- To inform wider public discourse on the social impact and repercussions of perinatal death. This may help inform the public on the needs of couples at the time of loss and throughout the pregnancy that follows.

Personal Reflection

This doctoral journey has been one of the most challenging experiences of my life. It has been all consuming for the past eight years, as I spent 18 months exploring the literature and deciding on a research topic before I registered in January 2012. My interest in the area was twofold. Firstly, it was informed by my clinical midwifery experiences in caring for women and their partners at the time of their losses and in subsequent pregnancies. Secondly, it was informed by my own personal experience of loss and grief, although not perinatal loss.

Throughout the entire process, I was mindful that the couples' experiences were the research priority. I was very cognisant of my own personal experiences and worked very diligently to ensure that they did not unduly influence the research process at every stage. Nonetheless, I am aware that in qualitative research, the researcher is the instrument and I have tried to acknowledge the impact that I may have had upon the study throughout.

At the outset of my study I was asked, "Could you not have picked a happier topic?" and my answer was always, I did not pick the topic, it picked me. I felt driven to explore this particular topic, to provide a better understanding of couples' experiences. Nothing can assuage the sorrow and grief that couples experience at the death of their baby but a greater understanding of their experiences may improve the care and support they receive throughout their loss and the pregnancy that follows. In so doing, this may improve outcomes for couples.

I was aware that in interviewing couples together, they might not be as forthright as they may be if interviewed separately. With hindsight, I could have conducted

additional, individual interviews to see if there were any differences in the experiences discussed. However, I was reassured by the experiences of other studies that did not find any significant differences in the findings between interviewing couples together and separately. In fact, joint interviews permitted each couple to hear again one another's stories and unearthed rich, powerful data about their experiences.

I was also aware of my gender as a researcher and was concerned that men may find it difficult to talk about their experiences with me. I was reassured throughout by the men's willingness to engage in the interview process and their eagerness to share their stories.

I was aware at the outset that this project could be an emotionally challenging one. Hearing couples' stories of loss was indeed difficult at times. I utilised the entire gamut of supports throughout the research process from reflective journaling through to peer debriefing, which proved very beneficial. The experience of conducting this study has been immensely rewarding due to the depth of rich data shared by the couples.

The doctoral journey (Appendix 19) provided me with the opportunity for tremendous personal development from the learning gleaned in the taught modules of the Doctor of Nursing programme, to the opportunities to present my work at international research conferences, and the opportunity to publish in peer review publications (Appendix 20).

Conclusion

This study examined the lived experiences of eight heterosexual couples during pregnancy after stillbirth. The context for the study was outlined at the outset and the implications of stillbirth presented. The literature was reviewed to identify the research question and appropriate methods to answer that question. IPA methods were deemed the most appropriate approach. Following appropriate ethical approval, suitable couples were invited to participate. Data were collected by in depth, face-to-face, joint interviews. Data were analysed using IPA principles and the findings presented herein. Discussion, situating the unique contribution of this study within the existing empirical and theoretical research was presented including recommendations for practice, policy and education. My hope is that I have done the couples stories justice and accurately reflected their lived experiences of pregnancy after stillbirth.

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Appendices

Appendix 1: Reproduction Permissions

no-reply@copyright.com

Tue 04/07/2017 17:16

To:Murphy, Margaret(Nursing) <mgt.murphy@ucc.ie>;

THE LANCET

Thank you for your order!

Dear Ms. Margaret Murphy,

Thank you for placing your order through Copyright Clearance Center's RightsLink® service.

Order Summary

Licensee:	University College Cork
Order Date:	Jul 4, 2017
Order Number:	4142001004288
Publication:	The Lancet
Title:	Stillbirths: recall to action in high-income countries
Type of Use:	reuse in a thesis/dissertation
Order Total:	0.00 USD

View or print complete details of your order and the publisher's terms and conditions.

Sincerely,

Copyright Clearance Center

RE: Who do I approach about reproductions of figures from NPEC reports

Meaney, Sarah

Wed 05/07/2017 10:19

Inbox

To:Murphy, Margaret(Nursing) <mgt.murphy@ucc.ie>;

Hi Margaret,
There is no problem reproducing them, or pasting them in as long as they are referenced.
Hope that helps?
Best wishes,
Sarah

From: Murphy, Margaret(Nursing)
Sent: 04 July 2017 17:48
To: Meaney, Sarah <S.Meaney@ucc.ie>
Subject: Who do I approach about reproductions of figures from NPEC reports
Importance: High

Hi Sarah
I wonder could you tell me please who do I approach and how do I go about obtaining permission to reproduce figures from NPEC (2017) Perinatal Mortality Report for 2015 for my thesis?
Thanks

Kind regards

Margaret

RE: Permission to use the Salutogenesis Umbrella image

Monica Eriksson (HV) <monica.eriksson@hv.se>

Mon 06/11/2017 07:43

Inbox

To:Murphy, Margaret(Nursing) <mgt.murphy@ucc.ie>;

1 attachments (122 KB)

Umbrella 19 okt 2016.jpg;

Dear PhD Student Margaret Murphy,

Nice to hear that you like the umbrella. You are allowed to reprint it in your thesis with the following reference. Reprinted with permission from the author. Eriksson and Mittelmark, 2016.

In the reference list: Eriksson, M. & Mittelmark, M. B. 2016. The Sense of Coherence and Its Measurement. *In:* Mittelmark, M. B., Sagy, S. Eriksson,, M., Bauer, G. F., Pelikan, J. M., Lindström, B. & Espnes, G. A. (eds.) *The Handbook of Salutogenesis, p. 103.* New York: Springer.

Best regards,

Monica Eriksson
PhD, Associate Professor
Head of the Center on Salutogenesis/Projectleader ARK
Department of Health Sciences
University West
Gustava Melinsgata 2, SE-46186 TROLLHÄTTAN
Phone +46 520 22 3861
www.salutogenesis.hv.se

Get the **Handbook of Salutogenesis** FREE at http://link.springer.com/book/10.1007/978-3-319-04600-6

Doctoral thesis **Unravelling the Mystery of Salutogenesis.** The evidence base of the salutogenic research as measured by Antonovsky's Sense of Coherence Scale. For information please contact Monica.

Appendix 2: Clinical Research Ethics Committee Approval Letter

UCC
Tel: + 353-21-490 1901
Fax: + 353-21-490 1919
Coláiste na hOllscoile Corcaigh, Éire
University College Cork, Ireland

COISTE EITICE UM THAIGHDE CLINICIÚIL
Clinical Research Ethics Committee
Lancaster Hall,
6 Little Hanover Street,
Cork,
Ireland.

Our ref; ECM 4 (d) 14/04/15

9th March 2015

Dr Patricia Leahy-Warren
Senior Lecturer
School of Nursing and Midwifery
University College Cork
Brookfield Health Sciences Complex
College Road
Cork

Re: Doctor and Nursing (DN) Research – couples experiences of pregnancy following previous perinatal loss.

Dear Dr Leahy-Warren

Expedited approval is granted to carry out the above study at:

- Cork University Maternity Hospital

The following documents have been approved:

- Application Form
- Research Protocol
- Letter of Invitation/Information Leaflet of Participants
- Consent Form
- Interview Topic Guide.

We note that the co-investigator involved in this study will be:

- Margaret Murphy, Lecturer, Dr Keelin O'Donoghue, Senior Lecturer and Professor Eileen Savage, Head of School of Nursing and Midwifery.

Yours sincerely

Professor Michael G Molloy
Chairman
Clinical Research Ethics Committee
of the Cork Teaching Hospitals

The Clinical Research Ethics Committee of the Cork Teaching Hospitals, UCC, is a recognised Ethics Committee under Regulation 7 of the European Communities (Clinical Trials on Medicinal Products for Human Use) Regulations 2004, and is authorised by the Department of Health and Children to carry out the ethical review of clinical trials of investigational medicinal products. The Committee is fully compliant with the Regulations as they relate to Ethics Committees and the conditions and principles of Good Clinical Practice.

Appendix 3: Director of Midwifery Approval Letter

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Cork University Maternity Hospital,
Health Service Executive,
Wilton
Cork.

08/04/2105

Ms. Margaret Murphy
Midwifery Lecturer
Catherine McAuley School of Nursing and Midwifery
University College Cork

Re: Research Proposal Couple's Experiences of Pregnancy following Perinatal Loss

Dear Margaret,

I have reviewed your research proposal *on "Couple's Experiences of Pregnancy following Perinatal Loss"* and I approve of this study being conducted here at CUMH. In the event that you interview any couple who require referral to a Healthcare Professional for any reason I trust that you will endeavour to communicate this to the relevant staff member.

May I wish you every success with your study.

Yours Sincerely

Olive Long

Olive Long

A/ Director of Midwifery
Ext. 20704
086 7872168

Appendix 4: Hospital Chaplain Letter of Support

Murphy, Margaret(Nursing)

From: Nuzum, Daniel
Sent: 26 January 2015 11:56
To: Murphy, Margaret(Nursing)
Subject: Re: Support for my doctoral study on couples expereinces of pregnancy after stillbirth

Dear Margaret,
Thank you for your email. I am delighted to be able to offer support and resource for your study participants.

Wishing you every good wish for your research and Doctorate.

Yours sincerely
Daniel

FROM:
Daniel Nuzum

On 26 Jan 2015, at 11:44, Murphy, Margaret(Nursing) <mgt.murphy@ucc.ie> wrote:

> Dear Rev. Nuzum
>
> I am applying for ethical approval for my doctoral study on couples experience of pregnancy after stillbirth.
> Further to our discussions I would appreciate it if you would act as a resource for my study participants should they require it.
> With this in mind I am writing to request your written support for the study. An email response will suffice.
> I will revert to you once I obtain full ethical approval.
> I look forward to your communication and thank you for your consideration of this request.
>
> *Kind regards,*
>
> *Margaret Murphy,*
> *Lecturer,*
> *Doctoral Student,*
> *MSc, BSc, PGDip Teaching,*
>
> 1
>
> *RM, RGN, IBCLC,*
> *School of Nursing & Midwifery,*
> *University College Cork,*
> *Ireland.*
> *mgt.murphy@ucc.ie*
> *00-353-21-4901644*
> *http://research.ucc.ie/profiles/C01/4/mgtmurphy*
>
> <image001.gif>

Appendix 5: Bereavement Midwife Specialist Letter of Support

Murphy, Margaret(Nursing)

From: Orla O'Connell [Bereavement and Loss Midwife, CUMH] <Orla.OConnell@hse.ie>
Sent: 26 January 2015 19:22
To: Murphy, Margaret(Nursing)
Subject: RE: Support for my doctoral study on couples experiences of pregnancy after stillbirth

Dear Ms Murphy,

I will be glad to act as a resource for the participants on your study.

You may give them my contact information and I will assess and support their needs from a bereavement and emotional perspective.
You may also liaise with me if you wish to discuss any concerns you encounter with the participants during your study.

Best wishes
Orla O'Connell

Counsellor/ & Psychotherapist
Clinical Midwife Specialist: Bereavement

From: Murphy, Margaret(Nursing) [mailto:mgt.murphy@ucc.ie]
Sent: 26 January 2015 11:44
To: Orla O'Connell [Bereavement and Loss Midwife, CUMH]
Subject: Support for my doctoral study on couples experiences of pregnancy after stillbirth

Dear Ms. O Connell

I am applying for ethical approval for my doctoral study on couples experience of pregnancy after stillbirth.
Further to our discussions I would appreciate it if you would act as a resource for my study participants should they require it.
With this in mind I am writing to request your written support for the study. An email response will suffice.
I will revert to you once I obtain full ethical approval.
I look forward to your communication and thank you for your consideration of this request.

Kind regards,

Margaret Murphy,
Lecturer,
Doctoral Student,
MSc, BSc, PGDip Teaching,
RM, RGN, IBCLC,
School of Nursing & Midwifery,
University College Cork,
Ireland.
mgt.murphy@ucc.ie
00-353-21-4901644
http://research.ucc.ie/profiles/C014/mgtmurphy

Appendix 6: Letter of Support Consultant Obstetrician

Murphy, Margaret(Nursing)

From: O'Donoghue, Keelin
Sent: 26 January 2015 13:03
To: Murphy, Margaret(Nursing)
Subject: RE: Support for my doctoral study

Dear Margaret

You have my approval to proceed with this study, as discussed

Regards

Keelin

Keelin O'Donoghue PhD FRCOG

Senior Lecturer, Department of Obstetrics and Gynaecology, University College Cork
Consultant Obstetrician and Gynaecologist, Cork University Maternity Hospital,
Wilton, Cork, Ireland

Mobile: +353 (0)86 3843203
Phone: +353 (0)21 4920500
Fax: +353 (0)21 4205025
Email: k.odonoghue@ucc.ie
Web: http://www.ucc.ie/en/abigyn/
Web: http://publish.ucc.ie/researchprofiles/C004/kodonoghue

From: Murphy, Margaret(Nursing)
Sent: 26 January 2015 09:18
To: O'Donoghue, Keelin
Subject: Support for my doctoral study

Dear Dr O Donoghue,
I am applying for ethical approval for my doctoral study couples experience of pregnancy after stillbirth.
I am writing to request your support for the study.

I will revert to you once I obtain full ethical approval.

Kind regards,

Margaret Murphy,
Lecturer,
Doctoral Student,
MSc, BSc, PGDip Teaching,
RM, RGN, IBCLC,
School of Nursing & Midwifery,
University College Cork,
Ireland.
mot.murphy@ucc.ie
00-353-21-4901644
http://research.ucc.ie/profiles/C014/motmurphy

Appendix 7: Letter of Invitation to Study Participants

Couples experiences of pregnancy following previous perinatal loss

Invitation to take part

You are invited to take part in a research study on

Couples experiences of pregnancy following previous perinatal loss

Before you consider taking part please take the time to read this information leaflet and to ask questions. Taking part in the research study is completely voluntary. Please do not feel hurried or under any obligation to make a quick decision. You do not have to take part in this study and if you decide not to take part, this will not affect your future care in any way.

Why is this research being done?

It is unfortunate but rarely some babies die around the time of their birth. Many couples go on to have another pregnancy after this loss. We know very little about what it is like for couples during this time. This research will explore what it is like for couples who are pregnant again after the loss of a baby in a previous pregnancy.

Why have you been asked to take part?

Your participation in this research can help to tell us what it is like for couples going through a pregnancy after loss and how best to support couples during this next pregnancy.

What will the study require of you?

If you are interested in taking part, you will be given the phone number for the researcher and asked to make contact with her. You both (as a couple) will be asked to meet a researcher during your pregnancy. This interview may take 45 to 60 minutes. She will meet you both at a time and a place that suits. She will go through the aims of the study, answer any questions you might have and get your consent to take part. Several other couples will also be interviewed for this study.

Who can take part?

Couples whose last pregnancy ended in the stillbirth of their baby, who have English as their first language and who are over the age of 18 years will be invited to take part.

Are there any direct benefits for you if you take part?

The potential benefits for you in taking part will be to have your stories told and your voices heard about your experiences of loss and pregnancy again after loss. This is particularly relevant for men whose voices are underrepresented in the research to date. Your participation will help improve our understanding of what a pregnancy after late miscarriage or stillbirth is like for couples and how we can support couples through this time.

Researcher Details: Margaret Murphy

mobile: 087-6502167 phone: 021-4901644 email: mgt.murphy@ucc.ie

Will the study pose any risks to me?

Taking about your experiences of pregnancy after loss will allow your voices to be heard and will help to inform the research knowledge available in this area.

Does the researcher have permission to carry out this study?

The researcher is an experienced midwife and a Doctor of Nursing student under the supervision of Dr Patricia Leahy Warren, Senior Lecturer from the School of Nursing and Midwifery, University College Cork. Full ethical approval has been given by the Clinical Research Ethics Committee of the Cork Teaching Hospitals and the Clinical Director of Cork University Maternity Hospital.

How will information be kept confidential?

All completed interviews will be treated in strict confidence. Information from the interviews will be *coded to a number, not to your name*. The names associated with the identifying numbers will be kept in a locked cabinet separate from the interviews. All interview files and transcripts will be kept in a locked filing cabinet, in a locked office with key access only by the researcher. All information you provide will be kept in locked cabinets in a research office at the School of Nursing & Midwifery, University College Cork.

The information from this study will be published both as a thesis and in academic journals and conferences. Please be assured that you will not be identified in any publications. Your anonymity and confidentiality will be protected at all times in any publication or presentation of the study results.

Who can you contact if you have any questions?

If you wish to discuss any questions, concerns or feelings in relation to the study please do not hesitate to contact the researcher, Margaret Murphy (contact details below).

Thank you for taking the time to read this information

Margaret Murphy

School of Nursing and Midwifery,

University College Cork,

Ireland.

Researcher Details: Margaret Murphy

mobile: 087-6502167 phone: 021-4901644 email: mgt.murphy@ucc.ie

Appendix 8: Study Consent Form

Consent Form

Couples experiences of pregnancy following previous perinatal loss

Name:

I have been invited to take part in a study about couples' experiences of pregnancy following previous pregnancy loss.

I understand that I will be asked to do an interview.

I know that the information I provide in the interview will be kept confidential.

I have been informed that my name will not be used or identified in any part of the research study or papers written.

Taking part in this research study is my choice and I know that I can withdraw from the research study at any time, or ask that the information I have given not be used and without question.

The research study has been explained to me and I have been given an information sheet. Questions about the research study have been answered to my satisfaction.

I know that I am free to contact the researcher at any time if I have further questions.

I consent to taking part in the study, *'Couples experiences of pregnancy following previous pregnancy loss.'*

Participant's signature:

Date:

Researcher Details: Margaret Murphy

mobile: 087-6502167 phone: 021-4901644 email: mgt.murphy@ucc.ie

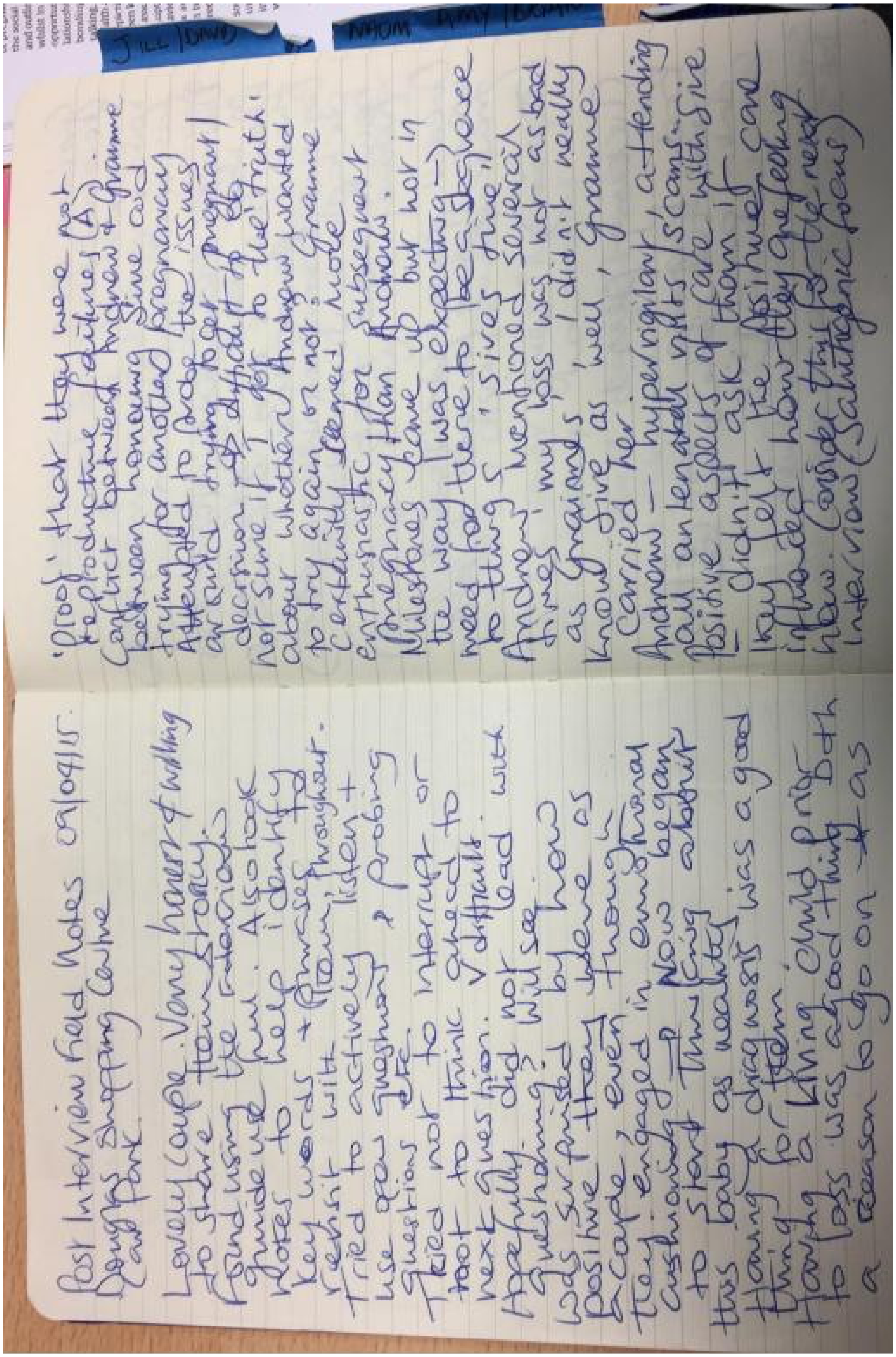
Appendix 9: Data Collection- Interview Topic Guide

Interview Topic Guide

What has it been like for you as a couple:

1. During this current pregnancy?
    a. Positive aspects
    b. Any concerns
2. Experiences of becoming pregnant after loss?
3. Reflections on previous loss
4. How has your past pregnancy influenced the present?

Appendix 10: Field Notes



Post Interview Field Notes 09/04/15.
Douglas Shopping Centre
Car Park.

Lovely couple. Very honest & willing to share their story.
Found using the interview guide useful. Also took notes to help identify key words + phrases to revisit with them, throughout.
Tried to actively listen + use open questions & probing questions etc.
Tried not to interrupt or to think ahead to next question. V difficult.
Hopefully did not lead with questioning? Will see.
Was surprised by how positive they were as a couple, even though they engaged in emotional cushioning → Now began to start thinking about this baby as reality.
Having a diagnosis was a good thing for them.
Having a living child prior to loss was a good thing. Both a reason to go on + as 'proof' that they were not reproductive failures (A).
Conflict between Andrew & Graeme between honouring Sive and trying for another pregnancy.
Attempted to probe the issues around trying to get pregnant / decision → difficult to say; not sure if I got to the 'truth' about whether Andrew wanted to try again or not. Graeme certainly seemed more enthusiastic for subsequent pregnancy than Andrew.
Milestones came up but not in the way I was expecting → need for there to be a sequence to things 'Sive's time'.
Andrew mentioned several times 'my loss was not as bad as Graeme's', 'I didn't really know Sive as well, Graeme carried her.'
Andrew — hypervigilant, attending all antenatal visits / scans.
Positive aspects of care with Sive — didn't ask them if they felt the positive care influenced how they are feeling now. (Consider this for the next interview (Salutogenic focus))

Appendix 11: Data Transcription Non-Disclosure Agreement

Seefin
Data Management Ltd.

Kerry
Seefin House Ballygologue Rd,
Listowel, Co. Kerry

Ph: 353 (0)68 22218
Mobile: (0)87 8346670
email: info@seefindm.com

ISO 27001

Non-disclosure agreement.

In connection with Ms. Margaret Murphy,Doctoral Student,MSc, BSc, PGDTLHEd,Lecturer,School of Nursing and Midwifery, University College Cork, (The Client") giving access to Seefin Data Management Ltd, Ballygologue Road, Listowel, Co Kerry. (The Company"),to data,design,concept and other business and client information ("the Information") for specified purposes or processing as agreed with The Client and in consideration of us obtaining the information, we agree to the following:

I. Without prior written consent by The Client, neither The Company nor our agents or employees will disclose at any time to any person or entity the fact that we have received any of the Information.

II. That neither The Company, our agents nor employees will disclose at any time to any person or entity any of the contents of the Information and that we will deem such Information confidential. The Company will arrange for the execution of a Declaration of Secrecy by the employees/ officers engaged in the provision of the Service.

III. That neither The Company, our agents or employees will use the Information for anything other than the Services.

IV. That on termination of the Agreement with the Client for the Services we will promptly deliver to the Client all the Information furnished to us without retaining copies, summaries or extracts thereof.

The Agreement will be governed by and construed in all respect in accordance with Irish law and shall be subject to the non-exclusive jurisdiction of the Irish courts for the purpose of any dispute in relation thereto.

Seefin Data Management Limited is registered with the Data Protection Commissioner as a processor of data under the data protection act and as a board member of CloudArena Ltd. adheres to their strict code of practice with regard to data protection. Seefin Data Management is accredited with ISO27001 status.

Please indicate your agreement by signing and returning a copy of this letter whereupon it shall constitute a binding agreement with respect to the subject matter.
We hereby accept and agree to be bound on the basis set out above in this agreement.

Signed: Margaret Murphy
For : Margaret Murphy. UCC

Dated: 30/04/2015

Signed: _____
For and on behalf of Seefin Data Management

Dated: 27th April 2015.

Appendix 12: Convention for transcription of audio files

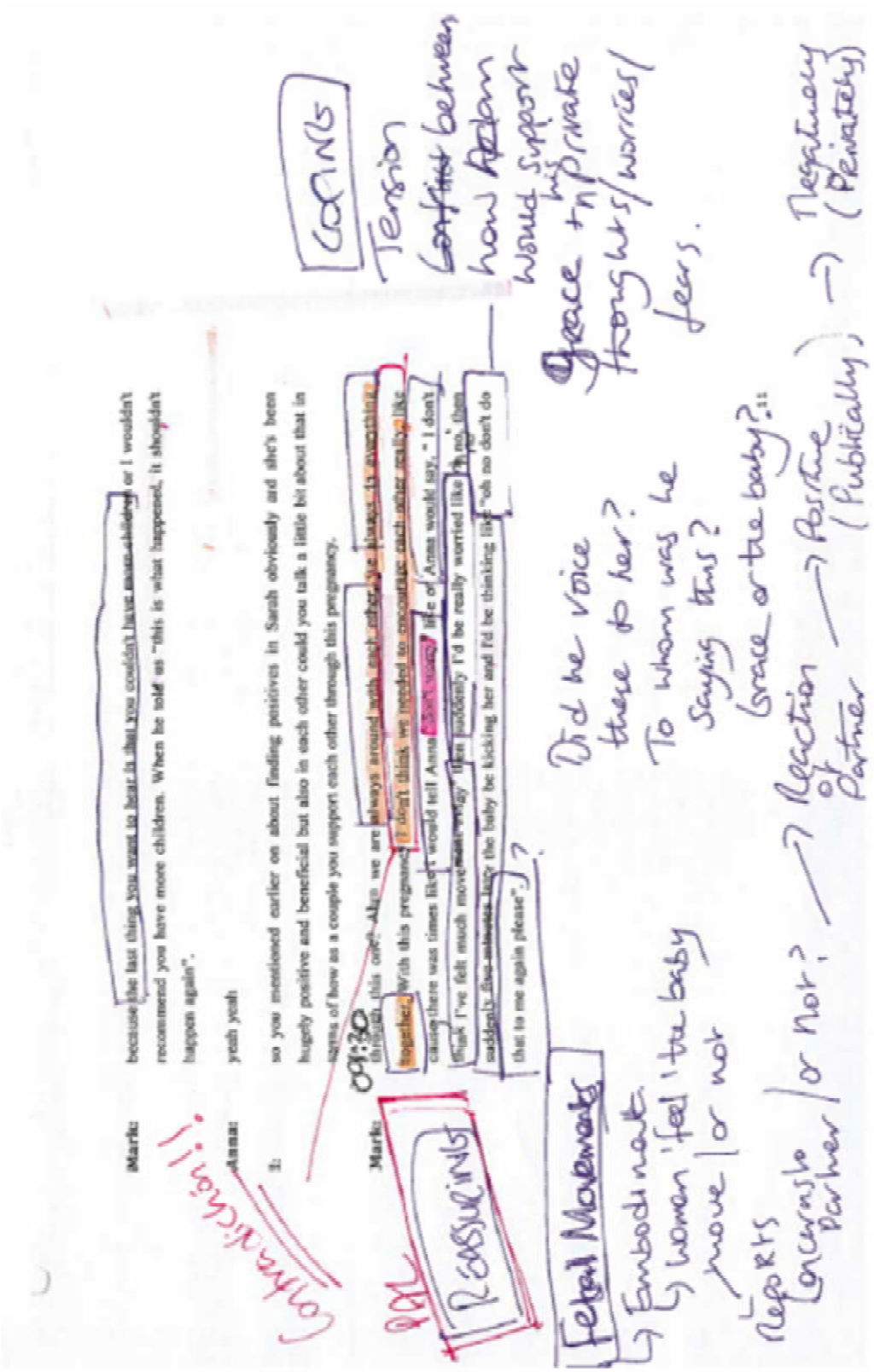
Page setup

- Landscape
- Margins 3cm on right and left, all others 5 cm.
- 1.5 spacing
- Font size 12
- Transcript headings
- File name
- Duration
- Date
- Interviewer = I
- Participant: F=Female and M=Male (researcher assigned pseudonyms)

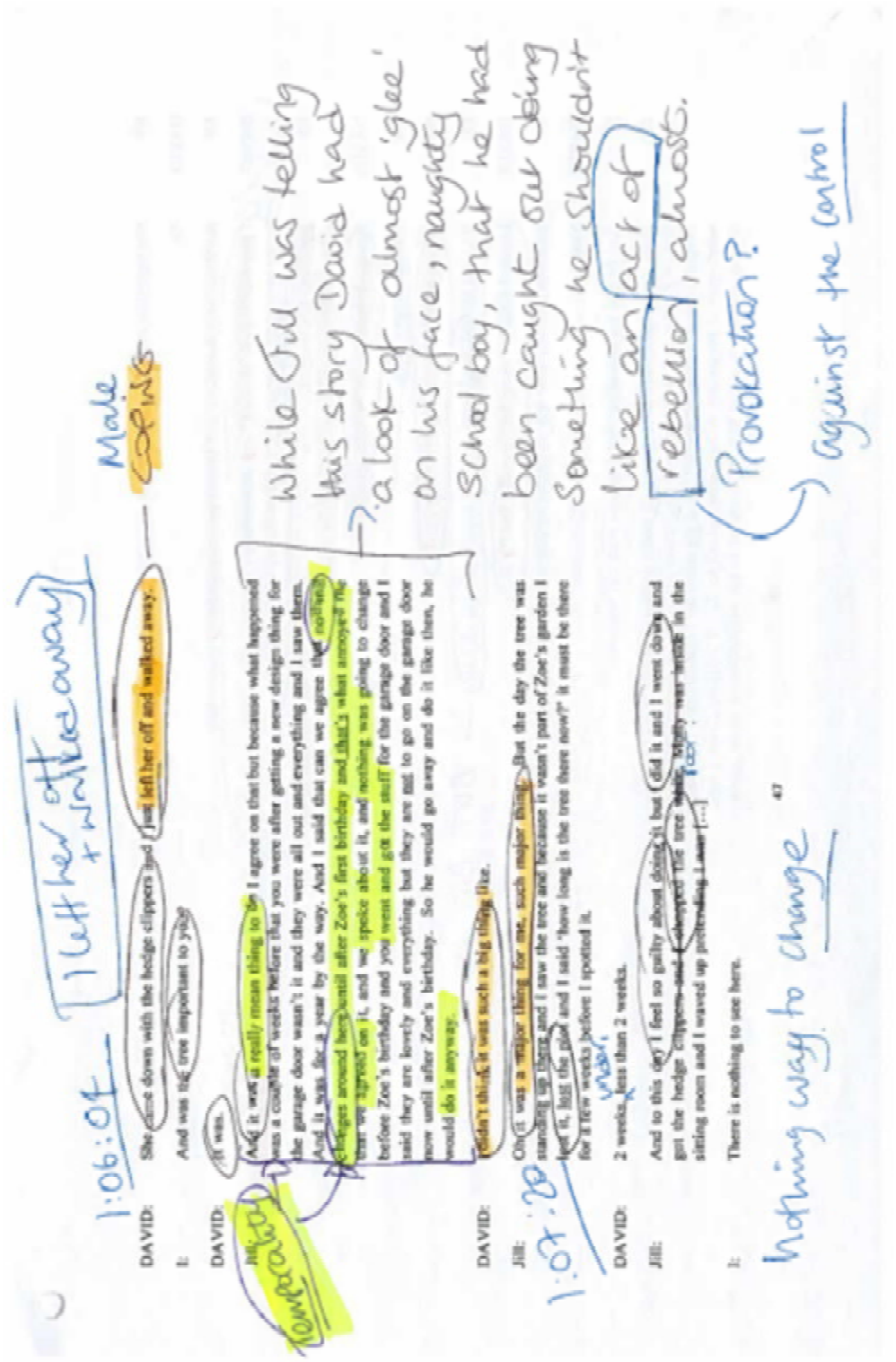
Transcript

- Verbatim transcript of narrative but no need to capture every confirmatory 'yes' or 'OK' used by the interviewer.
- Capitals for Names
- Use pseudonyms for original version
- [...] for missing text
- Best guess e.g. [childhood?] for words unsure about
- Every speaker receives his/her own paragraph.
- Discontinuation of sentences or abrupt stops within a word are indicated by a colon slash: /
- Punctuation is polished up in favour of legibility e.g. commas, full stops and question marks inserted as appropriate.
- A short drop of the voice or an ambiguous intonation indicated by a full stop rather than a comma.
- Pauses are indicated by the word Pause in parentheses (pause)
- Words that are emphasised by the speaker are underlined e.g. <u>indeed</u>
- Disturbances are noted in brackets e.g. (traffic noise)
- Emotional, non-verbal utterances (of both the interviewees and the interviewer) that support or elucidate a statement (such as laughter or sighs) are transcribed in brackets e.g. (laughs)
- Line numbers inserted from start of interview

Appendix 13: Data Analysis-Initial Noting 1

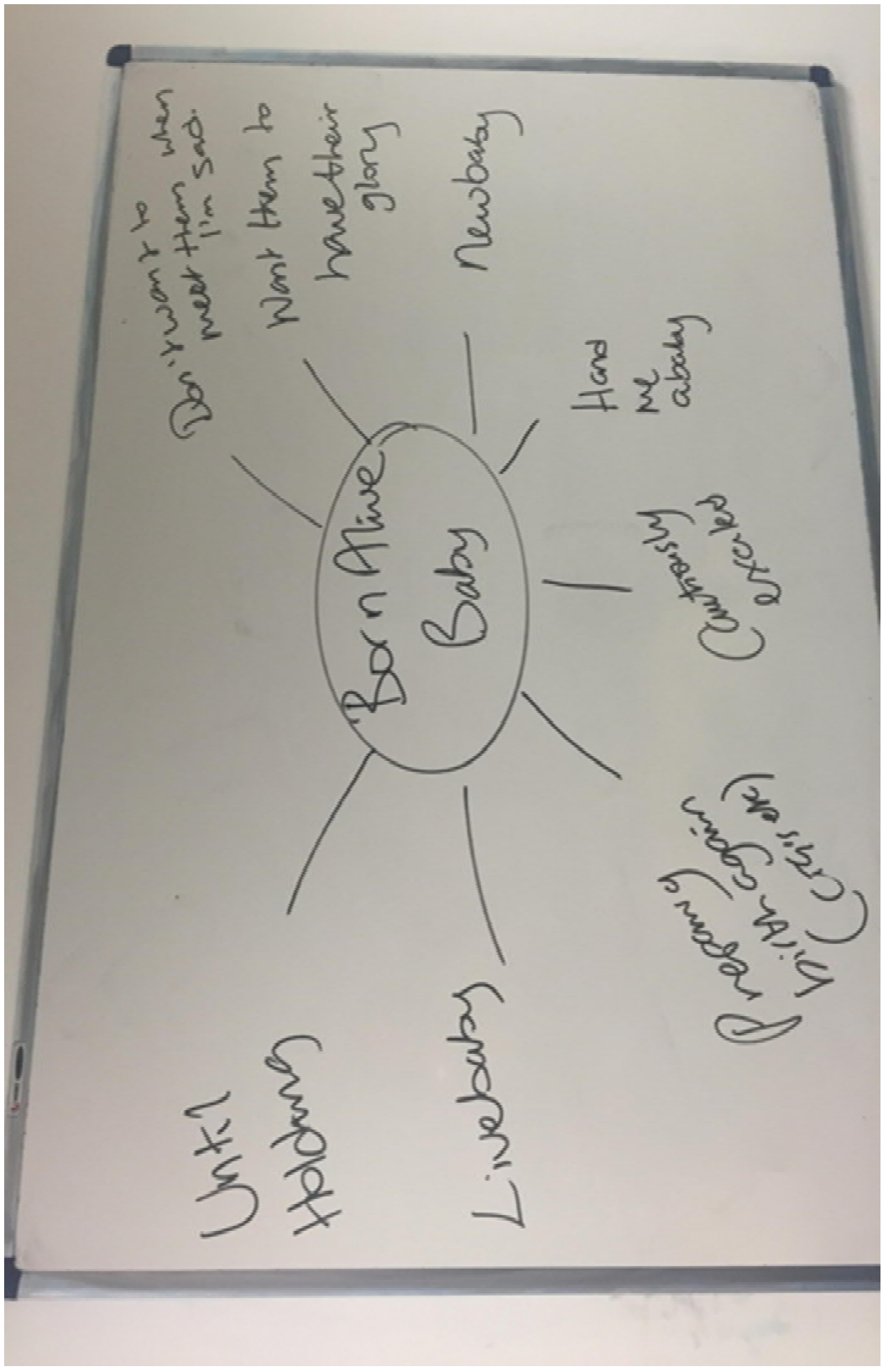


Appendix 14: Data Analysis-Initial Noting 2



Appendix 15: Data Analysis-Development of Emerging Themes

Appendix 16: Data Analysis-Searching for connections across themes



Appendix 17: Table of Themes for *Hoping for a Born Alive Baby*

Different babies
Not replacing the deceased baby "It's not that we wanted to replace her and have another baby" [Nadine 1488] "I had a big issue with replacing her (Kristine) at the start, didn't I? I was afraid that we would be replacing her, you know. But I don't think, as we get into it we are. This baby stands alone as well. It's not a replacement; it's just another one of our children. Kristine is one; this baby is one as well, please God" [Evan 410-414]
Continuing to parent the deceased baby "Yeah you feel like you've abandoned her. I'm not grieving right [Nadine 727] "If I had a boy will I be more sad? Because I'll be looking at him going 'Conor would have been one of four boys now'"[Amy 875-884]
Longing for a new baby "But from about week 17/18 I had actually gone into nurture mode. So I had a baby but I didn't have a baby and I was in nurture mode" [Amy 72-81] "I just want my baby so much, I'm longing for my baby, which you are, you are longing for this baby that you don't have" [Nadine 1490]
Trying to conceive
Reaching a decision "So the decision I suppose was always there and I knew that Adam was on board, he loves kids and he wanted kids as well" [Grace 241-243] "And it probably would have ended up with us having more arguments in ten years' time if we didn't try it again so. It's just, I think like, we'd made our decision no matter what way we were going" [Doug 1305-1309]
Intimacy was a functional act "It (sexual intercourse) was kind of a functional thing. Like, because, I don't know about other couples but relationships and all that was the furthest thing from my mind" [Jill 921-914] "It (sexual intercourse) was like, seriously, it was like homework" [Adam 443]
Difficulty waiting "That is a stressful time because when you are trying to get pregnant, you have your period and you're like, for the first one, I think for one of them I felt like I had lost Conor all over again, because it was like what if I don't get pregnant again?" [Amy 692-695] "Every time I got my period it was like; oh I was a mad women" [Jill 1230]
Impact on relationship "We had to decide how much we could put up with" [Naomi 73] "Yeah endure it; mentally and physically" [Doug 77] "…it was funny because, we had said from the start, when we first started trying 'I don't want to turn into one of those psychos'" [Grace 385] "but you did (laughs)" [Adam 387] "but I did, in a funny way, it didn't tear us apart" [Grace 386]

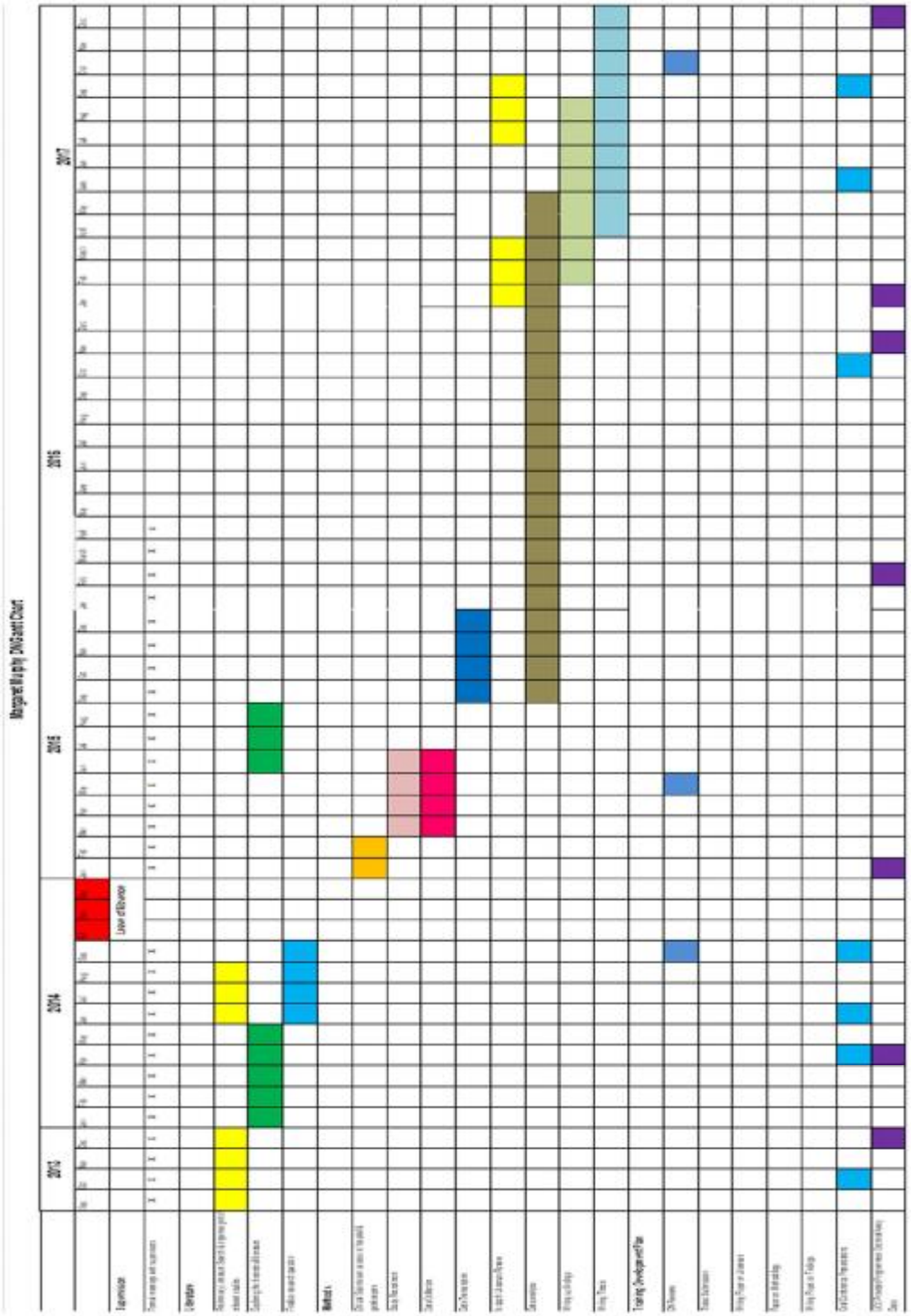
Cautiously hoping
Constant worry of another loss "It's just the worry of the whole thing…it's just the worry of something going wrong. And being told, again, but I know you could be told at any stage. That's it; it's just the worry of everything" [Iona 44; 47-49] "Grace was spotting (bleeding) one day I remember walking into the hospital I remember crossing the road from the shopping centre thinking 'God I can't go through this again now'… thinking we could, could be back doing this again now again" [Adam 31-35]
Being attuned to the live baby "I am actually very relaxed and chilled but definitely this time I am a bit more, like even if he has not moved a bit I am kind of panicky like" [Valerie 48-50] "But I think I'm over aware of it (baby's movement). That I am nearly want her to stick her head out and say 'I'm grand' and go back in even. I'd nearly want her going (moving) all the time and I don't want her to sleep" [Nadine 487-491]
Restrained hoping "It (new pregnancy) is brilliant because to be honest with you it has definitely lightened our spirits, there is no two ways about that" [Jill 612] "I think we are almost afraid of imagining that we're going to have the baby, in case anything happens. You're afraid of building it up and of having it all taken away again" [Jonah 924-925]
Revisiting the past to give birth to a born alive baby
A live baby "A live baby is my thing… live, we will cope with anything once the baby is alive" [Jill 530; 532] "No, I don't care, just that they are healthy and they live a long, happy, healthy life that's all I care about. We will take what we are given" [Evan 495-496]
Birth bringing it all back "I'm either going to have to come to peace with it or be really anxious. I would like to enjoy it, it will be painful but it's a joyful time. I think I'm either going to have to come to terms with it or going to be anxious and I don't want to be anxious" [Amy 714-719] "My counsellor was saying I have to try to look at a totally different and positive experience but obviously… things can go wrong and the last time, I don't know, I don't know, I think I just don't know. I can see that it (birth) might bring (it) back" [Kim 1147-1151] "I suppose I just have a little bit of worry of when I do go into labour that because she possibly died in labour… actually I probably can still see the room" [Valerie 1488-1491]

Appendix 18: Table of Themes for *Journey of Loss*

Unexpected death of a baby
Death was an unexpected event "You don't expect it to happen to you" [Iona 111] "It's against nature for your baby to die. Your baby is not supposed to die" [Nadine 124]
Realising something was wrong "We were awake all night" [Nadine 464] "Yeah it was this feeling in the pit of our stomach, we were just lying in bed and we knew there was something wrong" [Jonah 466-467] "This was done on a routine scan… I never in my wildest dreams thought that there would be no heartbeat. So it was an awful shock. I couldn't even dial Doug's number" [Naomi 1004-1014]
Clinging to hope "So I said look, I will wait until the morning and see… I still had that small bit of hope. When you are going up there (hospital) thinking 'It will be grand when you get there'" [Jill 105-109] "And you know you're not being rational; you know it's not logical. But it's just; it's your instinct as a mother. Because you still hope" [Amy 112-113]
Meeting our baby "We were nearly expecting her to cry when she came out" [Nadine 390] "Jees, it took me the bones of the first day to look at Dylan. Oliver was a bit easier. I didn't look into the coffin the first day, I don't think" [Doug 429-434] "The toughest thing to us was the fact that we had her and she was perfect. She was just like a sleeping baby" [Jonah 385-388]
Searching for reasons why "I went through every meal I had" [Naomi 1229] "I don't see my body is safe for her… I can't take that chance, Just don't feel my body at that point was safe for Imogen" [Nadine 131-134] "It (Julia's death) was just a fluke, so it was a complete fluke. There was no problem having more (babies) that gives you more confidence. It (was) more relief when you hear things like that, that it was a freaky, flukey thing" [Adam 107-113]
Grieving the deceased baby
Our baby was a person "But with Imogen, we physically held her and had our baby in our arms, we lost a baby" [Jonah 1430] "You are always trying to defend her or stand up for her" [Jill 572] "Like it is very, very sad, but it is not, it's different to me loosing Larry or John (older sons) to Conor. I knew Conor for 4 or 5 days, Amy knew him for 22 weeks, she knew the person. I didn't know the person" [Brian 220-222]

Finding our way through loss and grief "I will never shy away from saying anything to Adam, he will talk and talk and talk back, we talk things out … I say anything that was in my mind, I just come straight out with it" [Grace 196-201] "But as a man, I would see for that period our job was to mind (care for) Amy" [Brian 232-233] "I don't think men… they're almost expected to suck it up and take it on the chin for the kids and the woman" [Jonah 1239-1240]
Changed by loss "But when this (loss) has happened to you, your whole life has actually changed. You do feel different; you don't feel the same. I definitely don't feel the same person as I was 12 months age" [Jonah 721] "I think I have change, I have changed and I have toughened up. I don't really care about certain things" [Grace 1126-1132] "No, no I am a totally different person I don't think I could ever have seem more different to people that the way I was before and the way I am now, it's mad isn't it?" [Jill 278-280]

Appendix 19: Gantt Chart of Doctoral Journey



Appendix 20: Presentations, Publications, and Research Activity

International Research Conferences: Oral Presentations

- O'Leary J, Murphy M.M. (2017) Finding Hope: The Journey from Loss to the Embracing a Baby That Follows [Invited Workshop], 2017 Star Legacy Foundation International Stillbirth Summit, St. Paul, Minnesota, USA 21st-24th June 2017.
- Murphy, M.M. (2017) Listening to women and their partners: using an Interpretive Phenomenological Analysis approach to explore how couples make sense of pregnancy after loss [Oral Presentation] International Confederation of Midwives 31st Triennial Congress, Toronto, Canada 18th-22nd June 2017.
- Wojcieszek A, Shepherd E, Middleton P, Lassi Z, Wilson T, Murphy M.M., Heazell A, Ellwood D, Flenady V (2017) Care prior to and during subsequent pregnancies following stillbirth for improving outcomes: A Cochrane systematic review protocol [Oral Presentation] Perinatal Society of Australia and New Zealand 2017 Congress, Canberra, Australia, 5-7th April 2017.
- Murphy, M.M. (2016) Emotional impact and management of pregnancy after stillbirth. [Invited Lecture (Plenary)], 2016 ISA/ISPID International Conference on Stillbirth, SIDS and Baby Survival, Montevideo, Uruguay, 7-10th September 2016.
- Murphy, M.M. (2014) Integrative Literature Review of Men's Experiences of Pregnancy and Birth after Stillbirth. [Oral Presentation], 2014 ISA/ISPID International Conference on Stillbirth, SIDS and Baby Survival: Global Action Needed! Amsterdam, The Netherlands, 18th -2st September 2014.
- Murphy, M.M. (2014) Integrative literature review of women's experiences of subsequent pregnancy following stillbirth. [Oral Presentation], International Confederation of Midwives 30th Triennial Congress, Prague, Czech Republic, 1st-5th June 2014
- Murphy, M.M. (2014) Integrative Literature Review of Couple's Experiences of Pregnancy and Birth after Stillbirth. [Oral Presentation], Optimise Birth International Conference, Brussels, Belgium. 9-10th April 2014.

- Murphy, M.M. (2013) Birth after death: the journey to motherhood following stillbirth. [Oral Presentation], The Impact of Stillbirth: Multidisciplinary Conference, University College Cork, 2nd November 2013.

International Research Conferences: Poster Presentations

- Murphy M.M., O Donoghue K., Savage E., Leahy-Warren P. (2016) Stillbirth: The Diagnosis of Life-Limiting Fetal Conditions and Its Effect on Pregnancy After Loss [Poster Presentation] 21st International Congress on Palliative Care, Montreal, Canada, 18-21st October, 2016.

- Murphy M.M., O Donoghue K., Savage E., Leahy-Warren P. (2014) Pregnancy After Loss: Comparative Literature Review of Couples' Experiences [Poster Presentation] 2014 ISA/ISPID International Conference on Stillbirth, SIDS and Baby Survival: Global Action Needed! Amsterdam, The Netherlands, 18th -2st September 2014.

Peer Review Publications

- Wojcieszek AM, Boyle FM, Belizán JM, Cassidy J, Cassidy P, Erwich JJHM, Farrales L, Gross MM, Heazell AEP, Leisher SH, Mills T, Murphy M, Pettersson K, Ravaldi C, Ruidiaz J, Siassakos D, Silver D, Storey C, Vannacci A, Middleton P, Ellwood D, Flenady V. (2016) Care in subsequent pregnancies following stillbirth: An international survey of parents. BJOG: An International Journal of Obstetrics and Gynaecology DOI: 10.1111/1471-0528.14424.

- Flenady V; Wojcieszek AM; Middleton P; Ellwood D; Erwich JJ; Coory M; Khong TY; Silver RM; Smith GC; Boyle FM; Lawn JE; Blencowe H; Leisher SH; Gross MM; Horey D; Farrales L; Bloomfield F; McCowan L; Brown SJ; Joseph KS; Zeitlin J; Reinebrant HE; Ravaldi C; Vannacci A; Cassidy J; Cassidy P; Farquhar C; Wallace E; Siassakos D; Heazell AE; Storey C; Sadler L; Petersen S; Frøen JF; Goldenberg RL for The Lancet Ending Preventable Stillbirths study group† and The Lancet Stillbirths in High-Income Countries Investigator Group (Murphy, M.M.) (2016) 'Stillbirths: recall to action in high-income countries'. Lancet 387 (10019) DOI: http://dx.doi.org/10.1016/S0140-6736(15)01020-X

- Gold KJ, Storey C, Siassakos D, Leisher S, Boyle F, Farrales L, Heazell A, Horey D, Cassidy J, Murphy M, Murphy S, Cacciatore J and Flenady V (2016) 'Response to Redshaw et al (2016) Impact of holding the baby following stillbirth on maternal mental health and well-being: findings from a national survey'. British Medical Journal Open 2016; 6(8): e010996.
- Weathers, E. and Murphy, M.M. (2014) 'Theory of Meaning in Chronic Illness and Pregnancy Following Stillbirth' In: Fitzpatrick, Joyce / McCarthy, Geraldine (Eds). Theories Guiding Nursing Research and Practice. New York: Springer Publications.

Collaborative Research Activity

- Wrote successful bid and co-organised the International Stillbirth Alliance Global Conference 2017. Held in UCC 22nd-24th Sept with 400 international delegates.
- Elected as Member of the Executive Board of the International Stillbirth Alliance and elected Treasurer Sept. 2017.
- Member of the International Stillbirth Alliance, Scientific Advisory Committee Member: co-authoring position statements on key aspects of stillbirth prevention e.g. Reduced Fetal Movements (2015-Present).
- International Advisory Board Member to the Australian Centre of Research Excellence for Stillbirth prevention, Mater Research Institute, Australia (2016-Present).
- Cochrane Review co-author on “Care prior to and during subsequent pregnancies following stillbirth for improving outcomes: A Cochrane systematic review”
- Member of The Lancet Stillbirths in High-Income Countries Investigator Group and contributed the first Irish data to The Lancet Series on Ending Preventable Stillbirths 2016.