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Causes and consequences of pregnancy loss and perinatal death

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Glossary

BMI	Body Mass Index
CI	Confidence Interval
CUMH	Cork University Maternity Hospital
EDD	Estimated Delivery Date
IOL	Induction of Labor
IPA	Interpretative Phenomenological Analysis
IUFD	Intrauterine Fetal Demise
LOT-R	Revised Life Orientation Test
MROP	Manual Removal of Placenta
NPEC	National Perinatal Epidemiology Centre
OR	Odds Ratio
PLRG	Pregnancy Loss Research Group
PPROM	Preterm Premature Rupture of Membranes
PSS-10	10-item Perceived Stress Scale
PTL	Preterm Labor
PTS	Post-Traumatic Stress
PTSD	Post-Traumatic Stress Disorder
RCOG	Royal College of Obstetricians and Gynaecologists
RCPI	Royal College of Physicians of Ireland
RR	Risk Ratio
RTE	Raidió Teilifís Éireann
SD	Standard Deviation
UK	United Kingdom
WHO	World Health Organisation

Declaration

I declare that this thesis has not been submitted as an exercise for a degree at this or any other university. The work, upon which this thesis is based, was carried out in collaboration with a team of researchers and supervisors who are duly acknowledged in the text of the thesis. The library may lend or copy this thesis upon request.

Signed: _____ Date: _____

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Abstract

Over the past decades there have been major advances in reproductive medicine, however there is still a considerable risk that a woman may experience pregnancy loss and/or perinatal death. The impact of pregnancy loss and perinatal death have recently garnered the attention of the international research community. As a result there have been improvements in the provision of bereavement care highlighting the importance of good communication and the provision of useful information on the practical and emotional aspects of pregnancy loss and perinatal death. It is acknowledged that pregnancy loss and perinatal death are traumatic events further emphasising the need for empathetic supportive care. However, there is still a dearth of research identifying not only the most appropriate bereavement care but also how best to support parents in subsequent pregnancies.

In this thesis, I examined causes and consequences of both early and late pregnancy loss and perinatal death. Given the breadth of the research problem I utilised both quantitative and qualitative methods, where appropriate, to allow a depth of understanding that one methodology alone would not achieve.

The data from these studies revealed that the experiences of the bereaved parents were distinctly different depending on whether they experienced miscarriage, an ectopic pregnancy or perinatal death. These data further illustrated the profound impact that pregnancy loss and/or perinatal death has on both women and men, their relationships with each other as well as with their family and friends.

The findings from this thesis also indicate how the hospital environment can have a negative impact on parents when experiencing pregnancy loss and/or perinatal death. The parents in this study emphasised the importance of dedicated clinics and wards within the hospital. These dedicated spaces give parents and couples privacy and dignity at the time of their loss.

Pregnancy loss and perinatal death are the most common adverse outcomes in pregnancy. Pregnancy loss is often referred to as an 'invisible loss' as often the event may not publicly acknowledged. These data further illustrate this isolating effect of pregnancy loss as parents felt they could not discuss their pregnancy loss and/or perinatal death as it may create socially awkward situations. The qualitative data also indicated there is considerable misperception and misunderstanding in relation to pregnancy loss and perinatal death, which was not only evidenced in the individual

interviews but also throughout social media. How society understands and responds to pregnancy loss and perinatal death can be influential on an individual's experience. Thus, these data suggest there is a need for a better understanding of pregnancy loss and perinatal death throughout society.

As a result of the studies contained within this thesis a number of recommendations in relation to healthcare policy and clinical practice are made. Finally, possibilities for future research are identified in order to inform future intervention studies which in turn may improve the care provided to those who may experience pregnancy loss or perinatal death.

Chapter 1

1 Introduction

1.1 Introduction

Pregnancy and birth are mostly a joyous experience for parents as they welcome a new baby into the world; for some this will not be the case. Despite advances in reproductive medicine there is still considerable risk that a woman may experience loss during the perinatal period.[1-5] To date, much of international health policy has focused on a reduction of child mortality in line with the World Health Organisation's (WHO) Millennium Development Goals.[6] Recognising this discrepancy the WHO launched a new action plan in 2014 with an overall aim to reduce perinatal and infant mortality.[7] This included a plan to eliminate all preventable stillbirths in high income countries, such as Ireland.[7] In line with the WHO's action plan the Lancet launched their second series on stillbirth entitled "Ending Preventable Stillbirths" in 2016.[8] In order to achieve the goal of ending all preventable stillbirth the authors of the series identified five priority actions including (1) intentional leadership, especially from policy makers; (2) increased discourse by including the voice of those who experience stillbirth; (3) implementation of, as well as investment in, integrated interventions; (4) indicators to measure effect of interventions; and (5) investigation into crucial knowledge gaps.[8]

Studies indicate that during pregnancy parents have begun to develop bonds with their babies as they begin to plan for their future.[9, 10] Pregnancy loss and perinatal death can be an extremely difficult bereavement impacting negatively on both men and women's wellbeing and it is reported that the effects can endure for

a person's lifetime.[11-19] In many cultures there is still considerable stigma, blame and social isolation experienced following pregnancy loss and perinatal death which place a huge burden on parents.[20-25] The area of pregnancy loss and perinatal death has only recently garnered attention from the international research community and as a result many aspects of the causes and consequences of such losses are yet to be investigated.

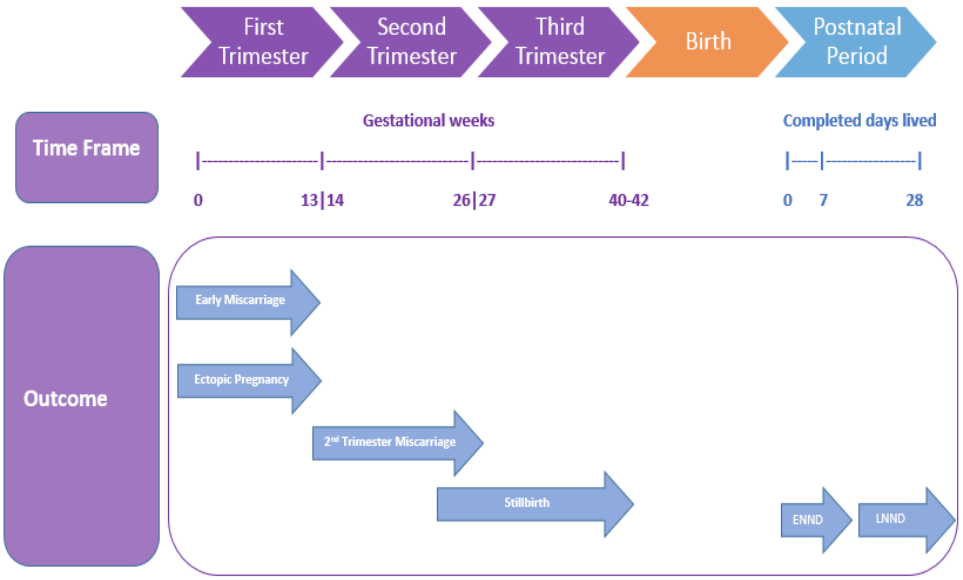
In this chapter I will provide definitions of pregnancy loss and perinatal death and briefly outline the incidence and aetiology of these losses. I will outline how this thesis intended to build on the research, to date, in order to continue to improve the quality of care provided to those who experience pregnancy loss or perinatal death. In order to achieve this I undertook a number of studies and this chapter will conclude with a brief outline of each of the studies. Finally, I will present the aims and objectives of the thesis.

1.2 Definitions

Pregnancy is defined as the period from conception to birth which lasts an average of 40 weeks from the first day of the last menstrual period to the estimated date of delivery.[26] As illustrated in (Figure 1.1). There are three trimesters in pregnancy, each trimester lasting between 12 and 14 weeks gestation (Figure 1.1). The focus of this thesis is to examine the causes and consequences of pregnancy loss and

perinatal death, meaning a loss which occurs during pregnancy or up to 7 completed days following birth (Figure 1.1).

Throughout the literature there is considerable variation observed in relation to how pregnancy loss and perinatal death are defined. These definitions have resulted in losses up to 28 weeks gestation being classified as a pregnancy loss while in other jurisdictions a loss at 20 weeks gestation is recorded as a stillbirth.[27-29] Depending on how they are calculated the rates can result in either conservative or in fact over estimates of either pregnancy loss or perinatal death. Due to the disparity in how countries define and record pregnancy loss and perinatal death it is difficult to ascertain rates which are comparable.



Note: ENND = Early Neonatal Death; LNND = Late Neonatal Death

Figure 1.1: Pregnancy loss and perinatal death

1.2.1 *Miscarriage*

Miscarriage is the most common adverse outcome in pregnancy and is more likely to occur in the first rather than second trimester.[30, 31] The rate of miscarriage is especially challenging to determine however, as there is no health system which consistently records pregnancy loss in the same manner as perinatal death. The rates of miscarriage are solely based on research studies, which can be limited by design, and these are reflected in the high variation in rates which range from 8% to 50% and higher for first trimester miscarriage.[1] Recorded rates of second trimester miscarriage are more consistent and it occurs in 1-2% of pregnancies.[32, 33] In Ireland, estimated rates of first trimester miscarriage are based on a study conducted in the United Kingdom which investigated pregnancy outcomes in women who attended an early pregnancy clinic with a threatened miscarriage.[3] Results of this UK based study indicate that up to one in five pregnancies will end in miscarriage.[3] The variation in the rates of miscarriage can in some way be attributed to the manner in which they are calculated as many studies record the outcome from clinically recognised pregnancies within the first 14 weeks of pregnancy.[1, 3, 34, 35] Consequently it is acknowledged that the rates within in the literature are likely conservative given that women may miscarry before making contact with the maternity services.

1.2.2 *Ectopic pregnancy*

Ectopic pregnancy is defined as a pregnancy where a fertilised egg implants outside the uterus. The majority of ectopic pregnancies (95%) occur within the fallopian

tube. The remainder occur where the fertilised egg implants in the ovary, abdomen or cervix. In Ireland the rate of ectopic pregnancy is 14.8 per 1,000 maternities.[36] An ectopic pregnancy can be a life threatening event and is reported as the leading cause of maternal death, worldwide, in the first trimester.[37] The rates of maternal death associated with ectopic pregnancy have reduced in developed countries, which is attributed to improvements in the management of these cases.[38] However, ectopic pregnancy is almost always incompatible with the delivery of a viable infant.[39]

Treatment for woman who experience ectopic pregnancy can be complex where firstly the location of the ectopic pregnancy needs to be identified which is followed by either expectant, surgical or medical treatment.[39, 40] Women report the experience of ectopic pregnancy as being a major life event whereby uncertainty in relation to fertility may arise.[41] To date, research examining the experience of ectopic pregnancy have sampled women alongside those who have experienced other pregnancy losses.[42] Therefore, as part of this thesis, one study aimed to gain insight into women's experience of ectopic pregnancy.

1.2.3 *Perinatal death*

For the purposes of this thesis the definition of pregnancy loss and perinatal death will be in line with the Irish Stillbirths Registration Act 1994 whereby a stillborn baby is defined as an infant born with no sign of life weighing 500 grammes or more and/or having a gestational age of 24 weeks or more.[43] In line with this a miscarriage is defined here as a pregnancy loss which occurs before 24 weeks

gestation weighing less than 500 grammes. The definition of perinatal death encompasses stillbirths and early neonatal deaths. An early neonatal death is defined as the death of an infant occurring within 7 completed days of being live born.[5] Using these definitions, the National Perinatal Epidemiology Centre (NPEC) reported that the Irish perinatal mortality rate was 7.0 per 1,000 births in 2014 consisting of a stillbirth rate of 4.4 per 1,000 births and an early neonatal rate of 2.4 per 1,000 live births. The overall perinatal mortality rate when corrected for congenital malformation was 4.7 per 1,000.[5] It is also important to note that there are much higher rates of perinatal mortality in twin pregnancies than singleton pregnancies. Rates in the UK and Ireland indicate that the perinatal mortality rate for multiple births was three times that for all babies.[5, 44]

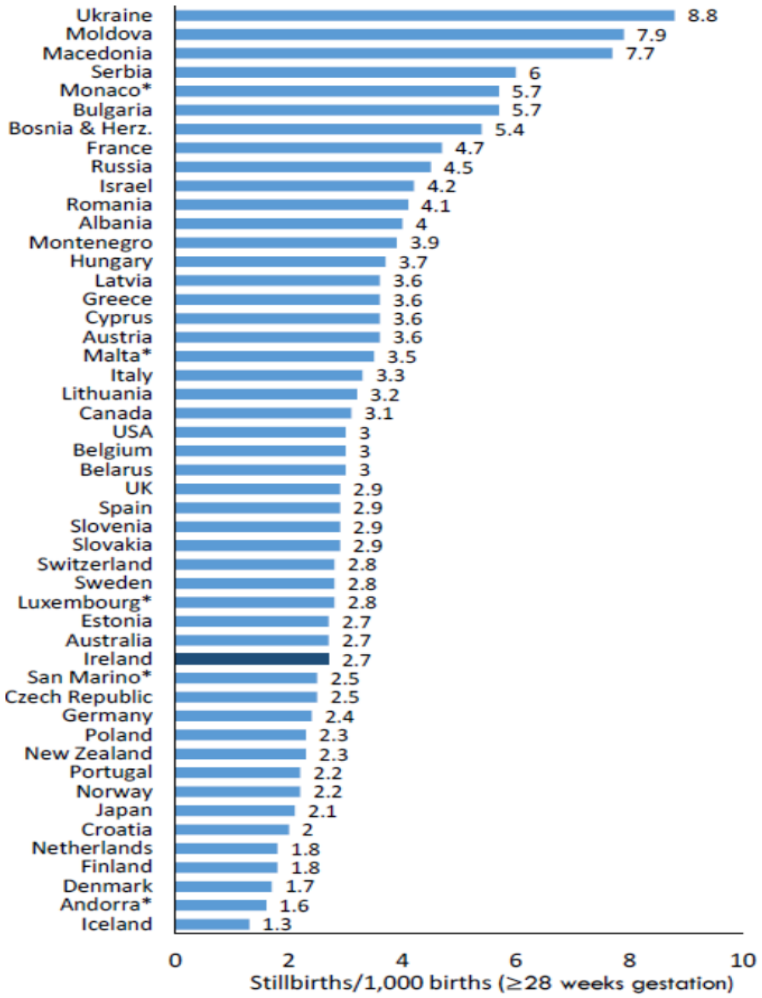
As previously mentioned the variation in reported rates is not limited to miscarriage but also includes those reported for stillbirth. Stillbirth rates have been reported as low as 2 per 1,000 with much higher rates of up to 40 per 1,000 reported in low income countries.[45] Some of this variation can be attributed to how stillbirths are legally defined by countries which are dependent on either the gestational age and/or the weight of the baby. The variation in rates related to the definition used can been seen in the Republic of Ireland. As illustrated by the NPEC the rates of perinatal mortality vary based on the criterion adopted; the criterion which was in line with the Irish Stillbirths registration act[43] or the WHO reporting guideline that recommends the criterion of a birthweight greater than 500grammes or more (Table 1.1).

Table 1.1: Frequency and rate of perinatal mortality in the Republic of Ireland, 2014[5]

	BWT ≥500g or delivery ≥24 weeks		BWT ≥500g	
	Number	Rate (95% CI)	Number	Rate (95% CI)
Total births	67,663		67,610	
Stillbirths	330	4.9 (4.3-5.4)	286	4.2 (3.7-4.7)
Early neonatal deaths	141	2.1 (1.7-2.4)	136	2.0 (1.7-2.4)
Perinatal deaths	471	7.0 (6.3-7.6)	422	6.2 (5.6-6.8)
Corrected perinatal deaths	317	4.7 (4.2-5.2)	276	4.1 (3.6-4.6)

Note: BWT=Birthweight; Rate per 1,000 births; 95% CI=95% confidence interval; Corrected perinatal deaths exclude deaths associated with or due to a congenital malformation.

The recently published Lancet Stillbirth Series estimates that there are at least 2.6 million stillbirth annually and the vast majority of these will occur in low to middle income countries during the intrapartum period.[46] Focusing on comparable rates from high income countries the Lancet Series illustrated there is still considerable variation between countries, despite the use of the World Health Organisation's (WHO) definition of stillbirth with the lowest gestational age limit of 28 weeks.[47] In 2014, stillbirth rates for high income countries varied from 1.3 per 1,000 in Iceland to 8.8 per 1,000 in the Ukraine. The Irish rate of stillbirth, using the WHO definition, was 2.7 per 1,000.[47] When the Irish stillbirth rate was corrected by excluding cases associated with or due to a congenital malformation it is adjusted from 2.7 to 2.5 stillbirths per 1,000 births (see Figure 1.2).[5]



Note: Rates based on stillbirths among births with ≥28 completed weeks of gestation.
* indicates countries with fewer than 5000 births.

Figure 1.2 Irish stillbirth rate in 2014 compared to the reported stillbirth rate for the other 48 high-income countries[5]

Irrespective of the issues with how stillbirths are defined what the recent Lancet Series clearly illustrated was, despite the lowest gestational age limit, there were still significant differences between the rates across high income countries.[47] The authors also examined the average annual rate of reduction of stillbirths from 2000 to 2015 which varied considerably from -0.5 to 6.8% (Figure 1.3). These findings indicate that additional reductions in the rates of stillbirth are in fact possible.[47] Thus, not only is it desirable to know the expected rates of pregnancy loss and

perinatal death, it is imperative to understand the causes and potential risk factors also.

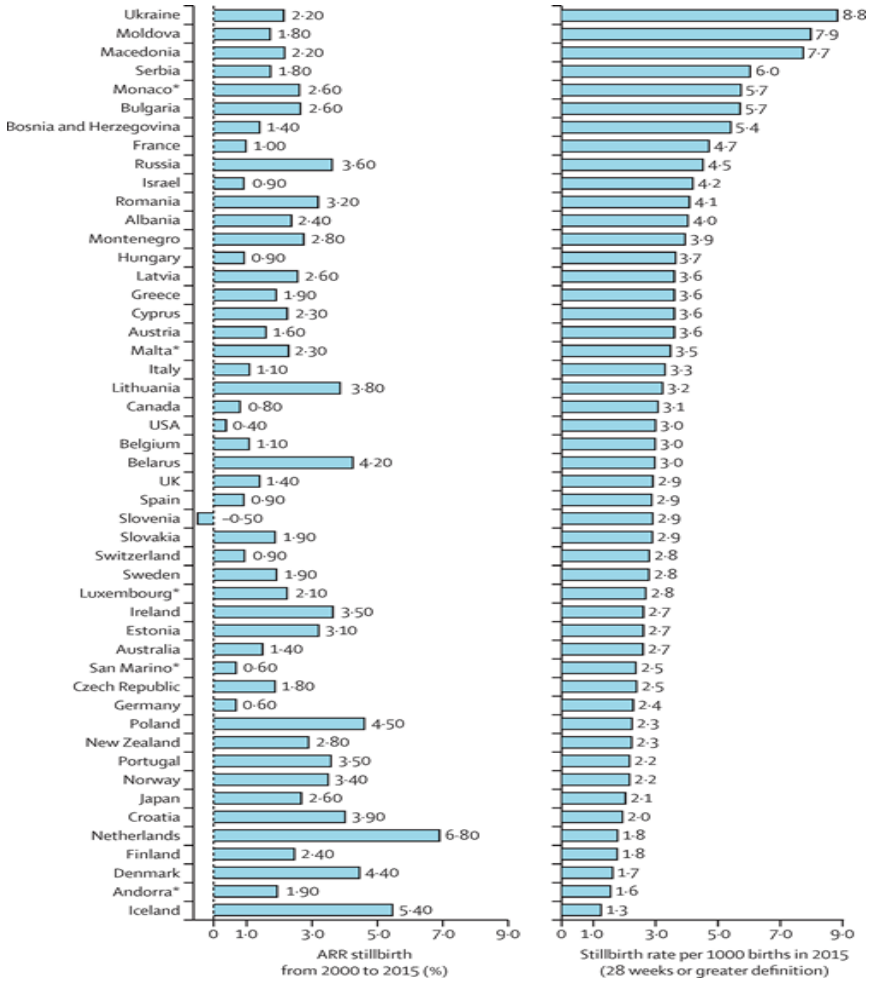


Figure 1.3 Rates of stillbirth and reductions in high-income countries 2000-2015[47]

1.3 Causes and risk factors of pregnancy loss and perinatal death

1.3.1 *Cause and risk factors for miscarriage*

Although there is considerable variation in the rates reported, miscarriage is the most common adverse outcome in pregnancy. It is reported that more than half of all miscarriages are due to chromosomal abnormalities.[47, 48] While a high

proportion of miscarriages are classified as unexplained.[1, 30, 49]. To date, the cause of miscarriage remains poorly understood and it is believed that these causes are likely multi-dimensional with biological, medical and behavioural risk factors. There are a number of risk factors for miscarriage which are now established including both maternal and paternal age, infertility and parity.[50-54]

However, as Maconochie reports how these risk factors for miscarriage interact is not fully understood.[30] There are a number of social and behavioural risk factors for miscarriage which remain unconfirmed, including the role of stress. Retrospective studies have recorded associations between miscarriage and stressful life events prior to and during pregnancy as well as high perceived stress and low emotional wellbeing.[30, 55-57].[30,55-57] To date Maconochie *et al*., 2007 have completed the largest population-based cohort study examining risk factors for miscarriage.[30] However this study, as well as the other retrospective studies, may be confounded by design whereby the women surveyed may have been influenced by recall bias. For example of the population surveyed by Maconochie *et al*., almost one fifth had their most recent pregnancy over 20 years previously.[30, 58] They therefore concluded that due to the limited research in the area such risk factors for miscarriage warrant further investigation.[30] The first study in this thesis was undertaken in order to address this research gap by undertaking a prospective cohort study to determine the association of stress with the risk of miscarriage

1.3.2 Cause and risk factors for stillbirth and neonatal death

Dependent on the system utilised to classify perinatal death, of which there are many[59], there are a number of potential causes of death ranging from the biological to mechanical. Up to one third of stillbirths are attributed to congenital abnormalities as well as one in ten of deaths in the neonatal period.[60, 61]

In Ireland, the NPEC report that major congenital anomaly was the primary cause of death in almost one in four stillbirths and more than half of the early neonatal deaths.[5] A placental condition was classified as the main cause of death of almost one in four stillbirths, with respiratory disorders classified as the other main cause of early neonatal deaths. Crucially, approximately one in four stillbirths were classified as unexplained.[5] This is a significant decrease from over half of causes recorded in 2010, but much of this may be attributed to changing the classification system employed whereby the Wigglesworth classification system would have previously been utilised.[5]

In 2014, the perinatal mortality rates for the United Kingdom (UK) were published which identified congenital anomaly as the primary cause of death in 6% of stillbirths and 28% of early neonatal deaths.[44] The authors of the MBRRACE report highlight that the management of pregnancies affected by a congenital anomaly varies widely due to factors such as legislation, cultural and religious differences in relation to termination.[44] Termination of pregnancy is only lawful

in Ireland in pregnancies where the mother's life is at risk and many couples will continue in a pregnancy following a diagnosis of congenital abnormality. Couples who continue on in pregnancy following a prenatal diagnosis of congenital anomaly will likely do so in anticipation that their pregnancy will end with the stillbirth or early neonatal death of their baby. As part of this thesis, I explore parents' experience of a prenatal diagnosis of congenital anomaly as well as their experience of perinatal palliative care.

The NPEC and MBBRACE reported that the cause of death in 15% and 46% of stillbirths respectively were unknown.[5, 44] As outlined in Table 1.2, international research has identified a number of risk factors associated with stillbirth.[46, 62] Research has also identified numerous maternal modifiable risk factors such as tobacco, alcohol and drug use, high body mass index however the complex interaction between the psychosocial and biological factors are not yet fully understood.

Table 1.2: Risk factors for stillbirth in high-income countries[5]

Risk Factor	aOR (95% CI)
Low socioeconomic Group	1.2 (1.0-1.4)
Previous Caesarean Section	1.2
Post-term Pregnancy (>42 weeks)	1.3 (1.1-1.7)
Primiparity	1.4 (1.3-1.4)
Pre-eclampsia	1.6 (1.1-2.2)
Low education	1.7 (1.4-2.0)
Eclampsia	2.2 (1.5-3.2)
Hypertension – Pre-existing	2.6
Previous Stillbirth	2.6 (1.5-4.6)
Assisted Reproduction (singleton)	2.7 (1.6-4.7)
Diabetes	2.9
No antenatal care	3.3 (3.1-3.6)
Small for Gestational Age (<10th Centile)	3.9 (3.0–5.1)
Ethnic Group	3-7 fold

Note: aOR = adjusted odds ratio

1.4 Investigations following pregnancy loss and perinatal death

1.4.1 *Miscarriage*

The investigations offered following pregnancy loss are dependent on the gestation of the loss and the number of consecutive losses experienced. The clinical practice guideline for the management of early pregnancy miscarriage recommended that practitioners should always consider sending tissue obtained at miscarriage for histological examination.[31] This examination may confirm the diagnosis of miscarriage and but can also help exclude the diagnosis of ectopic pregnancy or gestational trophoblastic disease.[31] However, in line with a number of clinical practice guidelines many hospital investigations will not be undertaken unless the woman has experienced recurrent miscarriage, defined as three consecutive

miscarriages, or a second trimester miscarriage (Table 1.3).[63-65] Karyotyping should be performed following recurrent miscarriage in order to inform prognosis of future pregnancy outcomes. Investigations for women with recurrent miscarriage or a second trimester miscarriage also include a pelvic ultrasound to assess uterine anatomy, while women with a second-trimester miscarriage should be screened for inherited thrombophilias (Table 1.3). Finally, these guidelines also state that all women who have experienced recurrent miscarriage and all women who have experienced second-trimester miscarriage should be screened for antiphospholipid antibodies before pregnancy (Table 1.3).

Table 1.3: Investigations following recurrent miscarriage and second trimester miscarriage

Guidelines	HSE STM	RCOG RM & STM	ESHRE RM	ASRM RM
Definitions				
Recurrent miscarriage (RM)		≥3 miscarriages	≥3 miscarriages	≥2 miscarriages
Maternal Investigations				
Full blood count	Yes		Yes	Yes
Blood glucose / HbA1c			Yes	Yes
Thyroid function tests	Yes		Yes	Yes (TSH, if abn then FT4)
Prolactin				Yes
Renal and liver function	Yes			
Kleihauer- Betke	Yes			
Thrombophilias				
Factor V Leiden	Yes	Yes (STM)		
Factor II (prothrombin) gene mutation	Yes	Yes (STM)		
Protein S	Yes	Yes (STM)	Trial setting only	Specific cases
Protein C	Yes		Trial setting only	Specific cases
Antithrombin-III	Yes		Trial setting only	Specific cases
Homocysteine (fasting)	Yes		Trial setting only	Specific cases
Antiphospholipid antibodies				
Lupus anticoagulant	Yes	Yes	Yes	Yes
Anticardiolipin antibodies	Yes	Yes	Yes	Yes
Anti- B2 glycoprotein			Yes	Yes
Maternal Microbiology				
Blood cultures	Specific cases			
MSU	Specific cases			
Vaginal and Cervical Swabs	Specific cases			
Maternal toxicology Eg. cocaine, metabolites	Specific cases			
Anatomical factors				
Pelvic ultrasound to assess uterine anatomy	Yes	Yes	Yes	Yes
Serial cervical monitoring in subsequent pregnancy		Yes (STM)*		
Parental Karyotyping				
Parental peripheral blood	Specific cases**	Yes (both)	Yes	Yes
Fetal Investigations				
Cytogenetics products of conception	Yes	Yes (both)	Trial setting only	Yes
Placental Histology	Yes		Yes	
Postmortem examination	Yes***			
External examination	Yes			

Note: RM= Recurrent miscarriage, STM= Second Trimester Miscarriage, TSH= thyroid-stimulating hormone, FT4= Free thyroxine*Case by case basis **If cytogenetics on products of conception fails or if a fetal balanced translocation is detected *** Gestation dependant

1.4.2 *Stillbirth and neonatal death*

Although a considerable number of unexplained perinatal deaths can be attributed to the classification system used, it is still the case that a large proportion of deaths will remain unclassified. It has been proposed that, at times, an unclassified death may in fact be an un-investigated death.[66] Studies have shown that perinatal autopsy can impact the reported cause of death in up to 76% of cases and therefore is a critical process to better understand underlying causes of perinatal death.[67, 68] Yet the rates of perinatal autopsy have consistently been declining not only in the UK and Ireland but worldwide.[5, 44, 69, 70] Much of the reduction in the rates of perinatal autopsy is attributed to the organ retention scandals which occurred in the UK and Ireland in the late 1990's which lead to a governmental inquiry in Ireland.[71-74]

The findings of the Irish inquiry into post mortem practice and procedures, published by Dr. Deirdre Madden, states that post-mortems which were undertaken in Ireland were carried out in accordance with best professional and international standards.[73] The report outlines that the key failure, in relation to the organ retention scandal was the manner in which parents were communicated with.[73] The finding from this report is indicative of the shift in medical practice from professional paternalism to increased patient autonomy which is concerned with improved communication between healthcare staff and patient.[73] Consent for autopsy was and still is hospital policy. However, this consent now includes

more information as to what is involved in the post-mortem examination as well limited examinations and opt outs for parents.[73]

Current practice guidelines recommend that all parents who experience perinatal death should be offered perinatal autopsy but data from Ireland illustrate that less than half of stillbirths and or early neonatal deaths had an autopsy undertaken in 2014.[5] The most recent NPEC report indicated that, of those who did not have an autopsy, the majority were offered the procedure. Within the report it is presumed that parents declined to have the perinatal autopsy undertaken but the data do not indicate why parents chose to decline the procedure.[5] As part of this thesis, one study aimed to gain insight into parents' perception of perinatal autopsy and their decision making process to accept or decline the procedure.

1.5 Impact of pregnancy loss and perinatal death

The impact on those bereaved by pregnancy loss and stillbirth has only recently come to be recognised as one which is of significance.[20-22, 75, 76] A number of studies indicate how extremely painful, upsetting and distressing an experience it can be to lose a baby at any gestation.[77-80]. The loss of a baby has both long and short time effects on mothers, fathers and their extended families.[11, 18, 81, 82]. High levels of stress and anxiety are reported to be experienced with studies indicating that parents report depressive symptoms, difficulties in coping and high levels of martial breakdown.[11, 22, 83, 84]. Evidence underscores the need for

familial and social support following the loss of a baby yet social support is often perceived as inadequate.[85, 86]

There have been vast improvements in the care provided to those who experience pregnancy loss or perinatal death and much of this has been aided by the introduction of guidelines.[31, 64, 67, 87, 88] These guidelines have been informed by research which indicates that focused interventions and empathetic supportive care for parents is not only effective but paramount for parents' wellbeing and recovery.[22] Further improvements can still be made as highlighted by a recent study undertaken in Cork University Maternity Hospital which, although supportive of the provision of many maternity hospital bereavement practices, identified omissions in care and called for aspects of such care to be reprioritised.[21] In addition, an editorial from the UK outlined what research clinicians, parents and other vested parties would like to see prioritised in the area of stillbirth.[88] These included identifying the most appropriate bereavement and postnatal care, not only for mothers, but for both parents following a stillbirth. It also included trying to identify how staff in healthcare settings can best support parents in subsequent pregnancies.[88] A number of studies in this thesis are focused on these research priorities.

1.6 Local research environment

Over the past decade, by adopting a bio-psychosocial approach, the Department of Obstetrics and Gynaecology in University College Cork have been developing

expertise in the area of pregnancy loss and perinatal death. In order to understand the complex interactions of the biological, psychological and social factors associated with pregnancy loss and perinatal death a multidisciplinary approach is necessary. To date, this is being achieved through both research and national audit practices. As a health sociologist my research interests primarily lie in examining the action and interactions between individuals, organisations and society. Within the Department of Obstetrics and Gynaecology I have contributed to the study design, data collection, analysis and/or review of a number of research projects. Thus, a number of these previous projects have informed the focus of this thesis.

Although the Pregnancy Loss Research Group[89] only formally came together in 2012, a number of research activities were under way in the Department of Obstetrics and Gynaecology which were indicative of the impact which pregnancy loss and perinatal death has on both parents, their families and the professionals who care for them.[90-94]. The evidence from these studies, as well as international literature, have informed the practice of the multidisciplinary clinical pregnancy loss team at Cork University Maternity Hospital (CUMH). One of the key strengths of the research undertaken by the Pregnancy Loss Research Group is that is not only facilitated by the clinical team but that the research agenda is driven by the gaps in care which these clinicians have identified while practicing in the Irish maternity services.

Quantitative studies have illustrated that there is significant psychological morbidity associated with prenatal loss at any gestation yet few studies have examined the lived experience of these losses. One of the focuses of the Pregnancy Loss Research Group is to undertake qualitative research to examine how bereaved parents understand and make sense of their loss.

The Pregnancy Loss Research Group also recognises the importance, for both parents and clinicians, of understanding the underlying cause of pregnancy loss. In doing so, not only may it help parents come to terms with their loss but may also provide reassurance for a future pregnancy. With this in mind the group have undertaken a number of cohort studies, including the Women's Health Study, to try and identify risk factors for miscarriage and stillbirth in the Republic of Ireland.

In 2006 the National Perinatal Epidemiology Centre (NPEC)[95] was established on foot of recommendations in the Lourdes Hospital Inquiry Report.[96] The mission of the NPEC is to collaborate with Irish maternity services in order to translate clinical audit data and epidemiological evidence into improved maternity care for families in Ireland. The NPEC's primary focus is to work at national level by collaborating with all of the Republic of Irelands' maternity units and conducts a number of audits and reviews the practice of the Irish maternity services.[97, 98] The NPEC produces annual reports including a report on perinatal mortality in Ireland which is an important indicator of quality of maternity care. In order to

make improvements in the area of perinatal mortality it is important to try and identify the underlying causes. To achieve this the NPEC has drawn on international learning to develop its audit tool and has moved from the Wigglesworth Classification[99] to the NPEC Classification[5] which was developed from the CMACE classification.[100] In doing so the NPEC now collects detailed information in relation to perinatal mortality including, maternal demographics and medical history, antenatal and delivery details, maternal and infant outcomes, autopsy uptake rates and finally not only the cause of death but any associated factors.[5] In doing so the NPEC has made a number of recommendations to aim to reduce perinatal mortality in Ireland if implemented.[5]

The collaborative efforts of the Pregnancy Loss Research Group and the National Perinatal Epidemiology Centre are committed to improving professional practice in order to improve maternity services and ensure the provision of appropriate support and information to parents bereaved by pregnancy loss and perinatal death.

1.7 Methods

This thesis is concerned with the exploration of the causes of pregnancy loss and perinatal death and to further examine the psychological and social effects of pregnancy loss and perinatal death. In order to achieve this a pragmatic approach was employed. A pragmatic approach values both objective and subjective knowledge and therefore advocates for the most appropriate research design to be

implemented in light of the research question posed. Given the research problem identified here it was believed that employing both quantitative and qualitative methods, where appropriate, would allow a depth of understanding that one methodology alone would not achieve.

As indicated earlier in this chapter, the existing literature in the area of pregnancy loss and perinatal death has not fully explored the unique experiences of these populations. Quantitative methods, especially in health related research, are concerned with the "what". In doing so it focuses on determining rates, causes, and risk factors of pregnancy loss and perinatal death. Qualitative research allows the healthcare professionals a window into the lived experience of their patients as it is concerned with how people make sense of the world and the events they experience.[101-103]

Given that a number of the research objectives of this thesis were exploratory, qualitative methods were considered most appropriate for six of the eight chapters. The aim of these chapters were to understand people's experiences of loss to allow for an accurate description and interpretation of the issues raised which would not be achieved by employing quantitative methods.[102, 104] This assumption is based on the belief that those who have experience of an event are better placed to judge which issues are most pertinent to explore, particularly in areas where there is limited existing research.[104-106] It has been argued that perspectives and ones interpretation of experiences is more apparent by means of qualitative exploration.[107, 108] The key strength of utilising many of the qualitative methods

is the inductive approach employed. The human experience is diverse and complex, and through interpretation the researcher can shed light on not only what is important to individuals but why it is important.[109, 110]

Within qualitative approaches there are multiple methods which can be applied, with content and thematic analysis being considered foundational as they provide the key skills which are useful when undertaking other qualitative analysis such as interpretative phenomenological analysis (IPA). For the purposes of this thesis both thematic analysis and IPA were undertaken. The two separate qualitative methods were determined by evaluating the method which was most appropriate for the data collected. Thematic analysis was undertaken on Twitter status updates in order to examine the public reaction to perinatal death. IPA was utilised to undertake an in-depth exploration of the individual personal and lived experience of mothers and fathers who experienced pregnancy loss and perinatal death which was collected through semi-structured interviews.

IPA has a phenomenological approach and is founded in the work of philosopher Edmund Husserl whereby the approach focuses on “a return to the things themselves” by appreciating how we construct meaning, understanding and knowledge inter-subjectively.[111] IPA enables the researcher to interpret the meanings which are ascribed to events and through an interpretative process those which are of significance can be identified.[101, 103] The analytical strategy for IPA includes predefined steps in order to code and interpret the data, the appendices contain detailed examples of this procedure (Appendix I). As an approach

phenomenology acknowledges that the researcher will never fully access the world of the research participant as their interpretation is complicated by the researchers own experiences, perceptions and worldview.[101] Consequently it is understood that the findings produced by the researcher are an interpretation of the participants' experience.[102, 112] Owing to this I have included a reflexive account in Appendix II.

1.8 Summary

Despite substantial reductions in perinatal mortality and other adverse pregnancy outcomes in high income countries, there are still a considerable number of people who will experience pregnancy loss and/or perinatal death. Given the sensitive nature of the topics under investigation, a justification for the study and the thesis outline will be given. Particular reference is made to recommendations from systematic reviews as well as reports commissioned by the Irish Health Service Executive. Following a review of the literature a number of gaps in the knowledge on pregnancy loss and perinatal death were identified. I undertook a number of studies for this thesis to address these gaps in the current literature by examining specific populations whose experiences have, to date, been overlooked in the literature.

To date, international health policy has focused on a reduction of child mortality and more recently stillbirth.[6, 7] In order to end preventable pregnancy loss and

perinatal deaths it is imperative to determine the cause of death. There have been positive developments in relation to perinatal death where countries continually investigate and report on the causes of perinatal death, identify potential risk factors and make recommendations on the management of women's care.[5, 44, 46, 47, 88] No such inquiry is undertaken for miscarriage. The estimated rates of miscarriage in Ireland are based on a study undertaken in the United Kingdom on an at risk sample of women who attended a clinic with threatened miscarriage which limits the study's findings.[3] To attend to this deficit the first two studies within this thesis will firstly examine the causes of miscarriage and secondly will investigate the management of these cases in an Irish context.

There is an assumption that the longer a woman is pregnant the stronger the attachment to the baby.[113] However, studies have indicated that early in pregnancy parents begin to develop bonds with their babies.[114] A systematic review suggests that although length of gestation may be a factor, there is very little research which focus on the impact of pregnancy loss at different gestational ages.[113] Thus, this thesis aimed to explore the experience of pregnancy loss and perinatal death from the earliest gestation, throughout pregnancy and following birth.

Previous research has indicated the need for emotional and psychological support following pregnancy loss and perinatal death which has resulted in improvements in care. [115] A number of recent reviews illustrate that despite the considerable changes to the guidelines and routine care offered to parents, there has been little

research examining the impact of these changes on grieving parents.[13, 16, 25, 116] Furthermore, as a recent meta-synthesis illustrates, a number of the studies which were undertaken are now dated.[12] As illustrated earlier in the chapter medicine has shifted from a paternalistic profession to an environment which promotes patient autonomy and therefore the requirements of these patients may in fact have changed since these studies were undertaken. In addition, a Cochrane Review from 2013 found there was no randomised control trial of any form of support aimed at supporting mothers, fathers and families who have experienced perinatal death.[18] In order to design and implement an appropriate intervention there needs to be a comprehensive understanding of the phenomenon. Utilising an exploratory sequential design it is possible to utilise the findings from qualitative studies to design appropriate interventions for future randomised controlled trials that will possibly help inform and improve healthcare practices.[117] It is envisioned that the findings of this thesis may inform future intervention studies which in turn may improve the care provided to those who may experience pregnancy loss or perinatal death.

The first three studies of the thesis are concerned with the cause, management and potential impact of miscarriage. The first study acknowledges that the causes of miscarriage, which are poorly misunderstood, are likely multi-dimensional with biological, medical and behavioural risk factors and thus examines the association between stress and pregnancy outcome. To date, studies indicate that up to one in three pregnancies will end in miscarriage. The majority of these losses will occur in

the first trimester. Miscarriage which occurs in the second trimester is not as common as it occurs in 1% of pregnancies. The second study examined the management of these cases. The third study related to miscarriage examined the experience of both men and women following miscarriage. The fourth study focuses on women's experience of ectopic pregnancy.

The remaining four studies relate to perinatal death and its impact on both parents and the wider community. Determining the cause of death is important for parents when they experience a loss in the perinatal period.[118] Perinatal autopsy is an important tool and can impact on the reported cause of death. The fifth study examines the potential factors that influenced the parental decision to have an autopsy performed or not following stillbirth. The results of this study informed the sixth qualitative study whereby the parental consideration and planning of a subsequent pregnancy following stillbirth is explored. Although twin and higher order multiples are at greater risk of perinatal mortality there are comparatively few studies on the parental experience of the loss of a co-twin. Thus, the seventh study examined the effect of the loss of one twin in the perinatal period.

Over the course of this thesis the maternity services in Ireland have garnered significant media attention both nationally and internationally. Although this focus was firstly related to the maternal death of Savita Halappanavar in 2012 it has since focused on a number of adverse incidents, most recently about a cluster of

perinatal deaths.[119, 120]Thus, the final study of my thesis aimed to explore the reaction on Twitter, a microblogging website, to the perinatal deaths that occurred in a maternity unit in the Republic of Ireland.

It is envisioned that the findings of this thesis may inform future intervention studies which in turn may improve the care provided to those who may experience pregnancy loss or perinatal death.

1.9 Thesis outline

The overall aim of my thesis was to explore the causes of pregnancy loss and perinatal death and to further examine the psychological and social effects of pregnancy loss and perinatal death. As outlined in Figure 1.4, this thesis aimed to:

1) Examine the aetiology of pregnancy loss
2) Explore the parental experience of pregnancy loss
3) Explore the parental experience of perinatal death
4) Examine the societal response to perinatal deaths

In this thesis I document a series of studies that examine the causes and consequences of pregnancy loss and perinatal death. Pregnancy loss can occur at any time during pregnancy, birth or up to 7 completed days following birth. There are a number of guidelines which inform clinicians how to manage the care of

patients who experience pregnancy loss or perinatal death.[31, 38, 121] Given that the pathways of care, as outlined by the clinical guidelines, vary for different scenarios of pregnancy loss and perinatal death, it is reasonable to suggest that the needs of the parents may be different to each other as well as to others who are attending the maternity services. Thus, this thesis aimed to explore the experience of pregnancy loss and perinatal death in an in-depth manner in order to identify the specific needs of these populations. The thesis begins with the examination of pregnancy loss from the earliest gestations, miscarriage and ectopic pregnancy, through pregnancy loss in the second and third trimesters, followed by perinatal death and an exploration of the care experienced in subsequent pregnancies. In order to achieve this, and taking into consideration the varying pathways of care, the outline of this thesis follows the timeline of pregnancy and the events related to pregnancy loss and perinatal death.

In order to achieve these aims, this thesis is comprised of a number of papers which are outlined below:

Chapter 2: Perceived maternal stress and emotional wellbeing as risk factors for miscarriage (paper 1)

Chapter 3: The postnatal morbidity associated with second-trimester miscarriage (paper 2)

Chapter 4: Parent's experience of miscarriage: a qualitative study (paper 3)

Chapter 5: Women's experience of ectopic pregnancy: a qualitative study (paper 4)

Chapter 6: Parental decision making around perinatal autopsy: a qualitative investigation (paper 5)

Chapter 7: Parents concerns of pregnancy after stillbirth (paper 6)

Chapter 8: Death of one twin during the perinatal period: a qualitative study (paper 7)

Chapter 9: Reaction on Twitter to a cluster of perinatal deaths: a mixed method study (paper 8)

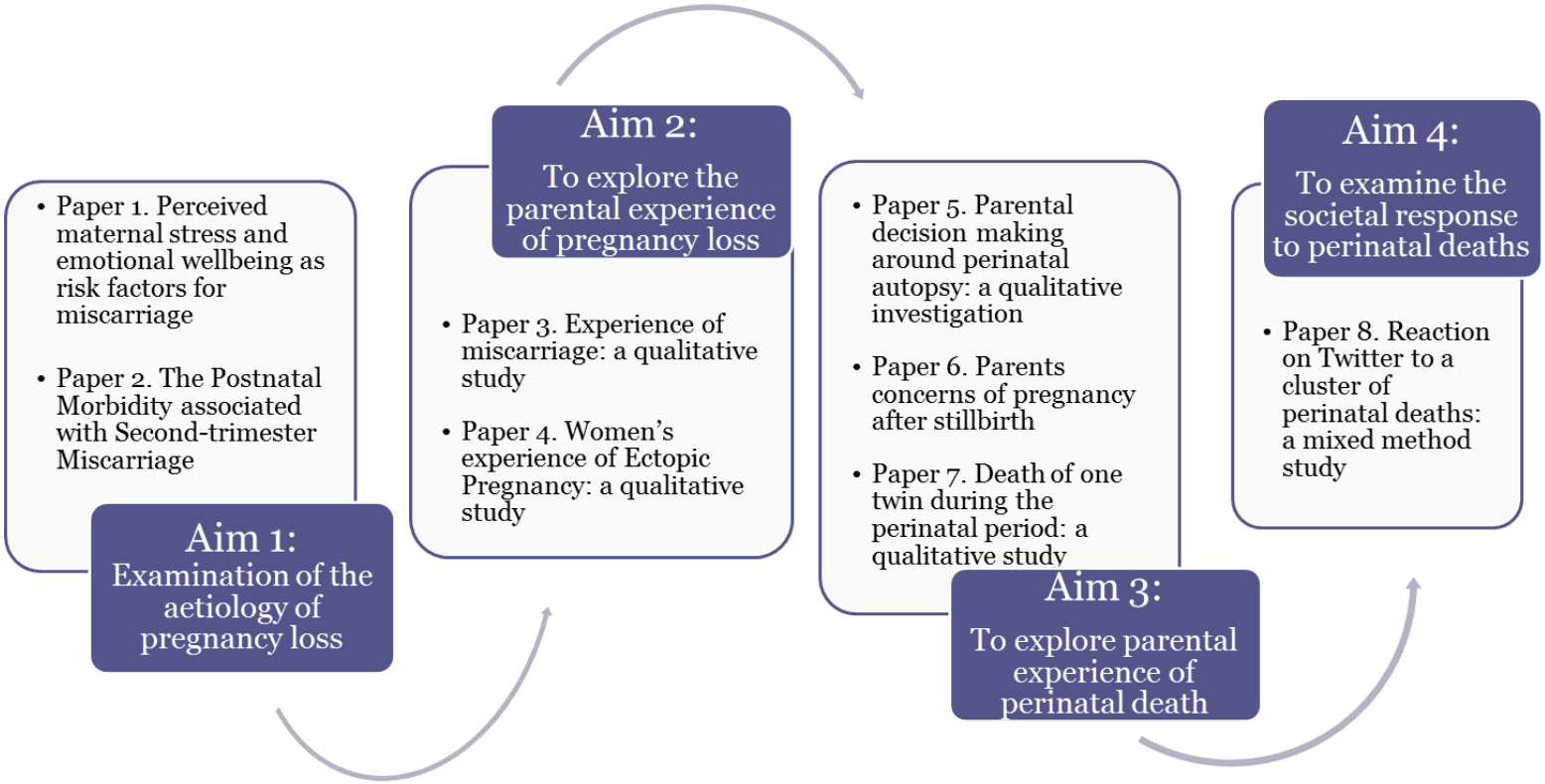


Figure 1.4: Thesis outline

Chapter 2

2 Perceived stress as a risk factor for miscarriage: A prospective cohort study

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2.1 Abstract

Objective: Miscarriage is the most common adverse outcome in pregnancy however the cause of miscarriage remains poorly understood. The purpose of this study was to examine the association of stress with the risk of miscarriage.

Design: A prospective cohort study.

Participants and setting: The study was conducted on women attending a large, tertiary hospital (~8,500 deliveries per annum). Women randomly selected at their first booking were asked to complete a detailed lifestyle questionnaire. Specific data were collected using the following validated psychometric tests; the RAND 36-Item Health Survey, the Maternity Social Support Scale, the Revised Life Orientation Test and the Perceived Stress Scale. Participants were followed up to determine pregnancy outcome. A multivariate binomial regression was conducted to assess effects of stress on miscarriage.

Results: Of the 417 participants, 32.1% (n=134) had a confirmed miscarriage at follow-up. When recruited, women with a continuing pregnancy reported better emotional wellbeing than women who miscarried (74.1% versus 59.3%). No differences in the rates of miscarriage were observed in relation to maternal social support, life orientation or women with a history of anxiety and/or depression. While these measures were inter-correlated, it was perceived stress that contributed significantly to risk of miscarriage after adjustment for obstetric risk factors.

Conclusions: Further work to develop and evaluate targeted interventions which could improve coping skills might be effective in lowering the risk of miscarriage.

Keywords: Miscarriage; pregnancy loss; perceived stress; maternal health; prospective cohort study

2.2 Introduction

Miscarriage is the most common adverse outcome in pregnancy. Retrospective studies indicate that one in five pregnancies will end in miscarriage; however prospective studies have reported as many as one in three pregnancies end in miscarriage.[30] A recent study undertaken in Australia has illustrated considerable variation in the rates of miscarriage for different groups of women.[1] In Europe, Ireland has the highest birth rate at 15.6 births per 1,000 population.[122] Given the lower estimate of one in five pregnancies ending in miscarriage and the number of births (72,000 per annum), approximately 14,000 women experience miscarriage in Ireland every year.[31] The cause of miscarriage remains poorly understood, and in contemporary obstetrics a high proportion of cases are classified as unexplained.[30, 49]

Approximately 25% of women report emotional distress during the prenatal period.[123] Stress during the prenatal period may have a direct effect by means of a psychobiological model in which the type of stress, duration and timing of stress experienced influences physiological factors subsequently leading to poor reproductive outcomes.[123, 124] Indeed, studies already report the association between psychological stress and increased risk of preterm labor, low birth weight and unsuccessful outcomes for IVF-assisted pregnancies.[55, 125-127] Although stress has been long suspected as a possible cause of unexplained recurrent

miscarriage[128], the mechanisms by which it may lead to miscarriage are complex and not clearly defined.[129]

We undertook a prospective cohort study to determine the association of stress with the risk of miscarriage. Studies indicate that there are factors which are influential on how an individual responds to psychological stress.[130] Consequently, our study aimed to examine a number of aspects of stress which might be influential including stressful life events, as well as using a number of psychometric scales which assess perceived stress, emotional wellbeing and social support.

2.3 Methods

2.3.1 *Study Design*

This cohort study was conducted in a large, tertiary maternity hospital (8,366 deliveries in 2012). Eligible participants included pregnant women attending the hospital outpatient department or the early pregnancy assessment unit. The early pregnancy assessment unit, is custom designed to provide antenatal care in the first trimester to pregnant women who present with signs of threatened miscarriage or who have a history of miscarriage or a history of recurrent miscarriage (three or more consecutive miscarriages). This study aimed to recruit approximately 400 women to achieve adequate statistical power. Using the standard 5% level of statistical significance, a study sample would result in >80%

statistical power to detect relatively uncommon risk factors. Upon agreement to participate, the women's age, gestation at recruitment, parity and marital status were determined from her obstetric case-notes. Women were then asked to complete a detailed lifestyle questionnaire. The questionnaire could either be returned to the research midwife or returned in a self-addressed envelope. Women were followed up whereby hospital records were reviewed by the research midwife through to delivery in order to ascertain pregnancy outcome. The study was approved by the Institutional Clinical Research Ethics Committee (Reference: ECM 4 (iii) 10/01/12).

2.3.2 *Measures*

Our primary outcome of interest was miscarriage. This was defined as any pregnancy loss which occurred before 24 weeks gestation in a fetus weighing less than 500 grammes. In the context of this study, women were categorised as either at high or low risk for miscarriage. High risk was defined as a woman who presented to the clinic with a threatened miscarriage or a history of recurrent miscarriage, i.e. three or more consecutive miscarriages. Women who did not meet these criteria were defined as low risk for miscarriage. Confirmation of risk status was determined through review of the women's obstetric chart.

Traumatic life events have been shown to increase risk of first trimester miscarriage.[30, 55, 56] Thus, based on a list developed by Maconochie *et al.,*

information on a range of traumatic events, e.g. loss of job, separation or divorce, serious accident or illness, death of someone close, previous miscarriage, stillbirth and death of a child were collected.[30] There were 13 events listed in total and women were asked to indicate if they experienced an event in the last 12 months, more than 12 months ago or not at all. A composite variable, previous pregnancy loss, was created to encompass previous miscarriage, stillbirth, or the death of a child.

Psychometric scales were also used to assess women's psychological state during early pregnancy. Firstly, the 10-item perceived stress scale (PSS-10) was developed to assess perceived stress. Using a 5-point scale ranging from never to very often, women were asked to indicate how often life situations were perceived as uncontrollable, unpredictable and stressful in the past month.[131] Higher summary scores indicate greater perceived stress. Secondly, emotional wellbeing was measured using a 6-item subscale of the RAND-36, which is one of the most widely used instruments to assess health-related quality of life.[132] Women were asked to report how often they had felt happy, tired, worn out, nervous, downhearted or sad over the past four weeks. Responses were measured on a 6-point scale ranging from 'none of the time' (score of zero) to 'all of the time' (score of five). Higher summary scores indicate a more favourable state of emotional wellbeing. Social support was evaluated using the Maternity Social Support Scale. This 6-item scale measures support from the woman's spouse, family and their

wider social network on a 5-point scale ranging from 'never' (score of 1) to always (score of 5). Higher summary scores are indicating higher levels of social support.[133] Finally, the Revised Life Orientation Test (LOT-R) is a measure of dispositional optimism and studies indicate that having a positive outlook is beneficial for physical and psychological well-being and therefore has important health implications.[134] The scale assesses individual differences in generalised optimism versus pessimism. The LOT-R is a 10 item scale whereby women chose from a 5 point scale ranging from I strongly disagree (score of 1) to I strongly agree to strongly agree (score of 5). Higher summary scores are indicative of an optimistic rather than a pessimistic outlook.

2.3.3 *Statistical Method*

Cronbach's alpha was used to assess the internal consistency of the psychometric scales in the study.[135] Descriptive statistics for all covariates were derived. In the absence of recommended cut-offs for the psychometric measures, low, medium and high levels of perceived stress, emotional wellbeing and maternal social support were represented by categories created based on tertiles. Associations between the psychometric measures were examined using chi-square tests. Associations between the categorical independent variables and miscarriage were assessed using chi-square tests and univariate binomial regression models. The findings from the regression were reported as risk ratios with their corresponding 95% confidence intervals. In cases where a univariate binomial regression model

involving one of the psychometric measures showed that women in two contiguous categories (e.g. low and medium or medium and high) had the same risk of miscarriage, these categories were merged in subsequent regression analysis thereby increasing statistical power while continuing to provide a fair representation of the data.

A multivariate binomial regression model was estimated including the psychometric measures as the independent variables in order to identify which of these independently contributed to risk of miscarriage. The measures selected from this model were then included along with established maternal and obstetric risk factors for miscarriage (maternal age, high risk pregnancy, booking trimester, previous loss and previous early delivery) in a final multivariate binomial regression model. Analyses were performed with PASW 21.0 (IBM) and Stata (version 13).

2.4 Results

Of the 715 women who agreed to participate in the study, 61.3% (n=431) completed the lifestyle questionnaire which included the psychometric scales. Of the 431 who completed the lifestyle questionnaire, pregnancy outcome was ascertained for 417 women (96.8%). Approximately one third of women (32.1%, n=134) had a confirmed miscarriage following review of their obstetric case notes.

Table 2.1 outlines the Cronbach's alphas calculated for each of these scales. It is of note that perceived stress, emotional wellbeing, maternal social support, life orientation and a history of depression and/or anxiety were all significantly inter-correlated ($p < 0.001$). As illustrated in Figure 2.1, women who reported high levels of stress also reported lower levels of emotional wellbeing, maternal social support, were more likely to have a pessimistic outlook and have a history of anxiety and/or depression.

Table 2.1: Internal consistencies of psychometric scales

Scale	**Cronbach's alpha**
RAND-36 Emotional Wellbeing Subscale	0.76
Maternal Social Support Scale	0.64
The Revised Life Orientation Test (LOTR-R)	0.79
Perceived stress scale (PSS-10)	0.70

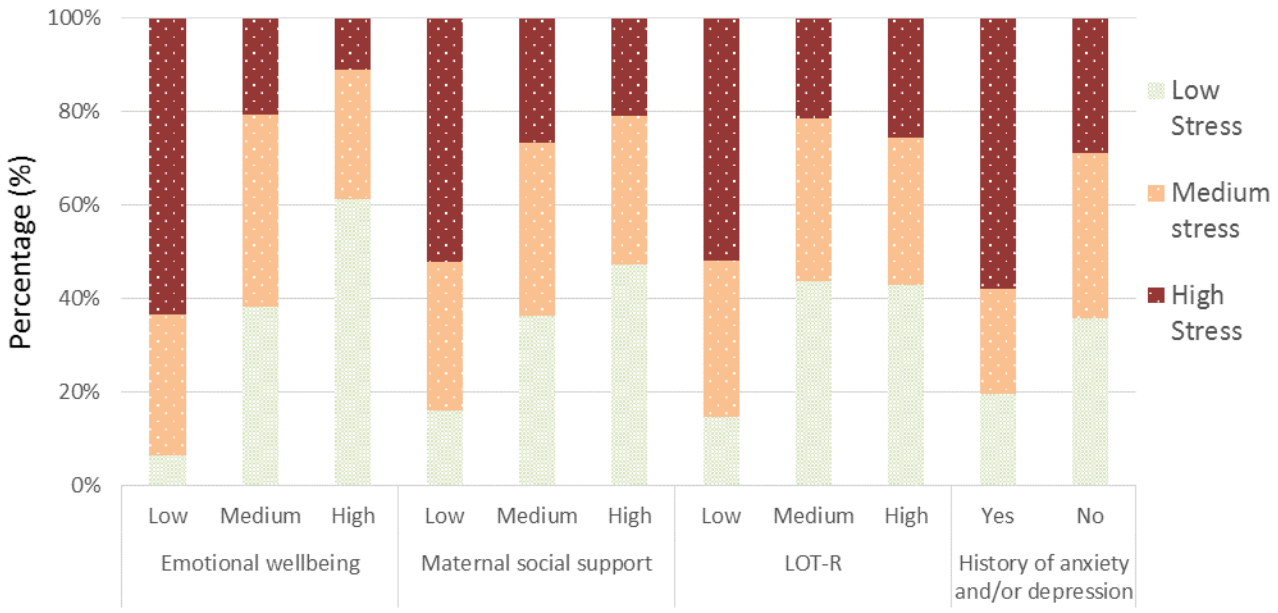


Figure 2.1: Psychometric scales by high, medium and low perceived stress levels

As outlined in Table 2.2, women who miscarried were more likely to be 35 years of age or older (43.6% versus 26.6%). Women who miscarried were twice as likely to report poorer general health (8.9% versus 4.6%) and were more likely to be overweight or obese prior to pregnancy (37.4% versus 31.0%). Women with a continuing pregnancy tended to be more highly educated.

Table 2.2: Maternal characteristics

	Miscarried (n=134)	Continued Pregnancy (n=283)
Age		
Under 35 years	56.4 (75)	73.4 (204)
Over 35 years	43.6 (58)	26.6 (74)
Ethnicity		
White Irish	81.4 (109)	79.1 (224)
Any other white background	12.7 (17)	15.2 (43)
Other including mixed background	5.9 (8)	4.3(12)
Marital Status		
Single	11.9 (16)	16.0 (45)
Married	63.4 (85)	61.7 (174)
Cohabitating	22.4 (30)	20.6 (58)
Separated/Divorced/Widowed	2.2 (3)	1.8 (5)
Education		
Some Primary and/or secondary level	32.3 (43)	25.6 (72)
Certificate and/or higher diploma	38.3 (51)	35.9 (101)
Undergraduate or postgraduate degree	29.3 (39)	38.4 (108)
Gestation at booking		
First trimester	42.9 (111)	57.1(148)
Second trimester	5.8 (6)	94.2(97)
Presentation*		
Low risk presentation	40 (29.9)	222 (78.7)
High risk presentation	90 (70.1)	60 (21.3)
BMI (kg/m^2)		
Underweight (<18.5)	0.8 (1)	2.3 (6)
Healthy weight (18.5-24.9)	61.8 (76)	66.7 (172)
Overweight (25.0-29.9)	23.6 (29)	20.5 (53)
Obese ($\geq$30.0)	13.8 (17)	10.5 (27)
General Health		
Excellent	26.9 (36)	26.1 (74)
Very good	40.3 (54)	47.0 (133)
Good	23.9 (32)	22.3 (63)
Fair	6.7 (9)	3.9 (11)
Poor	2.2 (3)	0.7 (2)

* High risk was defined as a woman who presented to the clinic with a threatened miscarriage or a history of recurrent miscarriage, i.e. three or more consecutive miscarriages. Women who did not meet these criteria were defined as low risk for miscarriage.

Women who presented to the clinic with a threatened miscarriage or a history of recurrent miscarriage had a markedly higher rate of miscarriage than women who were categorised as low risk (70.1% versus 21.3%). Women who attended their

first scheduled appointment with the maternity hospital in their first trimester rather than in the second had much higher rates of miscarriage (42.9% versus 5.8%).

There was no strong evidence supporting the association between individual life event stressors and miscarriage (Table 2.3). The rate of miscarriage was higher in women who had experienced a previous loss (38.9% to 26.6%; p=0.011). Thus, previous loss was included in the final multivariate model.

Table 2.3: Reported stressful life events

	Miscarried (n=134)	**Continued Pregnancy (n=283)**
Job generally demanding/stressful	53.2 (67)	57.4 (156)
Loss of job/job security	15.7 (20)	17.3 (47)
Husband or partner lost their job/job security	22.8 (29)	29.2(80)
Separation/divorce	5.6 (7)	2.9 (8)
Serious financial problems	17.5 (22)	16.0 (44)
Accident	8.7 (11)	6.2 (17)
Serious illness	7.1 (9)	4.0 (11)
Serious illness of someone close	25.2 (32)	19.9 (54)
Death of someone close	30.2 (38)	31.3 (86)
Death of a child	2.4 (3)	1.1 (3)
Stillbirth	4.8 (6)	1.8 (5)
Previous miscarriage	40.8 (51)	30.9 (85)
Other stressful/traumatic event	16.3 (20)	12.8 (35)

Note: Categories are not mutually exclusive.

Women with a continuing pregnancy reported better emotional wellbeing than women who miscarried (74.1% versus 59.3%, Table 4). No differences in the rates of miscarriage were observed in relation to maternal social support, life orientation or women with a history of anxiety and/or depression. Women who miscarried were more likely to report higher levels of perceived stress compared to women who continued on in pregnancy (37.0% versus 21.7%, Table 2.4). Univariate analysis indicated that emotional wellbeing and perceived stress were associated with miscarriage. However, following hierarchical regression analyses emotional wellbeing was not identified as a predictor of miscarriage and was removed from the final multivariate model.

Table 2.4: Reported psychological factors

	Miscarried (n=134)	Continued Pregnancy (n=283)
Emotional Wellbeing		
Low	40.7 (50)	25.9 (71)
Medium	34.1 (42)	42.3 (116)
High	25.5 (31)	31.8 (87)
Maternal Social Support		
Low	30.6 (37)	31.0 (80)
Medium	30.6 (37)	29.1(75)
High	38.8 (47)	39.9 (103)
LOT-R		
Low	33.9 (43)	31.9 (84)
Medium	31.5 (40)	36.5 (96)
High	34.6 (44)	31.6 (83)
Perceived Stress		
Low	31.5 (40)	39.3 (105)
Medium	31.5 (40)	39.0 (104)
High	37.0(47)	21.7 (58)
History of Anxiety and/or Depression		
No	84.5 (109)	86.9 (239)
Yes	15.5 (20)	13.1 (36)

In the adjusted log-binomial model (Table 2.5), the risk of miscarriage persisted for women with a high risk pregnancy (RR=2.58; 95% CI: 1.73-3.83) as well as for women with a history of delivering early in a previous pregnancy (RR=1.36; 95% CI: 1.10-1.68). Women who booked during their second trimester were less likely to miscarry than those in their first trimester (RR=0.10; 95% CI: 0.02-0.39). Experience of a previous loss was no longer associated with an increased risk of miscarriage after adjustment for the other factors. The risk of miscarriage in women reporting

high levels of perceived stress was 1.30 times greater (95% CI 1.01-1.68) than those with low/medium levels of stress.

Table 2.5: Crude and adjusted risk ratios for miscarriage

	RR (95% CI)	Adjusted RR* (95% CI)
Age		
Under 35 years	1.00 (ref)	1.00 (ref)
Over 35 years	1.63 (1.24-2.14)	1.22 (0.95-1.56)
Presentation**		
Low risk presentation	1.00 (ref)	1.00 (ref)
High risk presentation	3.40 (2.93-5.46)	2.58 (1.73-3.83)
Gestation at booking		
First trimester	1.00 (ref)	1.00 (ref)
Second trimester	0.14 (0.06-0.30)	0.10 (0.02-0.39)
Delivered early previously		
No	1.00 (ref)	1.00 (ref)
Yes	1.62 (1.13-2.33)	1.36 (1.10-1.68)
Previous Loss		
No	1.00 (ref)	1.00 (ref)
Yes	1.46 (1.09-1.95)	0.84 (0.66-1.07)
Perceived Stress		
Low/Medium	1.00 (ref)	1.00 (ref)
High	1.62 (1.22-2.15)	1.30 (1.01-1.68)

Adjusted for all other factors on table **High risk was defined as a woman who presented to the clinic with a threatened miscarriage or a history of recurrent miscarriage, i.e. three or more consecutive miscarriages. Women who did not meet these criteria were defined as low risk for miscarriage.

2.5 Discussion

2.5.1 *Main Findings*

This prospective cohort study found that one in three women miscarried which is similar to those of other prospective studies.[136, 137] This study was undertaken

to examine the relationship between stress and miscarriage, namely perceived stress, emotional wellbeing, maternal social support, life orientation and a history of depression and/or anxiety. While these measures were inter-correlated, it was perceived stress that contributed significantly to risk of miscarriage after adjustment for maternal and obstetric risk factors.

Although animal studies have determined that stress induces miscarriage, this finding is yet to be established in human studies.[57] Our study included a range of stressful life events which have previously been associated with miscarriage.[30] Life event stress is characterised by changes in a person's life that are sufficiently important in their potential impact that they cannot be treated as part of routine daily life.[55] With the exception of experiencing a previous loss, before adjustment in the final model, our findings found no evidence that stressful life events were associated with miscarriage.

Measuring life event stress does not take into consideration an individual's perception of their experience and their ability to control the event.[55] Although no association was found for stressful life events, our study did identify high perceived stress as a risk factor for miscarriage. To date, two studies have also indicated that high perceived stress has an association with sporadic as well as recurrent miscarriage.[30, 57] Immunological imbalances have been linked to miscarriage in women who reported high perceived stress[57] and women who

reported feeling stressed, anxious, depressed, out of control or overwhelmed in their first trimester had higher odds of miscarriage.[30] Early assessment in order to ascertain whether there are any sources of stress which are modifiable would be beneficial, particularly with women who have experienced recurrent miscarriage. Future studies may want to consider collecting biomarkers for stress, such as cortisol, and comparing them to the self-report perceived stress.

2.5.3 *Strengths and Limitations*

Our sample size of approximately 400 is larger than most previous studies in this area and it gave the study power to detect relatively uncommon risk factors. That the study was undertaken in a single maternity hospital limits the generalisability of the findings and the study was also limited by self-reported data. Bias from self-reported data is well documented as some health behaviours are either sensitive or difficult to recall. However, studies have indicated that maternal recall regarding health behaviours during pregnancy is reliable.[138] Another limitation of this study is that it was not possible to collect information on psychosocial factors for women who did not return the lifestyle questionnaire. Therefore, we were unable to compare responders with non-responders in this regard. However, our findings indicate there were no significant differences found in the rate of miscarriage for responders and non-responders.[139]

Consideration of established obstetric risk factors for miscarriage, such as previous loss, previous early delivery and high risk presentation, is a strength of our study. Our study has reaffirmed a number of these obstetric risk factors for miscarriage. Women with a high risk pregnancy, defined in this study as a woman who presented to the clinic with a threatened miscarriage or a history of recurrent miscarriage, had approximately a three-fold increased risk of miscarriage. This is in line with previous studies.[30, 54]

Almost a decade ago, the American College of Obstetricians and Gynecologists (ACOG) stated that psychosocial stress may predict a woman's attentiveness to personal health matters, her use of prenatal services, and the health status of her offspring.[140] ACOG advocated screening all women for psychosocial stress and other psychosocial issues during each trimester of pregnancy and the postpartum period. Several studies have reported that supportive care, particularly in early pregnancy, decreases the rate of miscarriage in those who had experienced recurrent miscarriage.[141] However, these studies have not demonstrated that the reduced risk of miscarriage was associated with reduced stress. As indicated in a review of the literature by few studies have examined interventions aimed at reducing stress in pregnant populations.[142] The findings of our study suggest that such studies are warranted.

2.6 Conclusion

This study has provided additional evidence that contributes to the growing body of research that perceived stress may be associated with miscarriage. Our findings suggest that high perceived stress levels have a greater influence on pregnancy loss as opposed to an increased accumulation of stressful life events. These conclusions underscore the need for supportive care in early pregnancy, particularly with women who may be more vulnerable to stress. Further work to develop and evaluate targeted interventions which could improve coping skills might be effective in lowering the risk of miscarriage.

Author Contributions:

SM, JEL, SG and KOD contributed to and were solely responsible for the conception and design of the study. NS was responsible for data collection. SM JEL and PC were responsible for analysis and interpretation of data. SM was responsible for the initial drafting the article. SM, PC, JEL, SG, NS and KOD contributed to revising the manuscript critically for important intellectual content; final approval of the version to be published; and the decision to submit the article for publication.

Chapter 3

3 Postnatal Morbidity associated with Second-trimester Miscarriage

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3.1 Abstract

Objective: To describe the complications, and their incidence, associated with the management and delivery of a distinct second-trimester miscarriage cohort.

Methods: A retrospective cohort study was undertaken in a large, tertiary-referral university hospital (8,500 deliveries per annum). All cases of pregnancy loss occurring between 14^{+0} and 23^{+6} were identified from July 2009 to June 2013 (n = 181). Medical notes were reviewed and the number of complications amongst this cohort was identified. Logistic regression was conducted to assess associations with clinical presentation and management.

Results: The mean gestation of loss was 18^{+2} weeks (SD: 2^{+2}). 64.6% (n=117) of the total losses were of intrauterine fetal demise (IUFD) with 17.7% (n=32) following preterm premature rupture of membranes (PPROM) and 17.7% (n=32) following preterm labor (PTL). All women required inpatient admission with 59.1% (n=107) undergoing medical induction of labor. PPROM cases, compared to cases of IUFD, had increased odds of requiring antibiotic therapy (OR 13.75, 95% CI: 4.88 – 38.72) and readmission (OR OR 4.15, 95% CI 1.12–15.36).

Conclusion: These women represent a small proportion of the obstetric population but remain a distinct cohort whose management is complicated by high rates of morbidity requiring medical intervention. An awareness of these risks should inform future clinical practice.

3.2 Introduction

Second-trimester (sometimes referred to as 'late' or mid-trimester) miscarriage is defined as pregnancy loss after the 12th and before the 24th week of gestation.[32] It should be noted that there are both geographical and historical variations to this classification where gestational limits are concerned.[143] This variation is a consequence of the heterogeneity of diagnostic gestational parameters of stillbirth. The World Health Organisation (WHO) defines stillbirth as a 'fetal death late in pregnancy' and allows each country to define the gestational age at which a fetal death is considered a stillbirth for reporting purposes. As a result, stillbirth may be defined as early as 16 weeks of gestation in some jurisdictions, while others use a threshold as late as 28 weeks.[67]

Given the lack of international consensus on gestational parameters of second-trimester miscarriage, these cases have often been classified and analysed together with first trimester losses or omitted altogether or, in the case of miscarriages that occur in the latter half of the second trimester, analysed with stillbirth cohorts.[32] While there are certainly similarities in terms of the aetiologies, management and investigation of both second-trimester miscarriage and stillbirth, these issues have contributed to a deficiency in the knowledge concerning the management of a distinct second-trimester miscarriage cohort.

Those who suffer a second-trimester pregnancy loss represent a heterogeneous

group with a wide variety of both presentations and aetiologies.[144] The association of second-trimester miscarriage with uterine malformations, infection, cervical insufficiency, fetal and placental anomalies, genetic and acquired thrombophilias and IVF-conceived pregnancies has been established.[145, 146] However, clinical presentations can be mixed and difficult to interpret, emphasizing the challenges of identifying dual, triple or even multiple contributory pathologies.[147]

Furthermore, these clinical presentations can often be a continuum of associated factors, with infection being a prevalent complication amongst second-trimester losses.[147] Allanson *et al*., within a retrospective case-control study, histologically demonstrated chorioamnionitis in 77% of cases of spontaneous mid-trimester losses compared with no infection found in a control group (induced labour for fetal anomaly).[148]

Where medical induction of labour is required, a combination of mifepristone and a prostaglandin is recommended as the first line intervention for induction of labor.[67] The side effects of misoprostol include nausea, vomiting, diarrhea, shivering and fever, and related complications include hemorrhaging, endometritis and, very rarely, uterine rupture.[149] Nonetheless, this combination has been found to be both safe and with a shorter time-to-delivery interval than other induction regimes.[150] Postpartum haemorrhage is often

anticipated in those women who deliver in their second trimester.[64] The rate of this complication has not been established nor the comparative prevalence where clinical presentation or management is concerned.

Following a second-trimester loss, significant perinatal morbidity has been described in subsequent pregnancies.[32] However, the literature concerning the postnatal morbidity experienced in an index, or any subsequent second-trimester miscarriage, is limited and often anecdotal. Complications following this specific pregnancy outcome have neither been examined nor had their rates been established.

The primary aim of this study was to describe the morbidity associated with delivery in a distinct second-trimester miscarriage cohort and, in doing so, to establish the prevalence of these complications.

3.3 Methods

A retrospective cohort study was undertaken in a single tertiary-referral university teaching hospital between July 2009 and June 2013. This is a large hospital serving a wide urban and rural hinterland with approximately 8,500 deliveries per annum. The study was conducted with approval from the Clinical Research Ethics Committee of the Institutional Teaching Hospitals.

All women with a pregnancy loss, singleton or multiple, between 14^{+0} and 23^{+6} weeks gestation were considered for inclusion. Two hundred and fifty eight second-trimester pregnancy losses were initially identified using the Pregnancy Loss and Delivery Registers that are recorded and held within the hospital.

Demographic characteristics and data concerning clinical presentation, management and postnatal events were collected through a detailed individual chart review. Where necessary, correlation was sought from clinical correspondence. Information was collected by the primary investigator, a resident in Obstetrics & Gynecology (AM), with assistance from a secondary investigator, a midwife in clinical practice (NS). Where there was any ambiguity regarding clinical presentation, management or intervention, it was discussed with the supervising clinician (KOD) and a final decision ascribed.

Demographic characteristics included age, body mass index (BMI), gravidity, parity, fetal number, gestation at diagnosis of pregnancy loss, any prior history of second-trimester pregnancy and any antenatal diagnosis received during this index pregnancy.

We presented these demographic characteristics in terms of three sub-groups; those women for whom this was their primary second-trimester loss, those who had a previous second-trimester loss and those who had an antenatal diagnosis of a fetal abnormality. In the absence of legal elective termination of pregnancy within our jurisdiction, this latter group of women may account for a higher proportion of this

cohort than elsewhere.

The date of diagnosis of the miscarriage was used to calculate the gestation at which the miscarriage occurred. This gestation was correlated with the estimated delivery date (EDD) that was confirmed at the time of the routine dating ultrasound to ensure accuracy.

For the purposes of this study, the clinical presentation of a second-trimester miscarriage was defined as one of the following three scenarios;

1. Intrauterine fetal demise (IUFD); defined as the absence of a fetal heartbeat confirmed on ultrasonographic examination.

2. Preterm labor (PTL) was defined as the presentation of a woman with cervical dilatation, which may be in association with the presence OR absence of abdominal pain, and a fetal heartbeat having been confirmed ultrasonographically as present on admission. This clinical presentation includes those women with cervical insufficiency.

3. Preterm premature rupture of membranes (PPROM) was defined as clinically confirmed rupture of membranes with a fetal heartbeat having been confirmed ultrasonographically as present on admission.

When coding individual management plans, the clinical events surrounding delivery were considered.

- Expectant management involved the admission and observation of a woman over a period of time following any of the three aforementioned presentations, and who then progressed to a vaginal delivery. It should be considered that in the absence of legal elective termination of pregnancy within the Irish jurisdiction, this is the predominant care pathway for those women who experience a PPROM and who are not otherwise clinically compromised.

- Medical management involved the administration of mifepristone and misoprostol (a prostaglandin) or oxytocin in accordance with hospital protocols to induce labor.

- Surgical management involved the procedure of hysterotomy, operative delivery of the fetus, and does not include any surgical intervention undertaken postnatally.

- Spontaneous 'management' involved cases where a woman presented and had already or imminently delivered the fetus.

Postnatal events recorded included need for analgesia, antibiotics and blood product administration, whether manual removal of placenta (MROP) was required, length of inpatient stay and if readmission occurred.

Of the 258 cases initially identified, 77 were excluded (Figure 1). Patients were excluded;

- in the absence of a dating ultrasound performed at the optimal gestational range between the 10th and 13th week of gestation. This criterion excluded cases of unconfirmed gestation, missed first trimester miscarriages and cases where no intrauterine pregnancy had been previously demonstrated (n=45).
- if the pregnancy loss was misclassified as second-trimester loss where it was, by definition, a stillbirth, i.e. within the Irish jurisdiction, a birth occurring beyond 24^{+0} weeks gestation or delivery of a fetus weighing greater than 500 grams (n=13).
- if the second-trimester miscarriage was as a result of either an induction of labor (IOL) or delivery in the interests of the maternal life (n=3).
- if there was insufficient data recorded in an individual's medical notes (n=9). The minimum data required for analysis included age, gravidity, parity and gestation at diagnosis of miscarriage.

Finally, there were cases where paper-based medical records were not obtained for review despite multiple attempts to locate them (n=7).

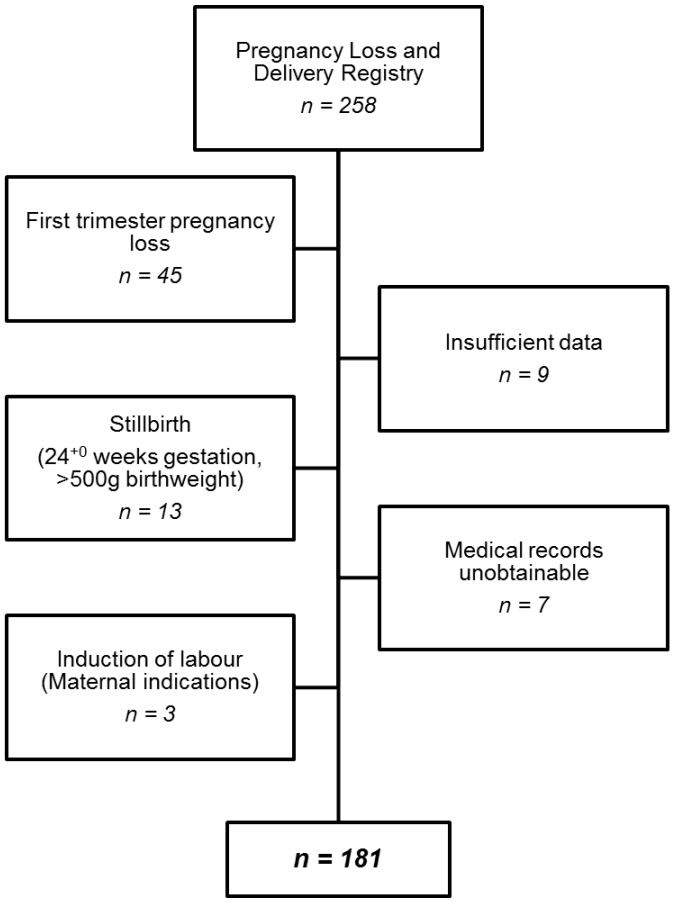


Figure 3.1 Exclusion Criteria

Twin pregnancies were analyzed in the same manner as singleton pregnancies with one exception; a dichorionic diamniotic twin pregnancy where there was an interval delivery time of 23 days between first and second twins, generating two postnatal courses.

In a woman who experiences more than one second-trimester loss, differing causal factors can predominate at different gestations in each pregnancy.[144] Consequently, where a woman had more than one second-trimester miscarriage in

the period covered by this study, each pregnancy and associated postnatal course was analyzed separately.

Descriptive analyses were used to describe the sample. Chi-square tests and a series of logistic regressions were used to determine the influence of clinical presentation on a number of dependent variables including analgesic and antimicrobial therapy as well as manual removal of placenta. All analyses were conducted using IBM SPSS Statistics version 22.0.

3.4 Results

Over this 4-year period, 181 pregnancies resulted in a second-trimester miscarriage with 182 postnatal courses analyzed. These maternities represent 0.5% of the total antenatal population accessing care in this centre during this period.

Maternal age ranged from 16 to 49 years, with a mean age of 33.5 years (SD: 5.6) and a mean BMI of 27.3 (SD: 6.5). Sixteen percent (n=29) were primiparous, 13.8% (n=25) were nulliparous and 70.2% (n=127) were multiparous. Twin pregnancies accounted for 5.5% (n=10) of pregnancies; the remainder were singleton (Table 3.1).

Table 3.1. Maternal socio-demographic factors, stratified by obstetric history

	Primary Late Miscarriage % (n = 147)	Previous Late Miscarriage % (n = 21)	Antenatal Diagnosis of Fetal Abnormality % (n = 11)
Maternal Age (Years)			
<20	2.0 (3)	0.0	0.0
20 – 29	17.7 (26)	28.6 (6)	0.0
30 – 39	70.1 (103)	57.1 (12)	81.8 (9)
≥ 40	10.2 (15)	14.3 (3)	18.2 (2)
Parity			
Nulliparous	18.4 (27)	0.0	18.2 (2)
Primiparous	11.6 (17)	38.1 (8)	0.0
Multiparous	70.1 (103)	61.9 (13)	81.8 (9)
Pregnancy			
Singleton	94.6 (139)	90.5 (19)	100.0 (11)
Multiple (Twins)	5.4 (8)	9.5 (2)	0.0
BMI			
Underweight (<18.5)	2.8 (4)	5.3 (1)	0
Normal (18.5-24.9)	36.1 (53)	42.1 (9)	50.0 (5)
Overweight (25.0-29.9)	31.5 (46)	5.3 (1)	16.7 (2)
Obese (≥ 30.0)	29.6 (44)	47.4 (11)	33.3 (4)

In 81.2% (n=147) of cases, this pregnancy loss represented their first second-trimester miscarriage, however 11.6% (n=21) had previously experienced a second-trimester loss. An antenatal diagnosis of a fetal abnormality had been received by 6.1% (n=11) in this current pregnancy. Six women had two separate second-trimester losses within this period.

IUFD accounted for 64.6% (n=117) of the total losses with 17.7% (n=32) following PPROM and 17.9% (n=32) following PTL. Table 3.2 outlines the management of these

pregnancy losses by their clinical presentation. Assessing all three clinical presentations, 59.1% (n=107) of women required medical induction of labour.

Table 3.2. Management of second-trimester loss, stratified by clinical presentation

	Intrauterine Demise % (n = 117)	**Preterm Premature Rupture Membranes** % (n = 32)	**Preterm Labor** % (n = 32)
Spontaneous Delivery	5.1 (6)	65.6 (21)	90.6 (29)
Surgical Evacuation	2.6 (3)	0.0	0
Medical Induction of Labor	88.9 (104)	9.4 (3)	0
Expectant Management	3.4 (4)	25.0 (8)	9.4 (3)

All women required inpatient admission with a mean stay of 2.7 days (SD: 3.0, Range 1–24 days). Table 3.3 demonstrates the average inpatient stay and readmission rates associated with each clinical presentation. Compared to the IUFD group, PPROM cases had increased odds of requiring readmission (OR 4.15, 95% CI 1.12–15.36).

Table 3.3. Inpatient stay and readmission rates, stratified by clinical presentation

	Intrauterine Demise % (n = 117)	**Preterm Premature Rupture Membranes** % (n = 32)	**Preterm Labor** % (n = 32)
Inpatient Stay *(mean days ± SD)*	2.2 ± 2.6	5.1 ± 4.0	2.3 ± 2.1
Hospital Re-admission	4.3 (5)	15.6 (5)	6.3 (2)

Where management is concerned, 61.9% (n=112) of women required intramuscular opioids for analgesic control. Antibiotic therapy, oral and/or intravenous, was required in 39.2% (n=71) of cases. MROP was necessary in 26.4% of cases (n=48). Table 3.4 illustrates the highest level of analgesia, antimicrobial and blood product therapies administered in addition to the rates of MROP required in the management of these miscarriages.

Table 3.4. Analgesic, antimicrobial and blood product therapies administered, need for manual removal of placenta, stratified by clinical presentation

	Intrauterine Demise % (n = 117)	**Preterm Premature Rupture Membranes** % (n = 32)	**Preterm Labor** % (n = 32)
Highest Level of Analgesia Administered			
None	15.5 (18)	16.1 (5)	37.5 (12)
Simple Analgesia	15.5 (18)	22.6 (7)	18.8 (6)
Intramuscular Opioids	67.2 (79)	58.1 (19)	43.8 (14)
Epidural/ Spinal Anaesthesia	0.9 (1)	0.0	0.0
General Anaesthesia	0.9 (1)	3.2 (1)	0.0
Antibiotic Therapy			
Oral	12.0 (14)	37.5 (12)	9.4 (3)
Intravenous	5.1 (6)	18.8 (6)	9.4 (3)
Intravenous + Oral	11.1 (13)	28.1 (9)	15.6 (5)
Blood Products	14.5 (17)	6.3 (2)	6.3 (2)
Red Cell Concentrates	1.8 (2)	6.2 (2)	3.1 (1)
Manual Removal of Placenta	29.9 (35)	25.0 (8)	15.6 (5)

On examining the three clinical presentations, PPROM cases have increased odds of requiring antibiotic therapy compared to IUFD cases (OR 13.75 95% CI: 4.88 – 38.72). Amongst the three clinical presentations, there was no statistical difference where blood product transfusion, analgesic requirements or need for MROP was concerned.

3.5 Discussion

By performing this study, we describe the morbidities associated with delivery after second-trimester miscarriage in this cohort and established the frequency of complications in these women. We demonstrate that, although these women represent a small proportion of our obstetric population, they remain a distinct cohort whose management is complicated by high rates of morbidity.

While this study was based in a single centre, catering to a predominantly Caucasian population, it is one of the largest tertiary referral centres in the country. This is a relatively small study; nonetheless, to the best of our knowledge, this cohort represents the largest discrete group of second-trimester losses studied to date. The incidence of second-trimester miscarriage in our centre is also comparable to the international-described incidences of 0.5% described in a low risk population.[151] However, the small number of women does limit the power of sub-analyses to detect statistical significance.

As this was a retrospective chart review, the ability to assess certain variables of interest was limited by the data recorded within medical case-notes and access to paper-based records limited the chronological parameters of this study. Furthermore as there were no controls for individual cases, any comparisons made with general population incidences are not as robust. However, the aim of this study was to initially describe the morbidity in this important cohort.

Considering the rates of medical intervention required in this cohort, it is clear that considerable resources are involved in the both the initial and postnatal management of these second-trimester losses. With two-thirds of women requiring medical induction of labor and all women requiring inpatient admission, the care of these women requires senior obstetric input and the expertise of midwives experienced in the setting of pregnancy loss. Where cases are complex, with medical or surgical comorbidity, or complicated by haemorrhage or infection, the involvement of other medical specialists may be required.

The ever-present clinical concern of infection in these cases is evident in the proportion of women requiring antibiotic therapy. Just under a quarter of these women (23.20%, n=42) required intravenous antibiotic administration. This study supports the established association between PPROM and infection as both an etiological and complicating factor, given that cases of PPROM had increased odds of requiring antibiotic therapy and readmission compared to cases of IUFD. However, it should be considered that this association may be confounded by the non-provision of elective termination of pregnancy in cases of uncomplicated PPROM within in our jurisdiction. Anticipation of the potential for such morbidity may aid resource distribution and the development of more appropriate patient care pathways and hospital-specific protocols for this pregnancy outcome.

While this study concerned the physical morbidity associated with the management of second-trimester pregnancy loss, the psychological impact of such morbidity should also be considered. A systematic review of post-traumatic stress (PTS) and post-traumatic stress disorder (PTSD) after reproductive loss performed by Daugirdaite *et al.* showed that length of gestational age is associated with an increased likelihood for diagnosis of PTS or PTSD.[115] Complications associated with the management of such pregnancy outcomes can compound an already traumatic experience; physical trauma being a significant risk factor for the development of PTS or PTSD after loss.[115]

An awareness and anticipation of the morbidity associated with second-trimester pregnancy loss should inform, not only our clinical practice but, also, our counselling and management of patient expectations in pregnancy. There should be a sensitive and well-informed discussion with women regarding rates of morbidity associated with their particular clinical presentation, an anticipation of such complications and an awareness of the implications that an intervention may have in their care.

Author Contributions:

AM, SM and KOD contributed to and were responsible for the conception and design of the study. AM and NS were responsible for data collection. AM and SM were responsible for data analysis. AM was responsible for the initial drafting the article. All authors; AM, SM, NS and KOD, contributed to revising the manuscript critically for important intellectual content and approved the final version for publication.

Chapter 4

4 The experience of miscarriage: an interpretative phenomenological analysis

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4.1 Abstract

Objective: The objective of the study was to explore the experiences of those who have experienced miscarriage, focusing on both men's and women's accounts.

Design: This was a qualitative study utilising a phenomenological framework. Following in-depth semi-structured interviews, analysis was undertaken in order to identify superordinate themes relating to their experience of miscarriage.

Setting: A large tertiary level maternity hospital in Ireland

Participants: A purposive sample of sixteen participants; comprising of ten women and six men, were recruited.

Results: Six superordinate themes in relation to participant's experience of miscarriage were identified: 1) acknowledgement of miscarriage as a valid loss; 2) misperceptions of miscarriage; 3) the hospital environment, management of miscarriage; 4) support and coping; 5) reproductive history; and 6) implications for future pregnancies.

Conclusions: One of the key findings illustrates a need for increased awareness in relation to miscarriage. The study also indicates that the experience of miscarriage has a considerable impact on both men and women. This study highlights that thorough investigation of the underlying causes of miscarriage and continuity of care in subsequent pregnancies are priorities for those who experience miscarriage. Consideration should be given to the manner in which women, who have not experienced recurrent miscarriage but have other potential risk factors for miscarriage, could be followed up in clinical practice.

4.2 Article Summary

4.2.1 *Strengths and limitations of the study*

This study uses interpretative phenomenological analysis in order to interpret the experience of miscarriage.

Much of the research in relation to pregnancy loss is focused on women's experience. Purposive sampling was undertaken to ensure that both women and men's experiences were included in this study.

Participants from this study were drawn from a large tertiary maternity hospital with a dedicated pregnancy loss clinic and it may be possible that their experiences may differ from those who attend a hospital where such a clinic is not available to them.

Miscarriage is the most common adverse outcome in pregnancy. This study highlights the need for the provision of appropriate clinical information as well as supportive information when counselling individuals who experience a miscarriage.

4.3 Introduction

Improvements in the quality of care provided during pregnancy have led to substantial reductions in perinatal and maternal mortality as well as a reduction in other adverse pregnancy outcomes.[152] However, these advances have had little effect on the high rate of miscarriage with between 20-30% of pregnancies ending in miscarriage.[30, 152] To date, much of the research has aimed to identify potential risk factors as the underlying aetiology of miscarriage is not well understood.[30]

Studies indicate the need for familial and social support following miscarriage as it can be an extremely painful and upsetting experience[153, 154] with some women experiencing medical complications.[155, 156] Quantitative studies indicate that the experience of miscarriage can negatively impact on both men and women's psychological wellbeing.[14-17, 116, 154, 157-159] These studies also report that the high levels of stress and anxiety experienced[116, 157] can endure for 6 to 12 months following miscarriage.[15]

By contrast, an interventional study in the United States examined the changes of women's feeling over the course of year following miscarriage. Swanson *et al*. found that women's responses recorded at one year were not significantly different from those recorded at 6 weeks.[160] Considering the high incidence of miscarriage and the reported impact on the emotional wellbeing of people, there are comparatively few studies that have qualitatively examined the experience of miscarriage. Of these,

most studies focused on the women's experience of miscarriage[153, 161-163] whereby the male experience has been reported based the women's perspective.[161, 164] Our study builds on these findings as it aimed to explore the experiences of people who have experienced miscarriage. The purpose of this study was to focus on both men's and women's accounts of miscarriage. Through a qualitative analysis the objective of the study was to gain detailed insight into their expectations of pregnancy as well as their experience of miscarriage diagnosis and management.

4.4 Methods

An interpretative phenomenological analysis (IPA) was undertaken, as this approach has its theoretical foundations in phenomenology.[101-103] Phenomenology examines perceptions and engages with the way individuals reflect on the experiences they deem significant in their lives.[101] Researchers who engage in IPA acknowledge how experience is subjective and is therefore only accessible through interpretation.[103] IPA has an ideographic approach which allows the researcher to rigorously explore how these experiences may impact a person.[103] IPA has increasingly been used in healthcare research as its ideographic approach facilitates researchers to rigorously explore how specific phenomena may impact a patient and consequently will impact on patient care.[103]

The study took place in a large tertiary-level Irish maternity hospital, with the approval of the Clinical Research Ethics Committee of the Cork Teaching Hospitals (Reference: ECM 4 (iii) 10/01/12). The sample was initially recruited from a list of women who had previously participated in a prospective cohort study regarding miscarriage[139] and agreed to be contacted for future research. It is important to note that there are geographical variations for the definition of miscarriage. For the purposes of this study miscarriage was defined as any pregnancy loss which occurred before 24 weeks gestation in a fetus weighing less than 500 grammes. As the aim of the study was to explore the lived experience of miscarriage there was no time limit placed on when the pregnancy loss occurred. Participants were eligible for the study if they were aged 18 years and older and had experienced one or more miscarriages.

Letters were sent to invite women and their partners to participate in the present study by the primary author. If an opt-out form was not returned, the primary author made contact to provide more detailed information about the study. Over the course of the study, six opt-out forms were returned. Participants were purposively sampled to ensure both public and private patients who required expectant, medical or surgical management were included in the sample in order to provide a range of perspectives on the experience of miscarriage. Purposive sampling also aimed to achieve variation on the basis of parity, gestation at loss and it also aimed include both the male and female experience of pregnancy loss (see Table 4.1). As the study progressed, the primary author identified that the sample needed to be further

supplemented to ensure the male perspective was adequately represented. Thus, three participants were recruited utilising snowballing techniques through contact with the Miscarriage Association of Ireland and/or through the bereavement and loss hospital team. Information on the study was forwarded to them and they made contact with the primary author to become involved in the study. None of the participants were known to the researcher.

The primary author recruited until data saturation was met. The final sample consisted of 16 participants (10 female and 6 men); four of whom were couples (Table 4.1). All the participants gave informed consent and were interviewed individually, by the primary author (an experienced female qualitative researcher), using a semi-structured interview schedule (Table 4.2). All the interviews were conducted in a room onsite in the maternity hospital or a location convenient to the participant, with the exception of one interview that was undertaken by telephone under participant request. Each interview was digitally recorded and contemporaneous notes were taken immediately after each interview. The average Interview was 43 minutes, ranging from 28 minutes to 69 minutes in length.

Table 4.1: Overview of the sample

Participant	Parent	Couple	Number of miscarriages	Time in months since most recent loss	Gestation of most recent loss	Living children	Management	Patient status
1	Female	1	2	18	6	0	Expectant	Public
2	Male	1	2	18	6	0	Expectant	Public
3	Female	N/A	4	13	10	1	Medical	Public
4	Female	N/A	3	7	9	1	Medical	Public
5	Female	N/A	4	18	5	1	Medical	Private
6	Female	2	3	19	15	3	Surgical	Private
7	Female	N/A	2	14	11	2	Medical	Private
8	Female	3	7	20	14	1	Expectant	Public
9	Male	3	7	20	14	1	Expectant	Public
10	Female	N/A	2	18	12	3	Surgical	Public
11	Female	N/A	3	8	10	3	Medical	Public
12	Female	4	2	16	9	3	Expectant	Public
13	Male	N/A	3	27	16	3	Medical	Public
14	Male	4	2	16	9	3	Expectant	Public
15	Male	N/A	2	96	7	2	Expectant	Public
16	Male	2	3	19	15	3	Surgical	Private

Table 4.2: Overview of the semi-structured interview schedule.

Area of interest	Example questions/prompts
Pregnancy	Tell me about your experiences of the pregnancy before you miscarried
	What were your expectations?
Diagnosis	Can you please tell me what happened when you miscarried
	Who was with you at the time?
	Can you remember how you felt and what you thought at that time?
Management	How were you cared for, by the hospital or GP, when you were miscarrying?
Support	What supports were offered to you in the hospital following your miscarriage?
	Did you seek support from family and friends?
Miscarriage: Knowledge and experience	Did you have any knowledge of miscarriage before your experience?
	Did you seek information about miscarriage? From your medical team? Family and or Friends? Websites? Support groups?
Future pregnancies	Have you been pregnant or considered another pregnancy since the miscarriage?
	If they had a pregnancy: can you tell me how you felt during that pregnancy?

The interpretative phenomenological analysis involved firstly listening and rereading the interviews a number of times to ensure a general sense of the participants' accounts were acquired. Secondly, emergent themes were initially identified which were then refined as similar themes were clustered together and subordinate and superordinate themes were identified. Patterns and connections across each individual transcript were examined. Finally, a master table of themes was created after each transcript was integrated into the final analysis. All analyses were carried out using Nvivo 10 software (QSR International Pty Ltd., Doncaster, Australia) by the

primary author; a health sociologist. The analyses were then presented to the co-authors for review.

4.5 Results

Analysis of the data indicated six superordinate themes in relation to participant's experience of miscarriage: acknowledgement of miscarriage as a valid loss, misperceptions of miscarriage, the hospital environment, management of miscarriage, support and coping, reproductive history and implications for future pregnancies.

4.5.1 *Acknowledgement of miscarriage as a valid loss*

As outlined in Table 4.3, participants gave accounts of the devastation they experienced when they were told that they had miscarried. Participants stated that the miscarriages were all experienced differently but it was important to them that their miscarriages, irrespective of gestation, were acknowledged by healthcare professionals in the first instance but also more broadly throughout society. The men in this study felt that they could not experience the loss in the same manner as their partner. Men however did reiterate that although they did not experience the miscarriage physically they were affected emotionally and, like the women, did go through a grieving process.

Table 4.3: Acknowledgement of miscarriage as a valid loss

- *But the miscarriage itself, I'd say it was until then…and the whole discussion became a very public thing… it was only at that stage that I started to move on from it and that would have been five years, five years later and it was always something that would of upset me … it is hard to know what you are grieving for in a way because it is fleeting, you know the whole experience of being pregnant and then not being pregnant and thinking if I didn't remember this baby then who would." (P15, Male, 2 miscarriages)*

- *"At this stage I think we had attended a couple of the, of the October, the ahhh annual ahhhh [prompt from interviewer; the annual service of remembrance] yeah. And again they are huge out pouring of grief, and of joy for life, but of grief. The people there and the support, but the fact that there are children and parents and grandparents, it just gives a sense that look it doesn't matter what age you are, doesn't matter how wealthy you are, doesn't matter what colour you are, we have all experienced this in our own way and we are all here today to remember that. And, I think for me, that, that was [pause] I haven't missed one yet and I'll still be going for another while yet. You know, that's a lovely outreach and very important." (P13 Male, 2 miscarriages).*

- "What I think happens, from my own experience, is I don't think it is recognised enough. Like cancer is recognised, god help us we have all had it and all those things. But a loss, it's a different loss when it's a child. They're still a child, they may not be grown but they're still a child " (P1 Female, 2 miscarriage)

The acknowledgment of the loss of miscarriage, not only by people but also through ritual, was of importance. Participants discussed marking or remembering their loss in a variety of ways such as keeping a diary, writing of poems and songs or through the organisation of a funeral or similar ceremony. Some participants spoke of the importance of rituals particularly around the anniversary of the miscarriage in order to continue to acknowledge their loss. A number of participants remarked about the significance of attending the annual service of remembrance, which is organised by the hospital.

4.5.2 *Misperceptions of miscarriage*

All participants spoke about how there is not enough discussion relating to miscarriage in the public domain. It was not until the participants had experienced a miscarriage themselves that they were made aware of a history of miscarriage in their own family or with those in their close network of friends. As the participants recalled the experience of their first miscarriage they recounted on how naive they felt, they said they had no inclination of what it was that they could and ultimately would experience. All participants asserted that increased discussion and awareness of miscarriage should be promoted in a wide range of contexts beginning with health education in school (Table 4.4).

Table 4.4: Misperceptions of miscarriage

- *"I got spotting and I thought surely it's not going to happen again, cause they [people] always say one spontaneous [miscarriage] but you never (pause) but I think with miscarriage people just don't talk about it and they just don't think that it happens to everybody and they don't think it is as common as it is until you talk to other people about it. So I think the perception I would have had was if you had one you're not really likely to have another, that's what I thought." (P3, Female, 4 miscarriages)*

- *"A friend of mine in work is pregnant and it's her first pregnancy and she's not kind of as worried as I am for her. She is oblivious and naïve and while I'm thinking 'oh god' she is saying 'it's fine' (P7, Female, 2 miscarriages)*

- *"Well when I did have the miscarriage and I said it to people, everyone says 'oh you know I had one' and it all comes out from the woodwork and em everyone knows someone who has had a miscarriage. It's so common how could you not but people generally don't talk about it….you don't have the knowledge…people need to know that this can happen (P11, Female, 3 miscarriages)*

The hospital environment and management of miscarriage

When the participants spoke about how they were treated in the hospital they remarked about how divergent an experience it was. The participants stated that any negative experiences in the hospital were related to the administration and/or physical design of the hospital specifically relating to the emergency department and the general clinics. When the women were miscarrying they firstly attended the emergency department and found it difficult to be sitting in the waiting area surrounded by women attending with varying complaints. This was considered one of the hardest aspects of the miscarriage experience as they felt they could not express any emotion, (e.g. anger or upset) relating to their loss, as they did not wish to distress the other pregnant women.

Once admitted for care in the emergency department they felt that the physical space heightened their distress. With only a curtain between them, the participants recalled hearing other fetal monitors recording an audible heartbeat or conversations amongst staff, as they received confirmation that they had miscarried. It was felt that having to be in this environment while miscarrying exacerbated the distress experienced by participants, who as a result believed that the hospital administration should be more sensitive to the situation. The women recalled how the early pregnancy clinic provided them with a better environment as there was more privacy which allowed them to more openly express their worry, anxiety or upset (Table 4.5).

Table 4.5: The hospital environment and management of miscarriage

- *"We came straight up here [the maternity hospital] and we went into the emergency place downstairs and we were seen straight away. But there were other patients and staff behind curtains, we were behind ours waiting on the doctor to come round. And there were nurses in there chatting and they were laughing and chatting and jokes and stuff, which they are entitled to have… but I was there with [husband] and we were worried sick that we were losing our baby and the doctor came in and she went through all the things and said 'No, I can't find a fetal heartbeat, it's gone'. Well, I started roaring crying, I was so upset but all the life was happening all around us, carrying on you know happily in behind the curtains…it was absolutely horrendous. But they organised for me to come back to the early pregnancy clinic, you know I didn't have to speak to anybody we just left the hospital [pause] that was hard" (P8, Female, 7 miscarriages).*

- *"That was hugely traumatic, cause em, I didn't miscarry the same as the last time it just went on and on and on. I was in and out of here [maternity hospital] every second day for blood tests. The first day they went up a bit and then they went down a bit and then it was kind of, like, and it was just two weeks really of turmoil" (P4, Female, 3 miscarriages).*

- *"I woke up an hour later and I just completely haemorrhaged and I passed out a couple of times. Then I got in the bath and em, I was saying god people should warn people or prepare people if they are going to have miscarriages, cause I didn't know what was happening to me. And em what I excreted was unbelievable cause I was 12 weeks. And I started vomiting and I passed out again and then he rang the hospital. I tried talking to the hospital but I couldn't get the words out I was so weak at this point, you know, and they told me to come straight in. So I did and they killed me [slang: were annoyed with me] when I got in cause they said I should've called the ambulance" (P3, Female, 3 miscarriages).*

- *"The first and the last were spontaneous and the last two I had to take medication but it would of happened inevitably but I, I just wanted to speed up [the miscarriage]..." (P5, Female, 4 miscarriages)*

Participants experienced anxiety about attending the hospital to get tests over a number of days to confirm the loss of their baby. This was relatively impractical for some with work commitments, but was also difficult as they didn't want to re-attend the hospital to face the inevitable diagnosis. Many of the women expressed how they had suspected that something was wrong but had no knowledge of what to expect or what is considered normal while miscarrying. Those who miscarried at a later gestation, discussed how they were wholly unprepared for the extent of the bleeding

when they miscarried (Table 4.5). When women had a choice, most chose to have some form of medical intervention. A number of factors influenced the decision to choose to intervene, with women citing other commitments such as having to take care of other children in the family.

4.5.3 *Support and Coping*

Keeping busy helped participants cope with their loss; this was particularly evident in the participants who already had children. Participants were hesitant to receive formal support by way of counseling and most opted for support from family, friends and/or support groups instead. Men felt that their primary role was to support their partners through the loss and, at times reluctantly, while planning subsequent pregnancies. During subsequent pregnancies the participants disclosed that high levels of anxiety were experienced. They spoke of how they navigated through the pregnancy focusing on specific gestational weeks as goals, including exceeding the gestation they had experienced their miscarriage(s) at, as well as those coinciding with clinic appointments at the maternity hospital. Many of the participants detailed how these actions meant they could not fully enjoy the experience of being pregnant.

Throughout the subsequent pregnancy(ies) participants indicated their satisfaction with the service offered to them in the early pregnancy clinic. It was felt that the staff in the clinic were not only knowledgeable but also cared for the women in a sensitive and understanding manner. The early pregnancy clinic provided reassurance to

participants by facilitating appointments whereby the women could be scanned at earlier gestations and more frequently. Of those who were under the care of the specialist bereavement team, both men and women commented on the emotional support provided to them by the specialist midwife. The relationship between the women and midwife, in particular, was considered vital as they felt that these midwives, and the dedicated team, truly cared about their welfare and wellbeing (Table 4.6).

Table 4.6: Support and Coping

- *"I was upset for a good while after but I had the other three [children] to keep me going [slang: busy] with school and everything…I had the D&C the same week as my daughter's communion, so I had to just go ahead and get on with things you know, I had to be happy for her." (P10, Female, 2 miscarriages).*

- *"I'd say we were slightly different in that if we had called it a day at the end of number seven, we both would have been extremely disappointed but you know I think, em, it's more about protection I suppose, I didn't want to have to go through it again. The decision was extremely difficult, now I mean [wife] was very much in favour of going forward and trying again, em, I would have been a bit more reticent I suppose, em a bit more, you know, a bit more nervous about it. Obviously she had major concerns but you I think, I think it was a case of a tough decision but we just went for it." (P9, Male, 7 miscarriages).*

- *"I love babies and if someone was to say on Friday that you are pregnant and you are going to have to have the baby tomorrow, I would say yeah that's great but I just can't do the, the nine months of worrying" (P7, female 2 miscarriages).*

- *"I went up to the [early pregnancy clinic] and they said 'the next time you get pregnant call us here and come in and we will do a scan, we will do an early scan, we will give you that reassurance'. That made a huge difference, it made a huge difference because it felt like ok someone is not saying 'yeah, yeah, yeah move it along, move it along, next person' someone is actually saying 'we care about you, we know this is hard and the next time you get pregnant we know it's going to be distressful for the first few weeks so come in and we will give you scans'. And they were so good about it and when I did get pregnant it was one of the first calls I did make". (P12, Female, 2 miscarriages).*

4.5.4 *Reproductive history and implications for future pregnancies*

Whether there were children in the family before the miscarriage made a difference to how the experience impacted on each individual. Those who already had children were better able to reassure themselves that they could successfully get pregnant and give birth. Participants who did not have children before experiencing a miscarriage recalled their concerns about their health, behaviour and/or fertility (Table 4.7).

Table 4.7: Reproductive history and implications for future pregnancies

• *"We already had a loss, I know they were two, two different losses but I was thinking not again, what is going on, is there something wrong with me, am I ever going to have children" (P1, Female, 2 miscarriages).*
• *"One of the things that I asked for was an appointment with [the specialist in pregnancy loss]to have tests done to see why I was having the miscarriages but I was told I would have to have 3 miscarriages before they would see me and I was kind of thinking, do they not take age into account? You know, you have to have three and I think two is an adequate level at my age. If I was in my twenties maybe you'd manage the three but not at my age." (P4, Female, 3 miscarriages).*

Medical investigations, such as karyotyping, are not offered to women unless they have experienced recurrent miscarriage [three consecutive miscarriages].[165] Participants expressed frustration that these tests were not offered to them following a second miscarriage. This dissatisfaction was heightened in women who felt that other risk factors, such as advancing maternal age, should be considered (Table 4.7).

4.6 Discussion

The findings of this qualitative study indicate that the experience of miscarriage has a considerable impact on both men and women. Findings from this study support what has been reported by others, that there is a need for increased awareness in relation to the frequent occurrence of miscarriage. Miscarriage is a common occurrence, yet as revealed by these participants it is not until a miscarriage was experienced that the participants were made aware of these high rates. A study from the United States also indicated that people believe that miscarriage is a rare complication of pregnancy.[166] The participants from this study believed that improvement of information provision would be beneficial allowing for individuals to better prepare for the possibility that their pregnancy could end in miscarriage and if it does occur that support is available.

Secondly, given that a cause cannot be determined in as many as 50% of miscarriages, it was felt that having this information in advance may alleviate some of the guilt experienced. Participants emphasised that such information provision should also focus on the physical aspects of miscarrying. These findings mirror those of Moohan *et al.*, whereby women felt unprepared when miscarrying spontaneously and were questioning of whether what they had experienced was normal.[167] Wong *et al*. support this finding by detailing how miscarriage may be a physically traumatic event as women may experience considerable and sudden pain, loss of blood and may need to be hospitalised.[168] Similar to the longitudinal study by Côté-Arsenault[169] the participants in this study indicated how pregnancy following

miscarriage was stressful. There is a need for improved communication between healthcare professionals and patients to better counsel patients through the miscarriage and provide reassurance in subsequent pregnancies.

One coping strategy adopted by both men and women was focusing on commitments, particularly taking care of other children in the family. In a review of the literature on grief following miscarriage, Brier states that having living children has also been used as an indicator for the importance attached to the pregnancy. This belief is based on the assumption that the absence of living children is associated with a relatively greater desire for children.[113] Wong *et al.* also highlight how given this belief it is also assumed that women with children will be less emotionally distressed and are less likely to receive emotional support from nursing staff.[168] In contrast, the findings from this study illustrated that these participants were affected emotionally and did go through a grieving process irrespective of gestation of the pregnancy loss or whether they had living children or not. The findings also indicated the importance that healthcare professionals acknowledge miscarriage and how appreciate participants were of the support given to them.

It has been documented that men and women grieve differently following miscarriage in the literature[170, 171] and these findings are also reflected in the accounts of the participants in this study. Similar to Johnson & Puddifoot, the men in this study indicated that they were less likely to openly discuss the miscarriage unless prompted by another person with a similar experience.[171] This was also the case

with discussing the impact of the miscarriage on them with their partners with the men identifying their primary role as that of a support to their partner. However, as outlined by Brier, this could suggest differences in the general expression of emotion and grief rather than affective reactions to miscarriage.[113] Although the men in this study did not actively seek out support they did reiterate that certain experiences and rituals were helpful for their grieving process as they allowed them to mark and remember their loss.

Participants in this study were reasonably satisfied with the care provided to them by the hospital. However, a number of shortcomings with the system were identified. When miscarrying the first contact with the maternity hospital was with the emergency room. It was felt that waiting for extended periods of time in an area with other pregnant women was particularly difficult and a situation which hospital management should be more sensitive to. Wong *et al.* outlined that in previous studies women believed that medical staff do not consider miscarriage as either important or an emergency and considered medical staff insensitive and unsympathetic about accommodation.[168] Our findings build on these results whereby participants identified this insensitivity to be as a result of the hospital setting rather than medical staff. Participants were appreciative of staff, especially those they considered not only to be knowledgeable but those who displayed understanding and compassion. The dedicated early pregnancy clinic was an environment they believed could be further developed to enhance the care currently provided to women when they are miscarrying.

Consistent with a number of other studies [152, 154, 168] all the participants expressed a desire to determine the cause of the miscarriage. Participants expressed dissatisfaction that they were ineligible to have tests to fully investigate the cause of their miscarriage as they had not experienced the requisite three consecutive miscarriages. In our study, this perceived inadequacy in service provision was amplified in women of advancing maternal age. As Brier outlines, maternal age can potentially influence an individual's goals with regard to childbearing.[113] Advancing maternal age in combination with a number of losses experienced by a woman may impact the duration and intensity of grief experienced. The women in this study expressed dissatisfaction with their ineligibility for investigations maintaining that staff should appreciate that although they had not experienced recurrent miscarriage there were other risk factors, such as their age, to be considered.

As part of the analysis it is important to consider any factors which may influence the results. The participants in the study all made reference to the dedicated early pregnancy loss clinic. This clinic is staffed by a dedicated pregnancy loss team. Such a dedicated clinic is not available in all hospitals. Thus, the presence of such a team in the hospital may have raised awareness about miscarriage amongst other medical staff and influenced how they cared for the participants sampled here. It is important to note, that although a qualitative methodology was deemed appropriate for this study, the findings of such studies are context specific. The experiences of the

women and men in this study may or may not reflect the experiences of those who attend other units with differing resources and practices. Notwithstanding these limitations, given the level of agreement with other studies we feel these results add additional insight into the experiences of miscarriage.

4.7 Conclusions

This study highlights that thorough investigation of the underlying causes of miscarriage and continuity of care in subsequent pregnancies are priorities for those who experience miscarriage. The provision of appropriate clinical information as well as supportive information when counselling individuals who are experiencing a miscarriage is important. Consideration should be given to the manner in which women, who have not experienced recurrent miscarriage but have other potential risk factors for miscarriage, could be followed up in clinical practice.

Author Contributions:

SM and KOD contributed to and were responsible for the conception and design of the study. SM and NS were responsible for data collection. SM was responsible for transcription, data analysis and the initial drafting the article. SM, PC, NS and KOD contributed to revising the manuscript critically for important intellectual content; final approval of the version to be published; and the decision to submit the article for publication.

Chapter 5

5 Women's experience of ectopic pregnancy: a qualitative study

Under review in Health Expectations September 2016

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5.1 Abstract

Background: Ectopic pregnancy is a potentially life threating condition. The grief experienced may well be overlooked compared to other pregnancy losses.

Objective: The objective of this study was to gain insight into women's experience of Ectopic pregnancy, focusing on the area of emotional recovery.

Research design: Seven women who had experienced an Ectopic pregnancy partook in in-depth qualitative interviews. In this study an interpretative phenomenological analysis was utilised as it allows us to gain insight into the women's experiences.

Findings: Interviews indicated how devastating the experience of Ectopic pregnancy can be. Responses included shock, disbelief and confusion as a consequence to diagnosis. The importance of the scan to confirm diagnosis was evidence of the coping strategy adopted and a form of self- protection. Findings outlined the importance of clear information on treatments, the need for bereavement counselling and an appropriate method to complete the outpatient care as these issues hindered closure and recovery for these women. With no forum available to discuss future pregnancies, apprehension about their fertility escalated and women were reluctant to conceive again.

Conclusion: These findings show that women had difficulty coming to terms with their diagnosis and its implication for treatment. The lack of follow-up care had a negative impact on their ability to recover from the Ectopic pregnancy and illustrated women's reservations to embark on future pregnancies. These results have

implications for the care of women who experience Ectopic pregnancy particularly in relation to how they are managed from diagnosis to completion of treatment.

5.2 Summary of relevance

Problem

Ectopic pregnancy remains the leading cause of maternal death in early pregnancy worldwide and given the nature of Ectopic pregnancy the resulting treatment can be complex and can cause uncertainty in relation to the woman's fertility.

What is already known

Studies related to Ectopic pregnancy have incorporated it with other early pregnancy losses and limited research has been dedicated to this event despite the fact that women report this experience as being a major life event.

What this paper adds

This paper identifies the aspects of care lacking throughout the experience and provides the caregiver with valuable feedback to improve the effectiveness of their care.

5.4 Introduction

Ectopic pregnancy occurs where a fertilized egg implants outside the uterus. The majority of Ectopic pregnancies (95%) occur within the fallopian tube, while the remainder can occur in the ovary, abdomen or cervix.[172-174] Early intervention plays a key role in treatment as this can be a life threatening event and is almost always incompatible with the delivery of a viable infant.[39] Ectopic pregnancy rates have increased over time[3] and it now accounts for 14.8 per 1000 pregnancies in Ireland. This increase may be due to a number of risk factors which present more frequently today including pelvic inflammatory disease or tubal pathology as well as the presence of intrauterine systems.[40, 174, 175] Cigarette smoking is associated with Ectopic pregnancy, and while the exact reason is unknown, it is thought that the inhalation of cigarette smoke may affect normal ciliary activity which in turn may affect fallopian tube function.[176, 177] Another risk factor is a previous Ectopic pregnancy, where the associated scarring may interfere with embryo-tubal transport. Studies also indicate that couples attempting to achieve pregnancy through assisted reproductive technologies are more at risk, and are also generally older, which also increases the chance of ectopic pregnancy.[39, 177]

Ectopic pregnancy remains the leading cause of maternal death in early pregnancy worldwide.[178] For the woman the experience of Ectopic pregnancy begins with the process of determining the location of the Ectopic pregnancy and is followed by treatment, which may include expectant, surgical or medical treatment.[39, 40] Given the specific nature of Ectopic pregnancy the resulting treatment can be

complex and can cause uncertainty in relation to the woman's fertility.[42] Studies into early pregnancy loss have shown that women viewed their loss as a major life event[179] and although one in 90 women will experience an Ectopic pregnancy[4] it remains relatively under-researched in terms of the emotional impact. Studies which have given exposure to Ectopic pregnancy have incorporated it with other early pregnancy losses[41] and review of the published literature shows little or no research specifically dedicated to Ectopic pregnancy.[180]

The lack of focus on Ectopic pregnancy may be a consequence of its modern management, where Ectopic pregnancy is not viewed in the same light as other pregnancy losses such as miscarriage.[40, 181] The increasing rates of medical management on an outpatient basis may translate into the woman being cared for in an environment that fails to acknowledge her loss and in doing so may discount the emotional aftermath of the experience. This study provided an invaluable opportunity in research to gain insight into women's individual experience of Ectopic pregnancy. By giving these women a voice it is hoped this will help to explore and understand the impact of this life event.

5.5 Method

5.5.1 *Ethical approval*

Ethical approval was sought and received from the Clinical Research Ethics Committee of the Cork Teaching Hospitals (Ref: ECM 4 (c) 04/02/14).

5.5.2 *Design*

This qualitative study involved conducting in-depth semi-structured interviews with women who had experienced Ectopic pregnancy. An Interpretative Phenomenological Analysis (IPA) was utilised as it has an ideographical approach which allows us to gain insight into the women's experience of Ectopic pregnancy. IPA is concerned with the human lived experience and the consequences of this exposure, successful IPA is empathetic and questioning.[101] The effectiveness of an IPA study is judged by the light it sheds on the topic explored. IPA involves the detailed, in-depth exploration of individual interviews in order to gain a thorough understanding of the experience being explored. Given the complexity of these analysis, smaller sample sizes are common.[101]

5.5.3 Recruitment

The primary inclusion criteria dictated that any potential participant had experience of Ectopic pregnancy. The participants in this study represent a reasonably homogeneous, purposive sample whereby all the women were either white Irish or European and all had attended the same maternity unit for the management of their Ectopic pregnancy. The recruitment process also ensured patients requiring expectant, medical or surgical management of their Ectopic pregnancy were within the sample. The sampling strategy also aimed to achieve variation on the basis of parity (see Table 5.1). Following extensive review of registers within the maternity hospital a sample of 14 women who were treated for an Ectopic pregnancy were identified during a period between September and December 2013. Invitation letters

were sent out, during April 2014, to the women inviting them to take part in the study. A follow up telephone call was made one week after letters were sent to answer any questions about the study and establish a rapport with the women. None of the women contacted were known to the researcher. Of the 14 women who received letters of invitation, 7 agreed to partake. Table 5.1 outlines the sample demographics.

Table 5.1: Overview of the sample

Participant	**Pseudonym**	**Age**	**Parity**	**Treatment**
Participant 1	Susan	33 yrs	Para 1	Medical
Participant 2	Deirdre	34 yrs	Para 1	Expectant/Medical
Participant 3	Mary	30 yrs	Para 0	Surgical
Participant 4	Noelle	27 yrs	Para 0	Surgical
Participant 5	Clare	27 yrs	Para 1+3	Surgical/Medical
Participant 6	Beth	37 yrs	Para 3+2	Surgical
Participant 7	Ruth	38 yrs	Para 2	Expectant

A semi-structured topic guide which was developed based on existing literature, an information sheet and consent form were provided to the women. All the women provided written informed consent. The majority of the women were interviewed in

their homes by the lead author. One participant was unable to attend for interview and requested for the interview to be conducted by telephone. The interview process took approximately 60 minutes and all were digitally recorded and transcribed verbatim.

5.5.4 *Analysis*

The analytic process for IPA involved the following: close listening and rereading of the interviews and field notes, taken after each interview, to gain familiarisation of the data and to ensure a general sense of the participant's account was captured. Secondly, preliminary themes were initially identified and then refined as patterns and connections emerged from the transcripts. Finally, a master table of themes was created and each theme was summarised in a table including evidence from each transcript by way of direct quotations. All analysis was carried out by the lead author; a female research midwife. The analyses were then presented to the co-authors; a health sociologist and a Consultant Obstetrician, for review

5.6 Results

IPA analysis identified five superordinate themes of 1) expectations, 2) self-protection, 3) management with subordinate themes of treatment and follow up care, 4) acknowledgement of loss 5) bereavement. In order to maintain anonymity the women were assigned pseudo names. Direct quotations from the women are used to illustrate these themes.

5.6.1 *Expectations*

The depth of feelings expressed by these women at interview was profound. The hopes for a new pregnancy brought excitement and plans for the future. The diagnosis of an Ectopic pregnancy resulted in intense sadness and feelings of not knowing what to grieve for. Their expectation was to nurture a new pregnancy. These women reported never anticipating any potential problem with this new pregnancy until their happiness was quickly replaced by confusion and grief. One participant had great difficulty accepting the diagnosis, in her mind she had never thought about the possibility of an Ectopic pregnancy, if anything went wrong it would just be a miscarriage. This woman believed she would have coped better with miscarriage as an outcome as she understood it better and would have felt supported.

"Surprised and excited…I never thought there would be a problem, so I was annoyed it was a negative experience." Deirdre

"Didn't realise I was pregnant but I was so delighted with the positive test, Two days later I started bleeding… I was still hopeful it would be ok. In my head it was a normal miscarriage or there would be nothing." Noelle

The resilience and hope within human nature is portrayed by two of the women who both suffered two Ectopic pregnancies. They reported feeling anxious to try for another pregnancy but were hopeful for a positive outcome. These feelings outweighed the worry and possible risk of another Ectopic pregnancy.

"Start of pregnancy I was delighted because of the positive test but nervous because of previous loss…I knew [the] risk of [having] another Ectopic pregnancy but never

thought it would happen again…I knew the scan was taking too long and the probe was moving around a lot…it's another Ectopic again isn't it? This diagnosis hit me like a tonne of bricks." Clare

"Ah…second time was 100 times harder than the first, the baby was still alive but in a place it couldn't survive…. Very hard taking the tablets…still very hard today thinking about it….at the time I thought it would survive…When the Ectopic was diagnosed I was devastated but had a feeling before doctor confirmed." Beth

5.6.2 *Self-protection*

As the interviews progressed it became clear that the women struggled to deal with having their hopes of a successful pregnancy dashed. These women were shocked and had to come to terms with the diagnosis and treatment over the weeks to come. The importance of both seeing the scan itself with a clear detailed explanation of the diagnosis was impressed time and again throughout the interviews by the women. These women also reported that the scan helped them to emotionally detach from the pregnancy and for some this was an important step towards their recovery.

"I was very very upset…first of all there was a new life and that's great and we would cope with it… (laughs) how would we cope with it? We had a giggle and everything else and then to be told no that's actually not the case… what I clung to all the time was even though they found a sac they never found a heartbeat… for me that was important." Ruth

The unspoken words between the women attending for frequent visits became a source of comfort and camaraderie.

"I think because I ended up coming in and out so often I was like, I knew I had to do it…I suppose a part of it… I knew I wasn't on my own, there were a lot of other women. I knew they were in the same situation I was in even though we never spoke to each other." Ruth

5.6.3 *Management*

Each of the treatment options of Ectopic pregnancy can bring distress and upset for women. Upon diagnosis the woman can very quickly be required to sign consent forms for emergency surgery. The women reported the outcome of the diagnosis allowed little time to process fertility worries and recover from the loss. The women struggled with repeat visits to the hospital for blood tests and medical review, as it became a weary procedure often involving many caregivers and was reported as clinical and uncaring. The management of these women will now be examined in the subordinate themes of treatment and the follow-up care received.

5.6.3.1 Treatment

The basis of any care with patients begins with effective communication. Women conveyed their dissatisfaction with different aspects of care, beginning at the early stage of diagnosis continuing throughout their care until they were ultimately discharged from the maternity hospital. Women expressed particular frustration

with not being listened to and reported errors with blood results and lost blood samples which added unnecessarily to their suffering.

"You know as much as we do... nobody could actually sit me down, I didn't know myself what was going on... they lost my scan report and my bloods… I didn't know what was happening, hospital could have dealt with it a lot better…. It still wrecks my head [slang term: frustrates me]." Susan

"Doctors didn't give a shit...I felt I was getting in the way." Deirdre

"Most staff were supportive but only one stands out as giving me time to talk." Clare

Women emphasised the importance of clear and detailed information on the diagnosis of Ectopic pregnancy and the treatment necessary in order for them to process what was involved and what to expect. They also expressed the importance of understanding the treatment options and the potential impact that each option would have on their future fertility. The information leaflets provided a certain level of explanation but these women reported feelings of shock and disbelief at their diagnosis and so found the literature on its own to be inadequate. They stated they had difficulties processing the information and that they deserved to be counselled rather than just receive the leaflets.

"I would like to have known where it was… (pregnancy of unknown location) I felt totally in the dark." Susan.

"Hospital could have given me quicker answers… was I going to lose my tube? Would I have another baby? I really could have done with someone to talk me through it." Deirdre.

Women attending for regular blood tests and review by medical staff recounted how this was a constant reminder of their grief. They struggled with witnessing other couples departing the unit with the joy of an ongoing pregnancy as this proved difficult in terms of acceptance and recovery.

"Upsetting experience sharing a room and listening to other people's experience" Deirdre

"Oh seeing other people coming out with scan pictures… delighted and happy and you're sitting there waiting for the doctor to confirm what you're dreading… I felt sad and guilty for feeling jealous…How could this be happening again?" Clare

"I wouldn't be able to go through anything like that again." Beth

Having to take methotrexate was a devastating experience for these women. The importance of allowing appropriate time to discuss concerns and allow for questions was highlighted as a priority. It was very emotional for two women as scans had shown a fetal heartbeat and so agreeing to the medication was difficult to come to terms with, as they felt they were terminating a wanted pregnancy.

"I couldn't get my head around terminating the pregnancy" "I said hold off and not do anything and see if the baby would survive." Beth

"So when I woke up after the laparoscopy, they told me they couldn't remove it cos where it was, I was shown the scan… this was so difficult cos the treatment was methotrexate…this baby was trying to grow… I was killing my own child." Clare

5.6.4 *Follow-up care*

With each of the interviews the women expressed concern with the lack of follow up care provided, this caused a lack of resolution and prolonged the grief process. Follow up care provides a good forum for discussion whereby concerns for future fertility can be addressed and potentially provide the women with the confidence to embark on future pregnancies. One woman stated that a telephone call from one of her caregivers could have provided her with support in her recovery; instead the Internet became her source of information and support.

" Not once was this treated as a loss or any follow up offered to me… Eighteen months on… I don't know what to do… I'm afraid to try for another pregnancy and now I feel guilty that I've started smoking again." Clare

"Once my levels went down to 0… goodbye, good luck… I kinda felt… ok what do I do now? I kinda felt there's a cut off point and you're done. Part of me was glad I didn't have to be a pin cushion anymore but I really could have done with someone to talk to." Ruth

5.6.5 *Acknowledgement of loss*

Women reported despair with the clinical approach encountered from diagnosis to treatment of their Ectopic pregnancy. The women treated with surgery felt that their concern about the surgery and risks were minimalized and that this took from their grieving process. Throughout the interviews with these women it was very apparent that the impact of their loss and the bereavement suffered was underestimated by the care givers. Positive affirmations by staff about their loss were reported as limited. Women reported that they had difficulty accepting the terms used to describe their loss, for example, “out of place” or “unknown location”; as a consequence these terms took away the chance the woman had to have a connection with her pregnancy. One woman related having experienced feelings of anger and frustration as she was not sure what to grieve for. This stemmed from the fact that she had told her partner the diagnosis over the phone as she had attended the hospital alone. His question to her was “Is this a natural baby?” The question itself shows how complex the diagnosis can be to couples and also how much emphasis should be put on the explanation of this diagnosis.

“To this day I still don’t know where it was [referring to pregnancy of unknown location].” Susan

“Always wonder whether the baby was a boy or a girl." Deirdre

"It was a baby to me from the start, the baby would have been 2 today, I’m still not even over it.” Beth

"My little star that never happened…still a pregnancy… there was potential life there…just not in the right place." Ruth

Mementos and memory keeping were also stated as an important part of the recovery process for these women. Their grieving was primarily within their family unit and with close friends. Discovery of an undisclosed loss by one woman's mother was revealed highlighting how hidden early pregnancy loss and Ectopic pregnancy was in previous decades. This indicates progress in society's ability to cope with such a sensitive issue and helps open up dialogue to aid recovery.[182] This daughter reported that the discovery helped her resolve some of her grief and strengthened her bond with her mother.

"Ok, we lit a candle at Christmas in the church for the baby and stuff...ya know that was our way of kinda acknowledging it I suppose." Deirdre

"My own mum, she got me an angel charm for my bracelet... I suppose it's only at that point that my mum told me that she had something similar happen between my brother and me." Deirdre

5.6.6 *Bereavement*

Grief and bereavement and how they manifest is individual and can leave the person feeling isolated. How healthcare professionals interact with anyone grieving, however trivial a gesture it may seem, can hold a lasting memory and contribute greatly to recovery. These women reported a lack of debriefing and bereavement

care during and after their treatment. It became apparent at interview that these women perceived that their sudden loss was compounded by the lack of sensitive support from their caregivers. This translated into prolonged grieving and the fear to try for another pregnancy in some cases.

"I got my meals and had my blood pressure taken and that was it…I remember one staff member with no empathy at all telling me to stop crying…I felt like a wreck when I went home…" Clare

"You don't even matter… you're just taking up people's time." Susan

"What did I do in my life to make this happen?" Ruth

"It's not something I really talk about… Like its fine but even my family know don't bring it up unless I bring it up…(crying) because they just don't know and they don't want to upset me either." Noelle

5.7 Discussion

The women in this study revealed how devastating the diagnosis and treatment of Ectopic pregnancy can be, as responses included shock, disbelief and confusion following diagnosis. These women also reported a lack of regard for their loss which in turn compounded their ability to cope with the event. Expectations for their new pregnancy were shattered with the diagnosis of an Ectopic pregnancy and as care givers we appear to underestimate the impact of the diagnosis on the woman, which can have a lasting effect.

It is widely documented that early pregnancy loss leads to emotional suffering for the woman.[183] Previous studies of Ectopic pregnancy and miscarriage have shown that women struggle with allowing themselves to grieve or even deny the depth of their pain which can have a long lasting effect on their lives.[39] Seftel refers to pregnancy loss as an invisible loss that in turn becomes invisible grief, “while the loss seems small to some and even invisible, in fact these unborn already have life stories in the hearts of their parents”.[182] This is mirrored in our findings where women reported the sense of failure attached to their inability to achieve an intrauterine pregnancy. The different methods of treatment were also responsible for having an influence on the level of emotional suffering. The difficulty of “feeling in the way” was reported by women returning for numerous outpatient visits where little or no acknowledgement of their loss was reported. Surgical treatment brought the extra burden of recovery from the procedure and worry for family during their hospital stay. Incorporated into all this was also the worry about their future fertility and what outcome treatment could have on their ability to conceive successfully again.

Women in this study highlighted the importance of ultrasound to reassure themselves that the pregnancy was not viable. This could be interpreted as a form of self-protection from the loss of a new life. The bonding process is known to begin at the early stages of pregnancy.[184] Some of the women reported that they protected themselves by not bonding with the pregnancy and distanced themselves from thinking of this Ectopic pregnancy as a baby.[40] Other forms of self-protection became evident as women revealed that sharing their diagnosis with friends,

colleagues and sometimes even family members was difficult and they felt it was easier to be selective who they told. These findings relate well to the study carried out by Van who examined strategies adopted by women who suffered involuntary pregnancy loss. Van found that for some women being introspective was beneficial. Yet, they also found that although women found positive conversations helped to process their grief, some found it difficult to open up about these feelings and continued to live with the grief in isolation.[185] Our study also illustrates the individuality of each of these women and the different types of coping skills adopted to deal with the grief encountered with Ectopic pregnancy.

It is well documented that the care provided by healthcare professionals is crucial to the pregnant woman's experience.[186, 187] Women in our study reported not being listened to, while insensitive comments about the loss they were experiencing were made by some healthcare professionals. Deepa *et al.* indicate that the longer the time interval between diagnosis and completion of treatment the less satisfied the women are with their care.[181] At interview, with some women in our study, it became apparent that requiring surgery following failed medical treatment of the Ectopic pregnancy added to their dissatisfaction with their care. Communication at all levels of a woman's care is central to her level of satisfaction with her care and her ability to recover.[181, 187] Guidelines into the practice of the diagnosis and management of the patient experiencing an Ectopic pregnancy give key recommendations into the care of the patient. However these guidelines are focused on the woman's medical management, and the emotional impact of Ectopic pregnancy is only briefly mentioned in the last paragraph.[38] Leaflets and websites

are informative but ultimately the best practice would not only be careful explanation with supporting literature but also the provision of a forum for the patient to ask questions.[181] The women in our study expressed the importance of clear and detailed information on the method of treatment, as this enabled closure and emotional recovery. Appropriate time should be given to validate the woman's loss and offer time for bereavement counselling.

Follow-up care and methods of follow up were also shown to be relevant to the women's recovery. During this time results can be discussed and time portioned to answer questions and plan for a future pregnancy. This could take the form of an appointment or a follow up telephone call by the caregiver. These women wished for an opportunity to discuss their experience in order to help them develop an understanding of this loss and acknowledge their grief. This was reported by Wheeler to help greatly in the woman's recovery and also provides an opportunity to offer other support through bereavement support groups.[42] Apprehension to embark on a new pregnancy became a very real concern for two of the women in our study as they both had suffered previous Ectopic pregnancies. The impact of this loss on future fertility becomes a real concern for the woman and the caregiver; this needs careful discussion and planning for subsequent pregnancy. Early pregnancy assessment services are highlighted as crucial once a positive pregnancy is diagnosed when there is a history of prior Ectopic pregnancy.[38] This gives the woman confidence in the care she receives and allows early diagnosis of all possible outcomes.

As an outcome of this study, improvement of various areas of these women's care needs to be addressed. The main areas found lacking in their care were communication, acknowledgement of loss, bereavement support and follow-up care. Advances in the treatment of Ectopic pregnancy has translated into an increase in medical management rates on an outpatient basis. This type of environment may in turn limit the acknowledgement that is given to the experience as a pregnancy loss.[181] Staff that interact with these women should display empathy and understanding, and adequate training should be available to staff to facilitate coping with all aspects of bereavement. A checklist for the treatment options could be developed which would ease the process for these women and reduce the possibility of errors and misunderstanding. A follow-up clinic should also be introduced to allow time for questioning and plan for a future pathway of care as it is important to educate on the risk of a repeat occurrence of Ectopic pregnancy.

5.7.1 *Strengths and limitations*

Due to the qualitative nature of the study these data may not be representative of women in the general population. The lack of inclusion of the partner's understanding of this event also needs to be considered. This gap could be developed into a future study to gain insight into the experience shared by not only women but their partners and extended families. The strength of this study stems from the fact that to our knowledge it is the first Irish qualitative study examining the experience of women following an Ectopic pregnancy. Given that the objective of this study was exploratory, qualitative methods were considered most appropriate. By examining

these women's experience in detail it gives a voice to their needs and provides the caregiver with valuable feedback to help improve the effectiveness of their care.

5.8 Conclusions

This qualitative study reveals how individual grief is and also how the experience is greatly coloured by the encounter the woman has with her carers in relation to Ectopic pregnancy. Effective communication and positive interactions could empower these women to recover from their loss and prevent prolonged distress. Appropriate follow up care is crucial to allay the fears surrounding future fertility and provide the reassurance needed to potentially embark on a future pregnancy.

Author Contributions:

NS, SM and KOD contributed to and were responsible for the conception and design of the study. NS and SM were responsible for data collection. NS was responsible for transcription, and NS and SM were responsible for analysis and interpretation of the data. NS was responsible for the initial drafting the article. NS, SM and KOD contributed to revising the manuscript critically for important intellectual content; final approval of the version to be published; and the decision to submit the article for publication.

Chapter 6

6 Parental decision-making around perinatal autopsy varies with type of stillbirth; A qualitative investigation.

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6.1 Abstract

Objectives: Decades of decline in uptake rates of perinatal autopsies has limited investigation into the causes and risk factors for stillbirth. This study aimed to qualitatively explore perinatal autopsy decision-making processes in parents who experienced antepartum and intrapartum stillbirths.

Design: A qualitative semi-structured interview format was utilised. The line of questioning centered on how parents came to decide on consenting or declining to have a perinatal autopsy undertaken. Interpretative phenomenological analysis was employed as the analytic strategy.

Participants and setting: Purposive sampling was used to recruit 10 parents who either consented or declined autopsy from a large tertiary maternity hospital in Cork Ireland, where there were 30 stillbirths in 2011.

Results: Findings revealed four superordinate themes influencing parents' decision-making which varied with type of stillbirth experienced. Those parents who experienced antepartum stillbirths were more likely to consent; knowing that the child was stillborn prior to delivery rather than on the day of delivery was associated with consent. In fact, these parents had more time for meaning-making; those consenting wanted to rule out self-blame and were fearful about future pregnancies. Parents who declined autopsy wanted to protect their infant from further harm.

Interestingly, parents' knowledge and understanding of the autopsy itself was acquired primarily from public discourse.

Conclusions: Parents' decision-making regarding autopsy is profoundly affected by their emotional response to stillbirth, clinicians and other health professionals may play a key role, especially if they can address parental concerns regarding the invasiveness of the autopsy procedure.

6.2 Introduction

Autopsy is an important tool for understanding pathophysiological processes and studying the natural history and epidemiology of diseases.[188] With almost half of stillbirths attributed to an unknown cause, perinatal autopsy is a critical process to better understand underlying reasons for perinatal mortality and direct future antenatal interventions.[28, 189] Studies have shown that perinatal autopsy can impact the reported cause of death in up to 76% of cases.[66, 68] This new information, or in some cases confirmation of diagnosis, can be reassuring and informative to both parents and clinicians. Such information can also guide future maternal care.[69] However, despite its benefits, perinatal autopsy rates have been declining worldwide, including in the UK and Ireland.[70]

If improvements in care and pregnancy outcomes are to be achieved, then it is imperative to work towards decreasing the number of unexplained stillbirths. A recent Cochrane systematic review has highlighted that, to date, there are no effective interventions to support parents' or clinicians' decision-making in this area, which is in part due to lack of research around perinatal autopsy.[118] To fill in these critical gaps a qualitative approach to explore the experiences of parents who were asked to consent to a perinatal autopsy following stillbirth is well suited. Indeed, Horey *et al.* undertook secondary analysis of data of 17 parents of stillborn babies from focus groups undertaken to consult on the revision of perinatal mortality guidelines. They found that decisions are emotionally laden and deliberations around autopsy are both complex and difficult.[118] Factors associated with having autopsy

were parents' readiness to make a decision, parental responsibility, consequences of autopsy and skills of clinician; while parents who did not have the autopsy for their infant experienced regret afterwards. However, despite this, little is known whether this decision-making process varies with type of stillbirth, i.e. intrapartum and antepartum. Thus, given the paucity of research in this area this study builds on the Australian study by undertaking in-depth one to one interviews. The purpose of this study was to specifically focus on parents' personal accounts of deciding on whether to undertake a perinatal autopsy. Through an in-depth analysis of the parents' experiences the aim of the study was to gain more detailed insight into parents' perception of autopsy and their decision-making processes.

6.3 Methods

For the purpose of this study, an interpretative phenomenological analysis (IPA) was undertaken, as this method investigates how individuals make sense of their life experiences.[101, 102, 109, 110] IPA has its theoretical foundations in phenomenology which highlights the importance of the individual and their perceptions to identify the essential qualities of an experience which may be shared or experienced by others.[101] Smith *et al.* outline when people experience an event they reflect upon it and these actions have meaningful consequences and therefore posit that these experiences can be understood by examining and interpreting the meanings which have been impressed upon them.[101, 102, 190] IPA aims to engage with individuals reflections as they experience something they deem very significant

in their lives, in the case of this study, the decision whether to undertake a perinatal autopsy.

6.3.1 *Recruitment*

A purposive sample was recruited from a patient list of those who had had a stillbirth at Cork University Maternity Hospital (CUMH), Ireland in 2011. CUMH is a large tertiary hospital with approximately 9,000 births annually. In 2011, there were thirty stillbirths. The recruitment strategy was to have a sample consisting of parents, both mothers and fathers, who had either consented to or declined a perinatal autopsy. Parents were initially informed by a specialist bereavement and loss midwife of the research being undertaken during a follow-up appointment. If parents indicated that they were interested in participating the lead researcher (SM) provided more detailed information and arranged interviews.

6.3.2 *Sample*

A sample of ten participants was recruited to adhere to the concentrated examination necessary when undertaking IPA.[101] IPA is committed to the detailed, in-depth exploration of individual cases. Examination of the similarities and differences between cases is only completed once each individual case is interpreted independently.[101] Samples sizes of four to six participants are common in studies undertaking IPA, as given the complexity of human phenomena a rigorous focus on a small sample is beneficial to gain a thorough understanding of the experiences been

explored by the researcher.[101, 102, 190] However, as this study wanted to account for the experiences of parents both who consented or declined to have a perinatal autopsy undertaken, a larger sample was recruited.

The sampling strategy also aimed to achieve variation on the basis of parity, gestation at loss and to provide perspectives from parents whose stillbirth occurred either before or during labour. Finally as the study aimed to explore parents experience both men and women were recruited (see Table 6.1). Parents were initially recruited as couples whereby the parents of six stillborn babies who cause of death was unknown were recruited. Two men declined to participate resulting in a sample of ten parents. All ten were Irish; six were female and four were male. Of these, six consented and four declined autopsy (see Table 6.1).

Table 6.1: Overview of the sample

Participant	Parent	Baby	Stillbirth Type	Gestation	Autopsy	Patient Status
1	Mother	A	Intrapartum	Pre-term	No	Public
2	Father	B	Intrapartum	Pre-term	No	Private
3	Mother	B	Intrapartum	Pre-term	No	Private
4	Mother	C	Antepartum	Pre-term	Yes	Public
5	Father	C	Antepartum	Pre-term	Yes	Public
6	Mother	D	Antepartum	Very pre-term	No	Public
7	Father	E	Antepartum	Term	Yes	Public
8	Mother	E	Antepartum	Term	Yes	Public
9	Mother	F	Antepartum	Pre-term	Yes	Public
10	Father	F	Antepartum	Pre-term	Yes	Public

6.3.3 *Data Collection*

Semi-structured interviews were conducted on a one to one basis. Parents were interviewed and discussed their experiences of the autopsy decision-making. The interviews were digitally recorded and transcribed verbatim. Interviews were conducted either in a room onsite or a location convenient to the participant.

6.3.4 *Ethics*

Ethical approval for the study was granted by the Clinical Research Ethics Committee of the Cork Teaching Hospitals (Ref ECM 4 (zz) 10/01/12). Recent research has shown however that participation in research by such vulnerable groups can be of benefit to participants.[191] All participants provided written informed consent.

6.3.5 *Data Analysis*

Once the transcripts became available they were analysed, as outlined by Biggerstaff and Thompson[103] and Smith *et al*.[101] manually by both SM and SG (see Figure 6.1). Close attention to semantic content and language is undertaken in order to identify the specific ways the individuals understand the issue they are discussing. It is important to note that the analysis is acknowledged as being the researcher's interpretation of the participants' experience[101, 102, 110, 190] in this case SM; a health sociologist, and SG; a health psychologist who interviewed the parents and undertook the data analysis. All authors were involved in the design of the interview schedule, which were guided by previously published literature in the area. In order to minimise any potential bias, data analysis, whereby emergent themes were identified, was initially undertaken independently by the authors SM and SG. Development of the master table of subordinate themes and their interpretation were then jointly undertaken by SM and SG. The analyses were then presented to JL; an epidemiologist, and KOD; a Consultant Obstetrician, for review. Critically, as IPA acknowledges that experience is never entirely accessible to the researcher as with all qualitative research approaches it is complicated by the researchers own

experience and perspective, the analysis of these data from a different perspective may produce different results.

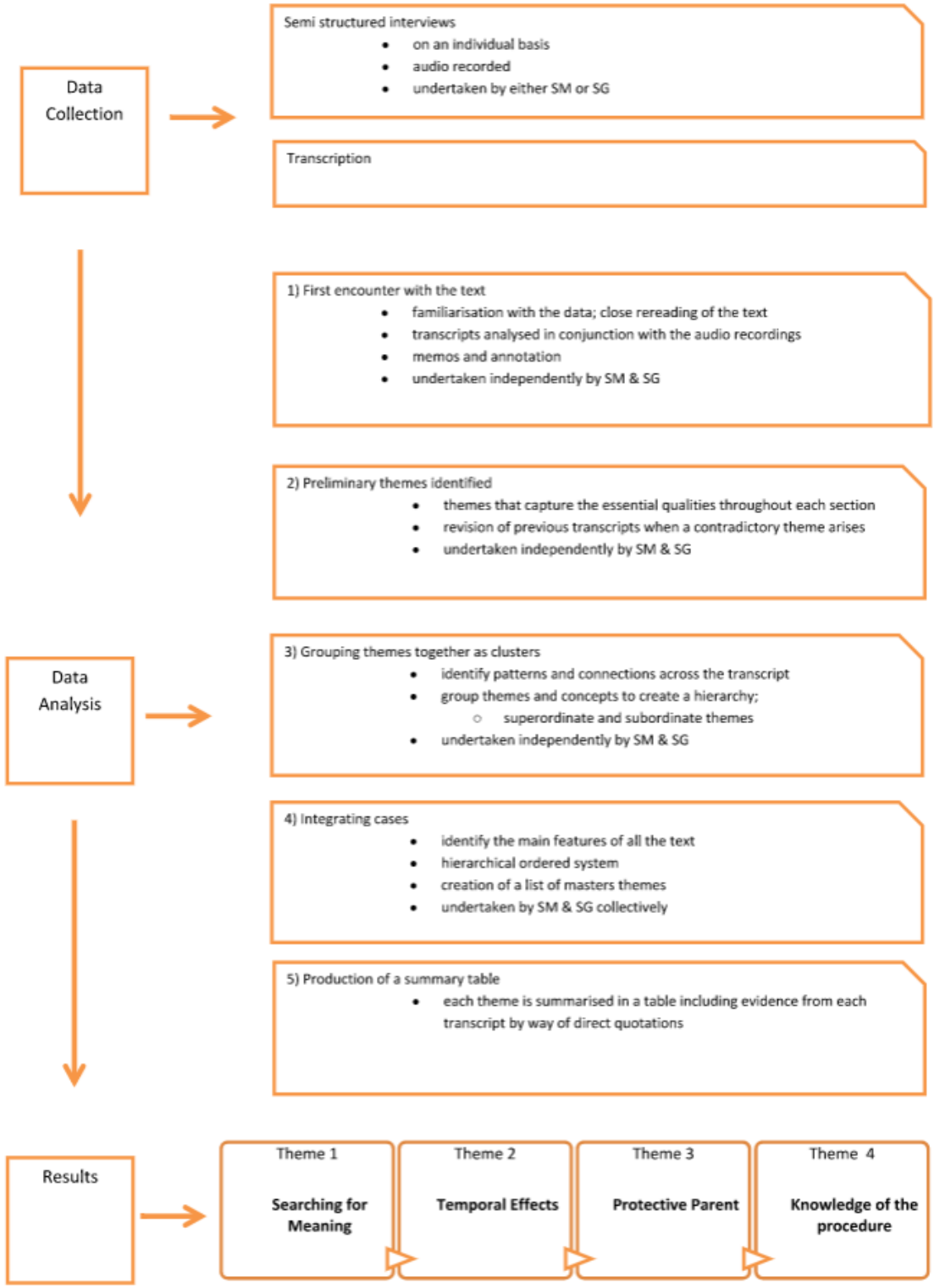


Figure 6.1: Interpretative phenomenological flowchart

6.4 Results

As can be seen from Table 6.1, parents who experienced an antepartum stillbirth were more likely to consent to having an autopsy. Further analysis of the data indicated four superordinate themes in relation to parent's experiences of consenting or declining a perinatal autopsy; searching for meaning, temporal effects, protective parent and knowledge of the procedure. In the following paragraphs, direct quotations from mother's and father's interviews are used to illustrate these themes.

6.4.1 *Searching for meaning*

When the parents were approached for consent for an autopsy, no medical examinations had been undertaken and therefore the cause of death was unknown. Irrespective of whether the parents consented or declined to have an autopsy undertaken, all parents searched for meaning and aimed to uncover the reason why such an event had happened to them. Those who consented illustrated how, irrespective of the low chance of finding a medical cause, they were resolute that all avenues of investigation be undertaken.

"*For Baby's sake to be honest first and foremost and to make sure that we know how he died. We knew we mightn't find out for definite why he died but at least we would know that we tried to find out and that we did everything that we could to find out*." (Participant 7; Father consented to an autopsy)

For some parents, the decision not to have an autopsy was made on insufficient medical evidence and was shaped by their personal feelings. Notable for these parents, the mothers in particular, spoke about how a cause which was inferred during or just after birth was sufficient and accepted as true; therefore they felt no need for further investigations, their search for answers was over.

"Do you know they were saying alright that it was a clot that done it and am I didn't want him touched" (Participant 1; Mother declined an autopsy)

"*I feel in my own heart and soul and I know no-body will ever be able to say for sure, but I feel my placenta failed because my body just, it just couldn't handle the viral infection*" (Participant 6; Mother declined an autopsy)

Thus, clinicians could impact on decision-making by not inferring cause, but rather seeking for evidence-based procedures. However, it is worth noting that wider influences such as family and religion had little or no impact on any of the parent's decision-making in relation to undertaking a perinatal autopsy. Parents discussed how they informed others about the decision to consent or not to an autopsy after they made their decision independently.

"No it [the decision to undertake an autopsy] was just between the two of us really. We did say it to his Mum that we were going to go, to, for the post-mortem you know and they, they were of the same mind of us as well you know that ya, that you need to get answers you know so they were of the same mind thank god we didn't have

anybody you know who was, I know obviously some people are completely against it but no." (Participant 8, Mother, consented to an autopsy)

All parents clearly indicated that uncovering the cause of death of their child was the priority, in most cases, a definitive medical cause was not found, leaving parents still seeking an explanation for why stillbirth had happened. For the mothers who did not consent to autopsy, their language made reference to how they also relied on their own gut instincts and perceptions of the event in order to attribute a cause of death themselves rather than accepting the medical explanation or classification of death.

"I dunno what but in my brain there was just something telling me there's nothing wrong here nothing happened it's just a freak accident." (Participant 3; Mother declined an autopsy)

Parents expressed how they were searching for meaning in their experience of a stillbirth as they experienced a multiplicity of emotions at this time including anger, fear and conflict. Many clearly wanted to lay blame for the death of their baby with somebody, while some sought to rule out self-blame. There was a distinction in the reactions of those with antepartum and intrapartum deaths. Those who had an intrapartum death discussed the responsibilities of the healthcare professionals and the liability of the hospital.

"Well they kept on telling me this was going to happen, but everything they told me was going to happen didn't happen, so they told me upstairs this will be fine it's going to happen …..but 'well why did youse wait ten minutes'. To me it was always like they were waiting on this doctor coming in to do it… cause none of them could do it." (Participant 2; Father, declined an autopsy*)*

Parents with an antepartum death blamed themselves and were concerned about what they had done wrong during the pregnancy. Fathers wanted to rule out self-blame and expressed concern as to whether their genetic material was a contributing factor to the death, which they felt would make them accountable for their loss. This concern amplified father's apprehension about the implications and possible outcomes of future pregnancies, which impelled them to have an autopsy.

*"I didn't say this to her now or anything, but I would be afraid to kind of have a baby again, do you know? In case the same thing would kind of happen, it would kind of frighten you, do you know? Obviously you don't want to go through that again like." (*Participant 5; Father, consented to an autopsy)

In contrast, mothers with an antepartum death focused on their own behaviours during pregnancy referring to fears that they perhaps they were negligent in some way. Women re-examined their behaviours during pregnancy trying to determine whether exercising too much or eating something inadvertently was harmful to the pregnancy, resulting in the death of their baby.

"You know what initially you really want there to be reason … the hospital couldn't have done anything and it hadn't been something I had done inadvertently as in mistakenly ate something or missed something or should have felt something." (Participant 9; Mother, consented to an autopsy)

Once the parents acquired some reason for the death of their baby, they spoke of the immense sense of relief they felt. The parents had absolution; they and their actions were not to blame.

"I would prefer an answer, you know, to know if I did something wrong … then midwife brought us down to her room then and that was just a big weight off our shoulders ….., it was brilliant." (Participant 4; Mother, consented to an autopsy)

6.4.2 *Temporal Effects*

All of the parents described a period of surrealism when told that their child was dead. Parents with an intrapartum death described a state of shock whereas those who had an antepartum death had to focus on the delivery of their baby following the diagnosis of stillbirth. Their future expectations were abruptly taken away from them and adjusting to a future without their baby seemed to take precedence over all other matters. In fact, Badenhorst and Hughes state that parents' capacity to make decisions is reduced when shocked and distressed and this is evident here.[11] The event resulted in their thought process and decision-making being incoherent and fuelled by emotion. In the extract below, this parent justifies what her immediate reactions were and how defensive and emotionally charged this moment was:

"The chat [amongst parents] was very small; do you want it [autopsy]? No. Do you want it [autopsy]? No, plain and simple… there was no, I suppose, it was just how I felt. I mean, something would flash into my mind when we were sitting there in the morning and I was sitting there holding her and I was kissing her… I mean she was only three pounds, yeah, you couldn't do that to her like she was too small. It was an emotional decision rather than based on any fact" (Participant 3; Mother, declined an autopsy)

Further, depending on the timing of the death these emotional reactions guided the decision-making process and were amplified by the lack of time available to the parents to make a decision.

"We just didn't know what was happening really …the whole thing was just really going minute by minute there was no structure…that's the way it felt to me anyway at the time like there was no, I never knew what was going to happen I was just sitting there pure [slang term; completely] dazed…there just seemed to be loads of people coming in and getting these leaflets here and there. At the time you were just saying 'yeah thanks' and I was just setting stuff down. I didn't know what was going on or who people were. For me it was all up in the air" (Participant 2; Father, declined an autopsy)

In fact, those who consented primarily were parents who had an antepartum stillbirth while those who did not had an intrapartum stillbirth. Those who had an

antepartum stillbirth often had a day or two before the birth to begin grieving and process the information in relation to the perinatal autopsy and discuss the intended decision amongst themselves or with healthcare professionals in advance.

"It's just it all happening to you but it's not it's like an outer body experience when it's happening, do you know, so and obviously it's really tough but I think even the first couple of days before its happening you can't you don't get your head around it at all, you know. Like you know he's gone but am…I found out the Friday and I had him the Saturday evening…. I suppose, the time, the time was good for us. That we got to be together just cry and talk about it and partner and I, and partner's mom came down and her friend turned up and they allowed them all to come into us. So having everybody there and having that time together is probably in a sense as we got to, I suppose we, we got our heads around it a little bit more." (Participant 8; Mother, consented to an autopsy)

"So eh I think the doctor came in then and he just did a scan on her or whatever you call it and it became quite obvious then. So em we came home that night…we rang home and I'd say my mother in-law rang our GP and told him. ... So we went in and they did some blood tests, we met a doctor and we met one or two midwives and she was scheduled for a section …they were very informative but there was very little they knew as well you know. It was quite obvious there was no eh, what's the word, there was no eh do you know sometime with stillbirths it's a cord accident but

there was known of that [unexplained stillbirth]. So em that was kind of a rough few days alright." (Participant 10; Father, consented to an autopsy)

6.4.3 *Protective parent*

All parents voiced the need for their baby to be recognised and accepted as a living child and not merely a loss. This is not unusual; the role of parent emerges well before the birth of a child and for men it begins as soon as they see the first scan.[114] The theme of the protective parent was only evident in those who declined to have an autopsy. Adopting this protective parenting role was perhaps a way to regain some degree of control over their situation during this emotional period. This was demonstrated by the manner in which they used language that exhibited that they were undertaking the primary role of a parent, 'daddy mode' and 'my little girl' which was the sense of obligation to protect your child from harm or injury. This was further intensified by parents' wishes to have the loss of their baby acknowledged and treated like any other death of a child.

"I had thought in my own head I would consent and then when she was born, my husband am, he kinda didn't see her as a baby till we went into the hospital, that this was just a loss … but as soon as she was born there was no way she was having a post-mortem cause he went straight into Daddy mode, this is my baby, this is my little girl and no-one is interfering with her" (Participant 6; Mother, declined an autopsy)

"The post-mortem might not have told that [cause of death] either. If we'd have gone through cutting her up and wouldn't have gotten any answer you'd have definitely felt worse. I could live with not knowing rather than having her all cut up" (Participant 2; Father, declined an autopsy)

6.4.4 *Knowledge of the procedure*

When discussing how parents were approached to consent to a perinatal autopsy parents stated how they had no prior experience of a perinatal autopsy. It was only until after the event of their stillbirth that they were made aware of others who had gone through the same experiences which is indicative of how little it is generally discussed in society. Many of the parents drew on media discourse, with particular reference to television. Consequently, dramatised events were among the primary knowledge source of the autopsy procedure. They therefore harboured negative connotations regarding the invasiveness of the procedure.

"I remember and it sounds stupid now but I was thinking back on something I saw on TV it was a CSI [Crime Scene Investigation] episode you know CSI and they were doing an autopsy on a baby … and I remember thinking this big cold grey metal terrible room and this tiny little baby on the table." (Participant 3; Mother, declined an autopsy)

Nearly all parents stated that even after being offered an autopsy in the hospital they were still not fully aware of what an autopsy procedure entailed. There was a stark difference in the language used by those who consented or not for an autopsy. For those who consented to having an autopsy, medicalised language was utilised to describe how the procedure to the best of their ability.

"Well to me a post-mortem is where they examine the body, they take tissue samples; obviously leave all his organs in him. Am like they need to carry out tests or whatever that is fine, that is all I was kind of aware of really, I wasn't too sure of what a post-mortem consisted of. You know, just trying, wanting to find out the cause of death was all I was really aware of you know."(Participant 4; consented to an autopsy)

In contrast, parents who did not consent for an autopsy continued to draw on the negative imagines from media discourse and used emotive language to describe the intrusive nature of the medical procedures.

"No, there was no explanation really of what, maybe if we had agreed they would have got into it, but there was no actual description of what was going to be done during the post-mortem... I have an image from the television, you know from the T.V. where you see people with their chests open and their routeing [prodding] around… I presumed something like that would be done to baby." (Participant 6; Mother, declined an autopsy)

"I wouldn't of wanted him touched anyway…I wouldn't of minded x-rays and that but as to regards cutting him or anything like that I would of said no" (Participant 1; Mother, declined an autopsy)

6.5 Discussion

6.5.1 *Main Findings*

This research suggests that parents' decision-making around perinatal autopsy is influenced by a number of key contextual and psychological factors. Four superordinate themes influencing parents' decision-making were identified; searching for meaning, temporal effects, protective parents and knowledge of the autopsy procedure. Irrespective of whether they consented or not all the parents in our study were driven by the desire to identify the reason for why their baby was stillborn. This finding is similar to those found by Heazell *et al.* who also discuss the variable nature of counseling parents for perinatal autopsy is undertaken by professionals.[192] The findings from this study indicated that parents' knowledge and understanding of the autopsy process itself was acquired primarily from public discourse (e.g. dramatised television programmes). Declining perinatal autopsy rates have been attributed to the general public's unfavourable view of the procedure and clinicians' personal attitudes toward autopsy.[193, 194]

6.5.2 *Interpretation*

The temporal context appears influential; given the acute timeline in which the stillbirth occurs there is little time for parents to adjust. As a consequence, emotion regulation is poor with feelings of shock and disbelief guiding the decision-making processes. As parents stated, in this emotional situation, rather than thinking with their head they are thinking with their heart. The relevant issue for clinicians is how to navigate the process of counselling parents for consent during this time of intense grief.[71] Findings from Stock *et al.* revealed that consent for autopsy was more likely granted when a senior member of staff counselled the parents.[72] Downe *et al*. also discuss whether a dedicated professional group should be solely responsible for obtaining consent, however they outline the challenge of staff availability when parents wished to discuss autopsy.[71] McCreight further discusses the difficulty clinicians' face identifying the needs of bereaved parents when clinicians themselves are not equipped with the appropriate knowledge or bereavement counselling. However, these authors emphasise the importance of communicating with parents to listen to their concerns.[77] Gordjin *et al*., state that the cause of death is important for counselling parents to allay any fears, guilt or doubt which they may be experiencing.[66] It is important that clinicians acknowledge parents' feelings and emotions when discussing the cause of death of their baby.[66, 71] This research illustrated that when clinicians infer a cause of death, this can be sufficient for parents and may then influence their decision not to permit an autopsy. Although there is a possibility that the results of the perinatal autopsy may not shed any further light on the cause of death, medical investigations can have therapeutic effects on

bereaved parents by indirectly demonstrating that their baby's death is viewed seriously by medical professionals.[195] Based on these findings, clinicians should avoid making such inferences about cause of death unless they are absolutely certain their clinical diagnosis is definite or if an antenatal diagnosis explains the death.

The role of parents as 'protector' was also a key determinant of the decision-making process. Tsitsikas *et al*. state that there is a hidden paternalism in avoiding discussing autopsy procedures assuming parents would find the subject distressing or the decision hard to make.[188] Tsitsikas *et al*. posit by assuming a negative attitude from parents and not offering them the chance to do something altruistic is detrimental but to not give parents the opportunity to investigate the death to the best of their ability is worse.[188] In this study, knowledge of the autopsy was informed by media discourse which shaped the decision-making process. Parents drew on information that they had acquired from dramatised television series. This finding affirms that clinicians face a challenge in overcoming public misperceptions of some autopsy procedures. Clinicians need to take time to sit down with parents when discussing information, and there needs to be an acknowledgement that parents interpret medical terminology differently than clinicians.[72, 196, 197] Holste *et al.* reaffirm that information provided to parents should be clear, simple and easily understood.[196] Parents who did not consent stressed how they did not wish to cause further harm to their child, these findings are in line with Holste *et a*l's. study on mothers' attitudes to perinatal autopsy.[196] Therefore in cases where clinicians

encounter very protective parents they may want to advocate for a partial autopsy where less invasive procedures can be undertaken.[198]

Searching for meaning and causal explanations of death were associated with having an autopsy or not. McCreight affirms how pregnancy is more than a medical experience and the acknowledgement of the death of the baby is crucial for parents to come to terms with their grief.[77] This finding is also reflected in our study and demonstrates that the decision to undertake a perinatal autopsy is not solely an impartial and dispassionate medicalised decision but an emotional one for parents. The decision is influenced by feelings of guilt and remorse and further influenced by how parents identify with their role as a bereaved parent; either to protect the baby from further physical harm or to make every attempt to seek out answers on behalf of the child. The findings from Breeze *et al*. echo our study findings whereby parents ascribed great importance on the results of the autopsy to determine cause of death and to reassure parents that they themselves were not at fault.[199]

Findings from this study clearly show that parents are not solely basing their decisions regarding perinatal autopsy on the clinically available information, but also drawing on their personal interpretation of what happened (e.g. *freak accident, medical errors*). Parents' decision not to have an autopsy was also strongly influenced by wanting to blame someone else, while on the other hand the need to rule out self-blame was a key driver of consenting to autopsy. Malacrida discusses how perinatal death is perceived primarily as a problem of failed pregnancy and parenthood and as a result, parents, particularly mothers, assume a tremendous

amount of guilt over the deaths of their children. Thus, a great part of the remorse and guilt parents feel stems from uncertainty as to the reasons for the death.[195]

6.5.3 *Strengths and Limitations*

One of the main limitations of our study is that we only interviewed parents whose babies were stillborn. Due to the in-depth and time consuming nature of qualitative analysis it is recommended that as homogenous a group as possible is studied, therefore, neonatal deaths were excluded. It is highly likely that medical examinations would be undertaken beforehand in the case of a neonatal death which, from the findings of this current study, we would suggest influences parents decision making and this warrants further research. The findings of qualitative studies are centre specific. However, qualitative analysis can identify factors within the setting which may influence outcomes. Parents were initially informed about the study by a specialist bereavement and loss midwife. This midwife is part of a dedicated pregnancy loss team who provide support to all bereaved parents in CUMH. The strong rapport with the staff and parents may have an influence on the findings as not all hospitals have such a team available to counsel and support parents. Our study, as well as other similar studies [19,26] have indicated that religion bore no influence on decision making, however it is important to note that this study was conducted on a group comprising solely of those of Christian backgrounds. Research is warranted on groups whose religious beliefs may have greater influence on decision making. Qualitative findings are not generalisable in the same manner as quantitative studies. Nonetheless, this study aimed to provide more than a

description of the phenomena but a comprehensive understanding of parents' experiences and how that influences their decision making; this could only be achieved through examining the rich detail of their individual accounts.

6.5.4 *Conclusion*

Parents' decision-making regarding autopsy is profoundly affected by their emotional response to stillbirth, clinicians and other health professionals may play a key role, especially if they can address parental concerns regarding the invasiveness of the autopsy procedure.

Author Contributions:

SM, SG, JEL and KOD contributed to and were solely responsible for the conception and design of the study. SM and SG were responsible for analysis and interpretation of data. SM was responsible for the initial drafting the article. SM, SG, JEL and KOD contributed to revising the manuscript critically for important intellectual content; final approval of the version to be published; and the decision to submit the article for publication.

Chapter 7

7 Parents concerns about future pregnancy after stillbirth: a qualitative study

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7.1 Abstract

Objectives: As stillbirth has a devastating impact, it is imperative to understand the importance of clinical and emotional care after stillbirth and how it influences subsequent pregnancies. The aim of the study was to gain insight into the consideration and planning of a subsequent pregnancy by parents in the weeks following stillbirth.

Design: A qualitative semi-structured interview format was utilised. Interpretative phenomenological analysis was employed as the analytic strategy.

Participants and setting: The recruitment strategy focused on couples whereby the parents of ten stillborn babies were contacted, however five men declined to participate in the study. The final sample of fifteen parents were all Irish; ten of whom were female and five of whom were male.

Results: Findings revealed two superordinate themes relating to a subsequent pregnancy after stillbirth; aspirations for future pregnancy and expectations of future care. Parents disclosed how the prospect of a subsequent pregnancy was daunting with fears about the potential loss of another child. Despite these fears parents aspirations differed in the days following stillbirth; mothers wished to plan a future pregnancy while fathers were reluctant to consider any pregnancies. Parents were unsure of what to expect in terms of the level of care that would be provided to them

in a subsequent pregnancy. Additional appointments at the maternity hospital were considered crucial to provide reassurance during a subsequent pregnancy.

Conclusions: These findings underscore the far reaching and contrasting effects of stillbirth on parents. These complex needs highlight the importance of the multidisciplinary team approach.

7.2 Introduction

As a bereavement stillbirth has considerable impact on parents. Throughout the literature the definition of stillbirth varies from 20 weeks to 28 weeks gestation. In Ireland a stillborn baby is defined as an infant born with no sign of life weighing 500 grammes or more and/or having a gestational age of 24 weeks or more. Research shows that parents experience distress and sadness as they grieve for their baby and it has been found that how parents are counselled following stillbirth has lifelong impact.[11-13, 18, 19] From the early literature it was recognised by the medical community that women who were bereaved by stillbirth would be distressed, but it was felt that it would be in the best interest of the woman to have another baby in order to help put the loss behind her.[11] In recent years, parents have become more involved in how they are cared for, as they reclaim control over their experiences.[200] With the recognition of the significance of stillbirth there has been some progress made[8, 88] including a shift in focus with research examining how best to support and care for bereaved parents.[22, 25, 86]

The Royal College of Physicians of Ireland (RCPI) state that supportive bereavement care should be offered following stillbirth, which parents may choose to access at their own discretion.[121] Both the Royal College of Obstetricians and Gynaecologists and the RCPI also recommend that in a pregnancy following stillbirth women should attend an obstetric consultant-led antenatal clinic and these women should have early access to care.[121, 201] Despite these developments, there is still

no clearly defined pathway of care for these women. Uncertainty surrounding the guidance given to health care staff on how best to care for parents following stillbirth particularly in relation to the next pregnancy remains.[202]

One of the facets of care that remains controversial relates to the timing of a subsequent pregnancy.[203] Studies have shown that over half of women who have a perinatal loss will become pregnant again,[203, 204] and many will do so within the year.[205] Research also indicates that women seek medical guidance regarding the optimal time for a subsequent pregnancy following a stillbirth.[203] Pregnancies following perinatal loss are reported as being anxiety-laden due to parental fear of recurring loss;[206] thus some clinicians recommend that parents need time to recover emotionally before another pregnancy.[204] Previous studies have reported that there were a number of determinants influencing the timing of the next pregnancy including, but not limited to, advice from relatives, guidance from medical professionals, maternal age and other social factors.[204]

Given the devastating impact of stillbirth, it is imperative that healthcare professionals understand the importance of clinical and emotional care after stillbirth and how it influences subsequent pregnancies for both women and men. To date, much of the research on stillbirth is focused on the mother's experience however studies have shown that perinatal loss can place considerable strain on the relationship between bereaved parents.[11, 22] Therefore, the purpose of this study was to examine both mothers and fathers' experiences with the aim of gaining more

detailed insight into the consideration and planning of a possible future pregnancy by both parents following stillbirth.

7.3 Method

For the purpose of this study, an interpretative phenomenological analysis (IPA); which has its theoretical foundations in phenomenology, was undertaken.[101] IPA is increasingly been used in healthcare research as its ideographic approach facilitates researchers to rigorously explore specific psycho-social phenomena which may impact on patient care.[102] IPA is a qualitative methodology which is focused on the perceptions of individuals as they make sense of a given life experience and highlights how this subjective experience is only accessible through interpretation.[102] Thus, IPA as a method aims to investigate how individuals reflect on and draw meaning from a significant life event. The experience of such an event is often not exclusive to one individual but, can be experienced or shared with other individuals, in the case of this study, a pregnancy ending in stillbirth.[207]

7.3.1 *Recruitment*

This study originated from a study undertaken to examine parental decision making relating to perinatal autopsy; full details of which are reported elsewhere.[208] During the course of the interviews, aspirations for future pregnancies arose from the participants narratives. From these interviews there was an indication that there

were disparities between men and women in relation to pregnancy following stillbirth. In order to fully explore this theme a second stage of recruitment was undertaken. These additional participants were recruited from a patient list of those who had had a stillbirth at a large tertiary maternity hospital in Ireland. In keeping with the original recruitment process parents were initially informed of the study by a specialist bereavement and loss midwife. If parents indicated that they were interested in participating, the lead researcher made contact by telephone in order to provide additional information in relation to the study and arrange interviews.

7.3.2 *Sample*

In maternity-related research women often act as gatekeepers for men. Given that this study wanted to examine the experiences of both mothers and fathers, the recruitment strategy focused on couples. Overall, ten couples were contacted, and ten mothers and five fathers agreed to take part. The final sample of fifteen parents were all Irish; ten of whom were female and five of whom were male (Table 7.1).

Table 7.1: Overview of the sample

Participant	Parent	Baby	Stillbirth Type	Gestation	Patient Status
1	Mother	A	Intrapartum	Pre-term	Public
2	Father	B	Intrapartum	Pre-term	Private
3	Mother	B	Intrapartum	Pre-term	Private
4	Mother	C	Antepartum	Pre-term	Public
5	Father	C	Antepartum	Pre-term	Public
6	Mother	D	Antepartum	Very pre-term	Public
7	Father	E	Antepartum	Term	Public
8	Mother	E	Antepartum	Term	Public
9	Mother	F	Antepartum	Pre-term	Public
10	Father	F	Antepartum	Pre-term	Public
11	Mother	G	Antepartum	Pre-term	Private
12	Mother	H	Antepartum	Term	Private
13	Mother	I	Antepartum	Term	Public
14	Father	I	Antepartum	Term	Public
15	Mother	J	Antepartum	Pre-term	Private

7.3.3 *Ethics*

Ethical approval for the study was granted by the Clinical Research Ethics Committee of the Cork Teaching Hospitals (Ref ECM 4 (zz) 10/01/12). All participants provided written informed consent.

7.3.4 *Data Collection*

Once recruited to the study parents were interviewed in relation to their experiences of stillbirth. Interviews took place between 4 and 16 months following stillbirth. All semi-structured interviews were conducted on a one to one basis either in a room onsite in the hospital or a location convenient to the participant. Interviews were undertaken by SM or, upon request, by SG as two fathers indicated their preference to be interviewed by a male. The semi-structured interviews were guided by an agreed interview schedule. The interview schedule provided an overview of the areas that the research was concerned with including: experience of the pregnancy, expectations of birth, experience of stillbirth, understanding of medical investigations following stillbirth, any considerations for a future pregnancy and finally expectations of future care in the maternity services. Semi-structured interviews were conducted to allow participants to introduce and discuss areas they considered important which may have not been included in the initial interview schedule. Interviews lasted between 35 and 95 minutes, were digitally recorded and transcribed verbatim.

7.3.5 *Data Analysis*

Transcripts of the interviews were analysed by utilising an interpretative phenomenological approach.[101-103, 190] The analysis, as outlined by Smith *et al*., was carried out manually.[101] The analysis, which was undertaken by both SM and SG, included the following five stages. Firstly, it involved familiarisation whereby each

transcript is read and re-read in conjunction with the corresponding audio recording. Secondly, the researchers independently identified emerging themes from each of the individual transcripts following a line by line analysis of the texts. Emerging themes are recorded as phrases or sentences throughout each individual transcript which aim to capture the essential qualities of data. As patterns and connections were identified across the transcript, similar themes were grouped together independently by the researchers. Throughout the process, as the researcher interpreted the data, emerging themes were defined and redefined with the integration of cases undertaken collectively by SM and SG. A master list of superordinate and subordinate themes was then created. The final stage was the production of a summary table noting each participant's contribution to the themes and supported by extracts from the transcripts.

7.4 Results

Interviews with the bereaved parents revealed how they experienced disbelief, shock, distress, anger, guilt and sadness as well as reporting how they felt a sense of failure following stillbirth. These emotions were tied up in the parents' search for meaning as they tried to come to terms with what has happened and why it has happened to them, as has been previously reported.[208] Analysis revealed that as parents begin to grieve their stillborn babies their thoughts were not solely focused on the baby they had just lost but were also focused on the impact this loss would

have on potential future pregnancies. Two superordinate and six subordinate themes were identified (Table 7.2).

Table 7.2: Superordinate and subordinate themes

Superordinate theme	Subordinate theme
Aspirations for a future pregnancy	Fear of recurrent loss Unhelpful societal responses Conflicting parental aspirations Disengagement
Expectations of future care	Reassuring medical guidance and support Need for consistent specialised care

The following two superordinate themes are now discussed relating to potential future pregnancy:

1) Aspirations for future pregnancy
2) Expectations of future care

7.4.1 *Aspirations for future pregnancies*

7.4.1.1 Fear of recurrent loss

Findings indicate that in the days following stillbirth parents begin to consider the possibility of a future pregnancy. Parents in this study revealed the impact that a stillbirth had on their expectations for a family as their plans were drastically and unexpectedly altered. Following the stillbirth these parents began to re-evaluate the process of pregnancy as each of the parents discussed their fears about the potential loss of another baby.

"I know that sounds stupid to wonder about stuff in the future but that's the way I look at it like when we got pregnant with baby, we expected to have a baby after nine months and the thing is if she got pregnant again you're running the risk of doing the whole thing over again" (Participant 2; Father)

While reflecting on the stillbirth, parents' previous assumptions about the risk of adverse outcomes in pregnancy were irrevocably altered. When they had embarked on this pregnancy they had not been fully aware of their risk of stillbirth. They discussed how their expectations rose once they had successfully progressed through the first trimester. Many of the parents spoke about how they considered the pregnancy to be a very positive experience as the mothers "flew" through the pregnancy without incident and how this, at the time, had reassured them. These parents emphasised how they had no indication or sign of what it was they were

going to experience. To then have a stillborn baby was a bewildering experience that left these parents questioning what had happened and why it had happened to them. This meant that a number of these parents now adopted a fatalistic approach to pregnancy. They stated that although healthcare staff informed them about their level of risk, they were not reassured and felt it was very likely that they could experience stillbirth again in a future pregnancy.

"*Yeah and they basically told us that we had the same chance of it happening to us again as if it had never happened to us. The same as any couple walking down the street. But the only thing I kept saying was that it did happen to us you know so they can't give any reassurances.*" (Participant 9; mother)

7.4.1.2 Unhelpful societal responses

Both mothers and fathers disclosed how the prospect of a future pregnancy was daunting, referring in particular to the toll it would take on them mentally. Following the stillbirth, family and friends would try and comfort them by reassuring them with platitudes. They were told that they were young and that they would plenty of opportunities to have more children. These parents remarked about how hurtful those statements were irrespective of their personal intentions to pursue another pregnancy or not. Parents disclosed how difficult and isolating an experience it was. If they were considering a future pregnancy they found it challenging to openly discuss their concerns as comments from family and friends reinforced the societal

belief that having children was just a natural part of life and not the anxiety ridden prospect they were now imagining.

"If she was to get pregnant and we found out tomorrow, I'd, before she'd get pregnant I'd want to know is there a big, big chance of this happening again or is there, what's the chances [of stillbirth]? And being honest I don't know what the chances [are] so until I know the chances or until I feel someway safe that's not going to happen again. That's something that's always going to be in the back of your head too, even if she was to get pregnant I'd still have it in the back of my head what happened last time round. You know I'd just be a nervous wreck during the pregnancy…one little kick and I'd just be, I don't know, I wouldn't even sleep." (Participant 5; father)

7.4.1.3 Conflicting parental aspirations

Before the stillbirth the parents recalled how pregnancy and childbirth were considered a part of life. These parents had hopes and expectations of having a certain number of children in their family and the experience of stillbirth now forced these parents to contemplate and reconsider these life goals. There were disparities observed between the aspirations of the men and women in this study.

Findings revealed that the mothers in this study started planning their next pregnancy in the days following their stillbirth. Despite their fears of another

perinatal loss, mothers wanted to proceed with planning a future pregnancy without delay. Many of the mothers spoke of the sense of failure they felt after the stillbirth. They were motivated by parenthood and the implications that their stillborn baby had on their family. There was great importance placed on the status of the stillborn baby within the families, in particular acknowledging their place within the birth order. However, many of the parents had intended on having more children after the pregnancy which ended in stillbirth and mothers in particular wanted to fulfil those aspirations.

"*my husband was saying he didn't want any more children. So I don't know if you count this much but someone who has lost a baby, for me I would have been pregnant coming out of the hospital again I wanted to be pregnant again that badly and then he was saying he didn't want any more at all and he wouldn't discuss it until after we got the results from the hospital.*" (Participant 6; mother).

"*But she's our fourth but we have three children if you know what I mean…Husband is adamant that we have had enough children like Husband would say that we are very blessed…but I think part of it with him is not that he doesn't want any more children, he wouldn't want to have another pregnancy, you know because of the outcome with baby*." (Participant 9; mother)

The fathers interviewed expressed a clear reluctance to consider any future pregnancies in the months following stillbirth. Some of the men considered the prospect of not having any more children as they perceived the stillbirth as evidence that there was something wrong, they were possibly genetically incompatible with the mothers of their baby. These fathers highlighted how pregnancy was a biological process over which they had no control and they also identified grave concerns for the possible impact of another pregnancy on themselves and their partners, both physically and emotionally. These men recounted how they saw their role as the primary support for their partner through their current loss and any potential future pregnancy. Throughout the interview the men restated on a number of occasions how they felt they had to be strong emotionally, at times putting aside their own grief, in order to be able to successfully provide such support. This illustrates how these men carry a different burden to the women, thus compounding their fears and reinforcing their reluctance to proceed with another pregnancy.

"It's something that's always in the back of your head, and in a way it kind of frightens you to have kids again…because I would be afraid to kind of, I didn't say this her now or anything but I would be afraid to kind of have a baby again in case the same thing would kind of happen. It would kind of frighten you, obviously you don't want to go through that again … I would be dreading it if she was pregnant again…I would be afraid of if it did happen again she would be, the two of us would be devastated. Even worse." (Participant 5; Father)

7.4.1.4 Disengagement

Communication played a key role in how parents were able to navigate through this experience. Many of these parents, especially the men, spoke about how their concerns about a future pregnancy were often left unspoken. For some of the women in this study the unwillingness of their partners to consider, or discuss, a future pregnancy had a detrimentally effect on them emotionally. One mother whose husband initially refused to consider a future pregnancy in the first months following their stillbirth likened the experience to suffering another loss. This mother recounted how her husband refused to engage in any discussions about a future pregnancy until they had the results of all the investigations undertaken following the stillbirth. She spoke of feeling anger and resentment during those months especially as she felt her preoccupation with the conflict between her and her husband hindered her ability to grieve the loss of her stillborn baby.

"At least I know that door isn't shut because I think that was, that was a second, grief it was sort of like I've lost one baby and I've lost any chance of having another one. So it was like two separate things I was grieving over and I felt guilty because I felt like, half the time I wasn't grieving for Baby I was grieving for the loss of some future baby, instead of thinking about her so once we got past the results I could just concentrate on baby again, as opposed to other stuff." (Participant 6; mother).

7.4.2 *Expectations of future care*

7.4.2.1 Reassuring medical guidance and support

One of the concerns for all the parents when considering a possible pregnancy was what to expect in terms of care in a future pregnancy. The women in this study said that being given practical information on what to expect and what to do in the next pregnancy was most useful. They were appreciative of clear guidance from staff about issues such as hospital appointments and the implementation of possible preventative measures such as taking aspirin or adjusting their diet and exercise routines. This information was generally imparted when they met with a consultant sometime after the stillbirth. The parents noted the importance of the time dedicated to this meeting as it facilitated the opportunity to ask questions about the stillbirth but also future pregnancies. Both doctors and midwives had also given an indication to some parents that they would be monitored more frequently in a future pregnancy following stillbirth. This was a relief to parents because if they chose to become pregnant again, they stated how they would want additional appointments with the maternity hospital for reassurance purposes. The information and guidance provided by staff helped these parents to contemplate a way to navigate through what would be an unknown experience to them, pregnancy after stillbirth. One participant placed such high value on this information that they carried a card with this written detail around with them on their person every day, so that they could implement any recommendations immediately if they were to become pregnant.

"*She [midwife] gave us a list, I have it in my bag, of everything to do the next time it's like taking aspirin, I'll be brought up for a scan every kind of three to four weeks, you know things like that… she said that I would be closely monitored, it was definitely a big relief for the two of us like when she told us that. You know, so she was very helpful.*" (Participant 4; mother)

"It was hard to come back to the hospital but it was good to get it done [debriefing with the consultant following the stillbirth] …she answered all our questions and she addressed an important thing as well cause we had already decided that we were going to try again to try for another baby at some point, so she answered all our questions and I know I'll be looked after very well [in a future pregnancy]" (Participant 3; mother)

7.4.2.2 Need for consistent specialised care

However, for some parents, they were not given enough specific details about the level of care they would receive. They had concerns that although they would be monitored more closely they potentially would not be seen as much as they would like.

"*Obviously you would love that they would have said 'look you can have more [children] and we found out what was wrong and we now know and that'll never happen'. But obviously that just wasn't the case, she [consultant] did say that if (wife) ever did get pregnant again that it would be a totally different pregnancy and that*

she'd be seen all the time. She was been seen every two months or something like that every eight weeks, I don't know. But she said she'd be seen a lot sooner a lot quicker and you know they'd be checking things, scans and stuff, all the time and it'd be a pure, she called it a medical pregnancy…but its words as well…it's easier to say oh we're going to do this, we're going to do that, but both myself and wife have both said what happens if instead they say right instead of eight weeks we want do it every six weeks or seven weeks it's not really that much more…they're not going to let you come every week or every second week, but maybe that's what you would want." (Participant 2: father)

Given these concerns having their care transferred to a 'high risk' antenatal clinic in future pregnancy, for some, was important. It would ensure they had access to the individualised and specialist care they felt necessary to proceed with another pregnancy.

"Of course you would have concerns, course you would have concerns but em we I suppose to alleviate that we know (Wife) will receive better care this time because she will be high risk and eh you know you have to trust again or you know you have to get on with things and put your trust in these people who know the most about these things you know. And that we will have a better outcome" (Participant 7; father)

7.5 Discussion

7.5.1 *Main Findings*

The findings from this study indicate that parents immediately reflect upon the possibility of another pregnancy following stillbirth. Two superordinate themes relating to future pregnancy were identified; aspirations for future pregnancy and expectations of future care. The thought of a possible pregnancy was a daunting prospect for both mothers and fathers with fears about the potential loss of another child at the forefront of their minds. Although both parents expressed fear, mothers were driven to plan a future pregnancy while fathers were reluctant to consider any pregnancies. Following stillbirth concerns were raised by parents about the possible emotional impact of another pregnancy. Another concern, shared by both mothers and fathers, was what to expect in terms of the level of care that would be provided in a future pregnancy. Additional appointments at the maternity hospital were considered crucial in order for the parents to be reassured during a subsequent pregnancy.

7.5.2 *Strengths and Limitations*

One of the key elements of qualitative analysis is the identification of any potential factors which may influence the results. This study was undertaken in one maternity hospital which has a dedicated bereavement and loss team. The presence of this specialised team may be influential in two ways. Firstly, the participants were informed about the study by a midwife from the team who was involved in their care.

Although the researchers who interviewed the parents are not part of the clinical team, having been recruited via the midwife providing their bereavement support may have influenced their responses. Secondly, not all maternity hospitals have such a dedicated bereavement team. Therefore, the experiences of these parents may differ from those who experience stillbirth in another unit, where staff may not place the same importance on discussing future pregnancy with bereaved parents.

As a methodology IPA acknowledges the experience of these parents will never be entirely accessible to the researcher and the interpretation of these events is influenced by the researchers own experiences and perspective. As a consequence the analysis of qualitative data from a differing perspectives may produce different results. Bearing this in mind, data analysis for this study was initially undertaken independently by the authors SM and SG; a female health sociologist and a male health psychologist. The final stages of analysis and their interpretation were then jointly undertaken by SM and SG. The results of these analyses were then presented to CE; a midwife, and KOD; a Consultant Obstetrician, for review. Notwithstanding these limitations, the value of this study is that these findings build on the current body of knowledge by providing additional insight into previously published quantitative findings.

7.5.3 *Interpretation*

As indicated in this and previous studies giving birth to a stillborn baby takes an enormous emotional toll on parents.[19, 22] There have been significant changes to

the care offered to parents[13, 18, 25] as studies have emphasised how the manner in which families are cared for is critical for their ability to cope.[22, 25, 86] One of the aspects of care which continues to garner attention is the timing of a subsequent pregnancy. Early literature suggested that mothers should focus on having another baby immediately[11], while more recent practice suggests that clinicians recommend parents take the time to recover emotionally before embarking on another pregnancy.[204] Yet Salfund *et al*. found that mothers were dissatisfied when advice was given on the timing of a subsequent pregnancy. These mothers stated that the decision of when to conceive again was a matter of personal choice.[203] Our study echo these findings as parents stated that when they were counselled following stillbirth they were most concerned with gauging the risk of recurrent stillbirth if or when they decided to conceive again, as opposed to focusing on the optimal timing of a future pregnancy.

Our study indicated that there was a disparity between mothers and fathers in relation to their aspirations for a future pregnancy. Mothers, in this study, were driven by the desire to have children and indicated that they wished to continue with another pregnancy, although aware that they would be hyper-vigilant in a future pregnancy. However, fathers expressed a clear reluctance to proceed with another pregnancy. Our study is in keeping with Mills *et al*. who findings indicate that during a subsequent pregnancy parents suffer similar anxieties and fears and identify how fathers do not openly express these concerns.[209] This is of particular importance as previous studies show that stillbirth has an adverse effect on bereaved parents'

relationships[11], with one in eight parents experiencing anxiety or depression.[210] Badenhorst emphasizes that this is even more the case if parents' grief is not experienced in tandem.[11] A study by Lin and Lasker (1996) examined the patterns of grief following pregnancy loss, including stillbirth, and found that overall there was a decline in grief after two years.[211] Although Lin and Lasker reported a normal grief trajectory, from high to low after two years, they also identified seven different grief patterns during the two year period.[211] The findings from Lin and Lasker illustrate the complex and individualistic nature of the grieving process.[211] Badenhorst further states that health care providers should identify specific interventions that will help support both mothers and fathers individually following stillbirth.[11] Our study further illustrates how both mothers and fathers have potentially different requirements for their follow-up care after stillbirth. Given the expected grief trajectory of these parents, timely follow-up care would be beneficial.

All parents in our study revealed a fear of recurrent stillbirth. In a recent review of the risk of recurrent stillbirth Lamont *et al*. stated that unexplained stillbirth is a poorly studied complication of pregnancy and priority must be given to establishing the cause of death in order to counsel parents appropriately about the risk of stillbirth in future pregnancies.[212] Evidence to date suggests that women are at a higher risk of stillbirth in a future pregnancy if their stillbirth was in their first pregnancy.[212] Clinical management should therefore take into account pregnancy history as well as making use of pre-pregnancy counselling services following stillbirth.[212] Such counselling services may be of the utmost importance as the fear

of recurrent stillbirth may result in prolonged delays or avoidance of future conception.

7.6 Conclusion

The findings of this study underscore the far reaching and contrasting effects of stillbirth on parents. These findings have implications not only for the psychological wellbeing of parents but also for clinical practice. The mothers and fathers interviewed illustrated differing needs and concerns relating to future pregnancies which requires heath care professionals to individualise the care they provide to parents after stillbirth. The complex needs of the mother and father highlight the importance of a multidimensional approach, including health and social care professionals, especially in the area of follow up and future care.

Author Contributions:

SM, SG, and KOD contributed to and were solely responsible for the conception and design of the study. SM and SG were responsible for analysis and interpretation of data. SM was responsible for the initial drafting the article. SM, CME SG and KOD contributed to revising the manuscript critically for important intellectual content; final approval of the version to be published; and the decision to submit the article for publication.

Chapter 8

8 Death of one twin during the perinatal period: an interpretative phenomenological analysis

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8.1 Abstract

Objectives: To date, few studies have examined the effect of the loss of one twin diagnosed with a congenital abnormality during pregnancy. This study aims to gain insight into parent's views in order to explore the impact of death of one twin in the perinatal period.

Design: A qualitative study was undertaken utilizing interpretative phenomenological analysis. Nine parents who have experienced perinatal loss, of whom all had a prenatal diagnosis of congenital abnormality, participated in in-depth semi-structured interviews.

Results: Parents recounted how distressed they were when initially informed that there was a complication. Upon diagnosis parents began a complex palliative journey, proceeding in the pregnancy grieving one baby while trying to ensure the welfare of the co-twin. As parents were encouraged to focus on the 'normal' twin they felt their opportunity to grieve was diminished. It was important that the surviving twin would be identified as a twin and know of their sibling, however parents conveyed feelings of deep sadness because this was also a reminder that one twin would always be missing.

Conclusions: Parents were not prepared for the complications they experienced in pregnancy. Clear and appropriate information in relation to perinatal palliative care should be provided to parents in twin pregnancies discordant for fetal abnormality.

8.2 Introduction

Twin and higher order multiple pregnancies, compared to singleton pregnancies, are associated with increased risks of adverse outcomes[213-216] including congenital fetal anomalies.[214, 215] Complications in twin pregnancy may affect one twin and may or may not have implications for the health of the co-twin, depending on chorionicity. The perinatal mortality rate for multiple births is three times that for all babies.[44, 217]

A recent study illustrates how perinatal palliative care has been a growing field over the past decades and allows for parents to better prepare for perinatal loss.[218] Yet, a study examining the provision of perinatal palliative care found a need to improve the palliative care provided to parents who continue on in pregnancy affected by a life-limiting diagnosis.[219]

Twin and higher order pregnancies may present more unique burdens relating to parental decision-making during the perinatal period when faced with potential morbidity and/or perinatal mortality.[216] To date, few studies have examined the effect of the loss of one twin in the perinatal period. Richards *et al.* examined the experiences of mothers whose infants died during the neonatal period.[214] Our study builds on these findings by examining the parental experience of the death of a twin with a prenatal diagnosis of congenital abnormality.

8.2.1 *Objectives*

The objectives were to explore parents' perception of pregnancy and loss, their experience of diagnosis of congenital abnormality as well as their experience of perinatal palliative care.

8.3 Methods

The primary inclusion criteria dictated that any potential participant had experience of a perinatal death during or after a twin pregnancy. Participants were eligible if they had received parental palliative care upon diagnosis of major congenital abnormality. The sampling strategy also aimed to achieve variation on the basis of gestation when the diagnosis was made. The recruitment process ensured that the sample included both male and female perspectives (see Table 8.1).

Participants who had experienced a perinatal death during or after a twin pregnancy were recruited. Of the 15 parents initially contacted, two women and four men declined to participate. The final sample of 9 parents were all Irish; five of whom were female and four of whom were male (Table 8.1). Parents were interviewed in a private room within the hospital. Almost all interviews were conducted on a one-to-one basis, with the exception of one couple who requested to be interviewed together. Ethical approval for the study was granted by the Clinical Research Ethics Committee of the Cork Teaching Hospitals (Ref: ECM 4 (q) 12/03/13).

An interpretative phenomenological analysis was undertaken.[220] The analysis included the following five stages; 1) familiarisation whereby each interview (both the transcript and audio recording) is analyzed independently, 2) preliminary themes are identified, 3) similar themes are grouped together as patterns and connections are identified, 4) cases are integrated with the creation of a master list of themes and 5) a final summary table is produced.

Table 8.1: Overview of the sample

Participant	Parent	Baby	Diagnosis suspected at ultrasound	Gestation at diagnosis	Outcome
Participant 1	Mother	A	Hydrops fetalis secondary to cystic hygroma	12 weeks	Intrauterine Death
Participant 2	Father				
Participant 3	Mother	B	Holoprosencephaly Trisomy 13*	20 weeks	Intrauterine Death
Participant 4	Mother	C	Anencephaly	12 weeks	Neonatal Death
Participant 5	Father				
Participant 6	Mother	D	Bilateral Cleft Lip Ventriculomegaly Trisomy 13*	16 weeks	Neonatal Death
Participant 7	Father				
Participant 8	Mother	E	Ventriculomegaly	20 weeks	Intrauterine Death
Participant 9	Father				

*Trisomy 13 diagnosis was confirmed at birth as parents declined amniocentesis during the pregnancy

8.4 Results

Analysis of the data indicated three superordinate themes: pathways of care, emotional conflict and acknowledgement (Table 8.2).

8.4.1 *Pathways of care*

As the prenatal diagnosis of fetal abnormality was completely unexpected, parents had difficulties processing the information. Most parents sought out additional information from the internet, despite the advice of healthcare professionals. Although distressing, parents disclosed a sense of relief when healthcare professionals spoke openly to them about the diagnosis. Throughout the pregnancy difficult decisions had to be made by some parents, and the need for empathic care was paramount. The acknowledgement of how traumatic it was to be given a prenatal diagnosis was of particular significance. Good communication with healthcare professionals meant an appropriate plan for the pregnancy could be put in place (Table 8.2).

Some of the information relating to how the pregnancy would advance was difficult for parents to understand. Termination of pregnancy is only lawful in Ireland in pregnancies where the mother's life is at risk. Some parents expressed anger that termination was not available to them, unless they chose to travel outside the country for private care, especially with a diagnosis of fetal abnormality in one twin,

where parents perceived the risk of the co-twin dying in utero was greater (Table 8.2).

8.4.2 *Emotional conflict*

Many of the parents recalled their booking visit with the maternity hospital and experiencing polarising feelings, where excitement about the possibility of having twins was matched with anxiety about being ill-prepared either physically, emotionally or financially for twins. Following diagnosis parents ruminated on those initial negative thoughts and concerns, resulting in them feeling guilt and responsibility for the later adversity they were confronted with (Table 8.2).

Having a prenatal diagnosis of fetal abnormality meant that parents were transferred to a team who were experienced in perinatal palliative care. Yet, their experience was even more complex, as they were proceeding in the pregnancy beginning a grieving process for one baby while trying to ensure the welfare of the co-twin. Parents revealed how challenging this process was as there was a stark contrast between how each parent perceived the prognosis for the affected twin (Table 8.2).

Given that parents had such conflicting expectations for the outcome of the pregnancy, this resulted in differences in not only how each individual parent grieved but when the grieving process began. For some parents this process was

initiated upon receiving the diagnosis and continued throughout the remainder of the pregnancy, while for others grieving did not begin until the death of the twin (Table 8.2).

8.4.3 *Acknowledgement*

The experience of carrying twins following a diagnosis of fetal abnormality was challenging as parents tried to comprehend what it meant to them and their family unit. Encounters while with work colleagues or while attending social gatherings brought a separate set of challenges for parents to contend with as they grappled with how to explain to others that although they were expecting twins it was likely that one would not survive (Table 8.2).

Some parents felt they were encouraged to focus on the surviving twin and in doing so that their opportunity to grieve was diminished. Following the birth of the twins, bereaved parents remarked on the importance of healthcare professionals identifying the surviving baby as a twin. It was also important that the surviving twin would know of their sibling, and this was often aided by the mementoes and photos taken within the maternity hospital. However, parents also conveyed feelings of deep sadness because this would also always serve as a reminder that one twin would always be absent (Table 8.2).

Table 8.2: Illustrative quotes

Superordinate Theme	Illustrative Quotes
Theme one: Pathways of Care	• "*When we got the news it was like someone tore, I don't know like they pulled everything down. I mean you go from feeling …you go from feeling over the moon, overwhelmed with joy, pride and everything else to a huge sense of loss and it is just so hard to describe it*." (Participant 6, Father) • *"It was surreal, so surreal…we were in a bit of a daze the two of us we didn't know what to think or what to say. We were trying to kind of be positive saying it mightn't be as bad as they think you know and then we started googling and that was a bad idea."* (Participant 3, Mother) • *"Ah it [termination] would have meant going away from home, it would have been going away from her family who we are very close to. It would have been losing her child and as I say from the outset we were both at tangents really. All [wife] could see was 'what's happening to my baby' while all I could see was 'how am I going to save the other baby'."* (Participant 2, Father) • *"We knew where we were going and what we were doing and that was the plan ... and it was never a fairy-tale with him, he wasn't nasty about it but he made it quite clear that this is, there is not going to be a happy outcome with this one and this is what we have to do."* (Participant 7, Mother) • *"I got a room on my own when the baby was born, which was great, and…because I went to a breastfeeding class. So [the midwife] asked us all what room we were in, so when I told her what room I was in, now she didn't say anything, but she called into me afterwards because she knew what happened. That was really good, she didn't say anything in front of anybody but to call in to check up on me and make sure everything was alright that was really good, it really was."* (Participant 3, Mother)
	• *"I suppose we went through phases of anger and guilt at what happened and why and, you know*

Theme two: Emotional conflict	*because our initial reaction I suppose both of our initial reaction with the first scan and we both realised it was twins, both of us, I know in my heart and soul both of us were like f**k… it was going to be bad enough to tell people we were pregnant again. But to tell people we were pregnant with two was going to be Then you have the guilt then because your first reaction was f**k and then you hear that there's a problem with one and you're like oh Jesus why did I say it, why did I think it, why did I feel it?" (Participant 1, Mother)* • *Because [Husband] was my rock during the pregnancy he firmly believed everything was going to be ok but then afterwards his world fell apart…So I felt that how we dealt with it, with each other the hardest part. Because you never go through, we've never been through anything this significant together." (Participant 5, mother)* • *"There were loads of things throughout it [the pregnancy]…because at one stage when there was the talks of Turner's and all the rest of it I think that was the big thing, big difference between myself and [Husband]. And we only discovered that recently ourselves in a counselling session. That I was preparing all the time for one good and one disabled baby of some sort. He wasn't. [Husband] was never preparing for that second child. To him that child was always, was never going to survive. Like he's real matter of fact. Once we were told really that it wouldn't, he put that out of his head. Whereas I always had the kind of …Whereas I always thought it would. Well, I always, I always thought it was a possibility." (Participant 1, Mother)*
Theme three: Acknowledgement	• *"I remember meeting someone with my mother one day…and I was very obviously pregnant, and she said to Mom; how are the twins? Because my sister has twins. And she said they're grand….and you've no other twins in the family have ye? And I'd say my mother was [thinking] you couldn't ask any other question …I, I know my mother didn't know how to answer that question. I was standing beside her, and I was having twins but I wasn't having twins." (Participant 1, Mother)*

	• *"I remember it was coming up to Christmas…and we put him into the car and I looked at him in the rear view mirror and…[feeling] a huge sense of loss, something missing." (Participant 6, Father)* • *"When they do their rounds everyday they'd come around and they would go this is [Baby Boy] twin one of twins and [Baby Girl] was twin two. And there was just such a real attachment to here [maternity hospital] because this is where she was because this is where she existed, this is where she was so real and you know they just made her so, her life her life, you know and they made it very real and that was so special." (Participant 5, Mother)*

8.5 Discussion

Our study found that parents were wholly unprepared for a prenatal diagnosis of congenital anomaly and in agreement with Parkes *et al*. that the diagnosis and subsequent death of one twin was not only unexpected but a very traumatic event.[221] Cacciatore and Downe *et al*. report how perinatal death can be an isolating event which results in mothers relying on their own ability to emotionally steer themselves through this event.[81, 86] Our findings indicate that both parents felt isolation and dependence on self-resilience following their diagnosis. Similar to that of Kollanti[222], these parents felt an overwhelming need to stay strong in the face of grief and adversity which in turn meant, comparable to the findings of Richards *et al.*[214], that some parents put their grief on hold. These parents felt that support should be offered separately to mothers and fathers, whose needs may be different, but also that additional support be provided for them as a couple.

Our study highlights how complex perinatal palliative care can be when the prenatal diagnosis of fetal abnormality is related only to one twin. Parents who perceived greater risk to the 'normal' co-twin were angry that termination was not available to them unless they chose to travel outside Ireland. However, making difficult decisions in relation to procedures which may put one or both twins at risk are decisions which occur in any country, and selective termination of one fetus in a multiple pregnancy is not a risk-free process. It is important that parents are counselled appropriately about the possible adverse outcomes following such procedures in a twin pregnancy especially when the parents' perception may be that the co-twin is at greater risk.

Parents in this study were appreciative when given direct information pertaining to the diagnosis. Those who sought out additional information online expressed regret they found some of the content upsetting and at times frightening. Downe *et al*. also emphasize the importance of honest and frank communication following perinatal death.[86] Communication during this period can be difficult between healthcare professionals and parents but studies have found that if parents are communicated with openly it has a long term positive impact.[86, 214]

Our study, in support of previous studies[214], has illustrated how the needs of parents in twin pregnancy can differ from other bereaved parents. As stated by Pector & Smith-Levitin twins are not a "collective baby" and the survival of one twin does not compensate for the loss that parents experience.[223] Thus, in agreement

with Wilson *et al.[224]*, the death of the co-twin should not be diminished as the surviving twin cannot and should not be considered a substitute. Furthermore, healthcare professionals need to consider that these parents experience conflicting emotions whereby they try to be strong to ensure the health and wellbeing of the surviving twin, while simultaneously grieving the loss of a baby.[224]

8.6 Conclusion

These parents were not prepared for the complications they experienced in pregnancy. The provision of clear and appropriate information on the possible care pathways for these pregnancies is important.

Author Contribution:

SM, PC and KOD contributed to and were solely responsible for the conception and design of the study. SM was responsible for analysis and interpretation of data. SM was responsible for the initial drafting the article. SM, PC and KOD contributed to revising the manuscript critically for important intellectual content; final approval of the version to be published; and the decision to submit the article for publication.

Chapter 9

9 Reaction on Twitter to a cluster of perinatal deaths: a mixed method study

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9.1 Abstract

Background: Participation in social networking is commonplace and the micro-blogging site Twitter can be considered a platform for the rapid broadcasting of news stories.

Objective: Our study aimed to explore the Twitter status updates, and subsequent responses, relating to a number of perinatal deaths which occurred in a small maternity unit in Ireland.

Methods: An analysis of Twitter status updates, over a two month period from January to March 2014, was undertaken to identify key themes arising in relation to the perinatal deaths.

Results: Our search identified 3,577 tweets relating to the reported perinatal deaths. At the height of the controversy, Twitter updates generated skepticism in relation to the management of not only of the unit in question, which was branded as unsafe, but also the governance of the entire Irish maternity service. Themes of concern and uncertainty arose whereby the professional motives of the obstetric community and staffing levels in the maternity services were called into question.

Conclusions: Twitter activity provides a useful insight into attitudes towards health related events. The role of the media in influencing opinion is well documented and this study underscores the challenges that clinicians face in light of an obstetric media scandal. Further study to identify how the obstetric community could develop tools to utilize Twitter to disseminate valid health information could be beneficial.

9.2 Introduction

During pregnancy women are invested in seeking out a considerable amount of information in relation to pregnancy and the services that are available to them.[225] To date the provision of pregnancy related information during the antenatal period has been through more traditional media.[225] These, including leaflets, magazines and advertisements, channel the information directly from source to target audience.[226] The use of such materials sees women limited to the passive viewing of pregnancy related content, which has been created for them.[227]

Rapid development in web based technologies has seen a shift in how women now access pregnancy related information. A recent study has shown that 95% of pregnant women in Ireland use the internet for pregnancy information.[225] The transition from more traditional to digitally based media may be related to two issues. Firstly that of access, whereby women of child-bearing age in developed countries have access to a wide array of technologies including personal computers, laptops, tablets and smartphones. Secondly, women may have more confidence in the information that they receive online given how Stapleton *et al.* found that traditional materials such as leaflets or books were considered not only limited and biased but that the information which was being provided was considered dated.[228]

Healthcare providers and policymakers need to address the information needs of pregnant women.[229] The benefit of internet based technologies for women is that

they are no longer passive users. The development of these technologies ensures that information provision is consumer-centered whereby users are encouraged to interact with others but also to create and share content through multiple digital channels.[230] Bernhardt *et al*. outline how this revolution in communication has already affected healthcare as a new generation of e-patients has emerged.[227] Digital media has empowered these healthcare consumers, allowing them to be even more engaged in their care and in turn to influence their current and future service provision.[227]

The expansion of social network platforms in particular has driven these developments. Participation in social networking such as the micro-blogging site Twitter is now commonplace. It reported that 38 million adults in the UK access the internet daily with over half of the population participating in social networking.[231] A national cross-sectional survey from 2015 indicated that 26% of the Irish population use Twitter, with one in three of those people using Twitter daily.[232] However, a tweet extends far beyond the individual status as it includes its audience; those who may read the tweet, retweet and/or reply.[233] As any status update can be seen quickly by a very large audience[234], Twitter must be considered a platform for rapid and immediate communication. These sites allow individuals to share their thoughts on the information they are currently consuming.[234] Such rapid communications amongst these new e-patients are very likely to be influential in how people consume information in relation to healthcare services.[234] Healthcare consumers now have a new digital space where they can discuss information that is

provided to them and evaluate their healthcare services as they experience it, either while attending a clinic or while watching a TV broadcast.[234] This phenomenon has already been observed in the UK where reforms in the National Health Service have been influenced by social commentary on Twitter.[235]

Social media is transforming health related research.[236] Studies have been undertaken from a wide range of disciplines, from epidemiology where real time responses to pandemics are analyzed[237] to the behavioral sciences where the way patients consume health related information online is examined.[227, 238] The manner in which women both access and respond to pregnancy related information needs to be evaluated as it is likely to be influential in relation to women's decision making.[228]

Reports in the media related to pregnancy and birth are common and these reports are often emotive.[239] Such reporting may have a detrimental impact as it can potentially misinform pregnant women which may possibly result in confusion and anxiety.[239] How news is communicated has altered dramatically as websites, social media sites and 24 hour rolling broadcasts have seen rapid growth.[239] Since 2012 there has been considerable national and international media coverage reporting a number of adverse incidents within the Irish maternity services, which in turn have resulted in a number of independent enquiries into the services. The media coverage of these adverse incidents stimulated much debate, including discussion in relation to a cluster of perinatal deaths in Midland Regional Hospital, Portlaoise in 2014.

Although research related to the causes of perinatal death, which aims to reduce the prevalence of perinatal death, is ongoing, there is still persistent stigma associated with perinatal death.[240] Stillbirth, in particular, is often referred to as a silent loss.[240] Thus, our study aimed to explore the reaction on Twitter to the perinatal deaths in order to gain insight into the understanding and perception of perinatal death in the Republic of Ireland.

9.3 Methods

9.3.1 *Setting*

In 2014, the Irish Central Statistics Office estimated that the Irish population was 4,593,100.[241] In Ireland, the Maternity and Infant Care Scheme grants women ordinarily resident in Ireland access to free maternity services. This public service is provided by both a general practitioner and a maternity health care provider. The majority of births occur in one of the 19 obstetric led units in Ireland.[242] Ireland has the highest birth rate in Europe with 15.6 births per 1,000 population.[243] In 2014, there were 67,462 births of which 330 were stillbirths; defined here as an infant born with no sign of life weighing 500 grammes or more and/or having a gestational age of 24 weeks or more.[217]

Raidió Teilifís Éireann (RTE) is an Irish television broadcaster. As a national public-service media organization the service which it provides are free to air.[244] RTE's flagship current affairs programme is Primetime. At the time this study was conducted, in 2015, RTE had 205,000 thousand followers on Twitter and the Primetime account had 69 thousand followers. On the 30th of January 2014 RTE

aired a programme entitled “Fatal Failures” on Primetime. The programme was concerned with a cluster of perinatal deaths that occurred in a maternity hospital located in the midlands in the Republic of Ireland. Following from this programme the Health Minister, James Reilly, requested that the Chief Medical Officer prepare a report on the issues identified in the programme. The Chief Medical Officer published the report on the 28th of February 2014.[120] The Health Minister also requested that the Health Information Quality Authority, an independent authority who are responsible for assessing quality and safety of healthcare services, undertake a review of the hospital in question.

9.3.2 *Design*

As this study was an observational study of Twitter status updates in relation to the reported perinatal death a mixed methods approach was adopted. By utilizing a mixed methods design the study was able to benefit from analyzing the data both quantitatively and qualitatively. For the purposes of this study the data were initially quantitatively analyzed in order to assess the frequency of status updates, the demographic profiles of users and to ascertain the potential reach of the status updates. Secondly, qualitative analysis was employed to generate themes from the content that twitter users shared publically.

9.3.3 *Search Strategy*

Status updates in English were manually searched utilizing the Twitter search function on its website. A search was undertaken on all public status updates from January 29th 2014 to March 31st 2014 relating to the perinatal deaths in the Republic of Ireland. This two month period was chosen as research indicates that public interest spike and the time of the event and decline rapidly thereafter.[245] This time limit was chosen to allow the examination of the immediate response to the reporting of the perinatal deaths and the subsequent reports published in relation to the perinatal deaths.

Seven searches were conducted independently by two researchers (SM and LC). The seven searches included: “fatal failures” [the name of the episode regarding the perinatal deaths], “rtept” [the current affairs programme which aired the episode], “death of a baby”, “maternity”, “stillbirth”, “perinatal death” and finally we searched the name of the hospital where the deaths occurred. Initially the searches were limited to using hashtags (#) which are useful to search for content on twitter as they group messages on a specific event together. However, we found that this limited the search. Therefore, we chose to proceed using the terms alone for the search process as it produced more results, including the hashtags related to the perinatal deaths. All data which were extracted from each of the searches were stored in Microsoft Excel. Each tweet was then reviewed and assessed for inclusion in the study.

Once these searches were complete, any demographic information available was collected from the user's public profiles. This included their biography, their location and the number of people who are following the user at the time of data collection in 2015.

Only data which were publically available were collected and no attempts were made to contact any individual therefore no ethical approval was sought for this study. Despite these data being publically available there is still an onus to ensure that ethical standards are met. Therefore, in line with similarly published studies[238, 246, 247] identifiable information, including individuals Twitter usernames, have been removed from the example tweets presented below.

9.3.4 *Analysis*

Both quantitative and qualitative methods were utilized for this study. Firstly, in order to determine the volume of social media communication in relation to the perinatal deaths descriptive statistics of all tweets, retweets and replies were calculated. If a user's biography was available this was coded by the researchers (SM and LC) in order for the demographic profiles of the users to be categorized. The biography on Twitter is limited to 160 characters and is the user's self-description. Therefore, the demographic data reported here is self-identified by the user. Consequently users were broadly grouped into the following categories which are reported here; parent, media outlet, media personnel, politic and health. These categories were not considered mutually exclusive whereby, for example, a

user may describe themselves as a “midwife and mother of two children” and therefore would be considered both a parent and a healthcare professional In order to ascertain the potential reach of the status updates the number of people that were following the user were collected.

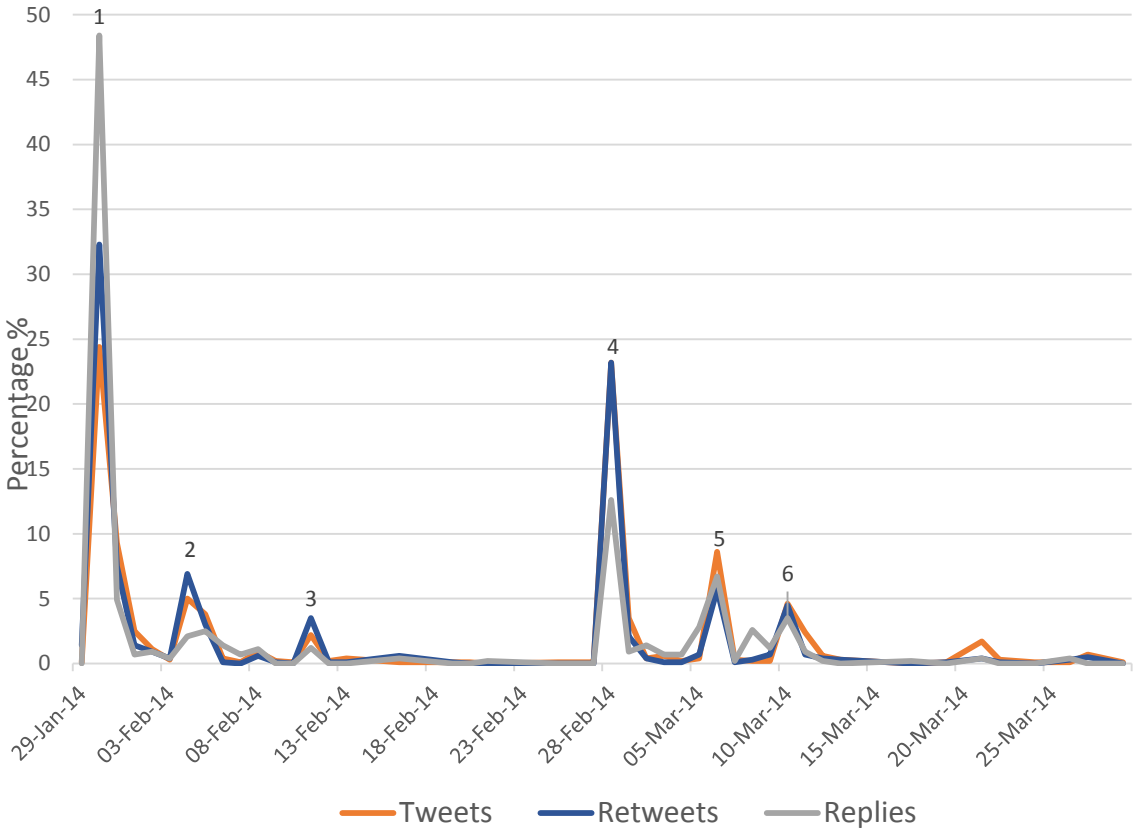
Given that this is an observational study a qualitative methodology which is more descriptive rather than interpretative was chosen. Consequently, a thematic analysis of the text within the Twitter status updates was then performed electronically using Nvivo 10 software (QSR International Pty Ltd., Doncaster, Australia). The analytic process, as outlined by Braun and Clarke (2006), involves familiarization with the data whereby the researchers read and re-read each tweet which were then coded individually.[248] These preliminary codes were reviewed and similar individual codes were identified and grouped together as categories. The final themes were then agreed by grouping related categories together.

9.4 Results

9.4.1 *Quantitative Results*

Over the two month period from January 29th 2014 to March 31st 2014, 3,577 Twitter status updates from 1,276 profiles relating to the perinatal deaths in Midland Regional Hospital, Portlaoise were identified. Of these status updates 45.1% (n=1615) were tweets, 38.9% (n=1392) were retweets and 15.9% (n=570) were replies.

As illustrated in Figure 9.1, 39.8% (n=1425) of status updates were posted between the 29th and the 31st of January coinciding the airing of the current affairs programme which investigated the perinatal deaths. Almost half of all status updates which were replies were posted on the 30th of January (48.4%; n=276). The second largest peak of status updates (21.5%; 770) related to the publication of the findings from the Chief Medical Officer's report.



1: Current affairs television programme Primetime air the episode entitled Fatal Failures relating to a cluster of perinatal deaths in Portlaoise hospital in the Republic of Ireland

2: Minster for Health makes an emotional statement after meeting the families who had a perinatal death and announces the investigation by the Chief Medical Officer

3: A mother releases a statement that she was only made aware that an investigation was undertaken on the perinatal death as a result of the Primetime programme

4: Findings from the Chief Medical Officer's report are published

5: It is confirmed that an independent investigation of the hospital will be undertaken by the Health Information Quality Authority

6: The Health Service Executive confirm that a perinatal death occurred in Portlaoise hospital on March 8th 2014

Figure 9.1: Frequency of status updates by date

The individual profiles of those who posted status updates were analysed to discern demographic characteristics. Of the 1,276 profiles, a biography was available on for

1,139 (89.3%). Profiles indicated that those who self-identified as being involved in media, healthcare and/or politics accounted for almost two thirds of status updates (62.8%; n=2249). More than one in 10 status updates were by those who self-identified as a parent (11.8%; 424) Table 9.1 outlines the distribution of status updates amongst these groups. Profiles which identified the user as either a media outlet or personnel working for a media outlet were responsible for over one third (36.8%; n=1317) of status updates. Of note, media outlets were more likely to create content; whereby the majority (83.3%) of their updates were tweets compared to other users. Parents and those involved in healthcare were more likely to question or discuss content with 29.0% and 24.2% of their updates being replies.

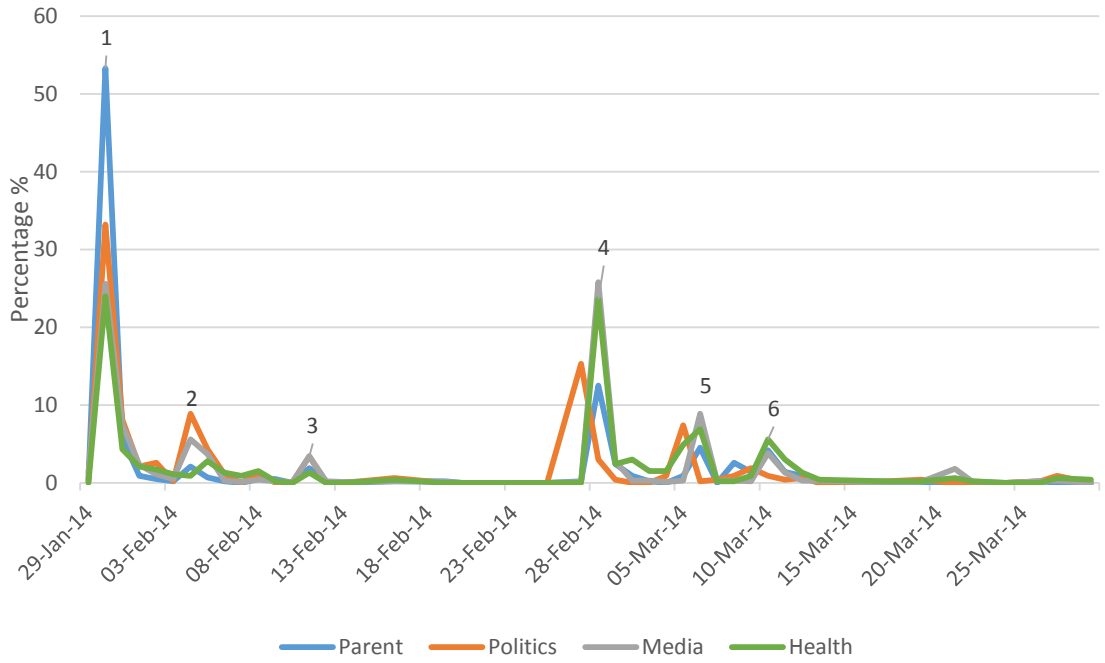
Table 9.1: Sample characteristics

	All status updates (n=3577)	Media Outlets (n=540)	Media personnel (n=777)	Healthcare professional (n=467)	Politics (n=465)	Parent (n=424)
Tweet	54.1	83.3	46.8	38.1	38.1	31.4
Retweet	38.9	16.7	39.9	37.7	43.7	39.6
Reply	15.9	0	13.3	24.2	18.3	29.0
Mean number of followers	11,709	59,437	5,667	1,902	3,663	1,138

All values are percentages (%) unless otherwise stated

Of the profiles related to healthcare (n=111), almost one third (29.7%) were from a diverse range of support organizations and online healthcare businesses, such as those who provide health, fitness and nutrition services online. One in five identified as either a midwife or a nurse. Fourteen percent identified as a medical doctor or consultant, however none were from the field of obstetrics and gynaecology. Of the political profiles (n=122), one quarter identified themselves as a political figure in Ireland such as a Member of the Irish Parliament or a local Councillor. One in six profiles saw individuals identify themselves as activists (16.4%).

Over half of the status updates (53.3%; n=226) posted by parents occurred on January 30th (Figure 9.2). One of the largest volumes of status updates, 13.2% (n=62), by those involved in politics occurred when the Minster for Health made an emotional statement while announcing a hospital investigation was to be undertaken. Almost one quarter (23.6%; n=110) of status updates by those involved in healthcare occurred when the findings from the Chief Medical Officer's report were published.



1: Current affairs television programme Primetime air the episode entitled Fatal Failures relating to a cluster of perinatal deaths in Portlaoise hospital in the Republic of Ireland

2: Minster for Health makes an emotional statement after meeting the families who had a perinatal death and announces the investigation by the Chief Medical Officer.

3: A mother releases a statement that she was only made aware that an investigation was undertaken on the perinatal death as a result of the Primetime programme

4: Findings from the Chief Medical Officer's report are published

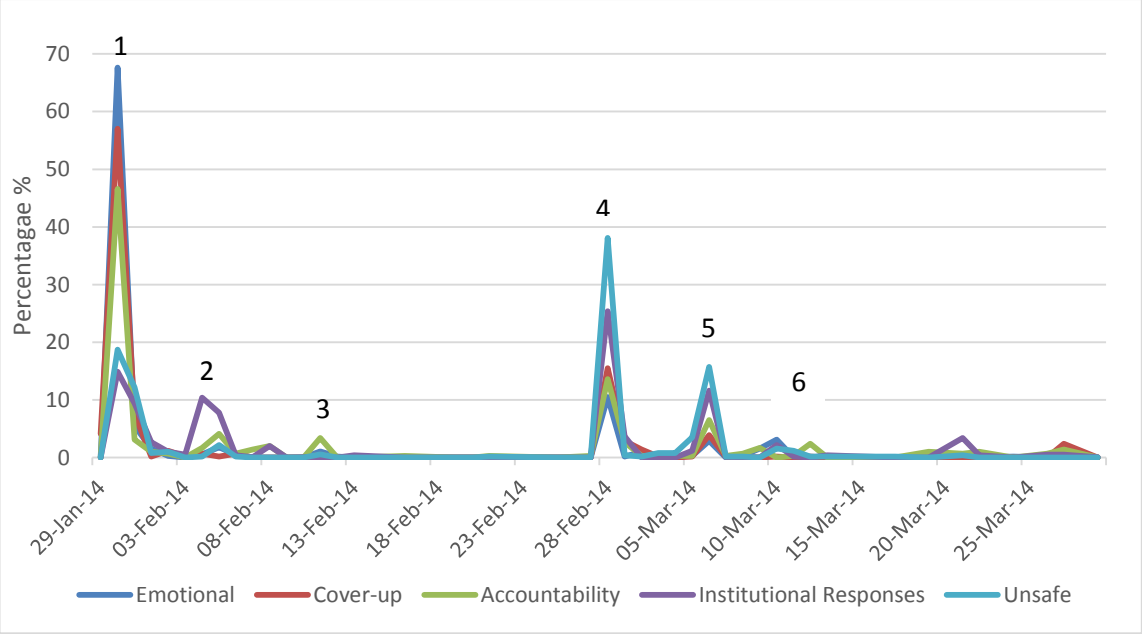
5: It is confirmed that an independent investigation of the hospital will be undertaken by the Health Information Quality Authority

6: The Health Service Executive confirm that a perinatal death occurred in Portlaoise hospital on March 8th 2014

Figure 9.2: Frequency of status updates by date and user

9.4.2 *Qualitative Results*

Qualitative analysis of the tweets resulted in the identification of five key themes; emotional reactions, cover-ups, accountability and governance, institutional responses and unsafe maternity services (Figure 9.3).



1: Current affairs television programme Primetime air the episode entitled Fatal Failures relating to a cluster of perinatal deaths in Portlaoise hospital in the Republic of Ireland

2: Minster for Health makes an emotional statement after meeting the families who had a perinatal death and announces the investigation by the Chief Medical Officer.

3: A mother releases a statement that she was only made aware that an investigation was undertaken on the perinatal death as a result of the Primetime programme

4: Findings from the Chief Medical Officer's report are published

5: It is confirmed that an independent investigation of the hospital will be undertaken by the Health Information Quality Authority

6: The Health Service Executive confirm that a perinatal death occurred in Portlaoise hospital on March 8th 2014

Figure 9.3: Frequency of status updates by date and theme

9.4.2.1 Emotional reactions

The majority of tweets; including retweets and replies, in this theme were characterized as negative affect responses where anger, distress and upset were communicated. As the current affairs programme "Fatal Failures" aired, tweets indicated that the viewers of the episode were shocked and upset by what was reported. A number of status updates indicated the frightening and distressing nature of the programme.

> *That was so incredibly sad #rtept. My son, nieces & nephews were born in portlaoise &I'll go to bed tonight counting my blessings.*
>
> *Heartbreaking and chilling at the same time- has unsettled me #expectingno3 #rtept*
>
> *So terrible looking at these beautiful babies that never got a chance to live their lives. Very distressing. #rtept*

Tweeters sympathized with the families for the perinatal loss they had experienced. The tweets reveal how individuals expressed empathy for these parents as they tried to comprehend the loss experienced, thankful that they themselves had not experienced such tragedy.

> *This is so upsetting. Feeling blessed that my little baby was delivered safely in Portlaoise. My heart goes out to those not as lucky #rtept*

Absolutely shocking #rtept Report Fatal Failures, heart goes out to families, should never have happened & should never happen again!

Just bawled my eyes out all the way through @RTE_PrimeTime My heart goes out to those families who lost their babies unnecessarily #rtept

My heart goes out to the mothers and fathers featured on #rtept #primetime I don't think I'd have the strength if I was in their shoes

@RTE_PrimeTime fantastic report, impossible viewing, inspiring families, cruel cruel system. Congrats. Hard not to be angry.

The shock and anger expressed on Twitter were aggravated by the portrayal of the hospital staff and management. The fundamental values of care and compassion, which are normally attributed to those who provide health related services, were at odds with the televised representation of those who were responsible for the care of the families who had experienced perinatal loss.

Can only imagine the torture of the uncertainty, questions, what ifs, maybes, if onlys these parents must have gone through for years #rtept

@RTE_PrimeTime absolutely shocking behavior. Hard to watch.

Can not believe what they did at portlaoise hospital, an utter disgrace to the medical profession. #Sickening

Heartbreaking watching #rtept Not good enough #HSE Shame on the hospital. My thoughts are with those brave families. Devastated lives.

Disgusted by the HSE and Portlaoise Hospital. Incompetent callous and cowardly #rtept

9.4.2.2 Cover ups

Tweeters indicated that they believed the hospital management's priority was to cover up the events surrounding the perinatal deaths rather than focusing on the appropriate care for the patients.

#rtept on neonatal deaths horrific viewing #HSE comes out poorly obstructing info to families, spokesman dodging issues, evasive.

#rtept I find the cover up so much more distressing than the actual deaths it was appalling for all but the mother who was left believing that something she did may have caused the death was just cruel

How do they sleep at night knowing they've sent somebody home not knowing why they're really leaving hospital without their baby. #rtept

As #rtept showed in heartbreaking detail tonight, real communication & open disclosure by health service is vital. Patients are what matter.

The Irish national broadcaster, and the journalists involved in the investigation, were praised for their role in informing the public firstly of the occurrence of the perinatal deaths but also of the suppression of information by the hospital.

#rtept Pubic Service Broadcasting at its best tonight! Harrowing stories of avoidable infant deaths at Portlaoise maternity hospital.

Common theme in Ireland on internal investigations, first instinct is to cover up, obstruct and frustrate. #rtept

Midwives in Portlaoise knew trouble was brewing and they were ignored. Maybe social media is the way forward so the public is informed.

Tweets indicated frustration with both the Irish Government and the Health Service Executive, whereby their actions were seen as reactive and defensive. It was suspected that the only motivating factor to investigate the health service was as a result of the expose by the Irish broadcaster rather than genuine concern for ensuring that healthcare standards are met.

Are we to assume reports were made available only because #rtept were investigating?

Reilly seeks report on baby deaths http://www.rte.ie/news/2014/0130/501123-prime-time-fatal-failures/ … surely our Health Minister doesn't need a TV docu to prompt an investigation #rtept shows again & again how reports are published & never implemented in our hospitals so women & babies die

We never learn! Barely a word about the HIQA #Savita report recommendations. Where is the sense of urgency about improving standards. #rtept

HSE guy - I regret ""IF"" any actions..... The usual PR speak. Maddening #rtept

Independent Hiqa inquiry into baby deaths in #Portlaoise hospital is essential. No point in HSE investigating itself. Families deserve truth

9.4.2.3 Accountability and governance

Tweets reveal immense dissatisfaction with the healthcare authorities as it was believed that if the recommendations of previous investigations on the Irish Maternity Services had been implemented these perinatal deaths would have been avoided.

#rtept sounds like complacency was rife in #Portlaoise no action taken on recommendations leading to unnecessary deaths, CTG, oxytocin

How many reviews and investigations do we need to have before change occurs - women and babies and all families deserve better #rtept

The tweets also revealed concern that there are no obvious implications when recommendations are not implemented or adhered to. Moreover, these tweets revealed how individuals appeared to be resigned to the fact that no official within

Government or the healthcare authorities would be identified and held responsible for these failures.

And tomorrow we Will discover that nobody Will be held accountable! #hse #rtept

The frustrating thing is nothing will change, where's the accountability, where is the governance. #Rtept

yes but we hear that "the hospital" is to blame, convenient to blame a building #noaccountability

James Reilly YOU are the head of the health service and have failed people across the board, change must come from the top down #portlaoise

It's so important that someone is held responsible for the deaths of the babies in Portlaoise Hospital. Can't be allowed to fade from media.

Given the belief that neither the Government or the healthcare authorities would take appropriate action, a criminal investigation was endorsed.

Isnt failure to act.....negligence, and when it results in death, manslaughter...? #rtept

Someone somewhere threw those baby reports on their desk & decided not to implement recommendations. Criminal. #rtept

@Newstalkfm what was allowed to continue is worse than negligence, it was criminal, the gardai should be sent into that hospital

Why all these toothless reviews re baby deaths at Portlaoise. Should be criminal investigation going to very top of hospital management &HSE

9.4.2.4 Institutional responses

Governmental responses, which were shared on Twitter by those in media, initially rallied behind the online reactions describing the events which occurred in Midland Regional Hospital, Portlaoise as inappropriate and unacceptable. The Government made assurances that a thorough investigation would be undertaken and the findings from this investigation would be acted upon to safeguard against similar events happening again.

Emotional Health Minister says Portlaoise concerns will be addressed http://dlvr.it/4sJVP7

Health Minister James Reilly says he was deeply disturbed by the RTE Prime Time revelations about child deaths at Portlaoise Hospital

Kenny: No family should have to fight for truth in our health system (via @thejournal_ie) http://jrnl.ie/1338933

Minister Shatter calls the manner in which Portlaoise Hospital treated families, as revealed in recent days, inexcusable.

Twitter was not utilized as a platform by any healthcare authority to release a statement in relation to the perinatal deaths. The initial response from medical institutions and professionals from the obstetric community utilized traditional methods of communication to inform the public that the maternity services were safe, making reference to the country's rates of perinatal death. These statements were then edited and tweeted by those working within media.

> *The @RCPI_ObsGyn has issued a statement to reassure people about Irish maternity services following last night's #rtept programme.*
>
> *Prof Fionnuala McAuliffe, @RCPI_ObsGyn, says Ireland is a very safe country in which to have a baby, with low rates of perinatal deaths.*

As concern, and its possible implication on service attendance, became more evident the Government focused on reassuring the public that the Irish Maternity Services were indeed safe.

> *EK: Portlaoise " will ensure that Ireland will continue to be recognised as one of the safest countries in the world in which to give birth"*
>
> *Gilmore reassures women over maternity services*
>
> *http://www.rte.ie/news/2014/0201/501627-maternity-portlaoise/ …*

9.4.2.5 Unsafe maternity services

Concern and uncertainty arose whereby the professional motives of the obstetric community and the Government were called into question. Status updates over the two months indicated the skepticism that was generated in relation to the management of not only the unit in question, which was branded as unsafe, but also the governance of the entire maternity service in Ireland.

> *Optimum ratio of midwives to patients 1:28. Ratios at Portlaoise hospital 1:75. How can this be possible?#unsafelabours*
>
> *#portlaoise maternity service cannot be regarded as safe and sustainable within its current governance arrangements*
>
> *I wonder if all maternity units were looked at would the others come out squeaky clean? So sad for those women and their families #rtept*
>
> *The claim that Ireland is one of the safest countries in which to give birth ringing ever more hollow #rtept*

The publication of the investigation by the Chief Medical Officer further reinforced doubts about the safety of Portlaoise hospital. In the report the Chief Medical Officer states that, in Ireland in a low-risk pregnancy, any maternal or perinatal death associated with labor or delivery are to be documented as perinatal 'never events'.[120]

HSE probe fifth baby death at Portlaoise Hospital as damning report brands it "unsafe"http://www.irishmirror.ie/news/irish-news/health-news/hse-investigating-fifth-baby-death-3194625 …

I suspect you will be hearing a lot about 'never events' and Portlaoise Hospital in the coming days. CMO report must be read to be believed.

In 2006, 08, 09 & 12, there were 4 neonatal deaths at the maternity unit in Portlaoise from 'never events' according to CMO

Portlaoise report recommends adverse events in low risk pregnancies to be deemed" never events".

Lack of confidence that the quality of care currently being provided could be considered safe saw women expressing fear, with some tweeting their reluctance to engage with or attend the services.

Id rather give birth on the side of the road than in that hospital #RtePT #HSE heartbreaking stuff

Heartbreaking and chilling at the same time- has unsettled me #expectingno3 #rtept

that won't ease my worries though, due to have baby in Portlaoise in early July :(

As someone due to give birth soon, I'll watching that CTG trace monitor like a hawk after #rtept & demanding fast action if needed.

9.5 Discussion

9.5.1 *Principal Results*

From the 29th of January till the 31st of March 2014 there were 3,577 status updates; including tweets, retweets and replies, posted on Twitter relating to a cluster of perinatal deaths that occurred in a maternity unit in the Republic of Ireland. Of these status updates, 40% were posted between the 29th and the 31st of January which coincided with the airing of the current affairs programme which brought the perinatal deaths to the attention of the public.

9.5.2 *Limitations*

The content of social media can be exploited by healthcare authorities whereby an analysis of tweets allows healthcare authorises to identify and respond to concerns.[227, 237] However our study may be limited by some factors. Firstly, the aim of the study was to evaluate the response on Twitter to the perinatal deaths; however we restricted our search to publicly available status updates. Twitter is an open forum where it is possible for connections to be non-reciprocal whereby a person may choose to follow an account and may not be followed in return. Yet, there are exceptions whereby account holders are given the opportunity to protect their account and make status updates available solely to those who they give permissions to. Twitter also provides the facility for users who are following each other to direct message each other, these messages are private and are not discoverable through the search facility on Twitter. Secondly, our study may be limited by our search terms, however we believe that given that our list of terms

were initially developed independently by two of the researchers (SM and LC) and that all terms identified by both researchers were included in the final list of search terms, that our search strategy was comprehensive. The data from this study show that interest in the events spiked and fell quickly which is similar to previous published data; it would however be of interest to examine the perception of perinatal death over a longer period of time to ascertain any differences in public reaction. Finally, studies have illustrated that Twitter is not fully representative of the general population[247] and therefore the results may be limited by selection bias. It would be of interest to ascertain if these findings would be observed following the examination of other social networking sites such as Facebook and/or following investigations which utilize more conventional social research methods offline.

9.5.3 *Comparisons with Prior Work*

The findings of this study support the statement, as reported by Ampofo *et al*., that people now use digital space to instantaneously evaluate and share their experiences of healthcare services while, in this instance, watching a national current affairs TV broadcast[234] By analysing this content our study identified a number of key themes highlighting the concern about the events which occurred in Portlaoise hospital but also regarding the governance of the entire healthcare service. During the course of the television broadcast the tweets indicated that individuals were both shocked and distraught by the events which resulted in four perinatal deaths. Over the course of

the broadcast the sentiment observed in the tweets transitioned from distress to anger. Of particular concern to the online community was the manner in which the hospital management were seen to have made attempts to supress information from parents about the events surrounding their babies' deaths. In the following days, as more details emerged and were shared by the media about the cases, the governance of the maternity services and the healthcare service as a whole were called into question. Our study identified such a level of dissatisfaction with the governance that a demand for a criminal investigation was called for. Similar to Burnap 2014[249], our findings illustrate that the frequency of tweet and retweets peaked in line with specific events; initial the broadcasting of the television programme and subsequently the announcement of an enquiry and the publication of the enquiry.

Research in relation to health communication is now focused on the participatory nature of the internet with particular reference to social media.[237] This reveals how the public can play a larger role in the various stages of knowledge translation which includes information generation, filtering and as well as knowledge amplification.[237] Our findings highlight the participatory nature of social media, in particular the filtering and amplification of knowledge generated around the perinatal deaths. This study found that almost half of all status updates which were replies were posted on the 30th of January when the TV episode "fatal failures" aired. Replies, when individuals were posting a response to a tweet, were indicative of individuals either supporting a statement or sentiment posted or querying the content which was posted. Chou *et al*. state how this process has transformed the

pattern of health-related communications, whereby online information sharing is considered more democratic given that it can be controlled by the patient, who shares the information of importance to them.[250]

However, these developments have raised concerns among health professionals and policy makers.[251] Due to the nature of social media information can be generated and circulated to a wide audience very quickly. Thus, although unintended, Chou *et al*. state that negative health impacts due to the communication of misinformation can occur.[250] The findings from this study indicate that the deaths which occurred were perceived as avoidable and that any future perinatal deaths should be prevented. Thus, given that the Tweeters were becoming increasingly distrusting of the Health Service Executive and the Government, our data would suggest that the users considered the information provided online and through the media as more credible. This finding is in line with those of Coleman *et al*. whereby people, in particular those from a lower socio-economic status, believed that information posted online by those similar to them was more credible.[252] Peterson *et al.* found that online user's perception of credibility varied and studies indicate that credibility of online information is linked not only with expertise but also trustworthiness.[253] This is illustrated in our study by the tweets in response to statements from both the obstetric community and the government. Efforts to reassure the women that the maternity services were safe, making reference to perinatal statistics, were considered deceptive and were believed to be misleading. This perception was reinforced following the publication of the Chief Medical Officers report which stated

these deaths should from now on be considered as perinatal “never events” and that if such an event were to occur in the future, no reassurance can be derived from summary statistics such as perinatal mortality rates.[120]

This study found that one third of all content generated on Twitter in relation to the perinatal deaths were by media outlet accounts or media personnel. Almost all of the content tweeted by media outlets were tweets of original content with individual accounts more likely to retweet such information. This activity is suggestive of the influence the media have within digital spheres and its potential to influence not only perceptions but also have an impact on patient’s decision making in relation to healthcare services. Ampofo *et al*. refer to this process as ‘mediatisation’ whereby the logic of the media guides behaviours and decision making throughout society.[234] This phenomenon was also identified in a study undertaken by Donelle and Booth who demonstrated that tweets and public discussions related to health promotion were shaped by a political-media social dynamic.[246] This author concluded that it is important to ascertain how the influence of this dynamic on the representation of health, through social media, impacts on the public perception and interaction with healthcare.[246] Our findings would suggest that during this period that Tweeters perceived the Irish maternity services as unsafe. A recent news article has indicated that there has been a 12% reduction in the number of births in the hospital under review, with the Health Service Executive confirming that in the direct aftermath of the controversy a reduction in attendances at booking clinics was observed.[254]

The findings from this, and other similar studies, have shown that Twitter may have the potential to influence patient decision making and behaviours. Twitter was not utilized as a platform by any healthcare organization or authority to release a statement in relation to the perinatal deaths. One consequence of this is that the message was broadcast through the media, which potentially inhibits the ability for the intended message to be delivered to its target audience. Lagan *et al*. stress that health professionals must acknowledge that decision making is influenced by the information which is sought and consumed by patients online.[229] These authors state that there is a need for health professionals to engage in this process and that this engagement would allow them to direct patients to both comprehensive and accurate information. Thackery *et al*. further state that is important that health care professionals and policy makers engage and exploit the participatory nature of these technological developments.[255] These new e-patients expect interaction and not that social media be used as "virtual pamphlet walls".[246]

9.6 Conclusion

Twitter activity provides a useful insight into attitudes related to health related events. The role of the media in influencing opinion is well documented and this study underscores the challenges that clinicians face in light of an obstetric media scandal. Given that patients are now likely to access health related information online it is imperative that healthcare providers are meeting the needs of potential service users. Our study highlights the need to exploit social media effectively in

order for healthcare providers and policy makers to identify and respond to concerns in relation to healthcare services. Further study to identify how the obstetric community could develop tools to utilize social media sites, such as Twitter, to disseminate valid health information could be beneficial.

Author Contributions:

SM and KOD contributed to and were responsible for the conception and design of the study. SM and LC were responsible for data collection. SM was responsible for data analysis and the initial drafting the article. All authors; SM, LC, RAG and KOD, contributed to revising the manuscript critically for important intellectual content and approved the final version for publication.

Chapter 10

10 Discussion

10.0 Discussion

Across the globe on a daily basis, there are women and men who will experience the loss of their baby either during pregnancy, labour or shortly after birth.[2, 8, 22] The care and support they receive varies greatly depending on the country in which they reside, and the health systems and standards that are in place.[2, 8, 22] For some, the burden has the potential to be even greater than usual, as many cultures assign blame to the woman, and she and her family may experience considerable stigma and social isolation.[23-25] To date, the existing literature has not fully explored the lived experiences of pregnancy loss and perinatal death of these populations.

To attend to this deficit, I undertook eight studies that aimed to further investigate both causes and consequences of pregnancy loss and perinatal death. The experiences of the bereaved women and men were distinctly different depending on whether they experienced miscarriage, an ectopic pregnancy or perinatal death of either a singleton or twin baby. However, I have identified seven main themes relating to their experience and the care they received. These include; 1) Initial reactions to the diagnosis of loss, 2) Acknowledgement of the loss, 3) Management of loss and perinatal death, 4) Impact of pregnancy loss and perinatal death on relationships, 5) Medical investigations for pregnancy loss and perinatal death, 6)Supportive care in early pregnancy and 7) Knowledge and perceptions. These themes reveal several important factors in relation to causes and consequences of

pregnancy loss and perinatal death. These themes will now be discussed separately and will be considered in light of clinical practice and healthcare policy. With these in mind, recommendations for future research related to these themes will be proposed.

10.1 Initial reactions to the diagnosis of loss

10.1.1 Main findings

There have been significant improvements in ultrasound and antenatal care, particularly in high income countries in recent times. As a result there has been a reduction in the rates of both perinatal mortality and morbidity.[47] Research indicates that due to these advancements in care, parents now have high expectations of a positive outcome once pregnant.[256] A recent study undertaken in the United States indicated that the American general population believed that miscarriages are an uncommon complication of pregnancy in a high income country.[166]

The parents who took part in the studies reported in Chapters 4-8, recalled how they were wholly unprepared for the possibility of pregnancy loss or perinatal death. Each of these losses left both parents shocked and devastated as they tried to come to terms with what their diagnosis meant. The parents recalled how they

were unable to fully comprehend the magnitude of their diagnosis, especially when the clinical management of their pregnancy took precedence over their emotional responses. Irrespective of which type of loss was experienced, they had to make a number of immediate decisions in relation to their care. Firstly, they may have had to undergo a number of scans or tests in order for clinicians to confirm the diagnosis, be it for an ectopic pregnancy, congenital anomaly or an intra-uterine death. Decisions then needed to be made in relation to their management, in some cases whether there was a need for medical or surgical interventions, and decisions in relation to the potential procedures which may be undertaken after birth. The studies' findings illustrate the overwhelming nature of these experiences as parents recalled their decision-making processes being emotive; it was guided by their hearts rather than by their heads.

Engaging with patients is now recognised as a fundamental component of good quality healthcare.[257-259] In a review of the literature Barello *et al.* illustrate how national governments support and advocate for patient engagement in care as it enhances care, the patient experience, leads to better health outcomes and also reduces the costs of care.[257] Heazell *et al.* outline the considerable cost of stillbirth alone, the authors outline how the costs of care are not only related to the direct costs of medical care but need to consider the long term costs as these patients return to the maternity services following loss as well as the non-monetary costs.[22, 260] This is in keeping with findings from Chapter 3 where the need for a

greater appreciation of the level of care required for women who experience pregnancy loss was identified.

Heazell *et al.* further argue that evidence based guidelines need to be developed which detail the most appropriate bereavement and postnatal care for both parents following a stillbirth.[88] Based on the findings of this thesis I would argue that such guidelines should, not only involve the patient while the guideline is developed, but should encourage patient engagement when being cared for. Crucially, healthcare professionals need to be conscious of the emotional state of parents upon receiving the news that their baby has died or may soon die. The temporal context appeared influential; given the acute timeline between a diagnosis and experiencing a loss, there may be very little time for parents to adjust. This emphasises the challenge for clinicians whereby shared decision making can be difficult in practice.[224]

The needs of all these parents are complex and they were appreciative when healthcare professionals spoke with them openly and frankly, but showing compassion and empathy. The diagnosis had already been unexpected, so parents needed to know what to expect next not only in terms of the management of the pregnancy, but also in terms of its potential impact on subsequent pregnancies. Previous literature has found that if there is good communication between parents and healthcare professionals that it has a long term positive impact.[86, 214] These

findings from my studies also further supports the literature in relation to patient engagement whereby not all patients will want to make clinical decisions but the majority have a desire to be fully informed about their diagnosis, possible pathways of care and ultimately about how their care will then be managed.[86, 261]

10.1.2 Implications for health policy and clinical practice

Whether parents experienced a miscarriage, ectopic pregnancy or perinatal death they recounted how they felt ill prepared for the diagnosis. Being an unexpected outcome added to the traumatic nature of the event. The parents in this study believed that improvement of information provision would be beneficial allowing for individuals to better prepare for pregnancy but also emphasising that there is a real possibility that pregnancy could end in either pregnancy loss or perinatal death. This finding underscores the need for public health campaigns in relation to pregnancy loss and perinatal death. Patient education has proven to be a valuable tool towards improving adverse health outcomes and therefore applying this to pregnancy loss and perinatal death could be very effective. Such a dedicated public health programme would not only educate prospective parents but enable them to engage more fully with the maternity services during their care which may in turn improve patient satisfaction.

10.1.3 Recommendations for future research

Pregnancy loss and perinatal death are the most common adverse outcomes in pregnancy but the findings from this thesis indicate that there is considerable misunderstanding of this amongst prospective parents and in wider communities. Raising awareness of pregnancy loss and perinatal death through a targeted education campaign could improve knowledge and understanding. In order to design such a campaign it would be informative to assess the knowledge and perceptions of the general population in relation to pregnancy loss and perinatal death, which to date remains largely unknown. Thus, there is a need for a large-scale study, with a nationally representative sample, to assess the public's current knowledge and perceptions. By determining the current knowledge gaps researchers will then be able to design appropriate and effective educational campaigns.

10.2 Acknowledgement of the loss

10.2.1 Main findings

There is considerable variation observed in relation to how pregnancy loss and perinatal death are defined, some of this variation is attributable to the legal definitions which are dependent on either the gestational age and/or the weight of the baby. Irrespective of the gestation at which their loss occurred, and the medical classification of the loss, all parents interviewed as part of this thesis revealed how the loss of their baby was a profoundly distressing experience. The

findings from chapter 4 emphasised the importance that their miscarriage was acknowledged not only by family, friends and healthcare professionals but also through ritual. These rituals included arranging ceremonies, writing of poems and keeping diaries in relation to their experience of miscarriage. As highlighted by McCreight pregnancy is more than a medical experience.[77] The role of parent emerges well before the birth of a child as bonds are built early on in pregnancy for both women and men.[114] In response, current practices within the maternity setting focus on the value of continuing these bonds with the baby in order to help parents make meaning of their loss.[21, 262, 263]

The findings within this thesis reaffirm the positive impact such bereavement practices can have. Parents who experienced miscarriage or perinatal death emphasised how appreciative they were when healthcare professionals openly acknowledged the loss of their baby and provided them not only with psychological support but also facilitated meaning-making through the provision of mementoes as well as rituals such as funerals and the annual service of remembrance. Upon attending the hospital for interview parents recalled how they had created a bond with the hospital and in many cases this was a positive one. One participant speaking of the 'comfort' she experiences when attending the maternity hospital expressing how 'this is where her baby lived', thus this was her baby's home. Literature illustrates that such bonds to a place are related more to the attachment process rather than the physical space itself.[264] It is the personal relationships

and culture within the maternity hospital which results in these parents developing bonds with the hospital as a place.

The social context is important here as pregnancy loss is often referred to as an invisible loss[20, 182] given that the loss occurs within the mother's body and often may not be publicly acknowledged.[21] Research shows that this lack of acknowledgement can result in pregnancy loss being a socially isolating event[21, 22, 86] The findings of my thesis further support this as parents recalled how they rarely discussed their pregnancy loss and/or perinatal death with people outside of their family, stating how in doing so would create social awkward situations with those in the wider community.

10.2.2 Implications for health policy and clinical practice

In 2016, the Irish Government published the first national maternity strategy for the Republic of Ireland. Within the national maternity strategy, the rates of pregnancy loss and perinatal death are reported, referencing how these rates are low when compared internationally.[265] There is no specific mention of any action that would endeavour to reduce the rates of pregnancy loss and perinatal death further, with the exception of expanding the current perinatal pathology services in Ireland. This may have been a missed opportunity to recognise and support global strategies such as the WHO's new action plan which aims to eliminate all preventable stillbirths in high income countries.[7] The omission of specific actions

within the National Maternity Strategy further emphasises how pregnancy loss and perinatal death, as a public health issue, are often overlooked, which reinforces the "silent loss" status within society.

Studies highlight how the acknowledgement of the death of the baby is crucial for parents to come to terms with their grief.[21, 77, 266] As indicated by the findings in this thesis there have been important changes over time, where the acknowledgement of pregnancy loss and perinatal death has had a positive impact on parents. Nevertheless, my findings indicate that improvements can still be made. Those who were less likely to report positive encounters were those who experienced a pregnancy loss at earlier gestations. The women who experienced ectopic pregnancy in particular did not receive the same, if any, bereavement care leaving these women with the impression that their loss was not a legitimate one. All parents in this thesis voiced the need for their baby to be recognised and accepted. Therefore, the forthcoming HSE standards for bereavement, which includes recommendations for the care of those who experience ectopic pregnancy, has the scope to further improve the care provided to all who experience pregnancy loss and/or perinatal death.

10.2.3 Recommendations for future research

Pregnancy loss and perinatal death have been referred to as a "silent loss", one associated with stigma and shame. This study recommends that there is a need for

increased awareness and acknowledgement of pregnancy loss and perinatal death. Consideration should be given to introducing a community level intervention in order to change attitudes and beliefs of the public. In order for such an intervention to be successful it may be beneficial to utilise social marketing techniques, as social marketing can influence social contexts therefore creating an opportunity for an intervention to be received more positively.[267] The impact of positive communication and discourse relating to pregnancy loss and perinatal death are areas for future research.

10.3 The impact of the environment

10.3.1 Main findings

Throughout a number of the studies in this thesis parents made reference to the hospital environment and how the physical environment influenced their experience of pregnancy loss and/or perinatal death. Many of the participants spoke about the importance of having dedicated areas for pregnancy loss and/or perinatal death, these included the early pregnancy loss unit, the pregnancy loss clinic as well as dedicated rooms on wards to give parents and couples privacy and dignity at the time of their loss. However, shortcomings were identified by these parents, in particular related to the hospital's emergency department. These women reported how they presented to the emergency department with, most of the time, unexpected pregnancy loss. It was within the emergency department that they had to receive the news that there might be something wrong with their

pregnancy and further, that they might have to return to the early pregnancy unit to have this confirmed. These parents disclosed how this environment aggravated an already difficult event. How the design of a medical department or ward can impact on the patient experience is not solely limited to the maternity services. Studies examining emergency departments have identified aspects of design which impact on patient privacy and confidentiality. In support of the findings in this thesis these studies identified that patients were more comfortable discussing their history or receiving a physical examination in private rooms rather than those in curtained areas.[268-271]

10.3.2 Implications for health policy and clinical practice

In 2016, the Irish Government published the first national maternity strategy for the Republic of Ireland. The development of the strategy was in response to a number of reports[96, 119, 120, 272-275] that highlighted deficits in the current maternity service. The purpose of the strategy was to implement and maintain a national service that ensures women are afforded care that reflects best practice.[265] The strategy document states that in order to improve the maternity services, it is imperative that national and international evidence-based guidelines should be implemented, including the forthcoming Standards for Bereavement Care following Pregnancy Loss and Perinatal Death from the Health Service Executive[275] which will see the establishment of trained bereavement teams in each maternity unit/hospital.[265]

However, all healthcare professionals, including bereavement teams, can be limited by the system within which they work. The findings from these studies indicated a number of shortcomings with the system which parents felt the hospital management should be more sensitive to. Parents felt small changes could make a substantial difference to their experience. In particular it was felt that waiting for extended periods of time for confirmation of a diagnosis in an area with other pregnant women was particularly difficult. They felt greater access to dedicated clinics, such as the early pregnancy clinic, could enhance the care provided.

To date, research illustrates the importance of providing access to space where privacy is ensured for parents who have experienced pregnancy loss or perinatal death.[78, 275, 276] The physical design of the maternity hospital contributed to some of the negative experiences by the parents in this study. Since this study was undertaken, Cork University Maternity Hospital (CUMH) redesigned and refurbished some of the departments in order to provide patients with more comfort and privacy while being cared for.

10.3.3 Recommendations for future research

Not all maternity hospitals have facilities such as the early pregnancy loss clinic and many of the women who come to the hospital experiencing pregnancy loss and/or perinatal death will often present at the emergency department first. Research from CUMH indicates that moving from curtain cubicles to walled rooms within the emergency department provides patients with more privacy ensuring patients were

more comfortable when discussing their presenting complaint as well as their test results.[277] Other maternity emergency departments should consider walled rooms instead of curtained cubicles when renovating or designing their departments. Future research should examine what the impact of these changes would have on the patient experience.

10.4 Impact of pregnancy loss and perinatal death on relationships

10.4.1 Main findings

Quantitative studies have indicated that bereavement from pregnancy loss and/or perinatal death is psychologically challenging for parents.[11, 14, 15] Major depressive disorders are reported in 10% to 50% of women who experience pregnancy loss.[15, 19] Distress can be experienced for a number of months after loss, with some experiencing it up to one year later.[15] Despite this, few studies have examined the lived experience of women, and even fewer recognise the experience of men. The findings of this thesis show the experience of pregnancy loss and/or perinatal death is a very traumatic event for both parents. In keeping with similar research, this experience can be isolating, where both women and men rely on their own ability to emotionally steer themselves through the experience. This was particularly evident in chapter 8 as parents revealed how challenging it was when the understanding and perception of the predicted outcome for their baby following a diagnosis of congenital anomaly differed amongst the couple. These parents reported how this resulted in vast differences in their grieving process which resulted in tension within the relationship.

How women and men respond to grief was reflected in the differing accounts of the parents in chapters 4, 6 and 7 also. It is believed that cultural norms can hinder men from expressing grief.[40, 113, 170, 211] This was illustrated in this thesis whereby the men identified their primary role as that of a support to their partner; this meant they would not openly discuss their own grief. Nonetheless my findings indicated that although men did not openly express their grief, they did find the experience distressing. Both parents grieved, but their patterns of grief differed, and this placed a strain on their relationships. Gold *et al.* examined parental relationships following pregnancy loss and perinatal death and found that these relationships are at a higher risk of dissolving compared to those where the pregnancy ended in live birth.[278]

10.4.2 Implications for health policy and clinical practice

Research consistently shows that those who experience pregnancy loss and perinatal death experience immense grief and require appropriate emotional support.[11, 16, 18, 19, 23, 211] Although research indicates that their grief trajectory is normal, from high to low over a two-year period, there are multiple different patterns of grief recorded during that period.[211] The findings from this study indicate that there is a need for individualised specialised care for both women and men following loss. Such supports may be of the utmost importance to aid both partner's emotional recovery following the loss but also to respond to any

of their potential concerns of recurrent loss. Such concerns, as illustrated from the findings of this study, may result in prolonged delays or avoidance of future conception. Therefore, another recommendation from this study is that bereavement support offers not only individual psychological support to mothers and fathers but should also consider the benefit of relationship counselling following pregnancy loss and/or perinatal death.

10.5 Medical investigations for pregnancy loss and perinatal death

10.5.1 Main findings

All participants in this study revealed their fears of recurrent loss and expressed a desire to determine the cause of the initial pregnancy loss. Research indicates that genetics are a factor associated with reproductive loss[279] and the parents in my work were keen to determine if this was the causal factor in their loss. The results of chapter 4 indicated how women who were ineligible to have tests to fully investigate the cause of their miscarriage perceived it as an inadequacy in service provision. These women believed that their eligibility for tests should not solely be determined by experiencing recurrent miscarriage but should take into consideration other risk factors with specific reference to advanced maternal age.

Common findings from chapters 4, 5 and 6 also indicate the importance of search for meaning, 'why did this loss happen to us' as parents question 'what did we do

to deserve this'. Their decisions to undertake investigations were therefore not solely based on the clinically available information. Their personal interpretation of what happened to them was being drawn upon; e.g. having had negative thoughts, loss as a consequence of physical over-exertion, or it being a 'freak' accident. While clinicians endeavour to determine the cause of pregnancy loss and/or perinatal death, these studies show that it is just as important that they acknowledge the emotional responses of these parents many of whom, in keeping with the findings of Malacrida *et al*., harbour considerable guilt for the loss of their baby.[195]

While all parents were willing to undergo investigations themselves to help determine the cause of their loss, findings from chapter 6 examined the parental perception of perinatal autopsy. Autopsy is an important tool to aid clinicians determine the cause of death however some parents embodied a 'protector' role. They themselves would undergo investigations but they were adamant that they would protect their babies from further harm: in particular, they refused consent for perinatal autopsy. In line with Holste *et al.*[196] the parents, in chapter 5, who refused to consent for an autopsy wished to ensure that no further harm would come to their child.

10.5.2 Implications for health policy and clinical practice

The results from these studies further emphasise the importance of communicating when counselling parents in relation to the various investigations which may or may not be undertaken after pregnancy loss. The role of perinatal pathology has

consistently been identified as a service, which may help further reduce the rates of perinatal mortality through robust investigation of the causes of death. However, in the National Perinatal Epidemiology Centre's report on perinatal mortality in Ireland, the rate of autopsy was just 43%.[5] The NPEC also reported that of those who did not have an autopsy, the majority (81%) of parents were offered the procedure.[5] Counselling parents at a time of intense grief is difficult and as the research detailed in this thesis has also indicated that there is a temporal effect that can constrain healthcare professionals. The findings in this thesis indicate that parents' decision making is profoundly affected by their emotional response, and that clinicians and health professionals may play a key role in parents decision making regarding perinatal autopsy. Therefore, there is a need for a multidisciplinary approach: it is not the case of simply making services available but a matter of making them acceptable to patients. In order to achieve this, there is a need to listen to and address parental concerns when counselling parents for consent.

Research indicates that there are many factors which affect pregnancy outcome that are often present before pregnancy such as alcohol use, smoking and high body mass index.[280] Nevertheless, as illustrated by the findings in this thesis couples have limited knowledge of their risk of adverse pregnancy outcomes. To minimise such risks in pregnancy couples can attend pre-pregnancy counselling to access information on general and personal risk factors where couples are introduced to possible preventive measures.[281] Pre-pregnancy counselling should

be targeted at the general pregnancy population in order to reduce women's risk of adverse outcomes in pregnancy but to date, with the exception of diabetes, there have been very few interventions introduced.[282] Based on the findings from this thesis I recommend the development of targeted pre-pregnancy counselling intervention for those who experience pregnancy loss and/or perinatal death. Following appropriate investigations of previous pregnancy loss healthcare professionals will be able to impart accurate information to parents about the potential risk of recurrent loss in a subsequent pregnancy. Such pre-pregnancy counselling will also allow for healthcare professionals and patients to consider how to manage a future pregnancy, taking both physical and psychological aspects of the pregnancy into consideration.[283]

10.5.3 Recommendations for future research

Almost half of pregnancy losses are attributed to an unknown cause.[189] All participants in this study revealed their fears of recurrent loss and were driven by a desire to determine the cause of their loss. Following a review of the literature Horey *et al.* found there was no randomised control trial relating to interventions for supporting parents' decisions about autopsy after stillbirth.[118] The qualitative studies in the thesis, as well as other previously published literature,[71, 192, 195] have indicated a wide range of contextual and psychological factors which may influence the medical investigations, including autopsy, being undertaken to determine the cause of pregnancy loss and perinatal death. These factors include,

but are not limited to: eligibility for investigations, dissemination of accurate information and communication skills; availability of specialist perinatal pathology and public discourse. There is the need to develop an intervention to supporting parents' decisions not only in relation to autopsy but also in relation to other possible medical investigations. It is imperative that the qualitative work guides the development of such an intervention and future research examine the efficacy of the contextual and psychological aspects included in the intervention.

10.6 Supportive care in early pregnancy

10.6.1 Main findings

The findings from this thesis indicate how both women and men harboured fears of recurrent loss. The fears of a recurrent loss were not only present when women became pregnant again but were evident when couples began to consider embarking on another pregnancy. Previous studies have indicated how pregnancy following pregnancy loss or perinatal death is stressful as women report high levels of fear of losing another baby resulting in hypervigilance of their pregnancy symptoms.[206, 284, 285] In chapter 2, I identified the detrimental effect stress can have whereby women who experience stress are more likely to experience miscarriage. These results are in keeping with similar prospective studies.[57, 137] However, the study further builds on these findings by identifying that it was women's perception of stress and their ability to cope which had the greatest influence on pregnancy loss. Findings also indicated that having a history for pregnancy and/or perinatal death was also associated with miscarriage and

therefore I recommend the need to develop and evaluate targeted interventions that could improve coping skills for women who may be more vulnerable to stress which might be effective in lowering the risk of miscarriage.

Throughout the qualitative interviews in this study resources such as the early pregnancy unit and support provided by staff were identified as supportive in early pregnancy when these women felt they were most at risk. In keeping with the studies by Clifford[286] and Côté- Arsenault,[287] these women expressed satisfaction with a dedicated service offering them reassurance and continuity of care. The cohort study undertaken by Clifford *et al.* highlight that if a certain level of support is provided in early pregnancy then there can be excellent outcomes in pregnancy after unexplained recurrent first trimester miscarriage.[286]

10.6.2 Implications for health policy and clinical practice

The education of staff on the importance of the provision of supportive care in the next pregnancy is pivotal. Research indicates that over half of women who have a perinatal loss will become pregnant again.[203, 204] Pregnancies following loss are reported as being anxiety-laden.[287] The findings from my study, in light of supportive literature,[286, 287] indicate the need for dedicated clinics where patients can attend to receive additional support and reassurance throughout a subsequent pregnancy. Despite this there are still no clearly defined pathways of

care for these women. The Royal College of Physicians of Ireland (RCPI) and the Royal College of Obstetricians and Gynaecologists (RCOG) recommend that, following stillbirth, women should attend an obstetric consultant-led antenatal clinic and these women should have early access to care.[121, 201] However there is still uncertainty around this guidance[209] and therefore there may be a wide range of practices and/or interventions being used in the various maternity hospitals and units across the country. There is need for greater clarity in relation to how best to support women in the next pregnancy in order to ensure there is greater consistency with how these women are cared for across maternity units.

10.6.3 Recommendations for future research

It has been acknowledged that psychosocial stress may predict a woman's use of prenatal services and the health of infants.[140] The findings from this thesis indicate that there is an inherent need to understand the correlation between the social, psychological and biological factors affecting pregnancy loss. We have provided additional evidence that stress may be associated with pregnancy loss. Building on the evidence in the wider literature there is a clear need for supportive care in early pregnancy. To date, few studies have examined interventions aimed at reducing stress in pregnant populations. The findings of our study suggest that a randomised controlled trial of intervention within the first trimester is needed to determine the best approach to providing emotional support and effective care for bereaved women in the next pregnancy.

10.7 Knowledge and perceptions

10.7.1 Main findings

One of the key findings of the thesis was the need for increased awareness in relation to pregnancy loss and perinatal death. With vast improvements in routine obstetric care the rates of mortality have decreased significantly. Healthcare professionals and the research community continually strive to further reduce the rates of perinatal mortality.[2, 8, 22] However, there will still be some parents who will experience loss at some point during pregnancy, labour or shortly after birth. Pregnancy loss is the most common adverse outcomes in pregnancy and yet the women and men who participated in my studies were completely unaware of their risk of experiencing pregnancy loss and perinatal death.

During pregnancy women seek out information in relation to pregnancy and the services that are available to them.[225] To date the provision of pregnancy related information from the obstetric community has been through traditional media.[225] However, pregnant women are now turning to online services in order to access pregnancy related information.[225, 267] Research shows that people, including pregnant women, consider that the information that is provided to them online is credible.[253] The credibility of online information, including media reports, is not solely linked to expertise but also the perceived trustworthiness of the information.[225, 252, 253] In spite of this, research also illustrates that media reports, including those online, which are related to pregnancy can potentially misinform pregnant women.[239]

The findings from all the qualitative studies, including the analysis of Tweets in relation in perinatal death in Chapter 9, illustrate some of the misperceptions in relation to pregnancy loss and perinatal death. These misperceptions can often be reinforced when authorities state that certain maternal and perinatal deaths in Ireland should be referred to and investigated as, 'never events'.[120] The findings in chapter 9 saw women expressing fear and a reluctance to attend non-specialist maternity units within Ireland as the professional motives of the obstetric community and the Government were called into question.

10.7.2 Implications for health policy and clinical practice

Since 2012 there has been considerable national and international media coverage reporting a number of adverse incidents, which in turn have resulted in a number of independent enquiries into the services.[96, 120, 272-274, 288] The national maternity strategy was published in response to these reports and acknowledges that currently, there is little confidence in the maternity services, identifying a need to regain the public's trust.[265] Based on the findings of this thesis I have identified a need for improved communication by healthcare professionals in order to disseminate valid health information in relation to pregnancy loss and perinatal death. In order to achieve this there is a need for healthcare providers and policy makers to engage with the public, listen to their concerns and address them, rather than providing "virtual pamphlet walls".[246] In doing so, there is an opportunity to

initiate positive dialogue in the public domain in relation to the care and support provided to those who experience pregnancy loss and perinatal death. Results from this thesis indicate that women, in particular, needlessly feel shame and assume an enormous about of guilt: they blame themselves for the loss. It is important that with the dissemination of valid information that women can feel reassured and supported if they do experience loss.

It order to achieve this it is important to acknowledge how people now access health related information. In Ireland, a study showed that the vast majority of pregnant women in Ireland use the internet for pregnancy information.[225] Research also indicates that people also consider information from both online and media sources up to date but also they are seen as more credible sources compared to traditional media such as magazines and leaflets.[228, 234, 253] It is imperative that health related information is provided to the target audience in a format they are willing to engage in. Based on the findings from this thesis there is a need to utilise both online and media sources to disseminate valid health information. Website and mobile applications in particular have great potential for such dissemination, given the recent developments in these technologies it would also allow for the information to be easily updated in line with any new emerging evidence.

However, first and foremost, there is a need for the Irish Government to regain the public's trust in relation to the maternity services in Ireland.[265] The use of a mass media campaign to direct target audiences to the source of valid information would be of benefit. As outlined by Wellings *et al.* there are both strengths and weaknesses for using the mass media in health promotion.[289] As evidenced by the publication of the first Irish maternity strategy mass media interventions provide a trigger for other initiatives. If utilised correctly the mass media may play an important role in informing the public and keeping pregnancy loss and perinatal death on the political agenda.[289]

1.7.3 Recommendations for future research

There is a great need for the dissemination of valid health information in relation to pregnancy and birth. Recent research demonstrates that the method patients chose to consume health related information is changing, with an increasing number turning to resources online. Further study to identify how the obstetric community could develop tools to utilise online resources, such as websites, mobile applications, and social media, to disseminate valid health information could be beneficial.

Media coverage relating to pregnancy and birth is often emotive, and results from this thesis highlight such reporting can potentially misinform the public, resulting in confusion and anxiety.[239] The longitudinal impact of such reporting on parental

perception is an area worth investigating. Building on the work of Nuzum *et al*., who identified how consultant obstetricians were fearful of media coverage due to concerns about medico-legal litigation,[90] there is also a need for further research into the long term impact on obstetricians, midwives, and other health professionals working within the maternity services.

10.8 Summary

International studies indicate that early in pregnancy parents begin to develop bonds as they plan their future with their babies.[114] However, research also indicates that there is a considerable risk that a woman may experience loss during the perinatal period. Evidence shows that women are at greatest risk of pregnancy loss in the early weeks of pregnancy.[1] Evidence also shows that twin and higher order pregnancies are also associated with increased perinatal risk, compared to singleton pregnancies.[5, 44]

Throughout published literature, there is considerable variation in the report of rates of miscarriage, ranging from 8% to 50%.[1] As part of this thesis, a prospective cohort study was conducted which examined the relationship between stress and miscarriage. This study found that one in three women miscarried and these women were most likely to miscarry in the first trimester. In order to ascertain how much stress women may experience, a number of self-report measures were included namely perceived stress, emotional wellbeing, maternal social support, life

orientation, and a history of depression and/or anxiety. Findings indicated that women with high levels of perceived stress were more likely to miscarry. It was therefore the perception of stress and the woman's ability to cope with it which had the greatest influence on pregnancy loss, rather than an increased accumulation of stressful life events. The findings of this thesis support those of a retrospective study in the UK whereby women who reported feeling stressed, anxious, depressed, out of control or overwhelmed in their first trimester had higher odds of miscarriage.[30] In light of these findings, this thesis illustrates that there is a need for supportive care, particularly in early pregnancy. Further work to develop and evaluate targeted interventions that could improve coping skills for women who may be more vulnerable to stress might be effective in lowering the risk of miscarriage.

Although there is considerable variation in the rates reported for miscarriage, much of this variation is observed in the first trimester. The rates of second trimester miscarriage, reported internationally, are more consistent. As part of this thesis, the morbidities associated with second trimester miscarriage were examined. The incidence of second trimester miscarriage reported at 0.5% in a low risk population, comparable to other similar international studies.[151] Findings from this study indicated that all of these women required an in-patient admission, staying on average for 2.7 days. The study found that within this population, two-thirds of women required medical induction of labour and two-thirds also required intramuscular opioids for analgesic control. Thus, there needs to be a greater

appreciation of the level of care required for women who experience a second trimester miscarriage and the psychological impact of such morbidity should be considered when counselling women experiencing a second trimester loss.

Existing research indicates that pregnancy loss and perinatal death can be an extremely difficult bereavement which impacts on the physical and mental health of parents as well as siblings, grandparents and subsequent children.[22] Acknowledging the extensive impact on both men and women's wellbeing, there have been significant changes to the care offered to parents in developed countries which have been informed by modern theories of bereavement[25].

Healthcare provision is transforming and, as evidenced by the Irish Maternity Strategy, is now been driven to be more consumer-centred allowing service users to be even more engaged in the care they receive. In order to achieve this there is a need to engage with parents' to explore how they make sense of their experiences and to establish if they feel that their needs are being met. Therefore, an interpretative phenomenological analysis was undertaken. These analysis allow for a deeper understanding of these parents unique experiences but also allow for a comparison of the specific consequences of pregnancy loss and perinatal death. Existing research has not addressed perinatal death and pregnancy loss in this way before. A major insight revealed from this thesis is how parents are not prepared for the possible complications they may experience in pregnancy. This finding is

further supported by the analysis of social media content related to perinatal death. Our study identifies a need to develop tools in order to disseminate valid health information in relation to pregnancy loss and perinatal death.

This thesis supports the provision of many maternity hospital bereavement practices but these parents also identified a number of omissions in certain aspects of their care. The studies within this thesis illustrate how experiences differ depending on the kind of pregnancy loss these parents had. The essence of these differences lies in the existing pathways of care for pregnancy loss and perinatal death. The care provided to women who experience miscarriage, Ectopic pregnancy or perinatal death varies considerably whereby women can be cared for either as outpatients or inpatients and parents will also have different access to bereavement services according to the pregnancy loss they experienced. However, these studies show that although their pathways and experiences are different, the impact of pregnancy loss and perinatal death is a very traumatic event in these people's lives. Differences were not only observed in relation to the type of pregnancy loss experienced but also between men and women. While existing research indicates that these parents will experience a normal grief trajectory the findings from this study show the complex nature of the grieving process and the possible strain it can place on relationships when the grief is not experienced in tandem. The findings from this thesis further illustrates how both mothers and fathers have potentially different requirements for their follow-up care after

they've experienced a pregnancy loss and/or perinatal death and in addition this thesis further emphasises the need for supportive care in future pregnancies.

10.9 Strengths and limitations

The aim of this thesis was to explore both causes and consequences of pregnancy loss and perinatal death. In order to achieve this both quantitative and qualitative methods were employed. Given the research problem identified here it was believed that employing both methodologies, where appropriate, would allow a depth of understanding that one methodology alone would not achieve. One of the key limitations of this thesis is that the quantitative studies were undertaken on one site. However, given that CUMH is one of the largest tertiary referral centres in the country it was felt that this approach was appropriate.

Six of the eight chapters within this study utilised a qualitative methodology, predominantly interpretative phenomenological analysis (IPA). This enabled me to gain detailed insight into both mothers and fathers experience of pregnancy loss and perinatal death. With the exception of chapter 5 which examined women's experiences of ectopic pregnancy the remaining qualitative chapters included men. It has been noted that the male perspective in relation to pregnancy loss and perinatal death has been in absence and great efforts were made to ensure that they were included in this thesis. During recruitment for the study related to perinatal autopsy, a number of male participants requested a male interviewer

which was facilitated by the research team. It is notable that in each of the qualitative chapters there are more women than men sampled, this was as a result of the sampling strategy whereby men were recruited via their partners. This limitation is not inherent to this study as women often act as gatekeepers for men in maternity-related research.

It is also important to acknowledge the context within which these studies were undertaken. All of the participants were recruited via CUMH. CUMH has a dedicated bereavement and loss team therefore the experiences reported here may differ to those who experience pregnancy loss or perinatal death in another unit without such a team.

When undertaking qualitative research it is acknowledged that there is a risk of researcher bias. While undertaking this research I fully acknowledged that the interpretation of these data were complicated by my own experiences and perceptions. This issue was addressed through continuous reflexivity while the final interpretation of the results was in agreement with my co-authors who were involved in various stages of the analysis.

Notwithstanding these limitations, the value of this thesis is that these findings provide additional insight into previously published literature. A number of reviews[18, 22, 118, 209, 290] further illustrate that there is a need for evidence-

based interventions for women and men who experience pregnancy loss and/or perinatal death. In order for an intervention to be effective the target audience must be engaged. The findings from this thesis have identified a number of factors which influence not only parental experience but also their decision making following pregnancy loss and perinatal death. As a result changes to the hospital environment and clinical practice have already been made at local level. Furthermore, these developments are the subject of a number of intervention studies to assess how these changes may improve the care provided to those who experience pregnancy loss or perinatal death.

10.10 Conclusion

The purpose of this study was to explore causes and consequences of pregnancy loss and perinatal death. The rates of pregnancy loss and perinatal death in high income countries have declined significantly since the 1980s, with much of this attributed to the improvements in ultrasound and antenatal care.[290] In recent years, it is evident that these rates have broadly stabilised.[8] Yet, as is evidenced from the findings in this thesis, millions of women and men around the world will still experience pregnancy loss and/or perinatal death annually. Although pregnancy loss and perinatal death are the most common adverse outcomes in pregnancy, to date, an attributable cause is frequently not identifiable. Medical investigations, including perinatal autopsy, are necessary to assist in identifying an attributable cause yet as the results from this thesis indicate there are a number of barriers which both parents and clinicians may face in having these undertaken.

The findings from this thesis, though supportive of the current literature in relation to pregnancy loss and perinatal death, revealed aspects of the parental experience which have not to date been the focus of an in-depth examination. It is evident from the results of this thesis that the experience of pregnancy loss and/or perinatal death has a profound impact on both women and men, their relationships with each other as well as with their family and friends. These findings further revealed misperceptions and misunderstandings in relation to pregnancy loss and perinatal death not only amongst the individuals interviewed but also within the media and the general public. How society understands and responds to pregnancy loss and perinatal death can be influential on an individual's experience. I would therefore argue that in order for there to be a better understanding of pregnancy loss and perinatal death there needs to be increased education, communication and positive discourse in relation to these losses via healthcare professionals and services, the research community and via the media.

As a result of these studies, a number of recommendations have been made in relation to healthcare policy as well as recommendations in order to improve clinical practice. In order for such improvements to be achieved there is a need not only for an effective interventions and strategies to be identified but also for these to be successfully implemented. Healthcare professionals work within the limits of

their environments and in order for improvements to be seen there is a need to foster support for interventions and strategies at local level.

10.11 References

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Appendix I

10 Interview Schedules

Interview Schedule – Miscarriage

Topic	Aspects to be explored
1.Name & family details etc..	Age Single/Married Other Dependent Children? Private/Public
2. History of miscarriage:	**Tell me about your experiences of the pregnancy before you miscarried?** What were your expectations? Probe about disclosure of pregnancy to family and friends etc. **Then if you like would you like to tell me about your experiences around the time you miscarried?** How did you find out? Who was with you at the time? **How did you react?** Can you remember how you felt and what you thought at that time?

	Did you have any knowledge of miscarriage before your experience?
3. Management:	**How were you cared for when you were miscarrying?**
	Hospital, GP, other
	What supports were offered to you following your miscarriage?
	From hospital, GP, other
	How did you find that experience?
	Did you seek information about miscarriage?
	From your medical team? Family and or Friends? Websites? Support groups?
	What kind of knowledge / information / understanding did you have or did you need to know?
4. Subsequent pregnancy	**Have you been pregnant or considered another pregnancy since the miscarriage?**
	If they had a pregnancy: can you tell me how you felt during that pregnancy?
	How long after the miscarriage?
	How did you find that experience?
	Did you feel prepared?
	Was it easier/more difficult than expected?
	Did you find you had support during this time?
	Probe family friends medical team etc.

What was important to you during this time?

Did you need any additional knowledge / information than what was provided at the diagnosis?

If they have not had a pregnancy: probe why

Looking back across the whole experience, what kind of things do you think the medical team could have done?

Anybody else?

Is there anything that you would like to add

that I have not covered?

Interview Schedule – Experiences of Ectopic Pregnancy

Topic	**Aspects to be explored**
1.Name & family details etc..	Age Single/Married Other Dependent Children? Private/Public
2. History of pregnancy:	**Tell me about this pregnancy before the ectopic was confirmed?** Your own expectations Expectations of partner, family & friends Social/Cultural expectations How did this pregnancy impact on you physically?
3. Diagnosis of Ectopic:	**Can you tell me about the diagnosis?** How did you discover there was a problem with this pregnancy? Who was with you at the time? Nurse/Midwife/Consultant/Family member/Friend **How did you find that experience?** What kind of knowledge / information / understanding did you have or did you need to know? **How did you react?** Tell me more about that – Why was that? **Any fears or anxieties?** Tell me about these – elaborate a little

What were your views/experiences/understanding of ectopic pregnancy previously?

Were you familiar with the term ectopic pregnancy?

Did you seek support from family/friends?
Did you seek information from websites, support groups and or your medical team?

Did you feel that you were adequately supported by Doctors and Midwife?

What aspects of the diagnosis were most difficult for you?

What aspects of the diagnosis was good or helpful to you?

Did you feel able to share your diagnosis with
Family/ friends/ neighbours/ co-workers?

4. Management of your ectopic:

Now I'd like to talk about after the diagnosis

Can you tell me about how you coped with managing the news of the diagnosis?

Once diagnosed how was your ectopic managed?
Were you attending for regular scans and blood tests as an out patient?
Were you admitted for surgery ie laparoscopy/laparotomy
Were you admitted in an emergency situation?

Outpatient:

As an outpatient, how did you find attending for scans and blood tests?

How were you feeling?

What response did you get from staff?

Elective Surgery:

How soon after confirmation of the ectopic was surgery arranged?

Did you feel prepared for this?

Did you have fears/anxieties?

Did you need any additional information other than was provided to you before the surgery?

What aspects of the surgery were most difficult for you?

What follow up was arranged for you?

Emergency admission:

How soon after diagnosis did this occur or had you had a diagnosis or any contact with your Doctor?

Were you unwell for a period before admission?

What is you recall of this event?

Did you receive adequate explanation before or after surgery?

5. Overall response

How was your physical recovery?
Have you fully recovered emotionally?
How did your partner cope?

Do you feel that enough attention was given to your situation as a pregnancy loss?
How do you feel this can be improved?
Do you feel that you received enough guidance from your medical team about your future fertility?

Is there anything that you would like to add that I have not covered?

Interview Schedule – Experiences Around Perinatal Post Mortem

Topic	**Aspects to be explored**
1.Name & family details etc.. Children?	Single/Married/Other Dependent
2. History of perinatal death:	**Tell me about your experiences leading up to the birth?** **Then if you like would you like to tell me about your experiences around the time the birth happened?** How did you find out? Who noticed? Who was with you at the time? Nurse/Midwife/Consultant/Family member/Friend
5. Post mortem	**Now I'd like to talk about the time you may have been offered a post-mortem** Can you tell about the time you were approached for permission to complete a post mortem? - Who approached you? - When, where and how did they approach you? **How did you find that experience?** What kind of knowledge / information / understanding did you have or did you need to know? **How did you react?**

Tell me more about that – Why was that?

Any fears or anxieties?

Tell me about these – elaborate a little

What were your views/experiences previously on this post-mortem?

Can you describe how you came to decide whether to have the post-mortem (who influenced them, and how)?

Alone/ With partner /Family Member/ Friend/ Medical Staff/ Religious beliefs /Other – directly or indirectly

Why were these important for you?

Why was it difficult/easier?

Has your opinions changed over the time? Why and how?

Looking back, what kind of things do you think the medical team could have done at this time?

Anybody else?

Other families who may have experienced this process – peers maybe?

7. Expectations of a post mortem

What kind of things would you be expecting from having a post-mortem

Understanding – clarity – help others

Length of time for results/ Outcome of pm / Communication of results

Respect – care and ethics

8. Meeting Expectations

Met – explore above aspects

Unmet – explore above aspects

Explore access / adequacy / satisfaction
Regrets or content _ Why
Suggestions for improvements?

Is there anything that you would like to add that I have not covered?

Interview Schedule – Stillbirth and Subsequent Pregnancy

Topic	**Aspects to be explored**
1.Name & family details etc..	Age Single/Married Other Dependent Children? Private/Public
2. History of perinatal death:	**Tell me about your experiences leading up to the birth?** **Then if you like would you like to tell me about your experiences around the time the birth happened?** How did you find out? Who noticed? Who was with you at the time? Nurse/Midwife/Consultant/Family member/Friend **How did you find that experience?** What kind of knowledge / information / understanding did you have or did you need to know? **How did you react?** Tell me more about that – Why was that? **Any fears or anxieties?** Tell me about these – elaborate a little
3. Subsequent pregnancy	**Can you tell me about the next pregnancy**

How long after the stillbirth?
How did you find that experience?
Did you feel prepared?
Was it easier/more difficult than expected?
Did you find you had support during this time?
Probe family friends medical team etc.
What was important to you during this time?
Did you need any additional knowledge / information than what was provided at the diagnosis?

Looking back across the whole experience, what kind of things do you think the medical team could have done?
Anybody else?

4. Meeting Expectations

Met – explore above aspects

Unmet – explore above aspects

Explore access / adequacy / satisfaction
Regrets or content _ Why
Suggestions for improvements?

Is there anything that you would like to add that I have not covered?

Appendix II

11 Supporting Material: Data analysis from Chapter 6 ‘Parental decision-making around perinatal autopsy varies with type of stillbirth; A qualitative investigation’

Table 11.1: Superordinate and subordinate themes

Superordinate theme	Subordinate theme
Searching for meaning	Blame/dimished responsibility Self versus other Guilt versus reassurance Answers - relief- weight lifted Conflict for those who decline: say no and no cause, still questioning, self blame
Temporal Effects	Antepartum or intrapartum stillbirth Inferred cause Disorganised thinking Communication Family
Protective Parent (only observed in those that didn't have a PM)	"Daddy mode" Size of the baby Precious/tiny Men disempowered during birth
Knowledge of the procedure	Labelling of the procedure Medical decriptors - minimised Television - SCI and silent witness Morgue Taboo Uncertainty

Table 11.2: Participant contribution to superordinate theme 'searching for meaning'

Participant	Transcript Cross Reference
1	139, 178, 179, 193, 205
2	94, 120, 160, 162, 166, 168, 184, 188, 212, 228
3	106, 108, 147, 169, 195,197, 199, 203, 205, 209, 211, 217, 219, , 233, 269
4	54, 60, 62, 64, 66, 74, 80, 90, 92, 94,96,98, 112,114, 116, 118,130, 132, 134, 186
5	34, 38,41, 47 59, 61, 63, 65, 71, 73, 79,91,95, 97, 101, 107,109, 111, 113, 115, 119, 121, 132, 143,144, 152, 154, 158, 174, 188.
6	282, 240, 242, 296, 300, 302, 304, 306, 308, 312, 313,320, 322, 324, 334, 338, 470, 540, 550, 553, 573, 577, 559, 591
7	24, 26, 32,60,62,70,74,86, 88,
8	54,56,62,70,72
9	40,42,44,48,54,62,66, 86,88,90,92,94,104, 128
10	4,6,32,34,36,42,44,54,60,68

Table 11.3: Participant contribution to superordinate theme 'temporal affects'

Participant	Transcript Cross Reference
1	139,177, 179
2	64, 84, 104, 131, 162
3	32, 38, 58, 82, 84, 86, 104, 169,217, 219, 241, 251, 257, 259
4	26, 24, 68, 70, 122, 124, 126, 127, 142, 144, 148
5	8, 28, 65, 105, 107, 109, 117, 119, 142, 168
6	134, 160, 278, 288, 298, 304, 306, 310, 559
7	60,70,86
8	32,36,48,52,54,58,62
9	30,44, 78, 96, 100, 122
10	4,26,38

Table 11.4: Participant contribution to superordinate theme 'protective parent"

Participant	Transcript Cross Reference
1	195, 197, 203
2	76, 90, 106, 206
3	141, 225, 227, 229, 230,231,235, 237, 239, 243, 245
6	240, 246, 248, 250, 260, 434

Table 11.5: Participant contribution to superordinate theme 'knowledge of the procedure

Participant	Transcript Cross Reference
1	130, 151, 195, 198
2	62, 84, 90, 104,106, 112, 128, 130
3	2, 183, 187, 221, 223, 225, 229
4	58, 68,72,74, 78, 80, 88
5	152, 154, 158
6	160, 250, 254, 260, 262, 276, 278, 664
7	66,88,90
8	44,54, 68
9	44,60,62,68,92
10	10, 36,42,62

Appendix III

12 Researcher's personal account

Researcher's Personal Account

A qualitative approach and the use of interpretative phenomenological analysis (IPA) encourages the researcher to be critically aware of their role of the process of data collection, analysis and ultimately interpretation. IPA acknowledges that the researcher can never fully access the world of the research participant which means that the findings from the data are an interpretation of the participant's experience. This interpretation is complicated by the researchers own experiences, perceptions and worldview. Consequently, there is an onus on the researcher to recognise their own disciplinary background and lived experiences prior to commencing data collection as well as during data collection and in the final process of interpreting the data.

Firstly, my disciplinary background is from the social rather than the medical sciences. My training as a sociologist introduced me to the development of society and how various structures influence how we function in society. My interest in health related research began when I took up a research post in the Department of Epidemiology and Public Health in 2005. It was here that the pragmatic perspective I now foster, where I believe in using multiple methods as long as they are appropriate to the research question being posed, was nurtured. I believe that by utilising both qualitative and quantitative methods, a researcher can provide a more comprehensive understanding of any given phenomenon. It was within this

role that I broadened my interest in health and in particular how patients are becoming more active in how healthcare is provided.

I was not introduced to the area of pregnancy loss and perinatal death until I took up my post as a research officer in the National Perinatal Epidemiology Centre (NPEC), based in the Department of Obstetrics and Gynaecology, in 2011. It was here while working on the national perinatal mortality audit that I began to become familiar with the area. The mission of the NPEC is to collaborate with the Irish maternity services in order to improve maternity care for families in Ireland. In order to achieve this, the patient needs to be at the centre of care and therefore in collaboration with my supervisor Dr. Keelin O' Donoghue I began to further explore pregnancy loss and perinatal death. The work of this thesis has not stood alone and has been under the supervision and guidance of those in the Department of Obstetrics and Gynaecology. It is building on and complementing other research being undertaken by fellow colleagues in the department. The design of each study was constructed in collaboration with a multi-disciplinary team which included obstetricians (junior and senior), midwives, midwives who specialise in bereavement, epidemiologists and psychologists. Following extensive reviews of relevant literature, I have presented and discussed each element of design and the interpretation of the data in detail with each individual. I believe that this multi-disciplinary approach strengthens and validates both the design but also the findings which emerged from the studies contained within this thesis.

Throughout the research process I made every effort to minimise the influence that the Pregnancy Loss Research Group and the clinical team may have had on this research. Although I am part of the research group, and my current understanding of the maternity services has been informed by my discussions with colleagues, I still remain an 'outsider' as I have never been part of the service either as a carer or as a patient.

In order to undertake research there must be access to a population and it was necessary for me to identify gatekeepers in order to recruit participants to the study. A number of colleagues from the Pregnancy Loss Research Group are part of the clinical team who work in Cork University Maternity Hospital. All of those who participated in this research were initially informed of the study by either a specialist bereavement and loss midwife or the healthcare chaplain. These individuals' roles as gatekeepers were invaluable to the research process. Given that these gatekeepers were themselves involved in research, they were supportive of the aims and objectives of this thesis and they ensured that the process of recruitment ran smoothly. However, the involvement of gatekeepers can also have a negative influence on research. The strong rapport between the staff and participants may have an influence on the findings whereby some people may have participated in order to please the staff who had previously provided support to them through their bereavement. In acknowledgement of this potential bias, I made every effort to ensure that the participant was aware that their contributions to this research were voluntary and that there was no obligation on their behalf to

participate. At the beginning of each interview, participants were reminded again that they could withdraw from the study not only at the beginning of the study, but at any point during the interview or in the weeks after their interview was completed.

The experience of birth, pregnancy and/or its loss are life events which I have no personal experience of. Accordingly, my research did not harbour presuppositions about the experience of pregnancy loss or perinatal death. In my previous posts I have interviewed participants in relation to their experiences of health services and care provision, but maternity care and the experience of pregnancy loss and perinatal death was absolutely unique. These participants shared their experiences openly, allowing me to see both their incredible vulnerability and exceptional resilience. In order to achieve this I found that it was essential to engage and build rapport with interviewees as quickly as possible.

I first trained to conduct qualitative interviews in 2004 and since then I have learned and employed various practices to help downplay the power imbalance that exists between interviewer and interviewee. These techniques began from recruitment onwards by allowing the participants pick and choose when and where the interviews were to be conducted. At the beginning of each interview I handed the digital recorder to the participant and demonstrated how it worked. This ensured the participant was in control of the interview and if they felt the need to

stop recording during the interview process that was their decision. The topic of pregnancy loss and perinatal death is sensitive and almost all participants became emotional and often cried over the course of the interviews. I had memorised each of the interview schedules, in advance, so as I didn't have to keep them directly in front of me during the interview. In doing so, it allowed the interviews to proceed more like conversations rather than an examination or interrogation of the participants. I also believe that my lack of personal experience allowed them this space to speak freely, to not assume my understanding, and simply recount and reflect on their stories as they made sense of their experiences.

Despite being mindful of the power balance between the participants and I, my primary role in the process was to obtain the data required from participants. While conducting the interviews I understood that I was not an objective spectator but I, as the interviewer, played an active role in the process. Data were not simply collected but were as a result of the interaction between the interviewee and me. I guided the participants through the interviews with minimal input as possible by using body language, facial expressions and being mindful of the tone I used to ask questions or probe responses.

Once the interviews were completed, I guided the analysis through consideration of the research questions of this thesis. The analysis I chose to undertake had a phenomenological approach, throughout the process I was careful to keep in mind

that the events experienced and the meaning ascribed to them differed for the different participants. This became most apparent to me when the differences observed amongst the couples who participated in the various studies were analysed. How context influences perception can be seen throughout the analysis of all of the studies within this thesis.

Finally, it would be remiss of me not to acknowledge the impact that the participants I interviewed had on me. I was amazed throughout the interviews at the lack of experiential blur. The participants recollected their experiences in minute detail: at times reciting conversations verbatim that had taken place months or even years previously. Through these interviews I witnessed the utter devastation pregnancy loss and perinatal death can have on a person. Partaking in these interviews was often emotionally exhausting and I am not only appreciative but cognizant of the critical role of one of my co-authors Dr. Stephen Gallagher who would debrief with me following particularly difficult interviews. This process was vital to ensure that my experience in one interview would not influence the next.

Despite the utter devastation it is important to note that these mothers and fathers drew positives from their experiences. Many took part in these interviews because they were motivated to play a part in improving the maternity system, not only for themselves but so that other families would not have to experience the loss as they did. Overall, witnessing such altruism has reinforced to me how important it is to

give voice to these families. I firmly believe that any improvement in the health services will only come about by taking these voices into consideration: the care and wellbeing of the patient must be at its centre.

Appendix IV

13 Publications and presentations

13.1 Articles published in peer-reviewed journals

Desmond, D. and **Meaney, S.,** 2016. A qualitative study investigating the barriers to returning to work for breastfeeding mothers in Ireland. International Breastfeeding Journal, 11(1), [ePub]

O'Connell O, **Meaney S,** O'Donoghue K. Caring for parents at the time of stillbirth: How can we do better?. Women and Birth. 2016 Feb 22. [ePub]

Nuzum, D., **Meaney, S.,** O'Donoghue, K. and Morris, H., 2015. The Spiritual and Theological Issues Raised by Stillbirth for Healthcare Chaplains. Journal of Pastoral Care & Counseling, 69(3), pp.163-170.

Nuzum, D., **Meaney, S.** and O'Donoghue, K., 2015. The Place of Faith for Consultant Obstetricians Following Stillbirth: A Qualitative Exploratory Study. Journal of religion and health, pp.1-10.

Morris, A., **Meaney, S.,** Spillane, N. and O'Donoghue, K., 2015. The postnatal morbidity associated with second-trimester miscarriage. The Journal of Maternal-Fetal & Neonatal Medicine, pp.1-5.

Meaney, S., Gallagher, S., Lutomski, J.E. and O'Donoghue, K., 2015. Parental decision making around perinatal autopsy: a qualitative investigation. *Health Expectations*, *18*(6), pp.3160-3171.

Lutomski, J.E., **Meaney, S.,** Greene, R.A., Ryan, A.C. and Devane, D., 2015. Expert systems for fetal assessment in labour. The Cochrane Library.

M Geisler, A O'Mahony, **S Meaney**, J Waterstone, K O'Donoghue. Obstetric and perinatal outcomes of twin pregnancies conceived following IVF/ICSI treatment compared with spontaneously conceived twin pregnancies. *European Journal of Obstetrics Gynaecology and Reproductive Biology* 2014; Aug 1; 181C:78-83

Nuzum, D., **Meaney, S**. and O'Donoghue, K., 2014. The provision of spiritual and pastoral care following stillbirth in Ireland: a mixed methods study. BMJ supportive & palliative care, pp.bmjspcare-2013.

D Nuzum, **S Meaney,** K O'Donoghue. The personal and professional impact of stillbirth on consultant obstetrician gynaecologists: a qualitative study. *British Journal of Obstetrics and Gynaecology 2014; 121 (8): 1020-8*

Lutomski, J.E., **Meaney, S.,** Greene, R., Ryan, A. and Devane, D., 2013. Expert systems for fetal assessment in labour (Protocol).

13.2 Published Abstracts

McNamara, K., O'Connell, O., McCarthy, M., Meaney, S., Greene, R.A. and O'Donoghue, K., 2016, April. Healthcare professionals' response to intrapartum death. In *BJOG-An International Journal of Obstetrics and Gynaecology* (Vol. 123, pp. 42-42).

Fawsitt, C., **Meaney, S**. and Corcoran, P., 2016, April. A cost-benefit analysis of a mobile application to monitor surgical wound post-caesarean section: a pilot-based, feasibility study. In *BJOG-An International Journal of Obstetrics and Gynaecology* (Vol. 123, pp. 55-55).

Spillane, N., **Meaney, S**. and Donoghue, K., 2016, April. A qualitative investigation of ectopic pregnancy. In *BJOG-An International Journal of Obstetrics and Gynaecology* (Vol. 123, pp. 79-79).

O'Reilly, S., **Meaney, S**., Kenny, A.M. and Riordan, M.N.O., 2015. OP36 The role of communication between health professionals and patients as a factor in patient complaints in obstetrics and gynaecology: a mixed methods review from an Irish maternity hospital. *Journal of Epidemiology and Community Health*, 69(Suppl 1), pp.A24-A24.

Meaney, S., Corcoran, P. and O'Donoghue, K., 2016, April. The death of one twin during the perinatal period: a qualitative study. In *BJOG-An International Journal of Obstetrics and Gynaecology* (Vol. 123, pp. 68-68).

Spillane, N., **Meaney, S.** and O'Donoghue, K., 2015. OP64 Women's experiences of ectopic pregnancy: a qualitative study. *Journal of Epidemiology and Community Health*, *69*(Suppl 1), pp.A37-A37.

Meaney, S., Cussen, L., Greene, R.A. and O'Donoghue, K., 2015. OP62 An obstetric media scandal: a systematic analysis of twitter status updates. *Journal of Epidemiology and Community Health*, *69*(Suppl 1), pp.A36-A36.

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Hearn, J., **Meaney, S.,** O'Mahony, M. and O'Donoghue, K., 2015, April. Congenital anomalies leading to stillbirth and early fetal demise in the Cork and Kerry region. A cohort from 1996-2012 as part of the European surveillance of congenital anomalies (EUROCAT) network. In *BJOG-An International Journal of Obstetrics and Gynaecology* (Vol. 122, pp. 112-112).

Hearn, J., **Meaney, S**., O'Mahony, M. and O'Donoghue, K., 2015, April. Congenital anomalies in a cohort born using assisted reproductive technology (ART): a cohort from 1996-2012 in the Cork and Kerry region as part of the European surveillance of congenital anomalies (EUROCAT) network. In *BJOG-An International Journal of Obstetrics and Gynaecology* (Vol. 122, pp. 110-110).

Rochford, M**., Meaney, S**. and O'Donoghue, K., 2015, April. Do our patients know what we're talking about?. In *BJOG-An International Journal of Obstetrics and Gynaecology* (Vol. 122, pp. 118-118).

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Nuzum, D., **Meaney, S**. and O'Donoghue, K., 2015. 459: Communication skills in obstetrics: the impact on bereaved parents. American Journal of Obstetrics & Gynecology, 212(1), p.S235.

O'Connell O, Nuzum D, **Meaney S,** O'Donoghue K. The Value of Prenatal Palliative Care in Cases of Lethal Abnormalities Diagnosed in the Prenatal Period. *Journal of Palliative Care* 2014; 30 (3): 195-246 (G01 – 219)

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