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The Spiritual and Professional Impact of Stillbirth



A Thesis submitted for the degree of Doctor of Philosophy

National University of Ireland, Cork

By

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January 2016

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Declaration

I declare that this thesis contains my own work and that this work has not been submitted to any other university.

I declare that full and informed consent was obtained from all participating healthcare chaplains, consultant obstetricians and bereaved parents.

I agree that the Librarian of University College Cork may lend or copy this thesis on request.

_____

Daniel Robert Nuzum

Dedication

This work is dedicated to Heather,

our children

Adam, Hannah, Callum, Rory and Killian,

and in memory of all those I have been privileged to care for at

Cork University Maternity Hospital

whose lives were too short but who left an everlasting imprint.

~~~~~

Hope

"Hope" is the thing with feathers -

That perches in the soul -

And sings the tune without the words -

And never stops - at all -

And sweetest - in the Gale - is heard -

And sore must be the storm -

That could abash the little Bird

That kept so many warm -

I've heard it in the chillest land -

And on the strangest Sea -

Yet - never - in Extremity,

It asked a crumb - of me.

Emily Dickinson
~~~~~

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The pursuit of a PhD is a challenging adventure. It has been both an academic goal and a transforming journey for me personally and professionally. This study was inspired by the many parents and their babies I was privileged to care for at Cork University Maternity Hospital in the midst of grief and pain. The motivation for this study was to contribute to the overall care we offer to bereaved parents and colleagues who give so much in the care we offer on a daily basis in what is a sad but profoundly poignant and hugely important part of the Irish maternity services.

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and at all times this was for me sacred ground. Their stories will make a difference to others.

Finally, I thank most of all, my wife Heather and our children Adam, Hannah, Callum, Rory and Killian for the considerable sacrifice and love they have shared with me and invested in this study especially when it was all-consuming.

I offer this prayer and blessing with thanksgiving to all who have shared this journey.

יְבָרֶכְךָ יְהוָה וְיִשְׁמְרֶךָ׃
יָאֵר יְהוָה פָּנָיו אֵלֶיךָ וִיחֻנֶּךָּ׃
יִשָּׂא יְהוָה פָּנָיו אֵלֶיךָ וְיָשֵׂם לְךָ שָׁלוֹם׃

בְּמִדְבַּר ו:24-26

The Lord bless you and keep you;

The Lord make his face to shine upon you, and be gracious to you;

The Lord lift up the light of his countenance upon you, and give you peace.

Numbers 6: 24-26

Publications and presentations

Publications

Heazell AEP, Siassakos D, Blencowe H, Bhutta ZA, Cacciatore J, Dang N, Das J, Flenady V, Gold KJ, Mensah OK, Millum J, **Nuzum D**, O'Donoghue K, Redshaw M, Rizvi A, Roberts T, Saraki HET, Storey C, Wojcieszek AM, Downe S, Stillbirth Series Steering Group. Stillbirths: economic and psychological consequences. Lancet. 2016 Jan 18. pii: S0140-6736(15)00836-3. doi: 10.1016/S0140-6736(15)00836-3.

Nuzum D, Meaney S, O'Donoghue K. The theological and spiritual issues raised for healthcare chaplains following stillbirth. J Past Care Counsel. 2015;69(3) 163–170.

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Nuzum D, Meaney S, O'Donoghue K. The provision of spiritual and pastoral care following stillbirth in Ireland: a mixed methods study. BMJ Support Palliat Care. 2014. DOI/10.1136/bmjspcare-2013-000533 (Epub ahead of print)

Nuzum D, Meaney S, O'Donoghue K. The impact of stillbirth on consultant obstetrician gynaecologists: a qualitative study. BJOG : an international journal of obstetrics and gynaecology. 2014;121(8):1020-8.

Published abstracts

Nuzum D, Meaney S, O'Donoghue (2015) Communication skills in obstetrics: the impact on bereaved parents. American Journal of Obstetrics & Gynecology, Volume 212, Issue 1, S235. doi.org/10.1016/j.ajog.2014.10.505

Nuzum D, Meaney S, O'Donoghue K. The Spiritual and Theological Issues for Chaplains providing Perinatal Bereavement Care in Ireland. 20th International Congress on Palliative Care, Montreal, Canada, 9-12 September 2014 Journal of Palliative Care 2014; 30 (3): 195-246 (C11-C – 211)

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Nuzum, D., Meaney, S., & O'Donoghue, K. (2014). PA.06 Breaking bad news: the impact on parents. Arch Dis Child Fetal Neonatal Ed, 99 Suppl 1, A18-19. doi: 10.1136/archdischild-2014-306576.51

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Presentations

Invited presentations

‘Spiritual aspects of perinatal palliative care’
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‘The role of the chaplain following pregnancy loss’
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‘The personal and professional impact of stillbirth on consultant obstetricians’. The impact of stillbirth: Inaugural Conference, University College Cork, 02 November 2013.

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Oral Presentations

‘The spiritual and pastoral impact of perinatal bereavement’. Annual Research and Education Forum, Irish Association of Palliative Care, Dublin, 06 February 2015.

‘The spiritual impact of stillbirth on healthcare chaplains and consultant obstetricians’. International Conference on Stillbirth, SIDS and Baby Survival, Amsterdam, 18-21 September 2014.

‘The spiritual and theological issues raised for healthcare chaplains providing perinatal bereavement care in Ireland’. The 20th International Congress on Palliative Care, Montreal, Canada, 9-12 September 2014.

‘Being human, being wise: the human impact of stillbirth on consultant obstetricians’. British and Irish Association of Practical Theology Annual Conference, York, UK. 13-15 July 2013.

‘The personal and professional impact of stillbirth on consultant obstetricians’. Annual Research and Education Forum, Irish Association of Palliative Care, Dublin, 07 February 2013.

‘The provision of spiritual care following stillbirth in Ireland’. Stillbirth, SIDS and Infant Survival International Conference. Baltimore, USA. Oct 2012. (Award for best conference presentation).

‘Weaving sacred threads: remembering special lives’. Stillbirth, SIDS and Infant Survival International Conference. Baltimore, USA. Oct 2012.

‘How do Chaplains identify theological questions as they care for families following stillbirth?’ British and Irish Association of Practical Theology Annual Conference, Chester, UK. 10-12 July 2012.

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Communication skills in obstetrics: what do parents think? 35th Annual Meeting of the Society for Maternal-Fetal Medicine –The Pregnancy Meeting, San Diego, USA. 02-07 February 2015.

Communication in perinatal palliative care: what do parents think? Annual Research and Education Forum, Irish Association of Palliative Care, Dublin, 06 February 2015.

Breaking bad news: the impact on parents. British Maternal and Fetal Medicine Society Annual conference, Harrogate, UK. 09-11 June 2014.

The personal and professional Impact of stillbirth for Consultant Obstetricians. 57th Annual Meeting for the Society for Social Medicine. Brighton, UK. Sept 2013.

The provision of spiritual care following stillbirth in Ireland. British & Irish Association of Practical Theology, York, England. July 2013.

Theological issues raised for chaplains providing perinatal bereavement care. British & Irish Association of Practical Theology, York, England. July 2013.

National Stillbirth Guidelines: does spirituality or faith matter? British & Irish Association of Practical Theology, York, England. July 2013.

The Personal and Professional Impact of Stillbirth on Consultant Obstetricians. British Maternal and Fetal Medicine Society Annual conference, Dublin, 25-26 April 2013.

What are the spiritual and theological issues for chaplains who provide perinatal bereavement care in Ireland? Annual Research and Education Forum, Irish Association of Palliative Care, Dublin, 07 February 2013.

When death comes before birth: the provision of pastoral and spiritual care following stillbirth in Ireland. Annual Research and Education Forum, Irish Association of Palliative Care, Dublin, 07 February 2013.

National Stillbirth Guidelines: does spirituality or faith matter? Stillbirth, SIDS and Infant Survival International Conference. Baltimore, USA. Oct 2012.

Glossary of abbreviations

ACOG	American College of Obstetricians and Gynecologists
ACPE (Irl) Ltd	Association of Clinical Pastoral Education, Ireland Limited
CAB	Chaplaincy Accreditation Board
CPE	Clinical Pastoral Education
CUMH	Cork University Maternity Hospital
GP	General Practitioner
HCB	Healthcare Chaplaincy Board
HSE	Health Service Executive
IPA	Interpretative Phenomenological Analysis
IUFD	Intrauterine Fetal Death
MDGs	Millennium Development Goals
NICE	National Institute for Health and Care Excellence
NPEC	National Perinatal Epidemiology Centre
PSANZ	Perinatal Society of Australia and New Zealand
RCOG	Royal College of Obstetricians and Gynaecologists
RCPI	Royal College of Physicians Ireland
SANDS UK	Stillbirth and Neonatal Death Society United Kingdom
SLCOG	Sri Lanka College of Obstetricians and Gynaecologists
SMS	Short messaging service
SOGC	The Society of Obstetrician and Gynaecologists of Canada

VACT(E)RL	**V**ertebral anomalies, **A**nal atresia, **C**ardiac defects, **T**racheo-oesophageal Fistula and/or **E**sophageal atresia, **R**enal and **R**adial anomalies and **L**imb defects
WHO	World Health Organisation

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Abstract

Stillbirth is without question one of the most devastating experiences of grief for parents and families. The death of a baby is also a distressing experience for healthcare professionals who share hopes of a live healthy baby at the end of pregnancy. It is a sad reality however, that in Ireland one in 238 babies will die before birth. The creation and nurture of new life in pregnancy is a spiritual experience as a new baby is at the same time experienced and anticipated. There is little in the published literature concerning the spiritual impact of stillbirth on healthcare chaplains who are the main providers of spiritual care for parents and staff colleagues in Irish maternity units. In addition there are few qualitative studies that explore the impact of stillbirth on consultant obstetricians and no published studies on the spiritual impact of stillbirth on bereaved parents.

This study explored the spiritual and professional impact of stillbirth on Irish maternity healthcare chaplains, consultant obstetricians and bereaved parents. Following an overall review of spiritual care provision following stillbirth in the Irish maternity services, thematic analysis was used in the first phase of the study following in-depth interviews with maternity healthcare chaplains. Interpretative Phenomenological Analysis was used in the second and third phases with consultant obstetricians and bereaved parents respectively. The data from both maternity healthcare chaplains and consultant obstetricians revealed that stillbirth posed immense personal, spiritual and professional challenges. Chaplains expressed the spiritual and professional impact of stillbirth in terms of perception of their role, suffering, doubt and presence as they provided care for bereaved parents. A review of spiritual care provision in the Irish maternity services revealed a diversity of

practice. The data from consultant obstetricians identified considerable personal, professional and spiritual impact following stillbirth that was identified in superordinate themes of human response to stillbirth, weight of professional responsibility, conflict of personal faith and incongruence between personal faith and professional practice.

Data from bereaved parents revealed that stillbirth was spiritually challenging and all parents expressed that stillbirth posed considerable challenge to their faith/ belief structure. The parents of only three babies felt that their spiritual needs were adequately addressed while in hospital. The data had six superordinate themes of searching for meaning, maintaining hope, importance of personhood, protective care, questioning core beliefs and relationships. Other findings from the data from bereaved parents outlined the importance of environment of care and communication.

This study has revealed the immense impact of stillbirth on healthcare chaplains, consultant obstetricians and most especially the spiritual impact for bereaved parents. Recommendations are made for improvements in clinical and spiritual care for bereaved parents following stillbirth and for staff wellbeing and support initiatives. Further research areas are recommended in the areas of spiritual care, theological reflection, bereavement care, post-mortem consent procedures and staff wellbeing.

Chapter 1: Introduction

Chapter 1: Introduction

1.1 Introduction

Stillbirth is recognised as one of the most challenging experiences of bereavement.[1-4] In pregnancy, parents begin a journey of expectancy and hope, with immense personal investment in a new future with their baby. New life is anticipated and experienced in ever-deepening reality as pregnancy progresses and for most couples it is a time of great joy. Parents develop bonds of attachment with their new baby during pregnancy as they plan for the future.[5-7] At an early stage this new baby takes his or her place within the story of their family. It is a sad reality, however, that not all babies will survive. The diagnosis that a baby has a life-limiting condition or has already died ruptures the experience of expectancy and hope for parents with the unwanted presence of death and grief.

Birth and death are the two most significant life events in their own right: in stillbirth they fuse inseparably, with devastating impact not just for the baby who has died but also for parents, families, healthcare professionals, communities and society. The ripples of pain go far and wide. The care that bereaved parents receive during this time can shape their whole grieving process.[3, 4, 8]

The reality of stillbirth is immense and has far-reaching impact for healthcare professionals, communities, society and most importantly for parents and immediate family members. For far too long the reality of this impact was under-acknowledged and it is only in recent decades that stillbirth has received the attention it deserves.[1]

The death of a baby is a profound challenge to the natural order of birth, life and death and it has an existential significance as expectant parents have to come to terms with the death and loss of life, hopes and dreams. Regardless of professed faith or belief, stillbirth is a profound challenge to our sense of meaning and human value.[9] For those of faith, stillbirth can rock belief structure to its core, with a long-lasting destabilising effect.[10, 11] Conversely, for others, the death of a baby can invite a deeper reliance on faith as a supportive anchor in the turbulence of grief.[12] For all, stillbirth is an experience of heart-rending sadness.

How parents and professionals are cared for in the midst of this pain was a foundational question for my study and research. What keeps us going when there are no answers, when expectation turns to pain? When the fullness of pregnancy and new life is replaced by the emptiness of death? These are strong and yet tender emotions. As healthcare professionals stillbirth invites and deserves our attention and the highest standard of care.

Increasing attention in recent years has been focused on how healthcare staff recognise and attend to the spiritual dimensions of health and illness. This has been a particular focus of spirituality and healthcare in North America. There is much in the current published literature on how the whole healthcare team (especially clinicians) should include spirituality in the care provided to patients.[13-17] I tested this in an Irish context as part of my study. I asked bereaved parents whether they expected obstetricians to address matters of a spiritual nature as part of their care following stillbirth. I also asked obstetricians if this was something they would be comfortable doing.

1.2 Stillbirth

1.2.1 What is stillbirth?

The definition of stillbirth, the death of a baby *in-utero*, varies from country to country and ranges from 20 to 28 weeks gestation.[18-20] In Ireland stillbirth is defined in the *Stillbirths Registration Act 1994* as 'a child born weighing 500 grammes or more or having a gestational age of 24 weeks or more who shows no sign of life.'[20] For the purposes of this study, the Irish definition is used.

1.2.2 Why is stillbirth important?

Stillbirth is a major global health challenge and is closely related in public health policy to overall maternal health outcomes and wellbeing.[18, 21, 22] The reality of the impact of stillbirth has only in recent decades been given the importance it deserves.[23] Slowly, over time, the impact of stillbirth on parents, families, communities and society has emerged from the dark shadows of silence and lack of acknowledgement, into the light of care, research and validation for what it is: a distinctive and painful bereavement and loss. In addition to the burden on society, stillbirth is widely recognised and validated as a particular bereavement risk, with long-lasting consequences and potential psycho-social trauma for parents and families.[3, 4, 24-34] It is increasingly recognised in the literature that stillbirth, like other workplace distress, has a considerable impact on healthcare professionals and their personal and professional wellbeing.[35-40] The impact of stillbirth on parents, families, healthcare providers and society is explored further in section 1.3.

Although stillbirth is recognised as an important adverse outcome of pregnancy with devastating consequences, historically it has failed to get the attention it deserves in global health policy or indeed in media consciousness.[1, 18, 41] Despite considerable improvements in stillbirth rates over recent decades, stillbirth remains one of the most common adverse pregnancy outcomes.[18] Stillbirth, with numbers almost as high as infant mortality, has been an overlooked area of public health policy and global reduction goal-setting.[42] At best, it is included in the wider health agenda of women and children and then tangentially included in the World Health Organisation (WHO) Millennium Development Goals (MDG) 4 (reduction in child mortality by two-thirds) and MDG 5 (improvement in maternal health through a reduction of maternal mortality by three-quarters and universal access to reproductive health).[1, 21, 43] Stillbirth has been a silent loss in public health terms; unacknowledged, under-reported, and under-resourced.[1, 18, 42, 44]

Recognising that the prevention of stillbirths was not adequately included in the MDGs, the WHO in 2014 launched an action plan, *Every newborn: An action plan to end preventable deaths,* which has included stillbirth reduction as a global target from 2015-35.[45] As part of a comprehensive plan to reduce overall perinatal and infant mortality, this global action plan aims to reduce stillbirth rates from a current global rate of 22 per 1,000 births to 10 or less per 1,000 births by 2035.[46, 47] In high income countries the ambitious goal is to eliminate all preventable stillbirths. As Lawn *et al* point out, however, this goal is very ambitious and, without adequate investment, has resulted in little progress thus far.[47]

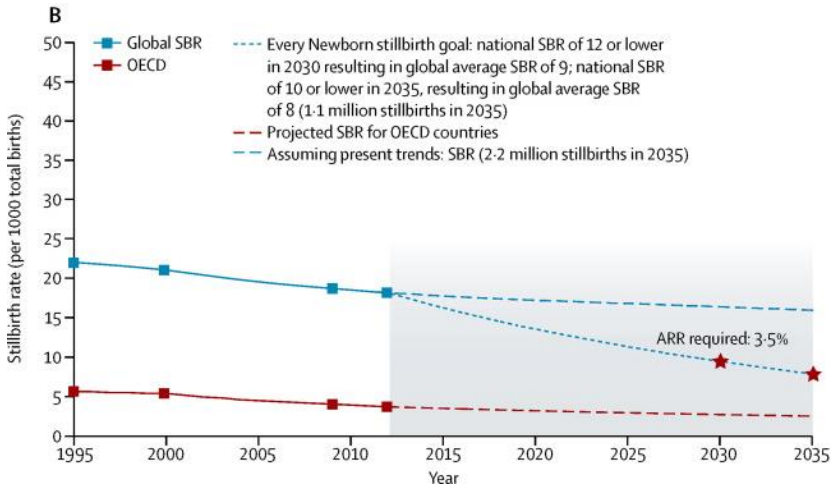


Figure 1.1 WHO Stillbirth reduction goal 2015-35[47]

1.2.3 How common is stillbirth?

The rate of stillbirth varies widely across the world from a high rate of over 40 per 1,000 births in Nigeria and Pakistan to 2 per 1,000 in Finland.[48] 98% of all stillbirths occur in low to middle income countries where the annual number of stillbirths is estimated at 2.6 million.[48] 45% of these stillbirths occur in the *intrapartum* period.[49]

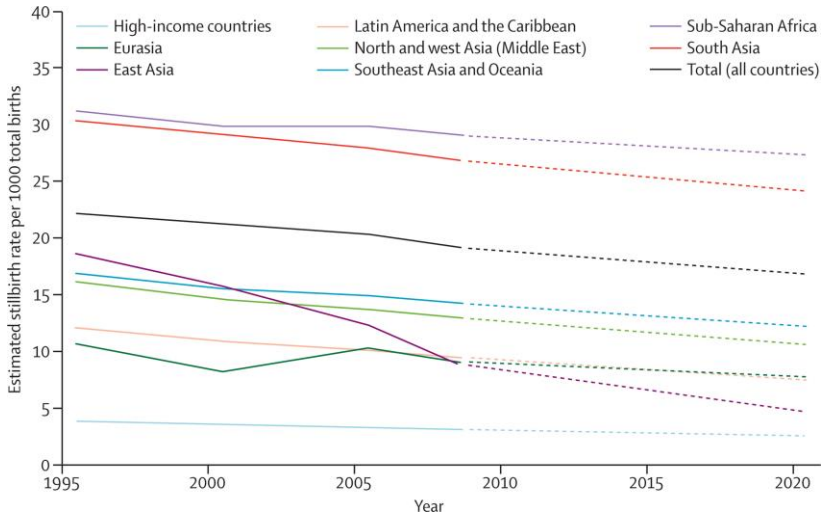


Figure 1.2 Global stillbirth rates 1995-2010[48]

Due to a high number of classification systems (>35), a lack of consistent recording of stillbirths and the lack of global consensus concerning the definition of stillbirth, the reported data does not give a consistent global picture, so the figure quoted is very likely to be conservative.[44, 48, 50, 51] For example, the WHO defines stillbirth as 'pregnancy loss at or after 28 weeks of pregnancy, or a birth-weight of at least 1,000 g'.[20, 48] This higher gestation is used for international comparison purposes but in doing so excludes a significant number of earlier stillbirths from the reported data.[48, 50]

The current stillbirth rate in Ireland is 4.2 per 1,000 births. This is consistent with reported data from high income countries and has remained relatively static since the 1990s.[22, 52, 53] The National Perinatal Epidemiology Centre reports that the Irish perinatal mortality rate has decreased by 10% since 2009.[54]

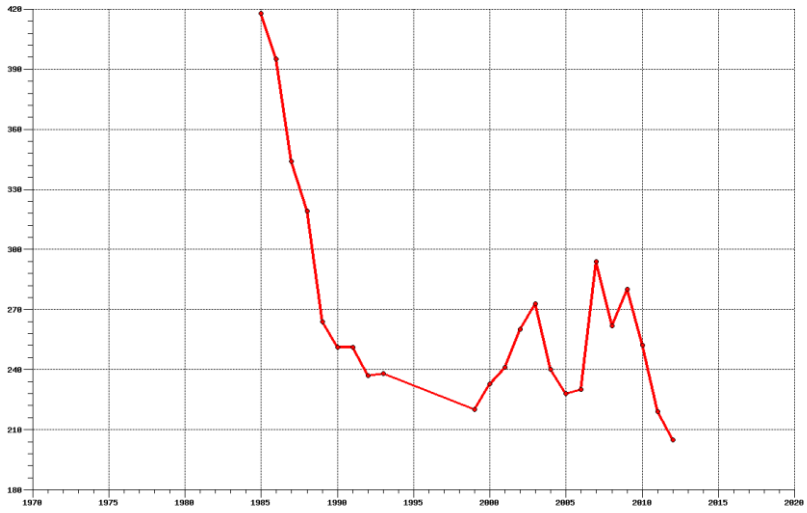


Figure 1.3 Number of Irish stillbirths >1,000g 1985 -2012
(http://data.euro.who.int/hfadb/)

The latest published data from the National Perinatal Epidemiology Centre reported that in 2012 there were 304 stillbirths in Ireland arising from 71,755 births.[52]

	2008	2009	2010	2011	2012
Total births (N)	75,421	70,250	70,182	74,265	71,755
Total perinatal deaths (N)	512	477	463	456	445
Stillbirth rate	4.7	4.8	4.6	4.3	4.2
Neonatal death rate	2.1	2.0	2.0	1.9	2.0
Uncorrected PMR (95% CI)	6.8 (6.2-7.4)	6.8 (6.2-7.4)	6.6 (6.0-7.2)	6.1 (5.6-6.7)	6.2 (5.6-6.8)
Corrected PMR (95% CI)	4.9 (4.4-5.4)	4.8 (4.3-5.3)	4.5 (4.0-5.0)	4.1 (3.6-4.5)	4.1 (3.7-4.6)

Figure 1.4 Irish stillbirth rates 2008-2012[52]

1.2.4 The causes of stillbirth

The causes of stillbirth have been the focus of much attention and research in recent decades as clinicians and scientists have worked to reduce preventable stillbirths. This has been most successful in high-income countries, where the rate of stillbirth has reduced dramatically from a high of 50 per 1,000 births in the 1940s to the current average of fewer than 5 per 1,000 births in the highest-income countries.[18, 22, 55]

One of the challenges in identifying causes of stillbirth has been the reducing rate of perinatal post-mortem examination in recent years. Post-mortem examination remains the gold standard in stillbirth investigation.[56-60] The reduction in perinatal post-mortem examinations occurred following organ retention scandals which became public in the United Kingdom in 1998 and in Ireland in 1999. The negative public and parental reaction to unauthorised organ and tissue retention left a legacy of strong feeling surrounding parental consent and decision making when consenting to a post-mortem following stillbirth.[61-65] In Ireland this led to a formal government inquiry and review of all paediatric post-mortem practice between 1970-2000,

resulting in the publication of the *Report of Dr Deirdre Madden on Post Mortem Practice and Procedures (2006).*[65] In Ireland the perinatal post-mortem rate declined by 54.5% between 1992 and 2002, from a high of 73.8% in 1992 to a low of 33.6% in 2002.[66] As a result of the organ retention scandals and subsequent recommendations, renewed efforts have been made to examine consent counselling procedures and information provided to parents to improve post-mortem rates. [61, 65, 67, 68] A Cochrane Review in 2013 failed to identify any randomised controlled studies concerning the effectiveness of interventions in parental decision-making processes for post-mortem following stillbirth.[69] The post-mortem rate in Ireland following stillbirth was reported at 48% in 2012.[52] This compares with a rate of 49% in the United Kingdom.[70]

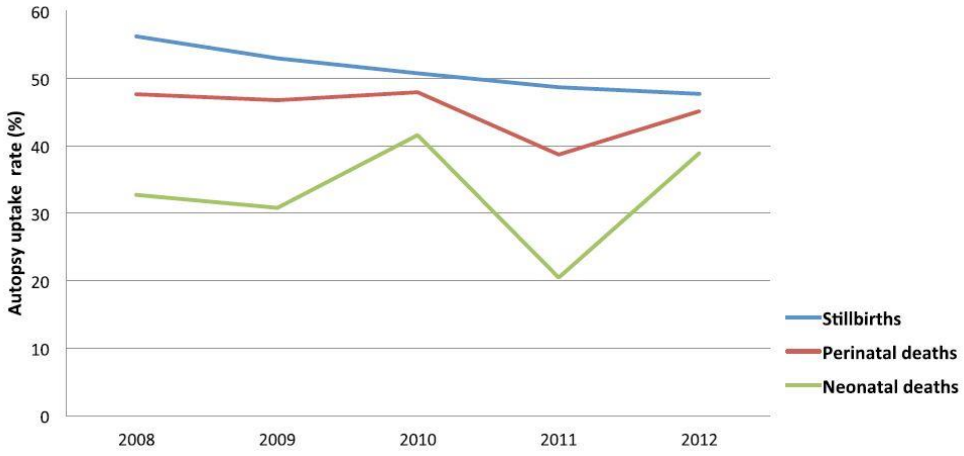


Figure 1.5 Autopsy uptake rate in Ireland 2008-12[52]

In the hospital where this study was based the rate of post-mortem following stillbirth has increased from a rate of 50% in 2009 to 80.6% in 2013.[71, 72] Of significance was the introduction in 2011 of a specialist perinatal pathology service led by a consultant perinatal histopathologist.

There are many recognised causes of stillbirth ranging from placental causes, infection, cord accidents, causes related to medical disorders of pregnancy, *intrapartum* events, congenital anomalies and, lastly, the elusive 'unexplained' category.[22, 73, 74] In Ireland the development of a new classification system by the National Perinatal Epidemiology Centre (NPEC) in 2010 has increased the level of identified stillbirth causes to 80%.[52]

For the purposes of this study there is particular significance for causes where parents have time to prepare for a possible stillbirth because of a diagnosed medical condition or congenital anomaly. These parents have time to prepare for the impending death of their baby and time to grieve before birth. In contrast, those for whom there is a sudden unexplained stillbirth with no identified cause, parents are given no forewarning of the possible death of their baby. For this reason I shall initially focus on congenital anomalies where parents have time to prepare for the impending death and birth of their baby; then on unexplained stillbirths, which by their nature are unanticipated and result in a short timeframe between diagnosis and birth. In both cases parents are left with the question 'Why?' which has personal and spiritual impact.

1.2.4.1 Congenital anomalies

Congenital anomalies accounted for 26% of stillbirths in Ireland in 2012.[52] Previous Irish reported figures for congenital anomaly in stillbirth have ranged from 26% to 48.6%.[75] The use of ultrasonography imaging in pregnancy has increased the antenatal diagnosis of structural congenital anomalies as part of antenatal care. In Ireland, however, the use of antenatal anomaly scanning is only provided in

identified high risk pregnancies. Coupled with the use of invasive antenatal screening such as amniocentesis to identify chromosomal anomalies, antenatal diagnosis of a life-limiting congenital anomaly has led in many other jurisdictions to the termination of pregnancy and in so doing has reduced the rate of stillbirth.[22] This is not the case in Ireland as termination of pregnancy is not permitted unless the life of a mother is at risk.

The diagnosis of a life-limiting congenital anomaly that is likely to result in stillbirth or neonatal death is a devastating experience for parents. For those who continue their pregnancy, it is a time of conflicting emotions, requiring a high level of supportive care. In Ireland, when a baby is diagnosed with a life-limiting condition the predominant and only lawful care pathway is one of perinatal palliative care.[76, 77] Although emotionally and spiritually challenging, an antenatal diagnosis of a life-limiting condition for a baby gives parents time to prepare for the death and birth of their baby and to create memories. A study by O'Connell *et al* (2014) of parents who had received a life-limiting diagnosis and who chose to continue their pregnancy revealed rich experiences of transformative growth for parents as they developed an evolving relationship with their baby during pregnancy amidst ongoing sadness.[77]

1.2.4.2 Unexplained stillbirth

The rate of unexplained stillbirth has been reducing in recent years due to the development of more robust classification systems and the increased availability of scientific testing and specialised perinatal pathology. The introduction of the Irish *NPEC Classification System* in 2010 has reduced the rate of unexplained stillbirth to

20% as reported in the NPEC 2012 report from a rate of almost 50% in previous NPEC reports which used the *Wigglesworth Classification System*.[52] However, Flenady *et al* (2011) argue that where unexplained stillbirth categorisation is higher than 5% this is often associated with failure to investigate adequately.[22] Decreasing rates of post-mortem examination also contribute to the categorisation of death as unexplained. However, the introduction of comprehensive placental pathological examination, cytogenetic testing, the development of national stillbirth guidelines and the use of a more comprehensive classification system has done much to identify causes of stillbirth and to reduce further the rate of unexplained stillbirth.

1.2.5 The risk factors for stillbirth

The identification of risk factors and causes for stillbirth has contributed to the significant reduction in stillbirth rates in recent decades. A meta-analysis of 96 studies from high-income countries by Flenady *et al* in 2011 identified that 'maternal weight, maternal smoking, maternal age, primiparity, small size for gestational age, placental abruption, and pre-existing maternal diabetes or hypertension were the most important and potentially modifiable risk factors' for stillbirth identified in the literature.[53] Ethnic origin and socio-economic disparities are also risk factors in high-income countries with associated contributory factors such as lower uptake of antenatal care, lower educational achievement and socio-economic poverty.[53]

Interventions to reduce the risk of stillbirth in high-income countries are focused on:

1: maternal health before, during and after pregnancy

2: the detection and management of pregnant women at risk of stillbirth

3: improving information and standards of care, including robust clinical perinatal audit.[22, 45]

1.2.6 How is stillbirth diagnosed?

The accurate diagnosis of stillbirth is an important clinical procedure that should be conducted sensitively and compassionately by a senior clinician through the use of ultrasonography. Clinical guidelines should inform good practice about how, by whom, when and where a diagnosis of stillbirth should be given to parents.[78-80] Communication of bad news should be clear, sensitive and unambiguous and parents should be given enough time and supportive care to come to terms with a diagnosis of stillbirth. Poor communication can add to distress and increase dissatisfaction with care.[81-83]

1.2.7 How is stillbirth managed?

The management of stillbirth is best achieved with an integrated team approach from the multi-disciplinary healthcare team.[78, 80, 84, 85] From the moment of diagnosis, how parents are cared for plays an important part in their overall grief experience and recovery.[1, 25, 27, 31, 86, 87] Starting with the historical position, I will then outline the current management of stillbirth care today.

1.2.7.1 Historical context of stillbirth management and care

Historically, the care of parents following stillbirth has a legacy of negative and traumatic experiences, in which bereaved parents felt that their grief and

experiences were not addressed appropriately or sensitively by healthcare providers, faith groups and society in general.[1, 9, 88, 89] Stillbirth, like all pregnancy loss, was a 'silent grief' that was unacknowledged.[9, 90] Parents and their stillborn babies were cared for in a clinically cold way with little understanding of the impact of this devastating grief.[88] In the absence of public ritual and burial, a societal reluctance to discuss such a loss led to isolation.[88, 89]

Stillborn babies (being unbaptised) were not buried in consecrated ground and were often buried in unconsecrated areas outside graveyards or in secluded areas called *'Cillini'*.[91] This practice continued until the 1970s in Ireland and was closely associated with the theological concept of 'Limbo' as articulated by the Catholic Church from the middle ages. The practice had a negative influence on the Irish approach to infant death and continues to impact on the grief of many, based on their negative and traumatic experiences following the death of their baby.[91-95] The Catholic Church clarified its position on the concept of Limbo with the 2005 publication and statement by Pope Benedict XVI of *The hope of salvation for infants who die without being baptised*.[93, 96] This document states that 'there are theological and liturgical reasons to hope that infants who die without baptism may be saved and brought into eternal happiness' thereby removing the sense of equivocation concerning the fate of babies born without baptism.[96]

1.2.7.2 How is stillbirth managed today?

The introduction of national guidelines in many parts of the world (mostly in high income countries) has contributed significantly to improving standards of care that should be provided consistently following stillbirth. [78, 80, 97-99] National stillbirth

guidelines benchmark standards of diagnostic investigations, induction of labour, delivery/birth, physical and emotional care, classification/ recording, audit and investigations that should be carried out consistently following stillbirth. The introduction of stillbirth guidelines ensures that, at a very minimum, parents should expect to receive comprehensive care, thorough investigation and bereavement support from diagnosis to delivery and postnatally following stillbirth. In addition, the publication of care guidelines by support organisations has complemented clinical guidelines with important insights from the experiences of bereaved parents. Of particular note is the pioneering work by Sands UK in its partnership with professionals, researchers and health services managers to develop stillbirth care, education, audit and research.[79, 100]

The diagnosis of stillbirth should ideally be made by a senior clinician using real-time ultrasonography and then should be confirmed by a second clinician.[78, 80] The diagnosis should be communicated without undue delay by the clinician clearly and sensitively, in a compassionate way and in an appropriately private environment.[101] It is important that the person communicating the news should acknowledge the baby's death. Parents should be given time to speak about their loss and to express their feelings and emotion in a safe and supportive environment.[102]

1.2.7.3 Labour and delivery

The care of bereaved parents as outlined in the forthcoming sections is based on the current (2011) Irish Clinical Practice Guideline, *Investigation and Management of Late Fetal Intrauterine Death and Stillbirth*.[78]

The management of birth should be discussed with the couple as soon as possible after diagnosis so that their preferences for care can be ascertained. Management of birth usually involves either expectant management where spontaneous labour is awaited or medical induction of labour. In either case parents may go home and return at a later time for the birth of the baby once there are no other medical contraindications. For a minority of parents a caesarean section will be the appropriate method of delivery. It is important that parents are given the appropriate support and twenty-four hour contact numbers for the relevant staff in the hospital prior to leaving the hospital.

1.2.7.4 Admission to hospital

The admission of parents to hospital following the diagnosis of stillbirth should be planned appropriately so that they can be met and accompanied to a single room in a dedicated area of the hospital away from other pregnant mothers and babies. On admission mothers should be given the opportunity to have their partner/ companion stay with them during their hospitalisation. Bereaved parents should at an early stage be made aware of and introduced to the different members of the bereavement team. On admission to the labour ward parents should be introduced to their midwifery and medical team and their care plan reviewed in consultation with the parents. Parents should be cared for in a dedicated area of the labour ward where their emotional and physical needs can be most sensitively and appropriately met.[80]

1.2.7.5 Birth

The birth of every baby is a unique event for parents. Every effort should be made to afford privacy and support in appropriate balance for parents as they give birth to their baby. Parents should be prepared beforehand about how their baby might look and be prepared for the fact that their baby will be silent. Appropriate medical management and support including analgesia is provided throughout, in conjunction with ongoing emotional support. Parents should be given the opportunity to care for their baby if they wish and staff should support them in their decisions and choices. Parents should be given as much privacy and time as they need following the birth of their baby. This is particularly important during the first hours post-delivery when their baby is still warm –often referred to as 'the golden hour'.[103-106]

1.2.7.6 Post-natal care

Bereaved parents should be cared for in a dedicated area of the hospital away from pregnant mothers and babies. Partners should have open visiting and should be facilitated to stay overnight. Parents should be supported in their choices to parent their baby. Some parents will choose to have their baby remain with them in their room and others will not. If parents choose not to have their baby remain in their room their baby should be cared for appropriately in a nearby area.[78, 79, 85, 106]

Parents should be supported by the bereavement team and their care should involve appropriate assessment of personal, physical, spiritual, cultural and emotional need. Appropriate support, information and guidance is given to parents in

their decision making and planning for ritual, ceremony, care, discharge and burial/cremation options in a sensitive, unhurried and culturally appropriate way.[78, 79, 89, 107] Parents may need particular support during the consent procedure for a post-mortem.[62, 67, 69, 78, 79, 108]

Parents should be offered the opportunity to create mementos such as handprints, footprints, photographs, a lock of hair and any other particular memories that are important to a couple. As the time following birth and before burial/cremation is finite, parents should be afforded as much privacy and unnecessary interruption as possible, yet balanced with appropriate support and accompaniment in accordance with their wishes.[78, 79, 85, 106, 109]

Parents should receive all the appropriate medical and midwifery care offered to all post-natal mothers and advice should be given concerning lactation suppression, which is of particular psychological importance following stillbirth. It is important that all future pregnancy-related appointments are cancelled and that the appropriate professionals including general practitioner and public health nurse are informed of the stillbirth. Parents should be given written information concerning ongoing support both from the hospital bereavement team and external bereavement support groups. This information should include a contact number. Due to the documented prevalence of post-traumatic stress disorder following stillbirth, information about bereavement counselling services and follow-up should be provided to all bereaved parents.[78, 79]

1.2.8 Support following stillbirth

1.2.8.1 Healthcare support

The provision of support for parents following stillbirth is a key part of overall care from the maternity services. This support should be initiated from the time of diagnosis and extend through the care provided in hospital and then following discharge for as long as is necessary.[78, 79, 85] The development of comprehensive support has been significantly influenced through the work of support organisations such as Sands UK.[79, 100] In particular, the development of the *Sands Audit Tool for Maternity Services* in the UK has contributed much to raise public and professional awareness of the importance of comprehensive stillbirth care for all bereaved parents.[79, 100, 110]

The provision of dedicated bereavement teams contributes much to the support offered to parents as trained and dedicated professionals can provide specialised and appropriate person-centred care and follow-up investigations for parents. The provision of professional support has been shown to reduce the level of post-traumatic stress disorder following stillbirth.[87, 111]

All bereaved parents should be offered follow-up care from the hospital bereavement team. This follow-up should include a formal appointment with their consultant obstetrician, in order to provide an opportunity to discuss the circumstances surrounding the stillbirth of their baby and any specific issues that are important for future pregnancies. Studies have shown that parents appreciate follow-up care and support from their obstetric team.[26, 112] Ongoing support should also be

offered from the bereavement and loss midwife specialists, pastoral care and bereavement counselling services as appropriate.[78] Support should continue for couples into and during their subsequent pregnancy.[112]

1.2.8.2 Role of support organisations

In recent decades stillbirth support organisations have played an important role in bringing the needs of bereaved parents to shape public policy and awareness of stillbirth. The contribution of research into parental experiences following stillbirth has also shaped the ongoing development of bereavement care.[85]

In Ireland the work of bereavement support organisations has contributed to an enhanced awareness of the lived experiences of perinatal grief. The two main stillbirth support organisations in Ireland are A Little Lifetime Foundation and *Féileacáin* (Stillbirth and Neonatal Death Association of Ireland). Both organisations play significant roles in advocacy and support for bereaved parents at local and national level. In addition, they provide important ongoing community support through online fora, social media presence, parents' support groups and the provision of practical support for bereaved parents in the creation of mementos and public remembrance. This is in keeping with the literature which shows that many bereaved parents find transformation in their loss, resulting in a commitment to improve health services and supports for other bereaved parents.[113-117]

1.2.9 Stillbirth as a global issue

Stillbirth as a preventable death in many cases has been the subject of a global focus in recent years. There has been a significant increase in research output commensurate with the increasing public awareness of the impact of perinatal grief. In addition to scientific advances in identifying risk factors and treating preventable causes of stillbirth, developments in perinatal audit and classification systems have contributed much to the global understanding and prevalence of stillbirth. There has also been considerable expansion in research into the psychological impact of stillbirth.

The most recent 'call to action' was in 2011 with the publication of The *Lancet* Stillbirth Series.[1] This global focus has emphasised the importance of preventable stillbirth by improving antenatal, obstetric and midwifery care especially in developing countries.[18, 22, 48, 49, 118, 119] The second *Lancet* Stillbirth Series is scheduled for publication in January 2016 and will look at the cost of stillbirth to society, parents and healthcare staff.[120, 121]

The provision of good obstetric and midwifery care has done much to reduce the numbers of *intrapartum* stillbirths and this continues to be a focus in the developing world. In addition, there has been a focus on more robust perinatal audit and the reduction of risk factors associated with stillbirth.[22, 51, 86]

1.3 The impact of stillbirth

Stillbirth by its nature impacts on many people. In addition to the inevitable tragedy for the baby who dies, the impact extends to the baby's parents and family, the staff who were caring for the baby and to community and society at large. I will look at each of these groups in turn.

1.3.1 Impact on parents and families

The impact of stillbirth on parents is extensively recognised in the literature and has been the focus of much attention and research in recent decades.[2, 3, 25-27, 30-34, 122-124] This is in line with the increased acknowledgement and awareness by society at large concerning the personal reality of stillbirth and a greater awareness of the depth of perinatal grief.[1, 34, 86, 103, 105, 122, 125, 126] Bereaved parents have themselves spoken very openly and publicly about the reality of their grief and, with the development of bereavement support and advocacy groups, this in turn has increased awareness about stillbirth and its associated grief.[79, 110, 127]

It is important to remember that grief, although a painful experience, is a normal experience and reaction to loss and death.[2, 3, 128, 129] Perinatal grief, however, is recognised and validated in the literature as a distinctive grief and the published literature reports significant and long-lasting psychological and emotional impact for parents following stillbirth.[26, 29, 32, 122, 123, 130-134] These include anxiety, depressive symptoms, post-traumatic stress, suicidal ideation, guilt, social phobia and remorse.[26, 32, 37, 122, 135-141] In many studies the prevalence of these symptoms is significantly higher in parents bereaved by stillbirth than for control parents

following a live birth.[29, 128] In some studies 60% -70% of grieving mothers are reported as experiencing significant grief-related depressive symptoms one year after the death of their baby.[137, 142-144] Many parents showed persistent feelings of remorse or guilt for not being able to save their child. The prevalence of psychological symptoms has also resulted in an increased recourse to the prescription of psychotropic medication in what some are calling a 'pathologizing of grief'.[135, 145-148] Nearly 40% of grieving mothers in a convenience-sample survey in the USA were prescribed psychiatric medication despite a lack of evidence for its efficacy in this population.[146]

Stillbirth has been shown to impact significantly on family relationships and the entire family system.[28, 29, 122] While most studies have demonstrated that the impact of stillbirth contributes significantly to relationship strain and breakdown, there is also evidence that stillbirth can bring some couples closer together.[141, 149, 150] Fathers have been shown to have increased levels of emotional distress that continue into a subsequent pregnancy but then tend to decrease after the birth of a subsequent live child.[32, 33] Mothers and fathers have also been shown to grieve differently and at different paces.[127, 149, 151] Stillbirth has also been shown to have a negative impact on siblings, grandparents, and other family members.[37, 124, 152, 153] In addition to the immediate personal impact of stillbirth for parents, various studies have found that psychological distress has continued into subsequent pregnancies, with conflicting emotions associated with a new pregnancy and the reawakening of grief and loss for a previous stillborn baby.[32, 133, 154]

The area where there is least agreement in the literature concerns whether bereaved parents should see and/or hold their stillborn baby. In the past a paternalistic approach considered that, to reduce the impact of grief, parents would be best protected from seeing or holding their dead baby.[126, 155] A 1970 study by Kennel *et al* noted that there were no unduly upsetting emotional reactions for bereaved mothers following tactile contact with their baby who had died.[156] As early as 1978 Lewis argued against behaviours that prevented mothers from adequately mourning.[41] In an influential study by Hughes *et al* better mental health outcomes during a subsequent pregnancy and one year subsequent to it were reported for bereaved mothers who had not held or seen their stillborn baby.[132] In another study Turton *et al* found an increased risk of relationship breakdown and traumatic symptomatology with mothers who had held their stillborn babies.[133] These studies led to considerable comment and engagement from bereaved parents, parent support organisations and other researchers.[103, 106, 157, 158] In contrast, a study by Rådestad *et al* found that mothers who had not received mementos or had not spent as much time as they wished with their stillborn baby reported higher levels of anxiety and depression.[30] These results are also consistent with subsequent studies in Europe and North America.[33, 103, 105, 109, 123, 135, 136, 159] Of note is the influence the research by Hughes *et al* and Turton *et al* had on official guidelines in the United Kingdom, where the 2007 UK NICE clinical guideline stated: 'Mothers whose infants are stillborn or die soon after birth should not be routinely encouraged to see and hold their dead infant.' (NICE CG 45, 2007). This has subsequently been revised to read 'Discuss with a woman whose baby is stillborn or dies soon after birth, and her partner and family, the option of 1 or more of the following: seeing a photograph of the baby, having mementos of the baby, seeing the baby, holding the baby.'[160] The

Irish Clinical Practice Guideline *Investigation and management of late fetal and intrauterine death and stillbirth* (2011) states that

> 'parents should be provided the opportunity if appropriate to: cut the cord, have the baby delivered into mother's arms, spend time alone with the baby, get to know their baby, facilitate mother and baby skin to skin contact, take and have a variety of photographs taken …parents may need to be gently guided in carrying out these tasks for their baby. The midwife will also facilitate this in the way she models the care of the baby as she would with a living baby … Parents are to be supported in parenting their baby, e.g. holding dressing, bathing and getting to know their baby.' [(78)]

A recent systematic review by Kingdon *et al* of studies reporting parental experiences and outcomes after seeing and holding their stillborn baby identified twenty-three studies, of which twenty-one reported positive outcomes for bereaved parents where they saw or held their stillborn baby. Negative outcomes were associated with subsequent pregnancy, lack of time with their baby, a decision not to see their baby and insufficient mementos.[(161)] Although stillbirth is mostly a negative experience for parents, there are some for whom stillbirth had positive impacts. Some studies report a sense of pride experienced by parents even though their baby had died. Some couples reported growing closer together following stillbirth.[(150, 162)] All parents indicated awareness that their lives had been transformed by their loss. For some parents their faith practice increased following stillbirth and they channelled the experience of stillbirth into altruistic activities such as bereavement support groups and stillbirth awareness campaigns.[(109, 113-115)]

1.3.2 Impact on staff

The impact of stillbirth on healthcare professionals is increasingly recognised in the published literature.[35-40] Healthcare professionals who are caring for couples in pregnancy are usually preparing for the safe arrival of a healthy baby so, when this journey changes to one of death and grief following stillbirth, the impact of this is considerable on staff.[35-37, 39] This impact extends to all who are caring for a couple and by its nature this care involves close contact with grief and associated emotional, psychological and spiritual pain.[35, 38-40, 86, 122]

I conducted (with three co-authors) a meta-analysis of studies published between 2000-15 concerning staff impact following stillbirth as part of a forthcoming second *Lancet* Stillbirth Series.[120] We identified 677 manuscripts in electronic databases; 98 duplicates were removed, 535 papers were deemed ineligible by abstract review and 6 additional papers were identified by hand-searching bibliographies. 49 manuscripts were reviewed in full. From this 49, 20 studies met the inclusion criteria in full and were coded qualitatively. These results were double-checked by my co-authors. The included papers are shown in Table 1-1.

Table 1-1 Studies on impact of stillbirth on staff

Name	Year	PSYCHOLOGICAL IMPACT	PROFESSIONAL IMPACT	NEED FOR SUPPORT	POSITIVE IMPACT
Ben-Ezra	2014	↑PTSD symptoms, ↑Depressive symptoms, ↑psychosomatic symptoms			
Clavel	2013	Denial, emotional distance	Defence mechanisms, poor inter-disciplinary team working, fear of adverse outcomes		
Farrow	2013	Grief, depression, self-blame, guilt	Fear of litigation		
Gold KJ	2008	Blame, guilt, considered leaving OBS	43% fear of disciplinary/ legal action		
Jonas-Simpson	2010	Emotion, needed time to reflect	Communication Fear	Need for support	Honour, growth, privilege
Kaunonen	2000	Difficult to forget the death, guilt when meeting family, powerlesness, anxious showing feelings, helplessness	Limited personal resources		
Kelley	2012	Blame, role challenge & communication fear, frustration with lack of reason		Feeling unprepared	
Liisa	2011	Anxiety, uncertainty, mentally & physically drained		Need for support	Previous experience helped
McAninch	2008		Fear of litigation		
McCool	2009	Potential humiliation	Public disparagement/ exposure, fear of litigation & loss of livlihood		
McKenna	2011	Traumatic event / emotional response	Challenge professional/ role beliefs	Need for support	Capable in the future
Nallen	2007	Guilt,		Need for support and training, pastoral support	
Nuzum (BJOG)	2014	Guilt, anger ,emotional distancing	Fear of litigation	No support	
Nuzum (SPCARE)	2014	Personal doubt, existential challenge		No support	
Pastor Montero	2011	Guilt, failure, overwhelmed by sorrow,emotional avoidance (for protection), frustration, impotence with outcome		Lack of education	
Puia	2013	Self doubt, shaken to the core, profound sadness, consuming thoughts, frustrations with care, emotional distancing		Lack of education	Special bond between nurse & patient
Roehrs	2008	Sadness, discomfort leading to emotional avoidance	Discomfort providing care	Lack of peer support, need for education	Sense of honour, experience, ↑comfort level & quality of care
Saflund	2000	Minority felt guilt, thought about the event afterwards	Worry about disciplinary action	More guidance needed	
Steen	2015	Difficulty handling own feelings -don't want to get hurt	Lack of commnication skills	Need for support	Experience increased ability/ enjoyed feeling needed

Each of the studies documented a substantial personal and professional burden for staff following stillbirth. Six studies, however, also reported positive effects for staff as they cared for parents following stillbirth. Four major themes emerged from the data: psychological impact, professional impact, need for support, and positive effects for staff.

The psychological impact of stillbirth was most frequently reported and had an overall frequency effect size of 95%. (Frequency effect size refers to the prominence of a theme in the literature and is calculated by taking the number of papers containing a particular finding and dividing this number by the final number of papers and excluding any duplicates from common parent studies).[163]

The psychological impact of stillbirth on staff ranged from traumatic impact and symptomatology, diminished emotional availability, guilt, anger, fear, anxiety, blame, stress, sadness, powerlessness, challenge to faith and a sense of humiliation.

The professional impact of stillbirth had an overall effect size of 65% and was characterised by fear of litigation, exposure, humiliation and of disciplinary action. For some this led to maladaptive coping styles at work and a level of discomfort in providing care for parents following stillbirth. In one study nearly 10% of obstetricians considered leaving obstetrics following the impact of stillbirth.[36] In another study, data suggested that attending a woman who experiences a stillbirth could result in 'loss of livelihood' and 'public humiliation' for the healthcare professional.[164]

The majority of studies (n=13) highlighted the need for further education and professional support for staff, especially in terms of the psychosocial care and communication skills that are required following stillbirth.[35, 37, 39, 165-173] The need for education and support had a frequency effect size of 65%. The lack of structured institutional and peer support was also highlighted, and many studies demonstrated that peer support was valuable, even though it was usually informal. Quantitative studies using a variety of measures emphasised the risk of vicarious traumatic stress and depressive and psychosomatic symptoms such as guilt, self-blame, self-doubt and grief. These quantitative findings are consistent with similar data from the qualitative studies. Healthcare professionals, especially obstetricians, who felt they had received adequate training in stillbirth care were less likely to report guilt and expressed less fear of litigation.

In six studies, staff also experienced positive gains in some respects, such as feeling a sense of honour or privilege at being able to support parents experiencing the death of their baby.[165-167, 169, 170, 172] The sense of positive gain had the lowest overall frequency effect size of 30%. Some staff also cited personal growth and the development of a special bond with parents and staff as a consequence. In four studies, staff reported more confidence and comfort, with fewer negative effects, when they had more direct clinical experience with stillbirth.[166, 167, 170, 172]

1.3.3 Impact on society

Stillbirth, in addition to being an obvious loss to parents and families and, in a personal and professional sense, a loss to healthcare professionals, is also a loss to communities and society at large. The death of any individual impacts on society yet

heretofore the loss of a baby to society has not been recognised as such. Stillbirth has traditionally been viewed by society (and experienced negatively by bereaved parents) as a lesser loss than for example the loss of a child.[90, 137, 159] The first *Lancet Series* on stillbirth explored the cost of stillbirth to society and yet there is little in the published literature about the economic costs of stillbirth to society other than the healthcare cost of stillbirth prevention.[49, 174] There is little in the literature that recognises the human cost/ value of stillbirth.[48] Such a personal loss is rarely acknowledged as a value and impact to society. This is incongruent with how society at large especially in an Irish context values, respects and acknowledges the lives of those who have died. This is also at odds with how death is viewed from a spiritual and pastoral perspective by world religions and philosophical structures. Death is a liminal event with profound spiritual significance. It marks the end of our earthly being and the beginning of a new reality. The philosopher Martin Heidegger describes human life as *Sein zum tode* (being towards death).[175] In most world belief structures life and death are inextricably linked.

A number of studies, notably by Gold *et al* and Mistry *et al* have established that stillbirth has a significant cost to the healthcare system during the care provided following stillbirth and in subsequent pregnancies.[108, 176] Other potentially unquantifiable costs include the impact and care associated with psychological distress, which has both a personal and societal cost. In addition, there is an impact on employment productivity, with associated welfare costs and through employment absence with 10% of parents remaining on leave from work for 6 months after their bereavement and thereafter 38% of mothers and 21% of partners reducing their working hours.(121)

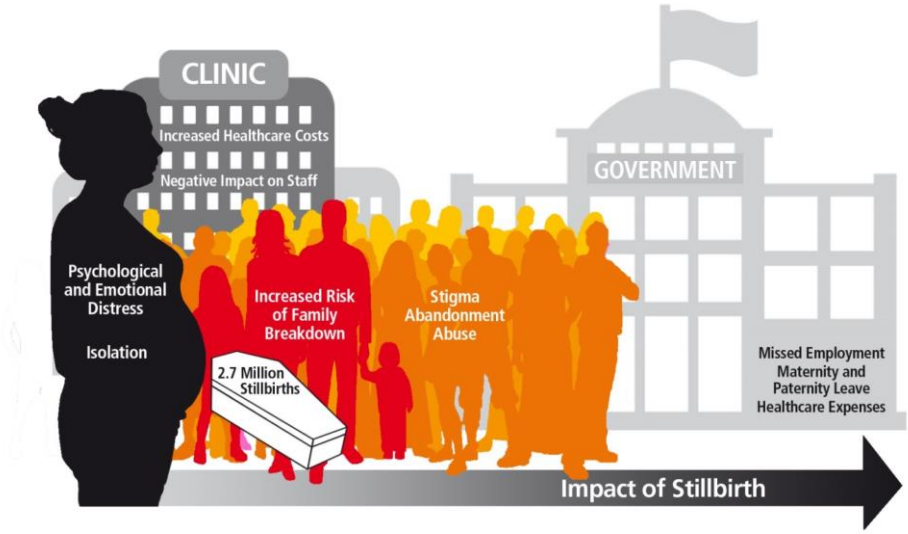


Figure 1.6 Impact on society, *Lancet stillbirth series*

(used with permission from Dr AE Heazell)

1.3.4 What is unknown?

A Cochrane review in 2008, repeated in 2013, investigating support for mothers, fathers and families following perinatal death, was unable to find conclusive evidence concerning the support provided to bereaved parents following perinatal death. The authors concluded: 'Primary healthcare interventions and a strong family and social support network are invaluable to parents and families around the time a baby dies. However, due to the lack of high-quality randomised trials conducted in this area, the true benefits of currently existing interventions aimed at providing support for mothers, fathers and families experiencing perinatal death is unclear.'[177] It can be argued that the provision of bereavement care cannot ethically be subjected to a randomised controlled trial and that observational studies are of importance in this area.

In the wider pregnancy loss literature there is recognition that emotional and psychological support is of value following miscarriage. In a study by Clifford *et al* a significant benefit to pregnancy outcome was associated with supportive care in early pregnancy following a previous miscarriage.[178] In a meta-analysis by Jeeve *et al* of the evidence-based management of recurrent miscarriage in studies between 1950 and 2014 the provision of emotional and psychological support was graded at Level III evidence.[179] In an Irish study by O'Connell *et al*, bereaved parents expressed the importance of ongoing supportive care and how it enabled them to grieve meaningfully and 'organically'.[180]

There is little in the published literature that addresses the provision of spiritual care for parents following stillbirth and most studies have focused on the place of ritual and the way in which ritual expresses grief and belief.[24, 107, 181-183] My study aimed to address this lacuna.

1.4 Spiritual care

1.4.1 What is spirituality?

There is much discussion in the literature concerning the definition of spirituality.[17] Broadly speaking, the debate thus far has focused on distinguishing between religious and spiritual care.[17, 184-187] While in many countries the words religious and spiritual are used synonymously, Gordon *et al* argue that in the European context 'the term "spiritual" is understood to be a broader concept which includes but is not confined to what has been traditionally been understood as

"religious"'.[187] Spirituality is a subjective reality that exists both within and without traditional religious belief structures and systems.[188] Spirituality in its widest sense relates to how human beings understand, express and live their lives in terms of ultimate meaning and value.[188]

The intersection between spirituality, religion and health outcomes has been the focus of considerable research in recent decades, with the role of spirituality in healthcare assuming greater significance.[14, 17, 185, 186, 188-195] Increased attention has been focused on the place of faith in healthcare, illness and recovery. The 2010 working definition of the European Association of Palliative Care defines spirituality as

> '*... the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred. The spiritual field is multidimensional:*
>
> - *Existential challenges (e.g. questions concerning identity, meaning, suffering and death, guilt and shame, reconciliation and forgiveness, freedom and responsibility, hope and despair, love and joy).*
> - *Value based considerations and attitudes (what is most important for each person, such as relations to oneself, family, friends, work, things nature, art and culture, ethics and morals, and life itself).*
> - *Religious considerations and foundations (faith, beliefs and practices, the relationship with God or the ultimate).*'[196]

1.4.2 What is pastoral care?

Pastoral care and spiritual care are used synonymously in the context of healthcare chaplaincy as they express how professionals attend to the spiritual need of patients. 'Pastoral' is historically associated with a Christian understanding. In recent decades the term has evolved to be inclusive of the spiritual needs of all.[197] Each individual is recognised as having a spiritual dimension. Not everyone, however, has a religious or faith expression or dimension to his/her life. For this reason, pastoral care has in many places evolved to be known as spiritual care, with a broader emphasis and application.

1.4.3 Spiritual or religious care?

Spiritual care is the discipline of attending to the spiritual needs of an other. In a healthcare context this means identifying, assessing and attending to the spiritual needs of a patient and family as they deal with illness, trauma or anything that challenges their life or meaning structure.[16, 184, 187, 193, 198-201] For many this will involve attending to specific religious needs but for others it will involve attending to broader spiritual needs and expression. Spiritual care can be understood as the broad and diverse expression of professional care provided by healthcare chaplains.[197] Pargament argues 'every person is a spiritual being as well as a physical, social and a psychological entity.'[202]

1.4.4 Spiritual care in healthcare

1.4.5 The historical position

Faith communities have always seen ministry and care of those who are ill as part of their core work and activity. There has been a relationship between religion and health since the beginning of human existence. Historically in the ancient world when little was known about the human body or medicine, the onset of disease was often ascribed to supernatural or divine power or threat.[(203)] The Christian churches trace the care of those who are ill or infirm back to a biblical imperative which was further strengthened through the ministry of Jesus Christ as recorded in the gospels. Historically, churches and religious orders were at the forefront of establishing hospitals and in the support and provision of medical aid to those in need. This was also part of a 'social gospel' of outreach and support for those who were socially disadvantaged or marginalised.

In Ireland the Christian churches were the main providers of healthcare chaplaincy by virtue of the Christian demographic in society. Most Irish hospitals were established and run by religious orders and churches. Gradually over time, as hospitals became more established, chaplains were appointed to provide for the religious needs of patients during illness and as part of their preparation for death. This ministry was unpaid, and primarily carried out by the clergy or by members of a religious community of nuns or brothers.

1.4.6 Clinical Pastoral Education (CPE)

As healthcare continued to develop and mature as a profession so too did the provision of chaplaincy and the training of healthcare chaplains. In the early 1930s in the USA, Anton Boisen, following his own experience of mental illness, recognised that ordained ministers were not adequately trained for ministry in a hospital environment. This experience led Boisen to explore the religious dimensions of mental illness psychopathology, in which he was inspired by the work of Freud. Boisen suggested that the terrors of mental illness were a religious problem rather than simply a medical one.

Boisen believed that, ordained ministers, although well-versed in theology and biblical studies, lacked the clinical skills necessary to care for those who were ill. Recognising this need, Boisen introduced a model of chaplaincy formation during which students studied the living human document in a supervised environment. Student and supervisor explored together the dynamics, patterns of relating and self-awareness of the student chaplain in ministry.[(204)] Building on this approach, Richard Cabot and William Keller introduced the elements of clinical skills and personal professional supervision respectively to create what was to become Clinical Pastoral Education (CPE). This action-reflection-action integrated model of education was to become the foundational internationally-recognised multi-faith building block for all professional healthcare chaplaincy training and remains so today.

CPE was introduced to the Irish healthcare system in 1982 at The Mater Hospital Dublin, St Vincent's Hospital Dublin, Cork University Hospital and St John of God Hospital, Stillorgan and later at Kerry General Hospital and St Luke's Home

Education Centre Cork and in Northern Ireland in 2006. As is the case of all churches in Ireland, CPE in Ireland is provided on an all-island basis, working in both jurisdictions. The standards of pastoral education in Ireland with a dedicated focus on the personal, pastoral and professional development of the chaplain, are maintained by the Association of Clinical Pastoral Education Ireland (ACPE Irl) in accordance with the international CPE movement.

Spiritual care demands a high level of professional competency on the part of the healthcare chaplain as the recognised spiritual care professional in the multidisciplinary healthcare team.[15, 205, 206] From a robust base of reflective practice and self-awareness on the part of the chaplain, spiritual care provides empathic transformative care, in collaboration with other colleagues. Spiritual care has developed as a clinical discipline in which spiritual assessment, diagnosis and care planning are core competencies of the professional healthcare chaplain.[190, 207-209]

In healthcare there has been a growing understanding of the importance of caring for the whole person, mind, body and spirit, rather than treating illness or disease. This has been part of a move from a biomedical to a biopsychosocial model of healthcare.[210] This 'holistic' approach to patient care has been shown to improve health outcome and patient experience/satisfaction and cost-effectiveness.[211-213] The WHO formally recognises spiritual care as an integral component of palliative care in its formal definition of Palliative Care, adopted in 2002.[214] In addition to generic chaplaincy training, healthcare chaplains, following additional training, also work in specialist areas such as palliative care, intellectual disability, mental health and perinatal care.

The provision of spiritual care is also an important part of hospital accreditation processes in which the physical, emotional and spiritual needs of patients are cared for during illness and recovery and especially during end of life care.[199]

1.4.7 Spiritual care in the Irish healthcare system today

All healthcare institutions in Ireland have officially appointed chaplains to care for patients/ clients and staff. While originally focusing on religious and sacramental need, the discipline of chaplaincy has evolved in line with the global trend to recognise the importance of broader spiritual need. Following the introduction of CPE and formal certification for healthcare chaplains, both ordained and suitably-trained and qualified lay chaplains are now employed as healthcare chaplains and are recognised as healthcare professionals. As part of the CPE curriculum and the formal certification process, all chaplains must have key competencies which enable them to provide generic spiritual care for all, regardless of faith or philosophical tradition.[215, 216]

As a discipline, healthcare chaplaincy in Ireland is currently undergoing considerable change and development. This involves significant challenges as Ireland becomes an increasingly diverse multicultural and multi-faith society.[217] In faith terms, the Irish people, by self-definition in the national census, define themselves overwhelmingly as belonging to a faith tradition and within that as predominately Christian with 84% identifying themselves as Roman Catholic.[218]

All healthcare chaplains in Ireland maintain a dual relationship with their place of employment (healthcare facility) and their faith tradition.[215, 216] This dual relationship is recognised in the literature as a challenge in which the chaplain can feel on the edge of both institutions.[194]

1.4.8 Spiritual care following stillbirth

Every maternity hospital in Ireland has officially appointed chaplains to provide spiritual care for babies, parents, families and staff colleagues.[39] Currently however, there are no dedicated education or training programmes for perinatal spiritual care in Ireland. Those who wish to train in this area do so mostly in the USA. The lack of formalised training in this area has been one of the focuses of my study. In addition, there are few resources available to support chaplains in this work. Notable exceptions are the work of Pierce and Kelly and resources provided by support organisations such as A Little Lifetime Foundation, *Féileacáin*, First Light, Sands (UK).[79, 89, 107]

1.4.9 Place of spirituality/faith in National Stillbirth Guidelines

National clinical practice guidelines establish a clinical care standard where treatment and care, in this case for stillbirth, are set out so that a consistent level of care and clinical procedures is available to all in a public health system. They are markers of quality assurance and are driven by clinical excellence, robust research, safe practice and comprehensive care. Various countries have developed national stillbirth guidelines in recent years as part of a growing global awareness of the

importance of thorough investigation and quality care following stillbirth. What is included in a clinical guideline is evidence of its importance or perceived importance. In looking at holistic care one might expect to see that faith/ spiritual needs would be included as part of a national stillbirth guideline.

As part of this study I conducted a review of seven national/regional stillbirth guidelines written in the years 2006-11 to establish if faith or spiritual needs and care were included as part of the overall standard of care. The guidelines were from SLCOG (Sri Lanka),[97] SOGC (Canada),[219] Sweden,[220] ACOG (United States of America)[99] RCOG (United Kingdom),[80] PSANZ (Australia/New Zealand)[98] and RCPI (Ireland).[78] Each guideline was reviewed to establish if spiritual or faith needs were included by the presence of key words such as ceremony, chaplain, faith, fetus, pastoral, religious, ritual, and spiritual. Where spiritual or faith needs were mentioned these were explored further to establish if this area is treated as an integral aspect of care or as a fleeting reference. The results of this review are illustrated in figure 1.7.

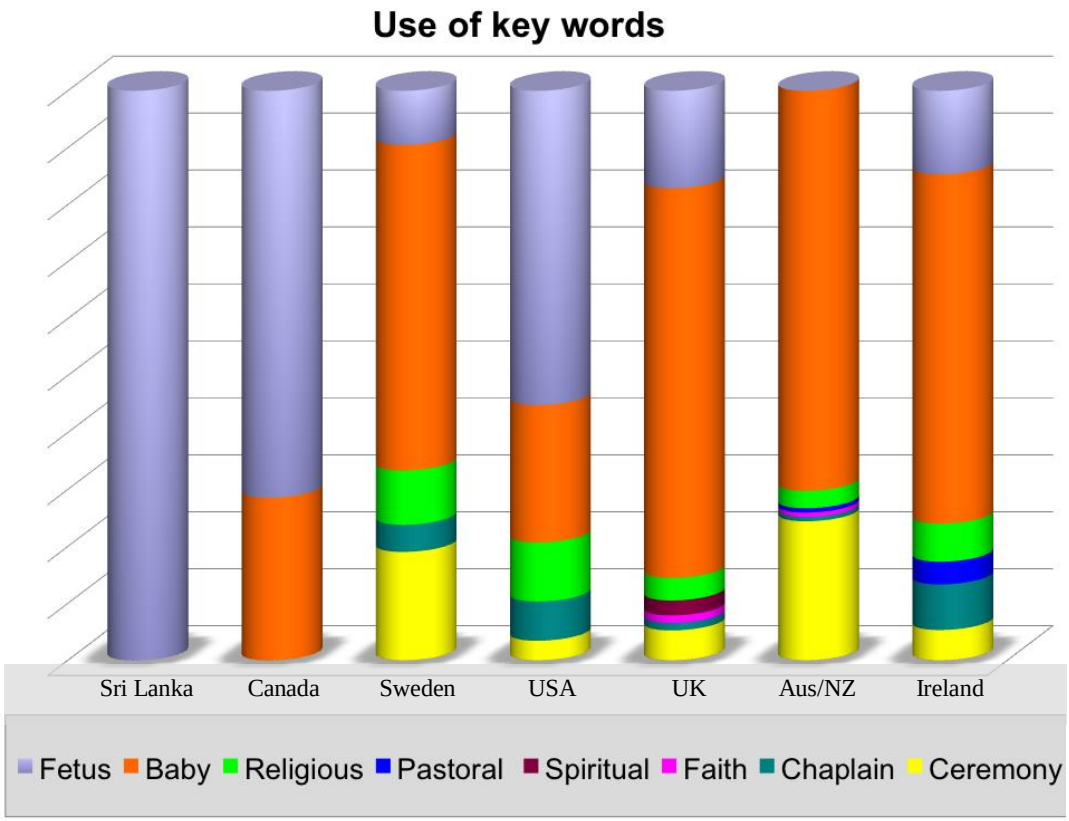


Figure 1.7 Inclusion of spiritual/ faith references in national guidelines

Whereas obstetric and midwifery practices and scientific investigations were generally consistent across the guidelines (with the exception of an agreed definition of stillbirth) the review highlighted a considerable variance in how spiritual and faith needs are identified or met. This varied from no inclusion of spiritual or religious care (n=2) to a functional religious referral (n=2) to an integrated approach where spiritual care is offered to all families (n=3). These findings correlate with how each guideline approaches the 'personhood' of a stillborn baby. Guidelines where spiritual care is not included referred to a 'fetus' and in doing so created distance or objectification of a stillbirth. Guidelines which included spiritual need and awareness as part of comprehensive stillbirth care also used the term 'baby' and demonstrated a more holistic and person-centred approach.

The findings of this review correlate with the identified lack of awareness of the spiritual dimensions and impact of stillbirth and how my study will seek to address this practice gap.

1.5 Bereavement

1.5.1 Impact of grief

Grief is a natural and universal human reaction and experience following loss. For most people it is an uncomplicated process, albeit not without pain, where family, friends and community provide the necessary support to enable the bereaved person to grieve and to adjust to life without his/her loved one. The intensity of grief is influenced by the relationship with the person who has died, the circumstances of the death and on the particular coping styles of the bereaved person.[221, 222]

1.5.2 Perinatal grief

Perinatal grief is recognised as a distinctive grief with lifelong impact for parents who often have complex emotional and psychological needs following stillbirth.[7, 24-26, 32, 34, 137, 177] There are no published studies that have studied differences between perinatal and child bereavement. In one UK study the impact on the mortality of bereaved parents following a stillbirth or the death of a child within its first year of life was immense.[29]

Perinatal grief has also been demonstrated to have a negative impact and strain on relationships with an increase in relationship breakdown following the

death of a baby.[28, 223] In one study however, with 22 couples bereaved through stillbirth, 18 reported that their experience of loss brought them closer together.[224]

1.5.3 Attachment theory

Attachment is a fundamental marker of loss. Without attachment one does not experience loss. To experience loss is to experience the loss or absence of something/ someone which/who held meaning in life. Attachment theory was developed by the British psychiatrist John Bowlby. Bowlby's understanding of attachment theory demonstrates how humans invest in and establish attachment and strong affectional bonds with a significant other (in this case with a new baby).[2, 225] When this relationship is broken, loss is experienced.

It is well established that in perinatal bereavement loss is not dependent on the point of gestation but on the significance of and depth of attachment. For some parents attachment begins before conception, for others when their baby is visualised on ultrasound or following awareness of a baby's movements *in-utero*.[226] The theory of perinatal attachment was developed from the early 1970s through the work of Rubin, Cranley and Muller.[227] Doan and Zimerman, as cited in Brandon *et al*, define prenatal attachment as '…an abstract concept, representing the affiliative relationship between a parent and fetus, which is potentially present before pregnancy, is related to cognitive and emotional abilities to conceptualize another human being, and develops within an ecological system.'[227]

In addition to parents, other siblings and family members also begin to attach to a baby as they too prepare to welcome a new member to their family.[226] An

understanding of attachment theory is an important part of perinatal bereavement care and is used to care for parents as they come to terms with the death or impending death of their baby.

1.5.4 Anticipatory grief

Anticipatory grief is a key component of grief work and grief therapy in perinatal bereavement and loss. Anticipatory grief prepares parents for impending death as they begin the process of mourning the baby and life that would have been.[226] As a process it enables bereaved parents to create memories and to start their grief work from the point of their first awareness of loss, which for many parents is at diagnosis of a life-limiting condition or anomaly.[226] In grief terms this is a unique grief because antenatally the baby who is the focus of grief has not yet been met face to face, unlike other grief the baby is not yet in a place for others to visit and to grieve. The womb becomes the 'tomb of death'[9] and yet paradoxically and bewilderingly the baby who is the focus of grief is still alive. Parents are faced with the devastating conclusion that every moment closer to their baby's birth is also a moment closer to his/her death.

Anticipatory grief is in its essence a palliative approach where couples are facilitated to create memories and to prepare for the birth and death of their baby.[228] In addition to facilitating a highly supportive level of care during pregnancy, anticipatory grief work also enables parents to prepare for the reality of having to make choices for their baby after death such as any particular religious/ cultural ceremony, funeral, burial or cremation in an unhurried way that then allows them to spend all of their finite time between birth and burial/cremation with their baby.

Anticipatory grief work enables parents to create and maintain continuing bonds with their baby into the future and to lay foundation blocks for a lifetime of remembering and prospective grief.[2, 3]

1.5.5 Continuing bonds

Attachment to a baby does not stop when a baby dies. Bereaved parents in their grief continue to experience a continuing bond with their baby following his/her death.[2, 11] This continuing bond is in many ways a continuation of anticipatory mourning and demonstrates the ongoing sense of relationship that parents have with their deceased baby. For some parents this ongoing relationship will be adaptive but for some it will be maladaptive.[2, 33] The sense of continuing bonds and enduring relationship or connectedness with their baby is in many ways a spiritual reality for parents and helps to create meaning and is a source of comfort.

1.5.6 Disenfranchised grief

Disenfranchised grief is 'grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported.'[229] For many bereaved parents stillbirth has historically been clouded in a cultural silence that compounded loneliness and isolation.[37, 149] Faith communities have only in recent decades recognised stillborn babies in their liturgies and ceremonies but there is still a traumatic legacy of pain and sadness at how babies were denied public ritual, ceremony or burial in consecrated ground in Ireland and beyond.[9, 88, 89] The 'nature of disenfranchised grief creates additional problems for grief while removing or minimizing sources of support.'[229] The experiences of

bereaved parents whose baby's death was minimised by family or healthcare professionals have compounded grief and trauma at an already difficult time.[37, 101, 230] Other complexities such as same gender parental grief, teenage pregnancy and sexual violence add to disenfranchisement and social isolation that impact on grief.[229] One study from 2011 identified a 'double disenfranchizement' for lesbian couples following bereavement.[231] Increased public awareness and the role of parental support groups have helped to lessen the isolation of stillbirth in public consciousness.

1.6 Summary

In summary, following an extensive review of the current literature, this chapter has outlined the impact of stillbirth on parents, healthcare staff and society. I have outlined the history and development of stillbirth care from a place of unacknowledged grief to a much more comprehensive understanding today including the current management of stillbirth. I have given a background to the place of spiritual care and the place of spirituality in healthcare generally and in Ireland in particular as it pertains to perinatal bereavement ministry. As stillbirth is without question a significant bereavement I have provided a background to bereavement theory as it applies to stillbirth. In this introductory chapter many questions have been raised and my study seeks to answer them and by doing so to contribute to the ongoing quality of care provided to parents during this devastating loss.

1.7 Objectives of study

This chapter has outlined that there has been much study in the field of stillbirth in recent years which has led to significant developments in care, both physical and psychosocial. As demonstrated above, there has been little study into the spiritual impact of stillbirth and how the distinctive spiritual needs of bereaved parents might be recognised and met as part of overall comprehensive care following this devastating experience.

Recognising that little is known about the spiritual impact of stillbirth, my aim was to explore this phenomenon. I wanted to explore the spiritual impact of stillbirth firstly with maternity healthcare chaplains as the main providers of spiritual care following stillbirth (Chapter 3). It became clear from the initial data that stillbirth had a considerable personal and professional impact on healthcare chaplains. Because of this insight from chaplains, I then aimed to explore the impact of stillbirth on consultant obstetricians in addition to looking at how consultant obstetricians recognise spiritual distress following stillbirth (Chapter 4). Finally I examined with bereaved parents what the spiritual impact of stillbirth was on them and how their spiritual needs were met following the stillbirth of their baby (Chapter 5).

By researching these areas, my study will bring greater understanding about the impact of stillbirth on healthcare staff. In addition, my study will explore how chaplains cope spiritually and theologically as they provide ministry in this challenging area. Finally, my study will provide greater insight into the spiritual dimension of stillbirth for bereaved parents and how those needs can be best met. As

a result of my study there will be a greater awareness of the spiritual dimension and professional impact of stillbirth and this information will contribute to ongoing comprehensive bereavement care and staff support. It is also hoped that the results of my study will serve to shape ongoing training and support for maternity healthcare chaplains in perinatal bereavement care.

Chapter 2: Methodology

2 Chapter 2: Methodology

2.1 Introduction to methodology

This chapter outlines the design of the study and the rationale for the chosen methodology to study the spiritual and professional impact of stillbirth on healthcare chaplains, consultant obstetricians and bereaved parents. It includes an outline of how I learned and applied the process of qualitative methodology starting with thematic analysis for the first phase of the study with maternity healthcare chaplains and developing this to Interpretative Phenomenological Analysis (IPA) for the second and third phases with consultant obstetricians and bereaved parents respectively. I will make a case for the justification of IPA as the most appropriate qualitative methodology for this study. I will outline how the interview schedule was developed and special precautions put in place to support participating bereaved parents as a vulnerable population. This is followed by an outline of the recruitment procedure, interview process, the methodological steps in the analysis of the data and the use of reflective journaling as part of on-going theological reflection during the study.

2.2 Study design

This was a qualitative study exploring the spiritual and professional impact of stillbirth and was designed in three phases. The first phase was with all Irish maternity healthcare chaplains, the second was with a purposive sample of consultant obstetricians working at an Irish tertiary university maternity hospital and the third was with a purposive sample of parents bereaved by stillbirth who had been cared for

at an Irish tertiary university maternity hospital. As the aim of this study was to research the spiritual and professional impact of stillbirth, a qualitative methodology was the most appropriate way to approach the area so that the voices, interpretations and meanings of the study participants would bring lived experience to bear on the subject of stillbirth.[232, 233]

2.2.1 Introduction to qualitative approaches

Qualitative methods are used to understand complex social processes, to capture essential aspects of a phenomenon from the perspective of study participants and to uncover beliefs, values and motivation towards care and service provision.[234, 235] A qualitative approach at its heart seeks to explore in an in-depth way the experiences and the understandings of study participants, 'Qualitative researchers study things in their natural settings, attempting to make sense of, or interpret phenomena in terms of the meanings people bring to them'.[233] Qualitative approaches are nuanced, diverse and range in complexity.[236] Qualitative research studies a human or social problem from an inductive perspective where the participants are empowered to share their stories unencumbered by theory or what is found in the literature.[232, 237] In this way a qualitative approach allows new insights to contribute to our knowledge base and understanding. Qualitative methodology focusses on depth rather than breadth. As an approach, qualitative methodology in a healthcare context researches the lived experiences and human impact of illness and significant health related life events.

Qualitative studies have grown exponentially in recent years in health and psychology research.[237-239] This has led to the development of a considerable corpus

of high-quality studies that in themselves serve as inspiration for further studies.[238] The use of qualitative methodology has brought new depth to the understanding of human experience and meaning-making in illness and trauma.[238, 240]

2.2.2 Learning the methodology

Qualitative methodology and analysis was new to me and so before embarking on the research design for this study I studied qualitative methodology and worked with a social scientist (SM) experienced in this area who works in the area of perinatal mortality. I gained experience of interview design and technique, data transcription, coding and analysis. This involved accompanying her during interviews and analysing data in a qualitative study being conducted.

I designed the interview schedules for my study and these were supervised by a social scientist (SM) and my primary academic supervisor who is a consultant obstetrician (KOD). For the first part of my study with healthcare chaplains I used thematic analysis as the qualitative methodology. This enabled me to get a good grounding in this methodology before progressing to IPA for my study with consultant obstetricians and bereaved parents. At each stage the data were analysed independently by a social scientist (SM) and a sample from each dataset by a consultant obstetrician (KOD). This incremental approach enabled me to develop a working command of qualitative methodology, study design and data analysis.

2.2.3 Thematic analysis

Thematic analysis is a foundational and widely used method for qualitative analysis and as such can be seen as the generic basic 'building block' of all qualitative analysis.[241] Thematic analysis is a core skill that is used across various qualitative methodologies and forms the basis for further analysis.[236] As a methodology it has rigour in its own right as a recognised methodology for qualitative research.[241] Thematic analysis offers a flexibility of approach to provide a rich and detailed account of data.[241] Thematic analysis is an active methodology that identifies, analyses and reports themes within data in rich detail.[241] I used thematic analysis in my study of healthcare chaplains to explore the experiences and reality of providing spiritual care following stillbirth. The process of thematic analysis is outlined in figure 2.1.

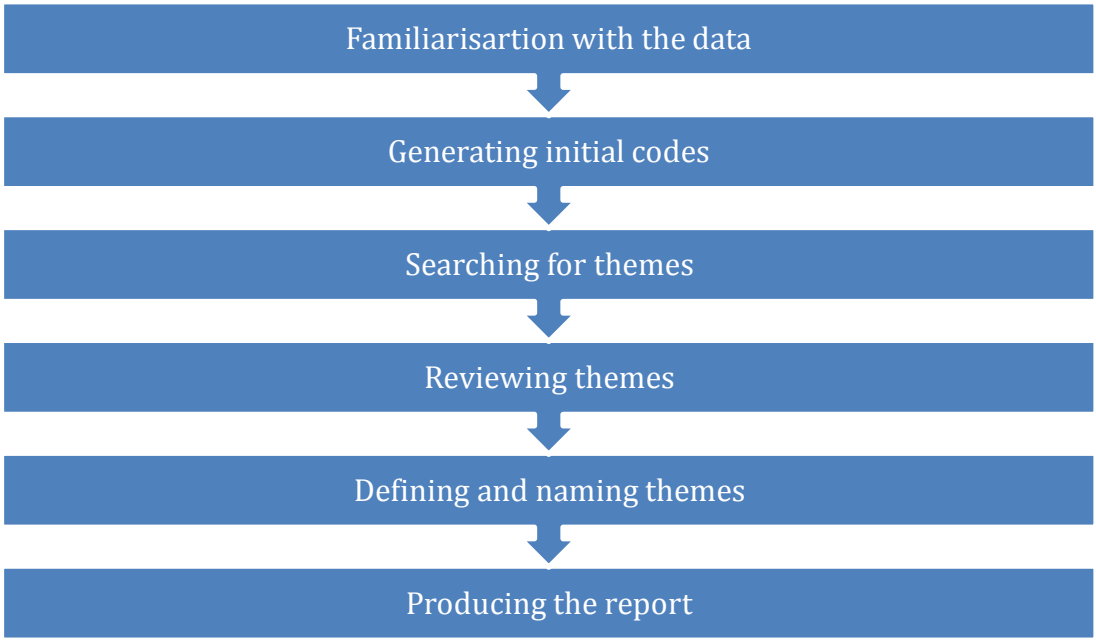


Figure 2.1 Process of thematic analysis[241]

For the purposes of the wider study, thematic analysis alone would not analyse the data at sufficient depth and so the generic skill of thematic analysis was used as a foundational 'entry stage' methodology; identifying themes during the coding process that were then further analysed using a phenomenological approach for the study of consultant obstetricians and bereaved parents. It can be argued that while a broad qualitative methodology is an appropriate overall approach, as this study was focussing on the particular experience and phenomenon of stillbirth for consultant obstetricians and bereaved parents a narrower and more focussed methodology was required.

2.2.4 Phenomenology

Phenomenology in its broadest sense seeks to look at experience itself, to 'return to the things themselves' as coined by the eighteenth century founder of phenomenology Edmund Husserl.[234] Phenomenology seeks to understand as far as possible the way the particular phenomenon is experienced within the context of the participant's life.[234] The goal of phenomenology as a methodology is to 'describe, interpret and understand the meanings of experiences' both for the individual and also at a general level.[236] For this study a more focussed phenomenological approach was important so that the meaning(s) attributed to the experience of stillbirth could be understood from the perspective of the participants. This necessitated the decision to choose Interpretative Phenomenological Analysis (IPA) as a specific theoretical and epistemological framework for this study where primacy is given to lived experience and attributed meaning by the participant, in order to understand the phenomenon of stillbirth from a spiritual and pastoral perspective.[235, 240, 241]

2.2.5 Rationale for Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) focuses on the specific and particular nature of a phenomenon or experience at depth and what it means for each individual participant.[240] IPA is a well-established qualitative research methodology that has grown from the field of health psychology and is used increasingly in health science research to understand how people make sense of their experiences.[235, 240] IPA is an inductive approach, where the analysis is data-driven rather than theoretically bound. Data are analysed without trying to fit into a predetermined coding or thematic frame or indeed the researcher's preconceived analysis.[241]

Analysis is an active pursuit and cannot be conducted in an epistemological vacuum. For this reason, it is important for the researcher to be self-aware about his/her own presuppositions and bias and for this to be acknowledged.[237, 241] Analysis is a continuous process and starts from the beginning of the study where the researcher is gaining new insights at every stage and most-especially during and following collection of data.[242] This 'back and forth' approach is an important element where meanings are explored and understood throughout the whole analysis process.[236]

In IPA the researcher is tasked with entering as far as is possible into the world of the participant who is the 'experiential expert' in an empathic way and to seek to understand the data from the participant's perspective.[235, 236] In IPA emphasis is also placed on the role of the researcher as they make sense of the experience of the participant. This involves a double hermeneutic where the

researcher is trying in make sense of the participant who in turn is trying to make sense of their experience.[234, 238]

IPA as a research methodology focusses on the depth and richness of data and, by their nature, IPA studies have small sample sizes to allow experiences to be studied in detail.[234, 237] Many IPA studies have sample sizes from five to fifteen and in some studies an argument is made for a single case-study, studied at depth.[238, 240, 243] Other methodologies such as grounded theory use theoretical sampling to keep selecting participants and data based on existing analysis until no new themes emerge and then to establish claims for the general population whereas IPA uses selective purposive sampling to illuminate a particular research question.[237] The participants represent an experience rather than a population.[240] The particular experience however, can then reveal truth claims that can be ascribed to a more general population that might have the same experience, 'the very detail of the individual also brings us closer to significant aspects of shared humanity'.[236, 238] Smith argues that a sample needs to be broadly homogenous where patterns can be seen across cases and yet still recognising particularities in individual accounts.[244]

IPA studies frequently address issues of existential importance for participants and these often concern significant transforming or threatening life events.[238] IPA has successfully been used in related studies in the area of gender, miscarriage, pregnancy, pain and end-of-life care.[245-250] Of particular note is a 2003 study by Maker & Ogden in the related field of miscarriage where IPA was used to explore the experience of miscarriage and the qualitative elements of psychological morbidity following pregnancy loss.[251] Previous studies had mainly focussed on

quantitative prevalence of psychological morbidity such as grief, depression and anxiety. The use of IPA brought a greater depth and richness to the field and in the study by Maker & Ogden IPA revealed three superordinate themes of 'turmoil, adjustment and resolution' as important experiences and stages following miscarriage.[251] In a 2014 study by Campbell-Jackson *et al* of the experience of mothers and fathers experience of having a child following a recent stillbirth, the use of IPA brought significant new insights around parental support, parenting style and grief patterns following stillbirth and brought new insights to bear in the area of ongoing grieving following stillbirth.[252]

IPA has also been used to study other aspects of care following stillbirth. In a 2014 study, Ryninks *et al* used IPA to study Mothers' experience of their contact with their stillborn infant.[126] This study contributed greater depth to what is an equivocal practice and a source of much debate in the literature. Based on how these studies have contributed to the perinatal bereavement literature, IPA is a proven methodology in this field.

As the focus of my study was the experience of stillbirth impact and care, IPA was the appropriate qualitative method to capture the lived experiences of consultant obstetricians and bereaved parents as it would bring to light personal lived experience and impact of stillbirth as a phenomenon.[235, 240]

2.2.6 Theological reflection

Theological reflection is the process of disciplined engagement and reflection on life experiences and their meanings in the light of understanding values and faith.[253, 254] It is an integrative and dynamic process where, in the words of Graham the 'connections between human dilemmas and divine horizons [are] explored, drawing on a wide range of academic disciplines including social sciences, psychotherapeutic and medical disciplines and the arts.'[253]

Theological reflection as a methodology has grown from the work of Anton Boisen, the founder of Clinical Pastoral Education (CPE), the liberation theology movement of the 1950s and the work of educational philosophers John Dewey and Donald Schön.[204, 255, 256] In the wider educational academy, professional reflective practice was further developed by Kolb in the development of the 'Experiential learning cycle' and in practical theology by the 'Pastoral cycle'.[254, 256] Theological reflection is closely aligned with the professional field of practical theology where critical engagement with human experience and understanding are core elements.[257]

Theological reflection is a cyclical process of experience, exploration/analysis, reflection and incorporation of new insight(s) to practice. There are many well-established theological reflection methodologies in use but all are based on the above cyclical process to a greater or lesser extent. As this study focussed on the spiritual and professional impact of stillbirth, the participants were themselves 'the living human documents' that Boisen referred to.[204] In the area of stillbirth, theological reflection offered a structured process of theological

engagement with the data in a way that opened up new insights from human experience into what is an acknowledged area of theological challenge.[9, 39, 107]

This study was rooted in the experience of stillbirth in a healthcare environment. As a healthcare chaplain trained in CPE methodology, I used this 'living human document' approach of Boisen and then integrated it theologically with the approach of Green in the use of the 'Theological spiral' as a theological methodology throughout the study.[204, 256, 258] A diagram of Green's Theological Spiral is shown at Figure 2.1.

This approach has an epistemological affinity with the focus of IPA in the search for meaning from experience where reflection brings forth 'thick descriptors' from human experience.[256] For the purposes of this study both approaches are hermeneutic, heuristic, experiential and data driven from the experiences of the participants. They recognise the role of the researcher as interpreter and therefore were judged as appropriate and complementary methodologies.[234, 240, 254, 256-260]

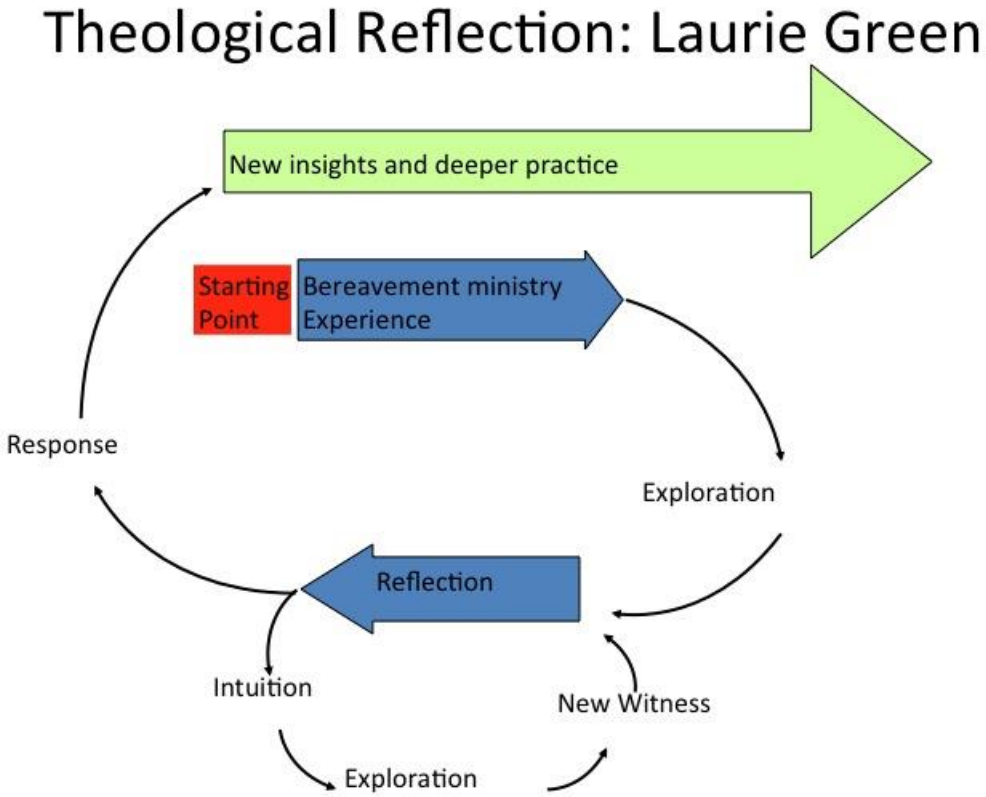


Figure 2.2 The theological spiral

2.2.7 Design of research schedule

I designed a semi-structured interview schedule in conjunction with my research team for each of the three subject populations. The interview schedule was based on the existing literature in the field and the experience of the research team who work in this area as a healthcare chaplain with specialist perinatal bereavement training, a social scientist working in perinatal epidemiology and a consultant obstetrician who is also a maternal-fetal medicine specialist. The semi-structured interview guides were the 'starting point' for data collection and by necessity were sufficiently flexible to allow the data to be participant-driven while at the same time maintaining a consistency of topic.[234] This enabled richer data to be shared, honoured the participant as experiential expert and maintained the importance of not

confining the data collection to the topics identified by the research team as part of the study design. This approach allowed each participant to tell their own story.[234, 236]

2.2.8 Content of research schedule

Copies of the topic guides for each of the three groups of participants are included at Appendix 1 -Chaplains, Obstetricians, Parents.

2.3 Participants

The study focussed on three groups of participants; healthcare chaplains at maternity units in Ireland, consultant obstetricians at a tertiary university maternity hospital and three groups of parents bereaved by stillbirth from each of the years 2008, 2010 & 2013.

Healthcare chaplains at all maternity units in Ireland were included in the study and as a phenomenological approach was taken for the consultant obstetricians and bereaved parents the study participants were selected purposefully so that their experiences of the phenomenon (spiritual and professional impact of stillbirth) were brought to light.[232, 234]

2.3.1 Inclusion criteria: healthcare chaplains

The inclusion criteria for healthcare chaplains to participate in the study were that they were the officially appointed chaplain to a maternity unit and that they had cared for parents following stillbirth.

2.3.2 Inclusion criteria: consultant obstetricians

The inclusion criteria for consultant obstetricians were that they were part of the permanent consultant staff at the study maternity hospital and that they had provided care for parents following stillbirth.

2.3.3 Inclusion criteria: bereaved parents

The inclusion criteria for bereaved parents were that they had experienced a stillbirth while in the care of the study maternity hospital, were not pregnant at the time of the study, were over 18 years of age, had capacity to participate, could communicate fluently in English and were from only one of the study years 2008, 2010 & 2013. The study were years were chosen to reflect the current year of the study (2013), the first full year since the opening of the hospital (2008) and the mid-point between (2010).

2.4 Procedure

2.4.1 Ethical approval

Ethical Approval for each part of the study was received from the Clinical Research Ethics Committee of the Cork Teaching Hospitals (Ref: ECM 4 (pp) 06/03/12), (Ref: ECM 4 (zzzz) 12/06/12) and (Ref: ECM 4 (jj) 04/12/12). Copies of the ethical approvals can be found at Appendix 2.

2.5 Recruitment process

The study participants were recruited in three phases starting with healthcare chaplains, then consultant obstetricians and finally bereaved parents. The recruitment process for each group is outlined below.

2.5.1 Healthcare chaplains

Healthcare chaplains from every maternity unit in Ireland (n=20) were contacted by letter or email to their place of work with an invitation to participate in the study, with the stated aim of reviewing the provision of spiritual and pastoral care provided to parents following stillbirth, and how they as chaplains provide that care. Chaplains from every maternity unit responded to the invitation to participate. However three units were excluded because the chaplains there did not meet the inclusion criteria of having personally cared for parents following stillbirth. Twenty chaplains from seventeen units met the inclusion criteria and participated in the study. Chaplains were invited to meet with the researcher for a semi-structured

interview at a time and venue of their choosing, or if unable to meet face to face they were invited to conduct the interview by *skype* or by telephone. A copy of the letter of invitation can be found at Appendix 3. A copy of the study information material can be found at Appendix 4 and a copy of the consent form is included at Appendix 5.

2.5.2 Consultant obstetricians

A purposive sample of 50% (n=8) of the consultant obstetrician population at a tertiary university maternity hospital were invited by letter to participate in the study with the stated aim to explore the impact of providing stillbirth care. The purposive sample was balanced between those who were primarily obstetricians versus primarily gynaecologists, those who had an academic portfolio and those who were exclusively clinical; there was also an equal gender balance. Obstetricians who agreed to participate were then sent a study information leaflet and consent forms prior to the arranging of a face-to-face meeting for a semi-structured interview. A copy of the letter of invitation can be found at Appendix 3. A copy of the study information material can be found at Appendix 4 and a copy of the consent form is included at Appendix 5.

2.5.3 Bereaved parents

Bereaved parents from each of the years 2008, 2010 & 2013 were purposively sampled from the database of parents bereaved by stillbirth at a tertiary referral hospital with a large pregnancy loss service. As the primary relationship is

between the hospital and a mother, it was deemed most appropriate to access both mothers and fathers through the bereaved mother in each case.

The mothers of six babies from each of the three years (2008, 2010 & 2013) were identified for initial contact to participate. These years were chosen to represent a broad grief timespan to include the year of bereavement, three years post bereavement and five years post bereavement. As bereaved parents are a vulnerable population each mother was contacted first by a bereavement and loss specialist midwife known to them to ascertain if they would be willing to receive an invitation to participate in a study exploring the spiritual dimensions of stillbirth.

The study protocol had identified that initially the parents of four babies from each of the three study years would be recruited for the study and that the parents of the remaining two babies would only be recruited if data saturation was not reached. As data saturation was reached with the parents of four babies from each year, no further parents were recruited. The participating mothers were divided evenly in each year between those who had an anticipated stillbirth following an antenatal diagnosis of a life-limiting condition and those who presented with an unexplained stillbirth.

Following initial contact from a bereavement and loss midwife and agreement to receive an invitation to participate in the study, I contacted each mother by letter, inviting them to participate in the study and provided them with a study information pack. In addition to information about the study and a consent form, each pack also contained a leaflet about support services available to parents in the

event that participation in the study caused any distress. Two bereavement and loss specialist midwives known to the participating parents were available throughout the study period to provide support to those who wished to avail of it. Each mother was invited to extend the invitation to their partner to participate in the study. Five fathers participated in the study: four as part of a couple with their partner and one who was interviewed separately by request.

A copy of the letter of invitation can be found at Appendix 3. A copy of the study information material can be found at Appendix 4 and a copy of the consent form is included at Appendix 5.

2.6 Data collection

All participants were invited to meet with me at a time and venue of the participants' choosing. This enabled the participants to meet with me in an environment where they felt most comfortable. The environment where the interview takes place and personal comfort can influence the depth of participation.[234] For the interviews with chaplains, most (n=14) were conducted at the chaplain's place of work. This also enabled me to visit their maternity unit and to experience the working environment where chaplains carried out their ministry. The interviews for obstetricians were all conducted at their place of work and in an undisturbed office environment. In one case the interview took place in a clinical setting but the obstetrician closed both access doors for privacy midpoint through their interview. Most bereaved parents (n=14) were interviewed in their home environment and the remaining (n=3) chose to return to the study hospital for their interview.

Each interview followed the semi-structured interview guide and was digitally recorded. Participants were given control of the recording device and were informed that if they wished to have a break or to stop the recording at any time that they were free to do so. This approach empowered the participant as the experiential expert and gave them control of the interview recording.[234, 235] Three parents and two obstetricians paused the interview when they were distressed. My role as the interviewer was to facilitate and empower the participant to tell their story in a trusting way and safe environment.

Following the interviews, data were subsequently transcribed verbatim and anonymised to protect the identity of the participants and their place of work in the case of healthcare chaplains. Each participant was given a unique identifier code known only to the researcher.

A reflective journal was also kept where additional material and observations were recorded following each interview. The reflective journal was used to capture data that would not be recorded by the digital recorder such as body language, emotion, gestures and where on one occasion a participant left the room when they got upset. Following each interview I took time to reflect on the interview and to record the impact of the interview on me as a researcher. In addition the reflective journal was used to record initial thoughts and theological insights based on the interview experience as a tool to aid continuing theological and personal reflection as part of the interview process and to aid a deeper theological and interpretative hermeneutic between me as researcher and the participants.[253-256, 260, 261] This

material also formed part of the on-going analysis at every part of the study.[242] Sample reflective journal notes can be found at Appendix 7.

2.7 Data analysis

The data were transcribed verbatim. Data from healthcare chaplains were analysed using thematic analysis to identify key themes for chaplains following stillbirth (see figure 2.1).[241] Data from consultant obstetricians and bereaved parents were analysed in great detail using the recognised five steps of IPA (see figure 2.3).[240] Data from healthcare chaplains were managed manually. Data from consultant obstetricians and bereaved parents were managed electronically using NVIVO Version 10 (QSR International). I conducted the analysis on the data and it was also analysed independently by a social scientist (SM) and a sample by a consultant obstetrician (KOD) and where there were discrepancies, agreement was reached by consensus. The process of IPA data analysis is outlined in the following sections.

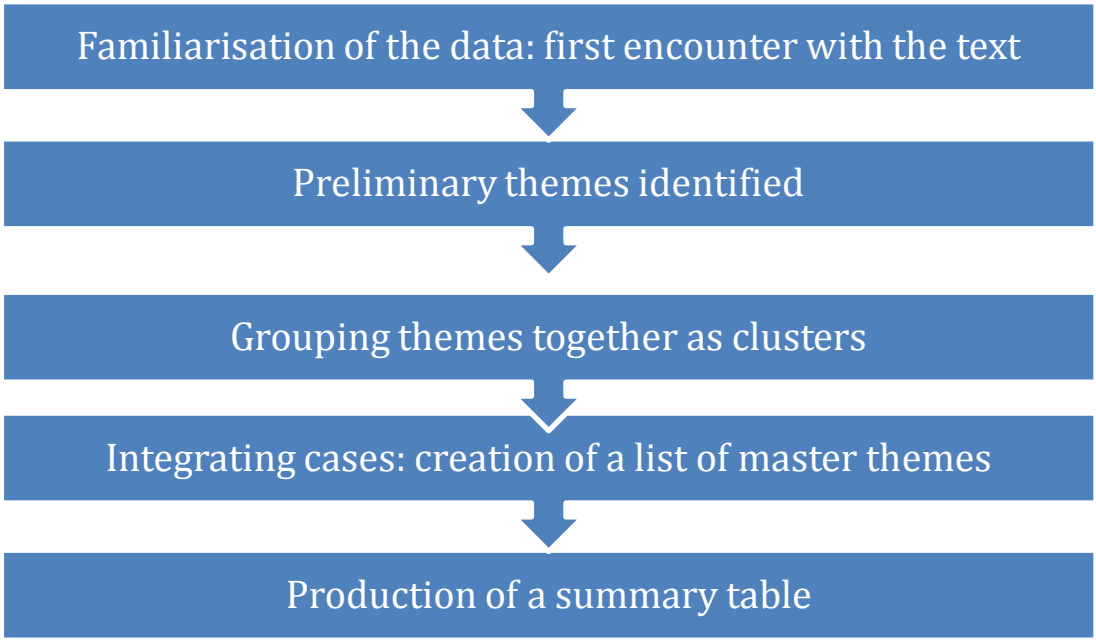


Figure 2.3 Interpretative phenomenological analysis

2.7.1 Familiarisation of the transcripts

As the researcher I was required to enter into an interpretative relationship with the data and this involved familiarisation with the transcripts and recordings. Each transcript was verified for accuracy against the original recorded interviews. Transcripts were read several times and the recordings listened to both with the transcripts and also separately to allow for nuances to be recognised.[236] I also relied on my reflective journal before and after listening to each interview to increase familiarisation with the data, the environment of the interview and to foster a deeper interpretative hermeneutic.[234, 242]

2.7.2 Preliminary themes identified

I analysed each interview separately to identify and code expressions and phrases relating to the spiritual and professional impact of stillbirth. This was done chronologically through the transcript as the phrases occurred. Coded words and expressions used by the participants were then revisited to identify preliminary themes from the entire transcript. Each transcript was studied separately and in detail and only when each one was completed did I move to the next case.

2.7.3 Themes are grouped together as clusters; related themes are arranged together

As themes emerged they were grouped together as related clusters where they had similarities or connections. As themes were clustered they were also checked against the original words of the participant to ensure authenticity to the source data. This iterative approach deepens the level of interpretation by the researcher and

maintains faithfulness to the words and expression of the participants. Themes are not chosen based on their frequency but on their meaning for the participant.[234] The process of theme clustering also helped to give shape to related groups of themes from each interview and in the process started to give shape to overall themes emerging in the field.

2.7.4 The creation of a master table of themes

The clusters of themes were further analysed to explore commonalities and contradictions. This stage of analysis allowed for the creation of a master list of themes and the identification of superordinate or overarching themes that were then made up of subordinate themes. This approach allows for clarity and overall shape to emerge as part of the interpretation of data. Themes that were not considered relevant for the focus of the study were excluded.

2.7.5 The integration of cases

Each transcript following detailed individual analysis was then compared across the data set to compare and contrast the themes to establish if there was an overall emerging pattern from the sample as a whole.[240] This stage in the analysis allowed an overall emergence of superordinate and subordinate themes to emerge from across the entire data set for each group of interviewees; healthcare chaplains, consultant obstetricians and bereaved parents. Where new themes emerged in subsequent cases the prior transcripts were revisited in light on this. This iterative hermeneutic approach strengthened the overall analysis of the data to produce the

final table of superordinate themes for the study. Direct material from transcripts was identified to demonstrate and back up each theme.[234, 240]

An example of coding and analysis of a transcript from a bereaved parent is included at Appendix 6.

2.8 Reflexive accounting

Reflexive accounting is the process of recording what one might expect to find in a study before the study begins. In my case this accounting was based on my experience as a healthcare chaplain working in a tertiary maternity hospital. I anticipated that stillbirth would have a considerable burden on chaplains, and obstetricians. I anticipated that most chaplains would engage in structured theological reflection and supervision as sustaining elements in their ministry. I expected that maternal-fetal medicine specialists would be highly invested in the care of bereaved parents and that consultants who specialised in gynaecology would not.

I expected to find that bereaved parents would struggle to reconcile their faith/belief in a loving God following the death of their baby and that parents would value the opportunity to share their experiences surrounding the birth and death of their baby.

2.9 Conclusion

A detailed account of the study design, my familiarisation with qualitative methodology, the recruitment process, methodological justification and the use of

IPA as an analysis methodology used in this study has been outlined in this chapter. Twenty healthcare chaplains, eight consultant obstetricians and seventeen bereaved parents -twelve mothers and five fathers- were interviewed for the study.

Chapter 3: Results

Maternity Healthcare Chaplains

3 Chapter 3: Results: Maternity Healthcare Chaplains

3.1 Introduction

Every maternity unit in Ireland has officially-appointed chaplains to provide spiritual care for patients and staff. In practice, due to demographics and history, as outlined in Chapter 1, all chaplains are from a Christian background. Spiritual care from other faith traditions or philosophical groups is available on a 'call-in' basis when the need arises.

In each maternity unit a significant proportion of ministry from chaplains will, by definition, involve caring for parents following stillbirth. As maternity units range in size from number of births of less than 2,000 per annum in the smaller units to 10,000 per annum in the larger units, so too will the number of stillbirths.[52] Of the 20 maternity units, 17 are co-located with acute general hospitals. Chaplains in these units also look after other hospital areas as part of their portfolio and therefore their capacity to specialise in the area of perinatal bereavement care may be limited. Yet, bereaved parents deserve the same standards of care, regardless of where they are cared for. One would expect this in obstetrics and midwifery and so the same standard should be expected in chaplaincy.

Caring for parents when their baby has died is demanding ministry and as part of this study one of my aims was to research what the impact of this care was on maternity healthcare chaplains. How do chaplains cope with the death of a baby? How do chaplains respond to the needs of bereaved parents both in hospital and following their discharge home? As people of faith, how do chaplains deal spiritually

and theologically with stillbirth? Does it challenge their faith when the natural order of birth, life and death is interrupted? A review of the published literature revealed that these areas had not been researched before.

Recognising that little research has taken place amongst Irish healthcare chaplains it was important to approach the study in a way that would facilitate maximum participation and trust in what is a very sensitive area. Matters of life, death and faith are personal and, for many people, private.

3.2 Study participants

At the time of the study (2012) there were twenty maternity units in Ireland. The geographical spread of these units is illustrated in figure 3.1. The chaplaincy teams at all Irish maternity units (n=20) were contacted by personal letter or email and were invited to participate in the study. Chaplains from every maternity unit responded to the invitation, but three chaplains from three medium-sized units with number of births of <5,900 per annum were excluded from the study because they had not provided care for families following stillbirth. Therefore, 20 chaplains from 17 maternity units participated. The participating chaplains represented most parts of Ireland and therefore the study gave a good overall view of the Irish maternity services. In one case, after the interview, a chaplain asked for comments he/she had made about the bereavement team in his/her hospital not to be included in the study. This section of data was removed as requested.



Figure 3.1 Irish maternity units[52]

3.3 Interviews and analysis

Of the 20 chaplains surveyed, 14 were interviewed face-to-face and six by telephone. Face-to-face interviews were conducted at the place of work of each chaplain in a private office environment. In order to achieve a consistency of topics covered, each interview followed the semi-structured topic guide. Interviews ranged from 28 to 75 minutes in length and were digitally recorded. Each interview was then transcribed verbatim and transcripts were checked against the audio recordings for

accuracy. Thematic analysis of each transcript revealed the experiences and reality for chaplains of providing spiritual care following stillbirth.

3.4 Findings

I will present the general findings about ministry following stillbirth in Irish maternity units first, followed by the analysis and findings from the thematic analysis of the data from healthcare chaplains (Section 3.7).

All participating chaplains were from a Christian faith tradition; 17 Roman Catholic and three Anglican. The majority (n=14) provided ministry as part of their overall chaplaincy portfolio at maternity units co-located with acute hospitals. Two were part-time chaplains, who combined their chaplaincy work with full-time parish ministry. Four participating chaplains work exclusively in maternity units (two full-time and two 0.75 time).

The personal demographics of participating chaplains concerning chaplaincy certification status, ordained or lay, gender, experience of pregnancy loss and parental status are illustrated in Table 3-1. Personal experience of pregnancy loss was defined as the experience of miscarriage or stillbirth in the close family of the chaplain.

Chaplain Demographics		
Board certified chaplain	**YES** n=12 60%	**NO** n=8 40%
Ordained/ lay	**Ordained/religious** n=14 70%	**Lay** n=6 30%
Gender	**Male** n=11 55%	**Female** n=9 45%
Personal experience of pregnancy loss	**YES** n=9 45%	**NO** n=11 55%
Chaplain as parent	**YES** n=8 40%	**NO** n=12 60%

Table 3-1 Chaplain demographics

All professional healthcare chaplains are accountable both to their hospital and to their ecclesiastical authority.[262] There is an inconsistency in approach in that an ecclesiastical authority, which in most cases is vested in the local bishop, can nominate an ordained priest of its choosing as a hospital chaplain even if the person has not received formal training or certification as a healthcare chaplain.[262] The expectation, however, is that the appointed chaplain would be formally trained and

certified in accordance with the standards of CPE and the appropriate accreditation board (the Chaplaincy Accreditation Board or the Healthcare Chaplaincy Board).[215, 216, 263] The results of my study identified an inconsistency in the standard of training and certification in that only 60% (n=12) of the participating chaplains were formally board certified (Table 3-1). It is of note that 100% of lay chaplains (6/6) were board-certified whereas only 43% (6/14) of ordained chaplains were. In an area of specialised ministry this is a cause for concern. Two part-time chaplains had never received any CPE training. Only one chaplain had received specialist training in perinatal bereavement. All other chaplains, when asked where they had acquired their skills, said that they 'learned on the job'.

There was a difference between board-certified chaplains who were working in this area as their main area of ministry and those for whom this was part of a broader portfolio or was combined with other ministry, such as parochial ministry. Those who were professional board-certified chaplains saw this ministry as their vocation and profession, whereas others saw it as part of a deployment, not necessarily an area that they would have chosen to work in. Board-certified chaplains demonstrated a higher level of investment in this ministry, evidenced by a high level of professional ministry, the provision of mementos, generic spiritual care, bereavement support, and integrated multidisciplinary bereavement care.

For 25% (n=5) of the chaplains interviewed this was their main pastoral speciality. These five chaplains cared for significant numbers of bereaved parents by virtue of working in the four large maternity units where almost 50% of Irish births took place in 2012.[52]

3.4.1 Bereavement support provided by chaplains

All chaplains were asked about the level of ongoing bereavement support they provided for parents following stillbirth. Eleven chaplains said that they provided follow-up bereavement care for parents in conjunction with their colleagues on the hospital bereavement team. The support provided might include a follow-up telephone call, an anniversary card, a Christmas card, an invitation to attend a service of remembrance and availability to provide support if parents wished. For some chaplains this meant telephone support and for others it was the provision of face-to-face support in their hospital environment. For five chaplains, there was some confusion about their role in providing bereavement support as part of the wider bereavement team. Nine chaplains said that they did not provide any support and furthermore that they did not see this as part of their role.

> *"I don't specifically* [keep in touch] *unless there is an ongoing relationship ... generally I wait for the first phone call to come back from the family. I don't initiate ... at that point the liturgy is done, the religious aspect has been taken care of by chaplaincy and then if the family want to initiate further contact that's fine."* Chaplain #03

Five chaplains had designed their own cards and other stationery and mementos such as bookmarks, candles, blessing cards and contact cards which were used in their care and support for parents. These materials usually involved the use of a designated symbol or logo which was recognisable as relating to stillbirth or perinatal death.

3.4.2 Generic spiritual care

The provision of spiritual care for all, while recognising and respecting differences of belief, is a core competency of the professional healthcare chaplain. All chaplains said that they are available to provide spiritual support for people of all faiths and none, however four 'feel nervous' about this, possibly due to the denominational approach that is commonplace in spiritual care in Irish healthcare. One chaplain expressed discomfort when families might expect him/her to lead prayers that were incongruous with his/her own personal beliefs but was shocked at this self-awareness:

> *"I have to try to marry it* [their belief] *with what I believe and not kind of compromise what I believe … I wouldn't be able to do it … if it wasn't able to sit with me …I wasn't prepared to dilute what I thought, what I believed…that's shocking, isn't it?"* Chaplain #6

Another chaplain expressed the positive experience of ministry in the midst of religious diversity as:

> *"I find that* [diversity] *stimulating … I don't need to check what their religion is or no faith indeed, essentially that's secondary to my meeting with people ... it provides variety and learning and what I notice I suppose in the current population of people … many are non-practising so it's not an issue for them about their own priest or pastor."* Chaplain #13

Chaplains described their ministry to bereaved parents following stillbirth as one that transcends faith and religious boundaries.

> *"I find the grief, the loss, and the pain and the ministry we do is the same … the pastoral care is the same … it's their baby and the most important thing is how they want to celebrate this baby … we respect their wishes … we ask 'How will we care for your baby or honour your baby?"* Chaplain #11

> *"It* [ministry] *is all interdenominational, so I'm meeting people of all denominations and the Roman Catholic thing doesn't come into it at all … I have come across people that are Muslim or Hindu that accepted who I was as a person … it's the same as far as I am concerned really because it's the loss and you know it has got nothing to do with the faith tradition really … I find that people who have … been atheists or whatever and have requested that they wanted to be ministered to and that they didn't want a mention of God or whatever, or were humanistic but it made no difference because the loss is still the same and you know what's, what is important to me … the patient is as they are."* Chaplain #07

> *"We have Church of Ireland, Methodist and Presbyterian* [chaplains] *any of them could be called or we could be called even when there is no apparent specific religious tradition because they just want to see somebody … we're available to everybody."* Chaplain #08

With one exception, chaplains said that their hospital organised an annual ecumenical service of remembrance for bereaved families. By definition 'ecumenical' means Christian, so no hospital organised a public multi-faith or secular ceremony of remembrance. One hospital organised a Roman Catholic mass of remembrance, which by definition can allow full participation only by Roman Catholic parents and staff.

3.4.3 Impact of stillbirth

The impact of caring for bereaved parents was considerable. All the chaplains spoke openly, and in many cases with emotion, about the impact of stillbirth on them personally and professionally. Deep existential questions were raised for some chaplains as they wrestled with the pain and reality of death. Death at the beginning of life and caring for young parents in the midst of raw grief was a burden for most chaplains. One chaplain expressed the personal impact of this pain:

> *"I'm past the theorising stage …I just don't bother anymore. I don't like it and it hurts an awful lot."* Chaplain #18

The reality of learning on the job had a deep impact on one chaplain the first time he/she cared for a stillborn baby.

> *"It very quickly brought the reality of what it was all about … the first time the ward sister showed me a dead baby I nearly fainted…"* Chaplain #12

Chaplains experienced considerable impact on their faith and belief following stillbirth and this is explored in section 3.5 below, in the thematic analysis.

3.4.4 Use of ritual

All chaplains used ritual and liturgical creativity to demonstrate the presence of God in the midst of suffering. All chaplains said that they regularly carry out blessing services, naming ceremonies, prayer services, removal services prior to burial/cremation and, in some cases, funeral services. Most Roman Catholic chaplains said that they would perform baptism for a stillborn baby but were not comfortable with this being acknowledged openly, as it was not in keeping with their church teaching. Chaplains feared that they would be in breach of their contract of employment where it is a contractual requirement for Roman Catholic chaplains:

> '*to uphold and adhere to the teaching and moral standards and practices of the Roman Catholic faith. … where issues arise relating to a Chaplain's failure to adhere to the Sacramental or Pastoral practices or the moral standards and teachings of the Roman Catholic faith, the Bishop of the Diocese has the ultimate responsibility by virtue of his Office for determining such matters and the Bishop or his nominee will have a role appropriate to that Office in the procedures to determine whether a chaplain has breached such provisions* (262)

These chaplains, preferring to take a pastoral approach to parental need, were happy to perform a baptism if that was what parents wanted for their baby. The importance

of a naming ceremony was stressed by all chaplains as part of their ministry following stillbirth. One expressed their attitude thus:

> *"The naming is so important because this is a very real, real, real, person, human being. I can see that the naming is so important and valuable. It gives me a greater sense of the creation stories you know, God naming this and naming that. That's what we do and we're a bit Godlike in that way, we're always naming things and we give a naming certificate because again affirming those parents that life you know, we are affirming it."* Chaplain #17

Many chaplains spoke of how they used liturgical creativity to attend to the individual needs of bereaved parents. These liturgical expressions involved music, symbol, art, poetry and craft. For example, one chaplain invited family members to hold a lighted candle as they shared their thoughts and prayers for their baby who had died. In this action of holding a candle while speaking, members of a bereaved family gave powerful expression of the personal care and immanence of a loving God.

3.5 Theological reflection

Theological reflection is a structured discipline of engaging with experience and faith and drawing on external resources to deepen understanding and insight.[254, 258] Theological reflection challenges the practitioner to face difficult questions and experiences, to seek to understand them in a deeper way and then to integrate this new insight into pastoral practice. It is the crucible where ministerial experience, in this case of stillbirth, is processed alongside faith and belief. In the experience of

stillbirth how does a chaplain reconcile the death of a baby with his/her personal experience of and belief in a loving and generous God as Christians understand God?

Theological reflection calls the chaplain back to the source of faith to wrestle, engage, reflect and grow and only after this to provide meaningful and transformative care for patients. No chaplain used a structured methodology of theological reflection. Most chaplains did, however demonstrate an ability to reflect informally on their experiences. Many chaplains did this during the interview process as they wrestled with their experiences of death. Chaplains wrestled with their belief and how they find strength and hope following stillbirth. Most chaplains said that they felt ill-equipped in this area and would welcome further training and support.

One poignant theological reflection was shared as part of the interview process by a chaplain who spoke of the reality of ministry and care following stillbirth. This chaplain drew on Christian and Jewish creation narrative in terms of presence and absence. As the chaplain spoke, he reflected on the reality of the presence of love and the absence of the baby, the presence and ministry of the chaplain and the absence of future hopes for a longed-for and much-loved baby; the presence of pregnancy and of absence after stillbirth.

> *"We recreate something using symbols. It might just be a teddy bear or a candle; they are both a sign of presence and a sign of absence.*
> *It's a mixture of presence and absence. It's a bittersweet moment. But it's that every symbol, every word you use, I am conscious of that, they're all really in a sense pregnant or alive with … significance and the*

devastation of the moment. … Some things, sometimes precious things hold more and are able to speak more, I think, both then and later on. The sort of thing, everything that is said, everything that is done there is in someways remembered, engraved if you like as well for always. So in terms of our response, ways of responding or being aware, I think it's a matter probably of being aware as far as possible of where they're at and what it is to lose, what it is … for a little one to die, especially before birth. It heightens one's awareness as well of the fact that they will have accompanied this little one for how long? -God knows, thirty weeks … " Chaplain #17

3.6 Spiritual assessment

Spiritual assessment is recognised as an important skill for chaplains formally to assess how patients are coping spiritually with changed reality or illness. In this case, how are parents making sense of, drawing strength from or finding support, meaning and hope following the death of their baby? There are many different forms of spiritual assessment available for generic hospital use but none specifically for perinatal bereavement. Spiritual assessment tools are not widely used in Ireland and, when asked, none of the participating chaplains said that he/she use a formal spiritual assessment or screening tool in their care of parents following stillbirth. Of the 20 chaplains, 13 said that if there was one available, they would consider using it as part of their practice. Analysis of the data demonstrated that most chaplains use their professional and personal intuition to make an informal spiritual assessment with bereaved parents.

3.7 Thematic analysis

It was evident from the data that stillbirth posed challenging questions with which chaplains in their ministry wrestle theologically and spiritually. Following thematic analysis of the data one general theme concerning perception of role and three theological themes of suffering, doubt and presence were identified in the data. I will explore each of these in turn. An overview of the thematic coding is provided at figure 3-2

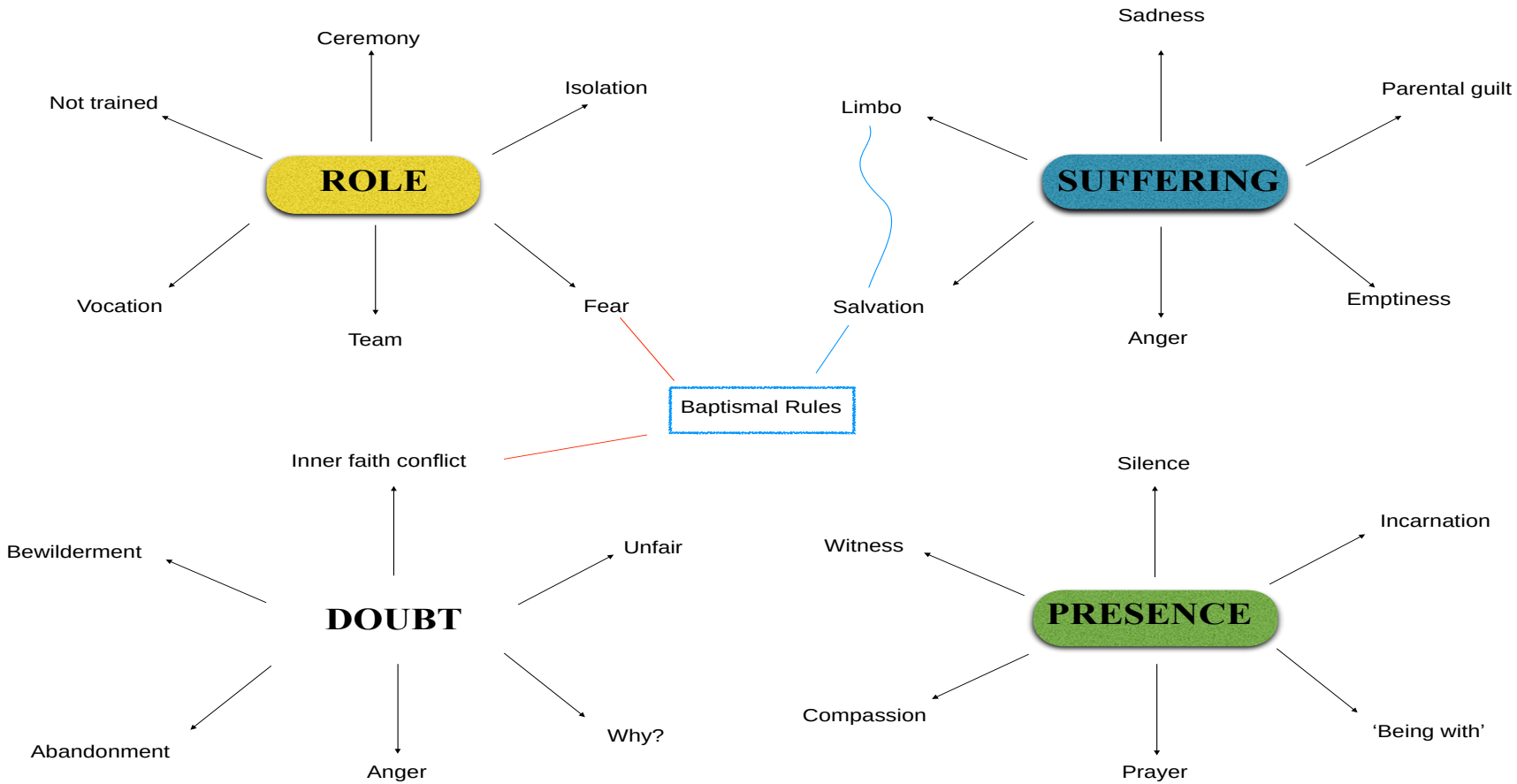


Figure 3.2 Thematic coding

Red lines indicate multiple theme impact. Blue free flow lines indicate ambivalence and uncertainty.

3.7.1 Perception of role

One of the tensions that arises in healthcare chaplaincy in Ireland is the balance between an understanding of a pastoral and ceremonial role. This is an historic tension, where a pastoral understanding has a broader more inclusive approach to ministry and a religious approach places more emphasis on meeting only the religious needs of patients and then exclusively from within the faith tradition of the chaplain or the patient. In a multi-faith and post-modern Ireland important considerations arise from the needs of an increasingly diverse population for many of whom traditional expressions of faith or ritual no longer have meaning. This can be summed up in what the sociologist Grace Davie calls 'believing without belonging'.[(264)] The use of formal religious ritual and structure is of huge comfort and support to many even if they are no longer practising their faith.

When asked whether they considered their role to be mainly pastoral or ceremonial, 16 chaplains understood their role as primarily pastoral. One full-time chaplain, responding to this question said:

> *"Oh, completely pastoral, I mean the religion wouldn't come into it unless the person I am visiting wants to talk about religion or whatever ... it would be totally pastoral. Our role is the presence, just being totally present … whether it is in the silence or in whatever way possible … it's not about doing, it's about being."* Chaplain #07

Three chaplains saw their role as being primarily ceremonial and one saw the role as both pastoral and ceremonial.

In reply to the question on their sense of being part of a wider team in their bereavement care, 13 chaplains said that they felt part of the multi-disciplinary team and seven felt they were not. The nature and depth of ministry following perinatal bereavement is such that professional support from the wider team is recognised in the literature as being an important part of professional wellbeing. It is therefore a matter of concern that 35% (n=7) of chaplains do not feel part of the multi-disciplinary team. One chaplain expressed a sense of professional isolation and loneliness:

> *"... I don't think that most of them* [the team] *are aware that I exist* [I feel] *utterly, utterly disconnected."* Chaplain #18

Another chaplain, who works in a co-located maternity unit, said that it was in this area of ministry that he/she felt the greatest sense of being part of the multidisciplinary team.

> *"I feel more of the multidisciplinary team* [in stillbirth care] *than dealing with the elderly ... the social workers, the nurses are very united with you in it."* Chaplain #04

It is interesting that this chaplain also said that his/her experience of team did not include a doctor: *"very little or seldom with the doctor though."* Chaplain #04

Without exception, chaplains who considered their role to be mainly ceremonial and those who did not consider themselves members of the team were chaplains who had not received any professional chaplaincy training or accreditation (n=7).

3.7.2 Suffering

The theme of suffering emerged as the dominant theme across the data. This theme was captured in the way in which chaplains recognised the suffering experienced by bereaved parents and how they experienced suffering themselves as professional carers. The spiritual impact of perinatal grief was recognised by chaplains in their work both within themselves and for bereaved parents. Chaplains most often referenced the topic of suffering with the question 'why?' Framing the theme around the question 'why?' brings suffering and theodicy together as two sides of the same coin. In a world of causality and the search for meaning, perinatal death opens up the often theologically barren area of needless pain and unjustified anguish. In perinatal healthcare ministry the enormity of theodicy comes into sharp and painful focus: the joy and happiness of new life and parenthood for most couples exists alongside heart-rending grief and pain for others in the same building. While most new parents leave hospital with their healthy baby, bereaved parents describe the physical pain of their 'empty arms' as they leave hospital without their baby. One chaplain recalled a bereaved mother saying

"I'm after carrying this baby for nine months and I'm going home with nothing." Chaplain #13

Describing the reality of shattered hopes, one chaplain who is not a parent but who has experienced stillbirth in his close family, became emotional as he described ministry with bereaved parents:

"The loss, the anger, as a life, a little one, is snatched away from them out of their lives; and the hopes, all the hopes and I suppose every parent does that? We all do that for, for, we all hope for their little ones, we're projecting forward. This is what's going to happen, they're going to have this kind of life … we are making projections all the time. Planning ahead, and then the loss of these projections … you can almost feel that you know, that they're part of some other, this was not supposed to be. There is supposed to be some other movie. This is part of some other picture. You know, this is not the picture we had and I guess the unfairness of it all." Chaplain #17

Chaplains recognised that the reality of grief and suffering for parents was immense and was often coupled with strong emotion which was at times difficult for a chaplain to witness. One chaplain recalled:

"She [a bereaved mother] *just kept asking God or just kept saying 'I can't understand why did you let me … have such a beautiful baby and be so happy and so excited and now you've taken her'. She just kept crying out loud to God."* Chaplain #11

The suffering experienced by parents was described by a number of chaplains as:

> *"a scene of utter, utter emptiness."* Chaplain #8

> *"It's a sadness, it's a struggle just to get through each moment, I think, for mums especially and then the devastation for the dad…"* Chaplain #3

> *"They're just totally distraught… helpless… they are expecting a child and there'd be all sorts of dreams and then all of a sudden it is decimated."* Chaplain #15

> *"The room was quite kind of dark and quiet and it was like the whole focus was on what was going on in here, so it was nothing to do with the delivery, it was nothing to do with … how she was physically or medically, it, it was… this deep pain and loneliness and then she would just cry and I think she just needed to cry and just cried and cried and I just looked at him* [the baby] *at one stage and I said 'he's really'* [chaplain tearful] … *He was … it was actually one of those that are really upsetting because of the fresh stillbirth. It looks like they are just asleep … the baby was still warm and she just admired him and then started talking about him and I think … she needed his life to have meaning and to be acknowledged and that he just wasn't, that she didn't carry him for nine months for nothing."* Chaplain #13

Chaplains described their own sense of suffering and the burden of stillbirth on them personally. One chaplain described how she reached the limit of her suffering:

> *"Sometimes it has been physically where I have had to come over here where I have a quiet space by myself ... where a situation has actually got into me and I'm upset. I hand them back to God and say 'Look, I can't carry these babies and I can't carry this couple'. I just hand it over and I bang the* [hospital] *door behind me and I'm gone ... and they're gone, they're behind, I've closed the door on it."* Chaplain #13

Another chaplain expressed the impact of suffering they experienced as:

> *"Sometimes you wish you were made of stone ... I broke down in the chapel ... I'm just like everybody else..."* Chaplain #5

The theme of suffering is further subdivided into two sub-themes: 'parental guilt' and 'salvation'. The theologically and pastorally challenging concept of 'limbo' was raised by many chaplains as part of their reflection on salvation and the status of a stillborn baby.

3.7.2.1 Parental guilt

A number of chaplains identified the area of guilt as being a significant burden for bereaved parents. It was expressed as part of a theological wrestling with

the cause of stillbirth, the 'why questions'. This theme was expressed by chaplains in terms such as

> *"Why them? Why them when they've done everything right? The big why and guilt. I've come across guilt as well ...*[a woman] *could have had a termination in the past ... and she's beating herself with guilt saying 'I'm being punished'."* Chaplain #06

> *"I never did anything wrong in my life, why did this happen?"* Chaplain #07

> *"Guilt, that is the constant ... it cuts across cultures and beliefs, people having belief or not having belief in the sense of formal religious belief ... it's universal practically, the way people interpret adversity and specifically the adversity of this experience* [stillbirth] *... people are victims of what we would call punitive animism you know, where misfortune, suffering or tragedy is interpreted as punishment for some unknown wrongdoing or imagined wrongdoing.* [Parents ask] *'Why did God allow this to happen? Why did God do this to us? What did we do wrong?'"* Chaplain #08

> *"They feel they are being punished by God or they are somehow to blame."* Chaplain #11

3.7.2.2 Stillbirth and salvation

The issue of the 'status' of the stillborn baby was raised by a number of chaplains. This was most often expressed in terms of bereaved parents asking for their stillborn baby to be baptised. The request for baptism was one that led some chaplains to reflect on the area of salvation. Most chaplains said that they would respond to the needs and wishes of parents and baptise a stillborn baby rather than abide by official church teaching which states that sacraments can only be administered to those who are living. One chaplain said that he was proactive in this area but even in the expression of this he was struggling when speaking about 'limbo'.

> *"We offer baptism, that's not eh maybe liturgical or sacramental and yet of course the church will say to care for the parents, what they want … the parents want a ceremony, a blessing or a baptism. I think in our Catholic tradition there are still … eh …some little bits of say limbo lurking around you know because em eh some parents still mention that. So we offer baptism even though it doesn't make sense in the real meaning of baptism."* Chaplain #04

I recorded in my reflective journal that this chaplain's body language and change of articulation expressed discomfort during this part of the interview.

> 'Chaplain #04 was holding his hands and readjusting his position to the side of the chair and finding it hard to express this sentiment. He also expressed facial grimacing during the conversation about limbo.' Reflective journal entry

Another chaplain expressed a sense of ambivalence about requests to baptise a stillborn baby.

> *"Sometimes now this* [is]*, it's kind of hard to put it, a dodgy theological area, but sometimes they actually want a baptism … the child would be dead … I baptise."* *Chaplain #15*

Three chaplains expressed discomfort when asked to baptise a stillborn baby and said that they offer a naming ceremony instead.

> *"I just wouldn't* [baptise the baby] *I would just explain to them gently that … we don't baptise after a baby has died, that we will gather in God's name and we will give your baby a name in God's presence … and they seem to be okay with that."* Chaplain #06

> *"There used to be a practice of baptising the little remains, you know, and we have been working to try and help people understand that that is not the best way to approach it … because it implies … well we needn't go into all that … and people are quite accepting of that but what we do have is a blessing of the baby."* Chaplain #08

> *"The problem is they'd be asking about baptism and we wouldn't be in favour of baptism, you know, because of the child being dead. I'd say to them*

'well we can't baptise the child because the child, you know, is dead'.'' Chaplain #14

One chaplain said that parents also reflect on this area especially if they have faith and often ask:

"Where is he or she, where have they gone? Is he in limbo if he wasn't baptised?'' Chaplain #12

"Where is my baby now?'' Chaplain #02

This chaplain went on to express that:

"In the Catholic Church we had a heaven and a hell and a … and … and a limbo: purgatory and limbo. In the past in the Catholic Church if the child wasn't baptised, the child was not allowed to be buried in consecrated ground. It had to be buried outside the walls. So where is the child now? The new teaching, the new theology in the Catholic Church is that, whatever state of pregnancy the woman is a, she's carrying a human being and in every human being there is a soul and it is the will of God that all should be saved. …I go on to explain to them [parents] *that the soul of the child is not the same as your soul or my soul or anyone else's soul. That's why the naming is so important. I always tell them to name the child …. That name is so important. You give it an identity. You give it a stamp. You give it a seal. It becomes a person.''* Chaplain #02

Another chaplain reflected that families find reassurance and salvific hope when God is mentioned:

> *"I find firstly* [parents] *are quite reassured by you bringing the God aspect to it, that this child is not going to just go into the ground and be forgotten, that we have the hope of the resurrection and that we rejoice in that … in there somewhere the belief is that we will be reunited and lots of families will say 'If I didn't believe that now I'd be devastated. I haven't believed it, but I have to believe from this day on because I cannot expect that my baby is going nowhere' … It kind of comes up because they cannot now visualise a place where they won't see their child again."* Chaplain #03

3.7.3 Doubt

Doubt as a theme emerged in most interviews as chaplains expressed how perinatal death challenged their own belief structures. For some chaplains this created an incongruence between what they believed themselves and how they provided spiritual care and ritual. Two chaplains struggled to express this doubt and were tearful as they revealed their inner struggle with faith and belief and how stillbirth impacted on their relationship with God.

> *"I'm just not sure I believe in anything anymore…"* *Chaplain #5*

"My faith has been challenged … I stopped attending Mass … I had to provide pastoral care … but not believing it was real…" Chaplain #12

"It challenges my faith … I go through my struggles." Chaplain #7

" [to God] *I know your Word is telling us that you do have a greater plan, and I'm trusting you that you are telling me the truth Lord. I would also just say 'Lord you know I do know you need me to do this. I know I am the one who has been chosen to do this and I need the grace, any of the graces that you can give me, be it in meeting others, in meeting people who can support me but I need your grace to stand up and to do this job because I am not doing it by myself' and I would acknowledge that every day of the week, that I can't do this by myself* [tearful] *I can't do this by myself, no, no* [silence] *… I don't think it's a job that you can really do by yourself."* Chaplain #03

All chaplains described the sense of dread that they experience when they received a call to visit bereaved parents following a stillbirth. It was described as amongst the hardest calls to receive in ministry. One chaplain captured it as:

"Every time there's a stillborn birth my heart misses a beat because it's a challenge to my faith … I'm angry with God … my faith is shaken." Chaplain #02

Chaplains revealed how their ministry in this area caused them to doubt the presence of God and left some feeling a sense of bewilderment when parents were faced with the sudden unexplained death of a longed-for baby. The reality of such a

death was difficult to reconcile with their faith in a loving and caring God. One chaplain expressed this sense of contradiction:

> *"I accept the love of God…in itself as a huge value… but at the same time I can't help struggling with this. 'How could you do this? How could you allow this to happen?'"* Chaplain #17

For another chaplain, the fact that some parents were easily able to accept the death of their baby and find support in their faith caused confusion, as the chaplain was struggling to come to terms with the baby's death.

> *"Sometimes I wonder … sometimes my faith is challenged because the person whose baby has just died has such a sense of faith. That, that throws me completely so I am saying 'How in the name of God can they believe in any kind of God in a situation like this?'"* Chaplain #13

One chaplain explained how she tried to cling onto faith in the midst of doubt and questioning

> *"Why does this happen? It just seems so wrong, how can a loving God … why does a loving God allow suffering …* [I feel a] *helplessness and then I suppose I try to hold onto the trust that God is suffering with them, is in this with them, that God is pure love which is very hard to hold onto when you are sitting with somebody who is just totally devastated … somehow I try and*

hold onto that sense that … they will be carried through this, that they haven't been abandoned even though it does feel like that." Chaplain #11

Two chaplains said that stillbirth is not a challenge to their faith and described it as being *"part of life"*. Chaplains #4 & #20

3.7.4 Presence

In describing how they provide pastoral care following stillbirth, most chaplains described the art and skill of pastoral 'presence' as their approach. Theologically, presence was expressed in the ability to care empathically for bereaved parents and to enter what is a painful place by coming alongside them and accompanying them on their grief journey.

"I listen at that deep level … just sitting there in silence … until the silence becomes comfortable." Chaplain #20

"I bring myself first of all and this is me. … I come to people before the event [stillbirth] *and I tell them 'I'm here to support you and I will do as much as I can'. I am offering all of myself to that family and they know it and I hope they feel it is genuine … I would get cards back from families* [tearful] *saying 'the way you held our baby' or 'the way you handled our child' and how much that meant to them."* Chaplain #03

"I suppose the biggest thing we can do is being present and not hiding behind a chart or a procedure, which I find nursing and medical staff do and they're not a bit comfortable. … It's just me. To just be there, to be present to whatever they're feeling and let them talk … let them cry … being available, giving them all that time and reassuring them that we're with them, that we're there for them … giving them freedom to cry and not to be bottling it in or putting out a bright side and just to be themselves … it's a safe, safe place." Chaplain #06

"[I care for people] *as if they are the only one, nobody else exists, there's nobody else to be working with and that's their reality so I try to make it as personal as I can."* Chaplain #13

Another chaplain described their ministry of presence as one of

"Compassion… that really deep sense of love to be able to enter into somebody else's world, not knowing what it is really but to try and get a sense of it, the deep woundedness that a person is going through with the loss of a little baby." Chaplain #7

Chaplains expressed their ministry of presence by the concept of 'being with' people to express good pastoral care of chaplain for patient.(265) There was considerable diversity in how presence was expressed. The quotations above illustrate a deep empathic presence. One chaplain expressed presence in a more demonstrative way:

"As soon as I go in, the first thing I do is I look around and observe the scene. I know then exactly how many's in there or what the situation is. I embrace them and hug them." Chaplain #02

Most chaplains recognised the importance of accompaniment and support for bereaved parents. Those who saw their role as purely ceremonial did not share this view. For them, their role was to perform a religious ceremony and not to have any pastoral relationship or supportive role beyond that for parents.

"The nurses check with them [bereaved parents] *if they would like to see a priest to come and have a chat or to say some prayers. So it's either to arrange for a burial or to say some prayers, it's one of those two things. I go down to the family, I just meet them and give them a second. I'd know before I go in what they're looking for. Other times what they want is just a few prayers and usually that's all they want and a little blessing."* Chaplain #15

Chaplains who were not board-certified placed more emphasis on a ceremonial relationship with parents. This was expressed in the performance of ritual such as naming, blessing and prayers following death.

"I'd go in and do the blessing and then I would sign it [the blessing card] *and put the date on it."* Chaplain #16

Chaplains had a strong incarnational expression of presence and recognised that for many parents their ministry was an embodiment and expression of the presence of God.

> *"In terms of being a Christian, I know we can give witness* [to God] *by our presence."* Chaplain #06

Chaplains expressed a strong sense that the presence of God was more of a spiritual than a religious experience for parents and that this required a high level of sensitivity to their needs.

3.7.4.1 Positive impact of stillbirth

As part of the theme of presence chaplains also expressed the positive impact of stillbirth on them as individuals. Many spoke of the sense of privilege in caring for bereaved parents.

> *"*[I am touched] *... by their trust, their willingness to be open, to reveal their emotions with a stranger, to give me access to that space ... by their courage and their strength I think they're amazing because they're all so young, most of them so young."* Chaplain #06

"My work is a gift really … every person I meet really is a total gift and I feel I've nothing to give really compared to what I receive .. and I think tears can be a gift as well." Chaplain #07

"You see how people cope with [tragedy], *people are at their very best sometimes when things are at their very worst and you see great love and great compassion and great kindness … it just doesn't fall off the trees, that's definitely coming from a greater energy and source than us."* Chaplain #12

"One of the blessings of the job is the people we meet … we meet the most absolutely fabulous people and couples and individuals who've been bereft and they are extraordinary how they interact with us, how they can be so grateful." Chaplain #13

3.8 Summary

I have outlined the breadth of chaplaincy participation and provision of spiritual care following stillbirth in the Irish maternity services. The study has revealed the attitude of chaplains to their role in stillbirth care. The services and ministry provided by chaplains has been documented from the data. In addition, the data have revealed the impact of stillbirth on healthcare chaplains in what is a very demanding area of work. I have shown from the data how chaplains wrestled theologically with stillbirth.

The three main theological themes which arose for chaplains following stillbirth were suffering, doubt and presence. Each of these themes has been

illustrated by direct quotations from the data. The results reveal how chaplains are not adequately resourced in training or education in this area but it also highlights their willingness to embrace opportunities for growth and professional development.

Chapter 4: Results

Consultant Obstetricians

4 Chapter 4: Results: Consultant obstetricians

4.1 Introduction

Obstetricians enter the field of obstetrics to specialise in the care of pregnant women and their developing baby with the expected aim of a live healthy new-born baby. It is a sad reality however, that pregnancy and birth, while natural processes of life, are not without complication. Stillbirth remains one of the most common adverse outcomes in pregnancy.[1, 18] The development of obstetrics as a discipline has contributed much to improved maternal healthcare and the reduction of maternal and perinatal mortality as obstetricians diagnose and treat many complications of pregnancy and birth. This has been greatly enhanced by the development of diagnostic technology and highly specialised training. These developments have also meant that a diagnosis of a life-limiting illness or anomaly can be made much earlier in pregnancy than heretofore. The outcome may ultimately be the same, however obstetricians are faced with the challenge of communicating this news to expectant parents at a much earlier stage in pregnancy, thereby shattering parents' hopes and changing the trajectory of care from one of hoped-for life and joy to one of uncertainty and sadness.

The impact of death as a burden for physicians is well recognised in published literature.[266-272] This part of my overall study explored two dimensions of stillbirth care from the perspective of obstetricians:

- What is the impact of stillbirth on consultant obstetricians personally and professionally?

- How does stillbirth impact on the belief and faith structures of obstetricians? In the midst of distress and challenge, do obstetricians find support from their personal belief structures or faith/meaning system? Do obstetricians recognise if stillbirth has a spiritual dimension for bereaved parents as they come to terms with the death of their baby?

4.2 Study participants

The study site was a specialist tertiary referral centre where the number of births is c.8,500 per annum and a stillbirth rate of 3.7 per 1,000 births, which is marginally lower than the Irish national stillbirth rate of 4.2 per 1,000 births.[52, 71] The hospital had a staff complement of sixteen consultant obstetricians. A purposive sample of half of the permanent consultant obstetricians (n=8) participated in the study. In a centre such as this with a tertiary referral maternal-fetal medicine service and subspecialists, the participating consultant obstetricians care for a high number of complex pregnancies. Personal demographics concerning gender, age range, years of obstetric experience, sub-specialisation and religious practice of participating obstetricians are shown in Table 4-1

Gender	**Male**	**Female**
	4	4
Age range	**40-50 years**	**50+ years**
	5	3
Years in obstetrics	**0-15 Years**	**15+years**
	2	6
Sub-specialty	**Maternal fetal medicine**	**Gynaecology**
	4	4
Religious practice	**Christian practicing**	**Christian non-practicing**
	5	3

Table 4-1 Personal demographics consultant obstetricians

4.3 Interviews and analysis

Each participant took part in an in-depth semi-structured interview in a private work-environment of their choosing. Interviews were digitally recorded and ranged in length from 27 to 58 minutes. Each interview was transcribed verbatim and transcripts were verified against the audio recordings for accuracy. Following each interview I completed a reflective journal account where I identified key themes and other personal observations that were relevant to the interview such as body language. An example of a reflective journal entry for a consultant obstetrician interview is included at Appendix 7.

Each transcript was analysed using Interpretative Phenomenological Analysis (IPA). Analysis of the data for personal and professional impact of stillbirth revealed

two superordinate or overarching themes of ‘Human response’ and ‘Weight of professional responsibility’, each containing two subordinate themes of ‘personal impact’, ‘how it shapes care’ and ‘professional burden’, ‘medico-legal concerns’. These themes are illustrated at figure 4.1. The data revealed a further two superordinate themes concerning the place of faith/belief for consultant obstetricians following stillbirth: ‘Conflict of personal faith’ and ‘Incongruence between personal faith and professional practice’. The results on personal and professional impact of stillbirth will be presented first, followed by the place of faith for obstetricians following stillbirth and finally results concerning the positive impact of stillbirth. Direct quotations are used to demonstrate the results of the study and to illustrate each superordinate theme and subordinate theme. The Superordinate and subordinate coding scheme are illustrated at Figure 4.1

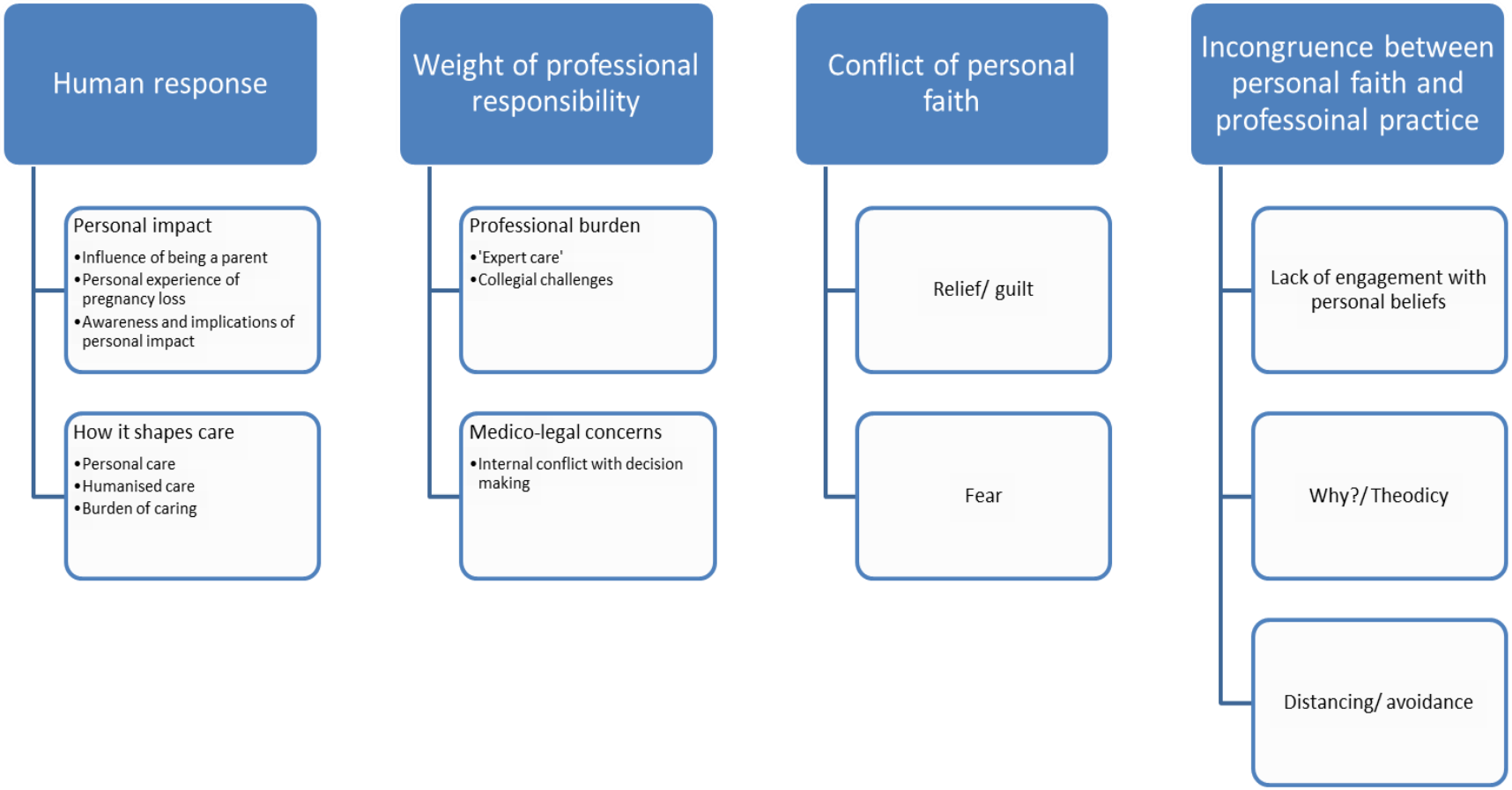


Figure 4.1 Superordinate and subordinate themes: consultant obstetricians

4.4 Results: The personal and professional impact of stillbirth

Each consultant spoke openly about their experiences of breaking bad news, caring for families following stillbirth and what that was like for them. In response to the question 'what is the hardest part of being a consultant obstetrician?' six consultants identified stillbirth as one of the most difficult parts of their job; the other two identified 'the hours' and 'paperwork and management'.

All consultants interviewed, care for parents following stillbirth as part of a wider multidisciplinary bereavement team that includes specialist bereavement and loss midwives, ward midwives, healthcare assistants, chaplains and social workers in addition to support provided to parents by two national perinatal bereavement support organisations A Little Lifetime Foundation and *Féileacáin*.

Two superordinate personal and professional themes emerged from the analysis of the data:

- the human response to stillbirth and
- the weight of professional responsibility.

The human response to stillbirth was characterised in two ways: the personal impact on the consultant obstetrician and how that in turn shapes the care they provide to parents. The weight of professional responsibility was characterised by professional burden and medico-legal concerns.

4.4.1 Superordinate theme 1. Human response to stillbirth

4.4.1.1 Education and training

All of the participating obstetricians care for parents following stillbirth, yet none of them has received any specialist training in perinatal bereavement care. Two consultants had received some training in communication skills early in their careers but they described this training as:

> *"I thought it was a load of rubbish at the time, but it was probably beneficial in a way."* Consultant 2

> *"To be perfectly honest we were sceptical as you would be told how to break bad news by patients who have never had to break bad news."* Consultant 5

All consultants said that they learned 'on the job' and from senior colleagues during their training years and from their own clinical experience. One consultant recalled this learning

> *"I remember a mum who came in at thirty nine weeks with no fetal movements. I was a registrar, the senior registrar was with me and no fetal heart on the scan and your job at that stage is just this, you know, talk, telling them the diagnosis and I remember I just wanted to wait for the senior reg to start talking and the senior reg was waiting because she knew that it was my job. This was a learning process for me to have to do it, and she just kind of*

elbowed me gently, in other words 'it's your job, come on, you've got to say this, you've got to talk about this'…" Consultant 1

Six consultants considered stillbirth to be worst outcome for parents, however two felt that lifelong disablement was an outcome worse than death.

"It's completely devastating … the worst thing in the world that they are ever going to have to deal with … however a stillborn is a stillborn … A devastating illness or disablement is for life. Down's syndrome is for life, Edwards is for life, Cerebral Palsy is for life." Consultant 5

"Even worse sometimes than death is the diagnosis of a long term very debilitating condition which is as bad if not worse than death sometimes. Death is not the worst thing in life you know. I mean, I think it's probably easier to look at a dead baby than it is to look at a baby that is going to end up having a very difficult life. … having to take home a disabled baby and having to live with that, in my mind is much harder…" Consultant 7

4.4.1.2 Personal impact

Consonant with the literature, there was a strong sense of the personal impact of stillbirth for each consultant. Consultants spoke about how stillbirth impacted on them at a human level. The interviews were emotional for six consultants, requiring the interviews to be paused for a time in some cases. Emotions expressed were of

sadness, fear, anger, disappointment and personal grief. All consultants described the experience of visiting bereaved parents postnatally on the ward following a stillbirth as something that is important to do and yet an experience that impacts on them. One consultant described it like this:

> *"It's important to be the same way you'd be if the baby was alive in the room … I think that's important. I do sometimes find it upsetting, particularly when you know them and the patient then wants to take a picture of you holding the baby and that's just like real …* [unable to finish sentence –tearful] *… you know that is upsetting. You know you just have to get on with it and its appropriate to show them that you are a bit upset, not to be bawling crying you know, but often in that situation, it's a baby you might have seen and scanned and you know they are very upset and you're just going ahhh this is just such, this is not the outcome you would hope for a couple… It's lovely that we're here and we got a baby who looks very well and you know, a baby who's certainly going to be, and has been well loved you know, but it's kind of ahhh inside, you know, I suppose it comes back to 'it's not the way, it's not the way things are designed to be."* Consultant 6

The experience of recalling particular situations opened painful and vivid memories for some consultants during the interview process.

> *"My first night on call* [as a Senior Registrar] *… I was looking after a woman who came in … in full blown labour … the baby was a stillborn normal baby*

and I remember being absolutely devastated. This is my first night, first time … I was so devastated … I cried my eyes out." Consultant 8

"I still remember those initial cases I dealt with. I still remember the names of those patients that I dealt with as a junior … dealing with some challenging stuff and there was no recognition of that." Consultant 6

The impact of stillbirth extended beyond the working day and the hospital environment for a number of consultants who found it hard not to think of the situations when they left work.

"I find it difficult to separate the job at work … and coming home and just switching off." Consultant 1

4.4.1.2.1 Influence of being a parent

Some consultants referenced the reality of the personal impact of stillbirth in terms of being parents themselves. For these consultants this was a significant influence both on how they experienced the impact of stillbirth, and also on how they provided care. Being a parent was expressed as influencing their ability to be more empathic and having a greater understanding of what bereaved parents were experiencing.

"Sometimes it would be something as simple as just holding one of them [their own children] *in a hug … might be enough to get me through what was a horrible day."* Consultant 8

"I find myself putting myself in the position of those parents who've had an adverse event; be it nobody's fault or be it somebody's fault and just not being able to turn the clock back and do things differently. I think of adverse events that maybe were difficult to predict or may have been caused by a decision that should have been done differently. I think they are difficult to deal with and I feel so sorry when trying to talk to parents because I kind of have an idea, having had children myself of what it must be like for them." Consultant 1

"You know, I think having had a family and being a more senior person I think it would affect the way I would talk to parents … would be different to when I was a junior person without a family." Consultant 1

"I think before I had children I would have thought that they [parents] *have lost a baby but now I see the child and the person. They haven't just lost a baby they've lost all the future …* [being a parent] *changes your perception of it and it changes how you deal with the parents as well. I think, well you feel more, you definitely feel their loss more."* Consultant 2

4.4.1.2.2 Personal experience of pregnancy loss

Six of the eight consultants had experienced pregnancy or perinatal loss in their close family (one miscarriage, four stillbirths and one neonatal death) and spoke about the impact of this. Recalling personal experience evoked emotions of sadness for five of these participants and they were tearful during the interview. One consultant speaking about their own personal experience of miscarriage said:

> *"I didn't know how I felt … it was odd …this shouldn't be happening to us … we medicalised it quite a bit but the day when it happened I found myself, my mind wandering and I couldn't keep my mind on what I was doing that day at all. It just, I didn't know what to think. I knew that it might happen, I just felt very sorry … but we never, never afterwards did we ever talk about it…"*
>
> Consultant 1

Two consultants expressed that they had grown up being aware of an older stillborn sibling but it was '*never spoken about*'. In response to the question "have you experienced stillbirth or pregnancy loss in your close family?" neither of these participants referred to their stillborn sibling. It was later in the interview when they revealed that that they had a stillborn sibling.

Three other participants said that their personal experience of loss has shaped how they care for bereaved parents in their professional practice.

"I guess you compare the situations you've been in … and how they [bereaved parents] *would feel and what they would like to hear and often they don't want to hear the clinical stuff they just want somebody human … they remember for the rest of their life a few people associated with that. It's more your expression, your body language and … how you are with them."* Consultant 4

4.4.1.2.3 Awareness and implications of personal impact

The depth and complexity of the personal impact of stillbirth revealed feelings of loss, fear, remorse, sadness, discomfort and anger for the participants. One consultant described their personal experience of caring for parents following stillbirth as

"It's a real loss for me as an obstetrician … it is something that tugs, really tugs at my heartstrings. … No matter how dispassionate or professional we are, we actually are also human and it does knock you back and you also know you are going to be sad." Consultant 8

Strong feelings resulting from stillbirth were often experienced in personal and professional isolation. This sense of isolation was demonstrated by the inability of some consultants to discuss their feelings at work and unable to do so at home. No consultant identified any support structure that they avail of, and only three said that they would discuss their personal emotions with colleagues in an informal way. This

raised challenges as to where personal impact is recognised or addressed. One consultant said

> *"I don't get upset at work … but usually on the way home I end up pulling over* [in the car to cry]. *"* Consultant 4

Another consultant expressed:

> *"It's very easy for us as clinicians to get experience with the medical and clinical stuff, some of the other stuff doesn't come so naturally and some people need some help with that. I think we all need opportunities to talk about how upsetting we can find these cases and em you know what we have talked about in the last half an hour isn't something that I would have been ever, I would have ever talked about at any point in all my years as a consultant. You just don't. There is no opportunity to talk about some of this stuff and you have to realise that it does affect you … it isn't a good thing."*
> Consultant 6

This consultant also described the sense of isolation experienced as a junior clinician and the lack of recognition of the impact of stillbirth:

> *"There was no recognition that it might be difficult …there was no training … there was no debriefing …and I think that's bad. You did it yourself … nobody cared if you got so psychiatrically disturbed you threw yourself off the roof the following week."* Consultant 6

Most of the consultants were aware of the impact of stillbirth on junior colleagues and recognised that experience made it easier to cope. For many of the consultants this was influenced by difficult personal experiences they had earlier in their own careers where they felt unsupported by senior colleagues as they cared for couples following stillbirth. As a result, these consultants recognised the importance of a senior obstetrician taking the lead in the provision of care.

> *"I don't want people in the same situations I was put in where I really had to find it out as I went along."* Consultant 4

4.4.1.3 How personal impact shapes care

Every consultant displayed a high level of awareness of the devastating impact of stillbirth for parents. Participants when asked to describe what they thought it was like for parents to be told that their baby had died expressed it as:

> *"I can only imagine it. I don't think anything can compare with it, I mean it's the loss of the highest order … it's unimaginable."* Consultant 2

> *"It's probably the most devastating thing that's going to happen to them … their worst nightmare."* Consultant 3

> *"It must be devastating."* Consultant 5

All consultants demonstrated awareness that stillbirth was one of the most difficult bereavements and that bereaved parents required a high level of care and professional time.

4.4.1.3.1 Importance of personal care from a consultant obstetrician

Recognising the impact of stillbirth for parents, every consultant expressed that giving their time to bereaved parents is important. Every consultant expressed that there should always be an acknowledgement to bereaved parents of their loss. Consultants displayed a high level of awareness of the impact of the diagnosis of stillbirth on parents.

> *"You feel the responsibility because when you walk into the room … 'you're going to tell us whether our baby's alive or not'. I suppose how you deal with this, how you tell them, what happens next … but that five minutes they will remember for the rest of their lives… I think their worlds fall apart. The situation is destroying their dreams. I have to make this terrible news bearable and get them through it … find a human way of finding out that someone has died, and how you hear that a loved one has died you'll never forget and people will always tell you that story. They won't tell you the story of what they looked like in the coffin or what the funeral was like. Really that's not it. It's about 'I remember what his or her* [doctor's] *face looked like."* Consultant 4

All consultants said that they tried to visit bereaved parents and their baby before they are discharged from hospital. Every consultant felt that bereaved parents should receive direct care from a consultant obstetrician. One expressed the importance of this for parents

> *"It's important that they* [parents] *know we realise that this is so important to them* [parents] *that we have our most senior person there helping them and looking after them… that they are not being batted off to somebody junior because nobody wants to have to deal with this … that we are taking this seriously …"* Consultant 1

> *"Out of respect for* [parents] *you have to be involved as the nominated consultant, you have to be there for them, absolutely … and it's not necessarily just in terms of the initial diagnosis* [of stillbirth] *but they have to be seen by a consultant several times … around the time of delivery and afterwards."* Consultant 2

While every consultant expressed that bereaved parents should receive care directly from a consultant obstetrician, two qualified this by acknowledging that at times another member of the team might be more appropriate if they had had primary contact with parents. In one case, a consultant felt that some colleagues were not good at caring empathically. This consultant felt that in sensitive and emotional situations it would be better for parents if another member of the team were primarily involved.

"I think they [consultant colleagues] *are scared to give, to give that bit of themselves … or maybe they've never thought what it would be like to be in that position themselves … some people have had a very blessed life that they just don't know what personal trauma is like."* Consultant 4

4.4.1.3.2 Importance of 'humanised care'

Every consultant expressed the importance of 'humanised' care where parents should be cared for sensitively and compassionately.

"I realise that this is the most devastating thing that could have ever happened to them so I'll go into them with that in the back of my mind … I've just got to switch off from everything else that's happening and I've got to immediately make as much time as they need … anything else can wait. … They will need my time to try and explain as best I can. So I'll go down there not knowing what has happened or why. It may have been something that's gone wrong that we should have anticipated, but no matter whether it is or isn't, that has to be dealt with. So I'll go in there with an open mind but not knowing immediately that they'll need me or whoever for whatever length of time it takes." Consultant 1

The importance of recognising the baby as an individual was an important sub-theme in this area characterised by a recognition of the importance of caring for

a stillborn baby as one would a live baby. One consultant described the importance of a baby's name and always using it.

> *"…the importance of the name, giving them an individuality, an importance."*
>
> Consultant 8

All consultants said that they would include the stillborn baby in the conversation during a ward visit.

> *"I introduce myself* [to the couple] *and see the baby, make a comment about the baby and look at the pictures, talk to them about the baby's name and just kinda involve the baby in the discussion especially if the baby is in the room … the baby is there, it's part of the family so you know even if you find it difficult, you need to get over that, you need to be involved and you need to show that the baby is accepted as part of the family, he's a real person I suppose in that sense … to be the same way you would if the child was alive in the room."* Consultant 6

The data revealed a high level of intent on the part of consultant obstetricians to provide sensitive and empathic care to bereaved parents. The care expressed by obstetricians corresponded with best practice in this area as outlined in various professional stillbirth guidelines.[26, 78, 79, 273]

4.4.1.3.3 Burden of caring

Concern was expressed that the emotional impact and burden of stillbirth is such that all consultants should share the case load. Concern was expressed by one consultant that for a clinician specialising in this area

> *"It would take more of an emotional toll if you did it twice a week… that's just too many stories to take on board … too many lives to get involved in … I think that is too much for one clinician."* Consultant 4

> *"…giving them a little bit of you and it would be draining if you did that the whole time."* Consultant 7

One consultant finds the expression of strong emotion by bereaved parents difficult to endure. In situations like this the consultant said that he excuses himself by saying '*I'll come back in ten minutes*' and then leaves the room.

The reality of the personal impact of stillbirth on consultants meant that some consultants remained emotionally distant from bereaved parents and thereby reduced their capacity to provide the depth of person-centred and 'humanised' care as espoused above. Consultants expressed this sense of remaining emotionally distant as:

> *"My personal emotion is not high on the list … you just know you can't get sucked in too much into the emotional side of it."* Consultant 3

"I try and stay away from the wider 'why did it happen to me?' so I try to keep it focussed … going over and over and over the same thing isn't necessarily positive for anyone … it's not positive for the patient and it's not positive for their partner." Consultant 7

"I have to admit the emotional upset for me is not high on the list … what I do is I deal with the facts." Consultant 3

4.4.2 Superordinate theme 2. Weight of professional responsibility

The superordinate theme 'weight of professional responsibility' had two subordinate themes of 'professional burden' and 'medico-legal concerns'. I shall present these separately with their associated subordinate themes.

4.4.2.1 Professional burden

The sense of professional responsibility following stillbirth was a dominant theme for all consultants. Every consultant spoke about the professional reality that parents have high expectations that attending a tertiary specialist centre that they will receive expert care.

4.4.2.1.1 Professional burden of 'expert care'

The reality of being a consultant brings with it a responsibility to be an expert clinician. For one consultant this was one of the hardest parts about being an obstetrician. The same consultant also expressed that it was very important for parents to know that someone is accountable for their care. When a stillbirth occurred it carried with it the burden of a sense of responsibility and fear on the part of consultants that they might have missed something.

> *"Being a fetal medicine expert I suppose we probably should have less stillbirths."* Consultant 5

Consultants who also had a private practice expressed that there was an added level of responsibility associated with this.

> *"That's what the private patients are paying for … ultimately you are the only person and you're completely responsible for what happens them."* Consultant 5

As a tertiary referral centre those who specialise in fetal medicine care for parents who have more complex pregnancies including those who will have a poor outcome, however expert the care. Participants expressed that this led to unrealistic expectations being placed on consultants. One expressed this as

"The hardest part now is that your name is at the top of the chart and when it all goes wrong even, if you're not involved … it all comes back to the consultant … you're ultimately responsible." Consultant 5

Another consultant expressed this sense of responsibility as

"What I find more difficult to deal with is a case where I haven't been around or I haven't been on call but the patient is under me officially. I may never have met her at all at any stage and something happens in the labour ward that may not have gone completely right that you had nothing to do with. Ultimately you're responsible because it's your name on her sticker and you find yourself trying to deal with this and you know parents can be very aggressive or their family members sometimes more often than they become very aggressive very quickly and you haven't had any part to play in it and you're trying to justify what may or may not have happened. I find it hard to let go of that and switch off when I go home…" Consultant 1

Professional responsibility extends to the expectations that consultants have of themselves as specialists in their field where, in addition to the expectations they feel from parents, their own professional expectations are also high.

"As a fetal medicine specialist you're not allowed to miss anything which is completely nonsense, but you don't allow yourself to miss anyone [mother/baby]*."* Consultant 5

4.4.2.1.2 Collegial challenges in care following stillbirth

Some consultants became very animated and expressive about the sense of professional responsibility they felt and in turn how they felt some of their colleagues evaded their responsibilities by not getting involved and referring to 'experts' on the team and thereby not discharging their professional responsibilities to care for parents following stillbirth.

> *"Sometimes we make it too easy for them."* Consultant 5

This feeling of collegiality or lack of it was also conveyed by a competitive undercurrent expressed by some consultants about how stillbirth care should be managed. Some felt that every consultant should share the case-load, while others felt that those with particular expertise were best placed to provide care. Those who were primarily gynaecologists, and who recognised that this was not their area of expertise, were positive about the facility to refer bereaved parents to a colleague with specialist interest and expertise in pregnancy loss. One of them articulated this as

> *"I don't see myself as the expert; with a stillbirth I'll see them* [parents*], I'll have … all the information but I'll be thinking I'd much rather X or Y would be doing that bit because they would be able to say more definitively what the cause was … but I accept that it's my job if they are my patient … but I feel as though I'm doing a half-hearted job because I'm going to be sending them to somebody else."* Consultant 3

There was a strong sense, however, that all consultants ought to be able to provide good care to bereaved parents and not to evade responsibility. One consultant while acknowledging the importance and role of the multidisciplinary team expressed the importance of consultant obstetrician responsibility as

> *"Often you find people feel out of their depth and so it would be nice to say to the couple 'Oh, we have a professional counsellor, we'll get them to talk to you.' ... If we lose our ability to comfort another human being, even if we're not that skilled at it, if we lose that ability, we actually lose our ability to be good clinicians."* Consultant 8

4.4.2.2 Medico-legal concerns

The medico-legal reality associated with obstetric practice is well documented by the *Clinical Indemnity Scheme* which manages clinical negligence claims and associated risks on behalf of the Irish State.[274] In Ireland, a third of all reported claims are from the discipline of obstetrics, resulting in a quarter of all medico-legal financial awards annually.[274] The proportionate claims are even higher in the United Kingdom.[275] This is further compounded by the widespread media reporting of medical negligence cases: medical negligence invites public comment and concern and is a source of much stress for consultants as their professional judgment and clinical care is discussed publicly. At a personal and a professional level, the potential exposure of a medico-legal case weighed heavily on some consultants.

For one consultant this was a dominant theme throughout their interview. The sense of a 'blame culture' and litigious environment following a perinatal death heightened the sense of nervousness associated with the outcome of stillbirth. The following sentiments were expressed in one interview:

> *"There's always someone to blame … and if I'm not to blame they'll* [the media] *certainly have a good go at it. We're working in a very suspicious environment."* Consultant 5

For this consultant their first thought on hearing of a stillbirth diagnosis was about their professional credibility.

> *"What's the post mortem going to show here? … You're only one bad baby away from the front page of the Irish Times, and that's the bottom line. … I think if anyone is honest, any medic, when something has gone wrong … you sort of think fuck -excuse my French! - what have I missed? … It's awful."* Consultant 5

4.4.2.2.1 Internal conflict with decision making

Some consultants expressed how they struggled with the decisions that others had made and how this in turn impacted on them as they reviewed decisions as part of debriefing with parents following stillbirth. One consultant expressed the

challenge of trying to balance openness with parents while not appearing to apportion blame.

> *"You have to be completely honest, you have to go through everything ... and usually have to do that several times ... and then those questions will have to be answered over and over again and sometimes you have to refer it on to midwifery management in terms of midwifery ... sometimes it will be obvious that a mistake might have been made on the ward and I can allude to that, but I'm not going to fully describe that because it's better for the parents when it's coming from the people actually doing it rather than me trying to point the finger ... everyone sees the buck stopping with us."* Consultant 2

Another consultant expressed this challenge of being open yet measured:

> *"If I don't know the answer I will say 'I don't know'. Then the difficulty would be with that situation is ... often you would see something where something may have been done differently that may have led to a different result which is always difficult because you could say for example 'why wasn't that done?' You might think, well yeah, perhaps it should have been done. So that can be difficult in trying to pass that information on without saying something categorically ... things can be subjective and you weren't there at the time and therefore you can't say objectively that this shouldn't have been done but that can be difficult if you think you know and often say 'maybe we could have done this' and 'things might have been different' but this decision was made for a reason .. so that can be quite difficult if you*

think maybe something wasn't right … and I'll often apologise but it's difficult if you think 'crikey something seriously was amiss here.'" Consultant 3

Medico-legal worries following stillbirth were predominately, but not exclusively, expressed by those who are primarily gynaecologists. This was characterised by the phrase 'what have I missed?' It carried with it a sense of guilt that they or a junior colleague might have missed something and professional fear about the potential public and legal outcome. One consultant expressed that his first thought when he received a call to see a couple with a suspected stillbirth was

"Was I involved in their care? Therefore have I missed something? Have we done something wrong? Has the hospital done something wrong?" Consultant 1

4.5 Results: Awareness of spiritual need

All participants recognised that the death of a baby raised spiritual issues and that it was important to attend to spiritual distress in bereaved parents as part of overall care. Most consultants felt unable to address this spiritual distress themselves and would refer bereaved parents to another member of the specialist perinatal bereavement team such as a chaplain or a bereavement and loss midwife specialist. Most consultants said that parents would express, even if only tangentially, that stillbirth was impacting on them [parents] at a deeply personal level. Only one obstetrician expressed that bereaved parents did not express spiritual distress to them, although the language used by this consultant to answer the question demonstrated the presence of spiritual distress.

"I've rarely, if ever, heard people talk about faith or God with regard to what is going on … it's more the injustice, the anger the 'why did this happen to us?' they'd express guilt or ask 'what have I done, why's God doing this to me?" Consultant 5

The same consultant recalled that bereaved parents have expressed very strong spiritual anger and distress and in response to my question 'Would they ever vocalise that [anger/distress] to you?' recalled it as

"They do, oh yeah they do .. Why me? Why me? I've heard them say 'fuck you' [said with strong emotion by consultant] *with regard to God and that sort of thing… I've heard that quite a few times … at that point I certainly keep out of* [laughter*] I don't stand up for God or anything at that stage."* Consultant 5

When consultants had made an antenatal diagnosis that a baby was likely to die before birth, most said that they would then involve the multidisciplinary team in anticipatory grief care and support before birth. One consultant said that if a baby was likely to die during birth

"I try and have a chaplain there almost at the birth so that the baby can be baptised immediately." Consultant 7

One consultant was hesitant about making a referral and is slow to involve the wider bereavement team at an early stage because it might be seen as negative or fatalistic.

> *"I feel as if I'm writing this baby off completely and you need to be careful with doing that because the odd baby surprises us."* Consultant 5

Consultants found it hard to express how they would identify spiritual distress or spiritual need with bereaved parents over and above an acknowledgement that stillbirth caused spiritual distress. All consultants said that they would refer couples to a chaplain as part of the wider bereavement team for spiritual support following a diagnosis of stillbirth. When asked how they might identify spiritual need most consultants use their intuition.

> *"I try to get a sense of where people are at."* Consultant 6

> *"I would always try and get a feel for what their background was. I would offer chaplaincy to all patients … even if they were atheist … most people have either a faith or spirituality or humanist principles."* Consultant 7

Most consultants expressed a sense of caution and reserve in how they approached spirituality in and with patients.

> *"I think you get a bit of an idea about that* [spirituality] *but on the whole kind of spiritual element I would never presume to judge. I don't presume where other people are at, as in what religious background they have or don't have*

... you'll also get it in terms of cues, you know, there will be some people who you'll have talked about it before if you were thinking something bad might happen. You'll also pick it up by, you know, some people will have, you know, religious, you know they might have a cross or they might have some other you know, something in the room and you think kind of, well this is vaguely important to them or they'll start mentioning something of relevance 'someone's saying prayers for us' or you'll pick up a sense that it is or isn't particularly important to them but I think it is something that is very hard to judge." Consultant 6

4.5.1 Impact of stillbirth on faith

All participating obstetricians were from a Christian faith tradition. Each consultant had worked in multicultural centres in more than one country where they cared for parents from diverse faith and philosophical backgrounds.

Each obstetrician recognised that the death of a baby was a devastating loss for parents but they also expressed the sense of loss they felt themselves as professionals.

"After all these years I haven't become hardened to that [sense of loss] *... I remember a consultant speaking to me after my first experience* [of stillbirth] *I was so devastated ... and to this day I can still remember her saying to me 'I hope in twenty years that you still have those heartfelt feelings when you're*

dealing with theses scenarios'. I can honestly say that I still have those heartfelt feelings". Consultant 8

The superordinate themes arising from the data relating to faith were:

- Conflict of personal faith and
- Incongruence between personal faith and professional practice.

4.5.2 Superordinate theme 3: Conflict of personal faith

Consultants expressed that their hardest struggle was with unanticipated stillbirth and this caused them to question their professional care and skills. The subordinate themes in this area were relief/guilt and fear. The theme of conflict with personal faith was captured in the phrase 'what have I missed?' which was used by four consultants. For some, this sense of fear impacted on their belief structure and faith, resulting in a questioning of God and divine purpose. This questioning revealed the tension of believing in God in the midst of deep suffering and inexplicable death.

"How could God let this happen?" Consultant 4

"I often think … God … life could be divvied up a little better." Consultant 7

"Why does this happen in the first place? What was the point of this? Some of the most challenging ones are you know term, you know, came in the day before she was due to have her section, nice big happy fat baby who is just dead and you look at that and you try and go 'what the, how can you make

sense of that like?' What was the point of this? You know, why did this have to happen? And I think as a human being that's difficult." Consultant 6

The challenge of having to be the person responsible for communicating such a devastating diagnosis was evident and had particular challenges when a stillbirth was unanticipated following a healthy pregnancy. This scenario raised a sense of needlessness that challenged the personal faith of consultants. One participant when asked 'what is your first feeling when you get a call to see a woman who has been diagnosed with stillbirth?' answered

"Oh, Holy God." Consultant 5

4.5.2.1 Relief/guilt

The subordinate theme of relief/ guilt was evident for consultants as they reflected on their own lives and how they felt blessed that they had not shared this experience of stillbirth and yet at the same time living with a sense of guilt that this caused for them when meeting bereaved parents who had experienced such devastation following stillbirth.

"I just look at my own children and think God this could have happened to them." Consultant 2

Two obstetricians expressed that stillbirth does not challenge their personal faith or beliefs. One used religious inference to express this:

> *"I take more of a religious view of it* [stillbirth] *that it's about the nature of God and that it was going to happen anyway."* Consultant 4

4.5.2.2 Fear

The subordinate theme of fear was expressed by consultants who found it hard to deal with the potential angry reaction of a bereaved couple. This was expressed in two contexts where consultants said that they would avoid attending a prayer service for a baby in case the parents would be angry with them or if they were fearful that a couple would get angry during a visit following diagnosis.

> *"If the couple get angry, I think 'Oh God, how am I going to deal with that?'"* Consultant 3

4.5.3 Superordinate theme 4: Incongruence between personal faith and professional practice

Most consultants said that they do not see their faith or beliefs as influencing their professional practice and conveyed that they saw these as distinctly separate areas. Five consultants said that they do not engage with their faith at work. The subordinate themes in this area were lack of engagement with personal beliefs, why?/ theodicy, spiritual distancing. (Theodicy is understood as the tension between

believing in a loving and caring divine being and the existence of suffering and is outlined further in section 5.5.5.1) Consultants saw their personal faith as a private part of their lives and did not demonstrate any congruence between their personal beliefs and their professional practice.

My experience during the interviews and reflected upon as part of reflective journaling was that the participants' body language when asked about their own faith demonstrated a level of discomfort. This was confirmed by verbal expressions like

> *"It's* [faith] *not something I bring to work with me."* Consultant 6

> *"I'm not that comfortable* [discussing faith] *and I don't know if it's my place either."* Consultant 5

The expression of discomfort meant that most consultants, while recognising the importance of the spiritual beliefs and the spiritual impact of stillbirth on bereaved parents, avoided the area in their practice and care. One consultant said that he had once asked a spiritual question as part of casual conversation during a postnatal visit but it caused offence when the consultant had made an assumption about the religious practice of a parent and following that experience this consultant thereafter avoided asking any questions that might be of a spiritual nature.

> *"I tend not to go there. I just don't feel comfortable. … You can't presume to know where people are on that spectrum … it can be a very private thing. …Why does this happen? How on earth could this do anything other than*

bring huge suffering to a family? … but I would very much try not to bring religious circumstances to work. We're only getting into them because of what we are talking about now [in the interview] *… I don't think it's what parents want from you as a doctor."* Consultant 5

For some consultants this meant that they also avoided attending a spiritual ceremony such as a prayer service in the hospital following a stillbirth as it was too painful.

"If [you've] *been involved in their care then they're more emotional and I think for your own protection you're better off staying away."* Consultant 7

"I've never attended one obstetrically but I have gone to some gynae [adult] *ones."* Consultant 1

One consultant who does try to attend a prayer service with bereaved parents if invited expressed the emotional impact of this as:

"I blub [slang: cry] *and it's awful, even thinking of it now* [tearful] *em I think it's important and it's a respectful thing you know for the baby and the couple to do that, but its hugely emotional. I mean the whole thing, I couldn't keep a dry eye and that's terrible, sort of embarrassing at times."* Consultant 2

For another consultant the annual hospital service of remembrance for pregnancy and infant loss was a difficult experience.

"I attended the service of remembrance and stood at the back and in five minutes I was in floods of tears and in ten minutes I had to walk out … I don't think it's very professional and it's not good to do in front of your patients because when you're in the church you are not a doctor but for the patients you are a doctor…" Consultant 4

The avoidance of addressing spiritual needs was evident in the data through the subordinate theme of distancing/ avoidance. Consultants, not feeling comfortable about matters of spirituality kept a distance from visiting this aspect of care with bereaved parents. This was also linked with the sense of emotional distancing expressed as part of self-protection following stillbirth.

"For [my] *own protection I try not to let it* [speaking with bereaved parents] *be emotional … you can't have parents being emotionally wrung out, so I try to keep it positive and upbeat."* Consultant 7

4.6 Positive impact of stillbirth

In addition to the negative impact and burden of stillbirth, it is important to report that there were also positive impacts from stillbirth for consultants. While all consultants acknowledged that stillbirth was a very challenging experience for them personally and professionally, it was also true that coupled with that challenge, consultants demonstrated a committed and compassionate experience of care for bereaved parents. Three consultants in particular spoke about the positive impacts of caring for parents following stillbirth. For one consultant this was one of the best things about being an obstetrician. Another consultant referenced the positive impact of how following a life-limiting diagnosis a couple has time to create positive experiences and memories in the time between diagnosis and death.

> *"I mean there's lots of positives, for instance somebody that's got a baby who I remember a couple of years ago and I remember thinking it was a lovely thought and saying to the couple, their baby had a known fatal abnormality and I remember saying to the mother 'every day the baby's alive inside you there's something to you know, celebrate' and you know death will be difficult but you will have memories. So in a way when a baby dies sometimes you think okay, well this is a little bit of closure for parents they'll always grieve this baby and this baby is perfect to them."* Consultant 7

For another consultant their most significant memories and experiences in obstetrics were from their care of families following adverse outcomes and especially following stillbirth.

> *"I must say some of the most satisfying interactions with patients that I've had over the years would have been with patients who would have had losses and just being with them and dealing, dealing with the process with them from a medical point of view but also from a human point of view. I think you'd need to be made of stone not to, you know, yes you have to be dispassionate to be professional but you don't have to be so dispassionate that you can't feel for somebody's absolute loss. Seeing some of those patients come back subsequently and go through the trauma of the next pregnancy with all the uncertainty and then they come out and have a baby and just the insurmountable joy they end up with. I think as a group of patients … because they've known the dark side of this whole thing that they probably have a clearer view of just how wonderful normal birth is … having descended into the depths they have now risen to the heights and I think they bring us with them …I consider myself extraordinarily fortunate every day of my working life because I think I am actually exposed or am fortunate enough to actually be involved with enormous joy and happiness. I think it also sobers us probably to actually have to deal with the loss that patients have to go through and then the enormous satisfaction that they get at the other end."* Consultant 8

4.7 Summary

In this chapter I have outlined the personal and professional impact of stillbirth for consultant obstetricians working at a tertiary university maternity hospital and the impact of stillbirth on faith for obstetricians. I have included demographic details of the participants and from the data I identified four superordinate themes: Human response to stillbirth and the Weight of professional responsibility, Conflict of personal faith, Incongruence between personal faith and professional practice. The data also revealed positive impact for consultants as they provided care for bereaved parents.

I have included direct quotations to illustrate each superordinate theme and the associated subordinate themes.

Chapter 5: Results

Bereaved Parents

5 Chapter 5: Results: Bereaved parents

5.1 Introduction

Bereaved parents are, more than any other group, at the raw and painful experiential edge of stillbirth. Parents have the closest relationship with their baby and therefore experience the impact of stillbirth most. Each of the parents who participated in this study gave generously of their time as they told their story and shared their experiences following the death of their baby. All parents were emotional during their interviews and the depth of expressed emotion demonstrated that, in keeping with the published literature, stillbirth had an enduring and profound impact on bereaved parents.

My study explored what the spiritual impact of stillbirth was on three groups of bereaved parents bereaved in three different years; the year of the study (2013), three years previously (2010) and five years previously (2008). The parents of four babies who died through stillbirth from each of the three years were included in the study. In each study year two of the babies had been diagnosed with a life-limiting condition and were not expected to live beyond birth. In these cases parents were prepared for the anticipated stillbirth of their baby. The remaining two babies from each year died unexpectedly through stillbirth with no prior indication during an otherwise healthy pregnancy.

5.2 Telling their story

As a vulnerable population, I was mindful that for bereaved parents, telling their story might be difficult and potentially distressing. Acknowledging this

possibility, I arranged for personal professional support through two bereavement and loss midwife specialists to be available to each participating parent as part of the study. No parent accessed this additional support. One of the interesting initial findings of the study was the fact that all mothers and the participating fathers were enthusiastic about participating in the study and appreciated the opportunity to talk about their baby who had died. Although the interviews were emotional, it can be argued that the experience of sharing their story was in itself therapeutic. This was illustrated by a SMS text message sent to me the morning after one interview with a couple when a bereaved mother wrote

> *"Thank you for yesterday. This was the first time that we have actually spoken properly with each other and about Thomas. We had no idea how each other felt. Thank you. XX"* [2010P2]

All names used in the direct quotations have been changed to protect identity.
In the days following each interview I wrote a personal thank-you card to each participant that included a reminder of ongoing support should they wish to avail of it.

5.3 Study participants

Following purposive sampling from the database of parents bereaved following stillbirth at Cork University Maternity Hospital (CUMH), the parents of twelve babies who died through stillbirth participated in the study.

The study hospital opened in 2007 following the amalgamation of three smaller maternity units in the region. I chose 2008 as the first full year after opening to be the first group for the study and 2010 as a mid-point between 2008 and the current year of the study (2013). I chose three distinct time frames to explore whether there had been differences evident over time for bereaved parents. As a leading pregnancy loss research centre the parent cohort are regularly invited to participate in studies so a deliberate effort was made to recruit parents who were not part of other studies.

Twenty four parents were invited to participate in the study: twelve mothers and five fathers participated. In total 100% of mothers approached and 42% of fathers participated. All couples were in the same relationship at the time of the study as at the time of the stillbirth of their baby. Eleven couples were married at the time of their stillbirth and one was in a long term relationship. This one couple expressed that the death of their son (their first child) had inspired them to plan their wedding within a year of his death. Each of the participants was cared for at CUMH and was known to the pregnancy loss team (but not to me). Details of participants including year of birth, whether parents were prepared or unprepared for the death of their baby, gestation, faith background, impact of stillbirth on parental faith, and whether parents felt their spiritual needs were met can be found at Figure 5.1 and Table 5.1. The gestation of babies ranged from 29 weeks and 0 days to 40 weeks and 3 days. There were 8 male and 4 female babies and all were singleton pregnancies. Three babies had unexplained deaths recorded.

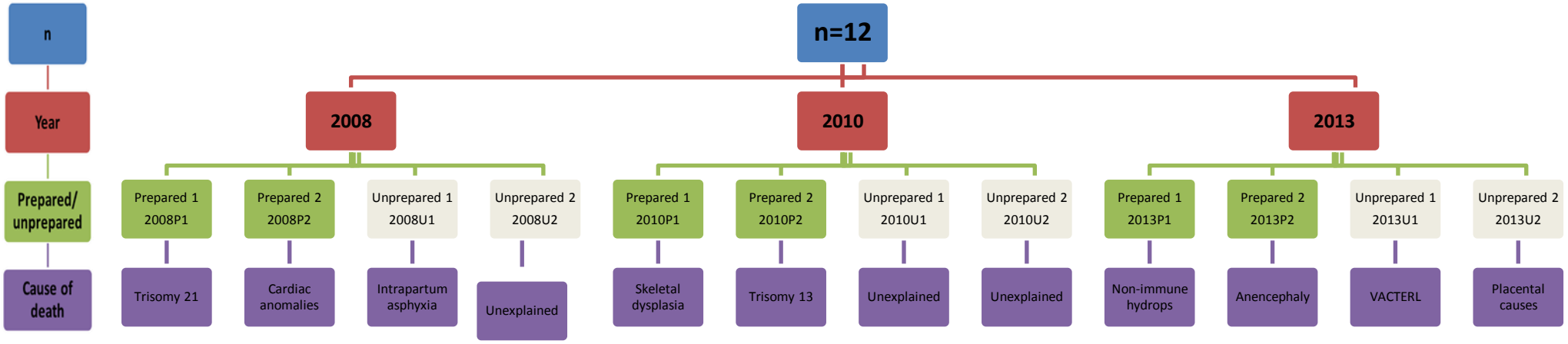


Figure 5.1 Details of participants: bereaved parents

5.4 Interviews and analysis

Each participant was interviewed at a location of their choosing. Fourteen parents were interviewed in their home and three chose to return to the study hospital for their interview and those interviews were conducted in a private office environment. Of the five couples, four were interviewed together at their own request, and one couple was interviewed separately due to their personal diary commitments. Interviews ranged in length from 31 to 104 minutes. Each interview was digitally recorded. Following each interview, I completed a reflective journal account where key themes, theological insights and other personal observations were recorded. An example of a reflective journal entry is included at Appendix 7.

I listened to each recorded interview several times before and after the data were transcribed verbatim. Each transcript was checked against the audio recording for accuracy. The data were analysed using IPA. Six superordinate themes were found in the dataset:

- Searching for meaning
- Maintaining hope
- Importance of personhood
- Protective care
- Questioning core beliefs
- Relationships.

A figure of superordinate themes and associate subordinate themes are illustrated at Figure 5.2

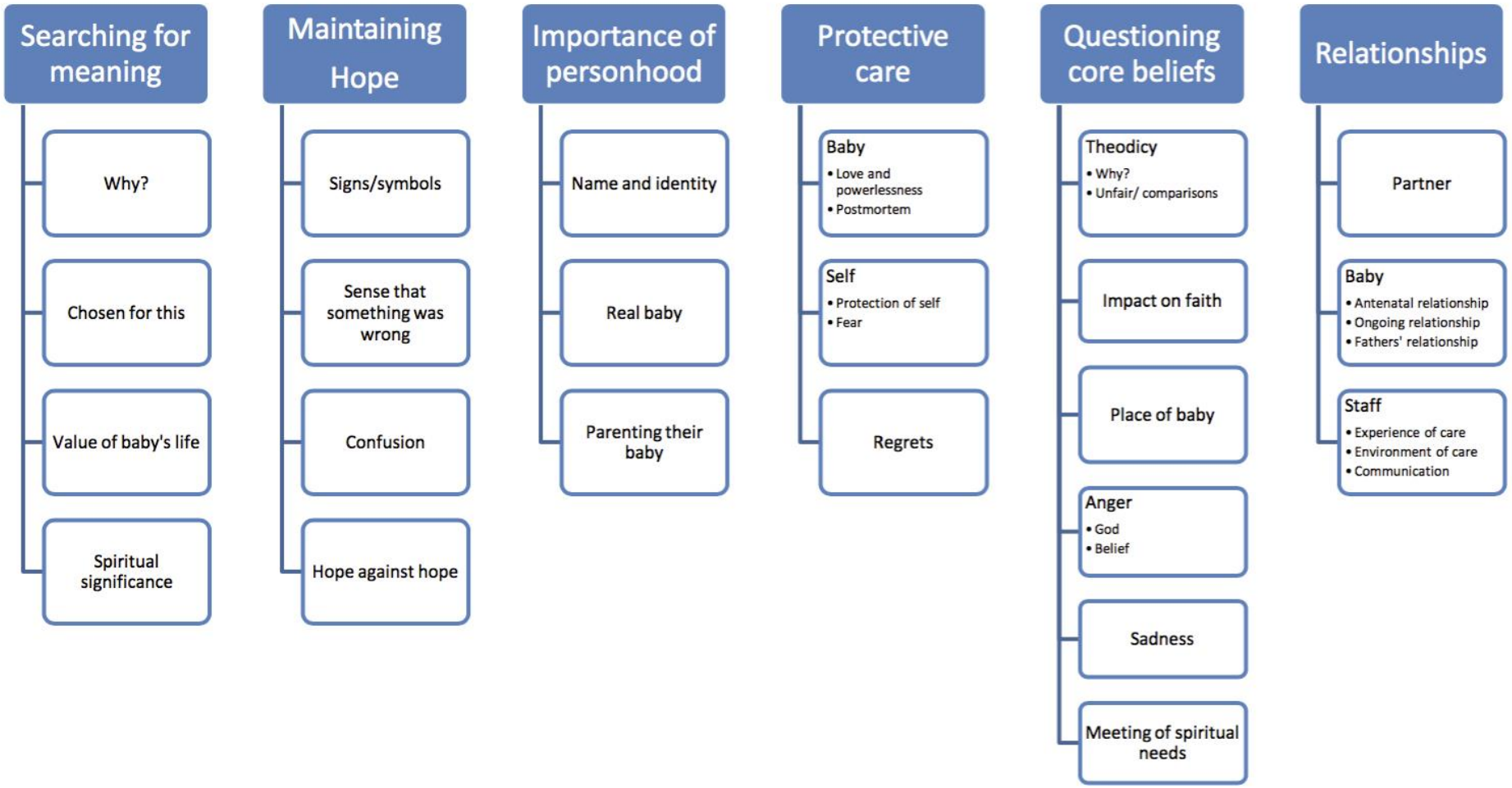


Figure 5.2 Superordinate themes and associated subordinate themes

5.5 Superordinate themes

The six superordinate themes to emerge from the data will be presented in turn. Direct quotations from the data will be used to illustrate each superordinate theme and associated subordinate theme. Each quotation is referenced by the year of bereavement and whether a baby had a prenatal diagnosis of a life-limiting illness with an expected outcome of stillbirth (P) or whether their stillbirth was unanticipated following an otherwise healthy pregnancy (U). Quotations from bereaved fathers have the code included 'F'.

Faith and demographic details of participants are outlined at Table 5.1

Year	Identifier	Prepared/ unprepared	Gestation (weeks+days)	Baby's Name	Faith background (Mother/ Father)	Faith Following Stillbirth (Mother/ Father)	Did parent feel spiritual needs were met?
2008	2008P1	Prepared	36+0	John	Catholic/ Anglican	Challenged	No
2008	2008P2	Prepared	33+0	Fiona	Catholic/ Catholic	Challenged	No
2008	2008U1	Unprepared	39+0	Michael	Catholic/ Catholic	Unchanged/unchanged	No
2008	2008U2	Unprepared	29+0	Bríd	Catholic/ Catholic	Weaker	No
2010	2010P1	Prepared	33+0	Áine	Catholic/ Catholic	Stronger	No
2010	2010P2	Prepared	37+0	Thomas	Catholic/ Catholic	Weaker/ weaker	No
2010	2010U1	Unprepared	40+3	Samuel	Catholic/ Catholic	Unchanged	Yes
2010	2010U2	Unprepared	40+0	James	Catholic/ Catholic	Weaker	No
2013	2013P1	Prepared	37+3	Aoife	Catholic/ Catholic	Unchanged/challenged	Yes
2013	2013P2	Prepared	31+0	Rory	Catholic/ Catholic	Challenged/weaker	No
2013	2013U1	Unprepared	38+0	Richard	Catholic/ Catholic	Weaker/ weaker	No
2013	2013U2	Unprepared	39+5	Paul	None/ None	Challenged	Yes

Table 5-1 Faith and demographic details of participating parents

5.5.1 Searching for meaning

Every parent expressed a deep sense of devastation and shock when they discovered that there was something wrong with their baby. This led to considerable personal reflection and questioning concerning the circumstances of the diagnosis and possible events leading up to diagnosis. Parents demonstrated a strong desire to seek to understand why their baby had an anomaly or died unexpectedly, especially during an otherwise healthy pregnancy. This questioning was expressed most often by 'Why did this happen to our baby, or to us?' In seeking to answer what are in many ways unanswerable and existential questions, parents revisited experiences and events that occurred during their pregnancy. Searching for meaning was an active pursuit and was a dominant superordinate theme throughout the data. A core part of searching for meaning was honouring the life of a baby; that his or her life was not in vain.

> *"Like I definitely feel that everything is meant for a reason. I think that's what made us happy, that this was Aoife's life cycle. This is all she knew. This was all she was meant for."* 2013P1

> *"I always think she probably made me a better mum* (emotional)*."* 2010P1

> *"I wanted what was best for Samuel and it was such a bad world and I thought 'yeah, he's in a better place than me' and what better way, why wouldn't a mother want, I hope anyway, a better life or maybe he was promoted. ... There was no reason for his death. There was no explanation*

for it, so I kept on hoping that he was taken for a good reason, that it wasn't bad." 2010U1

"Very important to me was to know that it [baby's death] *wasn't in vain."* 2010U1

The subordinate themes that made up the superordinate theme of searching for meaning were: being chosen, value of their baby's life and spiritual significance. These themes are explored in turn.

5.5.1.1 Being chosen

The sense of being chosen was an important subordinate theme in the data which only arose for mothers. The sense of being chosen was expressed in the data by mothers as an honour and a privilege and yet at the same time carried with it a certain conflict of wishing that they had not been chosen to be the mother of a baby who had died. Those who had time to prepare for the impending death of their baby were more expressive about being chosen for this 'special role' in the life of their baby. For some parents being chosen was attributed to an intentional act on the part of their baby whom they believed had chosen them. This ascription to an independent identity of a baby also features in a further superordinate theme of personhood.

"Aoife was a little angel and she needed to be born and she picked us to bring her into the world and that was our gift to her, was to bring her into the world. She knew from the outset that wasn't going to last longer than the

pregnancy and she needed someone strong to be able to bring her into the world and she picked me and James." 2013P1

Being chosen also conveyed an interpretation of inner strength on the part of mothers. They expressed a sense of pride that, as mothers, they were able to be parents of a stillborn baby with the inference that not all mothers would. Mothers who had experienced a sudden unexplained stillbirth expressed being chosen more as a posthumous hope as they reflected on their memories than as an experienced reality at the time.

"So when I was chosen there could be reasons Samuel came into my life to help me on my journey, that maybe he was helping God. He knew my faith was strong enough to go on his way or maybe God called him, I don't know. I got a good sense without any help from anybody; I was sensing all this in hospital." 2010U1

"I can remember [when people said] *'Oh God, he's chosen you' and I remember saying 'I wish he'd chosen me for something else.' But it was more, in some ways I kind of treasure the fact that we were chosen."* 2008U1

5.5.1.2 Value of their baby's life

All parents placed a strong emphasis on the value of finding meaning in both the life and death of their baby. This was an integral subordinate theme in parents' search for meaning. For parents who had received a diagnosis of a life-limiting condition, this subordinate theme was especially significant as they used the time

between diagnosis and death/birth to create memories, to make the most of every day and experience.

> *"Getting the diagnosis early I think was a blessing because I was able to enjoy everything."* 2013P1

Even though this was not the life that parents would have chosen for their baby, they nonetheless invested significance in the importance of the life of their baby in his/her own right as they searched for meaning.

> *"I don't think it would have mattered to me if he had two heads. He was lovely."* 2008U1

Parents who had an unexpected stillbirth recalled the experiences they had during pregnancy. This retrospective grieving and attribution of significance was an important part of honouring the life of their baby and establishing patterns of meaning that provided ongoing comfort.

> *"I see his life as being the nine months that he lived. He had his own kind of life. He didn't live the kind of life that I remember anyway. He didn't live any kind of life in my world, he lived his own life in another world, that was very real, very his own. He had his own experiences. He got to have all the adventures that I had. He got to go swimming; he got to go to San Francisco. He got to taste funny food. He got to taste bakery cakes. He got to go to the cinema. He got to have all those experiences in his own way. ... He had his*

own life. We shared in it in a lot of ways and we didn't in other ways … he must have seemed to be another part of me also." 2013U2

This subordinate theme of the value of the baby's life was also linked with another subordinate theme where parents cared for their stillborn baby as a live baby (see section 5.5.3.1) as part of the importance of the personhood of the baby (5.5.3). These two subordinate themes were closely aligned in so far as they embodied the experience of bereaved parents that their baby's life was of no less value than every other [live] baby.

5.5.1.3 Spiritual significance

All parents were from a Christian faith background although one mother did not now belong to any faith group. She described this as

"I really don't know how to define that [are you a person of faith?]. *I wouldn't call myself religious; I wouldn't attach myself to any particular religion now. I think nature is one of the defining forces in the world, in the planet, in our lives. I would say there is an awful lot going on that we have no grasp, that I have no grasp on … I don't associate that with a god or something, but I see it as a huge part of us. It's an area I don't have a huge inclination to define … possibly partly because of a lack of interest in a religion."* 2013U2

Most parents had a ceremony of naming/ blessing for their baby after he/she was born. Three couples had a baptism for their baby. Some mothers also engaged in

spiritual practices during pregnancy such as a service of blessing for their baby *in utero* following a diagnosis of a life-limiting condition. All parents had a funeral/ prayer service for their baby prior to burial or cremation. All parents expressed how their religious/ spiritual ceremonies helped them to attribute spiritual significance to their baby's life. Participation in a religious/ spiritual ceremony helped parents to express their grief and to confront the reality of physical separation by saying 'goodbye'. A spiritual/ religious ceremony was also something that parents were able to invest in for their baby as they planned an individualised ceremony. For many parents it was important that their baby received the same honour as every other baby in terms of ritual and ceremony.

> *"We had him Christened, same as the rest of us* (very upset)." [2013U1]

> *"It was in some way, it was before the service that was the really difficult part, the service was part of the process, you know the really hard parts were before the service because they had to be done before the service could happen. So it kind of pushed us into some things that we really needed to do. The writing of the service was as important as the having of the service. The finding of the painting and the working out the booklet and working out the words that I'd like to put in and things I wanted to say and what things I wanted to remember him by, what music I wanted."* [2013U2]

> *"I wanted to be able to choose the readings, choose the songs. I wanted me organising it and in a way by me doing that, I felt I was putting love into the service for John. That's what maybe I consider a bit of closure to have a*

moment of prayer and with people, immediate people. I only wanted the very few that were going to be there, that were invited … at my house. It wasn't, I didn't go to a church. I didn't want that. I just wanted something extremely private." 2008P1

5.5.2 Maintaining hope

All parents spoke about how it was important for them to maintain hope even in the midst of devastating sadness and loss. The superordinate theme of hope was expressed both in terms of how hope was an important part of coping with loss, and also a struggle to find hope when everything seemed hopeless. On analysis, this superordinate theme evolved from hopelessness at diagnosis to maintaining hope during the remainder of a pregnancy and into the future. The subordinate themes to emerge in this area were: signs and symbols, sense that something was wrong, confusion and hope against hope. I will explore each of these areas in turn.

5.5.2.1 Sense that something was wrong

The subordinate theme of 'sense that something was wrong' ranged from a feeling of premonition by mothers that something might be wrong with their baby or pregnancy before receiving a diagnosis, to an attachment of significance to particular events or experiences retrospectively. For many parents their retrospective association of memories and experiences was also part of their trying to find meaning in their loss. For those who had an unexpected stillbirth the sense that something was wrong was associated with panic and fear. One mother when she felt that something was wrong recalled:

"I remember lying up on my bed hitting my tummy trying to get some response…I went to the GP and I literally burst in the door and collapsed to the floor where I was hysterical." 2008U1

In the analysis of data there was some overlap between this subordinate theme and the superordinate themes of 'searching for meaning' and 'questioning core beliefs'. Mothers described their sense that something was wrong with their baby or pregnancy in these ways:

"I got an awful choking sensation in my throat and I knew then when I got up after being in bed that he was gone." 2013P2

"It was really weird that day. …about half six that morning I had such movement that just woke me. …. When I look back I don't know if was that when it happened? … Now I'd say it was a struggle inside, but it was more. I just felt that God woke me, maybe something going to happen today …. I don't know." 2008U1

5.5.2.2 Signs and symbols

Many parents spoke of how they had received various 'signs' which they interpreted as being from their baby or that pointed towards their baby. In addition, parents also mentioned that various symbols had taken on significance for them following the death of their baby. These signs and symbols were interpreted as being very closely connected with their baby's person and were of immense significance

and enduring comfort to parents. Signs and symbols were experienced as an ongoing connection with a deceased baby and were cherished by parents as embodying hope that their baby was still close to them. These signs of hope were described in liminal terms, as of threshold significance between this world and the next. Two signs in particular stood out for bereaved parents: white feathers and butterflies. Two mothers spoke about how butterflies were important symbols for them following the deaths of their babies.

> *"I remember the week after he was born … there were all these little white feathers on the path ahead of us. There's a lot of places you go and you find these little white feathers. You know, in your head you're thinking, that's him."* 2010P2

> *"You would go to bed and the next morning you would pull up the blind and there would be butterflies inside the house, it was just very weird. And right up until Christmas, Christmas Eve, there was a butterfly, so we all associate butterflies with the baby … I just always feel like it's baby saying 'hello'."* 2010P1

> *"…white butterflies, any white butterflies, of course we always used as a symbol for him …this little white butterfly was literally circling us* [on his anniversary] *and then he flew away … we went down to the beach and then it happened again … so they'd* [siblings] *be chasing them around and they get all 'Baby Michael's flying around us' and things like that. I feel that he is*

with us all the time anyway. I just feel, it's just a sign that he's [baby Michael] *reassuring me that he's never gone away or he's with us."* 2008U2

Other parents shared how they had other experiences that gave them closeness to their baby.

"Sometimes at night-time it happens here, someone blowing into my ear or my head. It's always my head and I think maybe Samuel is present. I don't know. It's very strange. It has happened three times and it wasn't my husband as he wasn't there so I take comfort in that." 2010U1

The subordinate theme of signs and symbols was also closely linked with the superordinate theme of relationships and the experiences parents had of ongoing connection with their baby where signs were an integral part of that sense of connection. I recorded in my reflective journal that parents expressed positivity and joy as they spoke about these signs and symbols associated with their baby.

5.5.2.3 Confusion

Parents expressed the inner conflict they experienced when they heard the news that their baby had died. This was mostly expressed by those who received a sudden diagnosis that an otherwise healthy pregnancy and baby had died through stillbirth. The sudden shift in emotion from expectancy to devastation and then the finality of death, unsurprisingly created inner emotional and stress-related conflict. For two mothers this was experienced as an out-of-body experience where they felt detached from what was happening.

"I was just sitting there looking at him; I didn't feel anything for ages. I couldn't (crying and barely able to speak during this part of interview) *... it was like I couldn't believe it or something. I was just sitting there looking at him. I couldn't even cry. It was like I couldn't believe he was dead. I was just out of my body, just looking at him, just staring at him."* [2013P2]

Where parents expressed confusion it was part of hoping that the news was untrue. It did not feel possible that their baby had died, especially if they had a normal pregnancy up to that point. For some parents their confusion stemmed from lack of clarity from staff especially at the time of diagnosis. One parent described this confusion from staff as:

"It was one of the toughest nights, because I didn't know what was wrong, because I didn't expect anything to be wrong (long pauses, crying and deep breaths) *and then there was no one to scan me so I had to go home and come back. ... It was the longest time I had to wait for anything* (crying and barely able to speak) [returning two days later] *then I had to wait for over two hours and he* [doctor] *just did the scan and said there was fluid in the baby's stomach and he didn't really explain what was wrong ... I was just in a daze then walking out the door, I kind of couldn't believe it*." [2013P2]

"I think mostly around that time I felt confused. But I don't understand, I didn't understand, I didn't understand, I still don't understand how, what has happened? It just seemed, it didn't make any sense. It just seemed beyond my

comprehension. The reality shifted. It didn't make sense. The basic law of physics just changed and it didn't make sense, the natural law. … I would say that, I don't know. It's just a new world, that was and the new world was just a new world. It's just is, this is the new normal. This change of life is the new normal. … I suppose on some level accepting this is the new normal, not grasping it and not understanding it. That confusion, this just is the new normal … everything has changed, this inexplicable instant shift and there's no getting used to it. It was just instantaneous, just that shearing of a certain future that isn't anymore. That shearing off has made, made a very different future. Everything is different; everything is different, because we're parents now. Parents, parents without a child. And that's a really strange place to be." 2013U2

One mother found it very difficult to bond with her baby following a diagnosis of Down syndrome. This created an inner tension, confusion and guilt and during interview this mother became very distressed at this point as she recalled these difficult emotions. In my reflective journal I recorded '[Name] became very distressed and tearful as she recalled her experiences of hating her baby. She cried a lot and needed time to process this. She displayed signs of shock and guilt/ shame and spoke very openly. After some time she regained her composure and although I offered her the opportunity to stop the interview she said "I need to do this, this is important".' This mother described her conflicting feelings towards her baby as

"I hated the baby the minute I heard that [diagnosis]. *Hated it, hated it, hated it. I couldn't say it any clearer than that. I was just hoping the baby would die*

and that was it … I finally came to the realisation after a heartfelt cry that I loved this little baby inside me and I would do anything to protect him. I wanted to call him 'he or him' as now I felt very close to him. I loved him and I was looking forward to meeting him, seeing him. The feeling of peace settled over me at last and I know I could deal with whatever was ahead with a clear conscience and love in my heart. … being in the hospital and having that peace and calm and actually loving this baby that I hated was very bizarre" 2008P1

5.5.2.4 Hope against hope

Many parents spoke of a sense of trying to maintain 'hope against hope' that perhaps the diagnosis about their baby was wrong and that somehow their baby might survive. Hope against hope was a strong instinct that was closely linked with the superordinate theme of 'protective care'. Parents found it hard to accept the reality that their baby had a life-limiting condition or had died. For parents who had an unexplained stillbirth they tried to maintain hope in the midst of panic, fear and confusion from the moment they suspected something was wrong until they received confirmation of their baby's death.

"He [husband] *said 'there's no heartbeat' and I said 'we'll wait, we'll see'. I still continued in labour as if my baby could still be alive. I wasn't grieving, I didn't grieve. Because I had a perfect pregnancy, it was perfect. I had no problems so why? There was a strong heartbeat* [two days previously] *so why, why can they say, why can it go from strong to nothing? Surely you go from strong to slightly weak and I only saw the gynae two days before and all*

was well. … I said, 'You know I'm not going to accept there's no heartbeat until I see my baby'. And then there was no (silence, unable to complete the sentence) *… the baby came and he wasn't alive so I had no words, just no words."* 2010U2

"I think I knew, my gut feeling was like, that I had either lost the baby or whatever, and I just didn't want it to become real. Because I suppose there was a chance they could save him." *2008U2*

The subordinate theme of hope against hope was characterised by the desire of parents to do something that might change the outcome for their baby. For some parents this meant hoping that the doctor had got the diagnosis wrong, and for others it was changing their lifestyle habits such as eating more healthily, exercising or taking bed rest. One mother following a diagnosis that her baby had a cardiac anomaly where she was informed that her baby was unlikely to live longer than two to four weeks after the diagnosis, expressed this sense of hoping against hope as:

"I started going to a homeopath … I took every remedy and supplement, everything you could think of, everything under the sun to try and make him stronger, that his heart might get stronger. So I felt like I really had to keep going for him. I kept trying to think of ways to make him better. I was reading and everything trying to find out things that might help him but Dr Y said I couldn't do anything" 2013P2

5.5.3 Importance of personhood

The importance of the personhood of their baby was a dominant superordinate theme for all parents. Parents spoke strongly about the uniqueness of their baby and how in his/her uniqueness each baby had an enduring importance as a human being that mattered. In the analysis of the data this superordinate theme was very much couched in terms of the pride that parents felt towards their baby and was closely related to the superordinate themes of 'protection' and 'searching for meaning'.

> *"He played a big part in our, in changing our lives in a year. Not only in his own presence and the changes he would have brought along but he also impacted in other areas of our lives as well. He was a very powerful little person."* 2013U2

Important subordinate themes in the superordinate theme of personhood were recognition of a stillborn baby as a real baby, the baby's unique identity, and how parents actively parented their baby as they would a live baby. Each of these subordinate themes will be explored in turn.

5.5.3.1 Real baby

The importance of a stillborn baby being recognised and treated as every other baby was expressed by most parents. Parents who had other children expressed that they felt the same love and care towards their baby as they had towards their other children. Parents wanted to protect their baby from being treated differently.

"...so I carried him out in my arms in a shawl and I remember the midwife, she was panicking and she was like ' I'll walk you down' and I was like 'no, it's OK' and she was like 'well what if someone stops you and says, you know 'your little baby's beautiful'? and I was like 'well he is'. And I carried him out in my arms." 2008U1

"We were sitting there holding him as if he was alive and breathing." 2010P2

"He was perfect, he was exactly the same as [every other baby] *in one sense it was nice but it wasn't nice."* 2013U1

"He had ten fingers and ten toes and his finger nails were perfect." 2013U1

"I still gave birth to him, exactly the same as I did [with the other children] *I had to physically go through it all and hard as it was even when I gave birth, I still felt joy as well. It was really strange. I had such a mix of emotions ... even in him, he was beautiful, he was 8lbs. and it was just like he was sleeping. He was really, really, he was all there you know. I still felt 'oh he's beautiful' like I would have for all my children. ... I wanted to know what he weighed and I wanted to know, you know, none of that mattered you know, that he wasn't alive, it was more, you know, to me he was still ours and we still had him and I felt all of that was lucky."* 2008U1

5.5.3.2 Name and identity

Parents created an identity for their baby both antenatally and also in how they related to him/her following his/her birth. The baby's identity was also an important way of relating to him/her following burial or cremation when they were no longer physically present. Central to the identity of a baby was his/her name. All parents spoke about the importance of naming their baby. In most cases this was done as part of a naming ceremony or service of blessing; for three babies it was part of baptism. Many parents spoke of the reasons and significance of the name chosen for their baby. One couple who were recently bereaved and very upset during the interview process were unable to use their baby's name during the interview. They referred to their son as 'the baby' throughout.

The identity of the baby as being part of the family was also important for parents, whether parents had other living children or not. Even when parents had no living children they still described their baby's place as being part of their family. This subordinate theme was also linked with the superordinate theme of 'relationships' and was integral to how parents related to their baby in an ongoing way.

> *"I suppose I created my own little personality for him and that he'd be a right old scamp!"* 2010P2

> *"We brought him home … and we brought him to my sister's. He was in all their houses, my dad, my mum and dad, they all had cuddles, all the kids, my nieces and nephews all had photos. … He is the most thought-of baby, for a*

baby that isn't here visually; he's not forgotten by anyone. If any of them go on holiday or something they might get a little flower or a little snow globe to put down at the grave. He's always remembered." 2008U1

"She'll be a member of the family regardless of how long we have her for. … She was my little baby, I just loved her … she's my daughter, I just see her as my daughter and they [extended family] *all saw her in the same way which was lovely."* 2013P1

The identity of a baby as an individual who was 'more' than his/her condition or illness was a strong subordinate theme for some parents. Parents in many cases were keen to protect their baby from being labelled, and were cautious about how and with whom they shared information about their baby and his/her illness. Parents placed a strong emphasis on the person of their baby as being of prime importance rather than his/her illness.

"She was Aoife, and she wasn't what her condition was." 2013P3

The subordinate theme of identity of a baby was also linked with the ongoing relationship that parents had with their baby as outlined in section 5.5.7.2.3.

5.5.3.3 Parenting their baby

The importance of parenting their baby was an important subordinate theme across the data. All parents spoke of how they invested significance in the opportunities they had to be parents to their baby. Parents expressed how they

appreciated being able to do what are considered ordinary acts of caring for their baby. One mother described how she enjoyed caring for her son when his body was oozing some blood after they brought him home.

> *"I suppose when he was so ready for life, he kept having little nosebleeds, because everything was so there like, and I loved it. I loved the fact that I got to do things for him. … a lot of blood came out of his nose and we had to use cotton wool and kind of plug it. All down my top and all his little cardigan, you know, which things, I've kept obviously because his blood stains are on it. I was cleaning him. I loved the fact that I got to do things for him … I just felt I got to mother him a bit which was lovely."* 2008U1

Some parents feared what it would be like to care for their baby and for two mothers it took some time to adjust following the births of their babies.

> *"It was like I got an awful shock because I really was dreading that I didn't know how I'd react when I see him because I knew he would be just so still. I really kind of, I couldn't even talk. I was just looking at him. He just had his eyes closed, do you know? When you see him, do you know when you have a newborn baby, they're just kicking, they're just so full of life? I didn't want to, I just didn't want to feel him dead."* 2013P2

Many parents emphasised the importance of the finite time between the birth of their baby and his/her burial/cremation. One couple expressed strongly that they

wanted to have their baby son with them as much as possible; to bring him home as soon as possible.

> *"I wanted time, I wanted to take him home. I wanted as much time with him as we could and I think that's probably why we probably left* [hospital] *even earlier than we should have that morning. We left the hospital at nine o'clock Wednesday morning. Like, I knew, I suppose we knew we wouldn't have long with him before we buried him midday Thursday."* 2008U1

If parents did not have the opportunity to perform acts of physical care for their baby this was revisited with regret afterwards. One mother said

> *"The only thing I really wished, I would have loved, eh I know it probably sounds stupid, but eh when baby was born I really wanted to give her a little bath or something. I don't know if it would have been possible but I would have loved to because there was just a little bit of her face that I would have loved to wash it* [vernix] *off you know."* 2010P1

5.5.4 Protective care

Each parent displayed a strong protective instinct towards their baby. The desire to protect their baby was also a challenge for parents as they faced the reality of their own powerlessness and inability to protect their baby from inevitable death following a life-limiting diagnosis. One father spoke about his sense of personal pain and how he would have gladly stepped into the place of death himself if that would have saved his son's life.

"I wouldn't be the crying type but it would just break your heart, it would shatter everything, everything you have; your family life, your beliefs, your everything (crying loudly). … *Like I don't drink, I don't go near … and you'd feel like opening a bottle of shandy or something and just letting go. … 'tis like a form of depression where you do not have tablets or anything. We are just suffering our way through it … you just have to take one hour at a time but I'd have preferred if I could have gone and let him stay. … I wish I could have gone and he could have stayed … and let him have a life* (long silence). ,, 2013P2F

The following subordinate themes in the data were part of the overall superordinate theme of protective care: love and powerlessness, post-mortem, protection of self, and regrets. I will explore each in turn.

5.5.4.1 Love and powerlessness

Most parents spoke of an overwhelming love they had for their baby and how they would do anything to protect their baby. For some parents this love became particularly focussed in the period between diagnosis of stillbirth and the birth of their baby. This was something that arose especially for those who had an unanticipated and sudden stillbirth. This protective love was coupled with a sense of powerlessness to change things for their baby: a disempowering and painful love.

"All I could think about was I wanted him out, I just wanted to see him and hold him. That's all I wanted. It was very hard those couple of days. Knowing

he was inside me, knowing that he wasn't out. So I just wanted to get him out and see him, meet him and hold him. I just had to see him and hold him." 2010U2

"All I could think of was my poor baby and I was just looking at him up on the screen …He was just lying there and I couldn't do anything … I was thinking 'my poor baby' (very emotional and tearful) *Can they do anything for him? I felt that I had to keep going for him because he came for whatever length of time he was coming for* (very upset) *and I had to mind him until he was gone."* 2013P2

For one mother her sense of protective love continued after her son's burial where she experienced strong feelings of powerlessness in her desire to protect him.

"I remember thinking at the time, God I just wanted to take him out of the ground because I actually felt very cruel actually putting him into the ground. Even now you'd be thinking do you know, are there spiders or anything around the ground and you'd be thinking, I hope nothing's touching him or that. … You'd be thinking, God I'd love to take him out and bring him home … why didn't we get a metal case? You'd hate anything to get at him." 2010P2

Three mothers said that they experienced difficult feelings of hatred and detachment towards their baby before his/her birth. One such incident is referred to above at 5.5.2.3 and in another case a mother was fearful antenatally about the appearance of her baby who had been diagnosed with Trisomy 13 and for the third,

her sense of shock and disbelief that her baby had died unexpectedly prevented her from feeling love initially. These were difficult feelings of powerlessness for each mother and caused upset as they were retold during interview.

> *"I couldn't bear to feel him getting cold. Even when I held his hand after, it was just so cold. I just wanted to keep him hot because I always felt that when he was inside me I used to be able to keep him warm and safe."* 2013P2

5.5.4.2 Post-mortem examination

The issue of post-mortem examination was raised by a number of parents as part of their sense of protective care for their baby. For some parents a post-mortem examination was seen as an intrusion. Two parents expressed that they did not want their baby to undergo a post-mortem examination as it felt like an unnecessary 'extra ordeal' for their baby. This was expressed from a protective parents' perspective, where parents felt they needed to protect their baby from any further tests and interventions from the medical team. In both cases these were unanticipated stillbirths. In one case the cause of death was recorded as *intrapartum* asphyxia and in the other the cause of death was officially recorded as 'unexplained'.

> *"We had the option obviously of the post-mortem but I didn't want it. I just didn't want them touching him. … and its funny because when I had lost him before they started my labour, I suppose for that initial moment I wanted to know what had happened because we had no answer obviously and she had said 'you know afterwards the baby can be taken off and they can do the post-mortem and he'll come back to you then obviously.' And I was like,*

yeah, yeah, yeah, yeah and the second I had him, I just felt, no way. I didn't want anyone touching him and I felt it wasn't going to make any difference." 2008U1

"We didn't do a full post-mortem because I didn't want him touched, I didn't want him cut open. I didn't want anything to happen to him." 2010U2

For two parents the reality of post-mortem was a distressing experience for them after they had gone home. In one case, although they had signed a formal post-mortem consent form, the couple had not understood that their baby's organs would be retained and then subsequently returned to them. This couple spoke very vividly of the distress caused to them when they received a telephone call 'out of the blue' from the hospital to collect their baby's organs. They found it to be a traumatic experience to return to the hospital to collect their baby's organs to bring home for burial. This couple buried their son's organs in darkness in his grave. The couple were very upset as they recalled this experience.
(Both were speaking during this dialogue 'M' = mother and 'F' = father)

"We had to go and collect the thing like. I suppose it's, the hardest thing was that we didn't realise when we signed the forms above [slang: hospital] *was that his organs would be coming back and 'twas* (F)

And we didn't know, forms said they took his organs, [both tearful] *they took his organs and we didn't know that.*(M)

Then after I don't know how long, a month or six weeks, I don't know how long. The phone rang one day and said that baby's organs were back [voice breaking and finding it hard to continue speaking] *and like you kind of have to go through the whole thing.*(F)

> *It was like going back to rock-bottom again like. You think you're getting yourself back together and you get this phone call and you go straight back down, down to the ground again.* (M)

And like, to bring them back and bury them again. The priest said not to make any issue out of it. 'Twas the summer and nine o'clock at night and no one will cop what's being done. So we buried them in the dark … We agreed with everything but you don't register what's going on … they should probably say "be prepared for six weeks' time when you will be getting a phone call *(2013UF)*

One mother spoke in a very animated way of the transforming experience when she received her baby son back from his post-mortem examination. In my reflective journal I noted that this mother's face 'lit up' as she told this story, her facial expression radiated pride and joy as she recalled meeting her baby boy again following his post-mortem which she was initially reluctant to give her consent for.

"The most wonderful thing happened when our baby came back [from post-mortem]. *I smiled, I laughed, I was full of joy. I saw my baby in a baby-grow of blue and white and all of a sudden things changed. I can't explain it. I said*

'wow, look at our baby' and he was someone, he was someone, and from then on he became someone to me." 2010U1

5.5.4.3 Protection of self

Parents described how they felt a need to protect themselves when they had received a diagnosis that their baby might not survive. Parents spoke of not wanting to share the news publicly and the need to protect themselves from ordinary social interactions when they might be placed in a situation of having to explain that something was wrong.

"We used to go on spins [slang: a journey] *to the beach* (very tearful) *to kind-of isolated places where you wouldn't bump into people."* 2010P1

"I didn't say anything to anyone in work, just close family, what was happening and let-on to the outside world that it was just a pregnancy as normal. I didn't want people to keep asking me what was the story?" 2010P2

Other parents expressed a protective approach against the reality and finality of death.

"I was holding him when he was hot but then I couldn't hold him then when he was cold." 2013P2

One mother explained about being very clear that she wanted her baby daughter (who had Down syndrome) to be presented to her looking pretty after she was born because she only wanted to be left with an enduring pretty image.

> *"There was immediate love there, that goes without saying. She looked perfect, that's what I couldn't get over. You wouldn't tell she had Down syndrome. I suppose in my head I didn't know what I was expecting. I know she was a sick child but she just looked so perfect and I just couldn't understand why. She looked very peaceful which was important as well. The one thing I did dictate, which in hindsight was a good thing was 'can you make her pretty?' because that's the one image I have of her."* 2008P1

Some bereaved parents felt a sense of exposure when they met other parents and their babies when they were leaving hospital or other pregnant women when waiting to have their stillbirth confirmed. This experience was evident in the data from 2008 but did not appear in the data from 2010 and 2013. This finding is further explored in section 5.6.

> *"When I look back I found that hard … the room … is it like a triage room? I could hear other women with their heartbeats obviously … I remember lying there hearing the other women and one woman was in labour and it upset me."* 2008U1

When bereaved parents encountered other parents and babies it evoked feelings of jealousy and a painful reminder of the reality of their loss. Parents

expressed how they appreciated being cared for in a single room in a dedicated part of the hospital and the fact that both parents could stay there.

5.5.4.4 Fear

Fear was a common thread in the protection of self. Fear ranged from the unknown about what had happened, to how parents were going to cope with the impending death and birth of their baby. Parents expressed fear about what their baby might look like and how others would react. Parents described their sense of fear as they prepared for the birth of their baby.

> *"I remember thinking that she might feel cold and I'd be afraid* (very upset and crying)*."* 2010P1

> *"I remember distinctly after having him, I just didn't want to hold him. I got an awful shock when I saw him because he wasn't, he wasn't a pretty baby. I often feel very guilty still of how I felt when I saw him. I still struggle with that all the time."* 2008P1

5.5.4.5 Regrets

The subordinate theme of regrets was identified as parents in hindsight had regrets about aspects of their care or decisions they had made. For some parents it was linked with parenting their baby and opportunities they did not have or did not avail of.

"I know it might sound ridiculous but I'd like to have seen all of him." [2010P2]

Others had regrets that they did not respond immediately to a symptom which in hindsight they felt was significant. These regrets were expressed as part of a revisiting of their story in trying to understand why their baby had died.

5.5.5 Questioning core beliefs

Parents expressed that they questioned their belief structure and practice following the death of their baby. For all parents the death of their baby caused them to reflect existentially on their life values and belief systems. For all but one, this was based on their Christian understanding of God and for one it was based on a more humanistic approach. One mother who was a committed Catholic before her baby died expressed the impact on her faith as:

"My faith has changed since Bríd. I used to go to mass all the time but I rarely go to mass now. … I was very much the traditional, go to mass, sit down and I suppose I always had that kind of spiritual side. The God I believe in is not the same as [formal church] *… I went to mass on* [last] *Sunday, the first time in a long time and I nearly walked out … the priest is doing the Catholic church thing, he said that people who voted for the abortion thing were evil and they should never go to mass … and I'm there thinking 'will we try for another* [baby]*?"* [2008U2]

Subordinate themes that were part of the superordinate theme of questioning core beliefs were theodicy, impact on faith, place of baby, anger, and sadness.

5.5.5.1 Theodicy

Theodicy is one of the most challenging aspects of pain and suffering for people of faith. Cooper-White's definition is perhaps the most appropriate for the context of stillbirth.[(259)] She defines theodicy as 'the tension between three mutually incompatible axioms: divine goodness, divine omnipotence/sovereignty and the existence of suffering …'.[(259)] In simple terms theodicy can be understood as 'why do bad things happen to good people?'

The struggle of some parents with theodicy found expression in feelings of unfairness and injustice at why their baby died.

> *"I wondered why this happened to me. I had no baby, Why me? It's beyond my capability of understanding, so I asked questions about God."* 2010U1

> *"Thirteen is a very unlucky number, looking back on this year anyway* (despondent)*."* 2013U1

> "I was angry and I said why is this happening to me? What did I do to deserve this?" 2013P2

> *"I can always remember the day I found out, that, I had the scan. I went outside the front door and there was a couple of girls there. I know this is a completely horrible thing to say, but they were out smoking out the front and they were as big as busses now and I don't mean to, I was thinking 'they're*

fine now and here am I, haven't touched a dri… [drink]*, I don't smoke, didn't drink and this is happening to me and these ones out smoking, like, fit to have their babies. I felt it very unfair: but that's life."* 2008P1

Parents who were practicing their faith found this area particularly hard as it jarred with their sense of devotion and religious commitment. It created an unsettling relationship with their faith and belief in a caring God. This is discussed further under the subordinate theme 'impact on faith.'

"Sure we always went to Mass and everything like, you're kind of saying 'why?' then like, wouldn't you? You'd be wondering what you did wrong, what you did to anybody that drew this down on your doorstep?" 2013U1F

5.5.5.2 Impact on faith

All parents experienced the death of their baby as challenging to their faith and belief. This challenge for twelve parents led them to question their faith and belief in a caring God with seven expressing that their faith was weaker as a result. One mother felt that her experience of stillbirth led her to a deeper faith. Four parents expressed that their faith, although challenged, remained unchanged following stillbirth. (See table 5.1)

"I still believe in God and I still believe as I did before but I just (deep sigh) *never expected this thing would be so hard. I never thought I would have to go through something like that* (voice breaking and emotional) *Life can be hard enough without going through something like that. It has made me*

worry about what's around the corner. It has made me fearful for my three kids that are here with me. I'd still say my prayers but sometimes I kinda feel 'is there any point?' It didn't work with the baby anyway." 2013P2

"When James died it was like, what? Why is he [God] *doing this and 'why would you do this to anyone?'"* *2010U2*

"I used to go to mass and that sort of stuff; I haven't gone for five or six months. I found it was something I was doing rather then something I was partaking in, I just find religion confusing now. It's like I'd be questioning at times, is there anything after? I just don't know." 2010P2F

The diagnosis of a life-limiting anomaly led some parents to express strong feelings of anger towards God yet at the same time feeling a sense of dependence on God to get them through the experience. This led to a confusing sense of dependent ambivalence.

"Oh I screamed at him [God], *I gave him the big finger there. I did suffer a long time. I just couldn't leave it, praying went out the door. I found it very hard to pray, but I spoke. I didn't say prayers, I spoke and I screamed and I roared at him … maybe I was given the grace to help me along because I was struggling so much …'Why am I going through this? God, why are you doing?' And at the same time going 'please help me, I'm leaving it in your hands.' … my faith got me through this without a shadow of a doubt."* 2008P3

Anger is explored further at section 5.5.5.4

5.5.5.3 Place of baby?

Many parents reflected on the question about where their baby is now. This subordinate theme was expressed as parents shared their sense of ongoing connection and relationship with their baby. For some parents it was closely linked with their sense of the after-life. Is my baby still a person? Where is my baby now? Parents wrestled with these questions as they shared how they still felt a close connection and relationship with their baby.

> *"I felt great frustration and confusion around where like, where would a spirit, where would that spirit go?"* 2010P2

> *"I kept getting reassurances that he's in heaven, and that was great."* 2010U1

One mother connected with her baby through a medium which was a source of comfort.

> *"She* [medium] *just said that the baby is very happy where he is and that he doesn't want us to be miserable, to be grieving over him, that he is just feeling loved. He just came to me to be loved, to feel loved and em just wants us to be happy."* 2013P2

An important subordinate theme in this area was the experience of loneliness and grief. Parents described this as the reality of the absence of their baby yet at the same time feeling close to their baby.

> *"The first three or four times we got the ferry out to the island, it was just the oddest thing. I got off the ferry and we had our bags and I was going, 'I'm missing something'. I'm missing, I'm missing a bag, there's a bag missing, there's something missing. I'm supposed to be carrying something else off the boat and I went down to the boat again and the man said 'no, no, no all your bags are up'. And I'm missing something. And then we get everything into the car and went to the house and he's* [partner] *also saying 'I'm missing something, I'm missing a bag.' I said 'no, I thought the same thing' and then an hour later it's like, 'I know what it is, I'm missing a baby.'"* 2013U2

5.5.5.4 Anger

Anger was a subordinate theme running through most interviews as parents expressed the pain associated with the death of their baby. As a subordinate theme anger challenged the world-view of parents where the natural order of birth and death are reversed and most especially where there were no identifiable reasons.

> *"With God you'd be saying 'why my baby? This is a baby that would have been loved', there's the bitter side to it."* 2010P1

> *"Sometimes you'd be quite angry how God can let something like this happen."* 2010P2

"When James died, it was like, what, why is he [God] *doing this and why would you do this to anyone? I just stopped doing it* [going to Mass] *for a good while … I was very angry, angry, just devastated. Just why? Why us? Why anyone? James was almost full term; you know moving around and kicking. So, yeah, very angry, very…"* 2010U2

Parents recalled expressing their anger to God during their pregnancy. Two parents found the experience of labour very difficult and were angry with God and with the healthcare team. One mother expressed:

"My husband was crying, I just went, I discarded God at that point and I shouted to Our Lady saying 'what's wrong with you, why have you left me?'" 2008P1

One father described his anger and sadness from a faith perspective because he and his partner were unable to have a funeral for their baby son in their church.

"I suppose because he hadn't been christened, we couldn't have a service in the church. … I remember the priest saying one day, 'you can't pick and choose what parts of being a Catholic you want to be' and I just thought to myself, then everyone in this room will have to get out " 2010P2F

Two parents expressed that stillbirth had transformed their relationship with God through the awareness of their anger. This transformative growth led to an

integration and acceptance of anger as a justified response to the death of their babies.

> *"Bríd has taught me that it's ok to be angry with God … He's very understanding and that he understands and if you got angry with him and said 'I'm cross' that he'd be ok with that … you can be cross with him and you can go away from him for a while and the door is always open and he's understanding."* 2008U2

5.5.5.5 Sadness

All parents described the profound sadness they experienced following the death of their baby. Sadness, unsurprisingly, was most acute for the parents who were bereaved in the current year of the study. As an emotion, sadness was closely related to all themes. In the data analysis sadness was most closely related to the questioning of core beliefs: an existential reflection on loss. Sadness was evident in the sheer and inevitable loneliness that parents experienced as they came to terms with the death of their baby. Sadness was an active emotion that was in many ways similar to what is often referred to as the 'work of grief'.

> *"I just* (deep tearful sigh) *never expected this thing would be so hard. I never thought that I would have to go through something like that* (very emotional, voice breaking) *Like, do you know, life can be hard enough besides going through something as traumatic as that … my heart is broken."* 2013P2

"It just all [life] *seems shattered you know. It all just seems (silence) maybe just waiting for the ending to come so em you can either meet him again or else you just go back into dust and there's no more suffering* (very emotional). *Because, when you start looking around this place, there's plenty of suffering and I'd always be optimistic, you'd look on the happy side of things, but it just kind of surrounds you. You see the ones around you and they are all suffering and there is nothing you can do. Looking at one another and watching them grow up knowing* (breaks down in tears) *that he* [baby son] *won't grow up. He won't be there with us physically."* [2013P2F]

5.5.6 Spiritual needs

Parents expressed in section 5.5.5 that they struggled with existential questions following the diagnosis of a life-limiting condition or stillbirth of their baby. As demonstrated in section 5.5.5 all parents shared emotions that indicated spiritual distress. Most parents availed of chaplaincy services during their time in hospital, however, these services were reported as being exclusively for ceremonial functions such as naming/ blessing ceremony or a baptism. While this was valued by parents, thirteen parents felt that their deeper spiritual needs were not adequately met while in hospital. The parents of three babies felt that their spiritual needs were met during their time in hospital.

"I met with [chaplain] *she came up and had a chat with me and she was lovely … I suppose in a way nobody did address my faith or where I was there…I guess you need somebody to knock off the question to 'why is God so horrible?'"* [2008P2]

"He [chaplain] *blessed the baby but I suppose we didn't really have any … I suppose we could have asked, but we didn't have anyone that sat down and kind of talked about the spiritual side of it."* 2013P2

No parent had received any follow-up pastoral care from the hospital. Of note, only three of the twelve babies had a ceremony/ funeral in a church prior to burial/cremation. Most parents had a private ceremony in their home or at the hospital prior to discharge.

Participants were asked if they would have appreciated if their obstetrician had discussed their spiritual needs as part of their care. Only one parent said that they would have valued this. All other parents said that they felt this was not something they would expect from their obstetrician but would like him/her to recognise that they needed support.

"I would be okay. I don't know whether [partner] *would be though … you'd have to use your judgement."* 2008U2

"I would have been shocked if she [consultant] *had asked me* [if the baby's death was impacting on faith/belief] *… I would assume that her job is to look after the mother and the baby … she'd be in there hours if she started asking questions like that."* 2008P1

"I didn't need to go into depth with faith [with consultant] *to be perfectly honest with you. At the time I was more concentrating on the scans, my faith is always there. I didn't need* [doctor] *to ask me about my faith as such. It was more 'How are you doing overall?'"* 2008P2

"I would rather they asked you than not say anything about it and just ignore it, because it did happen and you do want them [doctors] *to acknowledge it."* 2010U2

Three parents said that they felt that their obstetrician and bereavement and loss midwives were very sensitive to their deeper needs and provided deep empathic care.

"Every time we went in [for appointments] *it was a case of we sat down and we talked for about five minutes or so* [about how I am in myself which this participant described as spiritual] *before we went into the medical stuff. Not pregnancy related stuff, not up in your head. They were phenomenal … so caring all the way through."* 2013P2

5.5.7 Relationships

All parents expressed that the stillbirth of their baby had impacted on various relationships; some positively but most negatively. The superordinate theme of relationships was a dominant one throughout the analysis as parents shared how their baby in his/her life and death had changed so many aspects of their lives. The data revealed three different patterns of relationships: with partners, with their baby, and finally with staff. I will explore each of these in turn.

5.5.7.1 Relationship with partner

All but three participants reported that the death of their baby had impacted negatively on their relationships. This was a difficult theme for parents to express and it was the source of emotion and sadness as parents spoke of how their relationships had changed since the death of their baby. Of note, was the reality of different styles of grieving and how this created loneliness between partners. Most parents said that they found it hard to communicate with their partner about their feelings of grief and how this impacted on their relationship and ability to support each other. Of couples interviewed together only one couple said that they communicate easily with each other.

> *"In the beginning, after he was buried we did* [talk to each other]. *We talked and cried but we don't talk about it much anymore because it's too painful to. I don't know, it's very hard and it's like I'd have a good day and Paul might be having a bad day or it could be the other way around. Then if I'm having a bad day I'd feel like I shouldn't make Paul feel that bad day, do you know? Do you know, it's kind of, it's very hard to, I find, when you're in pain yourself, it's very hard to, I find it hard to comfort Paul because em I can just feel the pain off him as well. It's like a double pain then or something."* 2013P2

This couple were interviewed together and the mother's partner then said

> *"It just breaks your heart because like eh everything we have done together has been ruined, tainted, this is what we are left with* (both tearful and upset)." 2013P2F

In contrast, one mother was very expressive about how her relationship with her partner was strengthened following their baby's diagnosis of a life-limiting condition.

> *"Like me and my husband, we were never so united, than ever, you know what I mean, from then we were never so united. We spent a lot of time together, we talked about everything."* 2010P1

5.5.7.2 Relationship with baby

5.5.7.2.1 Relationship during pregnancy

All parents said that they felt a strong relationship with their baby during pregnancy. All spoke about how everything seemed to be 'normal' until they received their diagnosis of a life-limiting condition or sudden awareness that something might be wrong. Parents had strong levels of anticipation and excitement in pregnancy before they realised something was wrong.

> *"I couldn't wait because we had a girl at home as well. I suppose it was more special as well because it was a boy … from the minute we found out* [pregnancy] *he was James."* 2010U2

> *"Definitely the minute you find out you were pregnant you're planning, you're planning your future. You are wondering God, is it a girl or a boy? You're planning and hoping."* 2010P1

"It was literally like he waved at me, literally across the screen and I like to think myself that that was kind of him, I don't know, saying hello or saying goodbye. But I remember having a real fuzzy feeling, a nice feeling when I saw this, because I really felt I knew him from that scan." 2008U1

"I really didn't see him very much as independent, so it was kind of; he was part of me like my foot is a part of me. He just was, and he was very much there. He did make his presence felt but he was just a complete part of me." 2013U2

"We were over the moon and we didn't tell anyone for the twelve weeks and it was the most wonderful secret." 2008U2

"I suppose I just learned to love him and be his mummy in a different way. I still feel that we have the chance to be his parents and he's still ours … we include him in everything." 2008U1

"We were very close. She was part of our lives already" *2008U2*

5.5.7.2.2 Relationship following a diagnosis of a life-limiting condition

The diagnosis of a life-limiting condition allowed parents time to prepare for the impending death of their baby. Half of the study group had received a diagnosis that their baby was unlikely to survive beyond birth. In each case their baby was

stillborn. Parents appreciated the time they had to create memories with their baby before their baby's death.

> *"I was just going to be grateful for what I could get and for every kick I was 'I'll remember now where I was' and she did this and I'll remember where I was when I first felt this. ... So that's when we started feeling much better you know, we're enjoying it, like she's our baby, no matter what, we'll just have to meet her. ... Getting the diagnosis early I think was a blessing because I was able to enjoy everything."* 2013P3

The initial diagnosis for all parents was a shock and for one mother it took time to adjust before being able to bond with her baby

> *"It did take me probably about another two weeks to kind of accept that no this is a baby, this is her, her little life is inside of me."* 2010P1

Fathers expressed that they only started to bond with their baby following his/her birth. This was expressed by some fathers as a source of personal tension as they were envious of the relationship their partner had with their baby.

> *"I think* [partner] *had a lot closer connection to him than I had, because I suppose I see my time with him as, when he was born to when he was buried. ... I remember thinking he's my son but he's not* (very upset). *"* 2010P2F

Fathers expressed a protective sense towards their baby and how this was particularly so after their baby was born. Two fathers following unanticipated stillbirths said:

> *"I didn't sleep at all for the first twenty four hours. I don't think I slept for two days solid because I'd stay up at night … you kind of hate leaving him alone."* 2013U1F

> *"It* [time] *went so fast and so slow. … we wouldn't have changed any of that."* 2008U1F

5.5.7.2.3 Ongoing relationship with their baby after death

Most parents expressed that they had a strong ongoing relationship with their baby. This was expressed by a sense of 'closeness' and proximity to the spirit of their baby.

> *"There'd be windmills and that kind of thing on the grave and you'd feel that's his energy."* 2010P2

> *"I just go and talk to him and tell him what's happening and tell him what's happening with his sisters. Bríd is old enough now so she talks to him, so she knows that's her little brother … if we're driving past the graveyard we say goodnight or good morning … just to know he's there."* 2010U2

For most parents their baby's grave was an important place where they felt particularly close to their baby. Parents spoke of going to visit the grave often.

> *"When we were at the grave it* [a voice] *was coming up and I heard something and it wasn't my husband. I knew it wasn't my husband because it was different. 'I am here' and where did it come from? It didn't come from someone physically talking. I heard it and it confused me as well. 'I am here' ... I don't know. I mean I was at the grave. I relate to Samuel when I'm here. ... I was asking myself 'why am I here?' Things weren't making sense but I heard 'I am here'."* 2010U1

One couple, with no living children visits their baby's grave every night in addition to the baby's mother calling in several times per day. This couple were bereaved within the year of the study.

> *"We go back every night* [to grave] *to say good night to him before we go to bed. And the next day you'd often, you'd talk to him; have conversations with him* (very tearful)*."* 2013U1

Parents expressed individuality at their baby's grave by referring to how they planted flowers, placed mementos and artefacts such as decorations and windmills to remember their baby. Two parents said that they did not 'feel' anything at their baby's grave and prefer instead to remember them at home.

"It became for me about letting him, letting him go onto his own journey." 2013U2

One mother spoke of how she was able to maintain an ongoing connection with her baby through a medium.

"She was able to connect with the baby's spirit and I think that's what kept me going. I used to feel much better after going to her. She used to be able to make me feel like I was connecting with him. I could just feel him more and more around me and more with me. … I always feel he is with me. I always feel he is just here beside me, just with me. … I do feel that there is something, that there is someone with me, someone who is helping me through this because I don't think I'd be as strong as I am if I didn't have someone on the other side helping me because I have never gone through anything so horrific … so I just feel there is someone there giving me the strength." 2013P2F

5.5.7.2.4 Fathers' ongoing relationship with their baby

Four fathers expressed that they had a more private ongoing relationship with their baby. One father shared how he felt very close to his son when he visited his grave. This father visited his son's grave every night. He had never told his wife about this and they became tearful during the interview as they spoke about it. After three years this was the first time they had spoken openly in this way.

"[I feel close to him in the graveyard] *I just prefer it if there was no one else in the graveyard. I would definitely only feel it when I'm there on my own with him."* 2010P2F

Another father visited his baby's grave regularly and felt a sense that his baby was looking after him. This father passed by the graveyard every day and said:

"I'd be passing often and do you know, at the end of the day why wouldn't you think of him? You know, you kinda hope that he is watching down on us really, like that's all we can hope … (tearful)*."* 2013U1F

One father shared that he experiences a strong sense of ongoing connection and relationship with his baby son in the context of his family and family events.

"… he's spoken about in this house every day. At some stage he is always mentioned in everything, you know. Even the smaller ones who never met him, you would swear that he is upstairs or something because he's spoken about, which is a good thing you know. There's nothing, there's no hush or anything. You know what I mean? It's spoken about. Like they have all their pictures of him up in their rooms." 2008U1F

5.5.7.3 Relationship with staff

All parents spoke of the relationships they had with the staff who cared for them during their pregnancy and following the birth of their baby. The data revealed that how staff interacted with parents left a lasting impression that was equally vivid

across the three year groups. The experiences that parents shared were examples of what is considered both good and bad practice.

> *"The midwife that delivered him, I mean there was tears streaming down her face. It was, it was so, so emotional for all of us. It really was special, it was, it was lovely."* 2008U1

> *"It was lovely, it was really beautiful and the way they* [staff] *just took her and gave her to me without having to say anything like. It was just, it wasn't a case of 'I'm sorry she didn't' or anything, there was nothing to apologise for. It was just the way it was and what we expected. It was lovely, it was a beautiful moment."* 2013P3

> *"I could feel the kindness off her* [consultant]*. I knew she really cared."* 2013P2

> *"We received a monumental amount of kindness and compassion … from everyone in there* [hospital] *there is some sense of a kind of community around the hospital. One striking memory is one of the days we went back up to see Paul and we were looking for the prayer room and we spoke to a lady in security looking for directions. She was a very nice woman and she just kind of looked and she said 'is it for yourselves?' and I said 'yeah' and she said 'I'm so sorry' and she's saying 'how long?' and 'how are you?' and she put her hand out, she held my hand and she said 'do you know something? Life's a BITCH sometimes' and I just thought, you know what, you're absolutely right and I thanked her for saying that."* 2013U2

Parents who had negative experiences recalled them with anger towards the staff involved.

> *"During the first scan she was measuring this and measuring that and she told me she was a trainee, and in my own head I was going 'go out and get someone who knows what they are doing because you obviously haven't a clue.' And she said 'I can't get a date, maybe I'm doing something wrong' and she said to go away and come back in two weeks"* 2010P2F

> *"I don't think that consultant really is a people's person."* 2008P3

> *"I met him* [consultant] *for the results of the post mortem and he wasn't very nice ... I questioned what was the cause of Samuel's death? I suffered a lot of stress after it and I questioned whether it could have been my reaction, is it a factor? And his answer was 'no' dismissive like. That I was asking a question, like why should I interrogate him? It was in that way that he knows more than me.... I was all over the place and that should have been accepted, that I'm the one suffering. I came away thinking 'What have I done?' Why should I be thinking that way, this was a hospital and he was my consultant?"* 2010U1

5.5.7.3.1 Experiences of care

A common subordinate theme that was present in relationships with staff was parents' experiences of care. All parents recalled their experiences of care in close

detail. Parents who had been diagnosed with an unexpected stillbirth recalled the period of waiting between diagnosis and birth as being particularly difficult and for one mother it was a source of trauma and distress. This mother was in the operating theatre being prepared for an emergency caesarean section following fetal bradycardia when staff discovered on the operating table that her baby had died. I noted in my reflective journal that this mother became very distressed as she retold this part of her story.

> *"I think I was just numb. I think when I came out of the surgery and they put me into a room at the side and I think I was just numb. I could not believe what was going on. … they basically said 'you know there's no heartbeat and no we won't be doing any operation'. I could not believe what was happening and to go for that couple of days, to go from the Thursday to the Tuesday with nothing happening. Knowing that he was dead inside me and just be carrying him around, that was just the worst. I just wanted him out. I didn't understand why they didn't do the section there and then when I was in the theatre and to get him out then. I just thought this was the cruellest thing ever to make a woman carry a dead baby like that. We were told to go home and come back in when labour started. … so eventually* [five days later] *I got blood poisoning, I had an infection so they had to run me down that night for the* [emergency] *section and I was put out. It was horrendous."* 2010U2

In contrast, two mothers spoke of the pressure they experienced from family members who were angry that a caesarean section was not being offered. Both of these mothers expressed the importance of natural vaginal birth for their babies.

"You know some people's reactions were 'my God, why can't they section you?' but when I look back on all of them, on all my five children I did everything the exact same. I had my labours. I still gave birth to him, exactly the same as I did everyone else and, you know, things like that I think mean a lot I think. It's not as personal if they just put you to sleep and just took the baby out and said 'that's it, sure it's finished'. Because I had to physically go through it all … as hard as it was even when I gave birth I still, I felt joy as well. It was really strange. I had such a mix of emotions … he was beautiful. He was eight pounds, and it was just like he was sleeping, I mean he was all there … I still felt Oh he's beautiful." 2008U1

5.5.7.3.2 Environment of care

The experiences of parents from 2008 included being in the company of other pregnant mothers when they received the diagnosis that their baby had died and also experiences where staff appeared uncomfortable with bereaved mothers bringing their baby home in their arms. Of interest in these findings is that parents shared this information without being asked directly. These areas of concern expressed by parents from 2008 were not present for parents bereaved in 2013.

"I remember the scan where I found out there was no heartbeat. I happened to be in the rooms where everyone was. There was just a curtain there and I think if there was a chance that there was going to be no heartbeat then I

should have been in a private room. That is the one thing that stuck out in my mind … " 2008P1

"I was put into a ward where there was three other ladies who had had their babies so they were up there with their babies and I was just like this. I was lying there in bed and just spent the whole night crying and I suppose it was just the upset around knowing eventually what would happen." 2010P2

In data from 2013 comments about being in the presence of other pregnant mothers or newborn babies did not arise with any participant.

"We really appreciated the fact that he [partner] *was able to stay the night in hospital and they got him a mattress and a blanket and a pillow, like he had his own little bed next to our bed in the room with us and he loved that. So he stayed the entire weekend and Aoife* [baby] *was here with us in the room too. I wouldn't be in the place that I am and wouldn't be as happy and as positive as I am if it wasn't for the support of the hospital … the care from the moment of diagnosis to even right now, you being here with me, it's just, it's absolutely amazing. And never once do you feel like people are just doing their job … everyone really cares and wants people to be as well cared for as they can."* 2013P1

Parents from the years 2010 and 2013 appreciated the opportunity to be cared for in a designated area of the hospital away from other pregnant mothers and live

babies. Parents also valued when there was continuity of care from staff. When this happened parents expressed the importance of building trust with staff.

> *"…they would have the same midwives look after you. It was the same people so you didn't have to explain your situation and that was a major factor as well that was brilliant."* 2010P1

Parents expressed that they were hurt when staff were insensitive to their needs or appeared not to be aware that they had experienced a stillbirth. Two of these experiences took place antenatally and one took pace during an appointment during a subsequent pregnancy. In one of the situations the conversation took place during labour.

> *"I suppose the only other thing that stands out in my mind is that. Do you remember the time before I went into labour, a trainee doctor came in and said 'Do you mind if I ask you questions?' And I said no, you know how you'd be thinking that anything that would help somebody else. She started asking all questions like, 'was this birth planned or unplanned?' and different things like that. Again I was kind of sorry that I didn't, I felt I guess that they weren't very appropriate questions."* 2010P2

5.5.7.3.3 Communication

Parents recalled in detail their experiences of when, where, and from whom they received the diagnosis that their baby had died. Parents appreciated when staff

took time to attend to their needs following diagnosis by being sensitive and spending time to discuss the diagnosis. An important aspect that was related to the subordinate theme of confusion (5.5.2.3) was the importance of clear and unambiguous language. One mother recalled her appreciation of this as:

> *"*[The consultant] *was very, very sensitive to me being on my own. She was very clear and precise with her words, as in I was able to understand her, whereas the other consultant used to muffle, so I understood everything clearly and I felt no stone was left unturned."* 2008P1

> *"I just felt Dr Y was so nice and that she actually cared. She saw us straight away and she did the scan and she showed us the scan and his* [baby's] *heart had stopped."* 2013P2

In contrast another mother felt frustrated when a doctor in the hospital was not communicating with her when she presented for a scan with reduced fetal movements following a referral from her GP who could not find her baby's heartbeat.

> *"He was really going all the way around trying to avoid I think, and it was clear, he didn't even have to tell me. We could see baby Michael was literally like that, he was literally floating … but he was just saying 'I need to get a second opinion, I need to go speak to my whoever' from his team…"* 2008U1

Parents expressed suspicion when they felt staff were using diversionary tactics to avoid communicating bad news or were deliberately withholding information.

> *"They seemed to know more than we're really being told… I felt like saying 'ye've known this for a couple of weeks and haven't told us. Why would you be hiding this [diagnosis] is it because ye didn't want to tell us?' I just didn't know, it was, a lot of it was 'can't you just do your job?'"* 2010P2F

Another area of communication that arose for some parents was how the wider hospital services communicated with them. This ranged from not communicating about cancelled appointments to experiences of dedicated care when bereaved parents were seen immediately and did not have to queue with other pregnant mothers.

> *"I remember we spent three hours driving up in the snow because we were told we had to be there. We were told the counsellor was from [place] near the city and they didn't come in. I was going 'we were told we HAD to be there', the next appointment would be weeks and weeks away. We were sat there for an hour before they told us the counsellor hadn't turned up. … and there was another situation like that as well, where I think the counsellor didn't turn up."* 2010P2F

5.6 Summary

In this chapter I have outlined the spiritual impact of stillbirth on bereaved parents from both those who had received a diagnosis of a life-limiting condition for their baby and were anticipating their baby's stillbirth and from those who had a sudden and unanticipated stillbirth. The results from this chapter demonstrate that bereaved parents experienced considerable spiritual suffering and that this had an enduring impact on their lives. The superordinate themes from the data were searching for meaning, maintaining hope, importance of personhood of their baby, protective care, questioning core beliefs and relationships. In addition to the qualitative findings the data analysis revealed important service information concerning the impact of communication and the place that the hospital environment plays in the overall experience of bereaved parents. Finally, most parents felt that while their religious needs were responded to, their deeper spiritual needs were not adequately met as part of their overall care. Most parents expressed that they did not expect their obstetrician to care for their spiritual needs as part of their care.

Chapter 6: Discussion

6 Discussion

6.1 Introduction

The impact of stillbirth as a distinctive experience of bereavement with considerable personal and psychological *sequelae* is well documented in the extensive literature review conducted as part of this study and included in chapter one. While there is widespread evidence that stillbirth has an immense impact on bereaved parents and their families, there are fewer published studies on the impact of stillbirth on healthcare professionals and society at large. Although there are some references to religious practice and faith in the published literature, there are no published studies that this author is aware of that examine the spiritual impact of stillbirth on bereaved parents, maternity healthcare chaplains or consultant obstetricians. Indeed, the most recent meta-synthesis of stillbirth literature carried out by the Joanna Briggs Institute for the Stillbirth Foundation Australia and published by Peters *et al* in 2015 made a relatively short reference to culturally specific care with tangential reference to the consideration of spiritual beliefs.[273, 276] Following an extensive literature review I set out at first to explore the spiritual impact of stillbirth for maternity healthcare chaplains, consultant obstetricians and bereaved parents.

The focus of the first phase of the study was initially on Irish maternity healthcare chaplains as the professional providers of spiritual care, and on consultant obstetricians as the lead providers of stillbirth care. During the data collection with healthcare chaplains it became obvious from the data that stillbirth had a significant personal and professional impact on staff as they cared for bereaved parents. Building on existing literature by Gold *et al* that identified the professional impact of

stillbirth on obstetricians from a quantitative perspective, the study was then expanded to explore the professional impact of stillbirth on consultant obstetricians from a qualitative perspective.[36]

In addition to researching the impact of stillbirth on healthcare chaplains and consultant obstetricians, I also set out to explore how these professionals met the spiritual needs of parents bereaved following stillbirth. This involved exploring if and how maternity healthcare chaplains and consultant obstetricians recognised and responded to spiritual need in bereaved parents. Recent data from the USA has placed much emphasis on the role of the clinician in recognising and attending to the spiritual needs of patients in his/her care.[13-17, 186] I sought to explore if obstetricians were expected to address spiritual need following stillbirth in an Irish context by examining this with both consultant obstetricians and bereaved parents.

The second phase of the study set out to explore the spiritual impact of stillbirth on bereaved parents and to ascertain if and how their spiritual needs were met as part of their overall care.

The results of the study found that stillbirth had a considerable personal and professional impact on both maternity healthcare chaplains and consultant obstetricians and that in addition stillbirth posed challenges to their faith and belief structures. A review of the provision of spiritual care in the Irish maternity services revealed that there was a diversity of approach nationally with inconsistencies in the education and certification of chaplains working in perinatal bereavement care. The data from bereaved parents highlighted that stillbirth had considerable spiritual

impact and distress; most parents expressed that their faith was challenged or weaker as a result. The data revealed that only a minority of parents felt that their spiritual needs were adequately met while in hospital. I will discuss these findings in detail in the following sections.

6.2 Spiritual impact of stillbirth

The spiritual impact of stillbirth, although not studied widely, has been recognised in the published literature from broader -mostly quantitative- pregnancy loss studies as being closely linked with religious practice and belief.[10, 109, 182, 277] Related studies on grief adjustment following loss in the wider sphere have focussed on the effect of religious practice and belief. However, there are no studies that explore the broader spiritual impact of stillbirth in a qualitative way. The results of this study affirmed the quantitative findings from previous studies where religious practice has been included, that stillbirth had a significant and lasting impact on bereaved parents.[10, 109, 182, 277, 278] The findings presented in chapter five support and demonstrate the presence of spiritual distress and ongoing spiritual struggle for bereaved parents. Discussion of the results from healthcare chaplains and consultant obstetricians will be followed by bereaved parents.

6.2.1 Spiritual impact of stillbirth on chaplains and obstetricians

For both healthcare chaplains and consultant obstetricians this study revealed that stillbirth impacted on the faith and beliefs of participants. As it is not possible to separate out our spiritual selves it is unsurprising that this spiritual impact extended to the professional and personal lives of participants as they cared for stillborn babies

and their bereaved parents. The presence of spiritual distress created incongruence and inner conflict for both chaplains and obstetricians as they engaged with suffering and grief. This is new information to contribute to the existing knowledge concerning the overall impact of stillbirth on healthcare providers. Each group will be discussed separately.

6.2.1.1 Spiritual impact on healthcare chaplains

Our spiritual beliefs are integral to our understanding of who we are and how we understand ourselves as human beings.[279] As chaplains provided spiritual care and support following stillbirth, the fact that some chaplains experienced immense challenges to their faith and belief created an incongruous environment when as a professional, a chaplain doubted his/her own core beliefs yet having to continue to provide ministry and care.[280] Chaplains described in detail the inner conflict of struggling with belief and yet accompanying grieving parents as they too struggled with their grief. The reality of providing spiritual care while experiencing inner doubts placed a chaplain in a vulnerable position of inner conflict and turmoil. This was encapsulated by one chaplain when she said *"Seeing devastation like that … my faith has been challenged. I stopped attending Mass … yet I had to provide pastoral care … but not believing it was real."* Chaplain #12 -page 127 The depth of spiritual distress experienced and shared by some chaplains is a cause for concern and has the potential to lead to spiritual and professional burnout.[281, 282] A recommendation from this study is that maternity healthcare chaplains should avail of personal spiritual supervision and support to enable them to attend to the realities of what is a spiritually challenging and demanding ministry.

The data from chaplains concerning theodicy and needless suffering was very similar to how bereaved parents and some obstetricians expressed these areas. Theodicy was a common struggle expressed by chaplains, obstetricians and bereaved parents as they wrestled with why a benevolent and caring God would allow a baby to die. This was particularly so with a sudden unanticipated stillbirth following an otherwise healthy pregnancy. The depth of emotion and expression of grief by chaplains was closely aligned with the expressions of grief by bereaved parents. Certified chaplains demonstrated an ability to express the impact of the grief they experienced in bereaved parents with greater depth than chaplains who were not certified or who had a primarily ceremonial role. As bereaved parents are a vulnerable group this finding suggested that uncertified chaplains did not have the necessary skills to meet their spiritual needs.

6.2.1.2 Spiritual impact on consultant obstetricians

There has been much interest in the area of spirituality and health in recent years with particular focus on health outcomes for patients. The place of religious and spiritual beliefs of clinicians and how these beliefs influence practice or are shaped by professional experience has been less studied.[40, 283, 284] Caring for bereaved parents following stillbirth brings obstetricians into close contact with acute grief and trauma. Data from consultant obstetricians in this study showed that witnessing the experiences of suffering in others raised difficult personal questions about suffering and theodicy. This was a challenge to personal faith and belief and in itself became a vicarious trauma.[39] In addition, where complex ethical issues arise, as they often do with antenatal diagnoses of life-limiting conditions, these can bring a sense of personal conflict when they are incongruous with the personal beliefs of

healthcare staff. Previous studies have identified that the decisions of clinicians in some areas of medicine were influenced by personal religious beliefs by those who identified as being 'religious' and that religious belief cannot be separated from professional practice or day-to-day life.[284-287]

Our spiritual lives are integral to who we are and how we live our lives. How then do consultant obstetricians understand, experience and integrate their belief or meaning structure while at work; especially when dealing with stillbirth? A study by Al Yousefi *at al* argued that for some people of faith, it is impossible to separate their personal beliefs from any area of their life including their work.[288] Consultants in this study expressed that their hardest personal struggle was with unanticipated stillbirth. This personal struggle was part of the superordinate theme of 'Conflict of personal faith' with associated subordinate themes of guilt and fear. For four consultants (50%) this was articulated by the phrase 'what have I missed?' The sense of fear and guilt following an unanticipated stillbirth impacted on the personal faith and belief structure of some consultants causing them to question God and divine purpose. These questions were similar to the questions posed by chaplains as they wrestled with stillbirth and 'needless suffering'. For both consultants and chaplains this questioning following stillbirth revealed the tension of believing in God in the midst of such suffering and inexplicable death.

All consultants recognised that stillbirth had a spiritual dimension and impact for bereaved parents but they felt unable to address this or to respond to it. Consultants avoided spiritual engagement at work both in their own lives and also in the lives of bereaved parents. The results from this study showed that consultant

obstetricians did not integrate their personal faith and their clinical practice when caring for bereaved parents following stillbirth. Most consultants said that they did not see that their faith or beliefs influenced their clinical practice and five (63%) said that they did not engage with their personal faith at work. Consultants saw their personal faith as private.

Spiritual beliefs are integral to self-identity so the 'compartmentalising' of personal beliefs and faith as something that can be left outside the work environment raises interesting questions about how self-aware obstetricians in this study were about their religious or spiritual views. During the interview process when asked about their faith, a number of participants appeared uncomfortable and this was evident through their body language and in expressions such as *"I'm not that comfortable and I don't know if it's my place either."* Consultant 5 –page 170 This discomfort might suggest that there is a low level of self-awareness in the area of spirituality which could mean that consultants avoided painful emotions with bereaved parents thereby reducing their capacity to empathise.[267, 289] It could also mean that if obstetricians are not aware of the place of their personal religious or spiritual views that these views were more influential than they realised. Personal faith and religious views have been shown to influence clinical decisions at end of life and have in some environments contributed to tension when personal faith and beliefs are in conflict.[284, 287, 290]

A low level of self-awareness of personal faith and spirituality as part of daily work life could also mean that consultant obstetricians were unable to draw on their faith and belief systems for support when they faced challenge, distress and grief.[272]

The fact that no consultant referred to any spiritual practices that they used for support during crisis strengthens this premise. Most consultants were emotional during interview, and in some cases the interviews were paused for a while suggesting that the enduring impact of stillbirth was significant for obstetricians. This is indicative of unprocessed loss and spiritual pain. If consultants are unable to draw on the supportive dimensions of their spirituality or beliefs there is potential for increased personal distress as workplace grief becomes disenfranchised.[229] It could also lead to an increased level of professional burnout and depersonalisation.[281, 282, 291] Consultants who expressed that they self-protect from emotional situations with bereaved parents displayed a level of depersonalisation which in turn can impact negatively on bereaved parents.

Healthcare chaplains are well placed to provide pastoral support to consultant colleagues as part of their ministry with the whole hospital community.[292, 293] The provision of professional and pastoral support for obstetricians is a recommendation from this study to foster a supportive culture where obstetricians (and by implication the whole healthcare team) are enabled to draw on the supportive aspects of their faith or belief structures. This support needs to be complemented by a commitment from health service managers to promote professional wellbeing. A culture of wellbeing and support amongst staff will in turn reduce the risk of depersonalisation and burnout and will impact positively on the care provided to bereaved parents.[291]

6.2.2 Spiritual impact of stillbirth on bereaved parents

This study revealed the considerable extent of spiritual existential wrestling and angst that parents experienced following stillbirth. All parents expressed that

their faith and beliefs were challenged following the death of their baby. Only one mother felt that her faith was stronger following the experience of stillbirth, one father and three mothers felt that their faith, although challenged, was unchanged and the remaining eight mothers and four fathers said that their faith was either challenged or weaker following the death of their baby.

Bereaved parents voiced strong feelings of emotion and spiritual distress towards God as they told their stories. Bereaved parents expressed the tension between believing in a compassionate God and yet at the same time also struggling with the reality of theodicy in what Jürgen Moltmann describes as the 'doubting and the believing side of faith'.[294]

The open expression of anger, fear, injustice and theodicy towards God/ higher power is not easy for people of faith and yet when reflected on theologically these emotions are very close to the strong expression of lament and existential pain recorded in many sacred writings. As most parents in this study were Christian, the most significant written sacred source is the Judaeo-Christian scriptures.[295] Many of the Hebrew psalms express the depth of human response and emotion following suffering, pain and death. These scriptural texts give voice to human emotions of pain, angst, anger, fear, loneliness and abandonment. Most of the parents in this study gave expression to the depth of pain expressed in Psalm 130 'Out of the depths I cry to you, O Lord. Lord, hear my voice! Let your ears be attentive to the voice of my supplications!'[295] As demonstrated in the direct quotations in chapter five, each of the participating parents wrestled theologically or philosophically with the

ultimate questions of life that are expressed in the quest to understand feelings of injustice, theodicy, anger, confusion: 'why?'

The spiritual distress expressed by parents was significant and equally vivid from parents bereaved in the current year, three years and five years previously. Considering the depth of spiritual distress evident from bereaved parents it is of concern that the parents of only three babies (25%) felt that their spiritual needs were met in hospital. When this information is compared with the data from maternity healthcare chaplains that showed 40% of chaplains are not certified chaplains it raises a concern about how spiritual need is met following stillbirth in Ireland. The data from bereaved parents reveals considerable spiritual distress that was not addressed which impacted negatively on overall recovery and wellbeing. A recommendation from this study is that all maternity units have access to appropriately trained chaplains to meet the spiritual needs of bereaved parents.

6.3 Professional impact of stillbirth

The professional impact of stillbirth for both healthcare chaplains and consultant obstetricians reported in this study was considerable. The impact of stillbirth was in keeping with previously published studies (including a recent meta-analysis in the Lancet Stillbirth Series 2016) amongst midwives and obstetricians that identified the presence of personal stress symptomatology and professional fear.[36, 37, 121] The results of this study confirmed qualitatively the results of previous quantitative findings by Gold *et al* concerning the personal and professional impact of stillbirth on consultant obstetricians. [36] The professional impact of stillbirth included professional isolation, uncertainty, fear, guilt, medico-legal concerns and

also for some, positive impacts from stillbirth. The discussion will focus on maternity chaplains first, followed by consultant obstetricians.

6.3.1 Professional isolation

6.3.1.1 Professional isolation for chaplains

Seven chaplains (35%) shared that they experienced professional isolation in their ministry with bereaved parents. All those who experienced a sense of isolation were chaplains who were not formally trained and certified in healthcare chaplaincy. These chaplains expressed a sense of disconnectedness from the wider multidisciplinary team. This was expressed most strikingly by one chaplain:

> *'I don't think that most of them* [multidisciplinary team] *are aware that I exist* [I feel] *utterly, utterly disconnected.'* Chaplain #18 –page 117

This isolation had potentially serious implications for the wellbeing of the chaplains concerned and in turn could impact negatively on their ability to provide holistic integrated care with bereaved parents at what is a very vulnerable time following the death of their baby. In addition, being part of a wider bereavement team provides support for a chaplain in what is demanding ministry.

6.3.1.2 Professional uncertainty and tension for chaplains

Chaplains who reported fears around the dual demands of both hospital and faith community struggled when these demands were in tension. This arose mainly

when the reality of pastoral practice was in conflict with what the chaplains considered to be official church teaching. The impact of this tension was heightened for chaplains who feared that if they didn't follow church teaching in matters of sacramental theology or pastoral practice that it would impact on their livelihood with the threatened loss of employment. For these chaplains the guarantee of anonymity was important as they expressed their views openly as part of the study. It was noteworthy that some chaplains said that they operated in a contradictory environment where their practice was at odds with what was expected of them and yet they felt powerless to challenge [church] authority. As can be seen in the discussion on baptism in section 6.4.5 the chaplains who struggled in this area appeared to be operating from a limited understanding and application of church teaching as documented in canon law and interpreted in canon law legal opinion to me in private correspondence as part of this analysis.[296] Further discussion about canon law and church teaching can be found in section 6.4.5.

A recommendation from this study is that all chaplains who are providing perinatal bereavement care should be acquainted with a current interpretation of church teaching concerning stillbirth and salvation and receive appropriate support and supervision in their duty.

6.3.1.3 Professional isolation for consultant obstetricians

Most consultants expressed that they experienced loneliness and professional isolation as they dealt with the challenging area of stillbirth. The data demonstrated that the impact of this was considerable and it is of concern that consultants were not

aware of any support available to them to address this distress. Consultants conveyed a level of personal and professional isolation which for some demonstrated a sense that to seek help was perhaps a weakness.

Some consultants expressed a competitive dimension that increased their sense of loneliness. Competitiveness serves to increase isolation and can potentially foster a competitive environment and will reduce the capacity to seek help from peers. One consultant demonstrated this when they requested clarification that the research interview would remain confidential from his/her peers. Two consultants expressed that participating in this study was the first time they had actually spoken about the personal impact of stillbirth with anyone. In one case the consultant contacted me following the study to express gratitude for the opportunity to speak about this area.

Building on the recommendation for pastoral support at 6.2.1.2 above, a further recommendation from this study is that professional support should be made available to all consultants in their work. In addition to supporting consultants it would also increase their ability to provide compassionate care rather than the emotional distancing that a number demonstrated as part of a protective mechanism in what was an emotionally challenging area of practice.

6.3.2 Medico-legal concerns for obstetricians

The results from this study confirmed that in an Irish context consultant obstetricians were impacted negatively by the reality of working in a litigious environment. The reality of this litigious nature with a disproportionate number of

obstetric-related claims is backed up by the reported data from the Clinical Indemnity Scheme of the State Claims Agency.[274] This created a sense of guilt concerning bad obstetric outcomes and fear about professional litigation and public exposure for obstetricians following the stillbirth of a baby in their care. It could be argued that the fear of litigation might reduce the capacity of an obstetrician to care empathically for bereaved parents, fearing they might be the focus of blame. This was demonstrated in the data when consultants shared that their first response when hearing that there was a stillbirth was 'what have I missed?' and that this carried with it a sense of blame. The RCPI in a position paper on physician wellbeing (2014) identified 'doctors engaged in legal proceedings' as being under extreme stress and needing additional support.[297]

Consultants who specialised in gynaecology rather than in obstetrics expressed a greater sense of fear about missing something in the care of a baby or his/her mother when a stillbirth occurred. This leads one to question the nature of the dual professional scope of consultants as obstetricians and gynaecologists. For those who were sub-specialists in gynaecology it could be argued that they were less skilled at dealing with pregnancy-related complications and yet they were required to work as obstetricians. In a tertiary centre though this would be balanced by the availability of maternal medicine sub-specialists and this was referred to by those who were primarily gynaecologists who valued the facility to refer to expert colleagues.

The fear of medico-legal challenge and exposure was a significant stressor that merits attention. It potentially impacts on the ability of the discipline to recruit

sufficient trainees. The fear expressed by one consultant that "you are only one bad baby away from the front page of *The Irish Times*" was indicative of the impact of significant high profile media coverage and public scrutiny of adverse obstetric and perinatal outcomes in Ireland in recent years. The impact of this media scrutiny warrants further research. Formal government investigations into adverse perinatal outcomes in recent years have also received extensive media coverage, most notably following the publication of the reports "*Investigation into the safety, quality and standards of services provided by the Health Service Executive to patients, including pregnant women, at risk of clinical deterioration, including those provided in University Hospital Galway, and as reflected in the care and treatment provided to Savita Halappanavar"* and the "*HSE Midland Regional Hospital, Portlaoise Perinatal Deaths (2006-date)*".[298-300]

The results from this study highlighted the personal and professional impact of medico-legal concerns from the perspective of consultant obstetricians. These insights have not been explored in this way before and so this study contributes this dimension to what is a challenging debate.

6.3.3 Positive impact of stillbirth

In addition to the negative impact and burden of stillbirth the reported positive impacts of stillbirth by chaplains and consultants in this study were consistent with the published data from other studies with healthcare professionals.[170, 301-305] It is of note, however that in each of the published studies reporting positive impact following stillbirth, the participants were exclusively midwives, obstetric or neonatal nurses or nurse managers. No studies included

obstetricians or healthcare chaplains. This study therefore has contributed the experiences of maternity chaplains and consultant obstetricians to the published data in this area.[35, 39, 40, 306] Chaplains and consultants both emphasised that caring for bereaved parents had positive impacts personally and professionally. In some of the previously published studies reporting positive impacts following stillbirth, it was reported that professionals found that experience of stillbirth made the task of caring easier.[170, 302, 303, 305] In this study this was not the case. Consultants expressed that they did not find it easier with experience and that it continued to impact on them considerably.

Positive impacts in the data helped to create a sense of balance in the midst of painful grief and for participants this was a sustaining aspect of their bereavement care. Positive impacts were mostly reported when caring for parents who had been given a life-limiting diagnosis for their baby. A life-limiting diagnosis enabled both chaplains and obstetricians to have time to create positive memories for parents between diagnosis and death. This highlights the importance of ongoing supportive care in the time between diagnosis and death/birth not just for parents but also for healthcare staff caring for them. Previous studies have highlighted the value of this care for parents but this study also acknowledges the importance for staff.

6.4 Provision of spiritual care following stillbirth in Ireland

The key findings from the quantitative data from the study with maternity healthcare chaplains revealed that there was a widespread diversity in spiritual practice and chaplaincy training.[39] It is a well-established norm that spiritual needs should be attended to as part of overall holistic person-centred care. This is modelled

most obviously in palliative care and end-of-life care.[190, 195, 214, 307, 308] The quantitative data highlighted chaplaincy education and training, the provision of mementos, ongoing bereavement care, spiritual assessment, theological reflection and baptism. These areas will be discussed in turn.

6.4.1 Chaplaincy education and training

The lack of specialised chaplaincy training and education in perinatal bereavement is an area that should be addressed as a matter of urgency so that chaplains working in this demanding area of ministry can consolidate their considerable pastoral experience with formal education to maximise their skills as professional spiritual carers.[39] It is recommended practice that all healthcare chaplains are formally trained and certified.[215, 216, 263] The certification of healthcare chaplains ensures that those who are appointed as chaplains in the Irish healthcare system have received appropriate formation, supervised education and learning as part of the CPE process of integrative reflective learning. At present in Ireland, 1,200 hours of supervised ministry is required before application for certification as a healthcare chaplain.[215, 216] Chaplaincy training is in addition to theological study and seminary formation for clergy and following an undergraduate degree in theology for lay chaplains. Specialised perinatal bereavement training is then availed of following certification. The fact that eight chaplains (40%) were not formally certified chaplains raises concerns about the professional approach and importance of spiritual care in this demanding and complex area of ministry. The data from this study highlighted that chaplains who were not certified took more of a ceremonial role in their ministry with bereaved parents. While the role of ceremony is not to be undervalued, it potentially means that the deep spiritual issues raised by parents in

the data were not appropriately attended to. This was confirmed by the data from bereaved parents in the study as the parents of only three babies (25%) felt that their spiritual needs were adequately met following the death of their baby. The data in chapter four from maternity healthcare chaplains revealed that there is a need for all chaplains working in the Irish maternity services to receive appropriate training in perinatal bereavement care. Specialist perinatal bereavement training should include bereavement theory, appropriate understanding of medical definitions and terminology used in perinatal bereavement, the role of the specialist perinatal bereavement team, liturgical provision following perinatal bereavement, anticipatory grief care, the provision of mementos. It is a concern that only one chaplain had received any specialist training in perinatal bereavement care.

6.4.2 Provision of mementos and ongoing bereavement care

Many studies in recent years clearly highlight the importance of both the creation of mementos and follow up care following stillbirth.[4, 27, 105, 111, 183, 309-312] The provision of religious and spiritual mementos are an important part of the overall tapestry of memory-making for bereaved parents and, with ritual, are important vehicles of grieving and hope.[10, 88, 89, 107, 158, 182, 313] Religious and spiritual mementos can include a certificate of blessing/naming, a candle, water used for blessing/baptism, rosary/prayer beads, and other personalised religious artefacts. The provision of support following stillbirth has been shown to positively affect overall recovery and positive mental health outcomes.[111, 314] Whether a chaplain was certified or not impacted on the provision of mementos and ongoing bereavement support: chaplains who were not certified did not see these areas as part of their role. Based on the results of other studies with bereaved parents the results of this study

recommend that the provision of mementos and ongoing bereavement support are provided by all chaplains in conjunction with bereavement teams.

The publication of the Irish clinical practice guideline *Investigation and Management of Late Fetal Intrauterine Death and Stillbirth* (2009) and the proposed draft *Standards for Bereavement Care following Pregnancy Loss and Perinatal Death* (2015) both recommend a standardised approach to the provision of bereavement care following stillbirth in Ireland.[78, 315] The diversity of practice among healthcare chaplains and the provision of spiritual support following stillbirth in Ireland identified in this study would also benefit from a standardised approach.[39]

6.4.3 Spiritual assessment

One of the aims of this study was to explore if and how consultant obstetricians recognise and respond to the spiritual dimensions of stillbirth as part of their overall care. Based on published literature from the USA which argues for the importance of physicians recognising spiritual need and incorporating this into care[14-16, 186] I tested this in an Irish context with obstetricians and their care of bereaved parents following stillbirth. It was clear from the data that obstetricians did not see this as part of their role and moreover bereaved parents in the main did not expect it. This is a new finding and is not in keeping with previous findings by Pulchalski *et al* and Balboni *et* al in studies from the USA.[14-16, 186, 191]

Both obstetricians and bereaved parents recognised that stillbirth had a spiritual dimension to it and that spiritual needs should be attended to but not by an obstetrician. Obstetricians indicated in the data that they would refer spiritual care to

a chaplain or to a bereavement and loss midwife specialist. (It is of note that a bereavement and loss midwife specialist would not ordinarily have any training in responding to spiritual distress.) A recommendation from this study is that a spiritual screening tool should be developed and piloted that can be used by healthcare staff to identify and refer parents who require referral to a chaplain for ongoing spiritual care. A proposed spiritual screening tool when developed should, of necessity, be easy to administer by an obstetrician and based on a small number of indicative questions. One example of a spiritual screening tool is the *FICA* tool designed by Christina Puchalski for use in palliative care.[15, 316, 317] The FICA spiritual screening tool involves short questions based on faith/belief, importance of beliefs in healthcare decisions, role of community and how the needs of a patient can be addressed appropriately as part of their care.[15] Examples of questions used in the FICA spiritual assessment tool are 'what is your faith?', 'Is it important in your life?', 'are you part of a spiritual/religious community?', 'How would you like your healthcare provider to address these issues in your healthcare?'.[316, 317] This tool would not be appropriate in its entirety for the context of stillbirth. A recommendation is that this tool could be adapted for an Irish and a perinatal bereavement context and piloted for use.

A further recommendation from this study is that all perinatal bereavement teams should include a healthcare chaplain with specialist perinatal bereavement training to assess and care for bereaved parents following stillbirth or where their baby has been diagnosed with a life-limiting condition.

6.4.4 Theological reflection

No chaplain in the study used the discipline of theological reflection in their ministry. In an area of ministry where chaplains themselves identified suffering, doubt and pain both for themselves and for bereaved parents, this is an area where structured theological reflection could contribute much to bridge the gap that many chaplains identified between faith and practice. The reality of personal doubt and suffering for chaplains raised important questions that theological reflection would do much to address. Reflection is a core component in CPE methodology and education and yet it was not something that chaplains transferred into their daily pastoral practice. The lack of intentional and rigorous theological reflection following stillbirth is a cause for concern. Not to address what are challenging and potentially destabilising personal doubts might lead to depersonalisation, burnout and spiritual distress.[281, 282, 291, 318]

There are many available tools for theological reflection. Green's 'theological spiral' is one suggested tool that the data in this study recommends as a supportive and engaging methodology for theological reflection.[258] Green's theological spiral offers a way of reflecting personally for the chaplain and also reflecting on the experiences of bereaved parents so that the suffering and doubt expressed by both chaplains and the bereaved parents are reflected upon together. This, I argue, would enable a more empathic reflection and yet, with awareness, would also reduce the potential for enmeshment with the emotions and distress of bereaved parents on the part of the chaplain. For chaplains who expressed symptoms of spiritual distress the discipline of theological reflection would foster an openness to face these difficult questions and through that process to find strength and support.

6.4.4.1 Theological reflection on suffering

'Suffering is the starting point for all pastoral and practical theology.'[259] There is an expectation that people of faith should be able to accept that God is all-powerful and will respond to requests for intervention and yet when this request is not being answered it calls into question the efficacy and reality of belief.

Rowan Williams, speaking after the trauma of the events commonly called '9/11' in New York in 2001, provocatively and yet in a profoundly honest way expressed that 'at times like this God is useless'.[319] This honest expression 'from the heart' of a theologian can at first be deeply unsettling yet when reflected upon is liberatingly true. Williams's utterance is not far from the words of participating chaplains in this study as they wrestled with the pain of stillbirth and theodicy.

"I'm just not sure I believe in anything anymore…" *Chaplain #5 –page 126*

"It challenges my faith … I go through my struggles." Chaplain #7 –*page 127*

Jürgen Moltmann in his influential book *The crucified God* writes of divine participation in suffering and abandonment as 'When God becomes man in Jesus of Nazareth, he not only enters into the finitude of man, but in his death on the cross also enters into the situation of man's godforsakenness. In Jesus he does not die the natural death of a finite being, but … the death of complete abandonment by God. The suffering in the passion of Jesus is abandonment, rejection by God, his Father.

God does not become a religion, so that man participates in him by corresponding religious thoughts and feelings. God does not become a law, so that man participates in him through obedience to a law. God does not become an ideal, so that man achieves community with him through constant striving. He humbles himself and takes upon himself the eternal death of the godless and the godforsaken, so that all the godless and the godforsaken can experience communion with him.'[320] Moltmann, like Williams opens up a new perspective of divine participation and presence at the point of apparent and experienced abandonment and loneliness following stillbirth.

To engage in the pain of suffering and theodicy in this theologically reflective way opens up new possibilities for meaningful engagement for a chaplain. It invites the chaplain to integrate his/her faith and practice in an empathic and supportive way. This 'engaging' with suffering is not a new exercise and can be traced through the historical writings of scripture and theology. The writings of the psalms for example 'unseals deep places, emotions otherwise buried … it provides an analogy for the unity or intelligibility of a human life lived in faith.'[321] The outcome of a chaplain engaging with the pain of stillbirth through theological reflection is, in the words of Williams, 'a pedagogy of compassion.'[321] This will bring new insights and learning for the chaplain and support what many chaplains practice as empathic care.

The practice of empathic care will respond to the existential spiritual needs of bereaved parents as chaplains enable parents to give voice to their deepest feelings and lament. Paradoxically in this place of spiritual darkness the words of bereaved parents (and chaplains) become the words of God: what Pamela Cooper-White

describes as 'God's solidarity with human suffering.'[259] Shaped by an Augustinian influence, Williams expresses it thus '…given the right to speak with this divine voice, reassured that what our human voices say out of darkness and suffering has been owned by him as his voice, so that it may in some way be opened to the life of God for healing.'[321] One chaplain captured this as they described how they practice empathic care:

> *"I suppose the biggest thing we can do is being present … It's just me. To just be there, to be present to whatever they're feeling and let them talk … let them cry … being available, giving them all that time and reassuring them that we're with them, that we're there for them ... giving them freedom to cry and not to be bottling it in or putting out a bright side and just to be themselves … it's a safe, safe place."* Chaplain #06 –*page 130*

6.4.5 Baptism

The question of whether or not it was possible to baptise a stillborn baby arose for a number of chaplains in the data. For some chaplains they saw this as an 'awkward' pastoral situation when parents requested baptism and the chaplain believed that it was not permissible or appropriate to accede to this request. As most participating chaplains were Catholic it is to be expected that those who had difficulty in this area referred to canon law as the authoritative source preventing baptism for a stillborn baby. As discussed in chapter one, the impact of a baby not being baptised has an historical and cultural dimension as those who were not baptised were not permitted to be buried within consecrated ground. In Christian

terms baptism has historically been seen as an integral part not just of entry into the faith community 'the Church' but also into society.[322] Although baptism is a religious event it also has cultural significance for many parents. It can be understood as a legitimation of the existence of a baby. In stillbirth this sense of legitimation can be challenged. Bereaved parents expressed in this study the importance that their stillborn baby would be treated the same way as their other (living) children which for some included the same liturgical rites such as baptism.

How baptism is understood is an important part of this discussion. For centuries baptism has been associated with infancy and the baptismal liturgies of many Christian denominations evolved towards baptism of infants as the norm.[322] This led to an almost universal expectation and practice of baptism being performed as soon after birth as possible. Baptism in this context was viewed as an integral part of salvation and with high infant mortality the possibility that an unbaptised baby might not achieve salvation was a potent fear for parents. It is from this context, coupled with the unhappy history of unbabtised babies not being buried in consecrated ground that the place of baptism continues to have strong meaning for many. The baptism of a stillborn baby is a challenging pastoral dilemma for chaplains and a source of much debate. The tension between meeting the expressed wishes of bereaved parents to have their stillborn baby baptised and expressing the authenticity of the sacrament of baptism as understood by chaplains was a struggle. The request for baptism for a stillborn baby was the focus of tension concerning role identity especially in terms of whether chaplains saw their role as primarily ceremonial or pastoral. Chaplains who felt unable to provide baptism for a stillborn baby could be described as having an approach close to that of pastoral theologian

Elaine Ramshaw who writes that 'the normative aim of the liturgy is not human comfort but the glory of God.'[(323)] Yet, as Ramshaw acknowledges 'the need for ritual expression and reinforcement of the symbolic world view is intensified in situations which threaten meaning or coherence.'[(323)] Ramshaw makes the case for liturgical honesty by responding to the request for baptism following stillbirth with alternative rituals such as a naming and/or blessing ceremony.[(323)]

As most chaplains who struggled with the issue of baptism inferred that this struggle arose from the requirements of Catholic canon law, it is of note that there is no explicit reference to the prohibition of baptism for a stillborn baby in the *Code of Canon Law.*[(324)] Rather it is in a wider inference that sacraments cannot be administered to inanimate objects.[(296)] In personal correspondence with a canon lawyer about this struggle he wrote that 'although the sacraments of the church are for the living, … that one should read this [the law] in conjunction with and in the light of the canonical principle that one should give the maximum benefit of doubt in the application of law.'[(296)] Chaplains who have concerns about baptising a stillborn baby should on the one hand be aware of the importance of the primacy of a pastoral rather than a juridical approach and on the other hand balance an authenticity of the nature of ritual to respond to human need. To diminish either could have potentially distressing consequences for bereaved parents following their request for baptism for their baby. Binary divisions between theological tradition and human experience create conflict and alienation from an incarnational understanding of God and are removed from a restorative understanding of pastoral care.

6.5 Parental experience of stillbirth

6.5.1 Communication from staff

Communication is a core competency in healthcare most especially in the delivery of bad or distressing news. The impact of communication features in the data from bereaved parents in this study. Parents recalled in detail their experiences of when, where, how and from whom they received the news that their baby had died or was unlikely to survive. The data from parents highlighted the importance of clear, unambiguous and sensitive communication from staff. Parents were negatively impacted when they felt staff were withholding information or using diversionary techniques to avoid communicating bad news. These experiences were mostly with junior staff and this raises the question about who is empowered to communicate with parents when they discover that something is wrong. One area that is worth further exploration is whether those who are conducting ultrasound scans should then be empowered to communicate with parents when they make a diagnosis rather than having to wait for confirmation from a senior member of staff.

When compared with the data from consultant obstetricians there is a high awareness and synchronicity from both consultants and bereaved parents about the importance of communication. The areas prioritised by consultants such as giving time, giving personal care and expertise from a consultant, follow-up care and expressing empathy and kindness were the same priorities that bereaved parents valued from their consultant. Analysis of the data showed that these experiences improved over time between 2008 -2013. On further analysis, where one couple

expressed negative experiences in 2013 it was when a consultant obstetrician was less involved in their care.

Communications from the hospital was raised as an important area for some parents in the areas of appointment scheduling and written information provided. Parents expressed distress when appointments were not honoured or written information received was ambiguous. A recommendation from this study is that a coordinated approach from the hospital is used for overall bereavement care including the scheduling of appointments and information about follow up services. A further recommendation is that ongoing communication training is provided to all staff who have responsibility for diagnosing fetal anomalies or stillbirth.

6.5.2 Perinatal palliative care

The term 'perinatal palliative care' has been coined in recent years to describe the growing awareness of the distinctive care pathway that is adopted for the ongoing care of babies who have received a diagnosis of a life-limiting illness or anomaly either *in utero* or following birth. Perinatal palliative care is based on the same principles as the wider palliative care philosophy to improve the quality of life of patients (babies) and their families 'through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'.[214] Irish maternity services have developed considerable expertise in this area over recent decades as there is no provision in law for the termination of pregnancy following the diagnosis of a life-limiting anomaly.[325]

Parents in this study who received a diagnosis of a life-limiting condition for their baby (n=6) were cared for with a perinatal palliative care approach. The results of this study validates work by O'Connell *et al* concerning the value parents place on the time they have between diagnosis and birth/death.[77] This period of time allowed parents to grieve for the baby they had been expecting, to integrate their loss and adjust to their new relationship with their baby. This period of adjustment extends to the impending death of their baby and enables parents to intentionally create memories, to plan for their baby's birth and to choose the ways in which they wish their family to spend time together following birth.

For some parents however, they experienced a strong conflict of emotion that was expressed in the superordinate theme of 'Maintaining hope'. For these parents there was a strong sense that their baby might get better and parents found it hard to accept that their baby would definitely die. This was also reflected in the superordinate theme of 'Protective care' as parents sought to protect their baby from harm. This was a conflicting experience for mothers as they wrestled in particular with the painful reality that while they were able to protect their baby *in utero* but that they could not protect their baby from death. This contributed to a spiritual conflict for parents as they struggled with finding meaning or purpose in their baby's life and death. Parents who struggled with their baby's diagnosis did not receive spiritual care during this time from the hospital team and expressed isolation and loneliness as they adjusted to the reality of the impending death of their baby.

> "W*e didn't have anyone that sat down and kind of talked about the spiritual side of it."* 2013P2 *–page 222*

It can be argued that parents who struggled spiritually with their baby's diagnosis might have found it easier to cope had they received spiritual support from a hospital chaplain. This may then have helped in the process of adjustment and memory making as part of anticipatory grief.

Although all parents found the diagnosis of a life-limiting condition to be challenging to their faith they appreciated the time they had between diagnosis and birth to prepare for a ceremony or ritual for their baby. In one case parents had a service of blessing at home for their baby before she was born and this was experienced as a very supportive event. In other cases parents invested considerable thought and preparation in a prayer service for their baby to celebrate his/her life before burial/cremation. Building on the sense of ongoing connection that parents said they had with their baby that was expressed as a spiritual reality at section 6.2.2, it could be argued that the time between diagnosis of a life-limiting condition and birth is also a liminal time for parents where the focus of relationship is profoundly altered. How parents are supported spiritually during this time is in need of further research to explore how spiritual significance and meaning can be supported.

6.5.3 Time between diagnosis and birth in unanticipated stillbirth

Parents described the time between diagnosis of an unanticipated stillbirth and their baby's birth as very challenging and distressing. This is in keeping with the literature where the time of waiting between diagnosis and birth has been identified as particularly challenging and is described by Malm *et al* as 'waiting in no man's land'.[101, 326, 327] A study by Erlandsson *et al* recommends that mothers should not

wait longer than 24 hours between diagnosis of stillbirth and birth.[326] Strong emotion from participating parents using words such as ‘horrendous’, ‘cruel’, ‘unfair’ revealed the depth of impact of this waiting time for bereaved parents. Some parents in this study felt unsupported both in their care and also in the communication about professional advice versus personal choice concerning vaginal birth or caesarean section and in the length of time between diagnosis of stillbirth and the birth of their baby.

An area of potential development based on this finding is that the principles of perinatal palliative care could also be extended to parents in the time between diagnosis and birth following the diagnosis of a sudden unanticipated stillbirth. Although it is a considerably shorter time frame, it is a period of time that has potential for improved experience. The depth of expression from parents indicated that this was a very traumatic time and that increased support would have been beneficial. A recommendation from this study is that parents are given a high level of support following the diagnosis of stillbirth and that in the time between diagnosis and birth that parents are offered choices to create memories and to invest in their baby’s care including starting the process of preparing a birth plan and opportunities to address spiritual need using the principles of perinatal palliative care.

6.5.4 Seeing and holding a stillborn baby

The place of seeing and/or holding a stillborn baby has been the topic of much debate in recent years. As outlined in chapter one this topic is not one that has been viewed with consensus. In the most recent meta-synthesis of evidence-based guidance for stillbirth care and practice Peters *et al* write that ‘it is unclear whether

seeing and holding a dead baby after birth is beneficial for mothers and parents'.[276] In another meta-synthesis of 23 studies by Kingdon *et al* in 2015, 21 studies reported positive outcomes for parents who had seen and/or held their stillborn baby.[161] The latest Irish clinical practice guideline and the *UK NICE Clinical Guideline 192* recommend that bereaved parents should be supported in their decisions to see and hold their baby if that is their wish.[78, 160]

In keeping with the majority of studies, the data from this study emphasised that for bereaved parents the opportunity to see and hold their stillborn baby was a positive and cherished experience. There were no negative effects or experiences reported by any bereaved parents in this study. The importance of what many refer to as the 'golden hour' in the literature was confirmed by parents in this study who spoke of how they found it harder to hold their baby when he or she was no longer warm.[104] All parents spoke about the importance of being able to parent their baby and it was a strong part of the superordinate themes of the 'Importance of personhood' and 'Protective care'. When parents expressed regret it was as a result of what did not happen or what they did not have the opportunity to do. Two examples of this were a mother who regretted not seeing all of her son's body and another mother who didn't clean the vernix from her daughter's face.

Data from both chaplains and consultants emphasised the importance of caring for a stillborn baby in the same was as they would care for a live baby.[87, 103, 104] This approach to care is congruent with the approach taken by parents who saw their baby and treated their baby with the same care as they would a live baby. Where the data diverged was when parents wished for their stillborn baby to receive

the same spiritual care as a live baby but for some chaplains this was problematic especially if parents requested a baptism for their baby.

6.5.5 Parental grief

Parents in the study demonstrated the range of symptoms identified in the published literature following stillbirth such as anxiety, depressive symptoms, post-traumatic stress, suicidal thoughts, guilt and social phobia.[34, 103, 122, 123, 131, 146] Although all parents were emotional, it was to be expected that parents who were bereaved in the current year of the study demonstrated the most acute expressions of grief. Parents from previous years expressed acute grief distress when they recalled traumatic experiences surrounding diagnosis or birth.

The differences in grieving styles between fathers and mothers has been the subject of a number of studies in recent decades. These studies have demonstrated the growing awareness of the impact of perinatal loss on fathers and differences in grieving styles.[114, 150, 328] The impact of grief following stillbirth on bereaved fathers in this study was immense and all participating fathers expressed strong emotions of sadness, powerlessness, anger and vulnerability. The findings in this study were consistent with the results of a study by Bonnette and Broom (2011) who identified *inter alia* that fathers experience strong feelings of grief and that this is particularly focussed in the time they spend with their stillborn baby after he/she is born.[328]

> *"I didn't sleep at all for the first twenty four hours. I don't think I slept for two days solid because I'd stay up at night … you kind of hate leaving him alone."* 2013U1F –*page 228*

It was interesting that fathers in this study found a particular focus in the grave of their stillborn baby and most fathers viewed their baby's grave as a particular locus of grief and connectedness. This was demonstrated by four fathers who visited their baby's grave regularly, often on a daily basis and in some cases without the knowledge of their partner.

The findings of this study reinforce the findings of Cacciatore and DeFrain *et al* that expressions of grief following stillbirth are 'varied profound and unique'.[150] The findings of this study reveal that while the theses of Cacciatore and DeFrain *et al* are valid concerning the unique expression of grief, there were many commonalities to grief following stillbirth in the study participants. These included profound sadness, disappointment, powerlessness, communication challenges, challenges to faith and belief. Bearing in mind the data from other studies concerning the negative impact of stillbirth on relationships and parental health[28, 29, 128, 134, 142, 154] the results from this study confirmed the importance of integrated multidisciplinary supportive care for bereaved parents that is sensitive and adaptive to their grieving styles and needs.

6.5.6 Relationships

The negative impact of stillbirth on the relationships of bereaved parents is recognised in the published literature ranging from relationship strain to relationship breakdown.[28, 123, 162] A 2008 Study by Cacciatore *et al* reported that the experience of stillbirth brought some couples closer together.[150] The results from this study confirmed that stillbirth was an immense challenge for most couples. It is of interest

that while all mothers contacted agreed to participate in the study, only five fathers participated. Doss and Atkins argue that women are more likely than men to seek help following an event that causes relationship strain.[329] It could be inferred therefore that mothers were more likely to participate in a study such as this. As fathers were invited to participate through their partner it is possible that this approach may have affected their decision to participate or not in the study.

The results from this study indicated that stillbirth had a diverse impact on relationships with only one couple saying it had brought them closer together, two couples said that they felt further apart and two more couples found it too difficult to talk about it to each other and in one case the couple spoke about their baby's death for the first time openly during the interview process. All but one mother who participated in the study without their partner said that their partner found it hard to talk about their baby's death. Of note, all couples were still in the same relationship as at the time of their baby's death. With one exception, couples who were most recently bereaved expressed the most acute levels of relationship strain. In these couples fathers were more expressive about the impact of their baby's death on their relationship. *"It just breaks your heart because everything we have done together has been ruined, tainted. This is what we are left with."* 2013P2F *–page 224*

Communication was a significant challenge for some couples especially when they were unable to communicate with each other about their grief and this in turn led to isolation and relationship strain. For some couples this was because each partner felt unable to cope with the grief of their partner in addition to their own. This raises a challenge as to how bereavement support can be provided for couples

so that both partners can process their loss. Differences in grieving styles are an important factor and this was raised most often by mothers when they described that their partners 'do not like to talk about it'.[125, 131, 162, 330] Inability to communicate and to process what is a traumatic loss has potential for ongoing psychological burden, disenfranchised grief and psychiatric symptomatology.[131, 134, 137, 146, 147, 229, 331] The results from this study indicated that parents were not availing of appropriate levels of bereavement support following stillbirth.

All parents described how they experienced an ongoing relationship with their baby who had died. This is consistent with the published literature about 'continuing bonds' after death.[129, 228, 328, 332, 333] For a number of parents their ongoing connection was experienced in spiritual ways through signs and symbols and their experience of the close proximity of the presence of their baby. In spiritual terms this is for many parents a lived expression of the 'communion of saints' and an eschatological hope that they will one day be reunited with their baby. This emphasis highlights the importance of supportive spiritual care that enables bereaved parents to draw strength and comfort from these experiences of connection with their baby.

6.6 Implications for practice

The data from this study highlight a number of areas where clinical practice and spiritual care can improve the overall experience for bereaved parents. The areas where spiritual care practice can be improved have been addressed a section 6.4. The areas for improved clinical practice relate to improvements in bereavement services, staff support and education and post-mortem examination consent process. I shall address each in turn.

6.6.1 Improvements in bereavement services

The data from bereaved parents when analysed highlighted various improvements in overall bereavement services at the study hospital over the previous five years. The fact that this was not the focus of the study gives strength to these findings as they are based on the shared experiences of bereaved parents. The improvements as highlighted in chapter 5, section 5.5.7.3.1 focus on environmental factors and interpersonal experiences.

The improvements in parental experience when tracked against service developments in the study hospital were aligned with quality improvement initiatives over the five years of the study. These improvements included the development of dedicated private ultrasound scanning areas, a dedicated area in the emergency room where mothers with a suspected stillbirth can be examined in a private area away from other pregnant mothers without hearing the fetal monitoring of other babies, the provision of a dedicated pregnancy loss ward with private accommodation for bereaved parents and the facility for a mother's partner to stay overnight. Each one of these developments was remarked on positively by bereaved parents.

Improvements in the communication skills of staff were noted in so far as parents who had negative and distressing communication experiences were from the earliest group in the study. During the five years of this study various educational programmes have taken place in the study hospital including the establishment of a dedicated multidisciplinary pregnancy loss team, communication skills training for all staff, multidisciplinary staff education at undergraduate, postgraduate and as part of continuing professional development. During this time the study hospital also

piloted and introduced a stillbirth awareness sticker that is placed on the medical notes of bereaved parents to increase awareness and to ensure that bereaved parents are cared for sensitively.

The findings from this study affirmed that the overall development of perinatal bereavement care services improved the experiences of bereaved parents during what was a very difficult time. As negative experiences concerning how bereaved parents feel cared-for during their hospital stay and how staff communicate with them can shape their overall grieving experience and recovery process these improvements in care should in turn decrease the potential of complicated grief.[31, 34, 85, 101, 125, 131, 326, 327]

The data from this study demonstrate that improvements in facilities and training do impact positively on the experience of bereaved parents. Therefore a recommendation is that maternity units should continue to develop infrastructure, facilities and educational provision in a proactive way.

6.6.2 Staff support and education

Consistent with the literature on caregiver burden, the combination of exposure to the trauma of stillbirth, the sense of professional isolation experienced by some chaplains and obstetricians and the depth of spiritual wrestling experienced by some chaplains, the potential for stress and professional burnout was considerable.[281, 282, 291, 318, 334]

The importance of physician wellbeing has been the focus of many workplace initiatives and studies in recent years due in part to acknowledged high levels of professional burnout amongst physicians.[36, 281, 282, 291, 318, 335-339] Responding to the growing awareness of the importance of physician mental health and wellbeing the Irish Medical Council has identified physician wellbeing as one of 'eight domains of good professional practice'.[340] As a professional and training body the RCPI launched a physician wellbeing programme in 2014 to prioritise the importance of personal and professional wellbeing for both trainees and fellows.[297] The RCPI also published a physician wellbeing position paper in 2014.[297] As part of this physician wellbeing programme, the RCPI offers courses in building resilience, and health and meditation for trainees in addition to a support and social programme.[297] The RCPI Institute of Obstetricians and Gynaecologists Clinical Practice Guideline *Investigation and Management of Late Fetal Intrauterine Death and Stillbirth* has as one of its key recommendations from 2011 that 'A system should be in place to give clinical and psychological support for staff involved with an IUFD.'[78] There was no evidence that the chaplains or obstetricians in this study were aware of or availed of such support or indeed that such support was provided.

Wellbeing initiatives that have been implemented and evaluated globally in recent years have focussed mainly on mindfulness-based programmes.[335-337] The only randomised controlled trial of a mindfulness-based initiative for physicians that this author is aware of was conducted by West *et al* in 2014. In the study by West *et al* the benefits of one hour per fortnight of protected time for personal activities demonstrated in the study control group a reduction in depersonalisation scales and an improvement in those reporting that work was meaningful. In the interventional

group the one hour per fortnight involved participation in a small group mindfulness-based programme for nineteen sessions. In the interventional group there was a substantial reduction in depersonalisation, emotional exhaustion and overall burnout. In both groups the improvements were sustained twelve months following the study.[335] A previous study by Fortney *et al* demonstrated that an abbreviated mindfulness programme led to reported improvements for participants on validated Maslach burnout scales.[336]

Resilience is a trait that is often coupled with professional wellbeing and yet it is a difficult one to measure or assess. A recent review of studies in this area by Balme *et al* found that there are many personal, organisational and sociocultural factors that influence resilience in doctors as they adapt to constant death, disability and distress in medicine.[341] Balme identified that there were no consistent definitions of resilience, no reliable measurements or any robust studies into what resilience is.[341] Balme, citing a review by McCann *et al* highlighted that 'being female and maintaining a work-life balance were the only two factors that were consistently, positively related to resilience' across a number of health disciplines.[341] Furthermore, Balme *et al* found that the evidence for the effectiveness of focussed resilience training was ambiguous with the recommendation that doctors need more support in their work rather than training in resilience.[341] The evidence did however identify that organisational and governance issues are important components of professional wellbeing.

A review by psychiatrist Laura Dunn (2008) conceptualised a negative/positive burnout/resilience model for physicians.[342] Dunn conceptualised

resilience as a ‘coping reservoir’ with identified positive factors such as psychosocial support, social/healthy activities, mentorship and intellectual stimulation as contributing to resilience. Dunn identified negative factors such as stress, internal conflict, time/energy demands as leading to burnout. Both the negative and positive factors identified by Dunn are backed up by the data from consultant obstetricians in this study.[35, 40, 342, 343] In addition Balme et al identified time management, self-awareness, CPD, support and mentorship as contributing to increased resilience.[341] These factors were also backed up by the data from consultant obstetricians in this study.

The results of these studies coupled with the results from my study make a strong case for a workplace mindfulness-related initiative to support staff wellbeing which in turn will improve patient care.

6.6.2.1 Clinical supervision

Clinical supervision provides an opportunity for clinicians to reflect on their practice in a supportive and trusting environment. Milne, building on previous work by Kadushin and Proctor describes clinical supervision as ‘normative (administrative), formative (educational), and restorative (supportive)’.[344] Clinical supervision is recognised as being an important component of lifelong learning and is one of a number of key recommendations following the publication in 2013 of the *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry in the UK*.[345]

Kilminster e*t al* define workplace supervision as 'a process of professional support and learning which enables individual practitioners to develop knowledge and competence, assume responsibility for their own practice, and enhance safety of care in complex situations'.[346] Clinical supervision has been demonstrated to enhance clinician wellbeing and improve patient outcomes.[345, 347] The data from this study indicates that consultant obstetricians would benefit from clinical supervision in their care of parents following stillbirth. As professional isolation and fear were strong expressions for consultants working in this area the opportunity for regular clinical supervision would provide a forum for support, education and reflection. In 2015 the HSE initiated a clinical supervision framework for nurses working in the Irish mental health services.[348] This supervision is 'by nurses for nurses' and highlights that 'clinical supervision: Supports nurses to develop their clinical skills and professional practice in response to service user needs; Values and enables the development of professional and practice knowledge to meet these demands; Provides relief from the emotional and personal stress involved in nursing; Helps nurses work in an effective way; Helps nurses gain information and insights, and promotes reflective practice; Encourages personal and professional growth; Is a part of lifelong learning; Is a component of clinical governance; Is an aid to improving standards and the quality of nursing care.'[348]

A recommendation from this study is that the provision of clinical supervision should be explored as a supportive structure for consultant obstetricians. Tomlinson, however cautions against supervision that is 'externally imposed, institution-centred or managerial…' as being less likely to gain acceptance.[345]

6.6.2.2 Continuing professional development

Continuing professional development (CPD) is a mandatory requirement for annual retention on the Specialist Register of the Irish Medical Council.[349] This acknowledges the importance of professional career-long learning and development for doctors. The introduction of training programmes aimed at skills enhancement in the care of bereaved parents has contributed much to staff education and professional skills. These programmes include technical approaches to stillbirth investigation and audit, communication skills and broad perinatal bereavement training. It is a recommendation from this study that perinatal bereavement training should be a mandatory component for CPD on an annual or biennial basis for those on the Obstetrics and Gynaecology specialist register. The following are well-established programmes and it is a recommendation from this study that these programmes or locally adapted versions of them are provided in the Irish maternity services for all staff who provide perinatal bereavement care.

6.6.2.3 IMPROVE perinatal education programme

The IMPROVE interactive perinatal education programme developed by the Stillbirth Alliance of Australia and New Zealand based on the perinatal guidelines of the Australia New Zealand Perinatal Society is one programme that could be adapted for regional use in Ireland and the UK.[350] As none of the participating obstetricians in this study had received any formal education in perinatal bereavement care an experiential training programme covering autopsy communication, clinical

examination, placental examination and investigation, classification, and audit of stillbirth would be of benefit.

6.6.2.4 Sands bereavement training

Sands UK has developed considerable expertise and resources for staff education and audit of perinatal bereavement care.[79, 100] Sands perinatal bereavement training is multidisciplinary in nature and has been developed from robust clinical practice and evidence based methodology. As a parent support organisation, Sands UK has designed bereavement training programmes that have been shaped by the experiences of bereaved parents.[120] Based on the respected Sands UK *Pregnancy Loss and the Death of a Baby: Guidelines for professionals* these training courses are appropriate for all professionals providing perinatal bereavement care.[79] This training programme deals in particular with hospital and perinatal bereavement care pathways, facilities and communication.

6.6.2.5 Communication training

Communication is a core competency in perinatal bereavement care. A recommendation from this study is that all staff providing perinatal bereavement care should receive appropriate communication skills training. *Delivering bad news* is a multidisciplinary interactive and experiential communication training programme designed and provided by the Irish Hospice Foundation that has been used extensively in the Irish healthcare system in recent years.[351]

The reality of the burden of stillbirth for healthcare staff is highlighted from the data from maternity healthcare chaplains and consultant obstetricians in this study and a recommendation to healthcare management is that educational opportunities are provided as part of a comprehensive staff bereavement training programme in each maternity unit.

6.6.3 Post-mortem examination consent process

Post-mortem examination, as the gold standard test following stillbirth, has been in decline over recent decades for reasons outlined in chapter one.[56, 59] This decline has only in recent years begun to be reversed, albeit slowly. In the literature there has been much emphasis on how parents are counselled before post-mortem.[67, 69] What parents understand about post-mortem examination is also an important area to consider. A recent study by Meaney *et al* reported that parents are influenced by media and television drama reports of post-mortem practice and that this in turn influences parental decision making concerning post-mortem for their baby.[61] The process of consent before post-mortem has been explored from the perspective of bereaved parents and also of staff who do the counselling and consenting procedure.[62, 67, 69]

The reaction of parents to post-mortem examination following the stillbirth of their baby in this study was mostly expressed from a protective stance taken by parents when they did not want anything else to be 'done' to their baby. This was expressed in terms of protecting their baby from 'further harm' or unnecessary intervention. This protective stance by bereaved parents is in keeping with a recent study by Meaney *et al*.[61]

It is of interest in terms of the consent procedure, that some parents declined post-mortem when they had been given a provisional diagnosis from their obstetrician. The diagnosis was given in an equivocal way as a possible diagnosis and it would appear that when this happened parents accepted this diagnosis and didn't wish for post-mortem to be carried out that would (potentially) confirm the exact cause of death. This raises an important practice point about the giving of a possible diagnosis before a post-mortem examination is carried out. A recommendation from this insight would be that a diagnosis should only be given when the clinician is confident that the diagnosis is unequivocal.

It can be inferred from the comments of some parents that they were not adequately informed about what was involved in the post-mortem examination procedure which backs up the important points made by Heazell *et al* and Meaney *et al* concerning how healthcare staff are taught about having what is a 'difficult conversation'.[61, 62, 67] Naturally this is a challenging balancing-act between giving sufficient information and yet not causing unnecessary additional trauma.

Building on the recommendations of the report of Dr Deirdre Madden into post-mortem practice in Ireland following the organ retention scandals[65] it was clear from one couple in the data that the consent procedure in this area did not work. This couple, although they signed a post-mortem consent form, did not realise that their baby's organs would be retained and that they would be contacted afterwards to collect their baby's organs for burial. This raises an important practice point concerning how information is communicated to parents at what is a very traumatic

time for them. This couple make a valid recommendation which is worth endorsing as a recommendation from this study. The recommendation is that written information is given to parents and that they are told very clearly that they are likely to receive a follow-up telephone call concerning the return of their baby's internal organs following post-mortem.

> *"We agreed with everything but you don't register what's going on … they should probably say "be prepared for six weeks' time when you will be getting a phone call". '* *2013U1 –page 209*

While discussion concerning post-mortem is often seen as a 'difficult conversation' it is of note that one mother (who was reluctant to consent to post-mortem following an unexplained stillbirth) expressed that it was only after her son returned from post-mortem that she recognised him as a person.

> *"The most wonderful thing happened when our baby came back* [from post-mortem]. *I smiled, I laughed, I was full of joy. I saw my baby in a baby-grow of blue and white and all of a sudden things changed. I can't explain it. I said 'wow, look at our baby' and he was someone, he was someone, and from then on he became someone to me."* *2010U1 –page209*

This example highlights the importance of how sensitive care continues for babies during and following post-mortem examination.

6.7 Summary of recommendations

The following recommendations from this study are made to health service managers, chaplaincy training and accreditation bodies, the Irish Medical Council, and individual chaplains and obstetricians.

- All maternity units and specialist perinatal bereavement teams should have access to appropriately trained, board certified healthcare chaplains with specialist training in perinatal bereavement care to meet the spiritual needs of bereaved parents.

- Maternity healthcare chaplains should avail of personal spiritual supervision and support.

- Maternity healthcare chaplains should engage with theological reflection as a supportive methodology in ministry.

- All chaplains who provide perinatal bereavement care should be acquainted with a current interpretation of church teaching concerning stillbirth and salvation.

- Professional and pastoral support should be provided for obstetricians and the wider bereavement team in their place of work.

- The provision of a supportive staff wellbeing programme such as a mindfulness based programme should be considered.

- Perinatal bereavement training to include communication, stillbirth investigation, audit and classification should be a mandatory CPD requirement for obstetricians on the specialist register of the Irish Medical Council.

- Clinical supervision should be provided for obstetricians as a supportive and educational resource.

- Caution should be exercised when giving a provisional diagnosis/cause of death following stillbirth as this may impact negatively on post-mortem consent.

- Written information concerning the post-mortem care pathway should be given to all parents as part of their consent process. This information should also be given to parents from whom consent is not sought if a post-mortem is part of a coronial process.

- Ongoing communication training should be provided to all staff who have responsibility for diagnosing fetal anomalies or stillbirth.

- Parents should receive a high level of support following the diagnosis of stillbirth. In the time between diagnosis and birth parents should be offered choices to create memories and to invest in their baby's care including starting the process of preparing a birth plan and

opportunities to address spiritual need using the principles of perinatal palliative care.

- All maternity units should provide mementos and ongoing bereavement support by chaplains in conjunction with bereavement teams.

- All maternity units should work to improve physical infrastructure and facilities to provide dedicated scanning and care areas for bereaved parents both during and following diagnosis.

- A spiritual screening tool should be developed and piloted for use by healthcare staff to identify and refer parents who require referral to a chaplain for ongoing spiritual care.

- The provision of a coordinated hospital approach for overall bereavement care including the scheduling of appointments and information about follow up services.

6.8 Limitations of study

The limitations of this study are that all participating maternity healthcare chaplains were from a Christian faith group. The inclusion of participants from other faith or philosophical groups would add a broader perspective; however there are currently no chaplains from other faith groups employed in the Irish maternity services. In the study with maternity chaplains six of the twenty interviews were

conducted by telephone. On analysis, the depth of data in telephone interviews was less than with face-to-face interviews.

All participating consultant obstetricians were from one maternity unit and were known to me. This potentially impacted on the information shared by them and it may have made it more difficult for participants to decline to participate in the study. However, on the other hand this level of trust was also a strength that potentially enabled a deeper level of information sharing by participants. All participating obstetricians were from a single faith group; however, this is reflective of the general homogeneity of the Irish population where 90% of the population are Christian.[218]

All participating bereaved parents were from one maternity unit. This limits the data in terms of looking at broader developments over time in the wider Irish maternity services. However, a benefit of this was that it allowed some study of the impact of recent versus less recent bereavement. As was the case with chaplains and obstetricians all participating parents were from a Christian background, although one no longer considers themselves as a person of faith. Greater faith diversity would enrich the data. The lower rate of participation of bereaved fathers is a limitation in the study.

This study focussed on the impact of stillbirth on maternity healthcare chaplains and consultant obstetricians. The study did not include the experiences of midwives or other healthcare professionals. It is recognised in the published

literature that stillbirth also has considerable impact on midwives and so the absence of this in the current study is a limitation.

6.9 Strengths of study

The strengths of this study are that for each participating group, healthcare chaplains, consultant obstetricians and bereaved parents, the study adds previously unresearched data concerning the presence and depth of the spiritual impact of stillbirth. In addition it contributes new insights and data about the personal and professional burden of stillbirth.

It is the first study of its kind to research the impact of stillbirth on maternity healthcare chaplains as a distinct group and the first study to review the overall provision of spiritual care following stillbirth in the Irish maternity services.

This is the first study to explore the impact of stillbirth on the faith on consultant obstetricians in what is often considered a private and intimate world of faith and spirituality. The depth of qualitative data in this study exploring the personal and professional impact of stillbirth builds on previous quantitative findings in this area with obstetricians. Participant validation of the data following its presentation locally to participants is also a strength of this study.

This is the first study to explore in a qualitative and in-depth way the spiritual impact of stillbirth on bereaved parents. The inclusion of parents bereaved following anticipated and unanticipated stillbirths is a strength of this study allowing study of both groups.

The use of IPA as a methodology is a strength of the study. IPA as a well-established methodology in qualitative healthcare research brings considerable depth to the experience and attributed meaning given to stillbirth. Qualitative studies ordinarily have small sample sizes as the focus is on the depth of experience. The sample sizes for this study have contributed considerable depth and experience to this field of study. The experience of stillbirth and the care of bereaved parents following stillbirth in this study was essentially a human experience and story as professional human beings provided care for bereaved parents and for both the human and spiritual impact was considerable.

6.10 Further research areas

The results of this study identify a number of areas that are worthy of further research. These areas focus on bereaved parents, post-mortem consent procedures, healthcare staff and spiritual care.

A recommendation from this study is that greater support should be given to bereaved parents when they are given a diagnosis of unanticipated stillbirth. As there is usually a short and defined time period between diagnosis and birth, how parents experience this support and what was beneficial or unhelpful are areas for future research interest.

The sensitivities of the process of post-mortem examination consent are well documented. Building on the work of Heazell, Horey and Meaney and the latest Cochrane Review in this area, further research should explore whether parents who

declined post-mortem subsequently regretted their decision. The data from this study showed that parents who declined post-mortem had a formal 'unexplained' diagnosis recorded for their baby's death.

The fear of media coverage and exposure arose for a number of consultants in the context of blame and medico-legal litigation. The impact of this public scrutiny and exposure on current obstetricians including any potential negative impact on the recruitment retention of trainees into the speciality of obstetrics requires further research.

This study identified the considerable burden and impact of stillbirth on maternity healthcare chaplains and consultant obstetricians. These are two defined professional groups and therefore further study is recommended to research the impact of stillbirth on other professionals (for example non-consultant obstetricians, midwives, healthcare assistants, social workers) within the maternity services.

The results from this study highlighted that, contrary to previous studies from North America, neither bereaved parents or consultant obstetricians in this study considered it the role of the obstetrician to provide spiritual care for parents. Bereaved parents did however, expect that their spiritual needs would be recognised and attended to by the wider team. This indicates that the development and piloting of a spiritual screening tool would be one way to address this need and in turn it would identify parents for referral to a chaplain for ongoing spiritual care.

6.11 Conclusion

In this chapter the results of this study have been critically discussed against the background of the current published literature surrounding the spiritual and professional impact of stillbirth. This study has revealed that stillbirth had significant spiritual and professional impact for Irish maternity healthcare chaplains and consultant obstetricians.

I have discussed, in light of the current published literature in this area, the results of this study concerning the impact that stillbirth had on bereaved parents spiritually and personally. The study has confirmed results from previous studies concerning the impact of stillbirth on relationships and the potential benefits of seeing and holding a stillborn baby. The study has revealed new insights into the depth of spiritual pain and distress experienced by bereaved parents following the stillbirth of their baby.

Contrary to studies from North America the results of this study have demonstrated that neither bereaved parents nor consultant obstetricians expected that a consultant obstetrician should attend to the spiritual needs of bereaved parents as part of their care.

As a result of this study a number of recommendations have been made for improved practice and provision of spiritual care, professional support, professional wellbeing, clinical supervision and ongoing education for chaplains and obstetricians. In addition, recommendations have been made for improved clinical

practice in the areas of service development, communication and the post-mortem consent process.

I have outlined the limitations and strengths of the study and finally I have identified future areas of research in the area of spirituality and staff wellbeing.

The results from this study open up new insights concerning the spiritual impact of stillbirth on bereaved parents and healthcare staff in what is a little-researched area. In light of renewed global efforts in stillbirth prevention and care this study contributes important new data to the overall understanding of the immense impact that stillbirth has on bereaved parents, their loved ones, healthcare professionals and society at large. The data from this study highlights the commonality of the human experience, impact and burden of stillbirth for parents, chaplains and obstetricians. Building on previous studies where the physical, psychological and emotional aspects of stillbirth are now widely acknowledged, this study contributes an important spiritual dimension and understanding to the tragedy that is stillbirth.

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Appendices

Appendix 1 Interview topic guides

1. Interview topic guide –healthcare chaplains

Interview Schedule: Review of Pastoral, Spiritual and Religious care following Stillbirth

1. Demographics:	Name, Hospital, How many births are there in your hospital? Religious/ Faith tradition
2. Professional experience:	How long have you been working in Chaplaincy? Do you work exclusively in this area? Are you ordained? Are you an accredited chaplain? Have you worked in other areas? Abroad? Have you received any specialist training for perinatal bereavement? When? Where? Is it beneficial? (Probe) Do you feel part of the Multidisciplinary Team? Are you routinely called to provide pastoral or spiritual care? In your absence who provides care?
3. Stillbirth facts:	How do you define stillbirth? Do you provide pastoral care following stillbirth in your hospital? If Yes, roughly how many cases per year?
4. Current pastoral practice:	What care do you provide for families following Stillbirth? *prompts*: ceremony, naming, blessing, prayer, funeral, remembrance service, naming cert etc. Do you provide any mementos? What are they? Are they personalised for each baby or generic? Do you feel your ministry is mainly a ceremonial or a pastoral one? Do you minister to people of other denominations or faiths? How do/would you feel comfortable ministering with families outside your own faith tradition?
5. Resourcing:	What resources do you use on a regular basis? Do you feel that you are well resourced for this ministry?
6. Spiritual and pastoral issues:	What do you think are the main spiritual and pastoral issues for parents following Stillbirth? Do you use any system to assess how parents are spiritually? If Yes, What? If No, would you find an assessment tool useful? Working in this area is demanding. Does it raise any spiritual issues for you?...Can you tell me what they are?
7. Self care	How do you care for yourself? Is there anything else that we have not touched on that you feel is important in this area of care?

1.2 Interview topic guide –consultant obstetricians

Interview Schedule for Consultant Obstetricians and Stillbirth Care

Version 02/2012
23 May 2012 ECM 4 (pp) 06/03/12

When did you qualify?
How long have you been working in Obstetrics?
How long have you been working at CUMH?
What other hospitals have you worked in as an Obstetrician?
Any outside Ireland? Where?

What do you enjoy most about being an Obstetrician?
Whats the hardest thing for you in Obstetrics?

How many births do you care for in a year?
How often would you care for parents who have a stillbirth?

How do you find it? (what is it like for you?)

Have you received any training in the area of perinatal bereavement?
Undergrauate?
Postgraduate?
As a consultant?

I wonder can you imagine now that you receive a call from Ultrasound that a lady at 38+4 has presented with no fetal heart beat and a midwife asks you to come and see a couple. What is that like for you?

How do you break this news to them?

And when you break this news what do you think it is like for a couple?

What do you think are their biggest issues/ concerns?

If you would like to recall a particular situation how do you think a couple would describe how you cared for them following a stillbirth?

What do you find most difficult about stillbirth?

Would you find it helpful to have a short question-tool to help you meet the deeper needs of couples as they come to terms with the death of their baby?

Do you routinely see in person all public patients under your care who have a stillbirth?
Private?
In hospital ? followup?

Have you experienced stillbirth in your own family or close family?

How do you care for yourself?

Is there anything else you feel we have not covered that is important in how we care for parents following a stillbirth?

1.3 Interview topic guide –bereaved parents

Interview Schedule: Spiritual and Pastoral aspects of Stillbirth

Version 01/2013
20/11/2012

1: Introduction	Welcome and thank-you for participating. Introductory information about the study and that participant understands the consent process and support available.
2. Personal story:	Participant asked to tell me their story from when they discovered they were pregnant through receiving news of stillbirth and the care they received and follow up care. What were your feelings when you discovered you were pregnant? At what stage did you find out you were pregnant? Do you have any other children? Ages, names, gender. I wonder can you tell me about the time leading up to when you discovered that your baby {name} had died? Did you have an inkling that something was wrong? What were your feelings when you realised something was wrong? Where were you told the news? Who was with you? How did you think the doctor/ midwife felt when they told you? (Were they comfortable? Were they sensitive?) Can you remember the words he/she used?
Belief now? ↑ or ↓.	What were your feelings towards your baby at that time? Do you feel any sense of connection now towards your baby {name}? Do you always feel this way or does it change at various times?
Religion Practising	Did you have any sense of faith or belief before you heard that your baby {name} had died? How would you describe it? What were you feelings towards faith when you got the news? Was there anything that you felt kept you going?
What was it like for partner?	Did you feel that it was important to have any spiritual or religious ceremony for your baby? (blessing, naming, prayer service, funeral, cremation, burial etc) What did you do? Why? Was it helpful? Who facilitated this?
If you were thinking about who would care for your Pastoral needs. What sort of Person would it be?	Is there anything you feel didn't happen that you now wished had been offered to you? & vice versa Do you receive any mementos? What were they? Would you have liked your doctor to ask you about your spiritual concerns as part of their care of you? Is there anything else that we have not touched on that you feel is important in this area of care?

Appendix 2 Ethical approval

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

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

Our ref: ECM 4 (pp) 06/03/12

21st February 2012

Dr Keelin O'Donoghue
Consultant Obstetrician & Gynaecologist
5th Floor
Cork University Maternity Hospital
Wilton
Cork

Re: A review of pastoral and spiritual care provision and practice following stillbirth in maternity facilities in Ireland.

Dear Dr O'Donoghue

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

- Maternity Facilities in Ireland
- Religious, Spiritual and Pastoral Care Providers.

The following documents were approved:

- Application Form
- Study Protocol Version 1 dated 20th February 2012
- Participant Information Leaflet Version 1 dated 20th February 2012
- Consent Form Version 1 dated 20th Feruary 2012
- Interview Schedule Version 1 dated 20th February 2012.

We note that the co-investigators involved in this study will be:

- Daniel Nuzum and Sarah Meaney.

Yours sincerely

Dr Michael Hyland
Chairman
Clinical Research Ethics Committee
of the Cork Teaching Hospitals

The Clinical Research Ethics Committee of the Cork Teaching Hospitals, UCC, is a recognised Ethics Committee under Regulation 7 of the European Communities (Clinical Trials on Medicinal Products for Human Use) Regulations 2004, and is authorised by the Department of Health and Children to carry out the ethical review of clinical trials of investigational medicinal products. The Committee is fully compliant with the Regulations as they relate to Ethics Committees and the conditions and principles of Good Clinical Practice.

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21st February 2012

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Consultant Obstetrician & Gynaecologist
5th Floor
Cork University Maternity Hospital
Wilton
Cork

Re: A review of pastoral and spiritual care provision and practice following stillbirth in maternity facilities in Ireland.

Dear Dr O'Donoghue

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- Religious, Spiritual and Pastoral Care Providers.

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Our ref: ECM 4 (pp) 06/03/12

21st February 2012

Dr Keelin O'Donoghue
Consultant Obstetrician & Gynaecologist
5th Floor
Cork University Maternity Hospital
Wilton
Cork

Re: A review of pastoral and spiritual care provision and practice following stillbirth in maternity facilities in Ireland.

Dear Dr O'Donoghue

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

- Maternity Facilities in Ireland
- Religious, Spiritual and Pastoral Care Providers.

The following documents were approved:

- Application Form
- Study Protocol Version 1 dated 20th February 2012
- Participant Information Leaflet Version 1 dated 20th February 2012
- Consent Form Version 1 dated 20th Feruary 2012
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We note that the co-investigators involved in this study will be:

- Daniel Nuzum and Sarah Meaney.

Yours sincerely

Dr Michael Hyland
Chairman
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Appendix 3 Study letters of invitation

3.1 Letter of invitation -healthcare chaplains

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Cork University Maternity Hospital,
Health Service Executive,
Wilton,
Cork.

A Review of pastoral and spiritual care provision following stillbirth in maternity facilities in Ireland.

Dear

As a Healthcare Chaplain, I am undertaking some study in the Department of Obstetrics & Gynaecology at Cork University Maternity Hospital/ University College Cork exploring the spiritual and pastoral aspects of stillbirth. As part of this study I would like to conduct a review of current pastoral practice in our care for families following stillbirth in maternity facilities in Ireland. This study is being supervised by Dr Keelin O'Donoghue who is the Clinical Lead of our Pregnancy Loss Services at Cork University Maternity Hospital.

The purpose of this short review is to get a snapshot of current pastoral practice and to learn from the depth of experience of fellow professionals in this area across the country. Following this review, I hope that the information will be of use to us all in our ministry. It might also identify areas of common concern for further development.

Participation in this review is voluntary and all information gathered will be anonymised to protect the identity of each participant and the healthcare facility you work in. If you are willing to participate in this study I will send you a copy of the information leaflet and a Consent Form and will arrange to meet with you for a semi-structured interview at a time and place of your choosing.

If you would like to speak with me about any aspect of this review please do not hesitate to contact me at (021) 4920500 or by email at daniel.nuzum@hse.ie
If you would like to speak with Dr O'Donoghue about any aspect of this study she may be contacted at (021) 4205019 or by email at k.odonoghue@ucc.ie

I hope that you will be able to contribute to this work.

Yours Sincerely,

Daniel Nuzum
Healthcare Chaplain

Dr Keelin O'Donoghue
Senior Lecturer
Consultant Obstetrician &
Gynaecologist

Ospidéal Máithreachais na hOllscoile Corcaigh
Cork University Maternity Hospital

Women, babies and their families are the centre of our service as we strive for excellence and innovation.

3.2 Letter of invitation -consultant obstetricians

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Cork University Maternity Hospital,
Health Service Executive,
Wilton,
Cork.

Thursday 14 June 2012

A study of the views of Consultant Obstetricians and how they care for families following stillbirth.

Dr (Name)
Consultant Obstetrician & Gynaecologist
Cork University Maternity Hospital,
Wilton, Cork

Dear (Name),

As a Healthcare Chaplain, I am undertaking some study in the Department of Obstetrics & Gynaecology at Cork University Maternity Hospital/ University College Cork exploring the spiritual and pastoral aspects of stillbirth. As part of this study I would like to explore the views of Consultant Obstetricians and how they care for families following stillbirth. This study is being supervised by Dr Keelin O'Donoghue .

The purpose of this aspect of my study is to explore the views and perceptions of a cross-section of Consultant Obstetricians and Gynaecologists concerning the care they provide for parents following stillbirth. Thank you for agreeing to participate. It is very much appreciated.

Participation in this study is voluntary and all information gathered will be anonymised to protect the identity of each participant. As this study is being supervised by a fellow clinician all identifying data including who participates in the study will remain confidential to Daniel Nuzum alone.

Please find enclosed copy of the information leaflet and a Consent Form and I look forward to meeting with you on **Monday 25 June** to conduct the interview.

If you would like to speak with me about any aspect of this review please do not hesitate to contact me at (021) 4920500 or by email at daniel.nuzum@hse.ie
If you would like to speak with Dr O'Donoghue about any aspect of this study she may be contacted at (021) 4205019 or by email at k.odonoghue@ucc.ie

Thank you for your willingness to participate in this work which we hope will deepen and enhance the care we provide for families following stillbirth.
Yours Sincerely,

Daniel Nuzum
Healthcare Chaplain

Dr Keelin O'Donoghue
Senior Lecturer
Consultant Obstetrician & Gynaecologist

Ospidéal Máithreachais na hOllscoile Corcaigh
Cork University Maternity Hospital

Women, babies and their families are the centre of our service as we strive for excellence and innovation.

3.3 Letter of invitation -bereaved parents

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Cork University Maternity Hospital,
Health Service Executive,
Wilton,
Cork.

A study of the spiritual and pastoral needs of bereaved parents following stillbirth

Dear

Thank you for taking our telephone call inviting you to participate in our study into the spiritual and pastoral aspects of stillbirth for bereaved parents. We appreciate that this is a very personal area for you and we thank you for you willingness to explore this with us before you decide if you would like to participate in the study.

We understand that the death of a baby from stillbirth is a devastating experience. How we care for parents following stillbirth is very important to us at CUMH: as a university hospital we aim to provide the highest level of care. One important part of the care we provide is how we meet the deeply personal spiritual and pastoral needs and wishes of bereaved parents at a very difficult time. These needs can be religious ones, spiritual ones or a combination of both. As part of this study we would like to hear directly from bereaved parents about what your deepest needs were and whether we were able to meet those needs in a meaningful and appropriate way. Parents are the experts in this area and we believe that we will learn a lot from you that will in turn help us to provide even better care into the future.

This study is being supervised by Dr Keelin O'Donoghue who is the Clinical Lead of our Pregnancy Loss Services at Cork University Maternity Hospital.

Participation in this study is voluntary and all information gathered will be anonymised to protect the identity of each participant. When you have read the enclosed material if you are willing to participate in this study I will arrange to meet with you for an interview at a time and place of your choosing.

If you would like to speak with me about any aspect of this study or to explore it further please do not hesitate to contact me at (021) 4920500 or by email at daniel.nuzum@hse.ie.

Yours Sincerely,

Daniel Nuzum
Healthcare Chaplain
PhD Student

Ospidéal Máithreachais na hOllscoile Corcaigh
Cork University Maternity Hospital

Women, babies and their families are the centre of our service as we strive for excellence and innovation.

Appendix 4 Study Information Sheets

4.1 Study information sheet -healthcare chaplains

Participant Information Sheet

A review of pastoral and spiritual care provision and practice following stillbirth in maternity facilities in Ireland

Version 1/2012

20/02/2012

Please Read Carefully Before Signing Informed Consent

Invitation to take part in a research study: You have been invited to take part in a review entitled "A review of pastoral and spiritual care provision and practice following stillbirth in maternity facilities in Ireland". The study is being conduct by Dr. Keelin O Donoghue of Cork University Maternity Hospital, as well as Daniel Nuzum and Sarah Meaney,

What is my role?
You will meet with either Daniel Nuzum or Sarah Meaney for an interview which should last approximately 60 minutes at a time and place that is most convenient for you. You will then be asked to speak about your ministry and the provision of pastoral and spiritual care following stillbirth and your perceptions about the spiritual and pastoral needs of parents and how we might best meet those needs in ministry.

What are the benefits and risks?
The focus of this review is to identify, acknowledge and hopefully to improve the overall level of pastoral and spiritual care that is provided to families based on best practice and the sharing of experience and insight. There are no personal risks in participating in this study. The importance of confidentiality will be maintained by the anonymising of the data collected so that no individual person or maternity facility will be identified.

Can I change my mind?
If, at any point, and for any reason, you wish to withdraw, then you may do so.

What happens to the information?
Any information that we obtain from this study about you, including your name, and your place of ministry will be confidential and will not be disclosed to third parties. Interviews will be digitally recorded and will be anonymised when they are transcribed. The digital recording will then be deleted and the written transcripts will be stored securely at Cork University Maternity Hospital. The written transcripts will be identified by an interview number to maintain confidentiality.

Do I have to sign anything?
Yes, if you agree to participate we will ask you to sign a Consent Form. This is to show that you have understood what is involved and that you have read the Information Sheet. Please be aware that even though you may sign the consent form you can still withdraw from the study at any time.

If you have any questions or would like further information, please feel free to contact Dr Keelin O' Donoghue (021- 4205019) or via e-mail k.odonoghue@ucc.ie or Daniel Nuzum at (021) 4920500 or by email at daniel.nuzum@hse.ie

If you have any concerns about this study and wish to contact someone independent you may contact: the Clinical Research Ethics Committee of the Cork Teaching Hospitals at 021-4345599.

4.2 Study information sheet -consultant obstetricians

Participant Information Sheet

A study of the views of Consultant Obstetricians
and how they care for families following stillbirth

Version 02/2012. 23/05/2012

Please Read Carefully Before Signing Informed Consent

Invitation to take part in a research study: You have been invited to take part in a study exploring the views of Consultant Obstetricians and how they care for families following stillbirth. The study is being conducted by Dr. Keelin O'Donoghue of Cork University Maternity Hospital, as well as Daniel Nuzum and Sarah Meaney

What is my role?
You will be invited to meet with Daniel Nuzum for an interview which should last approximately 30 minutes at a time and place that is most convenient for you. You will then be asked to speak about your experiences of stillbirth as a clinician, how you care for families following stillbirth, your perceptions about the needs of parents and how we might best meet those needs.

What are the benefits and risks?
The focus of this study is to identify, acknowledge and hopefully to improve the overall level of care that is provided to families based on best practice and the sharing of experience and insight. There are no personal risks in participating in this study. The importance of confidentiality will be maintained by the anonymising of the data collected so that no individual person will be identified. As the principal Investigator is a fellow Consultant Obstetrician, all identifying information, including who participates in the study will remain confidential to Daniel Nuzum alone.

Can I change my mind?
If, at any point, and for any reason, you wish to withdraw, then you may do so.

What happens to the information?
Any information that we obtain from this study about you, including your name, will be confidential and will not be disclosed to third parties. Interviews will be digitally recorded and will be anonymised when they are transcribed. The digital recording and the written transcripts will be stored securely at Cork University Maternity Hospital. The written transcripts will be identified by an interview number to maintain confidentiality.

Do I have to sign anything?
Yes, if you agree to participate we will ask you to sign a Consent Form. This is to show that you have understood what is involved and that you have read the Information Sheet. Please be aware that even though you may sign the consent form you can still withdraw from the study at any time.

If you have any questions or would like further information, please feel free to contact Dr Keelin O' Donoghue (021- 4205019) or via e-mail k.odonoghue@ucc.ie or Daniel Nuzum at (021) 4920500 or by email at daniel.nuzum@hse.ie

If you have any concerns about this study and wish to contact someone independent you may contact: the Clinical Research Ethics Committee of the Cork Teaching Hospitals at 021-4345599.

4.3 Study information sheet -bereaved parents

Participant Information Sheet

What are the spiritual and pastoral needs of parents who experience stillbirth?

Version 1/2013 ~ 20/11/2012

Please Read Carefully Before Signing Informed Consent

Invitation to take part in a research study: You have been invited to take part in a study entitled "What are the spiritual and pastoral needs of parents who experience stillbirth?". The study is being conducted by Dr. Keelin O Donoghue of Cork University Maternity Hospital, as well as Daniel Nuzum and Sarah Meaney,

What is my role?
You will meet with either Daniel Nuzum or Sarah Meaney for an interview which should last approximately 60 minutes at a time and place that is most convenient for you. You will then be asked to speak about your experience following the death of your baby and in particular what spiritual and pastoral issues it raised or raises for you. You will also be asked to share whether you felt your deepest needs were met in a meaningful way and you will be invited to share any insights you have about how we can provide better care. You will also be asked to complete a short questionnaire about your experiences.

What are the benefits and risks?
The focus of this study is to hear from bereaved parents what their deep spiritual and pastoral needs are in the midst of stillbirth and the death of their baby. We hope that the information shared by parents will help us to provide a higher level of care for all families. We hope that sharing your story with us in a caring and trusting way will in itself be helpful in your healing journey. However, we also acknowledge that it can be a difficult conversation to have. We undertake to offer you the support of the whole Pregnancy Loss Team should the experience of participating in the study cause you any upset.
The importance of confidentiality will be maintained by the anonymising of your information so that no individual person will be identified.

Can I change my mind?
If, at any point, and for any reason, you wish to withdraw from the study, then you may do so.

What happens to the information?
Any information that we obtain from this study about you, including your name, and other identifying personal details about you or your baby will be confidential and will not be disclosed to third parties. Interviews will be digitally recorded and will be anonymised when they are transcribed. The digital recording will then be deleted and the written transcripts will be stored securely at Cork University Maternity Hospital. The written transcripts will be identified by an interview number to maintain confidentiality.

Do I have to sign anything?
Yes, if you agree to participate we will ask you to sign a Consent Form. This is to show that you have understood what is involved and that you have read the Information Sheet. Please be aware that even though you may sign the consent form you can still withdraw from the study at any time.

If you have any questions or would like further information, please feel free to contact Daniel Nuzum at (021) 4920500 or by email at daniel.nuzum@hse.ie

If you have any concerns about this study and wish to contact someone independent you may contact: the Clinical Research Ethics Committee of the Cork Teaching Hospitals at 021-4345599.

Appendix 5 Consent Forms

5.1 Consent form -healthcare chaplains

Department of Obstetrics and Gynaecology,
Cork University Maternity Hospital,
Wilton, Cork.

Participant Information and Informed Consent Form

Version 1/2012
20/02/2012

Date: _____ **Name:** _____

Study ID: _____ **Principal Investigator :** Dr. Keelin O'Donoghue.

You are being asked to participate in a review to identify the provision of pastoral and spiritual care to families following stillbirth. The purpose of this review is to identify existing pastoral practice in this area and to collate information about the provision of pastoral and spiritual care to families following stillbirth.

In order to decide whether or not you would like to be a part of this review, you should understand enough about its risks and benefits to make an informed judgement. This process is known as informed consent. This consent form gives detailed information about the review process, which will be discussed with you. Once you understand the nature of the review, you will be asked to sign this form if you are happy to participate.

We would like to discuss with you what practices are currently in place for parents who experience stillbirth, what you think are the greatest spiritual and pastoral needs of parents following stillbirth and areas where you feel we could make improvements in the care we provide as chaplains and pastoral carers. Only one discussion is needed which will take approximately 60 minutes to complete and at a time and venue that is most convenient for you. The discussion will be digitally recorded and subsequently analysed by a researcher. Following completion of the interview, you cannot be identified and the information you provide will be treated in confidence. The information will be treated in the same way that the National Perinatal Epidemiological Centre (NPEC) treats information concerning perinatal mortality so that no individual hospital will be identified.

Participation in this review is voluntary. You are free to refrain from participation in this review or to withdraw from the review at any time.

Agreement to Consent

The research project has been fully explained to me. I have had the opportunity to ask questions concerning any and all aspects of the project and any procedures involved. I am aware that participation is voluntary and that I may withdraw my consent at any time. Confidentially of records concerning my involvement in this project will be maintained in an appropriate manner. When required by law, the records of this may be reviewed by government agencies.

I, the undersigned, hereby consent to participate as a subject in the above described project conducted at the Cork Teaching Hospitals. I have received a copy of this consent form for my records.

If I have any queries about the study procedure I can contact Dr. Keelin O' Donoghue at 021- 4205019. If I have any questions concerning my rights in connection with the research, I can contact the Clinical Research Ethics Committee of the Cork Teaching Hospitals at 021-4345599.

After reading the entire consent form, if you have no further questions about giving consent, please sign where indicated.

Signature of Subject: _____ Date: _____

Witness: _____ Date: _____

5.2 Consent form -consultant obstetricians

Anu Research Centre
Department of Obstetrics and Gynaecology,
Cork University Maternity Hospital,
Wilton, Cork.

Participant Information and Informed Consent Form

Version 2/2012. 23/05/2012

Date: _____ **Name:** _____

Study ID: [ECM 4 (pp) 06/03/12] **Principal Investigator :** Dr. Keelin O'Donoghue.

You are being asked to participate in a study to explore how Consultant Obstetricians care for families following Stillbirth. This is part of a wider study exploring the provision of pastoral and spiritual care to families following stillbirth. The purpose of this study is to identify existing practice in this area and to confidentially explore how clinicians feel about caring for families following stillbirth. You will be interviewed by Daniel Nuzum and as the Principal Investigator is a Consultant Obstetrician your information including your participation in this study will remain confidential to Daniel Nuzum alone.

In order to decide whether or not you would like to be a part of this review, you should understand enough about its risks and benefits to make an informed judgement. This process is known as informed consent. This consent form gives detailed information about the study, which will be discussed with you. Once you understand the nature of the study, you will be asked to sign this form if you are happy to participate.

We would like to discuss with you what training you have received in the care of families following stillbirth, how comfortable you feel about caring for families following stillbirth, areas where you feel you might be better enabled to care and areas where you feel we could make improvements in the care we provide in a multidisciplinary caring environment. Only one discussion is needed which will take approximately 30 minutes to complete and at a time and venue that is most convenient for you. The discussion will

be digitally recorded and subsequently analysed by a researcher. Following completion of the interview, you cannot be identified and the information you provide will be treated in confidence. Participation in this review is voluntary. You are free to refrain from participation in this review or to withdraw from the review at any time.

Agreement to Consent

The research project has been fully explained to me. I have had the opportunity to ask questions concerning any and all aspects of the project and any procedures involved. I am aware that participation is voluntary and that I may withdraw my consent at any time. Confidentiality of records concerning my involvement in this project will be maintained in an appropriate manner. When required by law, the records of this may be reviewed by government agencies.

I, the undersigned, hereby consent to participate as a subject in the above described project conducted at the Cork Teaching Hospitals. I have received a copy of this consent form for my records.

If I have any queries about the study procedure I can contact Dr. Keelin O' Donoghue at 021- 4205019. If I have any questions concerning my rights in connection with the research, I can contact the Clinical Research Ethics Committee of the Cork Teaching Hospitals at 021-4345599.

After reading the entire consent form, if you have no further questions about giving consent, please sign where indicated.

Signature of Subject: _____ Date: _____

Witness: _____ Date: _____

5.3 Consent form -bereaved parents

Department of Obstetrics and Gynaecology,
Cork University Maternity Hospital,
Wilton, Cork.

Participant Information and Informed Consent Form

Version 1/2013 20/11/2012

Ethics Ref: ECM 4 (jj) 04/12/12

Date: _____ **Name:** _____

Study ID: *What are the spiritual and pastoral needs of parents who experience stillbirth?*

Principal Investigator : Dr. Keelin O'Donoghue.

Dear _____,

We know from feedback we receive from parents we have cared for that the death of a baby following a stillbirth is one of the most difficult experiences for parents to come to terms with. As a hospital we are always trying to improve the care we provide, so that even in the most difficult situations we are able to offer the very best level of care.

Following the death of your baby through stillbirth you are being invited to participate in a research study exploring the spiritual and pastoral aspects of stillbirth. The purpose of this study is to learn from you what your spiritual and pastoral needs were and whether those needs were met meaningfully. This information will help us to provide better care for all families into the future. We understand that it might be difficult to speak about what is a very personal area so we would like you to know that the resources of the entire Pregnancy Loss Team are available to you to offer any support you may need. A separate information leaflet about the Pregnancy Loss Services is included.

In order to decide whether or not you would like to participate in this study, you should understand enough about its risks and benefits to make an informed judgement. This process is known as informed consent. This consent form gives detailed information about the study, which will be discussed with you. Once you understand the nature of the study, you will be asked to sign this form if you are happy to participate.

We would like to meet with you to discuss with you what you felt were the spiritual and pastoral issues for you at the time of your bereavement and whether those needs were met. We also hope to explore with you if any deep questions were raised for you. You will also be asked to complete a short questionnaire. This study is researching the views and experiences of bereaved parents from all faiths and no faith and all

views are important to us. Only one discussion is needed which will take approximately 60 minutes to complete and at a time and venue that is most convenient for you. The discussion will be digitally recorded and subsequently analysed by a researcher. Following completion of the interview, you cannot be identified and the information you provide will be treated in confidence. The information will be treated in the same way that the National Perinatal Epidemiological Centre (NPEC) treats information concerning perinatal mortality so that no individual person will be identified.

Participation in this review is voluntary. You are free to refrain from participation in this review or to withdraw from the review at any time. Your participation or non-participation in this study will not impact on the ongoing care we as a Pregnancy Loss team have for you now or into the future.

Agreement to Consent

The research project has been fully explained to me. I have had the opportunity to ask questions concerning any and all aspects of the project and any procedures involved. I am aware that participation is voluntary and that I may withdraw my consent at any time. Confidentially of records concerning my involvement in this project will be maintained in an appropriate manner. When required by law, the records of this may be reviewed by government agencies.

I, the undersigned, hereby consent to participate as a subject in the above described project conducted at the Cork Teaching Hospitals. I have received a copy of this consent form for my records.

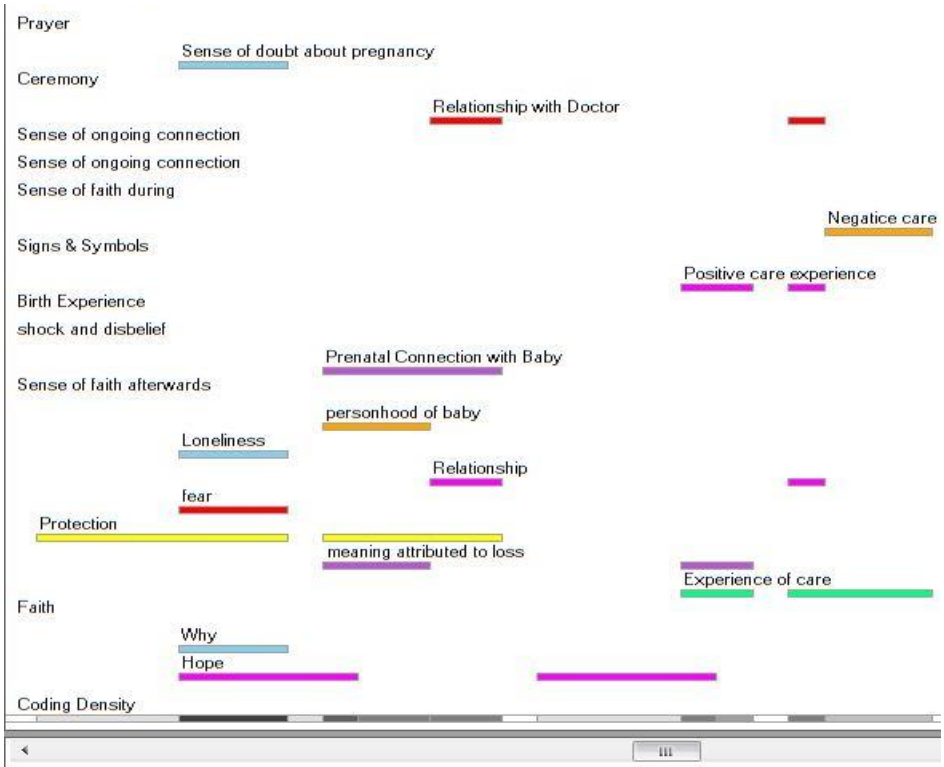
If I have any queries about the study procedure I can contact Dr. Keelin O' Donoghue or Daniel Nuzum at (021) 4920500. If I have any questions concerning my rights in connection with the research, I can contact the Clinical Research Ethics Committee of the Cork Teaching Hospitals at 021-4345599.

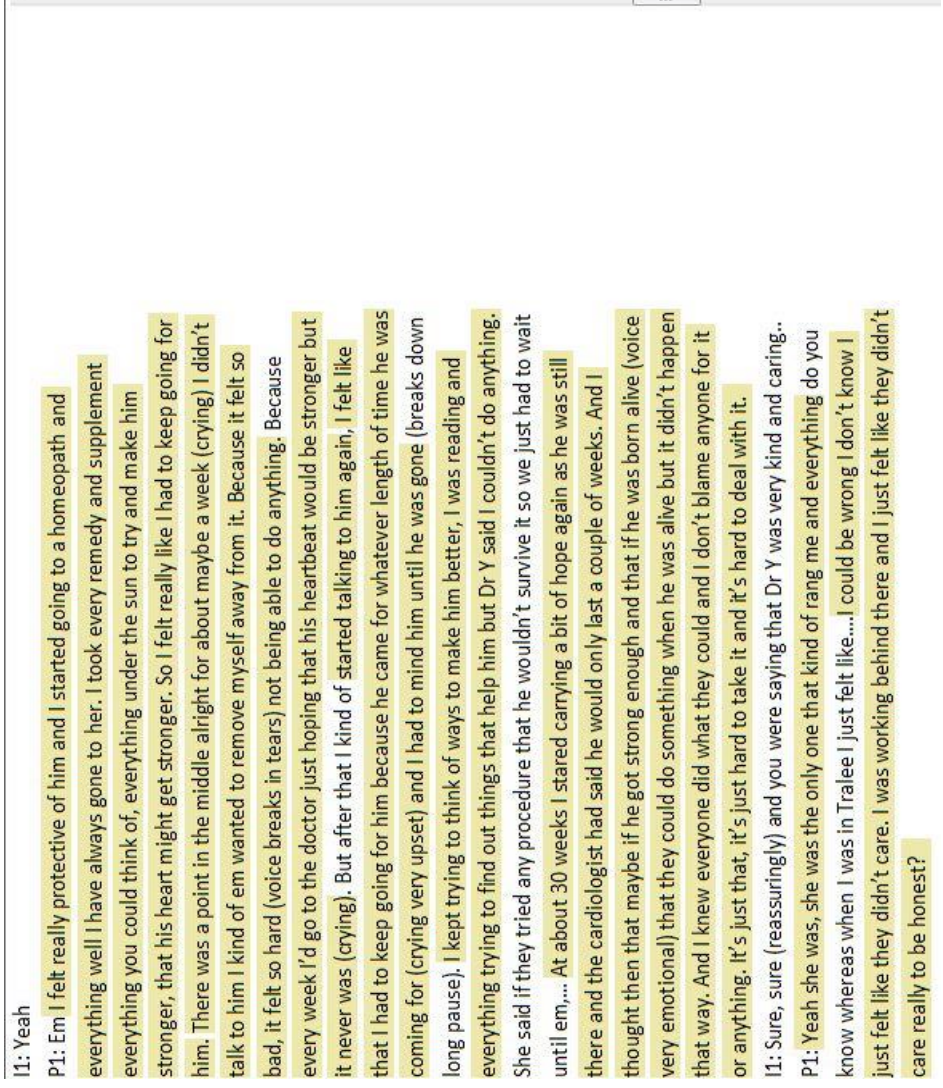
After reading the entire consent form, if you have no further questions about giving consent, please sign where indicated.

Signature of Subject: _____ Date: _____

Witness: _____ Date: _____

Appendix 6 Thematic Coding -bereaved parents




I1: Yeah
P1: Em I felt really protective of him and I started going to a homeopath and everything well I have always gone to her. I took every remedy and supplement everything you could think of, everything under the sun to try and make him stronger, that his heart might get stronger. So I felt really like I had to keep going for him. There was a point in the middle alright for about maybe a week (crying) I didn't talk to him I kind of em wanted to remove myself away from it. Because it felt so bad, it felt so hard (voice breaks in tears) not being able to do anything. Because every week I'd go to the doctor just hoping that his heartbeat would be stronger but it never was (crying). But after that I kind of started talking to him again, I felt like that I had to keep going for him because he came for whatever length of time he was coming for (crying very upset) and I had to mind him until he was gone (breaks down long pause). I kept trying to think of ways to make him better, I was reading and everything trying to find out things that help him but Dr Y said I couldn't do anything. She said if they tried any procedure that he wouldn't survive it so we just had to wait until em,... At about 30 weeks I stared carrying a bit of hope again as he was still there and the cardiologist had said he would only last a couple of weeks. And I thought then that maybe if he got strong enough and that if he was born alive (voice very emotional) that they could do something when he was alive but it didn't happen that way. And I knew everyone did what they could and I don't blame anyone for it or anything. It's just that, it's just hard to take it and it's hard to deal with it.
I1: Sure, sure (reassuringly) and you were saying that Dr Y was very kind and caring..
P1: Yeah she was, she was the only one that kind of rang me and everything do you know whereas when I was in Tralee I just felt like....I could be wrong I don't know I just felt like they didn't care. I was working behind there and I just felt like they didn't care really to be honest?

Appendix 7 Reflective Journal

7.1 Reflective Journal –healthcare chaplain

Chaplain was interviewed in private office at place of work on 23 April 2012

Casual informal conversation on way to office and atmosphere was relaxed.

Chaplain was very open about how difficult she finds caring for parents following stillbirth. Has received no training and 'learned on the hoof'.

Became tearful as she recalled a situation with a bereaved couple and how they expressed anger to her. Tearful as she recalled the sense of privilege it is to care for bereaved parents 'they teach me so much'. All I offer is myself, both arms hanging, I do' hide behind charts etc… Strong sense of personal identity in ministry -bringing presence and hope.

Spoke of her own loss and how this influences how she cares and this this is probably what brought her into this work.

Sense of frustration and strong feeling expressed about a hospital matter (the following day she telephoned me to ask that this section be removed from the transcript as she felt she had said too much and was worried that it might be taken out of context. This section was removed as requested)

Theological themes of sadness, incarnation, immanence, soteriology, after-life, baptism, theodicy, abandonment: 'My God where are you?'

I found this interview very demanding as chaplain became angry, feeling defensive about role and sense of place in team, isolation, carries burden of work home, finding new strategies to deal with stress…

7.2 Reflective Journal -consultant obstetrician

Consultant interviewed in private office at CUMH on 22 June 2012

Consultant appeared somewhat nervous at the beginning of the interview

During interview consultant spoke of own personal experience and became very tearful and got up to check that door was locked. (I felt the consultant was embarrassed by this.)

I offered to stop the recording and he/she agreed. There followed ten minutes of private supportive pastoral conversation during which he/she spoke of personal loss and experience. This was tearful. I provided pastoral support.

Strong feelings about colleagues were expressed: anger, frustration that some do not 'pull their weight' and leave the difficult situations to others. 'Some people have a blessed life'. Feels need to protect bereaved parents from some colleagues as they are insensitive (This was spoken quietly).

Strong feelings of isolation and loneliness were expressed.

Pulls over in the car on the way home to cry when upset, isolation (can not talk about this at work or at home).

Loves seeing new babies and goes to visit a new baby to cheer up during a bad day

Theological concepts: theodicy, anger, 'just part of life' yet strong expressions of injustice and suffering

I was not expecting this interview to be so emotional so it caught me off-guard. I as in a dual role as researcher and chaplain.

Consultant very appreciative of my care and sensitivity and opportunity to share their story

7.3 Reflective Journal -bereaved parent

Couple interviewed at their home on 08 August 2012.

Mid-afternoon in their living room.

Warm welcome from both X & Y. (X = Mother, Y = Father Z= Baby)

X contributed most in the first part of the interview. Y was quiet but appeared nervous. Y sat at opposite end of a couch from his partner and was restless.

X spoke very openly about their journey and her sense of loss following baby Z's diagnosis of skeletal dysplasia. Importance of memories.

Strong feelings of anger and frustration about scanning experiences: lack of trust expressed by both X & Y. They felt information was being withheld. Y was angry about this 'you've known this for weeks and didn't tell us'. They also found it upsetting to have to retell their story in hospital several times 'Have you not read our notes'. Not feeling cared for. Body language was tense.

Y became very emotional when speaking about baby Z and how he felt a lack of connection with him during pregnancy. At one point Y left the room in tears as he shared this part of his story and went outside and returned about 5 minutes later.

It became obvious to me during the interview that this couple does not talk openly about their experiences or about baby Z. This was a tearful awareness for both. I sensed a breakthrough here for this couple as their body language expressed a new intimacy as they moved closer to each other on the couch and then held and hugged each other following this part of the interview.

Feelings expressed were: Sadness, anger, disconnect, regret, annoyance, love, envy, protection.

Theological concepts: Hope, theodicy, ongoing connection/communion, signs and symbols (feathers, grave) other child sense of presence in house), relationship, eschatology/ reconnection, where is spirit now?

Following the interview (not recorded) both shared experiences of hospital staff leaving voicemail messages on a Friday evening and this caused them to worry all weekend…

Personal feelings: I found this interview intense as raw grief was expressed especially by Y who was very upset. I felt their palpable sadness as they spoke about the short life of baby Z.

I was aware of my own feelings of frustration about some aspects of their care and experience. A number of things raised left me with a feeling that 'we could have done better'. Much learning about communication, staff interaction, differences in grieving styles. I was able to bracket the awareness of my feelings so that I could engage with the couple during the interview..